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Development and Validation of a Patient-Reported Experience Measure for Older Adults Attending the Emergency Department: The PREM-ED 65 Study

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PHD

Development and Validation of a Patient-Reported Experience Measure for Older Adults Attending the Emergency Department: The PREM-ED 65 Study

Graham, Blair

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Development and Validation of a Patient-Reported Experience Measure for Older Adults Attending the Emergency Department:

The PREM-ED 65 Study

by

Blair Graham

A thesis submitted to the University of Plymouth
in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

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Dedication

“The emergency department staff introduce themselves; they sit down. They talk to you as a human being. They reassure you.”

Research Participant

This thesis is dedicated to all those who work in emergency care.

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Author's Declaration

At no time during the registration for the Doctor of Philosophy degree has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree at the University of Plymouth or another establishment.

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BLAIR GRAHAM **Date: 6th September 2024**

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Graham B, Endacott R, Smith JE, Latour JM. They do not care how much you know until they know how much you care: a qualitative meta-synthesis of patient experience in the emergency department. *Emergency Medicine Journal* 2019; 36: 355-363. doi: 10.1136/emermed-2018-208156

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Presentations

2018

- **Graham B**, Endacott R, Smith JE, Latour J. What do patients want from us? A qualitative meta-synthesis to identify the key determinants of ED patient experience [Free Paper]. *European Society for Emergency Medicine Congress,* September 2018.
- **Graham B**, Endacott R, Smith JE, Latour J. Determinants of Patient Experience in the Emergency Department: Translating qualitative research findings to the real-world context of the ED using meta-synthesis [Oral Presentation]. *International Conference for Emergency Nursing,* Melbourne, October 2018.

2019

- **Graham B**, Endacott R, Smith JE, Latour J. Development of a patient-reported measure for older adults aged over 65 attending the Emergency Department: An overview of the PREM-ED 65 Project [Poster]. *British Geriatrics Society 'Urgent Care for Older People'*, London, February 2019.
- **Graham B**. Development and testing of a Patient Reported Experience Measure for Older Adults aged over 65 attending the Emergency Department. *South West Emergency Academic Team Annual Meeting*, Bath, March 2019.
- **Graham B**, Endacott R, Smith JE, Latour J. Development of a patient reported measure for older adults aged over 65 attending the Emergency Department: An overview of the PREM-ED 65 Project [Poster]. *Patient Reported Outcome Measures Annual UK Research Conference*, Leeds, April 2019.

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- **Graham B,** Latour JM, Smith JE. Measuring what matters to older people in the ED: Development and validation of a patient-reported experience measure for ED patients aged 65 years and over A preliminary analysis. *Royal College of Emergency Medicine Annual Scientific Conference*, Belfast, October 2022.

Prizes

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Book Chapters

- **Graham B.** Emergency Medicine. In: Baldwin A (Ed). Oxford Handbook of Clinical Specialties. 11th Edition. Oxford: Oxford University Press; 2020. 568-623.

Plain English Summary

Emergency Departments (EDs) assess, diagnose, and treat patients with diverse health needs. Older adults attending the ED may have additional needs resulting from complex conditions, background health problems, effects of prescribed medications, and frailty.

High demand for ED services means that long waiting times, crowding, and delayed transfer to inpatient wards commonly occur. These issues lead to worse outcomes for older people, including an increased risk of in-hospital death.

Patient experience is an essential aspect of care quality and is associated with better outcomes across multiple conditions. Reliable patient experience measurement may allow hospitals and healthcare staff to identify where improvements are needed most, which may improve outcomes.

Patient-reported experience measures (PREMs) are questionnaires developed with patients, carers, and healthcare professionals. These survey instruments reliably measure patients' views of their care and treatment and can help ensure that efforts to improve care quality are person-centred.

This thesis presents a mixed-methods approach to develop and validate a PREM for older adults attending the ED (PREM-ED 65). Two reviews summarise the current evidence, while patient interviews and staff focus groups further expand the understanding of what matters to older adults attending the ED. These findings are used to create draft questionnaire items, prioritised by a group of patients and other stakeholders, and then refined using interviews. This resulted in an 82-item draft version of PREM-ED 65.

A team of researchers administered the draft PREM-ED 65 to patients attending 13 EDs in England, with over five hundred older adult patients responding. The analysis identified and removed unnecessary items, resulting in a 25-item version. This finalised version of PREM-ED 65 may be used to measure older adults' experiences of the ED environment, information provision, and pain assessment rapidly and reliably.

Abstract

Development and validation of a patient-reported experience measure for older adults attending the emergency department (The PREM-ED 65 Study).

Blair Graham

Emergency Department (ED) care traditionally focuses on resolving single-organ pathology, emphasising rapid patient flow. As such, ED care may fall short of addressing the holistic needs of older adults, where atypical and complex presentations exacerbated by frailty, comorbidity, polypharmacy, and sensory deficits are much more prevalent than in the general population. Older adults are particularly vulnerable to the effects of ED crowding and prolonged length of ED stay and suffer increased in-hospital mortality as a result.

Patient experience is a central determinant of quality of care and is positively associated with improved outcomes for acute conditions, including pneumonia, asthma, and acute coronary syndrome. Patient Reported Experience Measures (PREMs) assess patients' self-reported care experiences, identifying vulnerabilities in care from their perspective and providing impetus for patient-centred quality improvement. Other applications of PREMs may include individual and systems-level performance monitoring and comparison or benchmarking of services.

This thesis presents a mixed-methods methods study conducted to develop and validate a new PREM for adults over 65 attending the ED (PREM-ED 65). Justification for the study is provided through a critical discussion of the purpose of the modern ED, the concept of healthcare quality, and a critique of current

ED performance indicators. A broad conceptual exploration of older adults' experiences of ED care forms the basis for developing the PREM-ED 65 instrument. Firstly, a qualitative systematic review and meta-synthesis summarised findings from 22 studies, and thematic synthesis derived a novel conceptual framework for patient needs in the ED. A scoping literature review then identified and evaluated existing patient-reported measures applicable to the ED, highlighting the absence of a suitably validated ED PREM for older adults.

The conceptual framework was further expanded by undertaking in-situ interviews with older adults in the ED (n=24) and focus groups with ED care providers (n=37). Framework analysis and methodological triangulation of findings resulted in a comprehensive list of draft PREM items.

Draft items were assessed by multiple stakeholders (n=29) using a nominal groups technique, and final refinement was performed during cognitive interviews (n=7), resulting in an 82-item draft instrument.

The draft instrument was administered to patients across 13 different NHS Trusts in England. Analysis of the responses (n=511) consisted of hierarchical item reduction, exploratory factor analysis, and assessment of test-retest reliability. As a result, a finalised, 25-item version of PREM-ED 65 is proposed that provides reliable measurement of relational care, the ED environment, information provision, and pain assessment (Figure AB1, overleaf). Future work should include validation for patient cohorts admitted to the hospital, cross-cultural adaptation, validation to confirm measurement properties in underrepresented groups and the development of additional scales for older adults living with disabilities or sensory impairment.

PReM- ED 65

Measuring, Informing and Improving Older Peoples' experiences of emergency department care

[Institution Logo Here]

Please tell us about your experience in A&E today.

This questionnaire asks you about your experience in the A&E department today. It is two pages long and consists of twenty- five questions. It will normally take about 5 minutes to complete.

You can ask a friend or relative to help you complete the questionnaire, but the views expressed must be your own.

Please answer all questions that apply to you.

Your answers will be used to identify areas where we can improve care for older adults attending this A&E department in the future.

Thank you!

Details about your visit.

So that we can better understand your answers, please tell us about yourself and the reasons for your visit here:

Gender ☐ Male ☐ Female ☐ non-Binary ☐ Prefer not to say.

Age Range ☐ 65—74 years ☐ 75—84 years ☐ 85 years and above

Ethnic Group ☐ White ☐ Mixed/ Multiple ☐ Asian ☐ Black ☐ Another ethnic group

Arrival Transport ☐ Private Transport ☐ Ambulance ☐ Public Transport ☐ Prefer not to say.

Reason for today's visit ☐ A medical condition ☐ An injury ☐ Unsure ☐ Prefer not to say

Do you have an accompanying relative or friend? ☐ Yes ☐ No ☐ Prefer not to say

How well have we looked after you today?

Relational care looks at how well our staff have communicated and cared for you as an individual. Please tell us about your experience of receiving **relational care** in the A&E department today, by indicating with a ✓ how much you agree or disagree with the following statements:

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	Cannot answer
Staff thoroughly assessed my condition	☐	☐	☐	☐	☐
I understood why tests were needed	☐	☐	☐	☐	☐
Staff could locate the right equipment	☐	☐	☐	☐	☐
I was treated like I mattered during my A&E stay	☐	☐	☐	☐	☐
Staff explained what was going to happen	☐	☐	☐	☐	☐
Staff checked I understood what was said	☐	☐	☐	☐	☐
I felt able to ask questions	☐	☐	☐	☐	☐
Staff introduced themselves by name	☐	☐	☐	☐	☐
A&E met my expectations	☐	☐	☐	☐	☐
I felt ready to cope at home	☐	☐	☐	☐	☐
Staff asked my permission before treating me	☐	☐	☐	☐	☐
I was told when I was ready for discharge home	☐	☐	☐	☐	☐

Figure AB1: PREM-ED 65 Final Instrument (Page 1 of 2)

PReM- ED 65

Measuring, informing and **improving** Older Peoples' experiences of emergency department care

[Institution Logo Here]

What has it been like visiting our A&E department today?

Please tell us about your experience of the **A&E environment** today, by indicating with a ✓ how much you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Cannot answer
It was easy to find and use the toilets	☐	☐	☐	☐	☐
I could go to the toilet in dignity	☐	☐	☐	☐	☐
The A&E department was clean and tidy	☐	☐	☐	☐	☐
I felt safe whilst I was waiting	☐	☐	☐	☐	☐
I could get help if I needed it	☐	☐	☐	☐	☐
I was able to find a seat or bed	☐	☐	☐	☐	☐
My seat or bed was comfortable	☐	☐	☐	☐	☐
I felt cared for whilst I was waiting	☐	☐	☐	☐	☐

Have we kept you informed today?

Please tell us about your experience of **staying informed** in A&E today, by indicating how much you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Cannot answer
I was given updates whilst waiting	☐	☐	☐	☐	☐
I was informed about waiting times	☐	☐	☐	☐	☐
I was informed whether I could eat or drink	☐	☐	☐	☐	☐

Have we assessed your pain?

Please tell us about your experience of **receiving pain assessment** in A&E today, by indicating how much you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Cannot answer
I was asked how much pain I was in	☐	☐	☐	☐	☐
I was asked how much pain I was in more than once	☐	☐	☐	☐	☐

About PREM-ED 65

PREM- ED is a patient reported experience measure originally developed by Blair Graham, Jason E Smith, Pamela Nelmes, Jos M Latour, in association with the University of Plymouth, University Hospitals Plymouth NHS Trust, and supported by the Royal College of Emergency Medicine (UK).

Cite: Graham B et al, 2023.

For further information including associated publications, see https://premedstudy.wordpress.com/

Images: openclipart.org, no attribution required.

Figure AB1: PREM-ED 65 Final Instrument (Page 2 of 2).

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List of abbreviations

A&E	Accident & Emergency Department
BSc	Bachelor of Science
BNI	British Nursing Index
COSMIN	Consensus Standards for the selection of health measurement instruments
COVID-19	Coronavirus Disease-19
CASP	Critical Appraisal Skills Programme
CINAHL	Cumulative Index of Nursing and Allied Health Literature
ED	Emergency Department
EMBASE	Excerpta Medica Database
EFA	Exploratory Factor Analysis
FFTQ	Friends and Families Test Question
GIRFT	Get It Right First Time
HRQOL	Health-Related Quality of Life
HRA	Health Research Authority
HIR	Hierarchical Item Reduction
IFEM	International Federation of Emergency Medicine
ICC	Intraclass Correlation Coefficient
JLA	James Lind Alliance
LWBS	Left without being seen
LOS	Length of Stay
MADM	Mean Absolute Deviation from the Median
MCAR	Missing Completely at Random
NHS	National Health Service
NPS	Net Promoter Score
NGT	Nominal Group Technique
OECD	Office for Economic Co-Operation and Development
PPI	Patient and Public Involvement
PREM	Patient Reported Experience Measure
PREM-ED 65	Patient Reported Experience Measure for Adults aged 65 and over attending the ED
PROM	Patient Reported Outcome Measure
PROs	Patient Reported Outcomes
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PI	Principal Investigator
PSP	Priority Setting Partnership
RCEM	Royal College of Emergency Medicine
SDEC	Same-Day Emergency Care
SARS CoV-2	Severe Acute Respiratory Syndrome Covariant-2
WHO	World Health Organisation

Chapter 1 Introduction to the Research

What this chapter adds.

This chapter:

- Gives insight into the researcher's personal journey, research training undertaken during the doctoral fellowship, and positionality concerning the research.
- Outlines the context of emergency care delivery in the UK and the role of the ED from its historical inception to the present day.
- Briefly outlines the chapter structure and contents of the thesis.

1.1 Outline

Within this introductory chapter, I introduce myself as the researcher and highlight my key training, experiences, and achievements to date. I explicitly clarify my positionality within this research, which is particularly important when considering the reflexivity of the qualitative components of this research. The chapter then introduces the study setting (the emergency department (ED), or 'A&E' department), going beyond a description of the immediate physical and functional purpose of ED to consider its broader societal role, the challenges currently facing care delivery, future threats and opportunities, and the importance of balancing system demands against individuals' needs. I argue that validated and reliable means of measuring patient experience may help address some of these challenges. The final section of this chapter introduces

the onward structure of the thesis and provides a short chapter-by-chapter synopsis.

1.2 Prologue

I left school with A-levels in Chemistry, Biology, History, Psychology, and English, having enjoyed studying science and humanities. For a full year after, I worked as a healthcare assistant in the ED at the Ipswich Hospital. Here, I was taken under the wing of many of the nursing and medical staff. This year was formative in cementing my career ambitions and taught me a great deal about how to care for patients at the bedside, the importance of recognising my limitations, and the challenges ahead.

I completed my medical degree at Peninsula Medical School in 2012. As the first person from my immediate family to attend University, I remain proud to have graduated with distinction and was awarded the Sir John Tooke Gold Medal. During the 2010 academic year, I studied for a BSc (Hons) intercalated degree in Emergency Care from the University of Plymouth and was placed at Musgrove Park Hospital in Taunton. Formative to my intercalated experience was the mentorship I received from the late Dr Clifford Mann.(1) I remember Cliff working with humility and humanity foremost and accompanying this with intellect and clinical acumen. His belief in my abilities reinforced my ambitions to pursue academic emergency medicine, and his support during my early postgraduate years and this doctoral research always encouraged me.

Following medical school, I completed the Academic Foundation Programme in South Manchester. My good fortune with mentors continued, and I was closely supported by Mr Jonathon Ghosh, whose disciplined approach to work-life balance I still aspire to. I was later mentored by Dr Darren Walter and Dr Amy

Hughes for my foundation research project at the University of Manchester Humanitarian and Conflict Response Institute. My task was to identify competencies for emergency physicians responding to foreign disasters. This gave me a perspective on emergency care delivery in less-developed, disaster, and humanitarian settings and was consolidated during a short visit to St. Mary's Hospital in Lacor, Uganda. This experience has assisted me in considering the implications of my research in a broader, globally relevant context.

In 2014, I was appointed as a National Institute for Health Research (NIHR) Academic Clinical Fellowship in Emergency Medicine in Plymouth under Professor Jason Smith. During this time, I undertook some preparatory work looking at the role of patient-provider communication in the ED (2) and a cross-sectional study to identify strengths and vulnerabilities in patient-provider communication in the ED.(3) This work highlighted the potential for research to improve patient experience and outcomes in the ED and provided the foundations for the PREM-ED 65 project. I also undertook research methods training, including master's in clinical research (MClinRes) modules at the University of Plymouth. Other postgraduate qualifications include Membership of the Royal College of Emergency Medicine (MRCEM), Introduction to Teaching and Learning (University of Plymouth) and NHS Good Clinical Practice.

In some sense, I have had the best of both worlds whilst undertaking this research. As a researcher, I have received funding, training and support to conduct this work that will, hopefully, positively impact patient care. As a practising clinician, I have been humbled to diagnose, treat, and accompany

acutely unwell patients on their journey. Establishing a foothold in both clinical and academic camps represents a great privilege. Throughout, I have maintained awareness of my emic perspective as an ED clinician whilst also appreciating the new perspective that adopting an etic approach may bring, not least to enhance the objectivity of my research. The views of patients and other stakeholders have been integral to the evolution of PREM-ED 65, and the work would not have been possible without the voluntary contributions of many. As such, the final version of PREM-ED 65 is offered under a Creative Commons licence; together with my supervisors, I hope that the instrument will be used and adapted widely to measure, evaluate, and—crucially— improve care for older adults needing emergency care.

Positionality Statement

I explicitly recognise that my positionality has the potential to impact the design, delivery, and interpretation of this research. My experiences outlined within this section have undoubtedly influenced my perspective on health systems and healthcare delivery. As an educated white male doctor, I am in a position of considerable privilege compared to many in society. This will include some of my patients, study participants, and many groups likely to be affected by structural inequalities and health disparities. Recognition that my own experiences are different from those of others, not least older adults, has driven the design of much of this research—for example, through patient, public and stakeholder engagement. Throughout, I have endeavoured to design and conduct ethical research and ensure that findings are made applicable to practice and disseminated appropriately. Most importantly, maintaining a reflexive approach has helped ensure participants' views are truly reflected in the PREM-ED 65 instrument.

1.3 Introducing the study setting.

This section aims to introduce the emergency department (ED), beginning with a brief overview of emergency medicine's historical origins and development through recent history. I then outline the physical layout of the modern ED before considering the philosophy of emergency medicine. Emergency care in the UK is currently facing immense challenges, and it would be amiss not to recognise these and their influence on the PREM-ED 65 project. Finally, this chapter considers the outlook for the speciality, including opportunities posed by workforce diversification and emerging technologies.

1.3.1 Historical Context

The origins of emergency medicine can be traced back to the Napoleonic era when surgeon Dominique Jean Larrey of the French Army pioneered triage and pre-hospital care. For the first time, patients were conveyed by ambulance from the point of injury to a hospital based on clinical priority. Ever since, triage has remained a central tenet of EM practice.(4) In the civilian setting, the first EDs, or ‘casualty wards’, were established during the 19th Century in response to urbanisation.(5) During the 20th Century, EM has continued to share its evolution with advancements made during conflict. For example, World War II (1939-1945) saw the organisation of civilian emergency care to deal with casualties of bombing campaigns affecting the UK population;(6) the Korean War demonstrated the benefit of early resuscitation and rapid transport of trauma victims using helicopters, and the Vietnam era pioneered advanced skills in vascular repair and paramedicine.(7, 8) Recent 21st-century conflicts in Iraq and Afghanistan have revolutionised civilian approaches to care for the severely injured.(9, 10)

The National Health Service (NHS) was formed in 1948(11) and provided a foundation for a nationalised model of civilian emergency care. As demand for healthcare and injuries from road collisions increased, a specialist approach to emergency care emerged, exemplified by Sir Maurice Ellis's appointment as the first emergency medicine consultant in 1952.(12) Ellis formed the Casualty Surgeons Association, which later became the Faculty of Accident and Emergency Medicine in 1993.(13) Subsequently, the College of Emergency Medicine received Royal Assent in 2008 to become the Royal College of Emergency Medicine (RCEM). Currently, RCEM has over 10,000 Fellows and Members internationally.(14)

1.3.2 Present day organisation of Emergency Care in the UK

Today, services provided by the NHS may be broadly described as *Primary*, *Secondary* or *Tertiary*. The focus of primary healthcare is within the community. Secondary healthcare consists of general hospital services, including surgery and obstetrics. Tertiary healthcare comprises specialised hospital services, typically provided on a regional or national basis. The ED provides a link between all these interfaces.

In the UK, emergency departments (EDs) provide reception for patients with undifferentiated illness and injury within secondary care and are sub-categorised into three tiers:(15)

- **Type 1 (Major) EDs:** Consultant-led 24-hour service with full resuscitation facilities and designated accommodation for the reception of emergency care patients.

- **Type 2 EDs:** Consultant-led mono-speciality led mono speciality emergency care service (e.g., ophthalmology, dental) with designated accommodation for the reception of patients.
- **Type 3 EDs:** Another type of A&E/minor injury activity with designated accommodation for the reception of emergency care patients. The department may be doctor-led, general practitioner-led or nurse-led.

Some EDs have specialist designations such as major trauma, acute stroke, and cardiac arrest centres.(16-18) These have decreased mortality and hospital length-of-stay in afflicted patients.(19-21)

The PREM-ED 65 study will primarily focus on Type 1 EDs, which see a general emergency caseload, irrespective of additional designation. Type 1 EDs are numerous, with over 170 departments in England.(22) To patients and members of the British Public, the ED is more commonly known by the historical term ‘accident and emergency’ department, or ‘A&E'. As such, ‘A&E’ will be used interchangeably with ‘ED’ throughout this thesis, particularly in patient-facing literature.

1.3.3 The physical layout of the ED

The Type 1 ED provides a physical point of access to healthcare with patients able to self-refer, arrive via ambulance conveyance or referral from other clinicians or telephone triage (NHS 111).(23) The ED is normally divided into clinical areas and, following triage assessment (24), patients will typically be streamed to the most appropriate area depending on their clinical needs. As these will be referred to within this research, short descriptions of these areas are provided as follows:

- **Resuscitation Room:** This is an area for the reception, assessment, and treatment of the highest-acuity patients with life-threatening conditions such as compromised breathing or circulation. (25)
- **Majors:** An area where most non-ambulant patients arriving by emergency ambulance are assessed.
- **Minors:** This area is designated for patients with lower acuity or minor musculoskeletal injuries. Emergency Nurse Practitioners may lead this area.

1.3.4 Philosophy of Emergency Medicine

As a clinical speciality, the scope of emergency medicine is defined by the International Federation of Emergency Medicine (IFEM) as follows:

> *Emergency medicine is a field of practice based on the knowledge and skills required for the prevention, diagnosis, and management of acute and urgent aspects of illness and injury affecting patients of all age groups with a full spectrum of episodic undifferentiated physical and behavioural disorders; it further encompasses an understanding of the development of prehospital and in-hospital emergency medical systems and the skills necessary for this development.*
>
> Original IFEM definition of emergency care (1991) (26)

As mentioned, the ED is a critical interface between community and hospital services. In reality, this remit extends to the provision of urgent care, including for patients with unmet primary care needs, acute psychosocial issues, substance misuse, and exacerbations of long-term conditions.(27-29) As a result, the scope of practice of ED clinicians is broad. In the UK, the ED is the only hospital location where patients of all ages and acuities may be seen and treated.

Although the provision of highly specialised healthcare has long been viewed as desirable and may lead to improved outcomes in some contexts, the provision of generalist services—including those provided by ED clinicians—is recognised as an increasingly vital part of the health system. The benefits of general health services include a greater holistic assessment of patient needs, the provision of services that are readily accessible to patients, enhanced responsiveness to services that meet population-based health needs, and increased multidisciplinary collaboration.(30) Emergency clinicians effectively occupy both a specialist and generalist space, as outlined by past president of the British Geriatrics Society David Oliver (Quote 1):

> *"Emergency physicians see all-comers, including many patients with primary care sensitive, and multiple long term, conditions. Yet they also have specific skills in the first phase of acute care, overlapping with many other medical and surgical specialities and seeing patients of all ages."*

Quote 1: David Oliver (2016) (31)

In their review of emergency care decision-making, Al-Azri et al. highlight the higher risk of error and levels of uncertainty that emergency clinicians face compared to those practising in other hospital-based specialities.(32) The generalist aspect of Emergency care providers' skillset may be especially relevant for older patients, many of whom present with multiple and complex inter-related health problems. Such patients form an increasing cohort of ED attendee, with this trend exemplified by epidemiological data. For example, a cross-sectional study of 1.7 million primary care attendances in Scotland estimates that 23.2% (95%CI 23.1-23.2) of older adults have more than one long-term condition, increasing to 64.9% (95%CI 64.7—65.1) in those aged over 65 years.(33) Similarly, 30.9% of adults aged over 50 years meet the

current definition of polypharmacy, defined as five or more regular medications.(34) For many such patients, holistic care is essential, and interventions such as complex geriatric assessment may have quantifiable mortality and morbidity benefits and reduce hospital admission and ED attendance rates.(35) Although not historically considered within the remit of emergency medicine, which has been traditionally focused on time-critical assessment and treatment of single-organ pathology, multi-modal interventions for patients with high clinical complexity are necessary and achievable within the modern ED setting. (36)

In addition to its primary clinical remit, ED function extends to fulfil a broader social and humanistic purpose. The ED is often the primary healthcare provider for sectors of the population that are neglected and vulnerable to poor health outcomes. This includes those suffering social deprivation, unemployment, living in poor quality housing or with homelessness, poorly controlled long-term conditions, or low health literacy.(37-42) Despite UK guidance suggesting the remit of ED is for life-threatening problems, patients access care for many reasons, including limited access and low confidence in primary care services, self-perceived urgency of their problem, recommendations from others (e.g., family, friends and health professionals) and personal convenience.(43) As such, a challenge for ED providers is balancing the individual patient's needs against those of the wider population. This ensures that the utilitarian principle of distributive justice is respected while optimising patient outcomes and care experience.(44) Much work has been conducted to support this and define ‘appropriate’ ED attendance criteria. However, definitions of appropriateness remain unclear, with clinicians and policymakers concerned about the potential for poorly conceived definitions to create barriers to accessing emergency

care.(45) One systematic review of studies (n=31) conducted across the Americas, Europe, and Asia estimates pooled appropriate attendance rates vary from 20% to 40%. However, the individual studies applied an extensive range of criteria.(46) In a more recent UK context, O'Cathain et al. used clinical investigations, extent of treatment delivered, and disposition from the ED as indicators of appropriateness of attendance. A retrospective analysis of three years' hospital attendance data deemed 15.1% of attendances 'non-urgent'. The odds of such attendance were higher amongst those aged 16-44 years, compared to those aged 45-64 years (OR 1.42, 95%CI 3.78—3.85) and >65 years (OR 1.42, 95%CI 3.78—3.85).(42)

The Patients' Association and RCEM provide an alternative working definition in the report *Time to Act*.(47) The two organisations assert that such decisions are patient-specific:

> *'Urgent and emergency health needs are those that the patient perceives require a response on the same day they arise. The judgement of urgent and emergency is made by the patient and not by the clinician.'*
>
> Definition of emergency care, *Time to Act* (2015)(47)

The co-authors of the same report argue that "[because] the A&E brand is immensely powerful… it is futile to discourage attendances [to the ED], as those most likely to heed the advice may well be those whose need is greatest or most appropriate". A mixed methods study by Turnbull et al. included a literature review, semi-structured interviews and convened Citizen Panels to understand adults' health-seeking behaviours concerning urgent care needs. The authors determined that patients may struggle to differentiate urgent vs. emergency care needs and that emotional responses to illness, injury, and pain

drive many attendances. Proposed areas for intervention aimed at reducing unnecessary ED attendances included improving access to pain management, targeting moral beliefs on health-seeking behaviour, and navigating patients to alternative sources of care.(48) Despite attempts to implement initiatives targeting these themes, public demand for emergency care continues to increase and remains a key challenge for providers. Indeed, in a commentary specific to older people, Conroy discusses that the attempt to meet increasing patient demand and improve outcomes has led to complex systems of care and that a wicked problem of meeting the demand for emergency care may have resulted, which may be difficult or impossible to solve.(49)

1.3.5 Challenges Facing Emergency Care

The relationship between the ED and other components of the health system means it is often at the forefront of health service reforms and controversies, attracting a great deal of political and media interest.(50) The ED has long been recognised as an essential barometer of the NHS. Changes in attendance or deterioration in performance, detected using measurable indices such as waiting time, may be symptomatic of problems encountered within emergency care and other system areas.(51) The UK is currently experiencing severe challenges meeting population demand for emergency care, recently described as a “national emergency”.(52) This crisis is exacerbated by recent systemic under-investment in health services in the UK. For example, growth in UK health spending has stagnated since the introduction of austerity measures by the UK government in 2008. Indeed, annual growth in UK government health spending between 2008 and 2025 is projected to be approximately 0.5% per annum, compared to a long-term average (since 1980) of 2.6% per annum.(53) Correspondingly, the UK NHS has fewer medical practitioners, hospital beds,

and imaging facilities than many comparable OECD economies.(54) In addition to under-resourcing, evidence demonstrates that overall demand for ED services has increased by 13.2% over the past decade and, in particular, high-acuity presentations have increased by 11% since the onset of the COVID-19 pandemic.(52) Largely due to a lack of social and rehabilitation beds for patients awaiting hospital discharge, the disposition of ED patients to inpatient wards is frequently delayed. When beyond four hours, this is termed ‘ED exit-block’.(55) ED exit-block leads to critical ED overcrowding and subsequent delays in offloading ambulance patients. This reduces the availability of emergency ambulance services in the community. The extent of ED overcrowding and ‘exit-block’ means that it currently represents a serious public health concern with quantifiable harms. Notably, a national retrospective cross-sectional study of patients admitted between April 2016 and March 2018 demonstrated a statistically significant increase in the Standardised Mortality Ratio for patients waiting beyond 6—8 hours from ED arrival, representing a 10% excess in those waiting beyond 8—12 hours. This was greater still in those with a background of frequent ED attendance, complex comorbidities, or social deprivation.(56) Extrapolation of these studies by RCEM suggests that 23,000 excess deaths may occur in the UK annually as a consequence of crowding and ED exit-block.(57) From a pre-hospital care perspective, the Association of Ambulance Chief Executives notes that currently, 200,000 patients experience delayed handover per month in the UK and that 185,000 per annum experience a delay of beyond one hour, with an attendant risk of ‘some harm’ estimated at 80%, and severe harm at 10% of this patient group.(58) Consequential effects of ED overcrowding and exit block may include decreased compliance with clinical guidelines, increased risk of interpersonal violence towards staff, increased staff

burnout, reduced staff training opportunities, and impaired recruitment and retention.(59) In response to the current crisis facing UK emergency care, the UK government has proposed a ‘plan for recovering urgent and emergency care services’, which proposes increasing hospital capacity, promoting same-day emergency care services, increasing telemedicine capacity via the NHS 111 service, and expediting hospital discharge.(60)

The impact of the ageing population

Currently, over 11 million people aged over 65 years reside in the UK, comprising 18.6% of the general population. This figure includes 1.7 million people over 85 years and more than 500,000 who are 90 years and above. By 2045, the proportion of older adults over 85 will double to 3.1 million.(61-63) The ageing population reflects societal successes, most notably preventive health policy and improved access to healthcare, which has reduced premature deaths from cardiovascular diseases and cancer.(64) However, the continued changing demographic also has implications for healthcare resourcing and demand, which must be considered in future planning.

Older adults are already a major Emergency Department (ED) user group, comprising over one-quarter of attendances(65) and are more likely to suffer from multiple, complex long-term conditions and have higher care requirements than the general population.(66, 67) In the context of emergency care, older people are more likely than other groups to arrive at the ED by ambulance, have higher acuity needs, spend more than four hours in the ED, and require inpatient admission to hospital. Once admitted, older people to hospital occupy the greatest number of bed days (65, 68-70) , and those admitted to the hospital on a background of frailty have increased 2-year mortality, even after a short ‘ambulatory’ admission.(71) As will be discussed in more detail later in this

thesis, the association between patient experience and outcomes means that developing a PREM for older adults attending the ED has the potential to measure and mitigate many of these negative effects.

1.3.6 Existential Threats

In addition to resourcing, ED exit block and the ageing population, emergency care provision challenges include non-communicable diseases. Conditions, including diabetes, obesity, and heart failure, are likely to continue to increase in the UK as inequality widens concerning smoking, physical activity, diet, and alcohol use.(72, 73). The risk for future novel infectious disease outbreaks and pandemics will likely persist, driven by an increasing global population, climate change, and globalisation.(74, 75) Due to the worldwide climate emergency, additional burdens on emergency care systems, including environmental injuries and urban air pollution's physical and behavioural effects, are already being observed internationally.(76)

1.3.7 Opportunities

Despite the many challenges, opportunities exist to improve the delivery of ED care. The Getting it Right First Time (GIRFT) initiative reviewed working practices in 90 Type 1 EDs and provides short-term recommendations for improving emergency care and reducing costs.(77) These include establishing same-day emergency care (SDEC) facilities, harmonising and ensuring the effectiveness of information technology systems, and optimising access to 24/7 clinical imaging.(78) In the longer term, emerging technologies, including artificial intelligence and telemedicine, may have transformative potential for patient assessment and management in the ED.(79) Continued diversification of the clinical workforce may help address current provider shortfalls and has been prioritised within a recent NHS workforce plan.(80) The academic credibility of

emergency medicine continues to grow, supported by increasing international research and recognition from bodies such as the UK National Institute of Health Research.(81) Emergency care research is increasingly shaped by prioritisation exercises involving multiple stakeholders, including patient and public representatives.(82, 83)

Altogether, proactively addressing future challenges and harnessing opportunities will further define the scope of practice, optimise clinical effectiveness, and strengthen the credibility of emergency medicine in the future.

1.3.8 Relevance to this research

This discussion has aimed to provide a critical overview of the physical and metaphysical environment and conditions under which PREM-ED 65 was developed and validated. It demonstrates the author's awareness of UK emergency care from a historical, clinical and policy standpoint. Understanding the purpose and function of the ED, including the challenges faced by patients and providers within the ED setting, is crucial to understanding the validity, transferability, and generalisability of this research and ensuring that PREM-ED 65 is relevant. Even since PREM-ED 65 was proposed in 2016, the landscape of emergency care has changed considerably, and demands on providers have significantly increased. As outlined in this discussion, the continued and emerging challenges facing emergency care providers mean that achieving a balance between patient-centred, individualised care and meeting the health needs of the broader population is likely to become a prominent concern. This makes the case for measuring patient-reported experience even more credible.

1.4 Introducing the thesis.

This thesis describes the conceptualisation, derivation, and validation of a Patient-Reported Experience Measure for older adults attending the ED. This section will provide a brief overview of the thesis structure and contents.

1.4.1 Structure of the Thesis

This is a hybrid thesis that includes published work. Accordingly, some chapters include research manuscripts published in peer-reviewed journals. Where this is the case, an authorship and contributorship statement is provided at the start. Each chapter starts with a short synopsis of key points ('this chapter adds' section) and finishes with an addendum emphasising the contribution of the work to the PREM-ED 65 study. This aims to ensure constructive alignment throughout the thesis, clearly framing each chapter within the specific context of development and validation of the instrument. The future publication strategy is also included when a research chapter is not yet published.

The thesis is structured in four parts. Firstly, Chapters 1—3 introduce the research and study methodology. Secondly, Chapters 4—7 conceptualise patient-reported measures and patient experience in the ED, including a qualitative exploration of older adults' ED experiences. Thirdly, Chapters 8-11 consist of the development and initial validation of PREM-ED 65. These include prioritisation using a multiple stakeholder nominal groups workshop, a multi-centre validation study, and evaluating student experiences administering PREM-ED 65 in a real-world ED setting. Finally, Chapter 12 provides the final discussion, conclusions, and epilogue.

Vancouver referencing has been used throughout to provide consistency with the house styles of the published articles.

1.4.2 Chapter-by-chapter outline

A chapter-by-chapter outline of the thesis is provided as follows:

Chapter 2 provides the study background and rationale. This chapter explores the definition of quality of care as relevant to the ED setting. Critical consideration of measures currently applied to assess ED patient experience and challenges facing emergency care confirms a rationale for developing a PREM for older adults in the Emergency Department. The chapter finishes with the statement of research aims and objectives.

Chapter 3 provides detailed insight into the mixed-methods approach to developing PREM-ED 65, justifying the ontological, epistemological, and theoretical positions. This is followed by presenting key elements of each study's research protocol, including the purpose, aims, inclusion/ exclusion, and practical/ ethical considerations.

Chapter 4 reports a qualitative systematic review and meta-synthesis of literature exploring ED patient experience. This presents a new conceptual model for patient experience in the ED, which forms the basis of the research moving forward.

Chapter 5 presents a scoping review of existing Patient-Reported Outcome Measures (PROMS), Patient-Reported Experience Measures (PREMS), and Health-Related Quality of Life (HRQOL) instruments developed, validated, or implemented in ED settings. The identified instruments are appraised, and a need to develop a PREM for older adults is identified.

Chapter 6 presents the findings of a qualitative study utilising interviews with twenty-four patients in the ED. This builds on the previous findings but specifically through the lens of older adults.

Chapter 7 presents the findings of the second qualitative study, engaging thirty-seven ED staff in seven mixed focus groups to further develop the conceptualisation of older peoples' patient experiences in the ED.

Chapter 8 presents the results of a multi-stakeholder consensus meeting with older adults, healthcare professionals, and other stakeholders. Using a nominal group technique, a prioritised list of items to include in the draft copy of PREM-ED 65 is determined.

Chapter 9 presents the findings of seven cognitive interviews conducted with participants following the multiple stakeholder workshop. It outlines final changes made to the draft instrument's content, formatting, and layout to maximise usability and mitigate potential response biases prior to final development and validation.

Chapter 10 presents the final development and validation study, conducted using a research collaboration of medical students across multiple EDs in England. This justifies a finalised, 25-item version of PREM-ED 65.

Chapter 11 reports a process evaluation of the final development and validation study. It summarises students' experiences of involvement in this research, the impact on their future development and likelihood of pursuing academic medical careers, and their experience administering PREM-ED 65 to patients.

Chapter 12 concludes the thesis with an integrative discussion summarising the research, its strengths and limitations, and the considerations for implementing

the finalised PREM-ED 65 instrument. The chapter finishes with a conclusion and epilogue reflecting on the author's experience of conducting this research.

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Chapter 2 Study Background, Aims and Objectives

What this chapter adds.

This chapter:

- Defines what ‘quality of care’ means using multiple sources, literature, and contemporary evidence.
- Critically evaluates quality metrics and measures currently used within the ED from a UK and international perspective.
- Considers the effect of an ageing global population and the unique needs of older adults when accessing the ED.
- Outlines the aims and objectives of the PREM-ED 65 programme of study.

2.1 Outline

This chapter discusses the concept of quality of care from a historical to a present-day context through key definitions, reports, and policy. It aims to determine to what extent the components of care quality are interrelated and, specifically, emphasise how patient experience may influence clinical outcomes in ED care. The role of Patient-Reported measures in evaluating quality of care is also specifically considered.

2.2 Quality of Care

2.2.1 Conceptual origins and definitions

As this section explores, definitions of quality of care have evolved, but in the most general sense, they relate to how health systems deliver optimal patient

outcomes. Historically, the origins of quality in healthcare are frequently attributed to early 20th century US surgeon Ernest Codman, who pioneered scientific analysis of surgical cases to identify the causes of suboptimal outcomes, progressing to complete the first example of a patient registry. (1, 2)

Interest in quality of care became more widespread in the post-war period as the first large-scale health systems and reforms emerged, including the inception of the NHS in the UK. During this period, US epidemiologist Donabedian derived and popularised a three-domain conceptual framework to evaluate the quality of medical care, focusing on Structure, Process and Outcome: (3)

- **Structure** is concerned with the settings where care occurs, extending to the adequacy of facilities and equipment, medical and nursing staff expertise, and organisational and administrative aspects of care delivery.
- **Process** of care relates to whether "good" medical care has been delivered. Namely, this is concerned with judgements relating to the accuracy of history taking and diagnosis, clinical decision-making, treatment selection, technical competence in performing procedures, and acceptability of patient outcomes.
- **Outcomes** concern recovery, restoration of function, and survival following an illness episode or healthcare encounter.

The Donabedian model of evaluating the quality of healthcare remains widely in use today and, in the context of emergency care, has been applied to improve standards of ED triage, (4, 5) implement a local pandemic response, (6) and formulate a conceptual model for standards of care for patients undergoing boarding in the ED.(7) Further research in a Canadian Major Trauma Centre

validates Donabedian's model, demonstrating significant correlations between structure, process and outcome measures. (8) The reach and impact of the Donabedian structure are further exemplified by its use within quality frameworks in emergency medicine, including those proposed by IFEM.(9, 10)

A recent milestone in defining care quality followed the publication of the 1999 report *To Err is Human*, (11) which quantified harms caused by medical errors. The report reconceptualised medical errors as events caused by system flaws instead of individual incompetence. The findings had international reach, contributing to the formation of the UK National Patient Safety Agency in 2001.

A further report published in the US, *Crossing the Quality Chasm*, highlighted the gap between actual and desired healthcare standards and was influential in providing a contemporary definition of quality of care.(12) In this report, Berwick defined quality of care using six dimensions:

- **Safety**: Avoiding injuries to patients from care intended to help them
- **Effectiveness**. Provide evidence-based care, avoiding overuse and underuse of care.
- **Patient- Centredness**. Providing care that is respectful of individual patient preferences and needs.
- **Timeliness.** Reducing waits and harmful delays.
- **Efficiency**. Avoiding waste.
- **Equitability**. Providing care that does not vary in quality based on patient characteristics.

Berwick's framework for defining quality care remains widely regarded and internationally influential.(13) In emergency medicine, the influence of *Crossing*

the Chasm has been wide-reaching. It extends to reporting and management systems for errors, increased focus on evidence-based medicine, implementation of time-based targets, and focus on patient flow and efficiency.(14)

In the UK context, Cochrane's publication of *Effectiveness and Efficiency* (15) highlighted the need for systematic approaches to healthcare. However, widespread interest in the quality of health services did not arise until the 1990s. This change was spurred by the recognition of serious systemic cultural and organisational flaws in the health service in the wake of the Bristol Heart Scandal. (16) The influential 1997 Labour government White Paper, ' The New NHS, ' embedded principles of quality improvement and evidence-based practice and heralded the standardisation of care using National Service Frameworks and the formation of the National Institute for Clinical Excellence.(17) A subsequent report, *High Quality Care for* All, led by Lord Azra Darzi, was commissioned in 2008 and aimed to put 'quality at the heart of the NHS'.(18) This report provided a simplified definition of quality of care based on three domains:

- **Patient safety is** how patients and carers perceive the process of care.
- **Patient safety** is ensured by avoiding unintended or unexpected harm during care delivery.
- **Clinical Effectiveness** application of best available knowledge, clinical expertise, and patient preferences to achieve optimal outcomes.

Additionally, the Darzi report issued recommendations for the development of integrated care and reconfiguration/ centralisation of services that required high levels of expertise. Specific to the ED setting, the report highlighted 'compelling

arguments for saving lives by creating specialist centres for trauma, stroke and heart attacks leading to acute clinical networks in London and throughout the UK. (19)

Defining quality of care from the patient's perspective

In common with each other, the definitions provided by Donabedian, Berwick and Darzi emphasise the importance of providing responsive, safe, and effective care. However, does this reflect what constitutes quality of care from a patient perspective? Literature to help address this question includes a pan-European survey of lay members of patient forums that explored this issue and revealed that the concept of ‘quality of healthcare’ is familiar to patients, with 79% of respondents from over 25 countries reporting familiarity with the term.(20) The same survey asked respondents to state dimensions of care quality, of which the highest ranking were timeliness, workforce skills, and safety. In addition, respondents demonstrated strong agreement with all WHO dimensions of quality. McCaffery et al. derived a new conceptual model of ‘good health care’ using concept mapping of statements derived by one hundred fifty-seven patients recruited within the US. This revealed ten determinants of high-quality care, as defined by patients, including ‘taking an active role’, ‘doctor/ provider competence’, ‘focus on clinical outcomes’, ‘individualised care’ and ‘staff communication’. Participants consistently emphasised all domains, irrespective of their demographic characteristics and social background.(21)

In summary, while the evidence is limited, domains for defining quality of care proposed by patients align closely with existing models proposed by Berwick and Darzi, lending further real-world credibility and face validity to these overarching definitions of quality of care.

2.2.2 Current Standards for Quality of Care in the ED

The WHO Emergency Care System Framework guides international standards of emergency care provision, encapsulating care processes starting at the point of injury or illness onset, continuing during ED assessment, to definitive care whilst considering human resource, system, and physical resource requirements.(22) It proposes quality metrics, including service accreditation, standardisation and protocolisation of care, compliance with training standards, and time-based performance metrics, such as ED length-of-stay. The WHO provides a standard approach to the international design of emergency care systems, with applicability to all settings, including low—and middle-income countries. The framework may be adapted to meet local needs depending on available resources.(23) Building upon WHO standards, IFEM has also been instrumental in setting standards for emergency care.(9, 10, 24) Updated quality guidelines published in 2021 focus on delivering clinical care, education and training, ED administration, patient-centredness, safety and risk management, and community engagement. The guidelines identify enablers for high-quality care in the ED, including staffing levels and skill mix, physical structures to provide ED care, internal ED care processes, co-located services such as primary care, and monitoring of outcomes. Quality indicators for each domain are suggested, with recommendations for outcome measures proposed using the Donabedian criteria. Concerning patient-centredness, indicators proposed by IFEM include structural components (physical environment including dedicated paediatric, psychiatric, and older adult assessment areas), process-related components (complaints system, LWBS rate) and outcomes-related components (patient experience, participation in care, use of PROMs and time to analgesia).

Although guidance from bodies such as the WHO and IFEM provides overarching principles to define and guide the quality of care in the ED, governments and professional bodies frequently set regional and national standards. Examples include Quality frameworks proposed by organisations in Canada, America, Australasia, and Africa.(25-29) In the UK, the Department of Health, the Care Quality Commission, and the Royal College of Emergency Medicine principally set standards for ED care.(30, 31)

2.2.3 UK approaches to measuring ED quality of care

In 2004, the UK government introduced a 4-hour standard mandating that all ED patients should be seen and treated within 4 hours of arrival. This led to initial improvements in waiting times but deteriorated late into the decade due to reduced funding and ever-increasing patient demand. Although still potentially valuable,(32) time-based targets for ED quality of care have been controversial, and they have been deprioritised in favour of five alternative measures as follows:(33)

1. Left Without Being Seen (LWBS) Rate
2. ED Re-Attendance Rate
3. Time to Initial Assessment
4. Time to Treatment
5. Total ED Length of Stay (ED LOS)

Using Donabedian's model, LWBS and ED-Reattendance rates are outcome measures, while time to initial assessment, triage, and ED LOS are process measures. These indicators may be meaningful for monitoring quality. For example, a telephone survey conducted with patients who left the ED before being seen (n=72) indicated that reasons for dissatisfaction included excessive

wait times, perceived triage inequity, inadequate pain management, and rudeness from ED staff.(34) In this study, such factors were negative determinants of ED experience, and 15.7% of patients interviewed stated they would not attend the same ED again. Even though patients with LWBS tend to be triaged as lower acuity, they may be more likely to re-attend the ED within 48 hours and require subsequent admission than the general patient population.(28) Whilst LWBS in the UK was estimated to be 7.2% by Goodacre and colleagues in 2005,(35) interventions have been demonstrated as effective in reducing LWBS, including the implementation of streaming and senior-led triage services in the ED.(36) Another of the proposed quality indicators, time to initial assessment, may be longer amongst patients from socioeconomically deprived groups, with these patients more likely to reattend ED and have a higher mortality rate post-ED discharge.(37) As discussed in Chapter One, robust evidence suggests that total ED LOS beyond 8 hours is associated with increased mortality.(38)

Quality of care measurement using discrete process and outcome measures is attractive due to ease of measurement, immediacy of feedback, and the quantitative nature of the data. However, such measures may not capture the full context of ED care, including how situational factors, clinical acuity, and case mix affect quality. Discrete process and outcomes indicators may be vulnerable to creating a ‘target culture’, where providers may be perversely incentivised to meet a target, deprioritising other aspects of patient care, disenfranchising clinicians, and potentially leading to negative unintended consequences. Perverse incentives can have serious implications and be highlighted as a significant contributor to the deficiencies in the quality of care observed at Mid Staffordshire NHS Trust within the Francis report.(39) As the

UK healthcare establishment reeled from the scandal, the development of patient-reported outcomes was heralded as having potentially transformative potential for improving healthcare quality.(40)

2.3 Patient Reported Outcomes

A fundamental limitation of existing performance measures is that they do not account for the patient's lived experiences of ED care and may risk overlooking what matters most to patients. Failing to appreciate patients' perspectives not only goes against the principle of person-centred care but crucially limits the potential for optimising the quality of care from the patient's viewpoint. Such oversight may lead to unrecognised vulnerabilities in care, resulting in harm. Additionally, health systems and society view personalised care as an ethical, legal, and moral obligation supported by regulatory frameworks.(41) Applying Patient Reported Outcomes (PROs) may present a time-, resource-, and cost-effective means of reliably measuring patients' perspectives of their care.(42) At their core, PROs are patient reports about their health condition or experience independent of clinician or third-party influence. Various methods exist to gather PROs, ranging from qualitative approaches, such as patient interviews and focus groups, to quantitative methods, such as questionnaires. In the emergency care context, the IFEM advocates for measuring patients' perspectives of care and recommends routinely using Patient Reported Outcomes (PROs).(10)

2.3.1 Approaches to Collecting PROs

Although interviews can offer rich and detailed insights into experiences, routinely collecting qualitative data is impractical in the ED setting due to time and resource constraints. Additionally, qualitative data analysis is labour-intensive and requires high expertise to perform with impartiality, rigour, and

reflexivity. In contrast, once developed and validated, survey instruments are easily scalable and can be distributed to large populations. Survey Instruments may provide a cost-effective and straightforward means of collecting data from large groups of patients in the ED.

2.3.2 PRO Instruments

Survey Instruments to assess patients' perspectives of healthcare include Patient Reported Outcome Measures (PROMs), which measure patients' perspectives of their health status or condition of interest; Patient Reported Experience Measures (PREMs), which measure patients; experiences of the healthcare system; and Health-Related Quality of Life (HRQOL) measures, which can be used to monitor the effectiveness of treatments on functioning or monitor conditions over time.(43) Using a structured format, PROMs, PREMs, and HRQOL surveys may identify strengths and discrete vulnerabilities in care from where targeted improvement can result. PREMs, PROMs and HRQOL instruments may be generic and intended for administration to an entire cross-section of patients or condition-specific and designed for specific patient groups.(44)

2.3.3 The role of the Friends and Families Test in evaluating UK ED Care

Despite being commonly utilised in other clinical settings, such as surgery and oncology,(45, 46) PROMs, PREMs, and HRQOL surveys are yet to be routinely adopted in the UK ED setting. Indeed, the 'friends and families' test question (FFTQ) is the most used metric to evaluate care experience in the UK ED setting.(47) This was introduced into the UK NHS in 2012-13 and consists of a single composite question:

> *"How likely are you to recommend this A&E to friends and family if they need similar care or treatment?"*

The FFTQ is a version of a net promoter score (NPS) first proposed by Reichheld in 1965 (48) who argued that businesses could predict loyalty and growth in a commercial context by replacing complex customer experience surveys with a single question indicating brand loyalty.

Whilst proponents of the NPS cite its simplistic appeal and adoption in several health questionnaires since the mid-2000s, the utility of NPS questions for measuring patient experience and satisfaction is unclear. In their discussion of the NPS, Krol et al. argue that the fundamental aim of the NPS, to promote growth, is analogous to increasing patient numbers, which is only sometimes desirable or feasible within healthcare.(49) Furthermore, patients may not understand the purpose of the FFTQ in a healthcare context:(50)

> *Individuals misunderstood and objected to the term "recommend," … while others criticised [the FFTQ] for implying patients have a choice, which is often not the case, particularly for emergency admissions.'*
>
> Davis in '*Are patients being heard? The friends and family test reviewed* (2014).(50)

Aside from difficulties with conceptual understanding, differential validity has been noted from FFTQ findings based on participant characteristics and mode of administration. Sizmur et al. (51) analysed FFTQ responses from 28,564 ED patients. They identified a linear positive association between age and proportions of likelihood to recommend, lower overall ratings amongst females, and the telephone versus online administration. In a systematic review of studies utilising NPS in healthcare settings, including the FFTQ, Adams et al.(52) stated a lack of evidence demonstrating the utility of the NPS to be used to drive improvements in healthcare, a tendency for NPS to over-simplify the

patient experience, and mixed perceptions of usefulness amongst patients and staff. As a result, the NPS is likely to be insufficient as an outcome to measure ED patient experience in isolation.

The considerable limitations of the FFTQ highlight the need for the development, validation, and application of specific measures designed to comprehensively evaluate the experience of patients attending the ED, as well as specific conditions and patient groups. The development of such measures may allow the patient's perspective of care to be meaningfully measured, identify areas for improvement effectively, and assist in meeting current and future challenges to help ensure EM continues to provide a high-quality, patient-centred service moving forward.

2.3.4 Review of currently available PRO instruments relevant to ED care.

A comprehensive scoping review of available PROMs, PREMs and HRQOL surveys relevant to emergency care is presented separately in Chapter Five of this thesis. This scoping review provides critical appraisal, quality assessment, and recommendations for routinely using some currently available instruments. It also highlights research gaps, including the need to develop a suitably validated and reliable Patient Reported Experience Measure for older adults attending the ED. Therefore, the remainder of this chapter will review the epistemology of patient experience, state the rationale for developing PREM-ED 65, and propose aims and objectives for the derivation and validation of the instrument.

2.4 Patient Experience

2.4.1 Patient experience in emergency care

Patient experience is defined by the interactions patients have with the healthcare system.(53) The Picker Institute has expanded this to include respect for patient values, care coordination, information provision, comfort and emotional support and continuity of care.(54) These principles are recognised internationally, and in the UK, the Darzi report—described at the time as "the world's most ambitious attempt to raise the quality and effectiveness of an entire nation's healthcare" (55) –was fundamental in highlighting patient experience as an independent indicator of quality of care. At its core, the report emphasised the importance of patient perspectives and delivery of person-centred care in decision-making:

> *The NHS, local authorities, and social care partners will help improve people's health and well-being by organising services around patients rather than people around services. This will lead to a patient-centred and seamless approach.*
>
> Lord Azra Darzi, Author of *High Quality Care for All* (2008)(18)

Delivery of person-centred care represents a deliberate effort by providers to develop collaborative relationships with patients and promotes shared decision-making aligned to patients' preferences. Patient-centred care may empower patients to take an active role in their assessment and treatment in the ED context, extending to shared decisions regarding investigations, treatment choices, discharge and disposition. Respect for patient dignity, privacy and empowerment is integral to providing patient-centred care, which respects the ethical principles of autonomy, beneficence, and non-maleficence. Involving patients in their care may also increase the efficiency of health systems and

reduce over-investigation, complaints, and litigation. In many healthcare systems, delivering patient-centred care and optimising the patient experience are considered independent dimensions of healthcare quality and value. In Value-Based Healthcare systems, patient-centred care may be linked directly to funding.(56, 57)

From a clinical perspective, evidence suggests that positive patient experience may be linked to improved outcomes, including acute conditions relevant to emergency care. For example, a systematic review conducted by Doyle et al. in 2013 examined the relationship between patient experience, patient safety, and clinical effectiveness.(58) Included studies were analysed for associations between patient experience and clinical outcomes. Positive associations were observed for relevant conditions, including inpatient-, one-year survival, and morbidity from subsequent anginal symptoms in acute myocardial infarction, improved technical care and reduced adverse events in pneumonia (59, 60) and reduced ED attendance with acute asthma.(61) For hospital inpatients in general, interpersonal or process-related problems experienced by patients attending a Swiss Teaching Hospital (n=1518) were associated with increased odds of adverse events, including hospital-acquired infections.(62) A further review by Price et al. (63) supports these findings and identified studies demonstrating positive associations between patient experience, clinical efficiency, and safety. This included patient perceptions of the discharge process and a lower 30-day readmission rate for Myocardial Infarction, Heart Failure and Pneumonia (64) and a relationship between responsiveness and incidence of hospital-acquired infections.(65) The same review also reported studies demonstrating an association between patients' experiences and staff perceptions of institutional safety culture.(66, 67)

Whilst this body of literature supports a link between patient experience and healthcare quality, there are some potential limitations. There is substantial heterogeneity in the methodology, conditions of interest, and outcomes among the identified studies. The effect of contextual and situational factors, including observational biases, cannot be excluded. Furthermore, these studies did not explore the reasons for an apparent statistical association between experience and quality. Due to the potential for confounding effects, a causal link between patient experience and clinical outcomes cannot be easily proven. In response to some of these limitations, Kelley et al. (68) undertook a systematic review and meta-analysis of randomised controlled trials to explore the influence of the patient-clinician relationship on healthcare outcomes. By including only studies with clearly defined objective outcome measures, this aimed to overcome some of the limitations. Included trials (n=13) were assessed as having a low risk of bias, revealing a small but statistically significant association between the patient-clinician relationship and outcomes. Two of the identified studies featured conditions of interest to EM providers. A pragmatic, cluster-randomised RCT conducted by Cals et al. (69) focused on lower respiratory tract infections presenting to primary care and issued enhanced communication skills training to general practitioners in the Netherlands (n=40). Compared to patients in the control group (n=204), those exposed to the intervention (n=227) had a significant reduction in antibiotic prescribing (27.4% vs 53.5%, $p<0.01$) and a non-significant trend towards decreased reattendance (27.9% vs 37%, $p=0.12$). In a separate RCT, Cleland et al. (70) randomised primary care nurses to receive training on communication skills concerning asthma management. Patients exposed to the intervention (n= 236) reported increased asthma-related quality of life scores (6.49 vs. 6.33, $p=0.03$).

Evidence of the relationship between patient experience and clinical outcomes highlights that in addition to a professional and moral imperative, a positive patient experience measurement may be related to improved functional outcomes, morbidity, and even mortality for a range of acute conditions relevant ED care. Therefore, the measurement of ED patient experience may assist in identifying vulnerabilities in care, highlighting structural or process issues where quality improvement may be most effective, and, in turn, enhancing both the person-centredness and effectiveness of emergency care.

2.4.2 Patient Reported Experience Measures

Patient-reported experience measures (PREMs) describe tools developed to gather information from patients regarding their interactions with health services.(71) PREMs are most commonly administered as survey instruments. However, patients' care experiences may also be captured using interviews, focus groups, diaries and handheld devices.(72) Irrespective of the method of administration, PREMs require careful development to ensure that they are appropriate and reliable. This ensures that instruments are attuned to the construct of interest and that responses remain stable over time. PREM development and validation are typically conducted using a multiple-stage process of identifying the target population/ conceptual exploration, item derivation, item prioritisation, survey development, field testing and psychometric assessment. To ensure content and face validity,(73) PREMs may be developed with the relevant stakeholders, including patients, carers, and public representatives. Indeed, Carlton and colleagues suggest a stepwise framework for the involvement of patients and public representatives at discrete points of PRO development, including item derivation, refinement and survey design. (74) Other groups that may be considered stakeholders include health

professionals, administrators, and governmental and non-governmental organisations. Figure 2.1 summarises a general PREM development process.

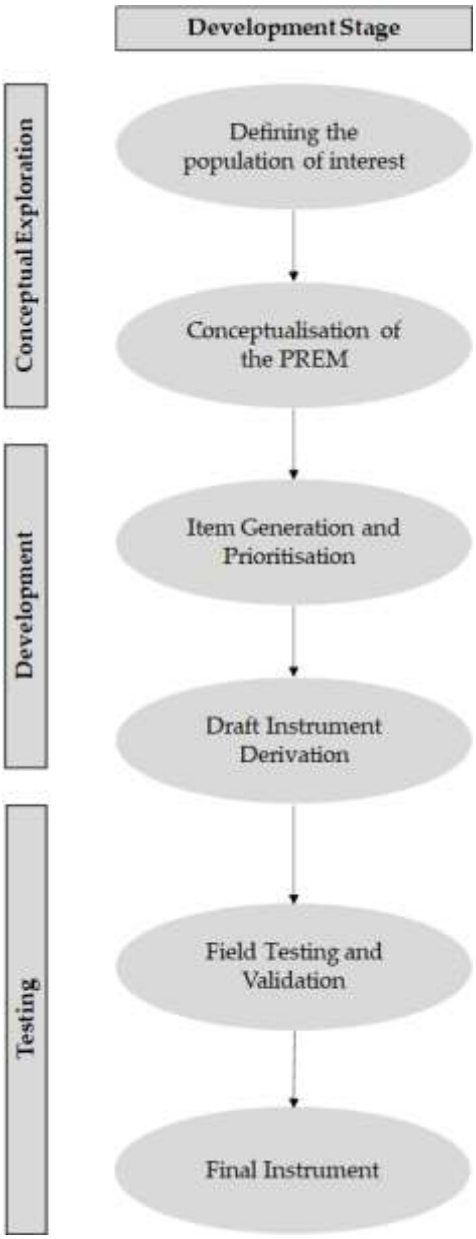

Figure 2.1 Flow chart illustrating the general PREM development process.

Individual patients' experiences and needs may vary due to various factors, including personal and demographic characteristics, presenting complaints, final diagnosis, treatment delivered, and outcome. As the population of patients accessing the ED is inherently heterogeneous, selecting an appropriate patient

population or clinical problem is realistically required to ensure the sensitivity of a resulting PREM. Conversely, the scope of the PREM should be sufficient to enable the inclusion of enough patients so that experience can be objectively assessed and meaningful improvement results.

Consequently, when formulating a PREM, population or problem selection may be based on one or more of the following factors:

- **Identification of a population of interest.** Populations of interest within the ED may include patients at the extremes of age, including children and young people,(75) patients with learning disabilities,(76) older adults,(77) patients with mental health crises,(78) or polytrauma.(79)
- **Identification of a condition of interest.** This may include identifying a common complaint or diagnosis presenting to the ED, such as pneumonia. Conversely, a disease-specific PREM may assess patients' experiences with a rarer diagnosis that may be especially significant, such as Acute Aortic Dissection.(80)
- **Identification of a process of interest.** Examples may include focusing on a specific care process, such as introducing emergency ambulatory care (81) or different regional models of emergency care.(82)
- **Identification of a structural issue of interest**. For example, the measurement of ED patients' experiences of crowding or corridor care.(83)

2.5 Study Rationale

This section will outline the rationale for selecting older adults as a population of interest for the new PREM and justify using chronological age as the single PREM inclusion criterion.

Older adults as a population of interest for a new ED PREM

Demographic shift describes how human populations change over time. In the context of ageing, this means that 2050 the worldwide population of older adults will have doubled.(84) Currently, 18.6% of UK adults are aged over 65, and this number is projected to rise to more than 25% by 2066.(85, 86) On an individual level, ageing manifests reduced physical and psychological functioning, the onset of frailty and increased risk of disease.(87) Ageing results in a cumulative functional deficit, increased incidence of multimorbidity, and occurrence of frequent non-specific geriatric syndromes, including effects from polypharmacy, impaired mobility, falls and syncope, behavioural disturbance, and skin injury.(88) As opposed to providing solely curative treatment, the management of geriatric syndromes tends to be holistically focused and aimed at preventing further functional loss through comprehensive geriatric assessment.(89) On a systematic level, demographic shifts and an ageing population will almost inevitably increase the demand for emergency care systems at a time when the global labour workforce is decreasing and may even present a fundamental threat to the long-term sustainability of health services.(90)

Currently, most EDs are designed to cater for patients with predominantly single-organ pathology and are increasingly focused on optimising patient flow. Developing and providing high-quality emergency care for the ageing population is a pressing priority.(91) This is reflected in the findings of a national emergency medicine research priority-setting partnership conducted by the James Lind Alliance, where the configuration of emergency care for older people formed the second highest priority:(92)

> *Is a traditional Emergency Department the best place to care for frail elderly patients? Would a dedicated service for these patients (involving either a geriatric Emergency*

> *Department or geriatric liaison services (within the Emergency Department) be better? Given that this population is expanding, should our current services be tailored towards this group?*

Priority #2, JLA PSP 2017 (92)

Current evidence suggests that older adults are already a predominant user group in the UK's Emergency Departments (EDs), accounting for nearly one-third of ED visits.(93) The rising proportion of older adults accessing ED care is attributed to rising comorbidities, lapses in primary healthcare, and escalating instances of recurring ED visits among this demographic. The clinical complexity of older adults, often characterised by high acuity conditions, atypical presentations, and non-specific symptomatology, poses substantial challenges for emergency clinicians.(94)

Factors including geriatric syndromes can make a physical diagnosis within the short duration of an ED visit especially challenging (95-97). The co-presence of frailty (98), cognitive impairment (99), and communication or sensory disturbances (100) makes the provision of holistic care an imperative for older adults. This may include the provision of comprehensive geriatric assessments within the ED, which are demonstrated to mitigate hospital admissions, reduce ED length of stay, and decrease mortality rates.(101) However, the practical implementation may be challenged by under-resourcing, crowding, and the prevailing focus on addressing single-organ dysfunction to optimise patient flow.(102)

The rise in the older population's ED attendance is paralleled by an overall increased demand for emergency care internationally.(103) Older adults may be especially vulnerable within overstretched and pressured emergency care

systems and at higher risk of protracted ED length-of-stay associated with increased mortality caused by delayed medication administration, fragmented care, susceptibility to nosocomial infection and circadian disruption.(99)

The development of a robustly developed and well-validated PREM specifically designed for administration to older adults in the ED is proposed to address some of the vulnerabilities encountered in the ED. Not least, by routinely measuring patient experiences, weaknesses in care may become apparent and meaningful areas for improvement may be identified. Emphasis on optimising patients' experiences of ED care may promote the provision of holistic emergency care focusing on individual needs in addition to normal medical and nursing care. PREMs may allow the effect of shortcomings in ED care, such as crowding and corridor care, to be captured from the patient's perspective. Such insights may support broader policy change. Ultimately, the patient-reported experience of ED care may provide a useful means by which the quality of ED care may be measured, in addition to existing structural and process-based metrics.

Significant changes in the provision of geriatric emergency care may be required to meet the challenges of population ageing. Existing examples include the provision of care pathways within existing ED infrastructure,(104, 105), the implementation of nurse-led frailty assessment in trauma,(106) bespoke older peoples' emergency departments,(107) and alternative emergency care pathways for older people.(108) Assessing patient experience is crucial for evaluating the effectiveness of healthcare responses to population ageing, and it offers important insights from the patient's perspective. The PREM-ED 65 project aims to address this need by comprehensively developing and robustly

validating a new PREM designed for administration to older adults attending the ED.

2.5.1 Chronological age as the selection criteria for PREM-ED 65

Defining older age is essential to help guide inclusion criteria and ensure the applicability of findings for research involving older people, including developing and validating patient-reported outcomes. From the outset, chronological age was proposed as the inclusion criteria for PREM-ED 65.

Many bodies, including the World Health Organisation, utilise chronological definitions of older age. For example, ‘later life’ may be defined as being over 50, while older adults are most frequently considered people over 65.(109) Furthermore, the ‘oldest old’ adults may include those aged 85 or above.(110) Chronological definitions may vary based on context and geographical location and may differ in developing regions such as Sub-Saharan Africa.(111) However, the concept of heterogeneity of ageing challenges the chronological definition of older age and considers the differences within the older adult population.(112) For example, many older adults may continue to engage in occupational or recreational pursuits throughout life, whilst others may become clinically frail, chronically ill or disabled. Recent research from the UK Biobank demonstrates that heterogeneity observed in the ageing of biological tissues may explain this effect and predict both life expectancy and risk of premature death.(113) To this end, definitions of older age and chronological age may include biological metrics, functional status, clinical frailty status or psychological age. In addition, subjective ageing—where a person states how old *they feel*—positively correlates with objective parameters.(114)

A chronological age of 65 is proposed as the sole inclusion criterion for the initial development and validation of PREM-ED 65. This is beneficial for several reasons. The chronological age of 65 remains the most widely used definition of older age within the UK.(115) This offers a standardised, recognised criteria that facilitates ease of administration of PREM-ED 65 in the busy clinical setting of the ED and ensures consistency and comparability across sites. Furthermore, an age-based cut-off ensures that the validated instrument represents the older adult age group, including patients who are more clinically frail or functionally limited. In time, chronological age may be combined with other ageing metrics to understand better the nuanced needs of specific sub-populations of older adults.

2.5.2 Summary of Rationale

Developing a new Patient Reported Experience Measure (PREM) for older adults is justified by recognising the demographic shift towards an ageing population. Older people are already a predominant ED user group, and the proportion of older adults requiring emergency care is likely to continue increasing. By 2050, the global population of older adults is expected to double, and the complexities of ageing, such as increased frailty and multimorbidity, present unique challenges for ED care. Geriatric syndromes and more complex presentations underscore the need for future innovation, including developing bespoke geriatric care pathways and emergency care facilities for older people.

The proposed PREM-ED 65 will focus on capturing older patients' experiences in EDs, identifying care vulnerabilities and areas for improvement. As patient experience is a crucial determinant of quality of care, it is envisaged that PREM-ED 65 will be vital for enhancing the quality of ED care and informing policy adaptations to serve the growing demographic of older adults better. The

chronological age-based selection criteria for PREM 65 aligns with its recognition as a standard definition of older age in healthcare. It facilitates ease of administration in the busy ED setting and ensures that the initial iteration is relevant to the older adult population.

2.6 Study Aims and Objectives

This study aims to develop and validate a Patient-Reported Experience Measure (PREM-ED 65) for adults over 65 who attend the emergency department.

Objectives of the PREM-ED 65 study are to:

- Conceptualise the determinants of ED patient experience for older adults.
- Identify currently available PRO instruments relevant to ED care.
- Involve stakeholders to develop and prioritise items for PREM-ED 65.
- Perform initial psychometric validation for PREM-ED 65.

2.7 Chapter Summary

This chapter has provided a robust rationale for developing and validating a new Patient Reported Experience Measure (PREM) for older adults over 65 attending the ED. As first highlighted by pioneers such as Codman and Donabedian and brought to the forefront of UK health policy by Darzi, patient experience is integral to care quality. Patient experience has recently been demonstrated to be linked to clinical outcomes for a range of conditions relevant to the ED. To measure patient experience, PREMs provide a potentially elegant means of identifying strengths and vulnerabilities in ED care processes, from which improvement may occur. PREMs may additionally be used to help assess providers and compare systems performance. As is outlined in the scoping

review (Chapter Five), some recent progress has been made in developing ED PROs. However, few specific measures have yet been designed to cater to the interests of patient populations, clinical conditions, or care pathways.

This chapter has provided specific justification for selecting older adults as a population of interest for developing a new ED PREM. Older adults already form a predominant ED user group in many developed settings, and the global population is set to continue advancing in age due to demographic shifts. Providers must adapt emergency care to meet the challenges posed by this phenomenon, including an inevitable increase in the incidence of ED presentations characterised by atypical presentations, clinical frailty, and geriatric syndromes. Crucially, the traditional emergency care pathway, focused on resolving single-organ pathology, may not be the most appropriate nor achieve the best clinical outcomes for older adults moving forward. Additionally, older adults are demonstrably more vulnerable to frequently encountered shortcomings in ED care, such as overcrowding, corridor care, and exit-block. As such, this chapter identifies the need for ED services to adapt and transform to meet the needs of older adults, including routine provision of more holistically focused care and, specifically, comprehensive geriatric assessment.

Whilst chronological age forms an imperfect definition of older adults due to heterogeneity of ageing, an age of 65 is justified as the initial selection criteria for PREM-ED 65 to promote its development and validation as an inclusive instrument for older adults in the ED and facilitate ease of administration in the busy ED setting.

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Chapter 3 Methodology

What this chapter adds

This chapter:

- Outlines the significance of the selected methods for developing and validating the PREM-ED 65 instrument.
- Gives a detailed insight into the research designs for each stage of the development and validation process.
- Discusses ethical issues pertinent to developing and validating the PREM-ED 65 instrument.
- Acknowledges limitations in the methodology employed to develop the PREM-ED 65 instrument.

3.1 Outline

This chapter provides a synopsis of the PREM-ED 65 study before thoroughly exploring its philosophical, theoretical, and methodological underpinnings. It will discuss the justification for the mixed-methods research approach and adherence to international COSMIN standards. Individual methodological choices are justified, and essential study techniques and procedures are described. Pertinent ethical aspects of the research are discussed, and a summary timeline of the research is provided.

3.1.1 Note on duplication

As a hybrid thesis, elements of this chapter will inevitably be duplicated within the published manuscripts presented in subsequent chapters. Nonetheless, this

integrative chapter aims to unite the individual methods used to develop and validate PREM-ED 65 and provide details on the theoretical approach and rationale for the methodological choices.

3.2 Summary of PREM-ED 65 Study

The PREM-ED 65 study comprised three phases consisting of (i) conceptual exploration, (ii) PREM development, and (iii) PREM testing. Research activity within each stage is summarised in Figure 3.1.

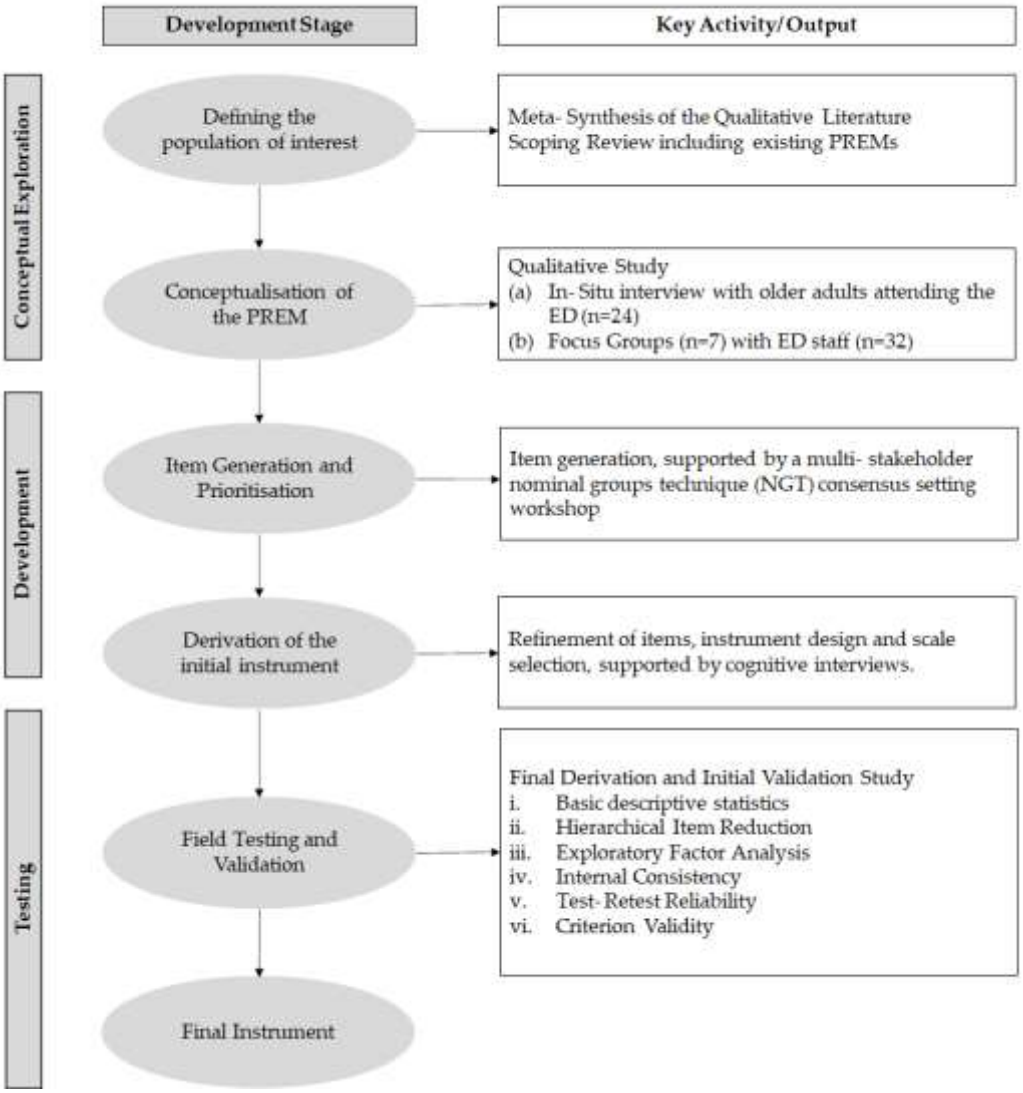

Figure 3.1 Flow diagram of the PREM-ED 65 development process.

This section provides a brief overview of the research activity within each study phase. Later in this chapter, the methodological choices and study procedures are described in more detail.

3.2.1 Conceptual Exploration (First Phase)

The first phase of the PREM-ED 65 study was conceptual exploration. This aimed to inform the development of PREM-ED 65. Firstly, the determinants of patient experience in the ED were conceptualised by performing a qualitative systematic review and meta-synthesis of existing research on patient experience in adult ED patients. Thematic synthesis of the included papers facilitated the generation of analytical themes and a new conceptual model, which focused on patient needs, to understand patient experience in the ED.(1, 2)

Following the qualitative systematic review, a systematic scoping review, conducted according to PRISMA-ScR guidelines, identified existing health measurement instruments already used in the emergency care setting.(3) This review also assessed each instrument's dimensionality, psychometric characteristics, external validity, and real-world usability.

The final part of the conceptual exploration focused on the specific experiences of older adults in present-day ED settings. This was accomplished by conducting interviews with patients over 65 during their ED stay and forming separate focus groups with ED clinical staff responsible for providing care to older adults. Separate framework analyses of the interview and focus group data provided further validation for the conceptual framework, identified the importance of team behaviours as a determinant of experience, and provided

insights into the impact of caring for older adults in suboptimal ED settings on staff wellbeing.

3.2.2 Development of PREM-ED 65 (Second Phase)

The second phase aimed to develop a draft version of PREM-ED 65 that could undergo field testing and psychometric assessment. A comprehensive draft item list was developed by triangulating findings from the qualitative meta-synthesis, interviews, and focus groups.(4) Using a one-day stakeholder workshop based on the nominal groups technique, multiple stakeholders assessed the comprehensibility of items and determined priorities for their inclusion within the PREM-ED 65 instrument.(5) This study sought to obtain consensus on the contents of the draft version of PREM-ED 65 before testing and validation. As a final step in development, ‘read aloud’ cognitive interviews were conducted with seven workshop participants to determine the draft instrument's final item structure and layout.

3.2.3 Testing of PREM-ED 65 (Third Phase)

Following the development of an 82-item draft instrument, field testing and psychometric validation were conducted among patients 65 years or older during an Emergency Department (ED) visit. Analysis eliminated unnecessary items and confirmed psychometric characteristics, including content validity, structural validity, internal consistency, test-retest reliability, and criterion validity. As a result, a finalised, 25-item version of PREM-ED 65 is proposed.

3.3 Research Philosophy

3.3.1 Ontological Perspectives

Ontology describes the philosophical study of the nature of reality.(6) From the perspective of PREM-ED 65 development, understanding the experiences of older adults receiving ED care is most closely aligned with a realist perspective.

The central tenet of realism lies in the assumption that reality may be objectively understood. As such, traditional realist approaches assume humans can develop an infallible understanding of reality and objectively measure all aspects of reality. Critical realism represents a further evolution of this paradigm that retains the core concept of an objective, single reality but also acknowledges that perception by the human mind is subjective and fallible. This is because of myriad factors, including language, socialisation, interpretation of sensory stimuli, and other unobservable variables.(7, 8) Compared to 'classical' realist theory, critical realism is more aligned with research involving patients' lived experiences by enabling acknowledgement of the complexity of healthcare and that different individuals' experiences of healthcare are likely to vary. For example, ED patient experience may be framed not only by the acute attendance but by interactions with pre-hospital caregivers, prior healthcare encounters, provider and institutional cultures, teamwork and human factors elements, governmental and clinical policies, and application of clinical evidence and guidelines.

3.3.2 Epistemological Perspectives

Guided by ontological assumptions, epistemology concerns the nature of human knowledge acquisition.(9) Fundamentally, the epistemology of PREM-ED 65 is centred on investigating and measuring older adults' reality in the ED. Prominent epistemological paradigms that may assist understanding of patient experience include positivism, interpretivism, and postpositivism.

Positivism, founded in the late 19th century, aimed to establish a scientific foundation for knowledge and the social sciences. Positivism focuses on acquiring quantitative data using experimental methods to draw generalisations and generate objective evidence.(10) In contrast, interpretivism arose as a

criticism of the positivist approach, focusing on investigating subjective reality through individuals' experiences.(11) Postpositivism, a critical evolution of positivism, acknowledges the fallibility of human-generated hypotheses and highlights that science often progresses by eliminating false theories rather than proving truth. Within healthcare, postpositivism acknowledges uncertainty in medicine and highlights the potential falsifiability of evidence-based medicine.(12) A prominent example within emergency care is the falsification of seminal work on early goal-directed therapy in sepsis, by later trials refuting original hypotheses.(13, 14)

Additional philosophical approaches that may influence the understanding of patient experience include humanism and postmodernism. At its inception in the 16th century, the Renaissance humanist movement promoted the study of human endeavour from a secular perspective, prioritising the pursuit of knowledge and recognising individual autonomy and agency. According to its protagonists, humanism brought medicine "out of medieval darkness to a new age."(15) Since the late 20th century, humanist approaches have informed the development of person-centred healthcare and professional standards for emergency medicine and nursing.(16, 17) Core tenets of humanism, including respect for patient autonomy, human rights, and delivery of compassionate care,(18) underpin much of the rationale for health and patient experience measurement.

The postmodernist movement arose in the 1970s and aimed to deconstruct and critique received wisdom, considering how societal structures and culture influence perceptions of the truth. Postmodernism has been described as 'incredulous' to metanarratives and specific to the healthcare context, has

challenged medical hegemony, emphasised the contribution offered by nursing and allied health professions, and shifted the balance of power from professionals to patients. (19, 20) Crucial to promoting understanding of structural inequality in healthcare, postmodernist approaches to health policy have recently contributed to debates surrounding the medicalisation of gender and self-identity.(21) Specific to patient experience, postmodernist theory may help explain the presence of temporal effects in experience and how differing cultural and social phenomena may influence patient experiences, health behaviours, and engagement with healthcare.

Although each approach described offers a perspective to help understand patient experience, none is singularly aligned to guide PREM development. In cases where a single epistemology does not address research requirements, adopting a pluralistic multi-epistemological approach may exploit relevant aspects of more than one paradigm. In doing so, multi-epistemology research may yield a deeper, multidimensional perspective on a research question or problem than is possible using a single epistemology. (22, 23) Multi-epistemology may be conducted using a dialectic approach, where each selected paradigm is assigned equal prominence, or focus on the complementary strengths of the paradigms.(24) At first glance, such approaches are an attractive proposition for PREM development as measures should allow individual patients' subjective experiences to be captured yet must also produce quantitative data from which more general assumptions can be made.(25) However, assessing the compatibility of different paradigms is an essential consideration when determining the feasibility of multi-epistemology.(26) Unfortunately, some fundamental conflicts are apparent when considering the paradigms mentioned above, particularly when

considering how each differs in its approach to understanding patient experience and measurement. For example, research that aims to produce a generalisable psychometric instrument is at odds with the individual-centrism of humanism and interpretivism, both of which resist the notion of reducing subjective data into generalised survey items. Postmodernism may reject health measurement altogether, proposing that reality is dynamic and recognising that no single instrument can account for all social or cultural groups.(27) Conversely, whilst positivist and postpositivist approaches champion data measurement and quantification, disregard for the subjective directly conflicts with the interpretivist paradigm.

Pragmatism as a way ahead?

As already identified, no single epistemology is ideally placed to guide PREM development. Furthermore, multi-epistemology is unsuitable for guiding PREM development due to irreconcilable conflicts between established epistemological paradigms. A very similar epistemological ‘crisis’ may be observed when considering clinical emergency medicine, which focuses on making sense of individual patients’ subjective signs and symptoms whilst also requiring its practitioners to quantify pre- and post-test probabilities and perform complex risk-benefit analyses.(28) Hence, as with PREM development, none of the described epistemological approaches perfectly align with emergency medicine at the bedside. This epistemological uncertainty contrasts with other clinical specialities where theoretical alignment with a single paradigm is more readily accomplished, such as the positivist approach that may be adopted when a pathologist or radiologist uses data to confirm a diagnosis.(29) This may more readily guide related research in disciplines with clear monoist epistemological foundations.

So, where *does* emergency medicine and its research belong? In a commentary discussing future approaches to emergency medicine research, Coats posits that ‘emergency medicine is a very practical speciality in which ‘what works’ is more important than ‘why’, making a case for the pragmatic paradigm as ideally aligned to the speciality practice.(30) Conceptually, pragmatism has been defined as an approach “that evaluates assertions solely by their practical consequences and bearing on human interests”.(31) Importantly, this permits pragmatist researchers to apply quantitative and qualitative methodologies to achieve a desired goal and supports the iterative development of new understanding, such as mixed methods research.(32, 33) Notably, the pragmatic paradigm emphasises the research subject as an individual and recognises that multiple stakeholders may contribute to understanding the topic, making pragmatism highly relevant to patient-centred research.(34) In the context of PREM-ED 65, alignment of the research with a pragmatist paradigm enabled the development of a measure that is not only theoretically sound but also user-friendly and capable of effecting change in an actual real-world ED setting. The applicability of pragmatism to emergency research is not limited to health measure development or observational studies; prominent emergency clinical trials have adopted this approach, including the CRASH-2 trial that investigated the effect of tranexamic acid on bleeding in over 20,000 trauma patients worldwide.(35) It is feasible that adoption of a traditional epistemological approach may constrain the scope, and resultant clinical impact, of novel emergency trials such as CRASH-2.

Summary of epistemological justification

This discussion has highlighted that no single epistemology perfectly aligns with PREM development. Whilst each approach discussed offers potentially valuable

perspectives to assist in understanding patient experience, established epistemologies, including positivism, interpretivism, postpositivism, humanism and postmodernism, are each too limited to facilitate the multiple methods design required for health measure development. Embracing epistemological plurality and integrating multiple approaches has intuitive appeal but, again, does not provide a solution for PREM development due to irreconcilable differences between paradigms concerning patient experience and health measurement. Conversely, pragmatism allows clinical researchers to select methods best placed to achieve a desired endpoint. It, therefore, provides a preferable epistemological foundation for clinical emergency medicine and much of its research, including PREM-ED 65.

Despite its positive alignment to mixed methods research and health measure development, the adoption of the pragmatic paradigm is accompanied by an essential caveat. While the approach permits considerable freedom in research design, careful consideration and justification for choices were necessary to ensure that PREM-ED 65 represents a valid and reliable instrument. Therefore, the next section of this chapter describes how the PREM-ED 65 study embraced both idiographic and nomothetic methodological perspectives. This is followed by critical justification for selecting theoretical approaches that informed the research.

3.3.3 Methodological Perspectives

"The particular eternally underlies the general,
the general eternally has to comply with the particular."

J.W. Goethe, 18th Century polymath (1749- 1832)(36)

The above quotation, attributed to 18th-century German polymath Johann Goethe, encapsulates the methodological challenge inherent in health measure development. That is, health measures must seek to respect and capture individual experiences while identifying general patterns in human perceptions from which broader assumptions can be made. As such, it was recognised that both idiographic and nomothetic methodological perspectives were required to guide the development of PREM-ED 65 . The initial qualitative research followed an idiographic paradigm defined by a detailed study of individual experiences.(37) This is reflected by in-situ interviews with ED patients and, to some extent, focus groups with professional caregivers. Idiographic research is exploratory and attempts to obtain rich, detailed data. In contrast, the progression of the study to prioritise candidate items and perform quantitative validation of the draft version of PREM-ED 65 followed a nomothetic paradigm. Nomotheism (derived from *gr.* 'law') describes attempts to identify broad, general patterns from trends in observed data.(38) Hence, nomothetic paradigms apply where PREM data is analysed on a population level to evaluate services, identify areas for quality improvement, and drive change.

Within health measurement, a frequent criticism levelled at the nomothetic paradigm is its reductionist approach, which can be defined as 'the practice of describing a complex phenomenon in terms of its simple or fundamental phenomena'.(39) A potential drawback of PREMs as a reductionist approach to capturing patient experience is the misassumption that determinants of

individuals' experiences are fixed. As such, the ‘narrative’ of an individual patient experience may be lost, and the importance of nuanced care experiences may be under-recognised.(40) This may create missed opportunities to improve care, especially amongst under-represented groups. Meadows (2021) challenges the nomothetic approach to interpreting patient-reported data and argues for the analysis of data using a multiple-methods approach guided by pragmatic epistemology.(41) In the future, subjecting patient-reported data to hermeneutic analysis instead of literal interpretation may promote a more reflexive approach that considers the underlying meanings of findings and the potential data limitations.(42)

3.4 Theoretical Approaches

The PREM-ED 65 study's theoretical approaches were qualitative inquiry, patient-centred care, cognitive theory of survey response, and psychometric theory. This section describes the justification for the choices made and the role of each approach in the research design and conduct.

3.4.1 Qualitative Inquiry

Qualitative inquiry is used throughout healthcare to explore and better understand patient experiences, generate theories and hypotheses, and offer detailed insights into phenomena that are difficult to measure or explain using quantitative methods. By focusing on the patient's perspective, qualitative research methods can uncover specific factors shaping lived experiences of care.(43, 44) As such, qualitative theory often guides the foundation of health measure development by ensuring that items are grounded in patients’ real-world experiences. For the PREM-ED 65 study, qualitative research aimed to conceptualise older adults’ ED experiences and inform the generation of candidate items. Qualitative approaches that were considered included

ethnography, phenomenology, and interpretive description. Each of these approaches will be discussed, and the choice to follow an interpretive descriptive approach justified.

Ethnography

Ethnography is a well-established qualitative approach within health research. It explores complex cultures through fieldwork and participant observation. With its origins in anthropology, the ethnographic approach aims to deeply understand a group's culture, including its norms, language, and external interaction.(45, 46) In the context of PREM-ED 65, ethnography was initially considered to generate a deep conceptual understanding of older adults' experiences in the ED, their interaction with staff, and their participation in healthcare. Examples of ethnographic research conducted in the ED include Hillman's exploration of patients' involvement in legitimising their ED attendance in a large UK ED. Through over 250 hours of observation, the study provided an in-depth insight into how patients interacted with triage staff to obtain desired care. The study highlighted that patients unable to justify their presentation were more likely to be redirected away from the ED, and that patients were expected to take responsibility for self-care.(47) Similarly, Olthuis explored patients' experiences in a single Netherlands ED using an ethnographic approach and identified discrete patient 'concerns' including anxiety, expectations, care provision, endurance and recognition.(48)

Whilst these studies confirm the feasibility of an ethnographic approach for gaining an in-depth perspective on patient experiences in relation to wider ED culture, limitations that precluded its adoption for the PREM-ED 65 study included time and resource requirements, the potential for observer bias amongst staff within the ED—especially given the researcher's coexisting

clinical role as an emergency physician—and a risk of generating an excessive quantity of data, leading to difficulty in generating candidate items. In addition, ethnographic observation does not yield insight into the underlying subjective meaning of observed patient experiences, which further limits the utility of this approach to generate candidate items.

Phenomenology

Phenomenology, first proposed by Edmund Husserl in the late 19th century, was also considered as an approach to conceptualising older adults' ED experiences. Husserl sought to describe the lived experiences of others whilst attempting to eliminate the influence of the researcher perspective through *epochè,* which describes the process of bracketing and separating one's emic perspective from the research.(49) Whilst descriptive phenomenology aims to provide insight into the meaning of a phenomenon without influence from the researcher, later proponents of the approach, notably Martin Heidegger, recognised the role of researcher interpretation and co-creation of meaning with participants, giving rise to interpretive phenomenology.(50, 51) Frank et al. provide a relevant example of phenomenology in the ED by interviewing patients to develop a measure of their participation in care.(52)

Relevant strengths of the phenomenological approach for conceptualising older adults' ED experiences include its inherent comprehensiveness, the potential to produce detailed descriptions and result in a thorough understanding of patient experience. However, like ethnography, the quantity and complexity of data may mean that translating phenomenological data into candidate PREM items is challenging. In addition, phenomenology requires advanced training and interpretive skills developed over time, which may mean phenomenology is a less suitable approach for a novice researcher new to qualitative research.(53)

Considering these limitations, the researcher's background, and flexibility conferred by the selected pragmatist epistemology, it was decided that an accessible and practically grounded method of qualitative inquiry was required to guide item generation for PREM-ED 65.

Interpretive Description

Interpretive description was considered a third theoretical approach to guide the qualitative component of the PREM-ED 65 study.(54) Developed initially in nursing, interpretive description provides a flexible approach to understanding clinical problems and patients' experiences that may be obtained using multiple methods, including interviews, focus groups, and observation. The approach is commonly applied by clinician-academics exploring health experiences, such as asthma, ED triage, and vulnerable populations.(55-57)

Interpretive description is a flexible approach designed to facilitate practical health research objectives. It is closely aligned with the pragmatic epistemology already selected to guide the development of PREM-ED 65. As opposed to the all-encompassing objective of ethnography or phenomenology, interpretive description permits a more focused strategy to explore and identify discrete determinants of the patient experience.(58) Significantly, this facilitates item generation for health measure development. As such, the interpretive descriptive approach was deemed the most appropriate theoretical perspective to guide the qualitative phase of the PREM-ED 65 study. Identified challenges of the interpretive descriptive approach include its potential for subjectivity, the potential for limitations in the transferability of findings, and the potentially resource-intensive nature of data collection and analysis.(59) Recommendations regarding reflexivity, rigour, and effective communication of findings have been followed to overcome some of these challenges.

3.4.2 Person-Centred Care

Person-centred care (PCC) is a multidisciplinary model that emphasises treating patients as individuals and equal partners.(60) Shaped by the emergence of psychology as a discipline, the increased influence of the nursing profession, and major human rights movements, PCC represents a departure from the 'benevolent paternalism' that predominated the patient-provider relationship for much of the 20th century.(61-63) For patients, person-centred care recognises individuals' potential to manage their health actively instead of being a passive care recipient, respecting the ethical imperative of patient autonomy and preferences. Whilst PCC is long established as a feature of primary and long-term care settings, evidence demonstrates a range of potential facilitators in the acute setting, including patient-centred care plans, optimisation of bedside communication and the delivery of integrated care.(64) In the ED, PCC provision may be further promoted by balancing relational and technical care provision, legitimising patients' decision to attend the ED, optimising relationships between staff and care for relatives, and reducing the stressfulness of the ED environment.(65) Delivering person-centred care leads to reduced ED length of stay, reduced LWBS and greater patient satisfaction. Barriers to delivering Person-Centred Care in the ED include crowding and exit-block, a stressful work environment, poor staff skill mix, and power differences between staff.(66) Furthermore, despite its importance, process and outcome metrics commonly used to monitor ED performance do not consider individual patient preferences. PREM-ED 65 may help resolve this problem for older patients by allowing care preferences to be stated and heard and providing an additional means of measuring system performance. As detailed later in this chapter, the involvement of patients, carers and other stakeholders throughout

the research ensured that PREM-ED 65 items represent what matters most to patients.

3.4.4 Cognitive Theory of Survey Response

Pioneered by social psychologist Norbert Schwarz from the 1980s onward, the cognitive theory of survey response provides a framework for understanding how people respond to survey questions.(67) The theory asserts that participants do not simply respond to items in a linear ‘question-answer’ format but form complex judgements resulting from their comprehension of the question and ability to retrieve and evaluate relevant prior information. Responses may also be framed by participants’ cognitive ability, prior knowledge beliefs and personal attitudes surrounding a subject, their emotional state and mood, cultural background, language proficiency, motivation, and desire to conform to social norms.(68) As such, survey answers may be formulated iteratively and, after a tentative judgement has been made, may be edited by participants based on factors such as social desirability, perceived expectations of the surveyor, or concerns about confidentiality or anonymity. By way of example, these effects were demonstrated in a recent assessment of situational judgement tests in health education.(69)

Explaining how participants respond to survey items gives insight into where measurement error and response bias may occur. For example, errors in comprehension may occur where items are too complex, ambiguous, or double-barrelled; retrieval errors may result from inaccurate recall of information; judgement errors may result from cognitive biases and heuristics; and response editing errors may result from deliberate misreporting to acquiesce or represent social norms.(70)

Understanding the cognitive theory of survey response has guided the multiple stakeholder workshop, questionnaire design, and scale selection and provided a clear rationale for performing cognitive interviews for pre-testing PREM-ED 65.

3.4.4 Psychometric Theory

Psychometric theory is the branch of psychology that focuses on the technique of psychological measurement and has influenced every stage of PREM-ED 65 development, including item generation and selection, instrument design, and testing.(71-73) Fundamentally, the application of psychometric theory ensures that PREM-ED 65 exhibits validity and reliably measures older peoples' ED care experiences. This section will consider how psychometric theory influenced approaches to item generation, item prioritisation and psychometric testing for PREM-ED 65.

Approaches to guide item generation

As discovered during the scoping review of existing measures (Chapter Five), techniques for item generation are often incompletely or inadequately described in studies of health measure development. This is surprising given the vital importance of this step, as emphasised by Streiner et al., who assert that “no amount of statistical manipulation after the fact can compensate for poorly chosen questions” within a measure.(72) Proposed approaches for item generation include derivation from the literature, informant interviews, clinical observation, or underpinning theory. Alternatively, primary research may be designed to identify candidate items, including literature reviews and primary qualitative studies.(73) The role of expert opinion in generating new items is contentious because of issues defining who constitutes an ‘expert’, and challenges obtaining a representative sample that may predispose to bias.

Nonetheless, Streiner suggests that experts can potentially contribute to representing the latest thinking in a subject area.(72) The PREM-ED 65 study selected a research-driven approach to conceptualising older adults' ED experiences and identifying candidate items de novo. This approach aimed to produce items that were comprehensive, original, and potentially reproducible. As described in Section 3.7, findings from the qualitative meta-synthesis, interviews with patients and staff focus groups were triangulated to formulate draft items, which were then clarified during the multiple stakeholder workshop.

Approaches to guide item prioritisation

Questionnaires that are excessively lengthy, difficult to comprehend, or contain irrelevant items may reduce participant engagement and response rates, and increase respondent fatigue and response biases.(74) To avoid these pitfalls in developing PREM-ED 65, developing structured methods to guide item prioritisation was considered at the study's outset.

As with item generation, the existing literature offers sparse guidance on prioritising items for inclusion in a health measure. A commonly employed approach is to obtain expert consensus, achieved through individual discussions with experts or as part of a consensus conference. While delivering rapid results, unstructured approaches do not provide a reproducible method and may be prone to bias.(72) These shortcomings may compromise the patient-centredness and content validity of the resulting measures. To overcome this, a structured and reproducible approach to item prioritisation was planned for PREM-ED 65, with both the Delphi method and the Nominal Groups Technique (NGT) considered. A joint strength of these approaches is that they are reproducible and offer a broader range of stakeholders the opportunity to interact and inform the draft item list. For PREM-ED 65, stakeholder groups of

interest included older adults, their careers, health professionals, and third-sector organisations advocating for older adults.

The Delphi method is frequently used for prioritisation and consensus setting in health research, including within health measure development.(75, 76) It consists of multiple questionnaires usually administered to subject matter experts but may extend to ‘non-expert’ stakeholders. Following each Delphi round, questions are modified based on participant feedback, and the process is repeated iteratively until adequate consensus is reached. Delphi studies are typically administered electronically using online survey platforms and consist of at least three rounds of questioning.(77) This method can represent a resource- and cost-effective means of performing prioritisation. It may be beneficial when involving participants from a wide geographical area for whom travel is impossible. However, obtaining representative samples of ‘experts’ within a topic area involving mixed groups of stakeholders, the requirement for sustained participant contribution over months, and resultant dropout between rounds are prominent limitations of the approach.(78) Specific to PREM-ED 65, administering a Delphi study to multiple stakeholders, including older adults and lay/ non-expert participants, was deemed likely to amplify these effects. In addition, Delphi risked excluding stakeholders with low technology literacy or no internet access, placing a sustained burden on research-naïve participants, and risking unresolvable conflict between diverse stakeholder groups or a situation where consensus was not possible.(79, 80)

The nominal group technique (NGT) overcomes some of the limitations of the Delphi method by seeking to perform prioritisation amongst stakeholders assembled within a single location. The NGT provides a structured ‘in-person’

approach to prioritisation and consensus setting that is generally performed in stages consisting of (i) initial idea generation, (ii) forming of a team to expand ideas, (iii) clarification of ideas, and (iv) voting/ re-voting.(76, 81, 82) For the PREM-ED 65 study, the NGT was the preferred approach for item prioritisation as it facilitates inclusivity and active participation from various stakeholders, including older adults and their carers, healthcare professionals, and third-sector representatives advocating for older people. Discussion between NGT participants to help generate ideas and resolve uncertainties is a key strength of the NGT approach; disagreement and constructive conflict may be beneficial in forming robust group consensus.(83) Potential problems such as individual participant dominance, interpersonal conflict, and potential for 'groupthink' were proactively tackled by delivering prior training to the group facilitators—for example, by playing a 'devil's advocate' role (84)—and delivering clear briefing instructions to participants. For PREM-ED 65, the NGT methodology was modified to reflect that a list of candidate items was already developed. Hence, the initial idea generation stage was not required. Instead, participants were asked to perform a comprehensibility assessment of the generated items and allowed to suggest any that were missing. This modification reduced participant burden and ensured item prioritisation could be accomplished within a day. Further details on the design and operationalisation of the NGT workshop are provided in Section 3.6.2 and Chapter Eight of this thesis.

Approaches to guide psychometric testing

In the context of health measurement, psychometric testing describes the approach to measuring an instrument's validity, reliability, and effectiveness. In the context of PREM-ED 65, psychometric testing was employed to identify unnecessary or irrelevant items, confirm the structural validity of items using

factor analysis, assess the internal consistency of measurement scales, test-retest reliability, and criterion validity compared to the NHS Friends and Families' test. Each approach is discussed in more detail in Section 3.6.3 of this chapter. The complete validation study is presented in Chapter 10.

3.5 Research Approach

The PREM-ED 65 instrument was developed using an exploratory sequential mixed methods approach, where 'researchers collect and analyse both qualitative and quantitative data within the same study'.(85) This definition differs from that of multi-methods research, where different methodologies may be applied independently but without the necessity of mixing or integrating the data.(86) For PREM-ED 65, harnessing the strengths of multiple research strategies was crucial to meet the project's aims. Whilst adding some complexity, advantages of mixed-methods research include obtaining a comprehensive understanding of an issue or finding, corroborating and evaluating findings using more than one approach, and obtaining richer data than possible using a single-method approach.(87, 88)

3.5.1 Adherence to COSMIN Criteria

From the outset, the study was designed to adhere to the principles of the international Consensus Standards for selecting Health Measurement Instruments (COSMIN) group. Over time, the COSMIN group has provided definitions of health instrument measurement properties,(89) guidance for conducting systematic reviews,(90) a risk of bias checklist,(91) and a study design checklist.(92)

Adherence to the COSMIN guidelines and documents throughout the PREM-ED 65 study promotes methodological rigour, standardised reporting of findings,

easy identification of limitations, facilitation of onward development, and adoption of health measurement instruments in the clinical setting.

3.6 Overview of Methodological Choices

Following the previous discussion of general theoretical and research approaches for the study, this section will consider the specific methodological choices made to develop and validate PREM-ED 65.

3.6.1 Methodological Choices to Guide Conceptual Exploration

Qualitative Systematic Review and Meta-synthesis.

Findings of individual qualitative studies may be challenging to transfer to external settings due to methodological limitations, including small sample sizes, sampling bias, limited external validity and limited transferability of findings to other settings. Further potential limitations of qualitative research include dependency on the individual researcher's skills, observational biases resulting from researcher presence, and difficulty demonstrating rigour.(93) Meta-synthesis provides a valuable means to address some of these limitations by identifying and rigorously reviewing a body of existing qualitative research and conducting an in-depth analysis and structured synthesis of the findings. As such, it may be more effective in helping inform clinical practices, policy development, and research priorities than singular qualitative studies.(94) A key strength of meta-synthesis is its ability to deepen understanding around a topic, enabling the generation of broader conclusions and recommendations.

As an early component of the PREM-ED 65 investigation, a PRISMA-compliant (95) systematic review was performed to identify qualitative studies exploring the experience of adult patients in the ED setting. From the data, the thematic meta-synthesis aimed to identify determinants of ED patients' experiences. This

led to the formulation of a new conceptual framework for understanding patients' experiences in the ED and informed the design and analysis of subsequent interviews and focus groups.

Scoping Review.

The scoping review aimed to identify existing PROMs, PREMs, and HRQOL instruments applicable to adult ED patients and provide an evidence-informed rationale for the PREM-ED study. As a research methodology, scoping reviews map the key concepts underpinning a research area, performing an essential role in generating and clarifying the extent of knowledge surrounding topics.(96) Unlike other evidence synthesis methods, scoping reviews are exploratory and broadly address questions. This includes understanding current research activity in an area, allowing for preliminary topic mapping before formal systematic review, summarising current research findings, and facilitating gap analysis.(97) Scoping reviews use a similar search strategy to systematic reviews, obtaining evidence from the academic literature. Still, they should also seek evidence from the ‘grey literature’, defined as documents not controlled by commercial publishing organisations. (96) Examples of grey literature include theses, dissertations, and reports from governmental and non-governmental organisations.(98)

For the PREM-ED 65 study, the remit of the scoping review was expanded to include an assessment of dimensionality, psychometric characteristics, and external validity/ ‘real-world’ usability of the included instruments. By doing so, the study identified gaps in current PRO provision for emergency care and detailed the methodological strengths and weaknesses of the currently available instruments. This knowledge guided the onward development of PREM-ED 65. It is hoped that the review will interest clinical providers who wish to identify

existing PROMS, PREMs and HRQOL instruments to support quality improvement and research activity in emergency care.

Interviews and Focus Groups

Following the scoping and qualitative reviews, interviews with patients aimed to explore older adults' ED care experiences specifically. The semi-structured interviews were conducted with patients aged over 65 during an ED visit and, as such, are referred to as 'in situ' throughout this thesis. The interviews were conducted immediately before or after the attending clinician's decision to admit or discharge the patient. The feasibility of this approach for obtaining qualitative data is implied within the existing literature and has been cited as a useful approach to complement other data collection methods.(99) Whilst the often chaotic environment of the ED may seem unsuitable for real-time qualitative investigation, in-situ interviews have been successfully used in emergency care research, including to explore patients' reasons for accessing emergency care and patient preferences in the ED.(100, 101) Furthermore, patient 'care rounds' conducted locally in a South West ED demonstrate that patients are amenable to being approached and asked to communicate their ED experience to a senior clinician during an attendance.(102) The lead researcher observed these rounds in advance of the study, enabling a first-hand assessment of the feasibility of this approach in the ED.

From a methodological standpoint, the benefits of the 'in situ' approach included mitigating the negative effect of recall biases that are prevalent with retrospective patient interviews, particularly among older adults.(103) In addition, fewer organisational and logistical barriers were encountered compared to retrospective recruitment, without loss to follow-up, which is frequently encountered with mail or telephone survey administration.(104)

Communication difficulties associated with remote/ telephone interviews were avoided.(105) Sampling biases were deemed less likely by recruiting patients during their ED visit, where it was straightforward to access a representative sample of participants, as opposed to retrospective selection.

For the PREM-ED 65 study, patient interviews aimed to expand on the findings of the qualitative systematic review and meta-synthesis, and directly contributed to the generation of the draft items. To accompany the patient interviews, focus groups with staff provided the additional perspectives of professionals caring for older adults in the ED. By doing so, focus groups helped ensure that the experiences of those under-represented within interviews, such as older adults living with severe frailty or communication difficulties, were considered in generating PREM-ED 65 draft items. In contrast to the single-centre interview study, focus groups were conducted across three centres to improve the transferability of findings.

As a methodology, focus groups may help to explore and clarify views in ways that are more accessible than in a one-to-one interview and are ‘particularly important to allow research participants to generate their questions and priorities’.(106) Compared to other qualitative methods, focus groups are inexpensive and efficient ways to gather qualitative data and are particularly relevant as ED staff share professional experiences.(107) In the PREM-ED 65 study, professionals’ perceptions were triangulated with patient interview data and the qualitative review findings to generate a comprehensive list of draft items.(108)

3.6.2 Methodological Choices to guide the development of PREM-ED 65

Multiple Stakeholder Workshop

Following the generation of the comprehensive list of draft items, the purpose of the multiple stakeholder workshop was to collaboratively refine and prioritise the comprehensive list of candidate items derived from the conceptualisation phase of the study. Engaging a broad range of patients, members of the public, professional caregivers and third-party representatives from organisations advocating for older people and emergency care aimed to promote the instrument's face validity and inclusivity before validation.

Functions required of stakeholder representatives included assessment of item comprehensibility and reaching consensus on items most important to service users. In addition to the invaluable first-hand experiences of patient and public representatives, involvement from healthcare professionals and third-sector experts offered broader perspectives on ED care, which has helped ensure the clinical relevance of PREM-ED 65. By combining viewpoints within a collaborative environment and reaching a consensus on the essential items, the workshop derived a finalised list of items attuned to the needs of the ED older adult population.

As justified within Section 3.4.4, the stakeholder meeting was structured using the nominal group technique (NGT). NGT provides a stepwise approach to group consensus generation, typically consisting of three stages: idea generation, group challenge, and group discussion.(81, 82) For PREM-ED 65, the NGT schema was modified, as draft items were derived from previous qualitative work, and formulating new ideas was not strictly necessary. This also conveniently shortened the consensus process and reduced participant burden.

Regarding its methodological strengths, the NGT's proposed advantages include obtaining a clear group consensus in a time—and resource-efficient manner.(109) As previously explained, this contrasts with other consensus-setting methods, such as the Delphi method, which requires multiple rounds of participant surveys, high levels of sustained engagement, and may suffer from high levels of participant drop-out. In contrast to survey-based consensus generation methods, the NGT promoted face-to-face discussion and encouraged direct engagement among participants, leading to rich discussions, exchanges of nuanced ideas and negotiation between participants.(76) This has been demonstrated as particularly advantageous when dealing with complex issues such as those encountered in healthcare.(110) Compared to focus groups, the NGT method promotes group participation among diverse participants, ensuring that all views are heard and valued. This approach aligns with creating a considered and patient-centred comprehensive final list of items.

Cognitive interviews.

Cognitive interviews (111) are an important part of survey design and aim to ensure comprehension, adequate interpretation, and concept coverage amongst a sample of potential survey participants. Cognitive interviews were held with seven consensus meeting participants, who were asked to complete the draft version of PREM-ED 65 whilst ‘thinking aloud’.(112) This provided final assurance on the comprehensibility of the prioritised items, eliminated or consolidated similar items, assessed participants’ ability to recall an unscheduled care encounter and provided a means of assessing participant interaction with the items. In addition, cognitive interview participants were advised on the questionnaire's visual format, layout, and user-friendliness of the four-point Likert scale.

3.6.3 Methodological choices to guide testing of PREM-ED 65

An 82-item draft version of PREM-ED 65 was developed. This was then tested using a multimodal, multicentre cross-sectional study design, performed in EDs across England and delivered by a collaborative of medical students and research clinicians. Testing consisted of two methodological aspects. These were initial item reduction, which aimed to reduce the number of irrelevant/ redundant items based on per-item response characteristics, and psychometric testing following COSMIN principles.

Initial item reduction.

The length of the draft version of PREM-ED 65 (82 items) was problematic and needed to be revised due to the risk of respondent fatigue and satisficing bias, especially amongst older adults in an acute care setting. Reducing survey items presents a recognised challenge for researchers, who—as was the case for the PREM-ED 65 study—may wish to eliminate redundant items while maintaining surveys' validity and reliability. To facilitate item reduction, the approach proposed by Goetz et al. was followed, which includes explicitly stating the objective of item reduction, maintaining the integrity of the original conceptual model, preserving content validity and psychometric properties and justification for retaining subsequent items.(113)

Hierarchical item reduction (HIR) involves obtaining ‘real-world’ survey responses and deleting unnecessary items or those that do not contribute to understanding the construct of interest.(114) Hence, in the case of PREM-ED 65, HIR aims to ensure that only items relevant to the population of interest are included in the final instrument. This has the clear benefit of minimising respondent fatigue and satisficing bias. In practical terms, reducing the item set

also optimises staff's ability to routinely administer to patients within the time-sensitive and resource-limited ED setting.

For PREM-ED 65, criteria for HIR were prospectively determined based on researcher consensus and consisted of (i) respondent non-engagement (>20% responses ‘I cannot answer’ or ‘Not applicable’ or blank); (ii) the presence of floor or ceiling effects (>50% responses ‘strongly agree’ or ‘strongly disagree’); (iii) presence of differential validity based on gender, age, or reason for attendance, and (iv) high inter-item correlation (>0.7). Items were excluded if any criteria were met, beginning with non-engagement and ending with inter-item correlation. The process is summarised as a funnel plot in Figure 3.2 (overleaf).

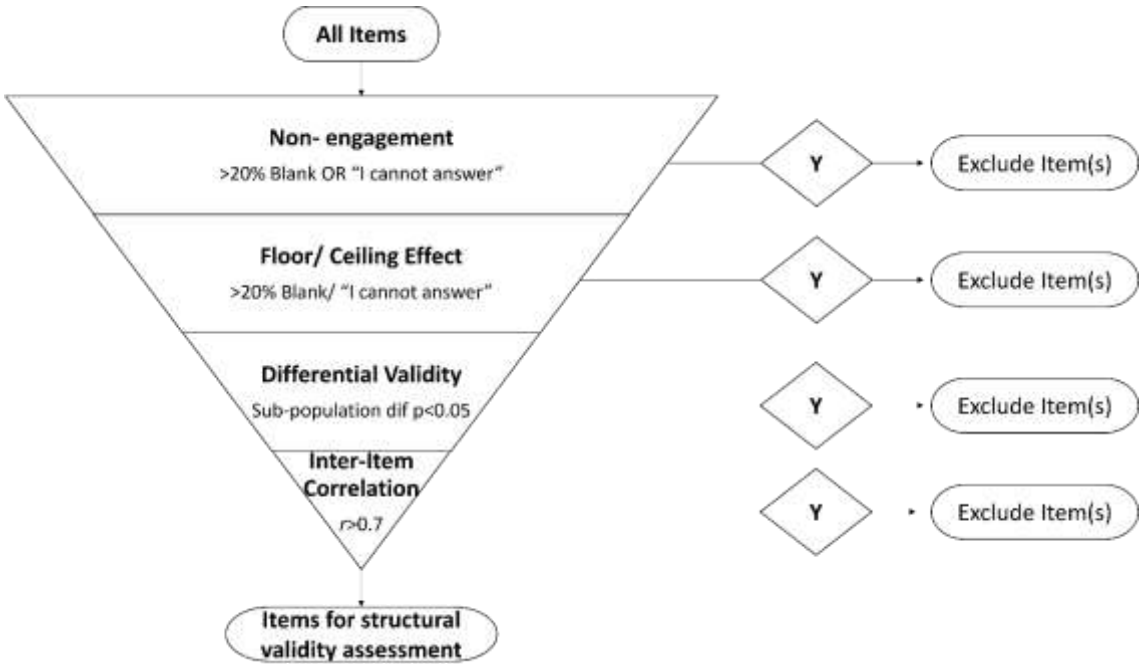

Figure 3.2 Hierarchical item reduction.

Psychometric Assessment

Psychometric testing for PREM-ED 65 consisted of structural validity, internal consistency, test-retest reliability, and criterion validity. The following discussion details each of these aspects.

Structural Validity

The COSMIN group defines structural validity as 'the degree to which the scores of an HR-PRO instrument are an adequate reflection of the dimensionality of the construct to be measured'.(89) In the case of PREM-ED 65, structural validity assessment aimed to ensure that participant-reported scores reflect the critical components of patient experience for older adults presenting to the ED. This was achieved using exploratory factor analysis (EFA), with a solution selected that meets the criteria defined by Schonrock et al.(115)(Table 3.1)

Table 3.1 Criteria for a preferred EFA solution

1. The point of inflection can conceivably be demonstrated on a scree plot,
2. Eigenvalues exceed 1 for all components,
3. The proportion of total variance explained by the components was more than 50%,
4. The average communality across all items was >0.5.

Internal Consistency

Internal consistency is a measure of reliability that describes interrelatedness between items within a measurement scale and should be calculated to ensure validity before a test or scale is applied in the real world.(89) Internal consistency is assessed using Cronbach's Alpha, expressed as a number (alpha) between 0, indicating no interrelatedness, and 1, indicating perfect interrelatedness.(116) The PREM-ED 65 study followed existing guidance

stating an acceptable alpha of >0.6. Where present, a low alpha value may be related to a low number of items within a scale, poor correlation between items, or heterogeneous constructs.(117)

Test-Retest Reliability

Test-retest reliability describes the extent to which reported scores remain the same between at least two discrete time points, assuming the participants' condition remains unchanged.(89) In practical terms, an instrument's test-retest reliability is computed by measuring subjects on two distinct occasions on the instrument and then computing the correlation. If the correlation is significant, this is considered evidence of good test-retest reliability.(118)

Criterion Validity.

Criterion validity measures how well a measure predicts an outcome compared to another. For PREM-ED 65, the concurrent validity of the remaining PREM-ED 65 items compared to the NHS ‘Friends’ and Families’ Test’ Question (FFTQ)(119) was assessed using the Pearson Correlation Coefficient, which measures the linear relationship between two variables.(120) To enable this, the FFTQ was measured as an additional item within the draft survey:

“I would recommend this A&E to my friends or family members if they were in a similar situation”

NHS FFTQ.(119)

3.7 Study Techniques and Procedures

Moving on from the justification of methodological choices, this section will provide an overview of the techniques and procedures related to participant selection, sampling, data collection, data analysis, and dissemination strategies.

3.7.1 Protocolisation of the Research

Each stage of the study, including interviews and focus groups, the prioritisation exercise, and the final validation study, was prospectively protocolised. The purpose of the research protocol has previously been described as a "game plan" for a project, providing a vision of the research and ensuring that the methodology, data collection plan, data analysis plan, and ethical considerations are sound.(121) In the case of PREM-ED 65, protocols were prospectively developed, iteratively reviewed, and revised with input from all co-researchers. Where applicable, disseminating the relevant research protocols ensured that additional investigators knew their responsibilities.

3.7.2 Patient and Public Involvement

Patient and public involvement (PPI) is recognised as essential to developing health measurement instruments and supports their role in person-centred care. In their scoping review of patient participation in developing patient-reported outcomes, Weiring et al. suggest the value of patient involvement in determining the construct of interest, item development, and comprehensibility assessment.(122) PPI is also recognised as increasingly important in informing emergency medicine research priorities and outcomes of emergency care research; a 2017 research priority-setting partnership conducted for RCEM by the JLA worked with patients, carers, and stakeholders to establish research priorities for emergency medicine. Optimising care for older adults was the second highest of all 72 priorities.(123)

Patient and Public Involvement was planned from the outset to inform the development and validation of PREM-ED 65. The initial study proposal was shared with members of the Sheffield Emergency Care Forum in 2017 (124); feedback highlighted the importance of providing empathic care, respect,

dignity, clarity of information, and a safe, caring environment for older adults in the ED. It was ensured that the clarity of the PREM design was recognised as a priority from the outset.

The PREM-ED 65 was then developed in partnership with patients, caregivers, members of the public and other stakeholders using the following approaches:

- **Interviews with patients** were conducted ‘in situ’ in the ED, and focus groups with caregivers as part of the conceptual exploration phase.
- **Multiple stakeholder engagement** to refine and prioritise items during the development phase.
- **Cognitive Interviews** with multiple stakeholders to inform item comprehension, relevance, design, and usability of the draft PREM before validation.

Each of these aspects of patient-public involvement is further discussed within the individual chapters of this thesis. Together, these methods aim to ensure that PREM-ED 65 is designed with the patient at the centre of the research design.

3.7.3 Study Settings

Research to guide item generation and prioritisation was conducted within the South West of England. This region represents a mixed urban and rural area with a population of approximately 5.7 million. Demographic characteristics include a higher proportion of older adults than the general UK population, although fewer residents are from a minority ethnic background compared to UK averages. Otherwise, the region compares similarly for educational attainment and socioeconomic status indices.(125, 126)

The initial interviews with patients were held within the region's tertiary referral and major trauma centre, with an annual ED census of approximately 90,000 and an established ED research unit. It was recognised that the single-centre approach risked reducing the transferability of findings; however, utilising the resources and support within this centre as a novice qualitative researcher ensured that the delivery of in situ interviews was achievable. Furthermore, to help overcome the limitations of the single-centre interviews study, the focus groups were expanded to recruit staff from two further centres, yielding perspectives from across the South West region, including tertiary and district general hospital settings.

The multiple-stakeholder workshop was held at a convenient and accessible location within the research locality (Devon, UK). This venue was also selected because it was accessible to older and disabled participants. These aspects are discussed further in Section 3.9.2.

The validation study setting was expanded to include 18 EDs across England, including the Southwest, London, and Northwest regions. In conjunction with a sampling matrix provided to site investigators (Section 3.7.4), this aimed to optimise the overall representativeness of the sample and, therefore, the external generalisability of the finalised instrument.

3.7.4 Participant Selection

Inclusion and exclusion criteria were carefully considered for each aspect of the PREM-ED 65 study. For the qualitative interviews, ED patients over 65 were eligible for inclusion. Exclusion criteria included patients who required ongoing emergency treatment, were non-English speaking, had delirium or pre-existing cognitive impairment, or were in police or prison custody. The focus groups

included clinical staff members who had worked within the study ED environment for at least six months, whilst those not permanently employed, with less than six months experience in the ED, or not responsible for delivering direct clinical care were excluded.

Multiple populations were eligible for inclusion in the stakeholder meeting. These included older adults with prior experience attending the ED (as a patient or carer), ED staff who provided direct clinical care to older adults, lay members of relevant patient and public involvement groups, and representatives from external organisations advocating for older adults. Exclusion criteria for the stakeholder meeting were limited to those who could not commit a full working day for participation, lacked the mental capacity to participate, or were non-English speakers.

Recruitment for the final development and validation study was performed across multiple sites. During the study period, adults over 65 deemed suitable for ED discharge between 0600 and 2100 were eligible, provided exclusion criteria were not identified (Table 3.2).

Table 3.2 Inclusion and Exclusion Criteria (Validation Study)

Inclusion Criteria	Exclusion Criteria
Adult aged 65 years and over. Initial ED assessment and treatment completed. Decision made by the attending clinician to discharge the patient from the ED. Deemed fit and healthy to complete PREM-ED 65 by attending clinician.	Admitted to an inpatient unit. Lacking mental capacity To complete the assessment.(127) Unable to speak, read or comprehend English. In Police or Prison Custody. Discharge before 0600 or after 2100. Confirmed or suspected COVID-19 infection.[1] Deemed unsafe to participate.[2]

[1] At the time of the study, patients with suspected or confirmed COVID-19 were commonly assessed and treated using specialised facilities and clinical pathways and, therefore, excluded.
[2] At the discretion of the local research team, e.g., due to agitation, violence, or mental distress.

3.7.5 Participant Sampling

An essential aspect of the development and testing phases was recruiting a representative sample of participants to ensure the final instrument's content validity. However, this had to be balanced against the demands of the research timeline and the researchers' availability. As such, a range of sampling approaches was employed to maximise representativeness while ensuring the study's deliverability within the required timeframe.

Stratified purposive sampling was employed for the patient-facing interviews to account for the heterogeneity of ageing and optimise the representativeness of the study population.(128)This method aimed to ‘capture major variations within strata’ and enable the identification of a ‘common core’.(129) Strata included the type of presentation (i.e., injury/ illness), age group, Rockwood clinical frailty scale score (130) and acuity. Participants were recruited within each sampling stratum until the researcher was satisfied that thematic saturation had been achieved.

Convenience sampling was used to recruit participants for staff focus groups. Therefore, an open invitation was distributed by email and posters to all clinical staff within each host ED. Following expressions of interest, participation was allocated on a first-come-first-served basis until the necessary group size was obtained (i.e., 4-8 participants/ group).

For recruitment to the multiple stakeholder workshop, open invitations were issued through relevant local patient-public involvement groups and third-sector

organisations, including charities advocating for older people. To ensure a mixed composition of the stakeholder groups, it was decided that the minimum number of service users (i.e., older adults aged over 65) and health professionals was six respectively.

Challenges in obtaining representative sampling across multiple sites for the validation study were mitigated by using a sampling matrix to guide the screening and recruitment of participants. This convenience and purposive sampling hybrid aimed to recruit balanced proportions of patients within defined strata, including age, gender, reason for presentation, and mode of arrival.

3.7.6 Data Collection

As with sampling, a range of data collection methods were necessary during the study. For the qualitative systematic review, searches of PubMed, CINAHL, BNI and EMBASE databases were conducted. Papers selected for inclusion were then downloaded into the Nvivo software to undergo thematic analysis, the steps for which are detailed later in this discussion. For the scoping review, searches of PubMed, CINAHL and EMBASE were conducted alongside bibliography searches of included papers, and selected grey literature sources. A standard data charting form was developed to record the key characteristics of the included papers.

Where practical, qualitative Interviews were recorded in a quiet area of the ED, typically a side room or seminar room. Focus groups with staff were conducted away from the ED shop floor in a non-clinical area, such as a seminar or teaching room. A high-definition audio Dictaphone was used for interviews and focus groups, and recordings were stored securely on a password-protected

computer. For the focus groups, separate field notes were obtained to record body language, utterances, and other observations.

For the multiple stakeholder workshops, the participants determined the comprehensibility of each item, with their feedback provided to the study team using standard reporting cards (Figure 3.3a). This allowed the research team to revise the candidate items rapidly during a subsequent break. Afterwards, participants could prioritise the items on a scale of 1 (least important) to 9 (most important). This task was supported by a grid issued to each participant, with data compiled by group facilitators (Figure 3.3b).

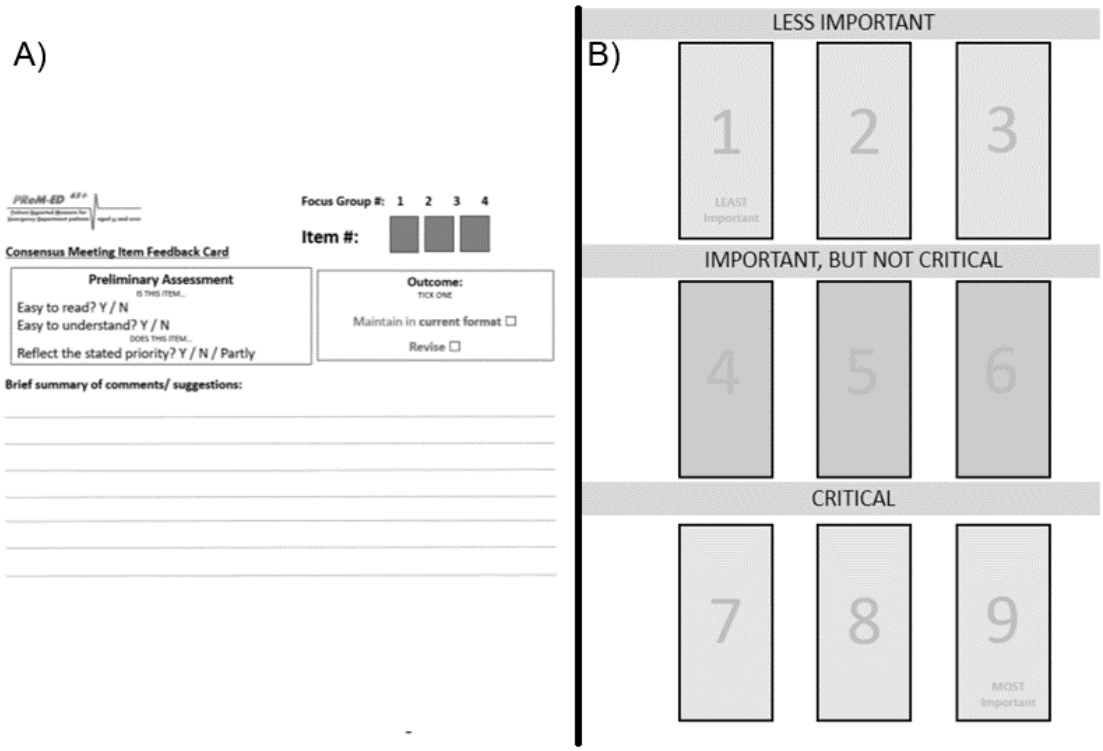

Figure 3.3 Multiple stakeholder workshop participant materials.

Left—Card used to provide group feedback on item comprehension to the research team; (b) Right—Card grid used by individual participants to assign item priority.

Data collection for the validation study comprised paper-based and electronic versions of the draft instrument. In addition to the 82 experience items, participants self-reported their basic demographic characteristics and length of ED stay. All were invited to complete a postal or online retest survey 7-10 days later. Data from electronic surveys were captured via SurveyMonkey (San Mateo, CA). Students transcribed paper-based responses into a secure online form, which was also hosted using SurveyMonkey. The study team downloaded and analysed the results using SPSS Statistics for Windows Version 25 (IBM Corp., 2017). Records that were blank, spurious, or lacking a unique participant identification number were excluded.

3.7.7 Data Analysis

Given the mixed-methods design of the PREM-ED 65 study, a range of different approaches were required for qualitative and quantitative data analysis. A vital function of the qualitative systematic review and meta-synthesis was to consolidate existing knowledge and generate new insights into ED patients' care experiences. Following a critical appraisal of included articles using the CASP qualitative research checklist,(131) Thematic analysis was used to synthesize the data from the included articles. This consisted of directly extracting text fragments representing the narratives of study participants. Fragments were then assigned codes within Nvivo, and codes were summarised into descriptive themes. Following this, overarching analytical themes were developed.(2) Links between the analytical themes were identified, forming a new conceptual framework and pragmatic recommendations for clinical practice directly from the synthesis findings. This process is further explained in Chapter Four.

For the scoping review, data was summarised within results tables following extraction. These included characteristics of the identified instruments, characteristics of studies administering the included instruments to ED patients, dimensionality of each instrument against analytical themes of the 'needs-based' conceptual framework, risk of bias assessment guided by COSMIN criteria, and real-world usability assessment.(90-92) This data not only helped inform the rationale of the PREM-ED 65 study but also provided a comprehensive overview of available instruments applicable to ED care; it may be of value to clinicians interested in selecting appropriate outcome or experience measures for quality improvement and performance monitoring purposes.

A dedicated assistant who was an Academic Clinical Fellow in Emergency Medicine helped conduct real-time data analysis throughout the multiple stakeholder workshops, using a pre-formulated electronic data collection tool developed by the lead researcher in Microsoft Excel (Redmond, WA, USA). This enabled near real-time presentation of the median priority, the mean absolute deviation from the Median score (MADM) assigned to each candidate item. These values demonstrated both priority and degree of inter-rater agreement, with the lower third MADM representing 'low' agreement, the upper third 'high' agreement, and the middle third 'medium' agreement.(75, 132) Therefore, items that were a high priority with the high inter-rater agreement could be 'included' in the finalised item list without further voting. Items assigned intermediate median priority scores or low inter-rater agreement underwent a round of dichotomous voting, with each participant indicating their preference to include or exclude each item.

Data from the validation study was cleaned, and blank or spurious responses to the draft questionnaire were excluded from further analysis. Blank and 'I cannot answer' responses were dealt with as missing data, and following confirmation that the distribution of these responses was random using Little's MCAR test, data was imputed using the SPSS Expectation-Maximisation algorithm.(133) This method estimates the value of missing reactions by considering the average value and variance of observed scores and is widely considered an accurate and reliable imputation method. Using data imputation over listwise or pairwise deletion enabled maximal utilisation of participant responses. Following imputation, EFA was deemed appropriate for confirmation of structural validity, as this was the first evaluation of PREM-ED 65 in a real-world setting. Principal Axis Factoring (PAF) was selected as this method does not make distributional assumptions. Rotation is commonly used in factor analysis to simplify the interpretation of the extracted factors. As it was assumed that a high degree of item correlation would be observed between PREM-ED 65 items, oblique (Promax) rotation was applied.(115)

The first step of the EFA procedure was to analyse the bivariate correlation matrix to exclude the presence of any item demonstrating an excessive correlation score of 0.8 or above. The exclusion of excessive bivariate correlations supports the holistic exploration of data. It avoids unneeded analysis of pairwise associations so that EFA ultimately more accurately represents the shared variance of data. Following this, one item exhibiting a commonality score of <0.2 was identified and excluded. The suitability of data for EFA was additionally confirmed using the Kaiser-Meyer-Olkin Measure of Sampling Adequacy and Bartlett's Test of Sphericity. When reporting a solution, we aimed to respect the criteria outlined by Schonrock et al.(115) This states

that the preferred solution is the simplest interpretable factor structure for which (i) the point of inflection could be conceivably demonstrated on a scree plot, (ii) Eigenvalues exceeded 1 for all components, (iii) the proportion of total variance explained by the components was more than 50%, and (iv) the average communality across all items was >0.5.

To confirm adequate internal consistency of the measurement scales, Cronbach's Alpha was calculated for each measurement scale derived from EFA. The test-retest reliability was assessed by calculating the Intraclass Correlation Coefficient. A two-way mixed effects model with absolute agreement was calculated according to guidance by Qin et al. to determine the test-retest reliability of patient-reported outcomes. ICC values between 0.5 and 0.75 represent moderate reliability, whereas those above 0.75 represent good reliability.(134) Finally, criterion validity was calculated by comparing each item's Pearson coefficient (*k*) against the NHS FFTQ. For the study, a *k* of 0.4-0.69 was considered moderate, 0.7-90.89 good, and 0.90-1.00 as excellent.(135)

3.8 Rigour

3.8.1 Positionality

In its simplest sense, positionality may be defined as 'where one stands in relation to another' and is affected by multiple factors, including researcher background, personal values, gender, race, socialisation, and sexual orientation.(136) By considering positionality in quantitative and qualitative studies, researchers may consider how their perspective and identity influence the research process and outcomes.(137, 138) The positionality of the researchers and participants has been an essential consideration throughout both qualitative and quantitative aspects of the PREM-ED 65 study, increasing

the credibility and applicability of the instrument to older adults attending the ED.

The positionality of the lead researcher is explicitly stated within the prologue (Section 1.2.1) and further explored throughout the introductory chapters of this thesis. In addition, the positionality of participants has been considered in study design to develop an inclusive and valid PREM. This includes the sampling measures already described in this chapter, such as considering occupation and educational attainment when analysing interviews and focus groups' data. The potential effects of group interaction and power dynamics were considered for staff focus groups and the multiple stakeholder workshops. At the same time, participants' views were respected, consent processes ensured informed involvement, and procedures ensured confidentiality and anonymisation of findings. Careful design of participant information, draft of the PREM-ED 65 instrument, and training of site researchers before the validation study also aimed to foster inclusivity.

3.8.2 Reflexivity

Reflexivity describes the practice of reflecting on positionality throughout the research process, helping uncover influences shaping the research journey. (139) For PREM-ED 65, reflexivity was a prominent consideration during the qualitative interviews, focus groups, and qualitative data analysis. Using a reflexive diary, field notes, and regular meetings between the research team helped ensure a neutral perspective, ensuring that the participant's views were represented in the final PREM. Further reflections on methodological integrity, including rigour and reflexivity, are provided within the final discussion chapter (Section 12.5.3).

3.8.3 Research Integrity

Research integrity is paramount to ensuring the credibility and reproducibility of scientific research. The consequences of poor research practice in healthcare may be profoundly serious, potentially contributing to patient morbidity and mortality and, more broadly, undermining public trust and engagement with healthcare providers.(140) Adherence to good research practice has been integral to the study. This includes adherence to the principles of the Declaration of Helsinki in relation to ethical study design, informed consent procedures, right to withdraw for all study participants and protection of participant confidentiality.(141) All research team members received NIHR Good Clinical Practice Training, and the research was conducted in accordance with professional standards stipulated by the General Medical Council.(142)

3.9 Ethical Considerations

3.9.1 Regulatory Approvals

Relevant approvals sought from the UK Health Research Authority (HRA)(www.hra.nhs.uk) and the University of Plymouth Faculty of Health Research Integrity and Ethics Committee (UoP FRIEC) are outlined in Table 3.3:

Table 3.3 Summary of Ethics Approvals for the PREM-ED 65 Study

Study Component	Approving Body	Ref
Patient Interviews and Staff Focus Groups	UK HRA	18/LO/1194
	UoP FRIEC	17/18-973
Multiple Stakeholder Workshop	UoP FRIEC	19/20-1173
Final Development and Initial Validation Study	UK HRA	21/PR/0458
	UoP FRIEC	2021-2527-1758

3.9.2 Risks to Participants

As a non-interventional study, the development and validation of PREM-ED 65 were considered low risk to participants overall, and no adverse events were recorded at any point during the study. The low-risk status is reflected in the external proportionate review obtained from the UK HRA for the interviews, focus groups, and validation study. As participants were not recruited from NHS settings, multiple stakeholder workshops did not require UK HRA approval. However, University approval was obtained to provide independent peer review and indemnification.

Informed participant consent was obtained for all study elements.(143) An example of a consent form used during the study is provided in Appendix 2. At least 30 minutes was afforded for participants to weigh up information before consent for both the interview and validation study. For all stages of the study, participants were informed of their right to non-participation and to withdraw from the study at any point.

The potential risks to participants unique to each study stage were considered. For in-situ interviews, this included interruption of usual clinical care, risks to patient confidentiality, and identification of clinical concerns or patient safety events. To mitigate the risk of disruption of care, the researcher sought assent from the attending clinical team to the patient before commencing recruitment. Patients deemed too unwell to undergo an in-situ interview were excluded. Interviews were usually conducted privately, and where this was not possible, lapel microphones facilitated normal conversation even within busy clinical environments. Participant information explicitly stated actions that would be taken in the event of clinical concerns or patient safety events being identified by the researcher (example of a participant information sheet used during the

study—Appendix 3). Patient confidentiality was maintained throughout, with personal details only featured on screening and consent forms. After that, patients were assigned an individual reference number. Interview data was not shared with anyone outside the research team before anonymisation.

Similar considerations were made for the staff focus groups. These were conducted away from the clinical setting at a time when staff were not responsible for providing direct clinical care. The Chatham House rules were used to protect participant confidentiality while allowing for sharing of information relevant to clinical practice.(144) Before anonymisation, focus group data was not shared with anyone outside the research team.

Considerations for the stakeholder workshop related to venue accessibility and safety, the potential for group conflict and participant recall of triggering or upsetting personal experiences. As such, it was confirmed that the venue had third-party insurance and appropriate risk assessments and that disabled access was provided throughout the building. As refreshments and lunch were provided, the allergy status of participants was confirmed beforehand, and a building evacuation briefing was issued at the beginning of the workshop. Workshop facilitators were issued with separate instructions to optimise group interaction and manage disagreements between participants constructively. Although no participant expressed upsetting or distressing experiences during the day, details of support organisations were compiled for signposting in case these were needed. All participants agreed to the Chatham House rules to protect confidentiality beyond the meeting.

As with the initial in-situ patient interviews, interference with usual clinical care was a potential risk for the validation study. As such, participants were recruited

once initial clinical assessment and treatment had been provided. Participants' identifiable details were only collected from the screening document and consent form. All other data was pseudo-anonymised by allocating participants an individual reference number. Participants were signposted to contact their local Patient Advice and Liaison Service if they would like to complain or make a compliment about their experience.

The draft PREM-ED 65 instrument's potential length represented a relatively high participant burden. Cognitive interviews helped shorten the survey in advance and, in addition, informed the survey's visual layout and simple response scale, which were designed to limit cognitive burden and fatigue as much as reasonably possible. Additionally, researchers ensured participants were afforded adequate time to complete the survey at their own pace.

To alleviate potential concerns regarding the impact of participation on care, participants were explicitly reassured that results would be fully anonymised before dissemination as part of research reports or publications. To reduce the potential for acquiescence or social desirability response biases, the value of constructive criticism for improving patient care was highlighted within the participant information.

3.9.3 Risks to Researchers

As a non-interventional study, risks to researchers were deemed low, and no adverse events were recorded at any point. Indemnity was provided through the University of Plymouth and NHS HRA for all elements. The lead researcher was familiar with the study settings for the interviews and focus groups, and the senior clinical team was made aware of their presence during participant recruitment days. For the stakeholder workshop, researchers were provided

with a briefing and supported by the study team to resolve challenges and problems that arose. The burden incurred by students who were site investigators for the validation study was considered. Specifically, it was ensured that the data collection period did not coincide with any academic assessments. Student participation was voluntary, with the right to withdraw at any point.

3.9.4 Data Governance

All participant data was handled according to the General Data Protection Regulations and archived within the research and development departments of participating trusts for the minimum period stipulated by the UK HRA.(145) No data breaches occurred during the study.

3.10 Research Timeline

The study commenced in October 2017, data collection ended in October 2023, and the study concluded in May 2024 following the acceptance of the validation study for publication. A summary research timeline is outlined in Table 3.4 (overleaf).

Table 3.4 Summary of PREM-ED 65 Research Timeline

	Data Collection		
Component	**Start**	**Finish**	**Publication Date**
Qualitative Systematic Review	Oct 2017	Jun 2018	Jun 2019
Scoping Review	Early 2019	Jun 2023[1]	TBC
Interviews with Older Adults	Sep 2018	Apr 2019	Feb 2023
Focus Groups with Staff	Oct 2018	May 2019	Feb 2023
Multiple Stakeholder Workshop	Dec 2019 (1 day)		Oct 2023
Cognitive Interviews	Feb 2020	Oct 2020	-
Process Evaluation	Aug 2021	Sep 2021	TBC
Final Development and Validation Study	May 2021	Aug 2021	May 2024

[1] The scoping review was completed initially in Aug 2019 and updated Jul '23.
TBC= To be confirmed.

3.11 Chapter Summary

This chapter has summarised the methodological approach for PREM-ED 65. Underpinned by a pragmatist approach, the study has successfully utilised mixed methods to develop and validate PREM-ED 65 in concordance with COSMIN criteria for content validity, structural validity, internal consistency, test-retest reliability, and criterion validity. Explicit consideration of positionality and reflexivity intends to ensure that the credibility and relevance of the instrument is optimised. Issues relating to participant selection, recruitment and consent ensure that the research aligns with relevant ethical and professional standards.

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Chapter 4 Qualitative Systematic Review and Meta-synthesis

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Contributorship Statement
Blair Graham (BG) conceived the idea for the review and contributed to the development of the review protocol; database searches; critical appraisal and selection of articles for review; qualitative analysis; production of the first draft of the manuscript and subsequent revised versions, and approval of the final version for publication.

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Jos M. Latour (JML) contributed to the development of the review protocol; database searches; critical appraisal and selection of articles for review; qualitative analysis and first draft of the manuscript and subsequent revised versions, and approval of the final version for publication. JS and JL acted as project supervisors.

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What this chapter adds

This chapter:

- Demonstrates the ability of the researcher to conduct a (i) systematic review of qualitative literature in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Criteria; (ii) Synthesise a body of qualitative literature to identify determinants of ED patients' experience; and (iii) formulate a conceptual model of patient experience for the ED.
- Reports available qualitative literature focusing on patient experience in the ED.
- Proposes a novel 'needs-based' conceptual framework focusing on patient experience in the ED.

‘They do not care until they know how much you care’: a qualitative meta-synthesis of patient experience in the Emergency Department.

4.1 Abstract

Background

Patient experience is positively associated with clinical effectiveness and patient safety and should be a priority for emergency care providers. While both quantitative and qualitative approaches can be used to evaluate patient experience in the Emergency Department (ED), the latter is well-suited to developing a detailed understanding of features influencing the lived experience of ED patients.

This study aimed to systematically review the literature of qualitative studies to identify determinants of adult patient experience in the ED.

Methods

A PRISMA-compliant systematic review was conducted using PubMed, CINAHL, EMBASE, BNI, and bibliography searches to identify qualitative studies exploring patient experiences in ED published in English between 1997 and 2018. Quality assessment was conducted using the Critical Appraisal Skills Programme checklist. Descriptive text and quotations relating to Patient experience were extracted from included studies and a meta-synthesis conducted using thematic analysis.

Results

A total of 625 records were screened from which 40 studies underwent full review and 22 were included. Results were coded by two researchers (BG, JML). Meta-synthesis identified 198 discrete units of analysis which were clustered around five analytical themes. These were based on the perceived

‘needs’ of patients visiting the ED and were defined as Communication, Emotional, Competent Care, Physical/Environmental, and Waiting needs. Findings were translated into a conceptual model for optimising patient experience in the ED.

Conclusion

This meta-synthesis provides a framework for understanding determinants of patient experience in the ED. The resulting conceptual model and recommendations may have the potential to directly inform practice and improve patient experience.

4.2 Introduction

The Emergency Department (ED) environment presents many conceivable barriers to providing an optimal patient experience. Patients often arrive following acute illness or injury, in pain and distress.(1) Time for the establishment of rapport with providers is limited, and patients find themselves the subject of many new interactions that occur over a short time.(2) Previously unanticipated investigations, procedures and treatments may be required, some of which may be invasive, painful, or infringe personal dignity. Additionally, the physical environment may be noisy, crowded and unfamiliar.(3, 4) Despite these challenges, providing patients with a positive experience should take high priority.(5) Positive experience is not only associated with improved satisfaction but superior outcomes across a range of domains including mortality, morbidity, length-of-stay and medication adherence.(6)

Qualitative research offers a means to rigorously address gaps in comprehension of the patient experience and facilitate the formation of a more detailed understanding than may be obtained by quantitative or cross-sectional approaches alone. This may facilitate the identification of specific determinants of experience, as viewed by patients themselves.(7, 8) Reliably transferring findings from individual qualitative studies into external settings is often cited as a limitation of the qualitative approach in general.(9) Meta-synthesis provides a potential solution to this problem by systematically identifying available qualitative literature surrounding a topic and subsequently undertaking detailed analysis, and structured synthesis of the findings. This provides a means of harnessing disparate qualitative studies to inform clinical practice, policy formation and research priorities.(9, 10) A key feature of meta-synthesis is that it aims to provide a deeper level of understanding, affording researchers new

confidence to suggest wider-reaching conclusions and even generate recommendations. Approaches to meta-synthesis included meta-ethnography and thematic synthesis.(11, 12) Meta-synthesis has been employed to enhance understanding of a range of issues in emergency care such as staff experiences of aggression and violence,(13) perceptions of people who self-harm,(14) and delay in seeking treatment for myocardial infarction among female patients.(15)

4.3 Aims

This study aims to (i) identify qualitative research exploring patient experiences of ED care and (ii) conduct a meta-synthesis to identify recurring themes that could be applied to a framework aimed at improving patient experience.

4.4 Methods

4.4.1 Design

A systematic review and meta-synthesis adhering to PRISMA guideline was conducted (Figure 4.1).

4.4.2 Eligibility Criteria

Publications written between January 1997 and June 2018 were identified. Studies exploring the experience of adult patients using qualitative data collection methods such as interviews, focus groups, observation and open-ended questionnaires were included. Papers focussing on a certain ED presentation or demographic group were included if the authors agreed that findings had relevance to the general ED population.

Quantitative studies including closed-ending questionnaires and cross-sectional methods, those conducted in non-ED settings, and those not written in English or accessible in full, were excluded from the review.

4.4.3 Information Sources

Database searches of PubMed, CINAHL and EMBASE and BNI were undertaken. Manual bibliography searches were also conducted.

4.4.4. Search and Screening

The search was undertaken using Medical Subject Heading (MeSH) terms where appropriate. An example strategy using the Pubmed database is provided in Supplementary Material SM4.1.

To determine suitability for inclusion a single researcher (BG) extracted study characteristics including year of publication, country, research question, methods, key findings, major limitations, and main conclusions. Papers with relevance to study aims were selected for quality appraisal.

4.4.5 Quality Appraisal & Rigour

Quality appraisal of include studies was then undertaken by two researchers (BG and JML). This included scoring against the ten-item Critical Appraisal Skills Programme (CASP) Qualitative checklist to assess for study validity, reporting of results and relevance.

Open dialogue between the researchers was encouraged throughout the review to identify and challenge assumptions. Reflexive notes and an audit trail were maintained.

4.4.6 Synthesis

Thematic synthesis was used to analyse the qualitative data from the included articles. The synthesis consisted of three discrete stages.(12) Firstly, text fragments representing narratives of study participants were coded to identify similarities. In the second stage, individual codes were grouped and data was summarised through the creation of descriptive themes. These were organised

into a hierarchical structure, representing the content of included studies. In the final stage of the thematic synthesis distinct analytical themes were defined. The result of the synthesis was therefore both to consolidate existing knowledge, and also generate new insights surrounding the topic. Uniquely, this review accomplished the latter by deriving pragmatic recommendations for clinical practice directly from the findings of the synthesis.

For this study, any text within the included studies that described the patient experience—either by patients themselves in the form of direct quotations, or authors in the form of discussion—was extracted into the computer aided qualitative analysis software QSR NVivo 11^{TM}. Analysis was undertaken collaboratively by two researchers (BG, JML). The opinion of a third researcher (RE) was consulted where agreement could not be reached. The face validity of pragmatic recommendations for practice were agreed by two researchers who are also practising emergency physicians (BG, JS).

4.5 Findings

A total of twenty-two studies were selected for inclusion. A PRISMA diagram summarising the search strategy can be found in Figure 4.1 (overleaf).

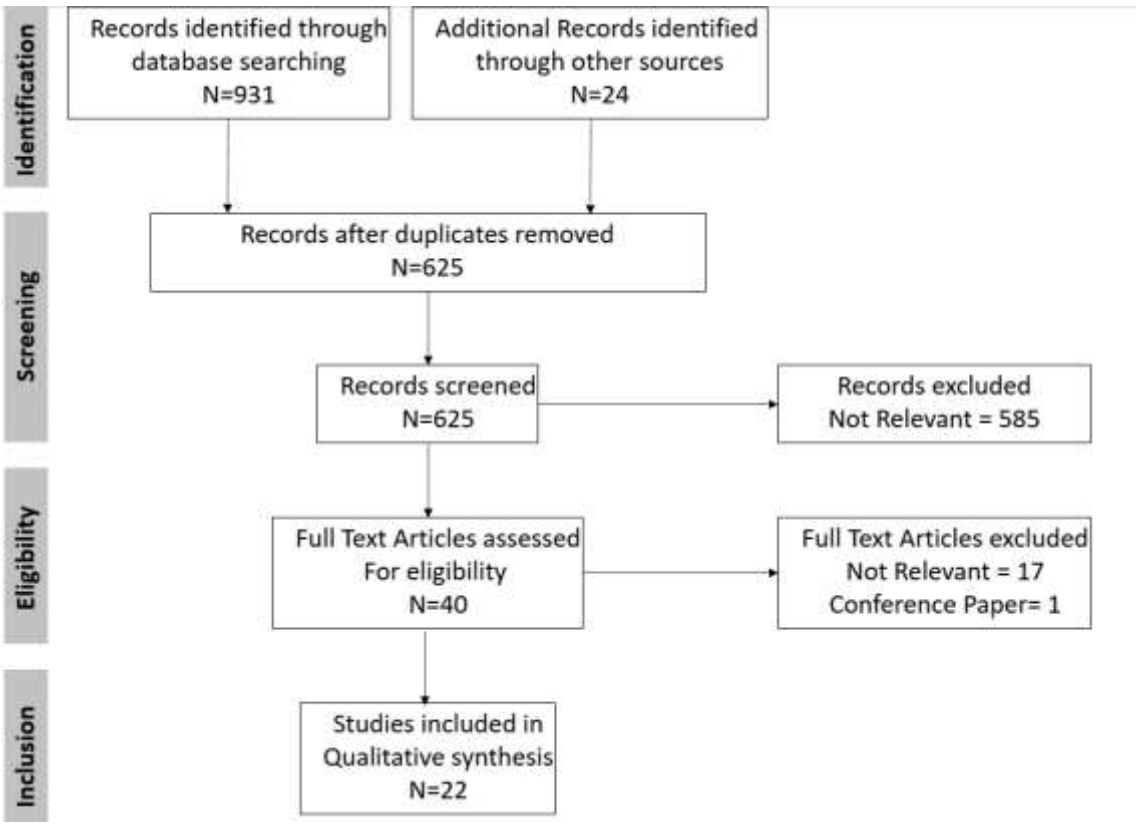

Figure 4.1 PRISMA Diagram for Qualitative Systematic Review.

4.5.1 Study Selection

Results of Quality Appraisal

All studies identified for this review met all 10 items featured on the CASP checklist, indicating adequate quality.

Study Characteristics

Included studies were published between 1999 and 2017 and were drawn from nursing (n=10), medical (n=7), social sciences (n=4) and health services journals (n=1). Studies most frequently originated from Sweden (n=7), Canada (n=6) and the United States (n=3).

Studies were conducted within more than 33 EDs, ranging from rural to large tertiary centres and geographic regions. At least 677 non- professional participants were recruited overall (range 7—60 per study). Two studies

sampled patients based on the demographic characteristic of older age. Four studies selected patients based on presentation, including major trauma (n=2), mental health and suspected miscarriage. Epistemological approaches included ethnography, phenomenology, grounded theory and descriptive analysis. Methods included interviews, focus groups and direct observation. A summary of individual study characteristics can be found in Table 4.1.

Table 4.1 Characteristics of studies and contributions to meta-synthesis

(a) Characteristics of Individual Studies						(b) Principal contribution(s) of individual studies to each analytical theme ('need')				
First Author (Year) Country	Setting	Summary of Aims	Approach Methods Sampling	Patient Population	Key Findings	C= Communication; E= Emotional; CA= Care W= Waiting P=Physical/ Environ.				
						C	E	CA	W	P
Burström (2013)[36] Sweden	Three EDs	To explore waiting in the ED	Grounded Theory Staff interviews and patient observation Theoretical Sampling	Observation of patients in waiting room.	Indicators of 'non-acceptable' waiting included physical densification, contact seeking, and emergence of critical situations. Staff were ashamed and frustrated with non-acceptable waiting. Waiting management may be achieved by changing the patient experience.	•	•		•	•
Caldicott (2005)[21] United States	Single ED	To compare the experiences of ED patients in the context of those 'turfed' to other specialities versus deemed appropriate.	Descriptive approach Semi-structured interviews Convenience Sampling	Twenty- Six adult patients	Ten themes divided between two main categories, which were (i) interpersonal issues' and (ii) technical/ systems issues. Themes classified as either 'favourable' or 'unfavourable'. Global experience was negative for 'turfed' patients.	•	•		•	•
Clarke (2007)[31] Canada	Single ED	To determine satisfaction with mental health care in ED	Descriptive approach Focus Groups Convenience Sampling	Twenty-seven adult mental health service users	Themes included: 'waiting in the ED', 'attitudes of treatment staff', 'diagnostic overshadowing', 'nowhere else to go', and 'family needs'. Devised a list for ideal services.	•	•			
Cypress (2014)[24] United States	Single ED	Experiences of patients triaged as 'critically ill'.	Phenomenology Interviews Purposive Sampling	Twenty-Three participants	Patients and relatives valued 'critical thinking', 'communication' and 'sensitivity and caring' behaviours in nurses. Desirable aspects of communication included listening, identifying, greeting and interacting with	•		•		•

				including ten patients	patients. 'Sensitivity and caring' included advocating for critically unwell patients and empathy.					
Hillman (2014)[37] United Kingdom	Single ED	To examine the concept of legitimacy and processes of negotiation between patients and staff in the ED.	Ethnography Observation with follow up interviews Thematic analysis Convenience Sampling	Fifty older adult patients.	Patients were compelled to legitimise their reasons for attendance and justify these in order to be perceived positively by staff, which shaped their access to resources and determined their ED experience.	•			•	
Kihlgren (2004)[25] Sweden	Single ED	To explore the experience of waiting in the ED.	Grounded Theory Observation Convenience sampling	Twenty patients aged >25 years.	Six core variables emerged, which were (i) Unpleasant waiting, (ii) Unnecessary Waiting, (iii) Lack of good routines during the waiting stage, (iv) Suffering during the waiting stage, (v) Bad feelings during the waiting stage and (vi) Nursing care during the waiting stage.	•	•		•	•
Lin (2008)[26] Taiwan	Single ED	To investigate the patient experience of empathy	Descriptive In depth interviews Convenience sampling	Twenty-eight participants including seven patients	Four themes emerged. These were (i) When patients expressed their feelings, physicians did not resonate with concerns, (ii) Patient required psychological comfort and (iii) Patients needed feedback from physicians but did not always get this and (iv) physicians found the physical environment difficult to overcome.	•	•			
MacWilliams (2016)[20] Canada	Three EDs One Tertiary Two Local	To explore the experiences of women attending the ED to get care for a miscarriage.	Interpretive Phenomenology Semi- structured interviews Convenience sampling	Eight female patients (suspected miscarriage)	Five themes resulted, which were: (i) Pregnant=Life vs. Miscarriage= Death, (ii) Deciding to go to the ED, (iii) Not an illness—a different type of trauma, (iv) Need for acknowledgement and (v) Leaving the ED: What now?. Patients felt that staff were dismissive of their loss.	•	•			
Nyden (2003)[30] Sweden	Single ED	To examine older peoples' basic needs in ED	Interpretive approach Interviews Convenience sampling	Seven participants between 65 and 88 years	Needs of older adults attending the ED were interpreted according to Maslow's Hierarchy of Needs. Basic needs at the lower tiers of the hierarchy were well represented. Higher needs tended to be neglected, including the need to know and understand. Patients needed to feel safe.	•	•		•	
Nystrom (2009)[27] Sweden	Single ED	To analyse and describe experiences of	Descriptive approach Interviews	Eleven patients	The non-urgent patient experience was interpreted as fragmented. Patients had difficulty being 'seen or heard', and were cognizant of the effect of non-urgent problems	•			•	

		being a 'non urgent' patient in ED	Convenience Sampling		on nurses' workloads and perceptions. Patients strived to maintain their own integrity.					
O'Brien (2004)[17] Canada	Single ED Level 1 Trauma Centre	To examine patient perceptions of trauma resuscitation in ED	Interpretive Phenomenology Semi-structured interviews Purposive Sampling	Seven adult patients with major trauma as the presenting complaint.	Four themes results, which were (i) "I was scared", (ii) "I felt safe", (iii) "I will be okay" and (iv) "I remember". System factors were contributed to a positive overall experience.	•		•		
Olsson (2001)[32] Sweden	Single ED	To explore patients experience of repeat ED attendance	Inductive Interviews Purposive sampling	Ten adult participants Frequent users of ED	Experience of repeat attenders was adversely affected when the patient perceives that use of the ED is inappropriate or when symptoms are belittled.		•		•	
Olthuis (2014)[28] Netherlands	Single ED	To determine the actual experiences of patients who received ED Care	Ethnography Direct observation Convenience sampling	Fifty- five patients in ED	Patients' "concerns" related to Anxiety, Expectations, Care provision, Endurance of symptoms, and need to receive or express recognition.		•		•	•
Revell (2017)[16] New Zealand	Single ED Tertiary Centre	To determine the information needs of patients receiving procedural sedation in the ED	Descriptive Interviews Convenience sampling	Eight adult patients who had received procedural sedation	Major themes included (i) Safety and Trust, (ii) Competence and efficiency of staff, (iii) Explanations of procedures and progress, (iv) supporting person presence, (v) medico-legal implications and (v) written information	•	•	•	•	
Rising (2015)[22] United States	Two related EDs	To examine the experience of ED discharge processes through return attenders.	Descriptive Semi Structured Interviews Convenience Sampling	Sixty patients who returned within 9 days	Themes included (i) Discharge Process (Wanted more tests/ wanted admission/ complaint unaddressed), (ii) Discharge Process (No problem/ problem understanding/ Rushed out/ limited explanation) and (ii) Prescriptions (Did not receive what was wanted)	•		•	•	
Shearer (2015)[35] Australia	Single ED	To explore why patient choose to attend a private ED in Australia	Content Analysis Semi Structured Interviews Purposive Sample	Thirty adult patients	Themes included (i) Prior experience of the hospital, (ii) Convenient location, (iii) Anticipated high-quality care, and (iv) anticipated short wait times			•	•	
Stuart (2003)[23]	Single ED	To identify 'consumer	Ethnography Focus Groups	Ninety eight adults	Major themes were communication triage, waiting area, cultural issues, and carers.	•		•	•	

Australia		expectations' with respect to the ED	Purposive Sampling	including minority ethnic and disabled groups						
Vaillancourt (2017)[29] Canada	Two EDs	To define outcomes of ED care that are valued by patients discharged from the ED	Descriptive Semi- Structured interviews Convenience sample	Forty-six adults	Patients valued outcomes that related to 4 themes. These were: (i) understanding the cause and expected trajectory of symptoms, (ii) reassurance, (iii) symptom relief and (iv) having a plan to manage symptoms, resolve the problem or pursue further medical care.	•	•	•		
Watson (1999)[18] United States	Three EDs	To describe elderly patients' perceptions of care in the ED	Descriptive, In depth interviews Convenience sampling	Twelve elderly patients	Five themes emerged, which were 'needs for information', 'observations of waiting time', 'perceptions of professional competency', 'concerns about process and facility design' and 'personal tolerance'	•		•	•	•
Watt (2005)[33] Canada	Calgary Region	To compare public expectations of ED care with healthcare professionals	Descriptive Focus Groups and interviews Purposive Sampling	Eighty Seven adults including 34 recent ED users.	Six themes emerged which included: (i) Staff communication with patients, (ii) appropriate waiting times, (iii) the triage process, (iv) information management, (v) quality of care, and (vi) improvements to existing services.	•		•		
Wellstood (2005)[34] Canada	Four EDs across one health system	To gain an understanding of patient perceptions of ED care	Descriptive In depth interviews Pseudorandomised sampling	Forty-one adults	Aspects of care most commonly negatively associated with experience were waiting times, patient perceptions of quality of care and staff-patient interactions.	•	•		•	
Wiman (2007)[19] Sweden	Two EDs (1 Trauma Centre; 1 Rural)	To explore trauma patients conceptions of their encounter with the ED team	Inductive Semi structured interviews Purposive Sampling	Twenty three adult patients with a presenting complaint of trauma	Three phases of trauma patient reception, which were: (i) the instrumental mode, (ii) the attentive mode and (iii) the uncommitted mode. The uncommitted mode could generate emotions of abandonment and dissatisfaction.	•				

4.5.2 Results of individual studies

Two hundred and twenty-nine units of analysis were extracted from the literature and were assigned codes. Data were then organised within four major descriptive categories (‘Personal’, ‘Technical’, ‘Cultural’, and ‘Physical and Environmental’ determinants of experience). Expansion revealed eleven descriptive subthemes. Consideration was then given to how subthemes represented patient ‘needs’ during their ED stay, resulting in the derivation of the analytical themes.

Figure 4.2 outlines the relationship between themes. The contribution made by individual studies towards each analytical theme can be found in Table 4.1.

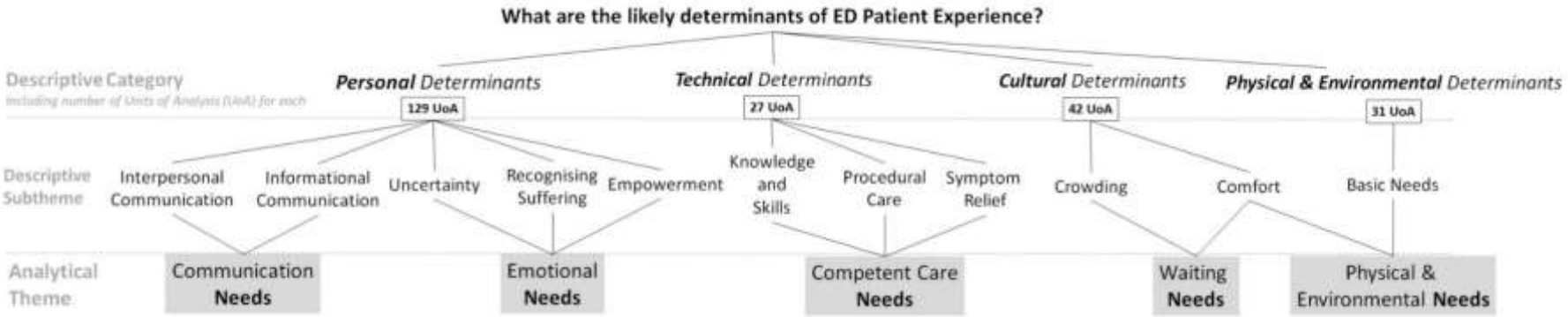

Figure 4.2 Determinants of ED patient experience.

4.6 Synthesis of Results

Findings of the meta-synthesis are reported by analytical theme, with discussion based around respective descriptive subthemes. Examples of how data, including 'verbatim' patient quotations and relevant analysis, has been extracted to inform each analytical theme is outlined within the text.

4.6.1 Communication Needs

The analytical theme of communication consisted of two descriptive subthemes: interpersonal and informative communication.

Interpersonal communication featured prominently and focussed on provider-patient interaction. Desired qualities included actively listening to patient concerns, maintaining eye contact and a calm tone of voice. (16, 17) Specifically, some patients reported that communication helped resolve anxiety and helped them stay calm during stressful procedures:

> *"I mean they were just telling me what they were doing really. Just probably that constant reassurance of knowing what is going to happen and how I am going to feel ... and yes, just knowing the situation I suppose."*[16, p.22]

When perceived as appropriate, humour could help reframe otherwise negative experiences (16,18) or defuse a difficult or tense situation.(19) Empathic interpersonal communication was frequently helpful in assisting patients to cope with their experience of illness and being in the ED(20) and included purposeful touch.(17)

Repetition of questions by healthcare staff frequently caused frustration amongst patients:

> *"It drives me crazy to have to say the same things over and over and over. I'm tempted to get a tape recorder"*[21, p. 107]

Patients also expressed the need for clear answers to their questions, becoming frustrated when this was not the case or where communication was inconsistent. Specific difficulties were encountered by patients who were non-English speaking, or who had pre-existing sensory deficits.(21-23)

Informative communication formed the second descriptive category of communication needs, and was recognised as a discrete component of the patient experience in the ED. Patients had a clear expectation for clear and accurate information and for this to be free of jargon.(18, 24) Where information was not forthcoming, patients became very frustrated and were more likely to complain.(25-27)

Ensuring patients receive a flow of information throughout their ED journey was important. For example, Wiman et al define an 'uninvolved' phase of the trauma patients' resuscitation that occurred following initial examination and treatment, often whilst the patient was waiting for tests or results:

> *"…here, 'lack of information about the injury and its consequences, or about further care …or information about the psychological consequences of the injury' were prevalent".* [19, p.719]

Contemporaneous delivery of information was appreciated, even where this was 'bad news' delivered within an imperfect environment.(21) In addition to psychological anxiety, Kihlgren at al reported that failure to give clear and timely explanations to confused patients could exacerbate delirium:

> *"Patients that arrived in a confused state became noticeably more confused if information was given in an unclear manner."* [25, p. 173]

Although written information is commonly delivered in settings such as the ED, the use of leaflets was directly challenged.(16, 17) Patients reported problems reading and retaining information when in acute distress and discomfort, and reported that written information lacked 'human warmth', compassion, and undermined confidence in providers' knowledge.

Discharge instructions are an aspect of informative communication in the ED. Within the identified studies, a lack of provision of discharge information was negatively associated with the experience of several patients, who desired basic information about follow up care. Crucially, where adequate discharge advice was not provided, patients did not always feel compelled to speak up:

> *"And then it was just like, 'Okay, we're done. See ya!.' You know? And it's like you just walk out of there and you're going 'Did that really happen? And was that…is that it?"*[15, p.507]

4.6.2 Emotional needs

The analytical theme of emotional needs encapsulates three subthemes: 'coping with uncertainty', 'recognition of suffering', and 'empowerment'.

Coping with uncertainty principally arose from a lack of information during care processes and generated anxiety for patients in several studies.(22, 25) More specifically, patients with extensive lived experience of long term health conditions expressed frustration when ED clinicians failed to take into account their perspective, or where clinicians expressed diagnostic uncertainty for a condition perceived as a relapse by the patient.(28) Patients were also critical of being allocated diagnostic labels which they perceived as trivial (e.g. 'viral illness') and could become concerned about 'missed' pathology.(29)

Patients became more anxious as their length of stay in the ED increased, out of fear that this could be due to the identification of a serious condition requiring further investigation, treatment or admission.(36)

Suffering expressed by patients included harmful events that might occur, such as falling from the bed, not receiving pain killers, and being 'forgotten' by ED staff.(25) Longer term fears amongst older adults related to the loss of independence resulting from an acute condition.(28)

Feeling lonely, abandoned and depersonalised whilst in the ED contributed to negative experience in several studies, including amongst older patients.(19, 20, 25, 27)

> *"…to sit here and wait, and the only contact I have with the staff is when they carry out tests on me, you feel that you're not being seen as a person…"*[25, p172]

The provision of simple measures such as a call bell was reassuring.(30) Boredom was an emotion expressed by one patient, although no solutions were proposed.(27)

Empowerment was identified as a further subtheme for codes describing or discussing measures taken by health professionals in the ED to encourage patient participation in their care. In particular, patients reported feeling empowered when encouraged to express themselves and their narrative during their ED stay:

> *"An important contribution to the experience of being cared for was that patients were given the opportunity to explain why they had come to the ED preferably at an early stage."*[25, p173]

Patients longed to be viewed as ‘sensible’, which in turn left them feeling empowered in their decision to attend the ED.(28, 31, 32) Where patients perceived that they were not being taken seriously, their experience was negatively affected:

> *“Patients felt listened to, reassured, and felt as if they were being given professional support and advice…stated that they wanted to be perceived as worthy people who were suffering and legitimately seeking assistance.”*[31,p128]

Patients greatly valued staff who took the time to empower them to feel safe and cared for in the ED, for example, by frequently checking observations, showing diligence, communicating certainty and reinforcing feelings of safety.(16,17,19,27) Patients also expressed a clear desire to be involved in shared decision-making processes.(25)

4.6.3 Care Needs

The analytical theme of care needs comprised three subthemes: ‘knowledge and skills’, ‘procedural care’ and ‘symptom relief’. Fewer units of information were identified for technically oriented themes in comparison to relational aspects of care. Indeed, patients were observers of a conflict between technical and relational aspects of care, and could be critical z`where they perceived the former to take precedence.(27)

Knowledge and skills featured relatively infrequently compared to other themes, however patients demonstrated that they could be pertinent observers of clinical processes and that these observations could influence their experiences. One such example occurred with trauma patients the study by Wiman *et al* who reported that witnessing the team operating in an organised and predetermined manner was ‘central to feeling safe’. Patients expected triage nurses to show

skill and efficiency in streamlining them to appropriate areas,(33) mentioning the need for improved training where this was not perceived to be the case.(31) Few patients in the studies were identified as the recipients of life-saving interventions, with the exception of a mother who remarked specifically on the technical skill employed by an emergency team when her child stopped breathing.

> *"The skill of the staff was absolutely incredible; not enough words of thanks could describe their efforts."*[23,p.371]

In the sub-theme procedural care, patients expected to receive diagnostic tests, observation and a 'definitive' diagnosis and immediate treatment whilst in the ED,(33) all products of technical competence and skill. Revell (2017) identified that inter-professional communication using technical terms during procedures reassured patients of providers' competence.(16)

Patients frequently commented on pain as a symptom requiring treatment, but also displayed a tendency towards tolerating pain as opposed to actively asking for analgesic medication.(17) Where there was failure to provide pain relief, it was of major concern to patients and negatively impacted their experience.(22) Inadequate pain management was also observed to contribute towards patient anxiety.(29)

4.6.4 Waiting Needs

Waiting needs were characterised by two sub-themes, which were crowding and comfort. Wait time was the most commonly reported determinant of experience in one study (34) and was described as *the* 'critical factor' in determining experience by another author.(18) Waiting was also commented upon in many other studies.(18, 26, 27, 30-33, 35) In particular, long waits were

a frequent source of dissatisfaction and complaints.(33, 34) Patients reported a desire from staff for information during their wait including the reasons for their waiting.(18,25) Revell observed that the provision of timely and accurate information could mitigate against the deleterious effects of waiting on a patient's satisfaction and experience, and that staff were generally aware of this need.(16)

Patients valued comfort, including the provision of regular and spare seats near the entrance area of the ED (36) but the 'milieu' of the waiting room environment created feelings of anxiety and uncertainty for some:

> *"The actual waiting situation was characterized by a lack of privacy, with the patients sitting on a chair or lying on a bed, in a waiting room or a corridor. A lot of activities took place at the same time, with uniformed staff coming or going and often running."*[25, p.171]

Patients were generally accepting of a long wait and could conceptualise that this was the result of higher priority patients requiring attention prior to them:

> *"If other patients need more help, of course I stand aside. If someone has heart trouble he must be taken care of before me."*[27, p.25]

The relationship between age and satisfaction with waiting is less clear. Whereas one study reported that long waits were a particular hardship for the elderly,(18) another observed that older adults were most likely to tolerate waiting without displaying dissatisfaction.(18, 30)

4.6.5 Physical and Environmental Needs

The ED environment was perceived as unfamiliar and uncomfortable to patients, and this was often remarked upon as being a negative determinant of experience. Examples of this include environmental determinants related to

noise, lack of privacy whilst waiting, not being able to reach the call buzzer, physical disorientation(28) and unfamiliarity with the environment.(36) Patients resented the use of physical barriers and glass windows in reception areas.(23)

The requirement for emergency departments to meet basic physical needs was remarked upon by several patients. This included the provision of comfortable beds and items such as clothing, blankets, toilets, food and drink.(13, 19, 25) In particular, nurses who were attentive to a patient's basic physical needs were seen as providing a positive experience.(25)

It was observed in at least two papers that older patients seemed less likely to express dissatisfaction overall, and they were especially perceptive observers of the physical environment.(18, 32)

> *"Well, I expect that [the beds] have to be made a certain way. But they just aren't very comfortable when you have to lay there for an hour or more."*[18,p.90]

4.7 Discussion

The identified literature suggests a particular focus on relational aspects of care offered by ED staff. This is in keeping with existing findings which suggest that the majority of complaints are related to communication skills rather than competence,(38) and that enhanced technical training may not translate to improved patient satisfaction.(39) Determinants of experience relating to interpersonal communication are prevalent in this review and highlight patients' desire for a kind, empathetic approach from within the ED. Informative communication relates to the need for timely and clear information delivery, as well as a preference for clear verbal communication, especially at times of pain or distress.

The need for patients to have emotional needs addressed is emphasised, as is ensuring an adequate environment. The concept of ‘patient suffering’ within the ED has previously been defined to include a range of elements such as nausea, vomiting, dizziness and anxiety.(40) This review has identified additional emotional components of suffering such as fear, uncertainty, isolation and loneliness. Although measures for pain scoring are now well developed,(41) there are no similar measures to monitor emotional consequences of being an ED patient. Further studies could explore whether a more holistic assessment of ‘suffering’ may improve patient experience.

Empowerment is defined by the World Health Organisation as “a process through which patients gain greater control over decisions and actions affecting their health” (42) and is important to patients in the ED. Within the identified studies, ED care providers frequently displayed skill to overcome challenges and deliver a sense of reassurance and empowerment to patients.

Waiting was most frequently reported as a determinant of experience and was considered an intrinsic component of ED culture in several studies. Waiting itself—particularly the uncomfortable waiting room environment—featured as a negative determinant of experience, with patients having to ‘endure’ this component of their stay. However, provision of information regarding wait times and the reasons for waiting may ameliorate this experience. Likewise, simple adaptations to the waiting room—such as the provision of ample and comfortable seating—is important to reduce negative experiences of waiting.

The impact of the physical ED environment, and the ability of the ED to meet patients’ basic physical needs was considered important. Patients cited the importance of the provision of food, water, blankets, and comfortable bedding

and toilet facilities as important to their experience. The emphasis placed on waiting by many of the studies identified in this review suggests that there is great scope to improve this aspect of the ED patient journey.

4.7.1 A proposed conceptual model for understanding patient experience in the ED

A conceptual model is defined as a diagram of proposed linkages among a set of concepts related to a particular problem.(43) Descriptive conceptual models are designed to provide paradigmatic ways of thinking through phenomena.(44) In the context of increasing understanding of a clinical problem, this may increase relevance of an otherwise academic synthesis to practising clinicians and policymakers. An appealing and user-friendly descriptive conceptual model of ED patient experience is therefore proposed as a result of this synthesis (Figure 4.3). The model is based around five core patient needs based upon the analytical themes of the synthesis. These are presented in the inner circle. In the middle circle, associated descriptive sub-themes are presented as determinants of experience. For example, the analytic theme ‘communication needs’ has been constructed from the subthemes ‘interpersonal communication’ and ‘informational communication’. In the outer circle of the model a range of practical recommendations are presented. These recommendations demonstrate how qualitative themes, derived as a result of the synthesis, can be translated into suggestions for clinical practice. Each recommendation represents a desirable care process reported by at least one patient in the literature. The majority of recommendations—such as offering a warm blanket or information during waiting—are simple and deliverable with minimal resource implications.

Further validation of this model is needed. Potential applications may include training and assessment of healthcare professionals and informing design of patient-centred care processes. The model also provides a basis for future research aiming to understand and optimise patient experience in the ED.

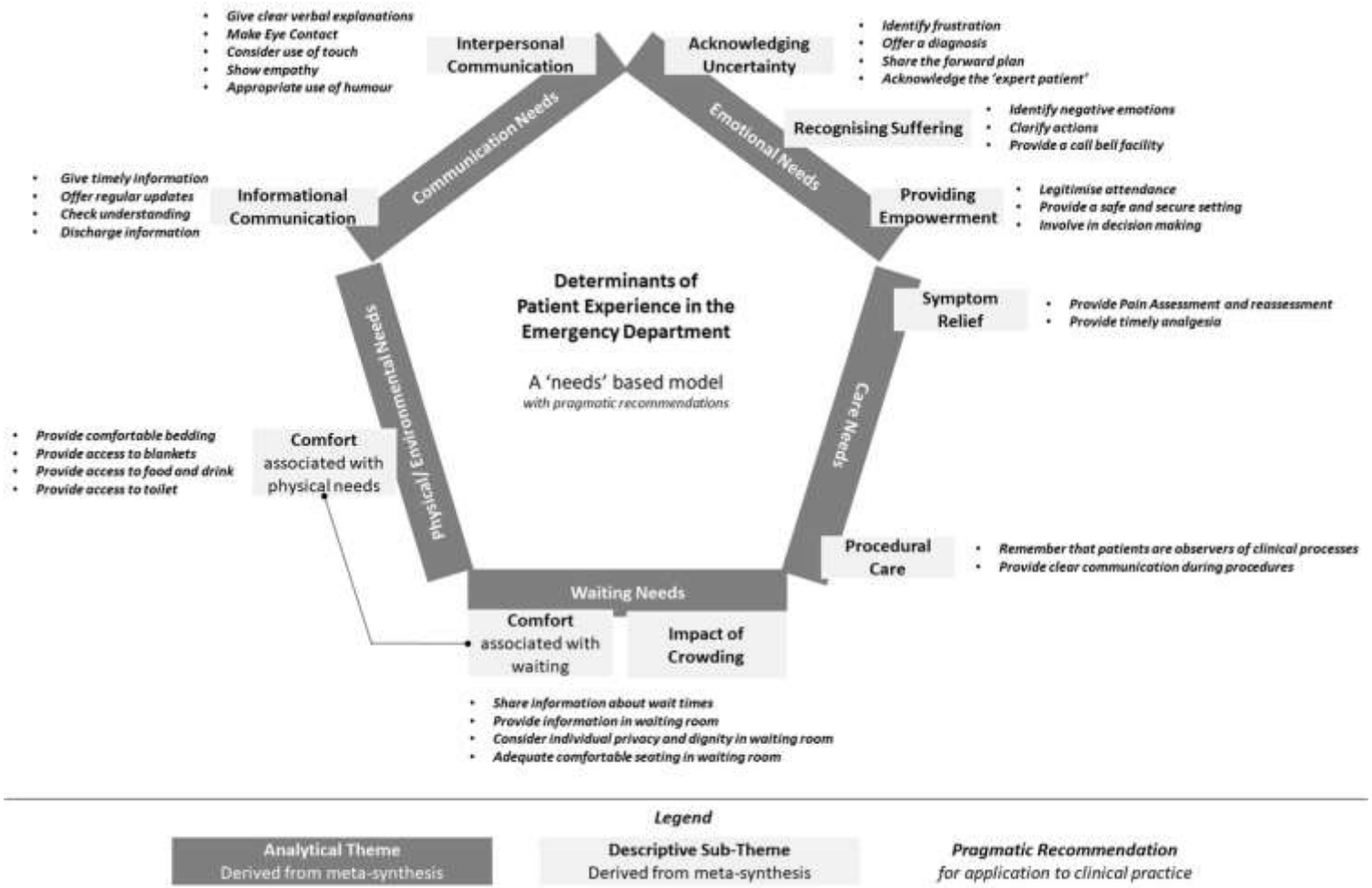

Figure 4.3 Conceptual framework with practical recommendations.

4.8 Limitations

The lack of a standard taxonomy of keywords for literature exploring patient experience means it is possible that some studies have been missed. Additionally, while effort has been made to describe some major contributions from identified studies towards the synthesis and resulting conceptual model, integrating an expansive body of qualitative literature into a single review is inherently challenging. Nonetheless, conceptual saturation was reached during the review, however, indicating that unidentified literature is unlikely to substantially influence findings.

The apparent priority assigned by patients to relational aspects of experience over technical skills may be as a consequence of selection bias to the included studies. Intuitively, interview participants are likely to have lower acuity problems. It is possible that those with higher acuity or life-threatening conditions would place more value on the technical skills and competence of providers. Indeed, this seems to be partly reflected in the paper by Cypress et al.(24) Future work should seek out this population to confirm or refute this possibility. It is also possible that interviews simply focussed on exploring relational aspects of care. Retrospective interviews are also likely to be subject to recall bias—patients with little knowledge of medical care may be more inclined to recall the interpersonal aspects of care afforded to them.

4.9 Conclusion

This meta-synthesis identifies a range of factors responsible for determining patient experience in the ED, and confirms that patient experience is associated with perceptions of care. As such, we would suggest that the aphorism ‘they [patients and relatives] don’t care how much you know until they know *how much* you care’ should be embraced at every stage of the patient journey by

care providers in the ED. With this in mind, the review offers a framework with pragmatic recommendations that may be translated to directly enhance ED patient experience. With further validation, this framework and its suggestions may be harnessed as a tool for engaging practitioners and organisations in providing better patient experience, potentially improving clinical outcomes and patient safety.

Post- Publication Addendum

Contribution to the PREM-ED 65 study

This systematic review and meta-synthesis formed the initial conceptualisation of patient experience in the ED. Aside from being of standalone practical relevance for clinicians and policymakers, the 'needs-based' analytical themes of the conceptual framework were used as the basis of framework analysis for data from the interviews with patients (Chapter Six) and focus groups with staff (Chapter Seven). Data extracted from this review were triangulated with interviews and focus group data and directly informed draft item generation for PREM-ED 65.

The next chapter outlines a scoping review of existing health measures relevant to ED practice, highlighting the strengths and limitations of currently available instruments and reinforcing the rationale for developing PREM-ED 65.

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Supplementary Material

SM 4.1 Example search strategy for qualitative systematic review

Database	Search Term
MEDLINE	Patient[.ti,.ab] AND (Emergency Department[.ti,.ab] OR Emergency Room[.ti,.ab] OR Accident and Emergency Department[.ti,.ab] OR Urgent Care[Title/Abstract) AND (Experience[.ti,.ab] OR Perception[.ti,.ab]) AND (Qualitative[.ti,.ab] OR Interview[.ti,.ab] OR Focus Group[.ti,.ab] OR Phenomenology[.ti,.ab] OR Ethnography[.ti,.ab] OR Grounded Theory[.ti,.ab]))[Limits: Jan 1997 to July 2018]

Group	Filter #	Database	Search Term
Population	1	MEDLINE	Patient*[.ti,ab]
Phenomenon of **I**nterest	2	MEDLINE	Satisfaction[.ti,ab]
	3	MEDLINE	Experience[.ti,ab]
	4	MEDLINE	Perception[.ti,ab]
Context	5	MEDLINE	Emergency Department[.ti,ab]
	6	MEDLINE	Emergency Room[.ti,ab]
	7	MEDLINE	Accident and Emergency Department[.ti,ab]
	8	MEDLINE	Urgent Care[.ti,ab]
Method	9	MEDLINE	Qualitative[.ti,ab]
	10	MEDLINE	Interview[.ti,ab]
	11	MEDLINE	Focus Group[.ti,ab]
	12	MEDLINE	Phenomenology[.ti,ab]
	13	MEDLINE	Grounded Theory[.ti,ab]

Example strategy:
(1 AND (2 OR 3 OR 4 OR 5) AND (7 OR 8 OR 9) AND (10 OR 11 OR 12 OR 13 OR 14))

Chapter 5 Scoping Review.

Authorship Statement
Corresponding Author:
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Contributorship Statement
Blair Graham (BG) conceived the idea for the study, constructed the search strategy, led the literature search, data collection, critical appraisal of articles, synthesis of literature, writing of the initial manuscript, revision of all subsequent versions, and approval of the final version.

Jason Smith (JS) contributed to revising draft manuscripts and approving the final version.

Jos Latour (JML) contributed to the critical appraisal of articles, synthesis of literature, revision of draft manuscripts and approval of the final version.

The agreed-upon percentage contributions toward the production of this manuscript are BG 85%, JS 5%, and JML 10%.

Conflict of Interest Statement
None of the authors have any conflicts of interest to declare.

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Publication Status
As of August 2024, this chapter has not been submitted for publication. However, the lead author intends to submit it as a scoping review to a relevant journal.

What this chapter adds

This chapter:

- Demonstrates the ability of the researcher to (i) design and conduct a scoping review using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Criteria; (ii) critically evaluate Patient Reported Outcome Measures (PREMs), Patient Reported Experience Measures (PREMs) and Health-Related Quality of Life (HRQOL) surveys using Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) Criteria; and (iii) synthesise academic and clinical expertise to generate 'real world' recommendations for the use of Patient Reported Measures in the ED.
- Considers the dimensionality of currently available instruments for measuring patient experience in the ED and highlights current literature gaps, including the need for more validated condition—and population-specific health measurement instruments in the ED setting.
- Helps provide an evidence-informed rationale for the PREM-ED 65 study.

Measuring what matters: A Scoping Review of PROMs, PREMs and HRQOL instruments for evaluating the quality of Emergency Department care.

5.1 Abstract

Background

Validated health measurement instruments, including Patient-Reported Outcome Measures (PROMs), Patient-Reported Experience Measures (PREMs), and Health-Related Quality of Life (HRQOL) surveys, may provide a means of reliably assessing the patient perspective of Emergency department (ED) care. However, the widespread adoption of the instruments is currently limited within emergency care.

Aim: This scoping review aims to identify and critically examine available PROMs, PREMs, and HRQOL surveys administered to ED patients, highlighting their applicability to practice.

Methods

We conducted a scoping review to identify studies reporting the development, validation, and administration of PROMs, PREMs, and HRQOL instruments for adults in the ED. Eligible studies were published in English and described the instrument's content and administration to adults attending the ED. Searches of MEDLINE, CINAHL, and EMBASE were conducted to identify studies published between January 2010 to July 2023. Study attributes were extracted and categorised based on their target population. The dimensionality of the instruments was compared to a pre-existing framework focusing on ED patients' needs. Instrument quality was appraised using the COSMIN checklist, and each was graded to indicate real-world usability in an ED setting.

Results

Following the removal of duplicates, 1,464 titles were examined. Forty-one studies met the inclusion criteria, revealing 37 discrete instruments categorised as PROMs (n=4), PREMs (n=24), and HRQOL surveys (n=9). The largest group of instruments were targeted to the general ED population (n=16), with others tailored for specific patient groups (n=6) or originally developed outside emergency care but subsequently administered to ED patients (n=14). Most studies evaluated ED care within high-income countries.

Instrument development comprised a combination of literature reviews, qualitative research, and consensus methods. When compared to the needs-based patient-experience framework, dimensions most frequently aligned with communication, waiting, and care needs. Instrument development and content validity were the most reported psychometric properties; hypothesis testing, cross-cultural validity, and responsiveness were infrequently reported. Nine instruments demonstrated a low risk of bias and high external validity and may be considered for administration to adult ED patients as part of quality improvement initiatives or research activities.

Conclusion

This scoping review demonstrates a growing interest in ED patient-reported outcomes within the literature. Whilst some instruments are rigorously developed, further validation of existing tools, such as the generic HRQOL instruments, is needed within the ED setting. Further development of the condition and population-specific instruments will ensure the outcomes and experiences of all patients attending the ED can be captured.

5.2 Background

The emergency department (ED) provides time-critical care for patients across the age and acuity spectrum, including those with unmet primary care needs, psychiatric issues, and acute exacerbations of long-term conditions.(1-4) Reflecting the diverse case mix, up to 70% of citizens in OECD nations access the ED annually.(5) However, challenges, including systemic under-resourcing, inadequate staff recruitment and retention, ED overcrowding, and exit block, can hinder the provision of high-quality, individualised ED care.(6-8) A resulting emphasis on efficiency and the optimisation of patient flow within the ED means that structural and process measures are most frequently used to assess the quality of care.(9, 10) However, these metrics may not capture the clinical outcomes or healthcare experiences that matter most to patients.

The International Federation for Emergency Medicine recommends routine measurement of Patient Outcomes and Experience.(11) These objectives may be accomplished using Patient Reported Outcome Measures (PROMs) to aid understanding of patient perspectives on their condition, Patient Reported Experience Measures (PREMs) for evaluation of care experiences, and Health-Related Quality of Life (HRQOL) Instruments for assessing overall quality of life impacts of treatments.(12, 13) In areas related to emergency care, including orthopaedics, oncology, and cardiology, PROMs have been shown to enhance outcomes by improving symptom tracking, patient-provider communication, and shared decision-making.(14, 15) Patient experience measurement may identify care vulnerabilities and drive targeted quality improvement.(16) Furthermore, improved patient experience is positively associated with outcomes in acute conditions, including myocardial infarction, pneumonia, and following acute surgery.(17-19) While most typically used for monitoring chronic conditions,

HRQOL instruments have been used to predict readmission risks in heart failure, guide personalised acute stroke care, and evaluate the quality of life following major trauma.(18, 20, 21)

While convincing evidence demonstrates that measuring patient outcomes, experience, and quality of life may improve patient-centredness and standards within acute care settings, PROMs, PREMs and HRQoL instruments are yet to be widely adopted in the ED. Potential barriers to adoption include a perceived lack of content or face validity of instruments, inadequate staff training, and organisational issues.(22) Emergency physicians have previously expressed concerns regarding the reliability of patient-reported data, deciding suitable timing for administration of questionnaires during an ED episode, the possibility of using patient feedback to critique clinician performance negatively, and uncertainty regarding the utility of individual data for driving broader changes.(23) A recent commentary on using PROMs in the ED highlights the need for instruments that properly measure outcomes of interest to ED patients and providers, minimise the burden on acutely unwell patients, and are relevant to capturing perspectives across the diverse ED patient group.(24) However, notwithstanding potential barriers, these studies recognise the need to better measure patient outcomes, patient experience and HRQoL amongst ED patients.

5.2.1 Aims

This scoping review aims to identify currently available PREMs, PROMs, and HRQOL instruments administered to adults attending the ED and provide insight into their dimensionality, reliability, validity, and real-world usability.

5.3 Methods

A scoping literature review was performed and is reported using the PRISMA-ScR 2018 statement.(25)

5.3.1 Eligibility criteria

To be eligible, studies must report the development, psychometric validation, and/or administration of PROMs, PREMs, and HRQOL instruments for adults attending the ED. To be included, studies were required to describe the measurement construct and content of the instrument, the intended population, and the context in which the instrument was administered to patients. Both general and condition/population-specific instruments were eligible for inclusion. Only studies that were accessible in full and published in English were included. Conference abstracts, research letters, and studies conducted outside a hospital ED setting were excluded.

5.3.2 Information sources

MEDLINE, CINAHL, and EMBASE were searched to identify potentially relevant titles. Bibliography searches of identified papers and searches for unpublished material were conducted from various sources. (Supplementary Material SM5.1)

5.3.3 Search

Search terms were identified and used in the full search strategy (Supplementary Material SM5.2). The results of the search strategy are presented in a PRISMA diagram. To ensure that the identified studies and instruments apply to current practice, the search was limited by publication date and only papers from 2010 were included. An initial search was conducted up until August 2019; this was again updated in July 2023. The search results have been integrated and full findings are presented here.

5.3.4 Data Charting Process

The researchers developed a data charting form to determine relevant fields to extract (Appendix 1). The lead reviewer (BG) charted the data, which was checked by another researcher (JML).

5.3.5 Data Items

Characteristics of the identified instruments and included studies were extracted and summarised in data extraction tables. Data collected in relation to the instruments included instrument name, type (i.e., PROM/ PREM/ HRQOL inst), summary of the development methods, measurement domains, and the type of response scales used. For the study characteristics, we recorded the author, year of publication, country, main methods, population, mode of instrument administration (e.g., self-administered vs interview), data analysis, sample size and key findings.

5.3.6 Synthesis of Results

Three predetermined categories were established a priori based on the study population in which the instrument was developed. The included studies were sorted into one of these three groups. The first group consisted of generic instruments developed for adult ED patients. The second group consisted of condition or population-specific instruments developed for adult patients attending the ED. The third group consisted of instruments originally derived in a different clinical setting, but subsequently administered to adult patients within an ED setting.

5.3.7 Additional Analyses

Assessment of Dimensionality

The number and names of measurement domains were recorded for each instrument. To facilitate comparative assessment of dimensionality,

measurement domains within each instrument were aligned to themes from a pre-existing conceptual framework focusing on ED patients' needs.(26) These themes consisted of communication, emotional, care, physical/ environmental, and waiting needs of ED patients.

Assessment of Psychometric Characteristics

The quality of included studies was assessed using the Consensus-based standards for selecting health measurement instruments (COSMIN) checklist. COSMIN is a comprehensive, internationally recognised 'gold standard' set of quality criteria to assess the quality of Health-related Patient Reported Outcome Measures. The COSMIN *risk of bias checklist* was developed to enable a standardised assessment of PROMs for systematic reviews.(27,28) As part of the appraisal process, two researchers (BG and JML) collaboratively assessed each criterion on the checklist and assigned a judgement ranging from doubtful to very good (Table 5.1). Disagreement was resolved by discussion between the researchers. Overall risk of bias was reported as 'low', 'intermediate' or 'high'.

Table 5.1 Risk of Bias Assessment for Scoping Review

Very Good	+++
Adequate	++
Doubtful	+
Not Reported	—

5.3.8 Assessment of external validity and real-world usability

The final stage of analysis consisted of a pragmatic summary assessment of the internal and external validity of the included studies. Based on the overall appraisal of the included studies, each instrument was assigned a graded recommendation for 'real-world' usability in the ED setting (Table 5.2).

Table 5.2 Grading of instruments for real-world usability

Grade	Summary Descriptor	Practical recommendation
A	The instrument has a methodologically rigorous and reported development process. Assessed as at least 'adequate' against most COSMIN criteria; low overall risk of bias; high internal and external validity.	Most likely to be suitable administration to ED patients.
B	Some description of development. Assessed as at least 'adequate' against some COSMIN criteria. Intermediate internal and external validity.	Possibly suitable for administration to ED patients; may depend on setting/ context.
C	The study does not describe the instrument development process, content validity, or face validity. It is also poorly aligned to COSMIN criteria, which increases the risk of bias and lowers internal/external validity.	Least likely to be suitable for administration to ED patients; it may require further development or validation.

5.4 Results

5.4.1 Study selection

After removing duplicates, 1, 464 unique titles were identified, of which 71 underwent full review. Among the 42 studies meeting inclusion criteria, 37 unique measurement instruments were identified, consisting of PROMs (n=4), PREMs (n=24) and HRQOL instruments (n=9)(Fig.1).(PRISMA Diagram- Figure 4.1). The largest proportion of instruments were those intended for administration to the general ED population (Group 1; n=16)(Table 5.3). The smallest proportion of instruments were developed for specific ED user groups, including those with a defined condition or presenting complaint (Group 2; n=7)(Table 5.4). Fourteen instruments were identified originally developed

outside of emergency care but subsequently applied to one or more ED populations (Table 5.5).

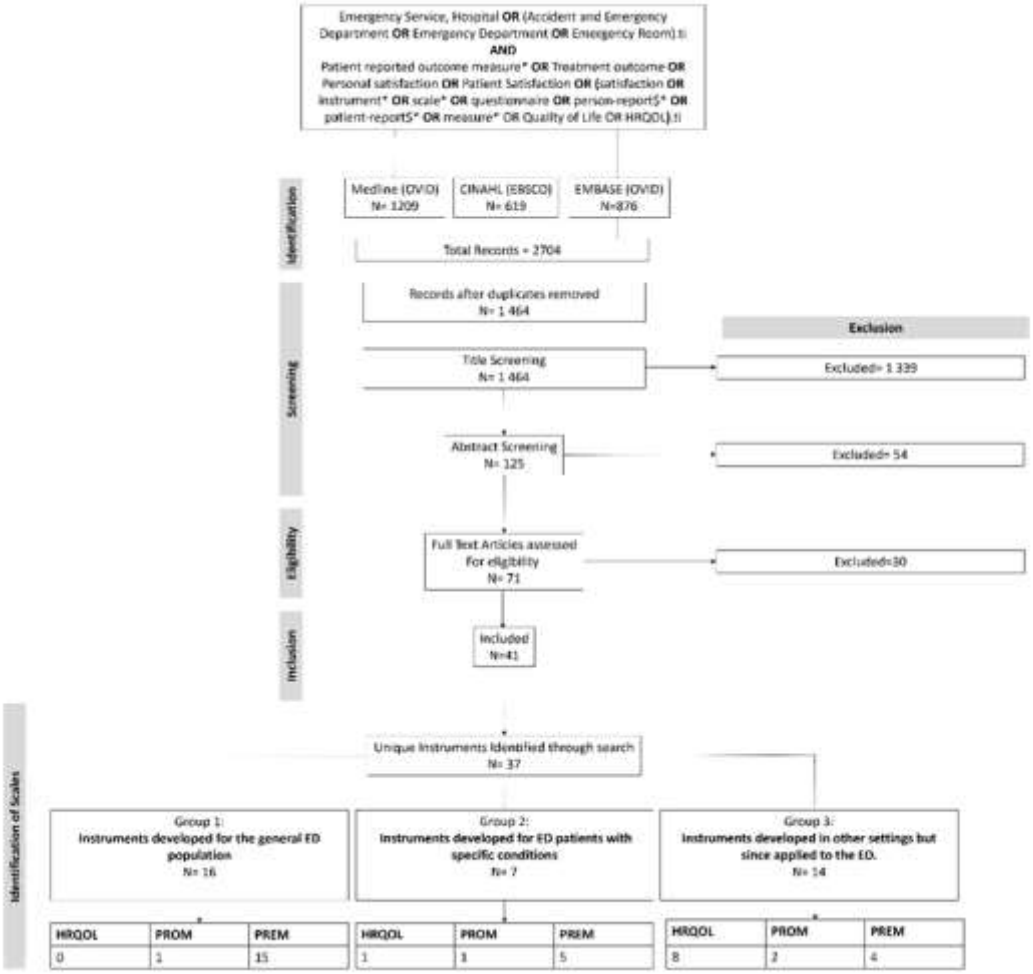

Figure 5.1 PRISMA diagram for the scoping review

5.4.2 Study Characteristics

Out of the 42 identified studies, 17 (40.5%) reported derivation or validation of an instrument. A further 19 (45.2%) reported cross-sectional administration of an instrument to ED patients without assessment of psychometric properties. Other study designs included instruments used as outcome measures as part of randomised trials (n=2; 4.8%), within cohort studies (n=3, 7.1%) and as part of an analysis of registry data (n=1; 2.4%). Studies most frequently originated from North America and Europe (n=20 (47.6%) and n=14 (33.3%), respectively).

Although single studies were identified within an Ethiopian and Iranian ED setting, low- and middle-income countries were under-represented. Most studies were of a single-centre design, and none were multi-national. Sampling strategies were predominantly non-consecutive, and convenience sampling was commonplace. There was wide variation in sample size, from less than 50 to over 1000 patients.

5.4.3 Instrument Characteristics

Within the group of instruments developed for the ED general population (Table 5.3), one PROM was identified as relevant for administration to the general adult population of ED patients. The 15-item PROM-ED 1.0 was developed in a Canadian setting and assesses symptom relief, understanding of health concerns, reassurance, and care planning. The remaining instruments within Group 1 (n=15) measured patients' perceptions of experience. These include the Consumer Emergency Care Satisfaction Survey (CECSS) (29) and the Urgent Care System Questionnaire (UCSQ) (30). Some instruments were more specific in their focus, targeting non-English speaking patients(31), exploration of an 'ethical environment' in the ED(32), and patient participation in ED care (PPED).(33) A single 16-item measure was developed for older adults aged 75 years and over in a US setting.(34)

Instruments measuring outcomes and experience of specific clinical conditions (Table 5.4) were organised within the second group. They included the initial development of a measure for ED asthma presentations (35), a full- and short-form version of the Quality of Trauma Acute Care PREM (36, 37), and a measure evaluating patients' perceptions of psychological stress during ED evaluation for acute coronary syndrome.(38) In addition, two HRQOL measures were identified. This included the Poverty-Related Quality of Life Questionnaire

for ED patients (PQoL-17), which measured six domains, including respondents' self-esteem, psychological well-being, and autonomy.(39) The Adult Sickle Cell Quality of Life Measure (ASCQ-Me) measured access to ED care, communication with ED providers and pain management. (40)

The third group of instruments were developed for use in other settings but subsequently applied to an ED patient population (Table 5.5). Correspondingly, a broad range of instruments was identified, including prominent HRQOL measures such as Short-Form 36 (SF-36). In a study by Banz et al., the SF-36 decreased perceptions of QOL in patients presenting to ED with non-specific abdominal pain.(41) The shortened, 12-item version (SF-12) was also used to assess QOL in general ED attendances and patients attending the ED with minor fractures.(42, 43) Other identified HRQOL measures included the EuroQol 5-dimension (EQ-5D) and RAND-12 Health Survey. (44-46) The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) assesses QoL from the individual perspective instead of applying pre-defined, prescriptive criteria. A cross-sectional survey using the SEIQoL amongst older adults in three Danish EDs revealed the importance of family, social activity, health status, everyday life and leisure activities in defining ED patients' HRQoL.(47) An additional, disease-specific HRQOL instrument reported independent predictors of reduced QoL of patients attending the ED with acute pulmonary embolus.(48)

Within this group, PREMs included the Care Transitions Measure-3 Item to evaluate the effectiveness of discharge processes from the ED.(49) Two measures—the Iowa Satisfaction with Anaesthesia Scale and Brice Anaesthesia Questionnaire—were administered by Johnson et al. to evaluate

patient experiences of conscious sedation in an Australian ED. (50) A Spanish version of the uncertainty of illness was validated to enable assessment of patient perceptions of their presenting conditions. (51) The Kansas City Cardiomyopathy questionnaire assessed domains including physical symptoms, QoL, Social Interface and Self Efficiency in heart failure. (52)

5.4.4 Development methods for the instruments

A range of methods were reported when developing concepts and deriving items for the included instruments, most commonly comprising literature reviews, qualitative research with patients and caregivers, cognitive interviewing/ debriefing, and consensus methods such as the Delphi technique. Instruments that adhered to key COSMIN criteria included PROM-ED 1.0, which involved a three-phase qualitative study and literature reviews for concept identification with a subsequent ranking of candidate items and participant validation using cognitive interviews. (53, 54) Among instruments intended for the general ED population, the development methods for the CQI-ED, (55) PPED, (33) and UCSQ (30) were clearly described. Some condition-specific instruments (Group 2) and those originally developed outside the ED (Group 3) utilised a rigorous approach to derive items and response scales. Examples include the measure for ED asthma patients (35) derived using a three-phase qualitative study comprising interviews, member checking and ranking, cognitive interviewing, and the dermatology quality of life index (DLQI), which was field tested amongst participants in the presence and absence of a dermatological diagnosis to ensure sensitivity amongst the latter group. (56)

5.4.5 Response options for the instruments

A broad range of answer option scales was utilised to facilitate the measurement of individual items. The most common response scales were

four- and five-item Likert scales. Deviations from this included 6-, 7- and 10-point agreement scales and dichotomous response scales.

Table 5.3 Scoping Review Findings—Group 1: Instruments developed for the general ED population.

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response scale**	Author (Year) Country	**Methods** Study Type	Setting	Population/ Key inclusion Criteria	Administration	Data Analysis/ Primary Outcome	**Results** Sample Size	Key finding(s)
Patient experience of the ED triage encounter	PREM	N/S	Information provision regarding wait time; triage process; clinical condition. Competence of triage nurse; reception by triage nurse. 23 items.	Various	Goransson (2010) (57) Sweden	Cross Sectional	Single ED	Adults	Self- administered	Descriptive analysis	146	Reception and care given by triage nurses were positive determinants of experience. Waiting time was a negative determinant of experience.
Patient Participation in Emergency Departments (PPED)	PREM	Input from ED patients and ED nurses for concept development; cognitive interviews.	Fight for participation; requirement for participation; mutual participation; getting basic needs satisfied. 14 items.	Likert (4 Point)	Frank et al (2010) (33) Sweden	Cross Sectional (Validation Study)	Three EDs	Adults	Self- administered	Structural Validity (PCA) and internal consistency (Cronbach α)	356 45.6% capture	All domains had satisfactory validity and reliability. The questionnaire makes it possible to evaluate patient participation in ED care.
Urgent Care System Questionnaire (UCSQ) UK	PREM	Existing questionnaires and qualitative research.	Patient Reported System Metrics; Descriptive aspects of patients' experiences; Patients views of experiences. 22 items.	Likert (5 Point)	O'Cathain (2010) (30) UK	Cross Sectional (Validation Study)	General Population Sample	Adults	Self- administered	Structural Validity (PCA) and internal consistency (Cronbach α)	457	Testing confirmed validity and reliability to measure the patient perspective of the emergency and urgent care system.
Consumer Emergency Care Satisfaction Scale (CECSS)	PREM	ED specific version of Riser Patient Satisfaction Scale. Developed using content experts.	Experience of Caring, Discharge, Teaching. 19 items.	Likert (5 Point)	Ekwall (2010) (29) Sweden	Cross Sectional (Cross- Cultural Validation)	Single ED	Adults	Self- Administered	Structural Validity (EFA)	157	The Swedish version of the scale is reliable and may be a useful tool for measuring satisfaction in different acute care settings.
					Messina (2014) (58) Italy	Cross Sectional	Single ED	Adults with lower acuity problems	Self-administered	Descriptive statistics with bivariate analysis to determine relationship between items and overall satisfaction	259	Deficiencies in experience centred around discharge processes, communication, listening and delivering reassurance.
					Hoonakker (2023) (59) United States	Cross Sectional	Single ED	Older adults with falls	Self-administered	Examined construct validity and per-item ceiling effects.		Addressed methodological issues with CECSS, provided recommendations for improvement.
Questionnaire to assess satisfaction with hospital emergency care.	PREM	Expert Consensus. Delphi Analysis.	Kindness, Personal Manner and Competence; Comfortable Service 30 items.	Likert (5- point)	De la Orden et al (2011) (60) Spain	Cross Sectional (Validation Study)	Single ED	Adults	Telephone	Structural Validity (PCA) and reliability (Cronbach α)	296	Two domains derived following factor analysis Comfortable and Personalised Service.
Ethical Environment in the ED Questionnaire	PREM	Expert consensus.	Staff skills, Compassion, Courtesy and Respect, Communication, Time with the doctor, Quality of Care, Overall Satisfaction 12 items.	Likert (5 Point)	Lin (2013) (32) Taiwan	Cross Sectional Survey, as part of quality improvement project.	Single ED	Adults	Self-administered paper survey	Basic descriptive statistics. Pre- and post intervention analysis.	313	Intervention successful in improving patients' perceptions of ethical environment in ED.

Table 5.3 (Continued)

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response scale**	Author (Year) Country	**Methods** Study Type	Setting	Population/ Key Inclusion Criteria	Administration	Data Analysis/ Primary Outcome	**Results** Sample Size	Key finding(s)
Satisfaction with ED service amongst non-English Speaking Patients	PREM	Literature review	Staff skills, Compassion, Courtesy and respect, Communication, Time with the doctor, Quality of Care, Satisfaction 14 items	Likert (5 point)	Mahmoud et al (2014) (31) Australia	Cross Sectional	Single ED	Adults	Self-administered survey	Basic Descriptive Statistics	828	Non-English patients were significantly less satisfied than English Speaking patients. Use of an interpreter improved the patients' level of satisfaction.
Consumer Quality Index in an Accident and Emergency Department (CQI-A&E)	PREM	Literature search, focus groups with patients, cognitive interviews. (55)	Attitude of healthcare professionals; information and explanation; environment; Leaving the ED; general information; rapidity of care 24 items	Likert Scale (Various)	Bos et al 2015 (61) Netherlands	Cross sectional (Validation Study)	Multi-Centre (21 EDs)	Adults and children aged ≥12 years	Self-administered within 1 month of attendance	Structural Validity (PCA) and internal consistency (Cronbach α)	4883	All domains demonstrated good reliability and were able to discriminate quality of care between EDs.
Brief Emergency Department Patient Satisfaction Scale (BEDSS)	PREM	Literature review and expert consensus	Experience of admission; nursing care; physician care; environment; waiting time; and general satisfaction. 24 items	Likert (4 point)	Atari (2015) (62) Iran	Cross sectional (Validation Study)	Two EDs	Adults	Self-administered	Structural Validity (EFA) and Internal Consistency (Cronbach α)	301	Satisfactory factor loadings for five scales: ED staff, ED environment, physician care satisfaction, general patient satisfaction and patients' family satisfaction.
					Al-Wathinani (2022) (63) Saudi Arabia	Patient Experience Cross Sectional Study	Single ED	Adults	Self- administered	Internal Consistency (Cronbach α) Hypothesis testing	134	Differences in reported satisfaction based on gender and nationality.
Assessment of client satisfaction on ED services	PREM	Not Described	Courtesy of staff, health care services, pharmacy services, laboratory services, and overall satisfaction	Likert (4 point)	Worku (2017) (64) Ethiopia	Patient Experience Cross Sectional Survey	Single ED	Adults	Face-to-face interviews/ Self-administered	Basic Descriptive Statistics	407	Lack of availability of medications was a negative determinant of experience. Security, availability of tests and cleanliness were positive determinants of experience.
Measures for older adults attending the ED.	PREM	Literature review	Personal care/ communication and problems with waiting times	Likert (3 point)	McKusker (2018) (34) Canada	Psychometric Validation Study	Four EDs	Adults Aged >75y	Self-administered questionnaire	Structural validity; Internal consistency (Cronbach α)	412	Identified two scales assessing important aspects of ED care experienced by older adults.
Press- Ganey ED Survey	PREM	Not Reported	Arrival, Nurses, Medical Provider, Tests, Personal Information, Personal Issues, and Overall assessment of satisfaction.	Likert (5 Point)	Sharp 2019 (65)	Cross- Sectional	Two EDs	Adults	Telephone	Basic Descriptive Statistics/ logistic Regression	1012	Patient reported experience may differ depending on site type, even when clinicians are the same.

Table 5.3 (Continued)

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response scale**	Author (Year) Country	**Methods** Study Type	Setting	Population/ Key Inclusion Criteria	Administration	Data Analysis/ Primary Outcome	**Results** Sample Size	Key finding(s)
PROM-ED 1.0	PROM	Qualitative interviews; Cognitive Debriefing; Item prioritisation using Delphi method (53)	Symptom Relief; Understanding of health concerns; Reassurance; and having a plan. 15 Items	Various (4, 5, 10 point scales)	Vaillancourt (2020) (54) Canada	Psychometric Validation Study	Single ED	Adults	Self-administered survey	Structural Validity (EFA) and internal consistency (Cronbach α)	200	Testing provided good evidence of validity and test-retest reliability
Perceived Quality of Healthcare in an Emergency Department	PREM	Existing Measures; Expert consensus	Accessibility and availability of care; facilities and physical environment; privacy; satisfaction with reception staff; triage; doctors; nurses; auxiliaries; technicians; evaluation of treatment; overall expectations; satisfaction and perceived quality of care. 44 Items	Likert (10- point)	Abidova et al (2020) (66) Portugal	Psychometric Validation Study	Single ED	Adults	Internet or telephone survey.	Structural validity (EFA) correlation of items with overall perceived quality of care.	340	Overall satisfaction with doctors and meeting expectations were the most significant determinants of quality of care. Meeting expectations was most important determinant of satisfaction.
Patient Reported Outcome Measurements (PROMs) After Discharge from the ED	PREM	Assessment of expectations at triage, and outcomes on discharge	Written therapy; Written prognosis; Physicians' and nurses' empathy. 3 Items	Dichotomous	Menditto et al (2020) (67) Italy	Initial Derivation	One ED	Adults with isolated limb injury	Self- administered	Descriptive statistics. Proportions of pre-defined expectations at triage compared to outcomes on discharge	96	Initial conceptualisation of potentially relevant PROMs for use in ED.
Accident and Emergency Experience Questionnaire (AEEQ)	PREM	Refinement of existing measure (Picker A&E Survey)	Overall impression, care and treatment, environment and facilities, information on medication and danger signals and clinical investigations. 46 Items		Wong et al 2023 (68) China	Derivation and Validation Study	Seventeen EDs	Adults	Self- administered survey	Derivation using focus groups and cognitive interviews. Structural Validity (EFA) internal consistency (Cronbach α) and test- retest reliability.	512	Valid and reliable instrument for routine administration to ED patients in China.

Table 5.4 Scoping Review Findings—Group 2: Instruments developed for ED patients with specific conditions.

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response Scale**	**Author (Year) Country**	**Methods Study Type and aim(s)**	**Setting**	**Population**	**Mode of Administration**	**Data Analysis**	**Results Response Rate**	**Key Findings**
Quality of Trauma Acute Care (QTAC- PREM)	PREM	Literature review; interviews with patients and providers. (69)	Timeliness; Skill and qualities of caregivers; Safety; Equality; Information and communication; Coordinated and comprehensive care; Patient care' Family centred care; End of life care (family version only) 46 items	Likert (5-point)	Bobrovitz (2012) (36) Canada	Cross Sectional	Single Level I Trauma Centre	Adults with Major Trauma	Self-Administered	Spearman's correlation coefficients and corresponding P values were calculated between each survey item and overall satisfaction to measure construct validity.	134	Confirmed feasibility of using a PREM to capture patients' experiences of major trauma.
					Bobrovitz (2015) (37) Canada	Cohort (Validation study)	Three Trauma Centres	Adults with major trauma	Self-Administered	Three subscales identified for the acute care measure.	400	Satisfactory psychometric characteristics for administration to trauma patients.
Pain Management: Association with Patient Satisfaction among Emergency Department Patients **US**	PREM	N/A (Standardised Interview Schedule)	Satisfaction with pain management 18 items	Likert (7-point)	Bhakta (2014) (70) United States	Cross sectional	Single Site	Adults	Standardised Interview	Descriptive Analysis	289	Effective pain management associated with improved patient satisfaction among ED patients with painful conditions.
Poverty- Related QOL questionnaire for individuals seeking care in EDs (PQoL-17)	HRQOL	Interviews with patients; classical item reduction theory.	Self Esteem/ Vitality; Psychological Wellbeing; Relationships with Family; Relationships with Friends; Autonomy; Physical Wellbeing/ Access to Care 17 items	5-point Likert Scale	Boyer (2014) (39) France	Derivation and Validation	Single Site	Adults	Self-Administered	Principal Components Analysis followed by Confirmatory Factor Analysis.	633	The PQoL-17 presents satisfactory psychometric properties and can be completed quickly, thereby fulfilling the goal of brevity sought in EDs.
Adult Sickle Cell Quality of Life Measurement (ASCQ-Me)	PREM	Literature review; interviews with consumer groups, service users and providers.	Access; Provider Communication; ED Care; ED Pain Treatment	27 Items	Evensen (2016) (40) United States	Validation	Multiple Centres (n=7)	Adults	Self-Administered	Descriptive analysis; structural validity; Criterion validity	561	Reliable and valid to assess experience of care amongst patients presenting to the ED with SCD.

Table 5.4 (Continued)

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response Scale**	**Author (Year) Country**	**Methods Study Type and aim(s)**	**Setting**	**Population**	**Mode of Administration**	**Data Analysis**	**Results Response Rate**	**Key Findings**
Short form Quality of Trauma Acute Care (SF QTAC-PREM) **Canada**	PREM	Developed from original QTAC questionnaire.	Information and communication; Clinical and ancillary care	Likert (5-point)	Bobrovitz et al (2017) (71) Canada	Cross sectional	Three Trauma Centres	Adults with major trauma	Secondary analysis of original validation dataset	Item reduction to form short version of QTAC- PREM	154	The short form tool has evidence of validity and reliability.
Measure for Emergency Department Asthma Patients	PROM	Three- phase qualitative study for concept identification	Symptom Improvement; Medication use and access; Asthma Knowledge 5 items	NA (In development)	Samuels Kalow (2017) (35) US	Initial development	Three tertiary care EDs	Adults with asthma or parents of children with asthma.	N/A—initial development	Qualitative analysis of interviews to determine five items for inclusion in measure	NA	Qualitative process can identify, rank and formulate questions based on patient- identified concepts.
Patient Perceptions of Stress during Evaluation for Acute Coronary Syndrome (ACS) in the Emergency Department **US**	PREM	Meta analysis	Perception of stress	Agreement scale (4-point)	White et al (2017) (38) US	Cross Sectional	Single site academic urban centre	Adults	Self-Administered	1000	Descriptive stats only	Found elevated stress perception levels in ED patients with both ACS and non-ACS diagnoses, linked to future development of PTSD symptoms

Table 5.5 Scoping Review Findings—Group 3: Instruments developed in other settings but since applied to the ED.

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response Scale**	**Author** (Year) Country	**Methods** Study Type	Setting	Population/ Key Inclusion Criteria	Administration	Data Analysis/ Primary Outcome	**Results** Sample Size	Key Finding(s)
Short Form 36- item (SF-36)	HRQOL	Existing health surveys, interviews with patients and consultation with health experts.	General Health; Physical Health; Physical Role; Emotional Role; Bodily Pain; Mental Health' Vitality; Social Function 36 items.	Likert (5- point)	Banz (2011) (41) United States	Cohort (retrospective)	Single ED	Adults with non-specific abdominal pain (NSAP).	Telephone	Patient variables influencing SF-36 outcomes, with adjustment for age and gender.	200	Persistence of NSAP beyond the ED visit may be associated with reduced QOL.
Kansas City Cardiomyopathy Questionnaire (KCCM)	PROM	Literature review; other available instruments; focus groups with patients and healthcare providers.	Physical Limitations; Symptoms; QoL; Social Interface; Self- Efficacy 23- items	Likert (5- point)	Sauser et al (2014) (52) United States	Cross sectional	Single ED	Adults with β Natriuretic Peptide >400	Self-Administered	Descriptive statistics, association between initial scores and readmissions	52	KCCMQ does not predict 30- day readmission but is suitable for detecting disease changes in an ED population.
Functional Assessment of Cancer Therapy–General Measure (FACT-G)	HRQOL	Interviews with patients and oncology specialists. Items prioritised by patients.	Physical Wellbeing; Social/ Family Wellbeing; Emotional Wellbeing; Functional wellbeing 27- items	Likert (5- point)	Grudzen (2016) (72) United States	RCT (Standard Care vs. Palliative Care intervention in ED)	Single ED	Adult patients with advanced cancer.	Face- to- face survey	Change in QoL score at 12 weeks post- ED attendance.	136	ED initiated palliative care improves quality of life in patients with advanced cancer and does not seem to shorten survival.
Short Form 12-item (SF-12)	HRQOL	Regression methods used to select and score 12 items from original SF-36.	General Health; Physical Function; Physical Role; Emotional Role; Bodily Pain; Mental Health; Vitality; Social Function 12- items	Likert (5-point)	Provencher (2016) (42) Canada	Cross-Sectional	Seven EDs	Older adults (>65 years) with Dx of minor fracture	Telephone / In Person	HRQOL at 3- and 6-months post ED attendance.	334	HRQOL inversely associated with frailty in older ED patients with minor fracture.
					Naseer (2018) (43) Sweden	Prospective cohort study	Four EDs	Older adults (>65 years)	Self-Administered	Relationship between HRQOL and time to first ED visit, or frequent ED visits	673	HRQOL is associated with time to first ED visit in older adults.
Dermatology QOL Index (DLQI)	HRQOL	Interviews with patients. Field tested in dermatology patients and healthy controls.	Symptoms and feelings; Daily Activities; Leisure; Work and School; Personal Relationships; Treatment 10 items	Agreement Scales (2-, 3-, and 5-point)	Alegre-Sanchez (2017) (56) Spain	Cross-Sectional.	Single ED	Adults with a cutaneous complaint.	Self-Administered	Descriptive results for DLQI and SF-12.	245	Patients visiting emergency units with cutaneous complaints experience a moderate/ large impact on QOL.

Table 5.5 (Continued)

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response Scale**	**Author** (Year) Country	**Methods** Study Type	Setting	Population/ Key Inclusion Criteria	Administration	Data Analysis/ Primary Outcome	**Results** Sample Size	Key Finding(s)
Iowa Satisfaction with Anaesthesia Scale	PREM	Expert consensus, review of existing literature.	Satisfaction with anaesthesia 11 items	Agreement scale (6-point)	Johnson 2017 (50) Australia	Cross-Sectional	Single ED	Adults requiring ED sedation.	Self- Administered	Descriptive analysis, correlation between experience and depth of sedation.	163	Greater satisfaction with deeper sedation, use of propofol, no pre-sedation opioid and non-orthopaedic procedures
Brice Anaesthesia Questionnaire	PREM	Expert consensus	Awareness during anaesthesia 3 items	Dichotomous (yes/ no)								
Medical Uncertainty of Illness Scale (UIS-ED)	PREM	Adapted from Mishel Uncertainty of Illness Scale for use in ED by expert panel	Uncertainty of illness 12 items	Likert (5- point)	Brito- Brito (2018) (51) Spain	Validation Study	Single ED	Adult ED patients	Self- administered	Descriptive statistics, structural validity (exploratory factor analysis)	160	Valid and reliable means of assessing uncertainty in an ED population
Care Transitions Measure-3	PREM	Developed from Care transitions measure 15. Original items generated using focus groups and expert consensus.	Preferences in care transitions; Understanding of care transitions. 3 items	Agreement Scale (4 point)	Sabbatini (2018) (49) United States	Cross sectional	Single ED	Adult ED patients	Telephone	Association between CTM-3 score, medication adherence and return within 13 days.	410	CTM-3 may capture effectiveness of discharge care transitions in the ED.
Revised American Pain Society Patient Outcome Questionnaire (APS-POQ-R)	PROM	Expert consensus.	Pain severity and relief; impact of pain on activity; Side effects; Information about treatment; Ability to participate in treatment decisions; use of nonpharmacological strategies. 44 items.	Agreement Scale (5 point)	Althagafi 2022 (73) Australia	Cross sectional	Single ED	Adults with acute pain	Interview	Multiple linear regression between APS-POQ-R responses and patient characteristics, including opioid administration.	200	The APS-POQ-R allows assessment of patient-reported outcomes of pain care in the ED.

Table 5.5 (Continued).

Description of instrument characteristics					Description of study characteristics							
Name	**Type**	**Development**	**Measurement Domains**	**Response Scale**	**Author** (Year) Country	**Methods** Study Type	Setting	Population/ Key Inclusion Criteria	Administration	Data Analysis/ Primary Outcome	**Results** Sample Size	Key Finding(s)
RAND-12 Health Status Inventory® (RAND 12)	HRQOL	Developed from the RAND-36®. Items selected on ability to capture essential aspects of HRQOL related to the eight domains.	Physical Functioning; Role limitations (physical); Role limitations (emotional); Social Function; Emotional well-being; Energy/ Fatigue; Pain; General Health/ 12 items	Likert Scale (3—6 point)	Jae-Yung Kwon (2022) (44) Canada	Cross Sectional	British Columbia	Adults	Telephone/ Online Interview	Compared the extent to which the VR-12 and the EQ-5D-5L distinguished among groups of ED patients with different levels of comorbidity burden and self-reported physical and mental or emotional health status.	5876	EQ-5D measures predominantly physical health status; RAND12 more effective at discriminating between patients with self- reported mental or emotional health status and having a mental health condition.
EQ-5D-5L	HRQOL	Multiple stage process including identification of health dimensions, development of a descriptive system, economic valuation of health states, and extensive validation and testing.	Mobility; Self- Care; Usual Activities; Pain/ Discomfort; Anxiety/ Depression	5-Point Categorical Scale Visual Analog Scale								
					Sayah et al (2022) (45) Canada	Cross Sectional	One region of Canada (Alberta)	Adults ≥16 years	Telephone/ Online interview	To examine the impact of COVID-19 pandemic on health-related quality of life (HRQL) of adult ED patients.	5927	The impact of COVID-19 pandemic on HRQL was minimal in adults seeking ED care.
					Gagnon (2022) (46) Canada	RCT (Standard care vs. Physiotherapy intervention in ED)	One ED	Adults 18—80 years	Self-Administered	Baseline HRQOL at presentation	69	In patients with MSKDs who present to the emergency department, higher levels of pain or pain interference are associated with decreased health-related quality of life.

Table 5.5 (Continued).

Description of instrument characteristics					Description of study characteristics							
					Author	Methods					Results	
Name	Type	Development	Measurement Domains	Response Scale	(Year) Country	Study Type	Setting	Population/ Key Inclusion Criteria	Administration	Data Analysis/ Primary Outcome	Sample Size	Key Finding(s)
Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW)	**HRQOL**	Guided by conceptual framework; patients nominate, quantify and weight five most relevant areas of individual QoL	Individualised measure, but suggested domains include family, relationships, health, finances, living conditions, work, social life, leisure activities and religion/ spiritual life	Visual Analogue Scales	Elkjaer et al (2022) (47) Denmark	Cross Sectional Study	Three EDs	Adults ages ≥65 years	Interview	Descriptive analysis; relationship between QoL assessment and those receiving home care and readmission.	406	Receiving homecare was associated to a significantly lower QoL score in "family" and "health" categories.
Pulmonary Embolism Quality-of-Life (PEmb-QoL) questionnaire	**HRQOL**	Modelled on the quality of life after DVT (VEINES-QOL/Sym) questionnaire- additional items related to limitations in daily physical activities, and emotional functioning	Frequency of complaints; ADL limitations; Work related problems; Social limitations; Intensity of complaints; Emotional Complaints	Agreement scale (2—6 point)	Weekes et al (2023) (48) US	Analysis of data from Prospective multicentre PE registry	Six EDs	Adults aged ≥18years with confirmed PE	Self-Administered	Descriptive analysis; differences in QoL domain scores for Clinical Deterioration, Right Ventricular Dysfunction, PE risk stratification and rehospitalization	788	Acute clinical deterioration, RVD, and PE severity were not predictors of QoL at 1-month post-PE. Independent predictors of worsened QoL were rehospitalization, COPD, and index hospital length of stay

5.4.6 Dimensionality

A total of 157 individual measurement domains were featured across the 42 instruments (an average of 3.7 domains/ instrument). To enable a more straightforward comparison of dimensionality between the instruments, domains were aligned to the most relevant analytical theme featuring within a needs-based conceptual framework of ED patient experience also developed by the author.(26) Assignment was based on an agreement between the research team. These findings are presented in Table 4.6. Instruments designed for administration to the general ED population most frequently measured interpersonal and informational communication, followed by symptom relief and waiting experience. Instruments developed for specific populations of ED patients or developed outside of the ED measured fewer dimensions overall and were most focused on providing symptom relief. Several instruments were unidimensional when assessed against the needs-based framework, including the UIS-ED (acknowledging uncertainty), (51) PEMb-QoL (procedural care) (48) and Brice Anaesthesia Questionnaire (Recognising suffering in the context of sedation awareness). (50) Only instruments designed for use amongst the ED population were assessed to measure physical/ environmental needs, such as physical comfort. The PROM-ED 1.0 (54) ‘Measures for older adults attending the ED’ (34) and CQI-ED (61) demonstrated the most extensive overall multidimensionality when compared with the needs-based framework, each aligning with six of the domains.

Table 5.6 Instrument dimensionality against patient needs

	Communication Needs		Emotional Needs			Care Needs		Waiting Needs	Physical Needs
	Interpersonal Communication	Informational Communication	Acknowledging Uncertainty	Recognising Suffering	Providing Empowerment	Symptom Relief	Procedural Care	Impact of Crowding	Comfort
Group 1: Instruments developed for administration to the general population of adult patients attending the ED									
Patient Experience of the ED triage encounter	X	–	–	–	–	–	X	X	X
PPED	–	–	–	–	X	–	–	–	X
UCSQ	X	X	–	X	–	–	–	X	–
CECSS	–	X	–	–	–	–	X	–	–
Questionnaire to assess satisfaction with hospital emergency care	X	X	–	–	–	–	–	–	X
Ethical environment in the ED	X	–	–	X	X	–	–	–	X
Satisfaction with ED services amongst non-English patients	X	X	–	X	–	X	X	–	–
CQI- A&E	X	X	–	X	–	X	–	X	X
BEPSS	X	X	–	–	X	X	–	X	X
Assessment of client satisfaction on ED services	X	X	–	–	–	–	X	X	–
Measures for older adults attending the ED	X	X	–	–	X	X	–	X	X
Press- Ganey ED Survey	X	X	–	–	–	X	–	X	–
PROM-ED 1.0	X	X	X	X	X	X	–	–	–
Perceived quality of healthcare in the ED	X	X	–	X	–	X	X	X	X
PROMs after discharge from the ED	X	X	–	–	–	X	–	X	–
AEEQ	X	X	–	–	–	X	X	X	X
Group 2: Instruments developed for administration to specific populations of adult patients attending the ED									
QTAC- PREM[a]	–	X	–	X	–	X	X	–	–
Pain management: association with patient satisfaction among ED patients	–	–	–	–	–	X	–	–	–
PQoL	–	–	–	X	–	–	–	–	–
ASCQ-Me	X	X	–	X	–	X	–	X	–
Measure for ED Asthma Patients	–	–	–	–	–	X	–	–	–
Patient perceptions of stress during evaluation for ACS	–	–	X	X	–	–	–	–	–
Group 3: Instruments developed in other settings and then evaluated in the emergency department									
SF-36[b]	–	–	–	X	–	X	–	–	–
KCCM	–	–	–	–	–	X	–	–	–
FACT-G	–	–	–	X	X	X	–	–	–
DLQI	–	–	–	–	X	X	–	–	–
Brice Anaesthesia Questionnaire	–	–	–	X	–	–	–	–	–
UIS-ED	–	–	X	–	–	–	–	–	–
CTM-3	–	–	–	–	–	–	–	–	–
APS-POQ-R	–	X	–	–	X	X	–	–	–
EQ=5D[c]	–	–	–	–	X	X	–	–	–
SEIQoL-DW	–	–	–	X	X	–	–	–	–
PEmb-QOL	–	–	–	–	–	–	X	–	–

For abbreviations see Tables 5.3—5.5

5.4.7 Psychometric characteristics of the instruments

Instruments were analysed according to the full COSMIN risk of bias checklist. Findings from the psychometric assessment are presented in Table 5.7. Instrument development was the most frequently reported property (40/42; (95.2%). This was followed by an assessment of content validity (37/42; 88.1%) of instruments, which aims to ensure the appropriateness of items to assess intended measurement domains. Assessment of instruments for structural validity was reported in half (21/42) studies and consisted of exploratory factor analysis or principal components analysis. Likewise, internal consistency, which measures the extent to which items in a scale measure the same construct, was also reported in half of the studies. Retest reliability assesses whether responses to an instrument remain stable over time. This may be relevant for instruments intended to evaluate short ED care encounters, which were reported within 13/42 (30.9%) of studies. Criterion validity compares instrument scores to an established gold standard, considered in 6/42 (14.3%) studies. Several studies (8/42; 19%) also tested a priori hypotheses. Responsiveness relates to the ability of an instrument to change a patient's condition over time; this was measured as part of the evaluation of the SEIQoL-DW (47) and the ‘Questionnaire to assess satisfaction with hospital emergency care’. (60) Cross-cultural validity was considered similarly infrequently, except for the translation of the CECSS to a Swedish version (29), the derivation/ validation of a Spanish version of the UIS (51) and the Chinese version of the AEEQ. (68) Findings from psychometric assessment are presented in Tables 5.7—5.9.

Table 5.7 Psychometric Characteristics of included instruments: Group 1

		Risk of Bias Assessment Outcomes											Real World Usability Assessment		
Name of Instrument	Paper(s)	Development	Content Validity	Structural Validity	Internal Consistency	Cross Cultural Validity	Reliability	Measurement Error	Criterion Validity	Hypothesis	Responsiveness	Overall risk of Bias	Internal Validity	External Validity	Recommendation for usability
Category: PROMS															
PROM—ED 1.0	Vaillancourt (2020)	+++	+++	++	+++	—	++	++	—	+ +	—	Low	High	High	A
PROMs after Discharge from the ED	Mendrin (2021)	+	+	—	—	—	—	—	—	—	—	High	Low	Low	C
Category: PREMS															
CECSS	Elwali (2010) Messina (2014) Hoonakker (2011)	++	+++	++	+++	++	++		—	—	—	Low	High	High	A
PPED	Frank (2010)	+++	+++	+++	+++	—	+++	+	+	—	—	Low	High	High	A
UCSQ	O'Calhain (2010)	+++	+++	+++	+++	—	—	—	—	—	—	Low	High	High	A
AEEQ	Wong (2023)	++	++	+++	+++	—	++	—	—	—	—	Low	High	Intermediate	B
Questionnaire to assess satisfaction with hospital emergency care	De la Orden (2011)	+++	+++	+++	+++	—	—	—	+	—	+	Low	High	Intermediate	B
CQI— A&E	Bos et al (2015)	+++	++	+	+++	—	+	—	—	—	—	Intermediate	Intermediate	Intermediate	B
BEDPSS	Alarifei (2015)	+	+	+	+++	—	—	—	—	+	—	Intermediate	Intermediate	Intermediate	B
Measures for older adults attending the ED	McKusker (2018)	++	++	++	+++	—	—	+++	—	—	—	Intermediate	Intermediate	Intermediate	B
Ethical Environment in the ED Questionnaire	Lin (2013)	+	+	—	++	+	—	—	—	+	—	High	Low	Low	C
Perceived Quality of Healthcare in an Emergency Department	Abidova (2020)	+	+	+	—	—	—	—	—	—	—	High	Low	Low	C
Assessment of client satisfaction on ED services	Worku (2017)	+	+	—	—	—	—	—	—	—	—	High	Low	Low	C
Satisfaction with ED service amongst non—English Speaking Patient	Mahmoud (2014)	+	—	—	—	—	—	—	—	+	—	High	Low	Low	C
Patient experience of the ED triage encounter	Gonansson (2010)	+	—	—	—	—	—	—	—	—	—	High	Low	Low	C
Press— Ganey ED Survey	Sharp (2019)	—	—	—	—	—	—	—	—	—	—	NA		Not Reported	

Table 5.8 Psychometric Characteristics of included instruments: Group 2

		Risk of Bias Assessment Outcomes											Real World Usability Assessment		
Name of Instrument	Paper(s)	Development	Content Validity	Structural Validity	Internal Consistency	Cross Cultural Validity	Reliability	Measurement Error	Criterion Validity	Hypothesis	Responsiveness	Overall risk of Bias	Internal Validity	External Validity	Recommendation for usability
HRQOL Instruments															
PQoL	Boyer (2014)	++	++	+++	+++	—	++	—	++	—	—	Low	High	Intermediate	B
PROMs															
Patient Centred outcome for ED Asthma	Samuels-Kalow (2017)	+++	+++	—	—	—	—	—	—	—	—	N/A		Not Reported	
PREMs															
QTAC	Bobrovitz (2012)	+++	+++	+++	+++	—	+++	+	+++	+++	—	Low	High	High	A
SP- QTAC	Bobrovitz (2017)	+++	+++	+++	+++	—	—	—	—	—	—	Low	High	High	A
ASCQ-Me QOC	Eversen (2016)	+++	+++	+++	+++	—	—	—	—	—	—	Low	High	Intermediate	B
Patient Perceptions of Stress during Evaluation for ACS in the ED	White (2017)	+	—	—	+++	—	—	—	—	—	—	High	Low	Low	C

Table 5.9 Psychometric Characteristics of included instruments: Group 3

		Risk of Bias Assessment Outcomes											Real World Usability Assessment		
Name of Instrument	Paper(s)	Development	Content Validity	Structural Validity	Internal Consistency	Cross Cultural Validity	Reliability	Measurement Error	Criterion Validity	Hypothesis Responsiveness	Overall risk of Bias	Internal Validity	External Validity	Recommendation for usability
HRQOL Instruments														
SEIQoL-DW	Ekjaer (2022)	+++	+++	+++	+++	—	+++	—	+++	+++	+++	Low	High	High	A
PEMB-QoL	Weekes (2023)	++	++	++	++	—	++	—	++	—	—	Low	High	High	A
RAND-12	Jae- Yung Kwon (2022)	++	++	—	—	—	—	—	—	—	—	Low	High	High	B
EQ-5D-5L	Jae- Yung Kwon (2022) Sayah (2022) Gagnon (2022)	++	++	—	—	—	—	—	—	—	—	Low	High	High	B
SF-36/ SF-12	Banz et al (2011) Provencher (2016) Naseer (2018)	++	++	—	—	—	—	—	—	++	—	Low	High	High	B
DLQI	Alegre-Sanchez (2017)	++	++	—	—	—	+	—	—	—	—	High	Intermediate	Intermediate	C
FACT-G	Grudzen (2016)	—	—	—	—	—	—	—	—	++	—	High	Intermediate	Intermediate	C
PROMs														
APSPOQ-R	Athagafi (2022)	++	+++	++	++	—	+	—	—	—	—	Low	High	High	A
KCCMQ	Sauser (2014)	++	++	+++	++	—	+	+	—	—	—	Low	High	Intermediate	B
PREMs														
CTM-3	Sabbahini (2016)	++	++	++	+++	—	+	+	—	—	—	Intermediate	High	Intermediate	B
Iowa Anaesthesia Questionnaire	Johnson (2017)	++	++	+	+++	—	+	+	+	—	—	Intermediate	Intermediate	Intermediate	B
Uncertainty of Illness Scale	Brito- Brito (2016)	++	++	++	++	—	—	—	—	—	—	Intermediate	Intermediate	Intermediate	B
Brice Anaesthesia Questionnaire	Johnson (2017)	++	—	—	—	—	—	—	—	—	—	High	Low	Low	C

5.4.8 Overall risk of bias

Based on the included studies, ten of the thirty-seven instruments (27%) were assessed as having a ‘low’ overall risk of bias following the assessment of psychometric characteristics. At a minimum, studies using these instruments in the ED setting include diligent reporting of the development process, confirmation of content and structural validity, and reliability/ internal consistency.

A further six instruments were determined to have an ‘intermediate’ risk of bias, where often the development process or reliability and validity testing may have been incomplete or partially adequate. The remainder of the instruments were deemed as high risk of bias; these instruments lacked evidence of structured

development or psychometric validation within the included studies. Per-instrument overall risk of bias assessment can be found in Tables 4.7—4.9.

5.4.9 Usability assessment

In addition to assessing psychometric properties and risk of bias, this review aimed to consider the 'real world' utility of the identified scales. For this, consideration of the external validity of studies was particularly important. Nine of the identified instruments—all of which were assessed as having a 'low' overall risk of bias following psychometric assessment—were deemed to also have high external validity; the research team agreed that all these instruments could be endorsed for use in an ED setting in their current form and were assigned a 'Grade A' recommendation. These instruments are listed in Table 5.10.

Table 5.10 Instruments assigned a 'Grade A' recommendation for usability.

Group 1	Group 2	Group 3
PROM-ED 1.0[a]	QTAC[b]	SEIQoL-SWc
CECSS[b]	SF-QTAC[b]	PEMB-QoL[c]
PPED[b]		APSPOQ-R[a]
UCSQ[b]		

a PROM, b PREM, c HRQOL

For abbreviations see Tables 5.3—5.5

Instruments intended for the general ED population with an intermediate (Grade B) recommendation include the AEEQ, (68) CQI—A&E and BEDPSS. (62, 63) The condition-specific ASCQ-Me (40) may be useful for assessing the experiences of patients with SCD but may benefit from further external and cross-cultural validation, specifically outside of a US context. Similarly, further work is required to ensure the relevance of prominent HRQOL measures, including EQ-5D, SF-36, and RAND-12, to an ED population.

5.5 Discussion

This scoping review offers a comprehensive overview of PROMs, PREMs, and HRQOL surveys administered to adult ED patients. The body of literature demonstrates a growing interest in using patient-reported outcomes to assess the quality of ED care internationally. Our findings confirm the feasibility of collecting patient-reported data in various ED settings, contexts, and patient populations.

We have identified a range of rigorously developed and validated instruments that may be relevant for measuring the quality of care amongst adult ED patients. These instruments measure consumer attitudes towards ED care (CECSS and CQI-ED) (29, 55), experiences of ED care (e.g., PPED, UCSQ) (30, 33) and patient outcomes amongst the general adult population (PROM ED 1.0). (54) Other instruments evaluate outcomes and experiences amongst specific patient groups, such as following major trauma (QTAC/SF-QTAC) (36, 37) and acute pulmonary embolus (PEmbQoL). (48) Generic HRQOL instruments, including SF-36, EQ-5D, and RAND-12, are probably underused in emergency care, especially compared to other clinical specialities. These instruments may potentially assess the impact of ED interventions on the quality of life, especially in research settings.

Although ED-specific measures were identified for sickle cell disease (40) and heart failure (52), comparatively few instruments evaluated outcomes and experiences for patients with specific emergency conditions or discrete ED patient user groups such as older adults and the frail elderly. As such, the continued development of PROMs, PREMs and HRQOL instruments tailored to specific conditions and ED populations is desirable. Additionally, studies within

this review were of varying methodological quality. Accordingly, our findings align with those from a prior review by Male et al. (74), leading us to agree that a standardised protocol for sampling, administration and reporting of findings may enhance the rigour of future patient-reported outcomes research in emergency care. Moreover, there is a need to develop instruments that include the range of different cultural, linguistic, and socioeconomic status of ED patients, especially given the current paucity of studies conducted in low and middle-income settings. (75, 76)

While this review did not examine the role of electronic patient-reported outcomes (ePROs) in emergency care, technology may enhance response rates, timeliness of patient feedback, and responsiveness. (77) This makes ePROs particularly appealing for settings with high patient turnover, such as the ED. Patient-reported measures should be at the forefront of future innovations, such as the adoption of artificial intelligence, to ensure acceptability from the patient's perspective. (78, 79)

5.5.1 Recommendations for Practice

We encourage emergency clinicians to select valid and reliable PROMs, PREMs and HRQOL surveys to help evaluate individual care, assess, and benchmark institutions, identify priorities for quality improvement, and report patient-oriented research outcomes. A key question is whether to develop a new measure or adopt an existing one. Development of PROMs, PREMs and HRQOL instruments should adhere to established standards, including the COSMIN criteria. However, the expertise required and the time- and resource-intensive nature of instrument development and validation may be outside the scope of many projects. As a result, selecting an existing tool ‘off-the-shelf’, such as those recommended in this review, may be preferable. In this case,

consideration of the chosen instrument's psychometric properties and external validity, or ‘local applicability’, is vital.

Factors to consider include the instrument's content validity (i.e., do the items address the specific research question or quality improvement objectives?), face validity (are the items relevant to the target demographic?), requirements for staff training, timing and mode of questionnaire delivery, and feasibility of administration to the target patient group.

Engaging patients, carers, and health professionals to verify an instrument's suitability is advisable. Cognitive interviewing (80) provides an effective method for preliminary testing and may identify problems with content, language, and instrument format. Where necessary, cross-cultural adaptation of an instrument should be considered. In a recent article, Roberts et al. report a streamlined approach for adapting instruments across different cultures and languages. (81)

5.5.2 Strengths and Limitations

This is the first attempt to integrate ED PROMs, PREMs, and HRQOL instruments within a single review. Whilst these instruments measure discrete constructs, they share a common overall objective to monitor and improve the quality of ED care from a patient perspective. Similarly, these instruments' development, validation, and critical appraisal follow a similar process. PROMS, PREMs, and HRQOL instruments provide complementary perspectives on ED care from a patient’s perspective, from how patients feel and function to how they perceive their care and the broader impacts of ED care on quality of life.

In addition, a broad range of instruments have been captured, including those initially developed for use within non-ED settings. Nonetheless, studies predating 2010 or not published in English were excluded. Although a range of

grey literature sources and expert authors were consulted as part of the review strategy, some instruments or studies may have been missed. Although the quality of included studies has been guided by COSMIN criteria and agreement between researchers carefully considered, assessment of the overall risk of bias and applicability of instruments to practice remains subjective. Further evaluation of instruments amongst experts and patient/ public representatives may be desirable before selecting an instrument to support clinical evaluation, quality improvement, or research.

5.6 Conclusion

This review has identified a range of PROMs, PREMs and HRQOL instruments for evaluating care among adult patients attending an ED. Suitable tools exist for measuring consumer expectations, patient experience, and care outcomes amongst the general ED population. While fewer condition-specific instruments exist, this review has also identified the need to develop a broader range of tools that reliably measure the outcomes and experiences of specific groups of ED patients, including populations such as older adults and the frail elderly. Future measures should aim to be inclusive and consider ED patients' cultural, linguistic, and socioeconomic perspectives. Further work is needed to evaluate the role of electronic patient-reported outcomes in emergency care and patient-reported outcomes in prospectively evaluating future innovations in emergency care.

Addendum

Contribution to the PREM-ED 65 study

This chapter provides a standalone scoping review of currently available PREMs, PROMs and HRQoL instruments applicable to emergency care.

Assessment of the psychometric characteristics and usability of each included instrument is intended to inform and enable clinicians to select and apply appropriate measures in the ED setting. This may include measures to evaluate clinical outcomes or the effectiveness of quality improvement initiatives and research.

Crucially, this work also highlights the expertise acquired by the researcher in the topic area, specifically their ability to appraise instruments and consider their applicability to inform emergency care practice and research.

Concerning the PREM-ED 65 study, common limitations of the identified instruments provide a clear rationale for the onward development of appropriately validated ED-specific health measures, including PREMs aimed at core ED user groups. Specifically, no validated PREM directed at older adults in a UK setting was identified. Furthermore, the dimensionality assessment failed to reveal any instrument completely aligned with the analytical and descriptive themes of the needs-based conceptual framework. This reinforces the relevance and originality of the onward research strategy for the PREM-ED 65 study, including research to interview patients and conduct focus groups with staff to better conceptualise older adults' ED experiences from all these perspectives. As a future implication, comparative analysis may be performed between PREM-ED 65 and measures identified in this review to help determine its criterion validity. Co-administration of established measures alongside PREM-ED 65 may also be relevant to explore additional dimensions of care quality, such as health-related quality of life.

Moving on from this review, the next chapter reports findings of in-situ interviews with older adults in the ED. This expands on the needs-based

conceptual framework presented in chapter four by highlighting the unique needs and determinants of experience amongst older adults.

Publication Strategy

At the time of thesis submission, this chapter is being prepared for submission to a peer-reviewed emergency medicine journal.

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Supplementary Material

SM 5.1 Grey Literature Sources for Scoping Review

Websites of the following organisations were reviewed:

- The healthcare foundation (UK)
- The Kings' Fund (UK)
- The Patients' Association (UK)
- The Picker Institute (International)
- College of Emergency Nursing Australasia (Australasia)
- Emergency Nurses Association (US)
- The American College of Emergency Physicians (US)
- The Australasian College of Emergency Medicine (Australasia)
- The Canadian Association of Emergency Physicians (Canada)
- The Royal College of Emergency Medicine (UK)
- The Royal College of Nursing (UK)

SM 5.2 Example Search Strategy for Scoping Review

1. Emergency Service, Hospital
2. Accident and Emergency Department
3. Emergency Department
4. Emergency Room
5. 1 OR (2 OR 3 OR 4).ti
6. Patient Reported Outcome Measure$
7. Treatment Outcome$
8. Personal Satisfaction
9. Patient Satisfaction
10. Satisfaction
11. 6 OR (7 OR 8 OR 9)
12. Instrument
13. Scale
14. Questionnaire
15. 12 OR 13 OR 14
16. Person Report$
17. Patient Report$
18. Measure
19. Quality of life
20. HRQOL
21. 16 OR 17 OR 18 OR 19 OR 20
22. 5 AND 11
23. 5 AND 15
24. 5 AND 11 OR 21

Databases: Pubmed, CINAHL, EMBASE

Limits: .ti, Date Jan 2010—Jul 2023, English.

Chapter 6 Interviews with Older Adults

Citation
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Contributor Statement
Blair Graham (BG) conceptualised the study, led development of the study protocol, performed the interviews, data transcription of interviews, data analysis, produced the initial manuscript draft and led revision of all subsequent versions.

Rosalyn Squire (RS) assisted with data transcription of interviews.

Pamela Nelmes (PN), Jason Smith (JES) and Jos Latour (JML) assisted with the development of the study protocol and assisted revision of the manuscript.

JS and JML acted as project supervisors.

The agreed approximated percentage contributions toward the production of this research are: BG 80%, RS 5%, PN 2.5%, JES 5%, JML 7.5%.

Conflict of Interest Statement
None of the authors have any conflicts of interest to declare.

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What this chapter adds.

This chapter:

- Demonstrates the ability of the researcher to (i) plan and deliver qualitative research, including semi-structured interviews with older adults in the ED; (ii) conduct framework analysis of qualitative data supported by computer-assisted qualitative analysis software, and (iii) report qualitative research findings in accordance with Consolidated criteria for reporting qualitative research (COREQ) guidelines.
- Apply qualitative research findings to expand understanding of older adults' experiences of ED care and the 'needs-based' conceptual framework.
- Triangulate qualitative findings, and findings from the literature (meta-synthesis) to suggest a comprehensive list of draft items for PREM-ED 65.

Initial Development of a Patient Reported Experience Measure for Older Adults Attending the Emergency Department: Part I—Interviews with Service Users.

6.1 Abstract

Older adults are a major Emergency Department (ED) user group who may be especially vulnerable to the consequences of crowding and sub-optimal care. Patient experience is a critical component of high-quality ED care and has previously been conceptualised using a framework focusing on patients' needs. This study aimed to explore the experiences of older adults attending the ED in relation to the existing needs-based framework. Semi-structured interviews were conducted during an emergency care episode with 24 participants aged over 65 years in a United Kingdom ED with an annual census ~100,000. Questions exploring patient experiences of care confirmed that meeting the communication, care, waiting, physical, and environmental needs were prominent determinants of experience for older adults. A further analytical theme emerged which did not align to the existing framework, focused on 'team attitudes and values'. This study builds on existing knowledge relating to the experience of older adults in the ED. In addition, data will also contribute to the generation of candidate items for the development of a patient reported experience measure for older adults attending the ED.

6.2 Introduction

Older adults aged over 65 years are a major user group of Emergency Departments (EDs), comprising over 29% of attendances in a recent UK retrospective cohort study. (1) In many countries, the number of older adults attending the ED is increasing above predictions based on population size alone. Contributors may include increasing comorbidity, gaps in primary healthcare, and increasing numbers of repeated ED attendances among frail older adults. (2, 3) Older adults are more likely to present to the ED with high acuity conditions (4), yet atypical presentations and nonspecific symptomatology are also more common. This clinical complexity may contribute to increased healthcare costs and ED resource utilisation. (5) Furthermore, older adults more frequently suffer from background comorbidities, long term conditions, and have more nursing care requirements. (6, 7) For all of these reasons, older adults encounter above average ED length of stay (LOS) (8) and are at increased odds of requiring hospital admission. (9)

In addition to the range of challenges posed by older adults, wider demand for emergency care is being encountered internationally. (10) Many systems have failed to keep pace with this demand. As a result, ED crowding is now a significant public health concern, responsible for an estimated 4,000 excess deaths in the UK alone during 2020-21. (11) Older adults fare unfavourably when treated within a pressured emergency care system and are significantly more likely than the general population to suffer 30-day mortality following a protracted ED LOS. The reasons for this are likely to be complex, but delayed medication administration, poor continuity of care, increased risk of nosocomial infections, and circadian disruption resulting from sleep deprivation have all been postulated. (12) The proportion of over 65s is projected to double in most

nations before 2050. (13) Consequently, the demand for ED services from older adults will likely reflect this trend. To meet the needs of older adults as a predominant ED user group and reduce the risks that they may encounter when accessing care, there is a pressing requirement to ensure that the ED environment and care processes are thoroughly considered and fit for purpose.

Effective and meaningful measurement of the quality of emergency care is essential to enable comparison between different settings and drive improvements in clinical outcomes, patient experience and safety. In many healthcare systems, this continues to be achieved using process-centred performance metrics. For example, recently introduced ED performance standards in England include timely ambulance handover, time to triage assessment, and ED LOS. (14) Whilst some performance metrics—such as time-based targets—have been demonstrated to lead to meaningful improvements in some aspects of care (15), a limitation is that they may fail to effectively capture outcomes of care that matter most to patients. To this end, the International Federation for Emergency Medicine (IFEM) recommends the adoption of both Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) within their recently updated framework on quality and safety in emergency medicine. (16) Patient experience is recognised within prominent definitions of quality of care and is associated with improved clinical outcomes and patient safety. (17, 18) However, meaningful evaluation of patient experience can be challenging. For example, surveys are frequently undermined by poor response rate and issues with face validity and reliability. (19, 20) Furthermore, generic surveys may not identify specific vulnerabilities in care processes from the patients' perspective, representing a missed opportunity to effect change and improve services. (21)

Patient reported experience measures (PREMs) are psychometrically validated questionnaires that are directly reported by patients and aim to provide standardised evaluation of individual experiences of care. (22) To ensure content validity, PREMs should be developed in conjunction with patients and care providers to capture aspects of care that are important.(23) Several PREMs relating to ED care have been developed, although limitations of these instruments include uncertain validity, reliability and responsiveness. (20) No instrument has yet been developed to specifically measure the experience of older adults, aged 65 years and above, in the ED.

The overall aim of our project is to develop and validate a PREM to address the unmet need of an instrument for older adults in the ED, known as the Patient Reported Experience Measure for patients attending the Emergency Department aged over 65 (PREM-ED 65). From the outset, the development process for PREM-ED 65 is designed to ensure the final instrument meets the internationally accepted COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines. (24) PREM development is planned using a stepwise mixed methods approach. This is summarised in Table 6.1.

Table 6.1 Approach to PREM-ED 65 Development

Step 1: Conceptualising Patient Experience in the ED	Systematic Review Qualitative meta-synthesis Derivation of the conceptual framework of patient experience of ED care (25)
Step 2: Understanding experiences specific to older adults in the ED	Qualitative study Part I: Interviews with patients aged over 65 years Part II: Focus groups with ED staff (professional caregivers)
Step 3: Generation and Prioritisation of Candidate Items	Consensus Setting (Nominal Groups Technique) Generation of initial candidate items from existing data (Steps 1 & 2) Generation and prioritisation of candidate items
Step 4: Psychometric Field Testing	Administration of draft PREM to patients Confirmation of structural validity and reliability

In order to derive suitable candidate questionnaire items, an initial systematic review of patient experiences in the ED has been conducted. This has resulted in a conceptual framework to guide understanding of patient experience in the ED. This framework is based around the needs of ED patients and includes five analytical themes: communication needs, emotional needs, care needs, waiting needs and physical/environmental needs. (25) The next step of the PREM-ED 65 65 development process is to consider how the five analytical themes are experienced by older adults attending the ED and health professionals responsible for delivering emergency care.

We conducted a two-part qualitative study aiming to explore the experiences of older adults attending the ED (Part I), and the experiences of emergency department healthcare professionals (see Part II—Focus Groups with Professional Caregivers). Part I aims to explore older adults' experiences of an ED visit in relation to the preestablished conceptual framework and to determine if any additional analytical themes emerge.

6.3 Materials and Methods

We adopted a qualitative design using semi structured interviews conducted with older adults aged >65 years during their ED visit. This study is reported following the COnsolidated criteria for REporting Qualitative research (COREQ) checklist. (26) Ethical approval was prospectively obtained from the UK Health Research Authority (18/LO/1194) and institutional approval from the University of Plymouth (17/18973).

6.3.1 Research team and reflexivity

Interviews were conducted by a male identifying researcher (BG) who is an academic emergency physician and research fellow with prior experience and formal training in qualitative research methods. Two female identifying clinical academic nurses (PN, RS) assisted in the transcription and initial coding of data. A male identifying professor in emergency medicine (JES) and male identifying clinical nursing professor (JML) with extensive experience of quantitative and qualitative research in acute care settings, were involved in data analysis.

Principles of rigour and trustworthiness for qualitative research were applied. (27) Researchers considered their own clinical experiences and the need to exclude these during the analysis and interpretation of findings. The first author maintained reflexive notes and discussed perceptions with coresearchers during the study. No relationship was established with participants prior to study commencement. Standard information was issued to all participants prior to recruitment and consent. Participants were told the research's purpose was to inform PREM development as part of the lead researcher's PhD study.

6.3.2 Theoretical Framework

The interviews were deductive, informed by the overarching definition of quality of care proposed by Darzi. (17) This definition encompasses three domains: patient experience, clinical effectiveness, and patient safety. Although our interviews focus on capturing the experiences of people in ED, the use of these three domains also allows for the exploration of clinical expectations and perceptions of safety in the ED, which are known to be related to experience. The three domains of the quality-of-care definition were used to formulate the interview questions in the interview guide.

6.3.3 Participant Selection

Inclusion criteria were adults aged >65 years attending the ED. Patients who lacked mental capacity to give informed consent (28), who were too unwell to participate or required immediate lifesaving treatment (‘Category 1’ triage category), did not speak English, or were in police/prison custody, were excluded from the study.

A purposive sampling strategy was used to encourage recruitment of a representative cross-section of patients attending the ED. Patients were sampled based on the presence of either traumatic injury or medical illness, age group, clinical frailty score (29) and acuity (Table 2). A sampling matrix was used to support the inclusion of patients from each sampling category.

Table 6.2 Purposive Sampling Categories (Interviews study).

Gender	Male Female
Age	65-84 years (old age) 85+ years (very old age)
Presentation Type	Primary medical complaint Primary traumatic injury
Acuity	Australasian Triage Category Triage Category 1—3 (Higher Acuity) Triage Category 4—5 (Lower Acuity)
Frailty	Clinical Frailty Scale (CFS) CFS 1—3 (Lower Frailty) CFS 4—6 (Moderate Frailty) CFS 7—9 (Severe Frailty)

Twenty-four patients were recruited during daytime hours (08001800) between September 2018 and April 2019. In addition, a single patient was recruited but then withdrawn prior to the interview occurring, due to them being transferred away from the ED. The computerised ED administration system was used to screen potentially eligible patients. Once the patient's attending clinician indicated that treatment was complete, the clinician was approached and asked to give their assent for the patient to be invited to participate. Eligible patients were then approached by the lead researcher who presented them with verbal information about the study, and a written patient information sheet.

Sampling was conducted until the researchers were satisfied that sufficient data had been collected through the interview process, to reach 'data saturation'. This suggests the collection of further data is unlikely to add value. (30) Based on insights from the literature, it was estimated that between 20 and 30 participants would be needed. (31)

Patients who were approached but did not wish to participate were not recorded and not recruited into the study.

6.3.4 Setting

Interviews were held within a single ED in the Southwest of England (Annual Census ~100,000/annum). As a regional major trauma centre, the ED receives patients from urban and rural settings within a wide geographical catchment (population ~1.65 million), and notably has a higher-than-average proportion of attendances from older adults. ‘In situ’ interviews, conducted within the ED during an acute care episode, were selected as the preferred approach to maximise ecological validity whilst minimising recall bias. A range of clinical areas within the ED were utilised for interviews and included bedspaces, ambulatory spaces, relatives’ rooms and the attached short stay clinical decision unit. Where a patient was identified for interview but was transferred to an inpatient setting before an interview within the ED was possible, the study protocol allowed for interviews to take place on the receiving inpatient ward, provided this was clinically appropriate and within 24 hours of admission.

6.3.5 Data Collection

The interviewer used an interview guide (Table 3). Three questions were posed to all participants, each exploring one of the three domains of Darzi’s original definition of quality of care. (17) Prompts were prospectively developed from our understanding of the existing literature and were suggested as part of the question guide, although the interviewer could deviate beyond these if discussion deemed it necessary.

Table 6.3 Question schedule for in-situ interviews

What do you feel has affected your experience of visiting the A&E Department today?
likes/ dislikes, areas for improvement, communication, emotional needs, technical competence of staff, waiting experience?
What did you expect from your A&E visit today?
Understanding, Reassurance, Medication, Other symptomatic relief, onward care/ referral to services?
How safe have you felt during your time in A&E today?
Feelings of security and vulnerability, experience of mistakes / mishaps, medication safety, ability to speak up?

Interviews were audio recorded using a digital voice recorder with noise cancelling technology and dual lapel microphone to ensure clarity. Interviews were transcribed verbatim, and a proportion of transcripts were crosschecked to ensure accuracy. Additional field notes were taken to capture appropriate nonverbal, paralinguistic communication, where appropriate.

6.3.6 Data Analysis

Transcripts were uploaded into NVivo Version 12 (QSR International, 2012), a software programme used for qualitative analysis. Framework analysis following a mixed inductive deductive approach was adopted, following the seven steps described by Gale et al. (32) The first two steps of this approach are transcription and familiarisation. For this, two members of the research team (BG, RS) took responsibility for transcription, and worked collaboratively to crosscheck each other's work. This ensured both accuracy of transcription and familiarity with the interview content. The third step is coding. Interview transcripts were selected and open coded using an inductive approach. A modified approach to step four—developing an analytical framework—was

adopted. Rather than develop a new framework, we adopted our preexisting needs-based framework. (25) As such, for step five—applying the analytical framework—we switched to a deductive approach to index codes under the existing analytical themes based on ‘best fit’. For the final two steps—charting and interpreting data—all researchers met to review data, summarise findings and identify illustrative quotations.

Where data was deemed not compatible with existing themes, these were discussed between the researchers and either a preexisting theme was agreed, or a new theme was formulated and agreed.

6.3.7 Presentation of Findings

Presentation of findings includes description of the study participants; coding and emerging themes, including the frequency (prevalence) of statements aligned to each theme; and detailed discussion of findings by analytical theme, supported by illustrative quotations.

6.4 Findings

6.4.1 Description of the study participants

Twenty-four participants were recruited and completed the interviews. Mean age was 74 years (range 65—91 years). A larger proportion of participants were female (62.5% versus 37.5% male). Almost all patients declared at least one long term condition or comorbidity (95.8%). Patients had a range of education levels ranging from no formal qualifications to professional qualifications. Participants were recruited from across the acuity spectrum and included a majority of ‘very urgent’ (Category 2) and ‘urgent’ (Category 3) presentations (35% and 54%, respectively). Two thirds of patients (66.6%) presented with a non-traumatic medical complaint. Most patients had lower or moderate levels of

frailty as assessed by the clinical frailty score (mean CFS= 2.6 out of 9, range 1—6). All but a single patient lived in his or her own accommodation. (Table 6.4). An overview of individual participant characteristics can be found in Supplementary Material SM6.1.

Table 6.4 Summary of participant characteristics for in-situ interviews.

	N (%)
Gender	
Female	15 (62.5)
Male	9 (37.5)
Age	
65 74 years	12 (50)
75 84 years	10 (41.7)
84 years and above	2 (8.3)
Highest level of Education	
Primary	10 (41.6)
Secondary / Vocational	7 (29.2)
Post secondary (e.g., degree)	5 (20.8)
Acuity (Australian Triage Scale)	
23 (Very Urgent/ Urgent)	9 (62.5)
4 (Lower Acuity)	15 (37.5)
Presentation Type	
Medical Illness	16 (66.6)
Traumatic Injury	8 (44.4)
Frailty (Clinical Frailty Scale)	
1—3 (Lower Frailty)	15 (62.5)
4—6 (Moderate Frailty)	9 (37.5)
7—9 (Higher Frailty)	0

6.4.2 Coding and emerging themes

Framework analysis of transcripts was conducted, and statements assigned to an existing analytical theme where appropriate. Five hundred statements were identified which were directly aligned to experience. Of these, 452 statements

were organised under one of the five existing analytical themes within the established conceptual framework. These were most prevalent around waiting needs (146 statements), followed by statements related to ‘communication needs’ (125 statements). ‘Emotional’ and ‘physical/ environmental’ needs were evenly distributed (67 and 66 statements, respectively). Statements related to ‘care needs’ were slightly less prevalent (48 statements).

During the framework analysis an additional analytical theme emerged, relating to Attitudes and Values of the Team. This was initially identified within the interviews data, to accommodate 59 unique statements relating to patients’ perceptions of the ED team members, teamwork and professionalism.

The data identified several new subthemes were also identified. These are presented in Table 6.5 and include Social Communication (under communication needs), Reassurance (under emotional needs), and Waiting Experiences (under waiting needs).

Selected statements within this report are presented with reference to the study participant number (Pn).

Table 6.5 Themes resulting from in-situ interviews.

Analytical Theme	Existing Subtheme	New Subtheme
Communication Needs	Interpersonal Communication Informational Communication	Social Communication
Emotional Needs	Acknowledging Uncertainty Recognising Suffering Providing Empowerment	Reassurance
Care Needs	Symptom Relief Procedural Care	
Waiting Needs	Impact of Crowding Comfort[1] (associated with waiting)	Waiting experience
Physical / Environmental Needs	Comfort[1] (associated with physical needs)	
Attitudes and Values of the Team (new)		Perceptions of teamwork Staff attitudes and professionalism

[1]For the purposes of the conceptual model, 'comfort' is considered a single concept, however comfort associated with waiting and comfort associated with physical needs are considered under the respective analytical theme.

6.5 Presentation of Findings

6.5.1 Communication Needs

The theme of Communication Needs encompasses statements that relate to patient provider communication. These are divided into interpersonal communication, which consists of components of experience typically featured within a healthcare consultation, informational communication, which consists of

the giving and receiving of information (for example, discharge instructions), and the new subtheme social communication which consists of components of communication such as conversation not formally considered within consultation frameworks or models.

Interpersonal Communication

The interviews confirmed that patients placed immense value on interpersonal communication with care providers and the wider ED team. Patients preferred for staff to display a communication style that was calm, unrushed and polite:

> *Well…..they spoke to you in a good way…. they sounded as if they were interested and they weren't rushing… they seemed genuinely polite (P13)*

Patients were able to detect when staff communicated with them in a way that encouraged them to feel valued as individuals, and this positively affected their perceptions of care:

> *They made you feel that you were an individual kind of thing. They made you feel….you know, that you were on a level with any dignitary paying a lot of money" (P18)*

Most patients confirmed that staff introduced themselves by name and role, and this was viewed as beneficial and could help demystify roles, especially in instances where the patient was unfamiliar with the ED environment or had not attended before. However, a succession of staff introductions could be confusing where patients were presented with multiple new members of staff in a short space of time, as was reported by one patient:

> *I find it very confusing I mean there were three or four nurses that came in and told me their names and then the consultant came in and said good morning my name is blur blur and before he started on me he disappeared and I haven't seen him again! (P4)*

Similarly, patients also wanted to know the role of staff members, particularly when they were administering a task. Patients understood that staff had a job to do including tasks that would potentially be unpleasant or uncomfortable. A friendly attitude meant that patients readily accepted such experiences, which might otherwise be aversive. Patients were sometimes cognisant of conversations happening around them in the clinical environment. In such instances, they wanted to be active participants in discussions relating to their care rather than passive listeners. Being talked about without the opportunity to contribute to discussions during a clinical handover was perceived as undermining by one participant:

> *I'm not stupid… they're talking about bed 'G4'…I'm G4! I'm not stupid, it's not rocket science. Weird. Just weird… I'd like to be in on the conversation, rather than just hearing in the distance. (P17)*

Some of the older participants reported that communication with medical staff had evolved compared to their historical experiences. Demonstrating politeness and offering explanations as part of the ED consultation positively affected patients' experiences:

> *'cos no matter what you ask them, they're there they speak to you politely and they don't dismiss you. The doctors explain everything to you which they never did years ago. So you know exactly what's going on and you know exactly what's wrong with you. (P24)*

> *In the olden days if you came into hospital everything was kept secret (laughs) if you know what I mean. But today it's quite relevant to let people know what's going to happen and what's going on. (P05)*

Sensory problems and impairments are frequent amongst the older adult population. Recognition of a hearing impairment and adaptation of communication strategy was essential in facilitating a positive experience for

one participant, but prevented communication of a test result for another. Regarding providing information, patients valued understandable and appropriately detailed explanations. Repetition of questioning was also noted as a common feature of the ED consult, which could adversely affect experience. When explanations were provided which were too advanced for a patient to fully understand, particularly where this occurred without checking understanding, this could result in some frustration as expressed by one participant:

> *Information needs to be broken down to suit your average patient. You know, we're not all nurses or doctors. And I've had this for years, people have come along and said this and that and I've not understood it. It doesn't work all the time for me. (P20)*

Although, reflecting the local population, participants were predominantly white British, the importance of cultural and language recognition was noted by one patient who had a Welsh background:

> *I got on with one particular nurse 'cos she was Welsh… she spoke in Welsh (P14)*

Informational Communication

In addition to valuing interpersonal aspects of communication, patients had a great desire to be kept informed of their situation and the progress of their ED journey. Although verbal informational communication was considered most frequently by participants, other methods of delivery including written information and multimedia delivery for example using 'on screen' presentations in the waiting area was also desirable. Positive experiences of informational communication also included the progress of tests and investigations, and communication of 'next steps' during physical procedures:

> *The doctor came in this morning and told me about my blood test… I've got to go down for an xray and I've got to go for scans. (P05)*

Social Communication

Although not routinely considered as a part of consultation or communication skills frameworks, social communication was mentioned by some patients as important to their experience and is therefore considered within this synthesis. Patients expected staff to be friendly towards them and use positive body language such as smiling:

> *It's nice to have a smiling face and just to be sociable and polite and I hope I'm the same to them. (P07)*

The use of humour by staff was seen as very welcome by some patients. Despite this, one patient who was previously a senior nurse remarked that the use of humour should adhere to professional boundaries and that using colloquial terms of endearment, rather than addressing patients by their name, was inappropriate:

> *Not being too familiar, you know… [I don't like] being called 'babe'. (P02)*

6.5.2 Emotional Needs

In the original framework, the theme Emotional Needs was divided into subthemes encompassing coping with uncertainty, recognition of suffering and empowerment. Following framework analysis, an additional subtheme of reassurance was added.

Coping with uncertainty

Perceptions of uncertainty were mentioned by several study participants and could be a fundamental emotion associated with attending the ED, particularly if not familiar with the setting previously. Uncertainty also elicited feelings of

vulnerability when patients were unsure of outstanding investigation or treatment plans:

> *"I was told 'do this and take your dressing gown off and put a nightdress on and we will do an ECG' or something like that, and I thought what's an ECG, you know?...it didn't worry me, but I was concerned what they were going to do!" (P06)*

Conversely, it was recognised that perceptions of uncertainty could be effectively managed by simple interventions such as keeping patients informed of the next stages of care. Even where patients were accepting of uncertainty, they still desired basic information, such as whether they would be staying overnight:

> *I did ask someone if I was stopping overnight, cos nobody had said, perhaps they didn't know but you know, sometimes it's helpful. (P13)*

Recognition of suffering

Recognition of suffering was addressed by several patients. This extends beyond pain, to include recognition and attention to other forms of suffering and distress. One patient, who felt her suffering was not recognised in ED, was able to give an example of an experience in oncology:

> *…with Oncology, immediately when you went in there was a member of staff with you. Whether it was a ward assistant of whether it was a nurse, somebody was with you, talking through your problems, how you felt and so you felt hum, you felt loved and comforted whereas I don't [in ED] (P11)*

Empowerment

Empowerment is defined by the European Patient Forum as "any process that helps people gain control over their own lives, and increases their capacity to act on issues that they themselves define as important". (33) Staff provided

empowerment to patients by making them feel like individuals, legitimising their reasons for attendance:

> *Yes I feel like my concerns have been taken seriously, yes I do. (P12)*

Although some older adults were appreciative of having appropriate say in their care decisions, others recognised the potential importance of following clinical advice, for example, surrounding a decision to admit to hospital:

> *It's no good talking to medical staff and completely ignoring what they have to tell you, and if they advise that I should be over night, because they want to find out why I've gone down twice … it's an obvious answer isn't it. (P19)*

On occasion the environment of the ED could be physically disempowering. One patient reflected humorously on her experience of being attached to monitoring equipment, likening this to 'being chained up like Houdini' (INT_14). Some patients expressed fear of judgement from staff, which could be disempowering and affect their ability to make decisions:

> *You can see them thinking 'how the fuck did he manage to do that?!' (laughs) ….do you know what I mean? And you feel as though you're being judged as a village idiot. (P17)*

Provision of reassurance

During analysis, several statements relating to the provision of reassurance were encountered. Many patients viewed the provision of reassurance as a key positive determinant of their experience, and a sense of reassurance was often conveyed through good patient provider communication:

> *[The staff are] quite happy, they introduce themselves, they sit down…they talk to you as a human being. That they reassure you. That's quite nice. (P04)*

Reassurance could also be provided as an active process; for example by the positive actions of staff, showing thoroughness and diligence, or in one case, giving passive reassurance that material property was safe:

6.5.3. Care Needs

The third analytical theme, Care Needs is subdivided into symptom relief and procedural care.

Symptom relief

With regards to symptom relief, pain management was central to achieving a good experience. Patients made clear that they expected pain assessment and the provision of analgesia early on in their ED stay as a priority:

> *Keeping the pain at bay, really, is the big thing (P16)*

Staff met patients care needs by maintaining comfort during potentially painful procedures, for example IV cannulation. Explanation of procedures was reported to be extremely helpful, including effects on physical dignity:

> *I had to take my bra off you see, and when [the nurse] was putting the pads on I said I'm sorry…. He said 'don't worry about that—I won't be worried about that!' (chuckle) He was very kind about that… I think when you get a bit older you get a bit embarrassed. (P03)*

Procedural Care

Procedural care is defined as care delivered during medical or nursing procedures. Competence was valued highly in relation to this subtheme. Patients were perceptive of when they were being seen by a junior member of staff and whilst they were happy to be attended by trainees, desired to have the attention of more senior clinicians. One patient, who attended following a therapeutic excess of paracetamol was a critical observer of the doctor who

made an antidote drug calculation. Even so, the friendly nature of the encounter mitigated any negative effect on overall experience:

> *Well I think he was struggling to calculate whether the amount of paracetamol taken was too much, I think he really struggled with the calculation*

(Interviewer: Did That affect your experience?)

> *No, not really because he was so nice. He came to me later on and apologised and said ' I'm so sorry for what you've gone through today' and that was so nice... yeah, so that was OK. (P22)*

6.5.4 Waiting Needs

The theme Waiting Needs was subcategorised into the comfort (associated with waiting), impact of crowding and a new subtheme, waiting experience:

Comfort whilst waiting

Waiting could be uncomfortable and witnessing other patients' suffering distressing. However, these negative aspects of the experience could be mitigated through accepting shared experiences, resulting in camaraderie amongst patients:

> *"I think there was a bit of... you know... the patients forming a group, and the doctors and nursing staff forming a group. We were all in the same boat." (P22)*

There was an awareness of the breadth of acuity presenting to the ED ("….you're dealing with the serious to ridiculous, aren't you?! (P11), that patients underwent triage, and that having a lower triage category could necessitate a longer wait. However, patients wanted to have accurate information about waiting times, which were not always provided:

> *"… they were giving answers they thought we wanted to hear, for example, ' somebody is coming'… well… somebody wasn't coming, and that was an issue!*

> *Somebody was coming 2 hours later!(laughs) … I think I'd rather be told the real state of things." (P11)*

Impact of crowding

The waiting room could be cramped, and being near other unwell patients was intimidating and upsetting for some. Patients frequently reported physical discomfort whilst waiting, which was due to the metal chairs and gurneys in the department:

> *The seats... oh the seats were dreadful! Someone was lying on the floor in preference to sitting on the chairs because they were in such a lot of pain! (P22)*

Providing basic comfort measures was a positive determinant of experience; even providing blankets improved the experience for some patients. Conversely, ambeint temperature was problematic for some patients, who reported thirst and headaches because of heat and inability to access refreshments:

> *I was cold…and I had a blanket brought to me straight away. I thought it was lovely.(P04)*

> *It would have been nice to have water. It's warm in here. I've got a bit of a headache now and I think it's just the heat. (P21)*

Being cared for in corridor spaces could provoke significant anxiety for patients, who perceived this experience as unsafe and undignified:

> *Just the thought of having to wait in the corridor…just waiting there. No, I didn't like that. Because everybody's walking by you and they're looking at you as if to say 'what's wrong with her'?! (P04)*

Waiting experience

Study participants recognised the necessity of waiting for their care to be initiated and were understanding and accommodating of the need to wait. Even

so, negative consequences of waiting were reported and extended beyond boredom and frustration. On occasion, participants found the waiting experience to be intimidating, particularly when in close confines with other patients and those who were acutely unwell. Patients expected waiting to feature as a part of their ED experience, and were tolerant of the need to wait, even where this was prolonged:

> *Waiting is part of life's rich tapestry isn't it? …You put up with it. (P20)*

6.5.5. Physical and Environmental Needs

The theme Physical and Environmental Needs describes how the physical environment of the ED influences patient experience. This includes the provision of fundamental needs such as refreshments. Interaction with the environment formed an important determinant experience for many patients and included the subtheme comfort (associated with physical needs).

The presence of clear signage to the department and reception was noted to be absent, which was a negative determinant of experience. Cleanliness and hygiene of the ED environment was a crucial factor in the experience of patients:

> *[The environment] has got to be clean, otherwise you get all of the bugs, don't you? (P03)*

There were several aspects of the ED physical environment which could be negative determinants of experience. For example, one patient remarked that the environment of the waiting area—including the presence of others who were intoxicated, violent or agitated—could be unsettling and frightening:

> *No. Just that….people screaming…you hear it in here…men, screaming. Alcoholics who want a drink. And*

> *that's upsetting when you're trying to go to sleep. And you don't feel safe then because you think are they going to come around here, you know. (P04)*

Background noise could be problematic, particularly for patients with preexisting hearing difficulties. Monitor alarms are a constant presence in some parts of the ED, and study participants experienced this as noise pollution.

> *".... all the buzzers and beeps… it is like having a train at the bottom of your garden."(P23)*

Comfort (associated with physical needs)

In terms of basic needs provision, patients appreciated the provision of refreshments and noticed when these were not offered:

> *"When we came in [to ED] we were offered tea, and it went so much more quickly" (P01)*

6.5.6. Attitudes and Values of the Team

As many statements related to perceptions of teamwork and staff attitudes and professionalism, a new analytical theme, labelled 'Attitudes and Values of the Team', and was added to the existing framework. The two subthemes associated with this theme are perceptions of teamwork and staff behaviours.

Perceptions of Teamwork

Patients were active observers of team based processes, and took reassurance from witnessing effective communication between different team members:

> *Yeah… when you're on a trolley you tend to watch. And what I noticed was how they were talking and passing information. And I thought that was brilliant. They knew exactly where to go, you could see it. (P04)*

Staff attitudes and professionalism

Patients expected professionalism from the wider team, and had a sense of the staff members working together for them as an individual patient:

> *I felt that everyone was part of a team that had one aim in focus which was to look after the patient which was me. (P17)*

Values that patients perceived staff exhibited during care episodes that contributed to a positive experience included kindness, politeness and an approachability were reported:

> *"Everybody's kindness and professionalism stood out today.*
>
> *(Interviewer: And what is it that gives you that impression of kindness?)*
>
> *...well, it's staff being attentive and… the fact that I've asked questions and the staff have always answered politely without being harassed. I really feel like I can approach them." (P09)*

However, some patients did find the number of team members and different roles confusing:

> *There is so many people doing so many different jobs, each with their own coloured uniform, and you just wonder what they were doing. (P22)*

Regarding continuity of care, some patients were aware of team shift changeovers and felt a burden when establishing a rapport with a new team. Shift changeovers during a phase of care could increase their sense of patients' vulnerability:

> *"…knowing that when staff finish their shift … that they are going…that they are passing you over, you lose that continuity. I know they all work as a team… but [as a patient] you may have to reestablish something emotionally [with the new team]" (P09)*

6.6 Discussion

This study aimed to understand the experiences of older adults in the ED. Framework analysis using a combined inductive deductive approach (32)

confirms the conceptual validity of a ‘needs based’ framework amongst older adults in a UK ED setting. Statements were notably prevalent around waiting needs and ‘communication needs’. There was also sufficient quality and quantity of statements to confirm the presence of the three remaining analytical themes. It should be noted that reporting of prevalence of themes within qualitative research is controversial and that the number of statements related to a theme is not necessarily proportional to its significance. (34, 35) However, in our case, presenting frequencies of statements related to the themes provides important assurance that data has been explored in its entirety. Accordingly, this ensures data used to inform item generation for PREM-ED 65 65 accurately reflects the full breadth of patient experiences reported in the interviews. (36)

In addition to the existing five analytical themes, a new descriptive theme emerged, describing the role of staff professionalism and teamwork in contributing to the patient experience. This is supported by previous literature suggesting that patients are direct observers of team-based processes (32, 33) and that observation of constructive teamwork is a positive determinant of patient experience in the ED.

Patients in our study have provided narratives that will contribute to the further development of PREM-ED 65 65. This study builds on the body of existing literature emphasising patients’ desire to have their basic human needs and comfort addressed during emergency care episodes. (25, 39, 40) If aiming to optimise patient experience, the provision of humanistic, holistic care should be considered an important caring aspect of the ED alongside the clinical objectives. Specifically, in our study, participants also expected their dignity and

privacy to be respected wherever possible. Including these factors in a PREM is desirable from the evidence of our patient interviews and findings.

Facilitators of a positive patient experience that were identified included personable communication, the provision of timely information relating to the progress of clinical assessment / onward disposition, and measures to promote both physical and emotional comfort. Whilst it is useful to conceptualise these facilitators as discrete elements of patient experience—for example, when identifying a focus for service improvement— they may not be mutually exclusive and can overlap. For example, when looking at facilitators related to the analytical theme of social communication, providers' use of humour may extend beyond a purely social function to promoting the development of trustful patient provider relationships. (41, 42) Hence, in this case, social communication may have a role in meeting both communication and emotional needs. The potential for themes to interact and overlap should be considered when applying the original needs-based framework to the real world setting.

Although the focus of participants' discussion focused on their perceptions of relational aspects of care, as opposed to technical care elements, the need for prompt pain relief and symptom control was a common topic within our study participants. This is also recognised in the literature, for example in a prospective observational study of pain management in the ED by Van Zanden and colleagues (43) where 43.7% of patients arriving in the ED desired pain relief, and the provision of pain relief was associated with higher satisfaction. Pain was also highlighted in a recent qualitative study exploring patients' experiences in an Australian ED.(40) Many patients in this study described pain as a memorable aspect of their ED visit. In contrast to the positive experience,

patients who do not receive timely pain medication had negative ED experiences, as confirmed elsewhere in the literature.

Our interviews suggest that both the length of wait, and care delivered whilst waiting for medical assessment and treatment, forms an important determinant of older adults' experience in the ED. Indeed, waiting is ubiquitously associated with accessing emergency care, and literature suggests that patients often expect a long ED waiting time.(40) In the UK setting, older patients wait longer, and have a prolonged stay in the ED compared to younger patients. (1) However, there may be some international variation in wait times experienced by older adults. (45, 46) As such, it is important that a PREM aimed at older adults examines the experience of waiting, which may give locally relevant insights into where improvement would be beneficial.

6.6.1 Strengths and Limitations

This study represents a unique attempt to interview patients 'in situ', within the ED, during their stay. Ecological validity is a concept originally described in the social sciences following recognition that experimental conditions must mimic the 'real world' to promote external validity.(47) Importantly, ecological validity may also be impaired if interviews and surveys are conducted away from the setting of interest.(48) To this end, in-situ interviews maximise ecological validity whilst also minimising recall bias, as patients are reporting experiences from 'in the moment', as they are lived. The effect of recall bias may be especially significant where the time spent in the ED itself is short; in this situation, self reported perceptions of a care episode are likely to be affected by subsequent admission to other hospital departments. Available literature also suggests that recall bias may be more pronounced in older adults, who have been noted to recall events more positively in hindsight. (49) Conversely, potential limitations

of the ‘in situ’ approach may include concerns about privacy, confidentiality and the effect of disclosing information on care. To mitigate against these potential effects, the informed consent procedure included explicitly informing participants that information would not be shared with caregivers. Furthermore, interviews were conducted in private settings within the ED, wherever possible. Another limitation of our study is that it did not include older patients meeting the Rockwood criteria of ‘very frail’. However a recent qualitative study was conducted across three EDs in the UK and specifically recruiting older adults with frailty (Rockwood CFS >5). The findings of this study derived some similar themes, including information and communication in the ED, time waiting in the ED, and environment/ personal comfort. (50)

The general experience of the researchers towards the ‘in situ’ approach to interviewing patients in the ED is a positive one. However, those utilising this approach in the future may consider prearranging a private space, away from the immediate clinical area, in which to conduct the actual interviews. This may optimise interviewer-interviewee communication and enhance comfort for both parties. Strategies to promote representativeness of the sample, including recruitment of ‘hard to reach’ groups, should also be considered. In our experience, recruitment of very frail older adults was difficult. This is also reported in literature, which suggests recruitment of this group may be improved by considering when to approach very frail participants (e.g., following a period of rest), building personal rapport when explaining the project, giving them more time to consider participation, and—with their agreement—discussing with, or indeed involving, relatives and trusted friends.(51) Whilst the time required to implement these strategies may seem at odds with ‘in situ’ interviews conducted during an ED stay, many older adults currently experience protracted waits for

admission, increasing the potential relevance and feasibility in the current context.(52)

Finally, it should be noted that patient interviews were conducted prior to, and were therefore not influenced by, the COVID19 pandemic.

In summary, these findings build on our previous conceptual framework. This confirms face validity amongst an older adult population attending the ED. In qualitative research, triangulation refers to using different methods to develop a more comprehensive understanding of phenomena. (53) Data from this study will be triangulated with both the existing literature (25) and an accompanying focus groups study with healthcare professionals. (Part II) This will yield a comprehensive list of candidate items for inclusion in PREM-ED 65 65+. Subsequently, shortlisting and prioritisation of candidate items for inclusion in the final instrument is planned using a nominal groups technique. This will involve a range of stakeholders, including older adults and their carers. (54) The fourth and final step of development will then consist of psychometric field testing of the draft instrument. The anticipated result will be an instrument which meaningfully and usefully measures patient experience for older adults attending the ED.

6.7 Conclusion

Older adults are a significant and growing ED user group, both within the UK and internationally. Understanding their experiences is essential to ensuring the design and provision of ED services to meet their specific needs. This study utilised ‘insitu’ interviews carefully conducted immediately following emergency care to gain real time insights into patient experiences and needs.

Findings from this study confirm that older adults' experiences of ED care can be categorised using a preexisting 'needs based' conceptual framework, although several new subthemes and an analytic theme emerged, which were not previously identified within a systematic review. Aside from providing discrete insight into the lived experience of older adults attending an ED, data from this study will inform a comprehensive list of items for inclusion, in a patient reported experience measure, named PREM-ED 65 65+.

Post-Publication Addendum

Contribution to the PREM-ED 65 study

This study aimed to expand and elaborate the findings of the qualitative systematic review presented in Chapter Four by investigating older adults' perspectives of ED care encounters in a UK setting. Framework analysis of the data expanded and added credibility to the original needs-based conceptual framework whilst revealing a new analytical theme focused on staff behaviours and teamwork. The PREM-ED 65 study's qualitative development phase, with these interviews at the core, ensured that the draft items were grounded in older adults' lived experiences of their ED care and represented essential determinants of experience.

The next chapter will elaborate further on these findings by presenting focus groups that explore the perspectives of staff concerning determinants of experience for older adults in the ED.

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Supplementary Material

SM 6.1 Table of Participant Characteristics for Patient Interviews

1	Female	67y10m	2	1	Headache	Own Home	Accounts Assistant	Yes	Nil formal	No	11:30
2	Female	70y9m	2	1	Chest Pain	Own Home	Nurse	Yes	Degree	Yes	13:03
3	Female	80y6m	3	4	Chest Pain	Own Home	Housewife	No	Nil formal	Yes	29:03
4	Female	70y9m	4	6	Hip Injury	Own Home	Housewife	No	Nil formal	Yes	17:11
5	Male	76y7m	3	4	Abdominal Pain	Own Home	Quarryman	No	Nil formal	Yes	22:53
6	Female	77y10m	3	6	Fall	Own Home	Housewife	No	Nil formal	Yes	19:30
7	Male	76y1m	3	1	Surgical Complication	Own Home	Administrator	No	Vocational	Yes	16:54
8	Male	83y11m	3	2	Epistaxis	Own Home	Builder	Yes (Partner)	Vocational	No	28:41
9	Female	70y7m	3	1	Head Injury	Own Home	Carer	Yes Daughter	Vocational	Yes	29:18
11	Female	82y9m	2	4	Chest Pain	Own Home	Archaeologist	No	Degree	Yes	29:03
12	Female	66y7m	3	1	Head Injury	Own Home	District Nurse	Yes (Husband)	Degree	Yes	41:47
13	Male	82y9m	2	5	Shortness of breath	Own Home	Civil Servant	No	Secondary Education	Yes	28:11

14	Male	85y6m	2	3	Palpitations	Own Home	Railway Worker	Yes (Daughter)	Vocational	Yes	35:25
15	Female	80y8m	3	3	Abdominal Pain	Own Home	Cashier	Yes (Spouse)	Nil formal	Yes	21:15
16	Female	83y	4	2	Fracture	Own Home	Shop Asst	Yes (Spouse)	Nil formal	Yes	27:03
17	Male	66y8m	2	1	Major Trauma	Own Home	Teacher	Yes (Spouse)	Degree	Yes	51:07
18	Female	68y1m	3	1	Syncope	Own Home	Cardiographer	Yes (Spouse)	Vocational	Yes	9:29
19	Male	89y1m	3	6	Fall	Annexe	Managing Director	Yes (Daughter)	Nil formal	Yes	24:29
20	Male	69y5m	2	6	Suspected sepsis	Own Home	Electrician	Yes (Spouse)	Vocational	Yes	28:64
21	Female	84y9m	2	1	Chest Pain	Own Home	Ret'd Housewife	Yes (Child)	Nil formal	Yes	18:15
22	Female	65y3m	3	2	Overdose (Accidental)	Own Home	Religious Minister	Yes (Spouse)	Degree	Yes	55:44
23	Male	66y	3	1	LRTI	Own Home	Financial Advisor	Yes (Spouse)	Degree	Yes	17:16
24	Female	66y4m	4	4	Ankle Injury	Own Home (Respite)	Retired	No	Vocational	Yes	25:03
25	Female	67y7m	2	3	Anxiety	Own Home	Housewife	Yes (Spouse)	Nil	Yes	24:25

Notes: ATS= Australasian Triage Score; CFS= Clinical Frailty Scale; AP= Accompanying Persons

Participant 10 chose to withdraw post- recruitment.

Chapter 7 Focus groups with professional caregivers

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Blair Graham (BG) conceptualised the study, led development of the study protocol, performed the focus groups, data transcription of focus groups, data analysis, produced the initial manuscript draft and led revision of all subsequent versions.

Rosalyn Squire (RS) assisted with data transcription of focus groups.

Pamela Nelmes (PN), Jason Smith (JES) and Jos Latour (JML) assisted with the development of the study protocol and assisted revision of the manuscript.

JS and JML acted as project supervisors.

The agreed approximated percentage contributions toward the production of this research are: BG 75%, RS 5%, PN 5%, JES 5%, JML 10%.

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What this chapter adds.

This chapter:

- Demonstrates the ability of the researcher to (i) plan and deliver qualitative research, including focus groups with healthcare professionals; (ii) conduct framework analysis of qualitative data supported by computer assisted qualitative analysis software, and (iii) report qualitative research findings in accordance with Consolidated criteria for reporting qualitative research (COREQ) guidelines.
- Apply qualitative research findings to expand understanding of older adults' experiences of ED care and the 'needs-based' conceptual framework.
- Triangulate qualitative findings, and findings from the literature (meta-synthesis) to suggest a comprehensive list of draft items for PREM-ED 65.

Development of a Patient-Reported Experience Measure for Older Adults Attending the Emergency Department: Part II—Focus Groups with Professional Caregivers.

7.1 Abstract

A wide range of healthcare professionals provide care for patients in the emergency department (ED). This study forms part of a wider exploration of the determinants of patient experience for older adults in the ED, to assist the development of a new patient-reported experience measure (PREM). Inter-professional focus groups aimed to build on findings from earlier interviews with patients conducted in the ED, by exploring professional perspectives on caring for older people in this setting. A total of thirty-seven clinicians, comprising nurses, physicians, and support staff, participated in seven focus groups across three EDs in the United Kingdom (UK). The findings reinforced that meeting patients' communication, care, waiting, physical, and environmental needs are all central to the delivery of an optimal experience. Meeting older patients' basic needs, such as access to hydration and toileting, is a priority often shared by all ED team members, irrespective of their professional role or seniority. However, due to issues including ED crowding, a gap exists between the desirable and actual standards of care delivered to older adults. This may contrast with the experience of other vulnerable ED user groups such as children, where the provision of separate facilities and bespoke services is commonplace. Therefore, in addition to providing original insights into professional perspectives of delivering care to older adults in the ED, this study demonstrates that the delivery of suboptimal care to older adults may be a significant source of moral distress for ED staff. Findings from this study, earlier interviews, and the literature will be triangulated to formulate a comprehensive

list of candidate items for inclusion in a newly developed PREM, for patients aged 65 years and older.

7.2 Introduction

Capturing older peoples' experiences of emergency care is essential, not least since patient experience may be positively associated with improved clinical outcomes and greater patient safety. (1) Understanding vulnerabilities in patient experience may also be used to drive meaningful improvements in care. (2) Existing literature places emphasis on the importance of communication, managing wait times and providing a 'frailty friendly' environment. (3, 4) A meta-synthesis of patient experience in the emergency department (ED) proposes a needs-based framework for optimising patient experience, focusing on communication, care, waiting, physical, and environmental needs. (5) Interviews with twenty-four patients during an emergency care encounter confirmed the face validity of these themes amongst older people. Furthermore, interviews suggest the emergence of a new analytical theme consisting of 'attitudes and values of the ED team'. (See Part I— Interviews with service users) Aside from building on the existing literature, these data will be specifically used to derive a list of candidate items for a Patient Reported Experience Measure for older people attending the ED (PREM-ED 65).

Older people are an increasing user group in Emergency Departments (EDs), comprising over a quarter of ED attendances in most developed countries. However, providing emergency care for older people represents a real challenge for healthcare professionals. For example, many major conditions encountered in the ED present subtly or atypically in older adults (6, 7), and the high prevalence of multimorbidity, polypharmacy and preexisting geriatric syndromes can make physical diagnosis challenging. (8-10) In addition, the frequent presence of frailty (11), cognitive impairment (12), and communication/ sensory disturbances (13) demands that older people receive holistic care. The

provision of complex geriatric assessment within the ED is well evidenced to reduce rates of hospital admission, ED length of stay and mortality. (14) However, issues such as under resourcing and crowding present barriers to the provision of holistic care. As a result, ED care is often focused on resolving single organ dysfunction and optimising patient flow. (15) Although training and competency-based education requirements in geriatric emergency medicine have been published, these are yet to be widely translated into physicians' working practice. (16) The importance of involving the multidisciplinary team has been emphasised within prominent guidelines (17, 18), and although not yet widespread, bespoke geriatric emergency departments have been suggested to further improve care. (19)

Patient interviews provide a recognised means to develop patient reported measures (20) as they provide in depth insights related to health care and beliefs. (21) Where acutely unwell and/or very frail patients are unable to participate in qualitative interviews, inviting emergency care professionals to share their perspectives, assures this patient group is represented in the development of PREM-ED 65. In addition, professionals may highlight important, additional determinants of patient experience not recalled or emphasised by older adults during interviews. In the context of developing the PREM-ED 65, professional focus groups capitalise on interdisciplinary interaction to formulate new ideas about determinants of experience for older people in the ED. Therefore, this study aims to explore emergency care professionals' perceptions of delivering ED care to older people and, specifically, to determine whether any additional analytical themes emerge in the conceptual needs-based framework.

7.3 Materials and Methods

This study used interprofessional focus groups of healthcare professionals working in the ED. We used the COnsolidated criteria for REporting Qualitative research (COREQ) checklist to report the study. (22) Ethical approval was granted by the UK Health Research Authority (18/LO/1194) and institutional approval from the University of Plymouth (17/18973).

7.3.1 Research team and reflexivity

The focus groups were led by a male identifying academic emergency physician (BG) who had earlier conducted interviews with older adults attending the ED. As reported in part 1 of the study, data analysis was supported by a male identifying professor in emergency medicine (JES) and male identifying clinical nursing professor (JML). Identical standards for rigour and trustworthiness were followed, including the use of reflexive notes and consideration of researchers' insider perspectives as clinicians. The researchers were known professionally by some of the participants. However, assurance was provided from the outset that anonymity and impartiality would be respected. Participant information highlighted the purpose of the study for the development of the PREM-ED 65.

7.3.2 Theoretical Framework

The methodological orientation of the focus groups was informed by a recognised definition of high-quality care (23) in order to investigate health professionals' perspectives on the clinical outcomes, provision of safe care and desired patient experience.

7.3.3 Study Setting

In order to maximise the potential for representative responses, focus groups were conducted at the ED of three hospitals in the South West of England. We selected one large teaching hospital which is also the regional major trauma

centre, and two medium sized district general hospitals with a mixed urban/ rural catchment area. One of these hospitals had recently developed a specialist Older Peoples' Emergency Liaison (OPEL) service, staffed by specialist nurses within the ED (Table 7.1.)

Table 7.1 Study Settings for the focus groups with staff.

Hospital 1	Type 1 ED Major Trauma Centre 100,000 attendances per annum
Hospital 2	Type 1 ED Regional Major Trauma Unit 80,000 attendances per annum
Hospital 3	Type 1 ED Regional Major Trauma Unit Specialist OPEL service 80,000 attendances per annum

ED=Emergency Department; OPEL= Older Peoples' Emergency Liaison Service ED= Emergency Department.

A purposive sampling strategy was used to recruit participants to ensure adequate representation from different professional groups and levels of seniority. An open invitation was issued by email to all clinical staff working in the EDs of the three participating study sites. Those interested were provided with a detailed information leaflet and consent form. Medical, Nursing, Allied Health Professional and Ancillary staff who worked within the ED for at least six months were eligible for inclusion. Staff for whom the ED was not their permanent place of work, who had less than six months' experience or who did not work in a patient facing role were excluded.

7.3.4 Data collection

The focus groups (n=7) were facilitated by the lead researcher (BG), who had previously received training in qualitative research methods. Participants were asked to self-report their age, staff group, level of experience and professional education level. The focus groups schedule directly reflected the questions

presented to patients during the patient interview study (Part 1), whilst also considering the need to obtain professional perspectives. Therefore, the use of a ‘question route’ (24) was proposed. This technique was used to facilitate the flow of constructive and in-depth conversations using principles of active listening. (25) Focus groups were audio recorded and field notes taken to capture nonverbal aspects of communication. Focus groups were conducted in a private room away from the operational ED setting.

7.3.5 Data Analysis

Data analysis was conducted separately to the patient interviews, although followed an identical strategy as detailed in Part I of this study. (26) As such, the qualitative data analysis used framework analysis and a conceptual framework of patient experience developed by the authors was used. (5) Units of analysis were identified from written transcripts, using NVivo Version 12 (QSR International, 2012). Data were then organised under the preexisting analytical themes of the framework.

7.4 Findings

7.4.1 Description of participants

Thirty-seven participants were recruited, consisting of 20 emergency physicians, nine emergency nurses, three OPEL specialist nurse practitioners, two healthcare assistants, one physiotherapist, one occupational therapist and advanced clinical practitioner. Participants were preassigned to a focus group held within their locality.

Focus group participants were more likely to be female (26/37; 70.2%). The length of the discussion ranged from 54 to 94 minutes per focus group, with an average length of 72 minutes.

A summary of focus group characteristics is presented in Table 7.2

Table 7.2 Composition of the focus groups with staff.

Hospital Number	Focus Group #	Duration hh:mm	Total n participants Occupational Group, n	Gender, n
01	1	01:18	Total 6 Physician, 5 Nurse, 1	Male, 2 Female, 4
01	2	00:54	Total 5 Physician, 4 Nurse, 1	Female, 5
01	3	01:09	Total 6 Physician, 3 Nurse, 1 Therapist, 2	Male, 1 Female, 5
02	4	01:34	Total 4 Physician, 1 Nurse, 1 ACP, 1 HCA, 1	Male, 2 Female, 2
02	5	01:24	Total 5 Physician, 2 OPEL Nurse, 3	Male, 1 Female, 4
03	6	01:00	Total 6 Physician, 2 Nurse, 3 HCA, 1	Male, 3 Female, 3
03	7	01:06	Total 5 Physician, 3 Nurse, 2	Male, 3 Female, 2

7.4.2 Coding and Emerging Themes

Using framework analysis, a total of 150 unique statements were linked to existing analytical themes and subthemes based on the conceptual framework (Table 7.3). Following its identification within interviews data (Part 1), the new analytical theme ‘attitudes and values of the team’ was included within this analysis, and a further 20 linked statements were identified.

Table 7.3 Themes from the focus groups with staff

Analytical Theme	Existing Subtheme	New Subtheme	Supplementary Theme[1]
Communication Needs	Interpersonal Communication Informational Communication	Social Communication	
Emotional Needs	Acknowledging Uncertainty Recognising Suffering Providing Empowerment	Reassurance	
Care Needs	Symptom Relief Procedural Care	Responsiveness	
Waiting Needs	Impact of Crowding	Waiting experience	
Physical / Environmental Needs		Fundamental Needs Equipment and Devices	
Attitudes and Values of the team (new)		Perceptions of teamwork Staff attitudes and professionalism	
Supplementary Theme[1]			Staff distress Recognising older people as a vulnerable user group Views on emergency care systems for older people

[1] Supplementary theme arose in addition to framework analysis and are related to participants' lived experience of caring for older adults.

7.4.3 Presentation of findings

Communication Needs

Healthcare professionals in all focus groups assigned a great deal of importance to giving adequate information to older adults. However, staff expressed frustration that time constraints and working pressures could undermine the desire to ensure that adequate information was provided. This could lead to a poor experience for patients.

> *When we are under pressure we don't have or allow enough time to explain the meaning of the attendance, and yes, we've focused on the diagnosis and ruling out conditions, which is good, but we might not have addressed their issue at all. (Nurse, Site 02)*

Healthcare professionals were also cognisant of patients' ability to receive information whilst in the ED, due to issues such as sleep deprivation and anxiety amongst older adults. The provision of easily accessible written information was viewed as important, although staff understood the limitations for those with impaired eyesight or limited literacy. For this reason, an appropriate verbal introduction and description of role was viewed as essential.

> *There are some aspects like 'who's who?', that's important, isn't it? We've made a poster which should be in every cubicle showing team colours… you could make a very good argument that if a patient doesn't have glasses...or even if they do... can they read it? So we've got to emphasise how you introduce yourself. Who you are, what you are... (Physician, Site 02)*

Additionally, staff discussed the prevalence of hearing loss amongst older adults. This was something commonly encountered and could have a detrimental effect on the quality of communication. There was a general recognition that the ED represented an unfamiliar environment for most older adults, and that commonly used terminology could be misunderstood. Provision

of adequate explanation was suggested by participants to overcome confusion resulting from an unfamiliar environment and improve experience as a result.

> *For us, ED is familiar… but to patients … they don't realise that majors is majors and minors is minors. They've got nothing to help them understand. [I think] that's a piece of work that needs to be done... [always] explaining where you are, what is going to happen, who is going to come and have some expectations of what is going to happen. (Physician, Site 01)*

Staff discussed the process and challenges of obtaining an accurate medical history. In particular, the repetition of questions and the use of jargon were viewed by participants as negatively affecting patient experience.

> *Repetition of questions can be a problem. It's not done intentionally but the level of communication between teams sometimes isn't there and patients sometimes get upset that they're being asked the same questions. (Physician, Site 03)*

When considering standards of interpersonal communication, the need to provide introductions was recognised as important in all focus group discussions. Positive communication with older adults could have an especially positive effect on those who were normally socially isolated.

Emotional Needs

The theme Emotional Needs identified 'acknowledging uncertainty', 'recognition of suffering', 'empowerment' and 'reassurance' as subthemes.

Staff recognised that uncertainty was likely to characterise attendance for older people and could result from multiple aspects of the ED stay. Discrete aspects of the decision to admit to hospital, arrangements being made at home—such as for pets—and implications for family life.

> *The uncertainty of whether they're going to be admitted. It's a big deal for everybody, but especially the elderly patients who may have other considerations like frail elderly partners, pets, those sorts of things... complications with families... I think one of the really big anxieties is 'am I going to be admitted' 'how long am I going to be in for', 'what are the knock-on effects for my family'. (Nurse, Site 02)*

Staff were adept at recognising suffering in older people across multiple dimensions, including fear surrounding possible death, anxiety around incontinence and access to toilet facilities.

> *I have people trying to pull my uniform and say "I really need the toilet" because they haven't been given a call bell, which happens very often, or because they're in the corridor unaccompanied and all they can do is wave frantically for help to go to the toilet. (Occupational Therapist, Site 01)*

Staff viewed empowerment of older adults as extremely important and an essential function of their role, but they discussed that many of the processes of emergency care could undermine efforts to involve older people as active participants in their care, and lead to disempowerment. This was recognised as something not only detrimental to the patient experience, but also leading to poorer outcomes of care.

> *The minute you disempower somebody... you put them in an ambulance, and you ask them to wait for a period of time, you immediately disempower them so that they don't care for themselves for that period of time and it doesn't take long for that to become a longer lasting state and because we are in this environment where there isn't enough space, it compounds the issue. (Physician, Site 01)*

Despite limitations imposed by the emergency care system, there was a clear desire to engage older people in decision making wherever possible. Staff discussed that doing so could have positive implications, especially with regards to discharge processes and long term care planning. Other clinicians

recognised that agreeing solutions with the multidisciplinary team could help prevent deconditioning and harm arising from preventable hospital admission, even if this meant the acceptance of a degree of risk. For example, one participant recalled a case where an older male patient was empowered to exercise personal autonomy and make an informed discharge decision, even though the consequences of this could lead to death. Providing early decision making around whether to resuscitate patients at risk of deterioration is recognised as good practice. The importance of this as a critical decision for older people was discussed recurrently within many focus groups. Staff thought it was important to have informed and honest conversations with older adults, specifically regarding the limitations of care they could provide.

> *Sometimes we undertake distressing things to elderly and frail people and the recognition of dying and [not providing] CPR as a normal course of death, and changing that so that people feel empowered to say 'let's sign this form'… I know it doesn't mean I'm not going to be treated but they know my ceiling of care'. (Nurse, Site 01)*

Staff recognised the potential role of accompanying persons, such as relatives and cares, in achieving patients' needs. The presence of accompanying persons, such as relatives, were generally viewed as positive for older people when attending the ED. Participants acknowledged that relatives could provide advocacy and collateral history, as well as help guide treatment escalation decisions. Conversely, the presence of relatives could sometimes introduce complexity or, at worst, interfere with processes of care.

> *I had a patient come into [the Resuscitation area] and the doctor came in to discuss the treatment escalation form and straight away the daughter said, 'you don't need to ask him anything, you can speak to me' and she said straight away he's for full resuscitation and the patient didn't even get a look in. The doctor was still trying to talk to him [the patient],*

> *and she was butting in all the time. (Healthcare Assistant, Site 03)*

Care Needs

From the healthcare professionals' perspective, meeting care needs centred around patients' individual expectations of care. Clinicians were cognisant of unique care needs resulting from physiological and anatomical changes as a consequence of ageing, for example when identifying occult injures in patients presenting with falls.

> *There is a lack of recognition of the occult injury or reason for presentation underlying injury in these patients... there's lots of evidence out there to suggest we are not assessing the underlying reasons that have brought elderly patients to us.... comorbidities, polypharmacy, the home situation, that sort of thing. (Advanced Clinical Practitioner, Site 01)*

Participants discussed that their own professional guidelines did not always account for the needs of older adults. Specifically, process/ time bound targets were often viewed as inappropriate and a potential barrier to the provision of holistic care.

> *If you look at things like the sepsis guidelines, they are very focused on fast tracking children but not the elderly ... [the elderly] just get lumped with adults. But actually a 20yearold is very different from a 90yearold. (Physician, Site 03)*

There was also a recognition that, on some occasions, the correct approach could be to do nothing, withdraw care, or facilitate end of life care within the ED. As opposed to being futile, such encounters were viewed as positive by clinicians, allowing them the opportunity to facilitate person and family centred care.

> *So we had a patient last week... and we stopped [active treatment] ... well, we spoke to the patient and asked her what she'd like and she said 'I want to go to sleep' so we*

> *tucked her up in bed. She's expressed her wishes and then we planned to discuss with the family about her expectations and agree a plan. And we signed the treatment escalation form and admitted her for end of life care. (Physician, Site 03)*

Participants recognised overall value of capturing and measuring outcomes that are meaningful to patients, for example through the collection of patient reported experience and outcomes measures.

> *I think achieving good clinical outcomes goes back to what the patient actually wants. For patients, going back to the PREMs [Patient Reported Experience Measures] is about looking at the clinical outcomes they actually want. So, if the pain gets under control so they are able to mobilise then that should be a good outcome. (Advanced Clinical Practitioner, Site 03)*

Physical and Environmental Needs

Ensuring that patients' basic physical needs were met, facilitated by a welcoming physical environment, was viewed as paramount to ensuring quality care by participants.

> *Most older people are not interested in their physiology, they are not particularly interested in having a lactate taken within seconds of arrival. They are interested in whether a window is there…whether there is a clock… and if the nurse offered them a cup of tea (field note: agreement from group). (Physician, Site 03)*

There was general recognition that essential needs included fluids, food, and toileting. However, staff recognised that these basic needs were often not met, due to a lack of resources, constraints on staff availability and the physical layout of the ED itself.

> *There's a general lack of dignity… a lack of privacy. It's not a ward here, but it gets used like a ward because people are here for hours and hours.... it's not satisfactory, is it? We'd like to give everyone a sandwich, but often we run out of them. We run out of chairs these days. (Healthcare Assistant, Site 02)*

Staff were also able to give examples where a lack of basic needs provision, such as hydration, may have contributed to clinical outcomes and need for admission.

> *Dehydration certainly makes it harder to discharge patients. Concentration, memory and focus all decrease. (Occupational Therapist, Site 01)*

Participants agreed that the physical environment often presented a barrier to facilitating a positive patient experience. In particular, the ambient environment could present patients with a range of noxious stimuli, including excessive noise, bright fluorescent lighting and even exposure to interpersonal violence and aggression. Clinicians also recognised that, in addition to providing a poor experience, such an environment could have a negative effect on clinical outcomes, by increasing the incidence of disorientation and conditions such as delirium.

> *I think the [ED] environment must be very distressing for them [older people] ... the hustle, bustle, police being around, monitors, alarms and swearing. (Nurse, Site 03)*

Use of monitoring equipment, manual handling equipment and furniture not designed specifically for older people—such as ED trolley gurneys—were also viewed as both a barrier to patient experience and a risk to patient safety.

Waiting Needs

Clinicians shared a common concern that waiting could be a frustrating experience, and the need to provide accurate information on waiting times was commonly recognised. Although anecdotal, a consensus emerged that older adults were more likely to tolerate protracted waiting periods without expressing dissatisfaction, compared to some other groups. However, this tolerance was perceived as potentially problematic.

The elderly patients are least likely to make a fuss... so they're most likely to be forgotten. Whilst you are busy with somebody who is exhibiting challenging behaviour and running amok in the department, the poor [elderly patient] in the corner has wet herself because she can't reach her call bell, or she lacks capacity to make herself heard. (Nurse Practitioner, Site 02)

There was an appreciation that, for some older adults, the uncertainty around waiting could be distressing especially when the surrounding environment was busy or fractious. Strategies for overcoming boredom, frustration and inefficiency arising from waiting included methods to provide distraction. Such interventions could be simple, such as the provision of reading materials or jigsaws, or more advanced comprising the use of technology. Waiting to front load other forms of assessment, alongside a medical ‘workup’, was seen as a better way to utilise time.

> *We could issue books to read, newspapers, a jigsaw puzzle. There are so many things you could think of introducing… to improve the experience. (Physician, Site 03)*

There was a widespread recognition of problems for older adults associated with crowding. Corridor care was viewed as an inevitable, albeit unacceptable, feature of the emergency care journey, which was an affront to patient dignity and could threaten patient safety. Clinicians expressed empathy with patients who had to endure corridor care, and they felt disempowered to change the situation. Some participants expressed that a sense of failure—or even shame— was caused by working in crowded environments

> *Sometimes it's like being on double beds, isn't it? The patients are coughing all over each other, so you fail on every nursing element ever imaginable... you fail on dignity, on infection control... every single thing that you've ever*

> *learnt you've failed on because of the crowding. And there's not an awful lot you can do about it. (Advanced Clinical Practitioner, Site 01)*

Attitudes and values of the team

Focus groups participants frequently discussed their role in the wider ED team. There was a recognition that, in the ED, nursing staff were often conflicted between providing basic patient care, technical tasks such as venipuncture and cannulation, and facilitating patient flow. This often meant that no one was allocated to meeting patients' essential needs, despite the recognised vital importance of this function. As a solution to this problem, there was an agreed expectation amongst participants that all members of the ED team responded to meeting patient's essential care needs. The sense of team ethos and flattened hierarchy that resulted from this was generally viewed as desirable and helped ED staff to develop a shared team ethos.

> *Patients have often said to me 'look at that doctor making the bed!', and I'm like 'yeah, that's called teamwork, that's what we do'. And patients and relatives are often surprised that doctors do basic care as well. (Nurse, Site 02)*

Conversely however, the onus on senior clinicians to perform basic care tasks could be a distraction from their core role, affecting professional efficacy.

> *In the past four months I have done more that I would deem 'out of my doctor role' because the nurses are short staffed. I am regularly giving medications and getting commodes and urine dips and urine bottles and fluids and stuff. Which is fine... but that then actually impacts on our role as doctors and what we can achieve. And we don't have the time either so what you've got is a group of professionals who are each interplaying with each other's job roles, and no one is taking responsibility for that person's care. (Physician, Site 01)*

Specialist team members who could provide care for older adults were praised by many participants. One department had established an 'Older Peoples'

Assessment and Liaison' Service consisting of senior nurse clinicians. This service provided holistic assessment of older people in the ED and was held up as a model of exemplary practice by participants. Input from the wider multidisciplinary team, including Physiotherapy and Occupational Therapy, was also viewed as beneficial in assisting clinical decision making for older adults and increasing patient satisfaction.

> *If you go back a few years, we didn't have therapy/ OT [Occupational Therapy]/ MSK [Musculoskeletal] practitioners at the front door. We now have a true MDT at the front door, and we know that's the right thing for older people. And everyone's happy to make their own decisions, and quite often if the therapy team is happy with their mobility, then they go home. And I think the patients like that. (Frailty Nurse Specialist, Site 03)*

7.4.4 Supplementary Themes

Three supplementary themes arose, separate from the framework analysis. These are 'staff distress', 'recognising older people as a vulnerable user group' and 'views on provision of geriatric ED services'. Whilst not directly linked to the original aims of the study, staff were keen to discuss their lived experiences of caring for older people in the ED, and the effect on their professional values and identity. These themes, therefore, provide important contextual insight into the challenges faced by healthcare professionals when providing care to patients in the ED.

Staff Distress

Although not the original focus of this investigation, focus groups participants reported significant distress when unable to provide older patients with a desirable experience

> *I just feel really guilty: sometimes you have a choice between providing medical care or providing compassionate care. (Physician, Site 01)*

During the focus groups, it was common for health professionals to compare their occupational experience of providing care with standards they would desire for their own loved ones or themselves. Such descriptions revealed a deep empathy for older people and revealed feelings of distress when desired standards were not met.

> *Sometimes you just feel ashamed. The poor patient is on a commode in a cubicle... it's just... you wouldn't want to be in that situation... you wouldn't want your mother to be in that situation. (Physician, Site 01)*

For some participants, the presence of service pressures and an emphasis on patient flow increased feelings of distress and could lead to conflict with others in the team.

> *We're the first point of contact for that patient coming in but we seem to be the last people to be drip fed any sort of budget...where we can make holistic improvements? You know, they're talking about redesigning and remodelling and rebuilding but ... it's just simple things we need, like, basic human comforts. (Healthcare Assistant, Site 02)*

In contrast, one doctor was able to reflect positively on the effort that her department made to care for older adults.

Recognising older people as a vulnerable user group

Despite perceived shortcomings in delivering healthcare to older adults, professionals identified that acquiescence was commonplace, with older adults appearing to tolerate suboptimal care and undesirable clinical outcomes, when compared to other patient groups. This could make them more vulnerable to experiencing poor care.

> *Yeah, I find that they don't want to trouble you as much as other patient populations…so they are sitting in pain for longer perhaps, and they don't want to ask to go to the toilet. I had one chap who even wet the bed, because it was*

> *so busy in the department he didn't want to trouble anyone because he saw it as a minor problem. (Physician, Site 01)*

One nurse viewed it as her responsibility to recognise older peoples' tendency towards acquiescence and ensure patients had an advocate.

> *Older people don't always have a voice, do they, not like the younger generation. They will just sit quietly and wait patiently... so it's making sure there's an advocate for them. They don't always have family... someone to stand up for them. (Nurse, Site 01)*

Views on emergency care systems for older people

As well as identifying problems and perceived deficiencies in ED care for older people, focus groups participants discussed their ideas for improving service configuration. Views regarding the ideal configuration for geriatric emergency care were mixed. Some favoured highly specialised services and designated areas for older people. Conversely, others recognised that due to demographic shift, older adults were likely to become the predominant user group of ED services, and that configuration of the department should reflect this.

> *Do you not make the older patients your core user group and others have to fit in around this, especially as we know this population is going to skyrocket in the future?*
>
> *…I think it should be more focused on the elderly... you should make that your core business and figure out how others fit around it, rather than put them aside. (Physician, Site 03)*

Finally, one emergency physician reflected on visiting a specialist geriatric emergency department which had recently opened in another locality. Although not commonplace in UK practice, this was seen as a gold standard model of care.

> *At [locality] they've just recently opened a geriatric ED run by a geriatrician. It runs from 8am to 10pm and everybody over 75 who goes into majors is seen in that area. They*

have a particularly high percentage of older patients. But they've really grabbed the bull by the horns by creating a separate environment and it's a nice structure to ensure there is daylight and more privacy and people are more oriented. And I think that's the way to go. (Physician, Site 03)

7.5 Discussion

The findings of our study provide some insight into professionals' experiences of caring for older adults in a UK ED setting. No new analytical themes or subthemes resulted from framework analysis. As such, this study further validates the existing needs-based conceptual framework developed from the literature (5) and expanded using interviews with patients. (Part I) However, staff offered additional perspectives in relation to the existing themes. Staff were attentive of the need to establish rapport and effective communication with older adults and prioritised identifying and meeting care needs that were tailored to the individual patient. This included not only the delivery of medical interventions such as investigative procedures and analgesia, but making decisions on treatment escalation and providing effective supportive care including dignified end-of-life care, where this was deemed the most appropriate option. Providing palliative care to older people has previously been recognised as an emerging and important function of emergency clinicians, despite the presence of barriers such as suboptimal access to information, collateral history and time constraints. (27) As well as recognising the need to provide high quality medical care, staff were intrinsically motivated to meet the most essential needs of older patients, such as providing ready access to food, drinks and toileting. The importance of providing a comfortable environment and protecting older peoples' dignity was explicitly recognised. However, participants reported that crowding and corridor care were commonly encountered and presented barriers to achieving the desired standards of care.

Such concerns are likely to be well founded, with the effect of ED crowding on mortality and patient experience well documented in the literature. (4, 28)

Teamwork has been previously recognised as paramount to improving patient safety, reducing clinical errors and improving efficiency of care in the ED. (29) Conversely, hierarchical power relationships—defined as relationships being "based on power from… expertise or experience"— may present a barrier to team cooperation, cognition, coordination and interdisciplinary exchange. (30) In our study there was a notable sense of solidarity and team spirit amongst the different members of the ED team, who recognised their common purpose in helping to achieve an optimal experience for older people. Although focus groups included members of staff at varying levels of seniority, no evidence of hierarchical power relationships was displayed within the group interactions.

This study builds on the findings of existing international research exploring nurses' perspectives of caring for older adults in the ED. Findings from this study provide a meaningful addition to this literature by incorporating perspectives from other groups of staff members, such as emergency physicians and allied health professionals. Within existing studies, Kihlgren et al (31) interviewed nurses in a Swedish ED and determined that a focus on providing medical procedures threatened the provision of holistic nursing care to patients. Such frustrations were reflected by clinicians from all professional backgrounds in our study. In addition, interprofessional discussions revealed a shared concern regarding the appropriateness of the ED as the optimal location for many older patients. Lennox and colleagues (32) undertook focus groups in an Australasian setting, which identified limitations in provider knowledge, suitability of equipment and environment, and limited time for discharge

planning as barriers to providing high quality care in the ED. Content an7alysis of over five hundred survey comments from ED nurses was undertaken by Boltz et al, (33) revealing the perceived importance of establishing effective communication with older people, having time to perform care, and fostering a safe and enabling environment. These themes were reflected by participants in the focus groups, highlighting their relevance to all those delivering ED care to older people, irrespective of professional identity, in the UK setting.

Staff were cognisant that experiences and subsequent clinical outcomes for older adults are likely to be related and gave examples where the two were linked—this included the provision of adequate drinks (hydration) in preventing delirium. (34) Even though recent efforts have been made to suggest standards of care for older people attending the ED, (16) participants in multiple groups drew comparisons with standards achieved for children within their ED. This demonstrated a perceived sense of inequality for older adults, who were recognised by participants as a vulnerable and a discrete user group. Despite this, participants did not reach a clear consensus on the benefits of bespoke services delivered by sub specialists in ‘geriatric’ EDs, over and above improving access to appropriate and training within their general ED environment. Codesign of services with staff and service users has previously been recognised as beneficial for improving the design of emergency care environments, and this is likely to be an area that would benefit from further investigation specifically for older adults. (35) However, even when perceived to be desirable, whole service reconfiguration may fail to improve either access to care or clinical outcomes and give rise to unintended consequences.(36) Smaller scale quality improvement (QI) initiatives can be initiated at a service provider or departmental level and promote rapid systematic change following

identification of a problem.(37) The QI approach is commonly advocated within emergency medicine (38) and has been demonstrated to improve processes of care and experience for patients attending the ED.(39, 40) Chartier et al states that problems to be addressed by QI methods should be important, occur frequently, demonstrate deficiency, and be realistic to address.(41) To this end, problems identified by ED staff—such as improving access to fundamental care, toileting and environmental optimisation—should be considered high priority. Additionally, the original needs based conceptual framework includes a range of pragmatic suggestions for improving older peoples' ED experience. (19)

Despite participants' best intentions, the focus group discussions revealed a significant gap between the standards of care desired for older patients and what was often achieved. Participants could recall instances of suboptimal care and reported feelings such as guilt and shame. Moral distress is a recognised phenomenon resulting from an inadequate working environment, (42) and has been defined as "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action". (43) Following a meta-ethnography of existing literature exploring emergency and critical care nurses' experiences of moral distress, Arnold (44) conceptualises an 'internal battle' as a metaphor for "moral distress as the nurses described their internal conflicts of conscience with doing what they are told to do versus what they feel is the right thing to do". Sub themes including the presence of challenging environments; feelings of anger, despair and guilt when experiencing moral distress, and effects on personal and professional relationships, were reflected by participants in these focus groups. As moral distress can have sustained effects on both staff wellbeing (45), recruitment and

retention of staff (46), and patient safety (47), mitigating its effects amongst those providing care for older patients in the ED is essential.

7.5.1 Relevance of focus groups findings to development of PREM-ED 65 65

The patient interviews study accompanying this paper has confirmed that older peoples' experiences of ED care can be categorised according to a 'needs based' conceptual framework, with the addition of a new theme of attitudes and values of the team. (Part I) Framework analysis of the focus groups findings further confirms this concept, reflecting and reinforcing themes encountered in existing literature and reported by patients. Moreover, focus groups provide valuable additional insights into the experiences of older adults, delivered through the critical lens of the healthcare professionals. Specifically, older adults were noted, in general, to report positive aspects of their experience during patient interviews. Conversely, the healthcare professionals in the focus groups were forthcoming in revealing perceived weaknesses and vulnerabilities in processes of care. Professionals' candid insights into the challenges faced when caring for older people in the ED are useful in highlighting determinants of suboptimal patient experience. Such vulnerabilities may be measurable and indicate important areas for item development within PREM-ED 65 65. In addition, an important function of the focus groups is to ensure that the views of groups of older adults potentially underrepresented in the interviews, such as very frail patients and those requiring end-of-life care, are also considered when generating a list of candidate items.

7.5.2 Limitations

Our study has several limitations to address. Despite attempting to capture a sample of healthcare professionals from across the multidisciplinary team,

views expressed in our focus groups may not be fully representative of all staff working in the ED. Another limitation is that we observed that participants were more likely to be female, and that physicians were overrepresented compared to other professions. Although we did not overtly observe dominant relationships during the focus groups, it is possible that this may have influenced expression of views by some other participants. Furthermore, our study was conducted in one geographical area of the UK and may not account for regional variations elsewhere or in other countries. Finally, another limitation relates to the nature of qualitative research methods, where the findings are not considered generalisable. Nonetheless, our study provides an addition to the existing body of literature in this area, offers some unique insight into the personal and professional challenges encountered by staff when caring for older people in the ED, and will help inform item generation for PREM-ED 65 65.

7.6 Conclusion

Interdisciplinary focus group discussions with ED staff further confirm the existing needs based framework. This framework provides a basis for conceptualising the determinants of older peoples' experiences of care in the ED. Irrespective of seniority or their professional role, staff prioritise provision of appropriate communication for older people, whilst identifying and meeting individual care needs. Although not always possible, staff have a desire to meet patients' basic human needs within an appropriate physical environment.

In addition, our study has also highlighted important supplementary themes. Specifically, a gap frequently exists between desired standards of care and those delivered in the real-world setting. Importantly, findings demonstrate that

this may result in significant moral distress for providers. By capturing patients' real-world experiences of ED care, PREM-ED 65 may provide a powerful means of identifying such vulnerabilities where they exist, so that improvement can result and these effects mitigated.

Post-Publication Addendum

Contribution to the PREM-ED 65 Study

Focus groups aimed to increase the comprehensiveness of draft items, and mitigate some key limitations of the interviews. For example, it was prospectively acknowledged that recruiting certain patient groups to the interview study would be challenging. This included older adults who were too unwell, living with severe frailty, and had language or literacy barriers or sensory impairments. Furthermore, it was recognised that the 'in situ' approach risked amplifying observational and response biases, such as social desirability bias, known to occur in observational research. Therefore, a prominent concern was that interviews might not yield appropriately critical opinions of ED care or fail to reveal important determinants of experience not obvious to patients. It was also recognised that the single-centre design of the interview study may limit the transferability of findings.

Through giving staff a voice, determinants of experience affecting underrepresented groups could be readily reported and reflected in the draft items. Staff were forthcoming in discussing perceived vulnerabilities in ED care processes for older adults and viewed patient experience through a critical lens. Discussions included the inadequate provision of fundamental care and the effects of the ED environment, crowding and exit block on older adults' experience and their clinical outcomes. Although not the primary focus of the

study, the distress and moral injury reported by these dedicated health professionals, resulting from witnessing and participating in suboptimal care, reinforced the rationale for the PREM-ED 65 study and was a powerful personal motivator to progress the study.

The next chapter details how focus group findings were triangulated with patient interviews and meta-synthesis data to generate items and how a diverse group of stakeholders prioritised the candidate items during a one-day stakeholder workshop.

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Chapter 8 Multiple Stakeholder Workshop

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Contributor Statement
Blair Graham (BG) conceptualised the study, led development of the study protocol, organisation and facilitation of the workshop, data analysis, produced the initial manuscript draft and led revision of all subsequent versions.

Ffion Barham (FB) assisted real-time data collection during the workshop and reviewed the final manuscript.

Jason Smith (JES) and Jos Latour (JML) assisted with the development of the study protocol, delivery of the workshop and contributed to revisions of the manuscript.

JS and JML acted as project supervisors.

The agreed approximated percentage contributions toward the production of this research are: BG 80%, JES 7.5%, FB 5%, JML 7.5%.

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What this chapter adds.

This chapter:

- Demonstrates the ability of the researcher to plan and deliver a multiple stakeholder consensus meeting using a modified nominal groups technique.
- Meaningfully engages multiple stakeholders, including patient and public representatives aged 65 and over, in the development of PREM-ED 65.
- Provides initial comprehensiblity assessment for candidate items, from the stakeholder perspective.
- Presents a prioritised list of candidate items for inclusion in the draft version of PREM-ED 65.

Involving patients and caregivers to develop items for a new patient-reported experience measure for older adults attending the emergency department. Findings from a nominal group technique study

8.1 Abstract

Context

Patient experience is an important component of high-quality care and is linked to improved clinical outcomes across a range of different conditions. Patient Reported Experience Measures (PREMs) are psychometrically validated instruments designed to identify where strengths and vulnerabilities in care exist. Currently, there is no validated instrument available to measure patient experience amongst people aged over 65 years attending the emergency department (ED).

Objective

This paper aims to describe the process of generating, refining and prioritising candidate items for inclusion in a new PREM measuring older adults' experiences in ED (PREM-ED 65).

Design

One hundred and thirty-six draft items were generated via a systematic review, interviews with patients and focus groups with ED staff exploring older adults' experiences in the ED. A 1-day multiple stakeholder workshop was then convened to refine and prioritise these items. The workshop entailed a modified nominal groups technique exercise comprised of three discrete parts-(i) item familiarisation and comprehension assessment, (ii) initial voting and (iii) final adjudication.

Setting and Participants

Twenty-nine participants attended the stakeholder workshop, conducted in a nonhealthcare setting (Buckfast Abbey). The average age of participants was 65.6 years. Self-reported prior experiences of emergency care among the participants included attending the ED as a patient (n = 16, 55.2%); accompanying person (n = 11, 37.9%) and/or as a healthcare provider (n = 7, 24.1%).

Results:

Participants were allocated time to familiarise themselves with the draft items, suggest any improvements to the item structure or content, and suggest new items. Two additional items were proposed by participants, yielding a total of 138 items for prioritisation. Initial prioritisation deemed most items 'critically important' (priority 7-9 out of 9, n = 104, 75.4%). Of these, 70 items demonstrated suitable inter-rater agreement (mean average deviation from the median < 1.04) and were recommended for automatic inclusion. Participants then undertook final adjudication to include or exclude the remaining items, using forced choice voting. A further 29 items were included. Thirty-nine items did not meet the criteria for inclusion.

Conclusions

This study has generated a list of 99 prioritised candidate items for inclusion in the draft PREM-ED 65 instrument. These items highlight areas of patient experience that are particularly important to older adults accessing emergency care. This may be of direct interest to those looking to improve the patient experience for older adults in the ED. For the final stage of development, psychometric validation amongst a real-world population of ED patients is now planned.

Patient and public contribution

Initial item generation was informed using qualitative research, including interviews with patients in the ED. The opinions of patients and members of the public were integral to achieving outcomes from the prioritisation meeting. The lay chair of the Royal College of Emergency Medicine participated in the meeting and reviewed the results of this study.

8.2 Introduction

Patient experience is an important component of high-quality, patient centred care and is associated with improved outcomes for a range of acute conditions including pneumonia, acute coronary syndrome, and asthma.(1-3) Older adults currently account for about a quarter of Emergency Department (ED) attendances and this proportion is likely to increase further given the ageing global population.(4,5) Older adults may have a range of additional care requirements and psychosocial needs when accessing emergency care, compared to younger adults.(6.7) Capturing older adults' experiences of care may identify where vulnerabilities and subsequent opportunities for improvement in the provision of emergency care exists.

Patient reported experience measures (PREMs) are validated, self-reported questionnaires that are directly reported by patients and aim to provide standardised evaluation of individual experiences of care. PREMs differ from Patient Reported Outcome Measures (PROMs), which measure patients' views of their health status, and satisfaction surveys, which measure to what extent care meets patients' subjective expectations.(8,9) Hodson and Roberts suggest that patient satisfaction measures often exhibit a ceiling effect, whereby responses are predominantly positive. Hence, satisfaction surveys may be less likely to identify negative determinants of experience compared to PREMs.(10) This is important, as negative determinants of experience may represent particularly useful areas for performing quality improvement. As such, the use of PREMs to capture patient experiences of emergency care is suggested within the International Federation of Emergency Medicine framework for quality and safety in Emergency Medicine.(11) However, a systematic review of existing PREMs in emergency care determined that there was significant variation in

quality of existing instruments including uncertain validity, reliability and responsiveness.(12) These findings are reflected in a further systematic review of 88 PREMs which reported inconsistent adherence to established criteria for the selection of health instruments.(13,14) Recently, PREMs have been developed to capture older peoples' experience of hospital and community care, although no instrument specific to the ED yet exists.(15,16)

The Patient Reported Experience Measure for patients attending the Emergency Department aged over 65 (PREM-ED 65) aims to address the current gap, by developing and validating a PREM for use in older adults accessing emergency care. The first stage of PREM-ED 65 development aimed to generate a comprehensive understanding of determinants of older adults' experiences of receiving ED care. Initially, a systematic review of qualitative studies was conducted leading to the formulation of a conceptual framework for patient experience in the ED.(17) This framework highlighted the importance of meeting patients' communication, emotional, care, physical/ environmental, and waiting needs. Confirmation of conceptual validity and expansion of the framework was then achieved by undertaking semi-structured interviews with older adults during an emergency care episode, and focus groups with staff responsible for the provision of emergency care to older adults across three EDs.(18,19)

This study aims to describe the process of generating and prioritising a list of suggested items for PREM-ED 65 by involving multiple stakeholders including patient and public representatives, healthcare professionals, and advocates for older adults.

8.3 Materials and Methods

8.3.1 Item Generation

An initial list of candidate items was developed by two researchers (BG and JML) following methodological triangulation of findings from prior studies conducted by the research team. These consisted of a qualitative meta-synthesis of twenty-two studies of patient experience in the ED (17); interviews conducted with twenty-four patients aged over 65 attending the ED (18); and interprofessional focus groups with thirty-seven ED staff.(19) Methodological triangulation describes the use of multiple data sources to study a phenomenon, and is useful to confirm findings, enrich data, and increase overall validity.(20) Therefore, similar findings that occurred across more than one of the studies was identified as particularly relevant as a focus for future measurement of older adults' experiences of ED care. Item generation focused on these recurrent areas. To enrich understanding, excerpts of relevant findings were highlighted, extracted and grouped together. Each group of excerpts was then summarised by the two researchers and translated into a single suggested item for inclusion in PREM-ED 65. To ensure the conceptual underpinnings of the study were respected, the research team discussed the meaning of each item and categorised each item according to one of the five analytical themes: communication, emotional, waiting, care needs, physical & environmental needs, or team attitudes & behaviours.

Following identification, the wording of each of the draft items was subjected to a readability assessment, accomplished by calculating a Flesch Reading Ease (FRE) score. The FRE provides a simple formula for assessing semantic difficulty and is commonly used to interpret the readability of health information.(21) The score signifies how easy a statement is to read on a scale

of 0 (most difficult (postgraduate reading level)) to 100 (least difficult (9-year-old reading level)). Typically, a score of 70 is assumed to be accessible to the average adult.(22) In practical terms, this represents the reading age of an average 12-year-old. Therefore, candidate items with a score of less than 70 at initial assessment were modified by simplifying the vocabulary, syllable count, and structure of the statement. Readability was considered satisfactory when a post-adjustment score of greater than about 70 was attained.

8.3.2 Prioritisation of items

A one-day workshop was held with multiple stakeholders (n=29) to prioritise the list of candidate items. The day was structured using an adaptation of the Nominal Groups Technique (NGT). The NGT provides a recognised method of gaining group consensus using a combination of discussion and voting. A particular advantage of NGT over other consensus methods is that it can provide a prompt result.(23,24) The workshop program consisted of (i) item familiarisation and comprehension assessment, (ii) initial voting, and (iii) final adjudication (Figure 8.1; overleaf).

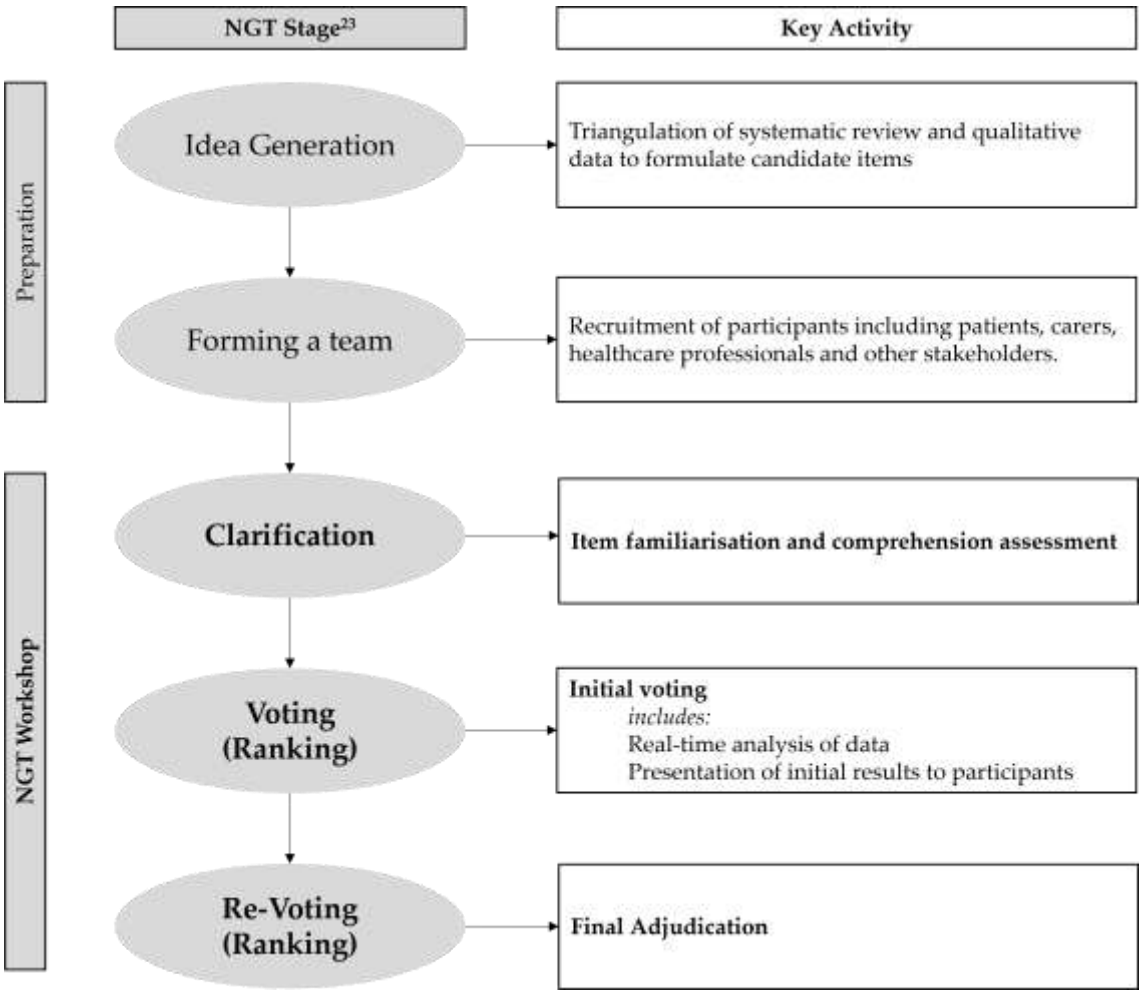

Figure 8.1 Flow chart summarising the Nominal Groups Technique.

A range of approaches was used to recruit a convenience sample of patients, carers, health professionals and relevant third-party stakeholders. This included e-mail advertisements to members of patient groups affiliated to local hospitals, clinical research departments, and the ambulance service. Information posters were also displayed in three participating EDs. In addition, the lead researcher (BG) promoted the workshop to members of the public at a research engagement event during September 2019, directly approaching stakeholders including relevant charities advocating for older adults (Age UK, Healthwatch) and the lay committee of the Royal College of Emergency Medicine. Upon

receipt of an initial expression of interest, potential participants were emailed a formal electronic invitation consisting of participant information sheet, written consent form and registration form. Participants were issued with joining instructions on receipt of their registration form.

The workshop was held in the conference facilities of a non-healthcare setting (Buckfast Abbey, Devon, UK), in December 2019. No incentive was offered but refreshments including lunch were provided, and participants' travel expenses were reimbursed.

The workshop programme was designed to minimise both participant burden and the potential for respondent fatigue during prioritisation exercises. It was recognised that some participants would be living with frailty or disability and provisions for ease of access was ensured during planning. The pace of sessions was monitored by five facilitators distributed throughout the room, and extended breaks were provided.

The study received prospective ethical approval from the University of Plymouth Faculty of Health Research Integrity & Ethics Committee (1920/1173).

8.3.3 Item familiarisation and comprehension assessment

For the first workshop exercise, participants were asked to provide a comprehensibility assessment of items. For each item, participants were asked to determine whether the item was (i) 'easy to read' (Yes/ No) and (ii) 'easy to understand' (Yes/ No). Participants were invited to suggest new items if any gaps were identified.

8.3.4 Initial Voting

The second workshop exercise was initial prioritisation. During this voting exercise, participants were presented with each item and asked to individually vote on the perceived importance for inclusion in PREM-ED 65. This was accomplished using a 9- point interval scale; priorities 1—3 were labelled “less important”, priorities 4—6 as “Important, but not critical”, and 7—9 were “Critically Important”.

The median priority and measure of interrater agreement (Absolute Deviation from the Median (ADM)) was calculated for each item.23,25 The Mean ADM (MADM) across all items was then calculated, and individual items with an ADM greater than 50% of the mean value were deemed as having insufficient inter-rater agreement. This was used to determine whether the item was eligible for inclusion, exclusion or final adjudication in a second round of voting (Table 8.1). Data collection and analysis for initial voting was accomplished in real-time by members of the research team (FB, BG) using a pre-formulated instrument developed in Microsoft Excel.

Table 8.1 Outcomes criteria for the initial NGT voting.

Priority to include item in PREM-ED65 (median score/ item)	Inter-rater agreement (IRA) (MADM)	Outcome
7—9 (Critical)	Sufficient	Include item
3—6 (Important, but not Critical)	Insufficient Any Insufficient	Final Adjudication
1—3 (Not Important)	Sufficient	Exclude item

MADM = Mean Absolute Deviation from the Median; Insufficient IRA threshold= MADM >50%

8.3.5 Final Adjudication

The third workshop exercise was final adjudication. This consisted of dichotomous voting for items which did not meet inclusion or exclusion criteria during the first round. During this exercise, participants were presented with the item and requested to vote to either ‘include’ or ‘exclude’ the item. To facilitate inclusion of only those items for which there was clear positive consensus, a majority threshold of at least 75% was prospectively agreed to determine the criteria for inclusion. This threshold is comparable with other studies.(26,27)

8.3.6 Participant evaluation

Participants were invited to complete an optional 10-item anonymised paper-based survey at the end of the workshop. This aimed to evaluate overall satisfaction with the NGT process, ability to meaningfully participate, and invite suggestions for future improvements.

8.4 Results

8.4.1 Initial item Generation

One hundred and thirty-six suggested items were derived following triangulation of findings from the meta-synthesis, interviews with patients, and focus groups with ED staff. Compared to the original conceptual framework, candidate items most frequently aligned to the themes of communication needs (33 items), care needs (33 items) and emotional needs (27 items). A smaller number of items concerned waiting needs (18 items), physical & environmental needs (15 items) and team attitudes & values (10 items).

Each of the initial 136 suggested items was tested against the FRE score. The median FRE score for the 136 items pre-adjustment was 67.3 (Range 11—100), equating to a reading age of about 15 years. Items with a score of less than 70 (n=68) were individually adjusted with the intention of increasing

readability. Adjusted items were then reviewed by the researchers to ensure meaning and construct validity was maintained. Following adjustment of items, the median FRE score of the participants increased to 80.3 (Range 66—86). The initial list of candidate items is available in Supplementary Material SM8.1.

8.4.2 Workshop Participants

Twenty-nine participants attended the consensus workshop (Table 8.2). The median age of professional participants was 55 years (Range 32—58 years) and lay participants was 73 years (Range 63—82 years). Eighteen participants (62.1%) were female. The majority were from a managerial or professional background (72.4%; n=21). Participants were surveyed on any previous engagement with emergency care. Twenty-seven participants (93%) had experience of emergency care either as a patient (n=16; 55.2%) and/or as an accompanying person (n=11; 37.9%). A further seven (24.1%) participants reported experiences as a health professional, and eight (27.6%) in another professional role, e.g., as a third sector representative from a patient advocacy organisation. Other experiences (n=14; 48.2%) included voluntary positions in the ED, with affiliated charities, and research 'patient and public involvement' group members. Additionally, eleven (37.9%) participants reported currently receiving care for at least one long term health condition. Participant characteristics are summarised in Table 8.2 (overleaf).

Table 8.2 Participant Characteristics (Stakeholder Workshop)

Characteristic	n (%)
Gender	
Male	11 (37.9)
Female	18 (62.1)
Age	
<35 years	1 (3.4)
36-55 years	4 (13.8)
56-65 years	4 (13.8)
66-75 years	15 (51.7)
76-85y	3 (10.2)
ND	2 (6.8)
Median Age	71 years
Professionals	55 years
Lay participants	73 years
Occupation	
Not Specified	4 (13.8)
Unskilled or Semi- Skilled	0 (0)
Skilled or Technical	1 (3.4)
Professional or Managerial	21 (72.4)
Voluntary/ Honorary Role	3 (10.2)
Personal Experience of ED care[a]	
Yes	
As Patient	29 (100.0)
As Accompanying person	16 (55.2)
As Health professional	11 (37.9)
As Third Sector worker	7 (24.1)
Other	8 (27.6)
	14 (48.2)
Long-term condition	
Yes	
No	11 (37.9)
Not Disclosed	14 (48.2)
	4 (13.8)

[a]Sum of responses does not equal 100% as participants were asked to report all experiences of emergency care.

8.4.3 Item familiarisation and comprehension assessment

To reduce the burden on participants, the 136 items were divided between four groups (34 items/ group). Each group was facilitated by either a member of the study team or a volunteer who was a final year medical student. All facilitators received prior training in the study protocol and NGT method. Group members were encouraged to assess allocated items for comprehension using a 'think aloud' technique, led by a group facilitator.(28) All items were retained and were assessed as being easy to comprehend. Two additional items were added and agreed between participants, both following a large group discussion relating to the perceived importance of recognising disabilities in the ED (Quotations 1 & 2).

"My disability did not get in the way of my care."

"Staff recognised my hidden disability"

Quotations 1 &2: Additional items suggested by participants

As a result, a final list of 138 items was generated.

8.4.5 Initial Voting

The final list of 138 items underwent initial prioritisation. Each workshop participant rated the priority of the each of the items using the predetermined 9-point scale.

The median priority assigned to items was 8 out of 9 (Range 1—9, IQR=6). Most items were considered 'critically important' (Priority 7—9; n=104; 75.9%). Only four items (3.1%) were considered 'less important' (Priority 1—3). The remaining items were 'important but not critical' (Priority 4—6; n=29; 21.1%).

Items meeting the threshold for satisfactory interrater agreement were eligible for automatic inclusion or exclusion in the first round. This was calculated as <50% of the overall mean average deviation from the median (MADM, <1.04).

Real time data analysis of first round prioritisation data yielded 70 (50.7%) items meeting criteria for automatic inclusion in PREM-ED 65 (Priority 7—9 and MADM <1.04). By way of example, the highest ranking ten items are presented in Table 3. All remaining items (n=68, 49.2%) required further voting; this included the four items identified as less important, as interrater agreement was insufficient to justify automatic exclusion.

Table 8.3 Top 10 ranking items included via Initial Prioritisation

(presented in rank order based on median priority and then inter-rater agreement (MADM).

Item	Median Priority	MADM
Staff who were learning were always supervised.	9	0.11
The pain relief medicine worked well.	9	0.19
I could trust the A&E staff	9	0.3
Pain relief medicine was brought to me quickly	9	0.3
Staff were thorough and paid attention to the finer details	9	0.33
Someone asked me about my views on being revived should my heart stop	9	0.44
The A&E team were respectful and polite	9	0.46
My disability did not get in the way of my care	9	0.46
I felt like staff had reached the right diagnosis	9	0.48
Staff undertook checks to make sure my skin wasn't at risk of damage	9	0.48

8.4.6 Item final adjudication

The 68 remaining items were subjected to final adjudication. Of these, 39 (57.3%) items received insufficient favourable votes, resulting in their suggested exclusion from the PREM-ED 65. The lowest ranked 10 items are presented in Table 4. Notably, all four of the items originally prioritised as 'less important' were excluded during this round (average proportion of 'favourable' votes for these items, 32.4%).

Table 8.4 Bottom 10 ranking items, excluded via final adjudication.

Item	Median Priority	MADM	Favourable Votes, %
Members of the team such as house- keeping staff and cleaners were helpful	7	1.56	30
Members of the team appeared well rested	6	1.59	30
Staff had a good sense of humour.	4	1.68	30
I was given a say in whether I was admitted	3	1.93	30
I felt in control of my own situation	6	1.07	22
Waiting in A&E is not too frustrating	5	2.11	22
I was aware of how the urgency of my problem compared to other patients also in A&E.	4	2.11	15
Staff recognised if I had a special event such as a birthday	2	1.82	11
The department was not too busy or hectic	5	2.15	0
I could chat or speak with other patients	1	1.11	0

8.4.7 Final prioritised list of candidate items for inclusion in PREM-ED 65

An additional 29 items were prioritised for inclusion because of final adjudication. Hence, a total of 99 out of 138 items remained eligible for inclusion in the instrument, representing 71.7% of the original items.

The finalised full prioritised list of included and excluded items are presented in Supplementary Material SM8.2.

8.4.8 Participant evaluation

Twenty-seven out of the original twenty-nine participants (93.1%) returned completed evaluation surveys. Overall satisfaction with the NGT workshop was high among all groups, extending to the quality of information provided during the day (100% 'Good'/ 'Very Good'), perceived relevance of the day to prioritising experience in the ED (100% 'Agree'/ 'Strongly Agree'), and ability to engage/ 'have an adequate say' during the day (100% 'Agree'/ 'Strongly Agree').

8.5 Discussion

This paper describes the process of generating and prioritising a list of candidate items for the PREM-ED 65. There is currently no accepted gold standard for generating or prioritising items for inclusion in either PROMs or PREMs, despite this being an essential step to ensuring face validity, content validity and representativeness of items to the target population. Approaches include reviews of existing similar instruments, generation of expert consensus, interviews, use of focus groups, and patient/ public involvement strategies such as utilisation of special interest groups.(29- 32) Previous studies have confirmed successful use of nominal groups technique both among populations of older people and multiple stakeholders.(33- 37)

PREM-ED 65 represents the first instrument to attempt to measure older peoples' experiences of ED care. We defined our intended PREM user group based on numeric age, as this provides the single most convenient and accessible inclusion criteria to facilitate routine usage of the PREM amongst older adults in ED settings. An age exceeding 65 years is commonly used to identify older people in the UK setting.(38) A mixed-methods approach has been employed for generation and prioritisation of items. This aims to produce an item set which captures all potentially relevant determinants of experience for the intended population. Methodological triangulation of the literature, and primary qualitative data from both patient interviews and professional caregivers, succeeded in generating a comprehensive list of suggested items that is well aligned to the original 'needs based' conceptual framework of ED patient experience. Presentation of the items to multiple stakeholders confirmed comprehensibility and indicated that the original list was likely to be representative of older peoples' experiences in the ED. The emergence of two additional items, through group discussions, ensures that PREM-ED 65 will measure recognition of disabilities amongst older adults accessing emergency care. This may be important, particularly as the prevalence of disability increases with age. For example, self-reported disability among the UK population in 2022 was 9% in childhood, rising to 59% in adults aged over 80 years.(39) Specific to emergency care, Tanderup et al included the presence of disability as a discrete geriatric condition when evaluating characteristics of older adults attending an ED in Denmark. In this study, the presence of one or more geriatric conditions was associated with poorer health outcomes following ED attendance.(40) Furthermore, improving transitions from ED care to

community settings may prevent functional decline and increased disability that occurs in older adults following ED attendance.(41,42)

Our experience is that conducting NGT amongst a population of older adults is an achievable and rewarding means to effectively prioritise items for inclusion within a PREM. Using this approach it was possible to assess and prioritise all items within a single day. To this end, NGT may be more efficient than other consensus building methods, most notably the Delphi method, where ongoing participant engagement is required during multiple asynchronous rounds of voting, often spanning months in duration. This requires high levels of participant engagement throughout the process, to avoid attrition.(43) Furthermore, NGT may yield highest levels of accomplishment and satisfaction, compared to either Delphi method or unstructured groups.(44) This is reflected in the high satisfaction reported amongst participants in this study, as reported through post-event feedback.

For the NGT, first round prioritisation revealed that most candidate items were deemed of ‘critical’ importance. Therefore, the method was effective in identifying very high priority items for inclusion in the instrument—i.e., those assigned 7—9 out of 9 and meeting the predetermined criteria for interrater agreement. The highest-ranking items related to themes including supervision of trainees, effectiveness of pain management, trustworthiness, and communication skills of caregivers. Specific to older adults, participants agreed that assessment of tissue viability (“Staff undertook checks to make sure my skin wasn’t at risk of damage”) was of critical importance. The latter is reflected in recent literature, highlighting that prolonged ED length-of-stay is independently associated with the development of hospital acquired pressure

sores. In the current international context, where ED crowding and prolonged length-of-stay is the norm, adequate tissue viability assessment and pressure sore prevention during the ED stay is essential.(45) Additionally, the importance of many of the other themes are prominently recognised in the literature. For example, stakeholders within this study were almost unanimous in emphasising the importance of clinical supervision for trainees in ensuring an optimal experience. Indeed, supervision of trainees in the ED has been recognised as essential to both ensuring patient safety, and facilitating clinicians' professional development.(46) In relation to pain management, older people may be more susceptible to receiving inadequate pain relief in the ED, compared to younger patients.(47)

Although the first round of voting was very effective in highlighting items for inclusion, it was not possible to exclude any item using this initial round, and it was therefore necessary to proceed to a round of dichotomous voting. Through the application of forced choice, it was possible to identify 38 items for exclusion. Examples of themes related to the lowest ranking items related to social communication (e.g., "I could chat or speak with other patients"), perceptions of the ED environment, and patient empowerment.

Exclusion of unnecessary, unhelpful, or otherwise redundant candidate items represents an important stage in the development of user- friendly health surveys. It is generally recognised that overly lengthy or cumbersome health surveys negatively affect participant engagement, potentially contributing to non-response bias, incomplete responses, and satisficing to 'reduce the cognitive burden of choosing'.(48, 49) Each of these factors may adversely affect the validity of results, potentially compromising instrument credibility.(50)

Furthermore, shortened questionnaires have been shown to effectively measure experiences of care.(51) The NGT has provided an initial means of reducing items for PREM-ED 65.

To validate the psychometric properties of PREM-ED 65, a quantitative study will be conducted with a population of ED patients. This study will aim to confirm how each item performs in a real-world setting by assessing participant engagement, floor/ceiling effects, and differential validity of the items. Any items with low engagement or problematic validity will be removed to reduce the length of the questionnaire. The remaining items will undergo exploratory factor analysis to confirm structural validity. Additionally, the study will assess the internal consistency of measurement scales and test-retest reliability. The goal is to make PREM-ED 65 suitable for assessing the experiences of a wide range of older adults in the ED.

8.5.1 Limitations

The generation of candidate items from primary literature and qualitative data is based on subjective interpretation. Participant engagement in the workshop activities was adequate throughout, and the aims achieved.

We utilised multiple recruitment channels to include opinions from various stakeholders. We were mindful of promoting inclusivity among older adults in attendance by carefully selecting the venue and workshop program. However, we acknowledge the limitations of convenience sampling. Notably, all participants in our study were White British and mostly from higher socioeconomic backgrounds (professional/managerial occupations). This apparent lack of diversity is reflective of the demography of the study locality, but nonetheless may affect the generalisability of results to ethnic minority

groups, as well as individuals with limited literacy, and those from lower socioeconomic backgrounds. As an inclusive patient-public workshop, we did not measure participants' level of frailty or use this as an inclusion criterion for the study; however, we recognised the possibility that severely frail people may be under-represented in our sample. We aimed to mitigate this potential bias by including participants who were carers or professional advocates for people living with severe frailty, such as the manager of a dementia care centre, an older peoples' falls service lead, nursing and allied health professionals. As it remains important for PREM-ED 65 to capture the experiences of the diverse population of older adults attending the emergency department, recruitment of a representative cross-section of older adults attending the ED will be prioritised during psychometric validation.

In our study, initial voting did not eliminate items. We suggest that actively encouraging nuanced discussion between participants, during the clarification stage of the NGT, may help enable differentiation of items earlier in the process. The lower priority assigned to some aspects of patient experience during final adjudication is incongruent with importance assigned within the literature, or by interview or focus group participants. Notably, workshop participants deprioritised items related to social interactions, shared decision making and physical comfort within the ED waiting room. This may be related to the sampling issues already discussed, but also potentially the phenomenon of rosy retrospection, which describes the cognitive tendency to both anticipate events and view the past more positively than was encountered.(52) As such, it is possible that some aspects of experience—such as the comfort of waiting room chairs, or friendliness of staff—assume a much greater importance whilst 'living'

an ED experience, as opposed to abstracting an experience during a workshop conducted in a non-healthcare setting.

General concerns related to group-based idea generation include individual dominance, ‘groupthink’, where a desire for group harmony impedes the generation of new ideas, or ‘peer pressure’, where fear of criticism may have a similar effect. Nominal group technique effectively aims to limit these phenomena, by incorporating a combination of independent ideas generation, group discussion, and individual voting. Specifically, nominal groups discourages a ‘single train of thought’ as might occur in unstructured group discussions.(53) Crucially, all participants in this study reported that they felt able to have an adequate say during the course of the workshop.

8.6. Conclusions

This paper describes a straightforward process for generating and prioritising candidate items as part of the development of an outcome measure instrument. The techniques described may be applicable to the development of other PREMs, PROMs and health surveys. The nominal group technique is both an effective and efficient method for identifying and prioritising critically important items for an instrument. However, forced choice adjudication may be necessary as a means of confirming items that are potentially redundant or unnecessary.

Findings from this study highlight areas of patient experience that are likely to be particularly important to older adults when attending the ED. In particular, the themes contained within the highest priority candidate items may be of direct interest to clinicians and policymakers concerned with improving the experiences of older adults accessing emergency care. In general, ongoing research is required to confirm the most reliable means to generate and

prioritise items for inclusion in patient reported measures. This is necessary to ensure optimum face validity, content validity, and reliability of all future instruments. As for PREM-ED 65, the final stage of development will consist of psychometric testing amongst a population of older adults attending the ED.

Post-publication addendum

Contribution to the PREM-ED 65 study

Triangulation of data from the qualitative meta-synthesis, patient interviews, and staff focus groups generated 136 draft items. It was recognised that, if translated directly, the length of the resulting PREM-ED 65 measure would be cumbersome and impractical for administration to ED patients. Therefore, the essential function of the nominal groups workshop was to prioritise and rationalise the items to a more manageable number. In addition, the stakeholders' assessment of each item confirmed comprehensibility and content validity.

The two-round voting process confirmed that participants deemed most draft items important to measuring older adults' ED experience. Nonetheless, participants were able to reach a consensus on some items that were deemed unnecessary and reduce the overall number by one-third to a final total of 99 items. Whilst representing a somewhat more manageable length for the draft instrument, the next chapter details how items underwent further scrutiny and some reduction using detailed cognitive interviews with a smaller group of seven stakeholders.

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Supplementary Material

SM 8.1 Candidate Items (by analytical theme)

a. Candidate items related to *communication needs*

1. Staff spoke to me as a person
2. Staff were kind
3. Staff introduced themselves by name
4. The staff spent enough time speaking with me
5. Staff made the right amount of eye contact.
6. Staff informed me if something did not go to plan
7. Staff ensured that I had heard what they had said
8. Staff met my cultural and language needs.
9. Staff involved my relatives or carers as much as I wanted.
10. I understood what was being said
11. Staff checked that I understood what they had said.
12. Leaflets or pictures were used to help me understand.
13. Staff explained everything in enough detail.
14. Staff explained the possible outcomes of tests
15. Staff let me know what the diagnosis might be.
16. Staff understood my point of view.
17. I received regular updates.
18. Information helped to reassure me.
19. I was informed whether I was likely to be admitted or discharged home
20. Staff helped me feel sure that I would be able to cope at home.
21. Staff told me when I should be well enough to get back to the things I normally do in life.
22. Staff told me when I should be well enough to get back to my normal level of mobility.
23. I did not have to repeat myself to many different staff.
24. I could ask the questions I wanted
25. Answers to my questions were clear
26. Staff gave me clear discharge instructions
27. Staff let me know when to return if things get worse.
28. Staff gave me a leaflet or information sheet to take home.
29. Staff gave me a discharge letter to give to my GP
30. Staff had a good sense of humour.
31. Staff checked how I would like to be addressed
32. Staff were friendly and cheerful.
33. I could chat with other patients if I wanted.

b. Candidate items related to *emotional needs*

34. I did not feel like I was treated differently because of age
35. Staff let me know how sick I was
36. I felt that staff understood my worries and concerns.
37. I felt like I was treated with respect
38. I felt like I was safe during my A&E stay
39. I had confidence in the care I received
40. I was able to make my own decisions about my care
41. Staff recognised if I had a special event such as a birthday
42. I was encouraged to walk around if I wanted to
43. I was given a say in whether I was admitted or discharged
44. Staff informed me why I was being admitted
45. I felt able to make my own choices about my care

46. I was helped to feel in control of my own situation.
47. Staff made sure I got exactly what I needed in A&E.
48. I did not feel lonely during my time in A&E
49. I did not feel vulnerable during my A&E stay
50. My relatives or carers did not get in the way of my care.
51. Staff asked about my ideas, my concerns and my expectations of care.
52. I was given a call bell or other means of summoning help
53. Being in A&E was stressful for my relatives or carers.
54. Staff reassured me.
55. Staff were thorough and paid attention to the finer details
56. Staff cared for my emotional needs.
57. I did not leave A&E feeling frightened or scared about my condition.
58. I could trust the A&E staff
59. I felt like staff had reached the right diagnosis
60. I felt safe to be discharged

c. Candidate items related to *care needs*

61. I was asked how much pain I was in
62. My pain levels were checked more than once
63. Pain relief medicine was brought to me quickly
64. The pain relief medicine worked well for me.
65. I was told why I needed medicine and about side effects.
66. I was given some choice about the type of medicine to take, such as tablets or a drip
67. Staff made effort to relieve my shortness of breath
68. Staff made effort to relieve my other symptoms
69. Staff undertook checks to make sure my skin wasn't at risk of damage
70. Staff explained what is likely to be causing my symptoms
71. Staff took notice of my long term conditions
72. Staff told me whether I could take my usual medications whilst in A&E
73. Someone asked me for my views on life support treatment should my condition get worse
74. Someone asked me about my views on being revived should my heart stop
75. My dignity was always protected
76. I was helped to the toilet
77. Staff were quick to respond when I asked for help with the toilet.
78. Staff let me know why I needed a procedure.
79. Staff explained what they were doing to me.
80. Staff asked for my consent before they did anything
81. Staff explained what I was required to do during a procedure
82. Staff explained the risks of tests and procedures
83. Staff let me know in advance when a procedure was likely to be painful or cause me discomfort
84. The pain I felt during procedures was about the same, or was less, than I was initially told
85. Staff who were learning were always supervised.
86. I did not have to wait too long for tests or procedures
87. I was monitored and observed for the right amount of time
88. I could see usually see a clock if I wanted to check the time
89. There were enough windows and natural light in A&E
90. Staff were quick to respond to my problems
91. Staff were attentive to my needs
92. Staff were competent
93. Staff informed me when they were unsure

d. Candidate items related to *waiting needs*

94. I had adequate privacy during my A&E stay
95. I felt safe and secure whilst waiting
96. I did not feel intimidated by the other patients in A&E
97. There were enough seats in the waiting room to go around
98. I was not required to wait in the corridor for a long period
99. I was looked after whilst waiting
100. I was aware of how busy the rest of the A&E department was, whilst waiting
101. Waiting in A&E was not too frustrating
102. I was given an estimate of how long I would have to wait when I was seen at triage.
103. There were enough staff on duty
104. The department was not too busy or hectic
105. The waiting room chairs were comfortable
106. Reception desks were easy to find
107. There were activities for me to do whilst waiting so that I did not become bored.
108. Staff kept me informed about waiting times
109. I was aware of how the urgency of my problem compared to other patients also in A&E.
110. I felt like I was a priority
111. The waiting room was calm, relaxed and pleasant

e. Candidate items related to *physical and environmental needs*

112. I was offered something to drink or eat
113. I had ready access to drinking water
114. I was informed whether I could eat or drink
115. It was easy to find the toilets
116. My bed or trolley was comfortable
117. My bed did not cause me physical problems such as back pains or sore skin
118. I was offered additional clothes to go home in
119. I was offered pillows and blankets
120. The A&E department was clean and tidy
121. The temperature in A&E was just about right
122. Staff did not have to spend time looking for pieces of equipment.
123. Signs were easy to read
124. The A&E department was not too noisy
125. The A&E department was not too bright
126. I was able to get some sleep if I desired

f. Candidate items related to *perceptions of the A&E team*

127. The whole team displayed kindness towards me
128. The A&E team is helpful and acted in a professional way
129. The A&E team were respectful and polite
130. Members of the team such as house keeping staff and cleaners were helpful
131. Members of the team appeared well rested
132. Staff wore uniforms and / or badges which made it easy to identify their role.
133. I was given the name of a key member of staff when I arrived in the department
134. It was clear to me that the A&E team communicated well with each other
135. The team worked in a way that was well organised
136. My A&E journey was efficient

SM 8.2 Results from Stakeholder Prioritisation

a. **Items included via Initial Prioritisation (presented in rank order based on median priority and inter-rater agreement (MADM).**

	Initial Prioritisation		Adjudication
Item	**Median Priority**[a]	**MADM**[b]	Favourable Votes, %
Staff who were learning were always supervised.	**9**	**0.11**	-
The pain relief medicine worked well.	**9**	**0.19**	-
I could trust the A&E staff	**9**	**0.3**	-
Pain relief medicine was brought to me quickly	**9**	**0.3**	-
Staff were thorough and paid attention to the finer details	**9**	**0.33**	-
Someone asked me about my views on being revived should my heart stop	**9**	**0.44**	-
The A&E team were respectful and polite	**9**	**0.46**	-
My disability did not get in the way of my care	**9**	**0.46**	-
I felt like staff had reached the right diagnosis	**9**	**0.48**	-
Staff undertook checks to make sure my skin was not at risk of damage	**9**	**0.48**	-
I did not feel intimidated by the other patients in A&E	**9**	**0.48**	-
Staff did not have to spend time looking for equipment	**9**	**0.52**	-
Staff made effort to relieve my shortness of breath	**9**	**0.56**	-
Staff were quick to respond when I asked for help with the toilet	**9**	**0.56**	-
My dignity was always protected.	**9**	**0.59**	-
There were enough staff on duty	**9**	**0.59**	
My bed or trolley was comfortable	**9**	**0.59**	-
I was given a call bell or other means of summoning help	**9**	**0.59**	-
I understood what was being said	**9**	**0.61**	-
Staff helped me feel sure that I would be able to cope at home.	**9**	**0.61**	
Staff let me know when to return if things get worse.	**9**	**0.61**	-
Staff told me whether I could take my usual medications whilst in A&E	**9**	**0.63**	-
Staff were competent	**9**	**0.64**	-
Staff explained the risks of tests and procedures	**9**	**0.64**	-
Staff let me know in advance when a procedure was likely to be painful or cause discomfort	**9**	**0.64**	-
I had confidence in the care I received	**9**	**0.64**	-
Staff asked for my consent before they did anything	**9**	**0.66**	-
Staff spoke to me as a	**9**	**0.75**	-
Staff ensured that I had heard what they had said	**9**	**0.75**	-
The A&E team is helpful and acted in a professional way	**9**	**0.78**	-

Someone asked me for my views on life support treatment should my condition get worse	**9**	**0.85**	-
Staff gave me a discharge letter to give to my GP	**9**	**0.86**	-
I had adequate privacy during my A&E stay	**9**	**0.89**	-
My A&E journey was efficient	**9**	**0.96**	-
Staff were friendly and cheerful.	**9**	**1**	-
Staff identified my hidden disability	**9**	**1**	-
The whole team displayed kindness towards me	**9**	**1.04**	
Staff were kind	**9**	**1.04**	-
Staff met my cultural and language needs.	**8.5**	**1**	-
Staff gave me clear discharge instructions	**8**	**0.58**	-
Staff let me know why I needed a procedure.	**8**	**0.59**	-
Staff explained everything in enough detail.	**8**	**0.68**	-
Staff took notice of my long term conditions	**8**	**0.74**	-
I was asked how much pain I was in	**8**	**0.78**	-
Staff informed me when they were unsure	**8**	**0.79**	-
Staff informed me why I was being admitted	**8**	**0.79**	-
My relatives or carers did not get in the way of my care.	**8**	**0.81**	-
I was able to make my own decisions about my care	**8**	**0.82**	-
My pain levels were checked more than once	**8**	**0.85**	-
Staff made effort to relieve my other symptoms	**8**	**0.85**	-
I was monitored and observed for the right amount of time	**8**	**0.85**	-
Staff introduced themselves by name	**8**	**0.86**	-
I was helped to the toilet	**8**	**0.93**	-
I was told why I needed medicine and about side effects	**8**	**0.96**	-
Staff were quick to respond to my problems	**8**	**0.96**	-
I received regular updates	**8**	**0.96**	-
Staff explained the possible outcomes of tests	**8**	**1**	-
Staff cared for my emotional needs.	**8**	**1**	
I felt safe to be discharged	**8**	**1.04**	-
Staff were attentive to my needs	**8**	**1.04**	-
Signs were easy to read	**8**	**1.04**	
The pain I felt during procedures was about the same, or was less, than I was initially told	**7**	**0.78**	-
Staff asked about my ideas, my concerns and my expectations of care.	**7**	**0.85**	-
Staff informed me if something did not go to plan	**7**	**0.86**	
Staff made sure I got exactly what I needed	**7**	**0.89**	-
The temperature in A&E was about right	**7**	**0.93**	-
Staff understood my worries and concerns	**7**	**0.93**	-
Staff reassured me	**7**	**1**	
Staff explained what they were doing to me	**7**	**1**	-
I could ask the questions I wanted	**7**	**1.04**	

b. **Items included via final adjudication (presented in rank order based on proportion of favourable votes (threshold ≥75%))**

	Initial Prioritisation		**Adjudication**
Item	Median Priority[a]	MADM	**Favourable Votes, %**
I felt like I was safe during my A&E stay	9	1.07	**100**
My bed did not cause me physical problems such as back pains or sore skin	8	1.11	**100**
I felt like I was treated with respect	8	1.11	**100**
I was informed whether I could eat or drink	8	1.33	**100**
The A&E department was clean and tidy	8	1.48	**100**
I had ready access to drinking water	8	1.59	**100**
I was looked after whilst waiting	7	1.26	**100**
I was offered pillows and blankets	7	1.44	**100**
Staff kept me informed about waiting times	6	1.41	**100**
I did not feel lonely during my time in A&E	9	1.11	**96**
Staff explained what I was required to do during a procedure	9	1.30	**96**
Staff checked that I understood what they had said	8	1.11	**96**
Staff involved my relatives or carers as much as I wanted	7	1.32	**96**
It was easy to find the toilets	7	1.51	**96**
I was able to get some sleep if I desired	5	1.56	**96**
Staff spent enough time speaking with me	7	1.21	**93**
I was offered additional clothes to go home in	7	1.40	**93**
Staff let me know what the diagnosis might be.	7.5	1.29	**89**
Staff understood my	7	1.25	**89**
Staff let me know how sick I was	7	1.43	**89**
I felt safe and secure whilst waiting	7	1.64	**89**
I did not feel vulnerable during my A&E stay	7	1.56	**85**
The waiting room was calm, relaxed and pleasant	5	1.19	**85**
Staff checked how I would like to be addressed	7	1.18	**81**
Reception desks were easy to find	7	1.37	**81**
Answers to my questions were clear	7	1.46	**81**
I was given some choice about the type of medicine to take, such as tablets or a drip	7	1.22	**78**
The A&E department was not too bright	6.5	0.9	**78**
I felt like I was a priority	6	1.48	**78**

Items excluded via final adjudication (presented in rank order based on proportion of favourable votes (threshold <75%))

Item	Median Priority[a]	MADM	**Favourable Votes, %**
I did not feel like I was treated differently because of age	8	1.18	**74**
Information helped to reassure me	8	1.57	**74**
I felt able to make my own choices about my care	8	1.54	**70**
I did not have to wait too long for tests or procedures	6	1.04	**70**

I did not leave A&E feeling frightened or scared about my condition	6	1.44	**70**
Being in A&E was stressful for my relatives or carers	6	1.78	**70**
I was given a say in whether I was admitted or discharged	3	1.93	**70**
Staff explained what is likely to be causing my symptoms	9	1.19	**67**
I was not required to wait in the corridor for a long period	8	1.30	**67**
I could see usually see a clock if I wanted to check the time	6	1.70	**67**
There were enough seats in the waiting room	7	1.19	**56**
The team worked in a way that was well organised	7	2.04	**56**
The A&E department was not too noisy	6	1.26	**56**
I was given an estimate of how long I would have to wait when I was seen at triage.	5	1.93	**52**
The A&E team communicated well with each other	7	1.22	**51**
Leaflets or pictures were used to help me understand	7	1.36	**51**
Staff gave me a leaflet or information sheet to take home.	6	1.46	**51**
There were enough windows and natural light in A&E	4	1.81	**51**
Staff made the right amount of eye contact.	6	0.92	**44**
I was offered something to drink or eat	3	2.11	**44**
I was encouraged to walk around if I wanted to	4	2.14	**41**
Staff told me when I should be well enough to get back to my normal level of mobility.	6	1.61	**37**
I was aware of how busy the rest of the A&E department was, whilst waiting	6	1.78	**37**
The waiting room chairs were comfortable	5	1.89	**37**
There were activities for me to do whilst waiting	4	1.96	**37**
Staff wore uniforms and / or badges which made it easy to identify their role.	7	1.67	**33**
I did not have to repeat myself to many different staff.	6	1.32	**33**
Staff told me when I should be well enough to get back to the things I normally do in life.	5.5	1.89	**33**
I was given the name of a key member of staff when I arrived in the department	4.5	2.11	**33**
Members of the team such as house-keeping staff and cleaners were helpful	7	1.56	**30**
Members of the team appeared well rested	6	1.59	**30**
Staff had a good sense of humour.	4	1.68	**30**
I was informed whether I was likely to be admitted or discharged home	3	1.93	**30**
I was helped to feel in control of my own situation	6	1.07	**22**
Waiting in A&E was not too frustrating	5	2.11	**22**

I was aware of how the urgency of my problem compared to other patients also in A&E.	4	2.11	**15**
Staff recognised if I had a special event such as a birthday	2	1.82	**11**
The department was not too busy or hectic	5	2.15	**0**
I could chat with other patients if I wanted	1	1.11	**0**

Chapter 9 Cognitive Interviews

What this chapter adds

This Chapter:

- Outlines the rationale for performing cognitive interviews as a final step to development of the draft version of PREM-ED 65
- Demonstrates how cognitive interviews were conducted with a subgroup of multiple stakeholder participants.
- Summarises key findings from cognitive interviews, including item comprehension issues, item relevance and content, response options, inclusivity, and overall PREM layout and formatting.
- Highlights implications of the cognitive interviews for draft PREM development.

9.1 Outline

This chapter will report the key findings from cognitive interviews with a subgroup of seven stakeholders, including patient-public representatives. It will also demonstrate how, in advance of the validation study, cognitive interviews confirmed and improved item comprehension and relevance, and informed a more inclusive and user-friendly draft PREM design.

9.2 Introduction

9.2.1 Context and Purpose

As previously described in this thesis, a comprehensive list of candidate items for PREM-ED 65 was formulated following methodological triangulation of findings from the qualitative systematic review and meta-synthesis(1),

interviews with ED patients (2) and focus groups with ED staff.(3) These items then underwent assessment for comprehensibility and were prioritised during a one-day multiple-stakeholder workshop comprising 29 participants.(4) As a result of the workshop, consensus was reached regarding the final list of candidate items for inclusion in the draft version of PREM-ED 65. However, the cited limitation of the stakeholder workshop was that only a minority of candidate items were deemed low enough priority to be excluded, leaving concerns regarding the length and utility of the candidate item list.

Cognitive interviews are widely used in survey design as a final stage of the development process prior to validation known as ‘pre-testing’.(5) In this context, cognitive interviews ensure that respondents can easily and accurately answer the items and meaningfully engage with the purpose of a survey. Cognitive interviews are aligned to the cognitive theory of survey response and may assess comprehension, participants’ ability to retrieve information, ability to make a judgement, and ability to respond appropriately. This may provide insight into where response errors may be likely to occur.(6)

9.2.2 Development of the initial draft PREM-ED 65

Following the stakeholder meeting, the lead researcher (BG) developed an initial draft of PREM-ED 65 in advance of the cognitive interviews. This contained the prioritised item list derived from the multiple stakeholder workshop. Key considerations to the design of the initial draft are considered here, including response scale selection and survey formatting.

Response scale selection

In developing the initial draft iteration of PREM-ED 65, the advantages and disadvantages of various response scales were considered. This included dichotomous scales, numerical scales, semantic differential scales, visual analogue scales (VAS) and verbal rating scales (VRS).(7) The identified merits and disadvantages of each type of rating scale for PREM-ED 65 are reported here. Whilst the most straightforward for participants to complete, a dichotomous scale was felt to be too limiting for identifying variation in patients' experiences and meeting the measurement objectives of PREM-ED 65. Semantic differential scales are widely used in psychology to measure emotion and subjective perception of phenomena. They provide an interesting approach to measurement by asking participants to connotate meanings to concepts.(8, 9) The semantic differential scale has been used in a range of PREMs relevant to COPD,(10) diabetes,(11) and epilepsy(12), and may provide rich data. However, the complexity inherent with semantic differential scales, likely lack of familiarity amongst ED patients, and increased interpretation and decision-making burden upon validation study participants were considered limitations especially when considering the length of the draft PREM-ED 65 and the time-pressured setting of the ED in which administration would occur. Verbal rating scales require participants to select a pre-defined response to an item, whilst visual analogue scales place a mark on a line. Both have been used successfully in pain medicine (9) and whilst these scales may provide sensitive data, they also place a reasonably high cognitive demand on participants. In addition, the VAS requires dexterity to complete and may be challenging for

some patients, such as those with tremor.(13) Analysis of visual scales may be more complex and responses may be non-linear as participants may not utilise the full scale.(14) Limitations of VRS may include subjective and culture-specific interpretation of descriptors and central tendency bias if a 'neutral' option is offered.

After careful consideration of these options, the Likert scale (15, 16) was selected as the preferred response scale due to its likely familiarity amongst participants, relative ease of completion for respondents, and simplicity of analysis for clinicians or researchers responsible for interpreting findings. As an example of their application amongst older adults, Likert scales are commonly used in measures of ageism.(17) However, important additional considerations that exist when adopting Likert Scales included scale length and the inclusion of a neutral option or forced choice element. To help inform these choices, scales included within some existing ED-specific instruments were reviewed (Table 9.1).

Table 9.1 Response scales in some relevant health measures

Name of Measure	Response Scale employed
Consumer Quality Index-Accident and Emergency (18)	2, 3 and 4-point Likert Scales
A&E department questionnaire	3, 5, and 7-item verbal rating scale
Patient Participation in the Emergency Department Questionnaire (19)	4-point Likert scale Agreement
Urgent Care System Questionnaire (20)	5-point Likert Scale
PROM-ED (21)	4, 5, and 10- point agreement scales

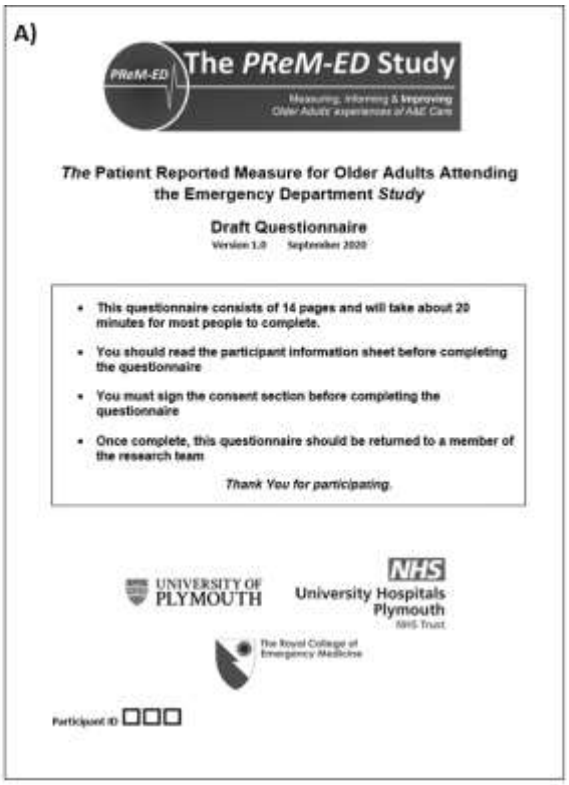
Scales in the existing instruments were noted to be typically 3 to 9 points in length. Although lengthier scales may theoretically provide more nuanced, granular detail of respondent attitudes or perceptions, the literature has challenged this.(22) Conversely, a shorter scale may be easier to complete and less likely to result in survey fatigue and non-response. The inclusion/ exclusion of a neutral response option presents a further dilemma. Potential benefits of a neutral response option include reducing cognitive burden for participants and allowing genuinely neutral attitudes to be reported. On the other hand, forced choice surveys encourage active decision-making and increased engagement with items and may improve the discriminatory power of responses by avoiding central tendency bias.(23, 24)

Considering these factors, the length of the draft instrument, study setting and population, a four-point forced-choice scale was selected for the initial draft. This was intended to limit participant burden, reduce the likelihood of respondent fatigue, and produce interpretable data compared to shorter dichotomous or trichotomous scales. Additionally, three separate fields were added to enable participants to indicate when an item did not apply to them: “I cannot recall,” “Does not apply to me,” and “I do not understand.”

Initial survey formatting

Following general guidelines for the creation of user-friendly public-facing health information,(25, 26) considerations for the initial survey formatting included clearly providing instructions on the front page of the instrument and presenting

items and response scales to facilitate participant engagement. An example of the front cover and response page of the initial draft is provided in Figure 9.1.



B)

Part 4: Your experiences of arriving and waiting in A&E *(continued)*

	Tick One Option				Alternative Options		
	Strongly Disagree	Disagree	Agree	Strongly Agree	*Does not apply to me*	*I cannot Recall*	*I do not understand*
I received relief for shortness of breath	☐	☐	☐	☐	☐	☐	☐
I received relief for symptoms other than pain or shortness of breath	☐	☐	☐	☐	☐	☐	☐
I was told whether I was allowed to eat or drink	☐	☐	☐	☐	☐	☐	☐
The temperature was about right in A&E	☐	☐	☐	☐	☐	☐	☐
I had enough access to blankets and pillows	☐	☐	☐	☐	☐	☐	☐
The department was clean	☐	☐	☐	☐	☐	☐	☐
The department was tidy	☐	☐	☐	☐	☐	☐	☐
It was easy to find the toilets	☐	☐	☐	☐	☐	☐	☐
It was easy to use the toilets	☐	☐	☐	☐	☐	☐	☐
I was able to go to the toilet in a dignified way	☐	☐	☐	☐	☐	☐	☐
My disability was recognised	☐	☐	☐	☐	☐	☐	☐
Staff were considerate of my hearing or eyesight difficulty	☐	☐	☐	☐	☐	☐	☐
My long term medical problems were recognised	☐	☐	☐	☐	☐	☐	☐

Figure 9.1 Initial design of PREM-ED 65, as used in cognitive interviews. (including front page (A) and example response page (B)).

9.3 Aims and Objectives

For the PREM-ED 65 study, cognitive interviews aimed to assess participants' interaction with the draft version of PREM-ED 65.

Objectives were to confirm adequate comprehension of the draft survey, relevance and content of the items, ease of interaction with the response options and appropriate layout and formatting of the instrument.

9.4 Methods

Cognitive interviews were performed using a read-aloud technique during March and October 2020.

9.4.1 Population

Due to the emergence of the SARS-CoV-2 outbreak in early 2020, it was not possible to perform in-person cognitive interviews with real-world potential participants in the ED. Therefore, an open e-mail invitation was issued to participants who attended the previous multiple stakeholder workshop in December 2019. Information was provided upon expression of interest, and informed verbal consent was obtained from participants who agreed to undergo an interview. At the beginning of the interview, all interviewees were informed of their right to withdraw at any point.

9.4.2 Cognitive Interview Structure

A question schedule was prospectively developed and agreed upon by the research team, adapted based on established principles, and guided by a schedule.(27, 28) The first phase was interviewee-driven, utilising the 'read

aloud' technique; subsequent stages were researcher-driven. The interview schedule is presented in Table 9.1.

Table 9.2 Question Schedule for Cognitive Interviews

1. Please begin by reviewing the questionnaire and letting me know your first impressions.
2. I would like for us to go through each of the questions. I would like you to read each question in your own time and to think about what the question is asking and whether you can clearly understand it. I would like you to speak your thoughts aloud if you can, and I will take note of any issues you may have.
3. I would now like us to consider the response scale. Do you have any comments about this?
4. Before we close the interview, I would like to ask about your overall impression of the questionnaire and how useful you think it will be for accurately capturing older adults' experiences of A&E care.

9.4.3 Data Collection

Interviews were conducted online via the Zoom (Zoom Video Communications Inc., San Jose, CA) platform at a time of the participant's choosing. A webcam was required on both the interviewer and participant device to enable rapport and assessment of non-verbal communication. Each interview was recorded using functionality within the Zoom platform; following the interview, recordings were downloaded and stored securely on the investigator's university computer.

Brief observations and field notes were taken during the interviews. In addition, the researcher annotated participants' comments and suggestions for revision onto a clean copy of the initial draft in real time using Microsoft Word's comment and review functions.

9.4.4 Data Analysis

Following the interviews, annotated copies of the initial instrument obtained from the discussion with each participant were merged. This enabled all comments and suggestions to be reviewed simultaneously. The research team reviewed all of the suggestions, which were implemented where deemed beneficial and practical. Following this, the revised version of the questionnaire was emailed to participants for their review and final approval.

9.4.5 Ethical Approval

Rather than aim to generate new or generalisable knowledge, cognitive interviews invited stakeholders to collaborate in production of the draft instrument. This ensured that their perspectives on content, relevance and design were properly represented. As such, the cognitive interviews were considered a patient-public involvement activity as opposed to research.(29) However, the cognitive interviews were listed within the HRA application for the validation study (21/PR/0458) and general ethical principles were respected throughout, including advance provision of information, informed verbal consent, right to non-participation, right to withdraw, and data management.

9.5 Findings

9.5.1 Participant Characteristics

Seven of the twenty-nine original workshop participants agreed to a cognitive interview (24%). These included two representatives from third-sector organisations (one aged over 65), an emergency physician, a senior paramedic, and three public representatives all aged over 65. Four of seven participants

(57%) were female; all were white British. The mean interview length was 59.5 minutes (Range 28—98 minutes).

9.5.2 Overview of findings

A total of 170 comments were recorded as MS Word comments (Mean 24 comments per interview; Range 17-42). This included 29 (17.1%) comments related to instrument layout and formatting, 58 (34.1%) comprehension issues, 54 (31.8%) Relevance and content of items and 13 (7.6%) interactions with the response scale. In addition, 15 comments (8.8%) were generated that did not fit one of these themes.

9.5.3 Relevance and content of the items

The interviewees confirmed the relevance of most items but highlighted several that were problematic. For example, some participants felt that the item “I was asked about my views on resuscitation” was inappropriate for inclusion in the validation study, which targeted older adults before being discharged home. One participant remarked that such a question, asked at the end of a visit, may trigger negative emotions, whilst another remarked the potential for this item to ‘open a can of worms!’, potentially adding complexity for research assistants and potentially induce framing effects for the assessment of subsequent items. The item “I was observed for long enough in ED” was recommended for exclusion, as it was not felt this was a concept all patients would understand. Similarly, the item “I received the correct diagnosis” was identified as likely to cause uncertainty amongst participants, with one interviewee remarking that it could be perceived as undermining by staff. The reverse items “I never felt

vulnerable” and “I never felt alone” were potentially confusing, and the importance of differentiating these, if included, was emphasised.

All interviewees expressed a keenness for PREM-ED 65 to be maximally inclusive, and some requested that the items more specifically assess mobility problems and sensory deficits. Other items that interviewees represented particularly high priority related to consent and pain management.

9.5.4 Interaction with the Response Scale

The interviewees agreed that the four-point response scale would provide participants with a straightforward means of responding to an item without overburdening them. However, some interviewees were concerned that the additional “I do not understand” and “does not apply to me” response options could lead to response bias. As such, a single alternative additional response category of “I cannot answer” was agreed upon as adequate by the research team. In addition, a fifth ‘not applicable’ response category was provided for items relating to disability and cultural/ interpretation needs.

9.5.5 Instrument layout and formatting considerations.

Participants unanimously shared concerns regarding the length of the initial draft instrument. All remarked that it may be intimidating for older adults during an ED visit. The participants, including the public representatives over 65, were keen for an electronic version of PREM-ED 65 to be made available to the research participants. This change was envisaged to accommodate the preferences of older adults familiar with electronic devices.

The cover page layout was commented upon as overly formal and potentially off-putting for participants; one interviewee suggested ‘softening up the appearance’ to make it more appealing to research participants, whilst another recommended the integration of cartoons/ informal graphics to achieve this. “The more visual you can make it, the better” was the advice from another interviewee. Ensuring that items were delineated was identified as a priority, and it was recommended the response page be changed to a portrait format to assist ease of completion by the participants.

9.5.6 Comprehension Issues

Comprehensibility of the items was a key focus for many of the interviewees. Even preceding the survey items, within the initial demographic battery, it was reported that gender was potentially confusing, and the interviewees preferred the terms ‘male’ and ‘female’. Terms identified as potentially problematic within items included ‘summon’, ‘procedure’, ’expectations’, and ‘proficient’. As such, participants recommended such terms be changed to more simple phraseology. Some terms, such as ‘professional’ were flagged as subjective and open to interpretation—interviewees recommended using unambiguous terms. The item “I was treated like a priority” was identified as problematic, as patients’ perspectives on their urgency compared to others are subjective. Accordingly, a recommendation was made by one participant to redact this to “I was treated like I mattered”. On a broader level, interviewees were mindful of research participants’ literacy and felt this should not be a barrier to completion. As such, they requested the optional assistance of a researcher be made available to participants of the validation study.

9.5.7 Other issues

Other issues identified included the formal writing tone on the cover page and within the survey instructions. One of the interviewees advised a ‘softer, more informal’ approach, while another suggested that ‘politeness of wording’ could be improved. Another participant felt that instructions on formally complimenting or complaining about the ED experience should be provided, e.g., at the rear of the instrument.

9.5.8 Overall Impression of PREM-ED 65

Interviewees were enthused about the development of PREM-ED 65 and recognised the importance of measuring older people’s experience of ED care. However, the interviews identified important issues relating to comprehension of some items, survey length, and appearance/format that necessitated re-drafting PREM-ED 65.

9.5.9 Re-Drafting the Instrument

Priorities for the re-draft

Priorities for the re-draft included adding the items to ensure inclusivity whilst, if possible, reducing the overall length of PREM-ED 65 to minimise future recruitment issues, response bias, or non-response bias. Another priority was to enact feedback relating to the format and presentation of the draft instrument to encourage and sustain validation study participant engagement.

Changes to content

Three items were added to assess the experiences of those living with hearing loss, visual loss, and mobility issues. The double-barrelled item ‘Staff met my cultural and language needs’ was separated into two, and another item included

for older adults needing interpretation. A separate item assessed interactions with portering staff. Items the interviewees identified as difficult to comprehend were revised. Examples of revisions are presented in Supplementary Material SM9.1. The research team reviewed and discussed any items the interviewees deemed similar, ambiguous, or irrelevant to the validation study population. Interviewees' recommendations were confirmed, and, if necessary, the relevant items were either revised or omitted based on the expert consensus of the research team. The removed items are presented in Supplementary Material SM9.2. In total, twenty-three items were removed. This was due to similarity with another item (n=14), irrelevance to the validation study population consisting of older adults discharged from ED(n=5), or ambiguity surrounding meaning or relevance (n=4). In addition, some of the retained items were grouped, and a common stem was implemented, reducing the overall survey word count and therefore, the burden incurred on participants (example—fig 9.2)

Part 6: My views on the A&E team

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
"The Staff looking after me…"					
…introduced themselves to me	☐	☐	☐	☐	☐
…told me their name	☐	☐	☐	☐	☐
…asked how I would like to be addressed	☐	☐	☐	☐	☐
…checked that I understood what they had said	☐	☐	☐	☐	☐
…spent enough time speaking with me	☐	☐	☐	☐	☐
…were concerned about my wellbeing	☐	☐	☐	☐	☐
…responded to my needs	☐	☐	☐	☐	☐
"Taken as a whole, I think that the A&E team was…"					
…kind	☐	☐	☐	☐	☐
…caring	☐	☐	☐	☐	☐
…respectful	☐	☐	☐	☐	☐
…helpful	☐	☐	☐	☐	☐
…competent	☐	☐	☐	☐	☐

Figure 9.2 Example of common stem question structure

Changes to formatting and appearance

As a result of the interviewee's feedback, changes were also made to the overall design and layout of the initial draft instrument. The entire document was transferred to a portrait format, and the front page and instructions for participants were rephrased with a more engaging tone that conveyed gratitude and was more respectful of participants' involvement. Open-source graphics (Example—figure 9.3) and informal typography were included in places to make the survey more visually appealing, and signposting to patient advice and liaison services were provided at the end to facilitate formal complaints and compliments. The re-drafted front cover and example response page can be viewed in Figure 9.4 (overleaf). The full draft instrument can also be viewed in Supplementary Material SM10.1.

Figure 9.3 Open-source graphic adapted for the final draft.

Following interview feedback and suggestions, this open-source graphic was placed after the first half of the redrafted PREM-ED 65, thanking participant for their involvement and encouraging full completion.

The PReM-ED Study

Measuring, Informing & Improving Older Adults' Experiences of A&E Care

Please tell us about your experience in A&E

"I would like to share my experience so that A&E can improve things for people like me in the future!"

Thank you for taking part!

This questionnaire is part of a research project looking at experiences of older adults when they attend the emergency department (A&E).

Please make sure you read the information leaflet and sign the consent form before completing the questionnaire.

The questionnaire will take about 20 minutes to complete.

Remember to ask if you would prefer a member of the research team to help you complete the questionnaire.

We are very grateful for your help with this project, which will help us to measure and improve emergency care for people aged over 65.

NHS University Hospitals Plymouth NHS Trust

UNIVERSITY OF PLYMOUTH

The Royal College of Emergency Medicine

Participant Number

PREM-ED 65+ Validation Study, Final Version 1.1, Updated 14 Apr 2021
IRAS ID 292424

B)

Part 1: My experience of arriving and waiting in A&E

Please tick (✓) one option per statement

	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
The signs in A&E were easy to follow	☐	☐	☐	☐	☐
The reception desk was easy to find	☐	☐	☐	☐	☐
The receptionist was kind	☐	☐	☐	☐	☐
The waiting room was pleasant	☐	☐	☐	☐	☐
I felt safe whilst I was waiting	☐	☐	☐	☐	☐
I felt cared for whilst I was waiting	☐	☐	☐	☐	☐
I was informed about waiting times	☐	☐	☐	☐	☐
I was given updates whilst I was waiting	☐	☐	☐	☐	☐
I felt like I could get help if I needed it	☐	☐	☐	☐	☐
I was offered a seat or a bed	☐	☐	☐	☐	☐
The seat or bed was comfortable	☐	☐	☐	☐	☐
I was told whether I was allowed to eat or drink	☐	☐	☐	☐	☐
I was able to get food or drink if needed	☐	☐	☐	☐	☐
The temperature in A&E was about right	☐	☐	☐	☐	☐
I had enough access to blankets and pillows	☐	☐	☐	☐	☐
The department was clean and tidy	☐	☐	☐	☐	☐
It was easy to find and use the toilets	☐	☐	☐	☐	☐
I could go to the toilet in a dignified way	☐	☐	☐	☐	☐

Figure 9.4 : Final draft version of PREM-ED 65

(includes (A) front page and (B) example of a response page)

9.5.10 Assessment of the re-draft

The re-drafted instrument was emailed to all interviewees. No further suggestions or recommendations for change were received. Hence, this version was selected to proceed to testing and validation.

9.6 Discussion

9.6.1 Interpretation of Findings

Cognitive interviews were conducted to pre-test the PREM-ED 65 items prioritised during the multiple stakeholder workshop before validation. Overall, the interviewees were enthusiastic regarding the development and potential utility of PREM-ED 65 but identified that the survey was burdensome due to excessive length and that language and layout of the instrument could be improved. By aggregating the interviewees' comments and implementing their combined suggestions and recommendations, it was possible to reduce the overall length of the draft instrument to 82 items, revise the wording of some items, improve relevance to those with mobility and sensory issues, improve the overall formatting, and enhance the layout and visual presentation of the paper-based instrument. Participants emphasised the importance of inclusivity and encouraged the development of an electronic option to be made available for the validation study. This is unsurprising, given that older adults now frequently use devices, including smartphones and tablet computers.(30)

9.6.2 Implications for PREM-ED 65 Development

As a result of the cognitive interviews, a re-drafted version of PREM-ED 65 was developed that, compared to the initial version, demonstrated increased brevity, comprehensibility and usability for older adults discharged from the ED. As

such, the potential for non-engagement, participant withdrawal, respondent fatigue and satisficing to occur during the validation study was mitigated. The proposed four-point response scale was well received; however, the number of additional response options was also reduced.

Overall, conducting online cognitive interviews was an effective, time-efficient, and resource-efficient means of obtaining feedback on general perceptions of PREM-ED 65, item comprehensibility, relevance to the proposed validation study cohort, and confirmation of measurement utility.

9.6.3 Strengths and Limitations

The recruitment of existing stakeholder representatives meant that PREM-ED 65 pre-testing was possible even during the outbreak of COVID-19, when it was not practicable to hold face-to-face interviews with older people in a hospital setting. Using an online platform ensured personal safety for interviewees when little was known about the potential impact of the pandemic and allowed interviews to occur at a convenient time, limiting the personal burden associated with involvement. This is in keeping with the increasing use of virtual methods for conducting interviews during and following the pandemic. (31) Due to their recent attendance at the multiple stakeholder workshop, the interviewees were invested in the study, had built a rapport with the investigator, and had existing familiarity with the purpose of the PREM-ED 65 and the candidate items. This meant interviewees may have been more forthcoming and not reticent to offer critical feedback necessary to make an impactful difference to both the content and design of the instrument.

The limited sample is a possible limitation, although literature confirms that even small numbers of interviewees are likely to elicit fundamental issues with survey design during cognitive interviews.(32, 33) However, theoretical saturation was not assessed and may not have been reached.(34) Additionally, excluding some items potentially limits the applicability of PREM-ED 65 to some populations of older adults admitted to the ED, including those admitted to the hospital. The expert consensus approach employed by the research team to review items highlighted by interviewees was a pragmatic step necessary to finalise the selection decisions for the draft instrument. Whilst the use of expert opinion to guide item generation is recognised within the literature,(35) interviewees' recommendations were respected where possible, in alignment with the stakeholder-led approach to item prioritisation. No unresolvable disagreements occurred between the research team and agreeing on the final 82 items for inclusion was straightforward.

Finally, the large number of items that were revised or removed may not be a limitation of the cognitive interview process but rather highlight limitations in the utility of the nominal group technique to reduce many survey items to a more manageable amount successfully.

9.7 Conclusion

Patient-facing cognitive interviews were not possible due to the outbreak of the COVID-19 pandemic. However, virtual interviews with seven stakeholders following a cognitive interviewing approach provided valuable insights into the proposed content, relevance and formatting of the initial draft of the PREM-ED

65 instrument. As a result, the subsequent version's length, appearance, and usability were improved, and it is conceivable that research participant engagement during the validation study was improved because of the cognitive interviews. In addition, the potential for response biases and respondent fatigue resulting from an overly burdensome survey was reduced. This approach shows the value of obtaining and maintaining stakeholder engagement throughout multiple stages of PREM development.

Addendum

Contribution to the PREM-ED 65 study

Cognitive interviews represented the final component of the PREM-ED 65 development phase before the multi-centre validation study. Even though COVID-19 made it impossible to perform patient-facing interviews, a small number of stakeholders who also attended the prioritisation workshop, helped reduce the overall number and length of items within the draft instrument. Their suggestions resulted in an improved, user-friendly format for PREM-ED 65. Combined with the comprehensive methods employed for item generation and the subsequent prioritisation, the cognitive interviews ensured a solid foundation for the subsequent validation study, presented in the next chapter.

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Supplementary Material

SM 9.1 Examples of items revised following cognitive interviews

Initial Item….	…Revised as
Staff who were learning were well supervised	Junior staff seemed well supervised
The pain relief medicine worked well	Pain medicine worked well
Staff were thorough	My condition was assessed thoroughly
My disability did not get in the way of my care	My disability was recognised
Staff undertook checks to make sure my skin was not at risk of damage	My skin was checked for damage
Staff did not have to spend time looking for the right equipment	Staff were able to locate the right equipment
Staff made effort to relieve shortness of breath	The seat or bed was comfortable
I was given a call bell or other means of summoning help	I felt like I could get help if needed
I understood what was being said	Everything was explained to me in a way that I could understand
Staff helped me to feel sure that I would be able to cope at home	I felt ready to cope at home
Staff let me know when to return if things get worse	I was told what to do if things got worse
Staff told me if I was able to take my usual medication	I was able to take my usual medication
Staff explained risks of tests and procedures	I understood the possible risks of treatments
Staff let me know in advance when something was likely to be painful or cause discomfort	I was told when something might be painful
Staff informed me if they were unsure	Staff told me if they were unsure about anything
Staff understood my worries and concerns	Staff were concerned about my wellbeing
Staff explained what they were doing to me	Staff explained what was going to happen
I did not feel lonely	I did not feel alone

SM 9.2 Items removed following cognitive interviews

(a) Items removed due to similarity with other(s)

Staff were quick to respond when I asked for help with the toilet

Staff ensured that I heard what was said

Staff identified my hidden disability

The whole team displayed kindness towards me`

Staff gave me clear discharge instructions

Staff let me know why I needed a procedure

Staff explained everything to me in enough detail

I was helped to the toilet

Staff cared for my emotional needs

Staff explained possible outcomes of tests

Staff were attentive to my needs

The pain I felt during procedures was about the same, or was less than I was initially told

Staff asked about my ideas, concerns and expectations

Staff reassured me

(b) Items removed due to irrelevance to study population

I was able to get sleep if needed

Staff let me know how sick I was

Someone asked me on my views on being revived should my heart stop

Staff asked for my views on life support treatment should my condition get worse

Staff informed me why I was being admitted

(c) Items removed due to ambiguity

I felt looked after while I was waiting

Staff explained what I was required to do during a procedure

I was monitored and observed for the right amount of time

There were enough staff on duty

Chapter 10 Final Development and Validation

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Contributor Statement
Blair Graham (BG) conceived the study and led the development, study design, recruitment of student researchers, data collection, analysis, writing of the first draft of the manuscript and all subsequent versions.

Jason Smith (JES) and Jos Latour (JML) contributed to the study design, data collection and analysis and reviewed the first draft of the manuscript and all subsequent versions.

Yinghui Wei (YW) provided a review of data analysis and results, reviewed the first draft of the manuscript and all subsequent versions.

Pamela Nemles (PN) contributed to the study design and recruitment of student researchers and approved the final version of the manuscript.

JES and JML supervised the project.

The agreed approximated percentage contributions toward the production of this research are: BG 80%, JES 7.5%, YW 2.5%, PN 2.5%, JML 7.5%.

Non-author contributors undertook local screening, recruitment, and data entry; site principal investigators provided supervisory oversight for student researchers and were responsible for local study conduct.

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None of the authors have any conflicts of interest to declare.

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What this chapter adds.

This chapter:

- Demonstrates the ability of the researcher to (i) plan and deliver a multiple site validation study from PREM-ED 65 and (ii) Conduct quantitative data analysis including hierarchical item reduction, exploratory factor analysis and reliability testing to determine psychometric characteristics (structural validity, internal consistency, test- retest reliability and criterion validity) of PREM-ED 65, and (iii) present a final version of PREM-ED 65.
- Highlights outstanding limitations of PREM-ED 65, focusing on the need to validate the instrument amongst different cultural groups and older adults living with frailty.
- Reports findings from a cross- sectional survey reporting undergraduate students' experiences of participating in the multi-site validation study.

Psychometric validation of a patient-reported experience measure for older adults attending the emergency department: The PREM-ED 65 Study.

10.1 Abstract

Introduction

Optimising ED patient experience is vital to ensure care quality. However, there is a lack of validated instruments to measure the experiences of specific patient groups, including older adults. We developed a draft 82-item Patient Reported Experience Measure (PREM-ED 65) for adults over 65 attending the ED. This study aimed to derive a final item list and provide initial validation of the PREM-ED 65 survey.

Methods

A multi-modal, cross-sectional study involving patients in 18 EDs in England. Adults aged 65 years or over, deemed eligible for ED discharge, were recruited between May and August 2021. Test-retest reliability was assessed at 7—10 days following the original attendance. Data analysis consisted of descriptive statistics, including per-item proportions of responses, hierarchical item reduction, exploratory factor analysis (EFA), reliability testing and assessment of criterion validity.

Results

Five hundred-ten initial surveys and 52 re-test surveys were completed. The median respondent age was 76. A similar gender mix (Male 47.5% vs. Female 50.7%) and reason for attendance (40.3% injury vs. 49.0% illness) was observed. Most participants self-reported their ethnicity as white (88.6%).

Hierarchical item reduction identified 53/82 (64.6%) items for exclusion, including inadequate engagement (n=33, 40.2%), ceiling effects (n=5,6.1%), excessive inter-item correlation (n=12,14.6%) or significant differential validity (n=3,3.7%). Twenty-nine items were retained.

EFA revealed 25 items demonstrating high factor loadings (>0.4) across four scales with an Eigenvalue >1. These scales were interpreted as measuring ‘relational care’, ‘the ED environment’, ‘staying informed’ and ‘pain assessment’. Cronbach alpha for the scales ranged from 0.786—0.944, indicating good internal consistency. Test-retest reliability was adequate (intraclass correlation coefficient 0.67). Criterion validity was fair (r=0.397) when measured against the Friends and Families Test question.

Conclusions

Psychometric testing demonstrates that the 25-item PREM-ED 65 is suitable for administration to adults 65 years of age or over up to ten days following discharge

10.2 Background

Patient experience is an internationally recognised dimension of healthcare quality, positively associated with outcomes for various acute conditions and increased adherence to ED discharge instructions.(1-3) Recent studies have sought to conceptualise patient experience in the ED, emphasising the importance of patient-provider communication, relational care, and an optimised ED environment.(4-6) These studies provide a theoretical foundation for understanding patients' experiences that may inform the development of interventions to improve patient experience in the ED. The International Federation of Emergency Medicine recommends routine assessment of ED patient experience, which may be accomplished using Patient Reported Experience Measures (PREMs).(7) PREMs are questionnaires usually developed with patients and other relevant stakeholders that provide a standardised method for capturing patients' views of their care.(8) As such, PREMs may indicate where improvement is needed and provide a means of monitoring service performance over time. PREMs supplement Patient-Reported Outcome Measures (PROMs), which assess patients' health status, and satisfaction surveys, which measure the extent to which care meets patients' expectations.

Past limitations of ED PREMs and PROMs include inconsistent validity and reliability, although recent instruments aimed at the general ED population are promising.(9, 10) However, few PREMs exist to measure the experiences of specific ED user groups, including older adults, who comprise an increasing proportion of attendances in many settings.(11) In response to the ageing global population, there is burgeoning interest in the ED care of older adults and increasing recognition of this group's often more complex, holistic needs.(12)

Current evidence emphasises older adults' vulnerability when attending the ED, demonstrating an increased likelihood of severe pain, increased length of ED stay, need for hospital admission, and subsequent in-hospital mortality compared to the general population.(13-15)

We have previously developed a new English-language instrument—PREM-ED 65—to enable valid and reliable measurement of older adults' ED experiences. (Appendix 1) The 82-item draft version (Supplementary Material SM10.1) has been derived using meta-synthesis, qualitative research, stakeholder prioritisation of candidate items, and cognitive interviews to inform design and usability.(6, 16-18) The research is summarised in Figure 10.1 (overleaf).

This study aims to provide a psychometric evaluation of the 82-item draft version of PREM-ED 65. The objectives are to (i) provide descriptive statistics, including per-item proportions of responses, (ii) eliminate draft items with inadequate response characteristics using hierarchical item reduction, (iii) confirm the structural validity of the finalised item set using exploratory factor analysis, (iv) assess the reliability (internal consistency) of measurement scales, (v) assess test-retest reliability and (vi) criterion validity of PREM-ED 65.

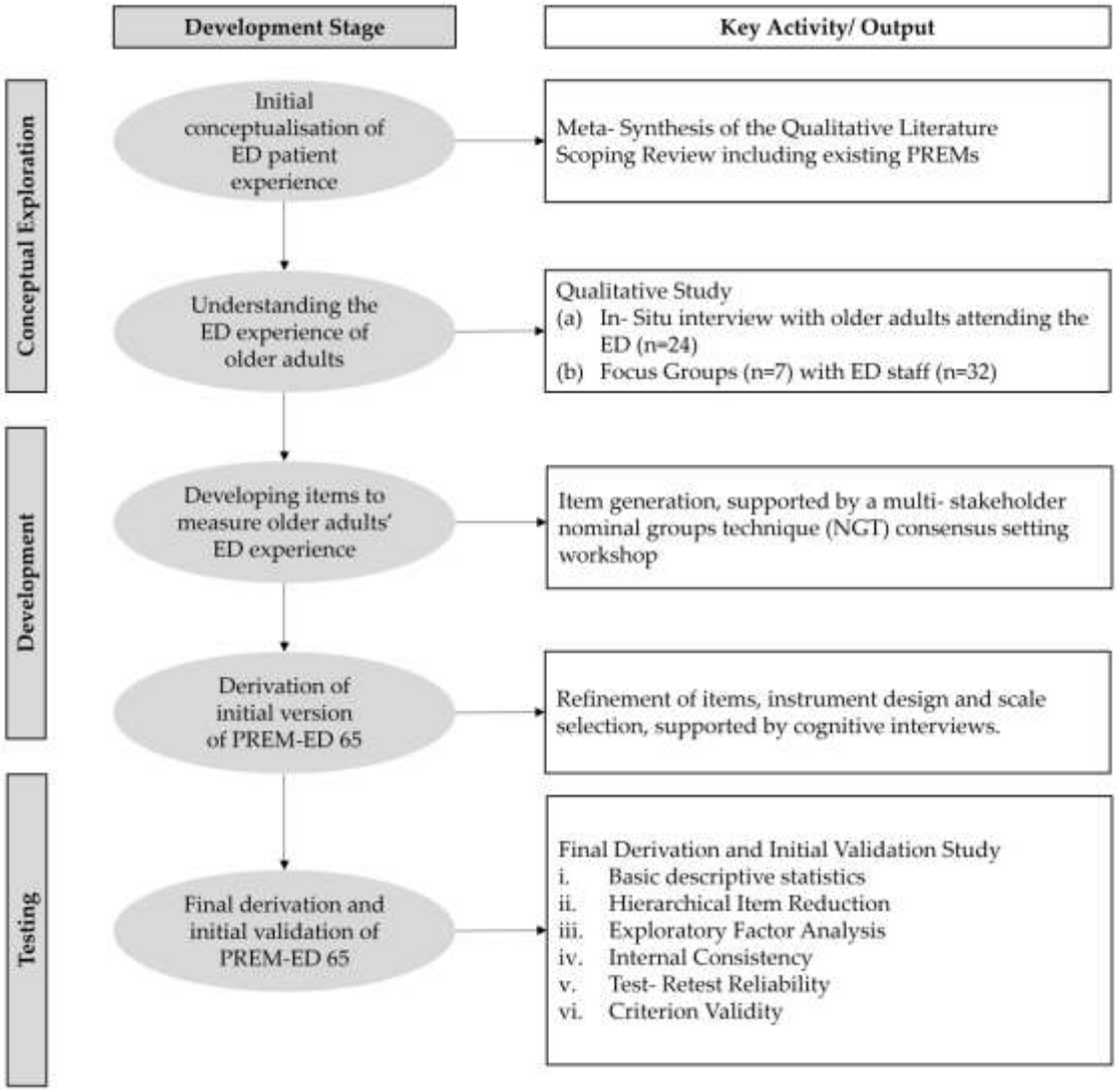

Figure 10.1 Flow Diagram of PREM-ED 65 development process

10.3 Methods

10.3.1 Study Design

This is a cross-sectional survey study. Practical recommendations for reporting scale development and the Consensus-based Standards for selecting health Measurement Instruments (COSMIN) guidelines have been followed.(19, 20) A multimodal design meant participants could complete either a paper-based or electronic version of PREM-ED 65.

10.3.2 Study Setting

Adults over 65 discharged from the ED between 0600 and 2100 hrs were recruited at the end of their visit. Data collection occurred between May and August 2021.

10.3.3 Inclusion and Exclusion Criteria

Eligible participants were those assessed, treated, and approved for discharge to their domicile by the attending clinician. Exclusion criteria included patients who were hospitalised, were too unwell to participate, had suspected or confirmed SARS-CoV-2 infection, lacked the mental capacity to provide informed consent (as assessed by the attending clinician), were in police/prison custody, or did not speak English.

10.3.4 Procedures

A collaborative research design was devised by the lead researcher (BG), who contacted EDs hosting medical students studying a one-year intercalated Bachelor of Science (BSc) programme in Urgent & Emergency Care (University of Plymouth, UK). Following local approval, students were invited to participate voluntarily as site investigators. Students were provided with training, and a

registered clinician provided oversight. Student responsibilities included screening, participant recruitment, informed written consent, data collection, and entry. Students received a certificate and were named collaborators. No additional incentives were provided.

10.3.5 Sampling and Recruitment

Opportunistic sampling, guided by a sampling matrix, aimed to maximise recruitment while accommodating students' clinical commitments. Based on COSMIN criteria, a total sample of 400—600 respondents (i.e., 5-7 responses per PREM item) was targeted. (19)

All sites were mailed study materials, including a tablet computer, to allow completion of the electronic version of PREM-ED 65, created using SurveyMonkey.

10.3.6 Survey Administration

Participants could complete either the paper-based or electronic version of the draft instrument. In addition to the 82 experience items, participants self-reported gender, age, ethnicity, mode of arrival, reason for attendance (i.e., injury/ illness) and length of ED stay. All were invited to complete a postal or online retest survey 7—10 days later.

10.3.7 Measurement Scales

Responses to each of the 82 draft items were measured using a four-point Likert scale, from least favourable opinion (1, 'strongly disagree') to most favourable (4, 'strongly agree'). An 'I cannot answer' option was included for all

items, and a ‘not applicable’ option was included for items regarding cultural needs, sensory impairment, and disability.

Data Collection and Cleaning

Data from electronic surveys were captured via SurveyMonkey. Students transcribed paper-based responses into a secure online form. The study team downloaded and analysed the results using SPSS Statistics for Windows Version 25 (IBM Corp., 2017). Records that were blank, spurious, or lacking a unique participant identification number were excluded.

10.3.8 Data Analysis

Planned Analysis

Analysis of PREM-ED 65 data consisted of six elements that were (i) descriptive statistics, (ii) hierarchical item reduction, (iii) Exploratory Factor Analysis, (iv) assessment of internal consistency, (v) Test-retest reliability, and (vi) criterion validity.

Descriptive Statistics

Site and participant characteristics were analysed. Per-item descriptive analysis included the Shapiro-Wilk test of normality, proportions of responses, central tendency (average rating assigned to each item) and spread.

Hierarchical Item Reduction

Hierarchical item reduction (HIR) was conducted based on established principles to eliminate irrelevant or non-contributing items. (21, 22) Prospective criteria for HIR consisted of (a) respondent non-engagement (>20% responses ‘I cannot answer’ or ‘Not applicable’ or blank); (b) presence of floor or ceiling effects (>50% responses ‘strongly agree’ or ‘strongly disagree’); (c) presence of

statistically significant differences in the distribution of responses (differential validity) based on gender, age, or reason for attendance, and (d) high inter-item correlation (>0.7). Items were excluded if any one criterion was met (Figure 10.2).

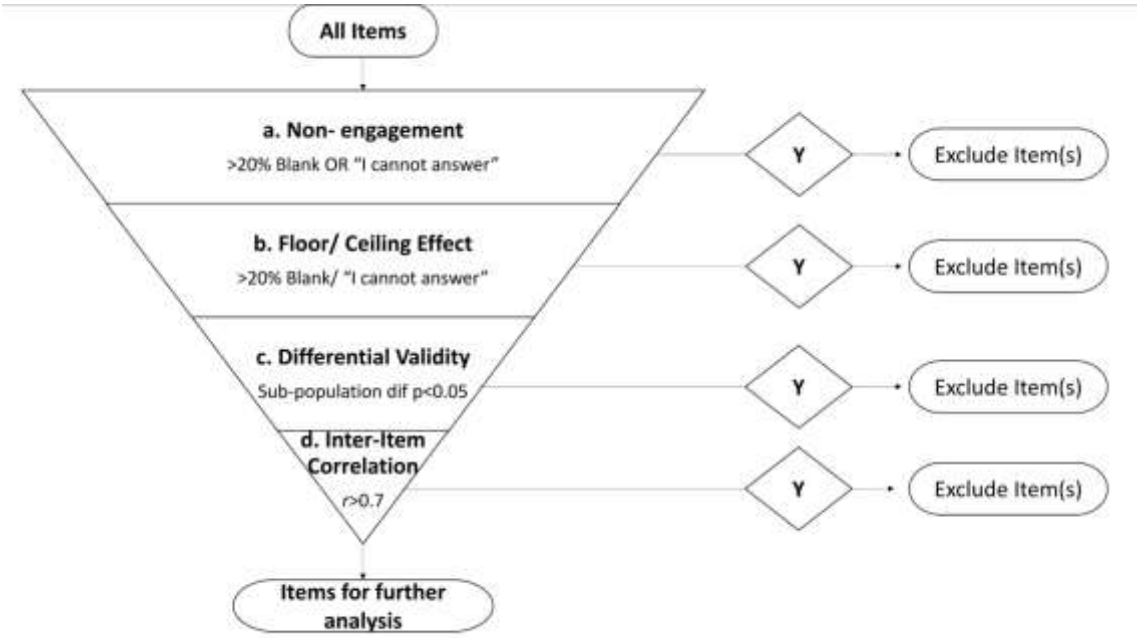

Figure 10.2 Hierarchical Item Reduction

Exploratory Factor Analysis

The need to minimise survey length, simplify subsequent analyses, and facilitate the identification of discrete areas for quality improvement using PREM-ED 65 was recognised. Thus, Exploratory Factor Analysis (EFA) was applied to identify patterns among draft items by grouping them into fewer variables known as factors.(23)

First, responses that were blank or marked as 'I cannot answer' or 'not applicable' had to be handled. Following assessment using Little's test, these

data were treated as missing completely at random. Single imputation using the expectation-maximisation (E-M) algorithm was performed using SPSS Missing Value Analysis.

The EFA then consisted of four steps. The first step was to exclude items measuring identical constructs (Inter-Item correlation >0.8). The second step was identifying and excluding items unlikely to be explained by the analysis (communality <0.2). The third step confirmed the suitability of the remaining data to undergo EFA using the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity. Finally, factor extraction using Principal Axis Factoring with Promax rotation was performed to identify patterns of correlation, revealing the underlying factors. Prospectively agreed quality criteria for factor extraction, based on established criteria,(24) stipulated that (i) only factors demonstrating sufficient variance, guided by Kaiser's Criterion (i.e., Eigenvalue >1) and scree plot inflexion, were retained, (ii) a minimum correlation between any item and its associated factor (factor loading) was >0.4, (iii) post-EFA communality for each item was >0.4, and (iv) maximum correlation between any item and another factor (cross-loading) was <0.4. Therefore, factors with an Eigenvalue <1 were disregarded, and items not meeting the other criteria were removed stepwise until a solution was identified.

Internal Consistency

Internal consistency describes how well items within a scale correlate, providing a measure of reliability. The internal consistency of each extracted factor was

considered satisfactory if Cronbach's Alpha (α) was >0.6, good if α>0.7, or excellent if α>0.8.

Test-retest reliability

The intra-class correlation coefficient (ICC) between initial and case-matched retest survey responses was calculated for individual items, scales, and the overall instrument. Test-retest reliability was considered adequate with an ICC between 0.5 and 0.75, or good if >.75.

Criterion Validity

The "friends and families test question" (FFTQ) is widely used to assess patient experience in the UK, consisting of the following question:

> *"I would recommend this A&E department to my friends or family if they were in a similar situation".*
>
> *FFTQ*

Responses for finalised items were compared to the FFTQ using Spearman's correlation coefficient (r). An r>0.4—0.69 was considered fair, and r>0.7 was considered strong.

10.4 Patient and Public Involvement

The study proposal was presented to the Sheffield Emergency Care Forum in December 2017. Interviews with older adults informed draft item creation between September 2018 and April 2019.(16) Patients and members of the public, health professionals and third-sector representatives assessed and prioritised draft items during December 2019.(18) Cognitive interviews with

seven stakeholder representatives, including three older adults, informed readability and design during October 2020.

10.5 Results

10.5.1 Characteristics of the study sites

Eighteen EDs participated, involving 23 students. Data collection was undertaken exclusively by medical students in 13 EDs, shared between students and clinicians in two EDs, and conducted by clinicians in three EDs.

A median of 20 patients were recruited per site (Range 5—98 patients; IQR 10.75) (Site Characteristics—Table 10.1).

Table 10.1 Site Characteristics (Validation Study)

Site Characteristics (n=18)	N (%)
Location	
Northern England	10 (55.6)
Central England	2 (11.1)
London	2 (11.1)
Southern England	4 (22.2)
Department Size	
Medium (census 60,000-99,000)	7 (38.9)
Large (census >100,000)	11 (61.1)
Case- Mix	
Metropolitan	9 (50.0)
Mixed Urban/ Rural	9 (50.0)
Designation	
Type 1 ED	18 (100.0)
Major Trauma Centre	9 (50.0)
Major Trauma Unit	9 (50.0)
Data collection	
Student Researcher only	13 (72.2)
Student Researcher and research clinicians	2 (11.1)
Research clinicians only	3 (16.7)

10.5.2 Characteristics of the participants

Of 525 ED patients recruited, 510 completed initial surveys were returned (97.1%). The median respondent age was 76 years (range 65-100 years); there was an approximately equal gender distribution (Female 50.7%). Most participants self-reported their ethnicity as white (88.6%). Participants' most typical mode of arrival was private transportation; 72% attended the ED without an accompanying person (Participant Characteristics—Table 10.2; overleaf).

Table 10.2 Participant Characteristics (Validation Study)

Participant characteristics (n=510)	N (%)
Participants Recruited	**525 (100)**
Withdrew before completion	15 (2.9)
Completed Initial Survey	510 (97.1)
Gender	
Female	259 (50.7)
Male	242 (47.5)
Not Disclosed	9 (1.8)
Age	
65—74 years	221 (43.3)
75—84 years	189 (37.1)
≥85 years	83 (16.3)
Not Disclosed	17 (3.3)
Median Age, Range	76 (65—100)
Ethnicity	
White	453 (88.8)
Black	6 (1.2)
Asian	13 (2.5)
Mixed/ Multiple	18 (3.5)
Other	10 (2.0)
Not Disclosed	10 (2.0)
Presence of an accompanying person	
Yes	128 (25.1)
No	377 (73.9)
Not Disclosed	5 (1.0)
Mode of Arrival in ED	
Ambulance	222 (43.5)
Private Transportation	233 (45.7)
Public Transportation	44 (8.6)
Not Disclosed	11 (2.2)

Table 10.2 (Continued)

Participant characteristics (n=510)	N (%)
Reason for Attendance at ED	
Medical Complaint	250 (49.0)
Traumatic Complaint	206 (40.3)
Other Complaint	47 (9.2)
Not Disclosed	7 (1.4)
Time spent in ED	
Less than 1 hour	17 (3.3)
Between 1 and 2 hours	40 (7.8)
Between 2 and 3 hours	98 (19.2)
Between 3 and 4 hours	81 (15.9)
More than 4 hours	253 (49.6)
Not disclosed	21 (4.1)
Mode of survey administration	
Paper	442 (86.7)
Electronic	68 (13.3)
Average time to complete survey	
Paper	NR
Electronic	13 minutes

NR= Not Recorded

10.5.3 Per item proportions of responses

Data completeness was 95.7% (4.3% missing item responses). Responses were non-normally distributed across all items (Shapiro- Wilk $p<0.01$) and demonstrated a left skew (average skewness -0.54) reflecting a high proportion of positive ratings (average proportion of "agree" or "strongly agree" responses across all items= 73.2% (Range 2.2—94.9%; IQR 41.7%)). Negative ratings of experience were infrequent (median proportion of negative [‘strongly disagree’ or ’disagree’] responses= 3.1% per item (Range 0.2—44.3%; IQR 5.5%)). The

median proportion of ‘I cannot answer’ or ’Not applicable’ responses was 13.7% per item (Range 0.4%-90.8%; IQR 34.8%). Table 10.3 presents the items with the highest proportion of positive and negative responses, respectively. Full per-item proportions of responses are presented in Supplementary Material SM10.2.

Table 10.3 Items with the highest and lowest proportions of responses

Items with the highest proportion of positive responses, ranked high to low	**“Agree” OR “Strongly Agree”**	
Item	**N**	**%**
I had confidence in the care provided.	484	94.9
Everything was explained to me in a way that I could understand.	481	94.3
My dignity was respected.	481	94.3
My privacy was respected.	477	93.5
Staff were respectful.	476	93.3
Staff were kind.	475	93.1
I did not feel vulnerable.	475	93.1
Staff Introduced themselves.	474	92.9
Staff were competent.	474	92.9
The department was clean and tidy.	473	92.7
Items with the highest proportion of negative responses, ranked high to low	**“Strongly Disagree” OR “Disagree”**	
Item	**N**	**%**
I was told whether I was allowed to eat or drink.	226	44.3
I was informed about waiting times.	213	41.8
I was given updates while I was waiting.	212	41.6
Staff asked how I would like to be addressed.	126	24.7
I was asked about pain more than once.	85	16.7
I was able to get food or drink if needed.	83	16.3
My skin was assessed for damage.	74	14.5
I could easily read name badges.	73	14.3
I had enough access to blankets and pillows.	66	12.9
The seat or bed was comfortable.	66	12.9

10.5.4 Hierarchical Item Reduction (HIR)

Using the predetermined criteria, 33 out of 82 items (40.2%) were excluded for non-engagement. Five items (6.1%) demonstrated ceiling effects. No floor effects were observed.

The remaining 32 items were assessed for differential validity based on the proportions of responses by age group, gender, and mode of arrival. No gender-specific differences occurred. Two items were excluded due to differences by age group. These were “I had enough access to pillows and blankets” (‘agree/strongly agree’ 44.0% <85 years *vs.* 58.4% ≥85 years (p=0.04)), and “I was involved in decisions about my care” (‘agree/strongly agree’ 68.5% <85 years *vs.* 58.4% ≥85 years (p=0.04)). A further item was excluded because of differences in responses based on the mode of arrival (“staff told me if they were unsure about anything”)(‘agree/ strongly agree’ responses 62.2% ambulance vs 44.2% all other transport (p=0.01)).

Inter-item correlation ≥0.8 occurred for six groups of items. The conceptual similarity of these items was confirmed, and a further 12 items were excluded.

In summary, 53 out of 82 items (64.6%) were excluded using HIR. Full findings can be found in Supplementary Material SM10.3.

10.5.5 Exploratory Factor Analysis

The remaining twenty-nine items underwent EFA. Little’s MCAR test was non-significant (p=0.825), confirming the suitability of E-M for imputation of missing values.

Pair-wise correlation coefficients between items were all lower than 0.8. One item (“Staff cared about my wellbeing”) had an initial communality <0.2 and was excluded. The KMO Measure of Sampling Adequacy and Bartlett’s Test of sphericity were both satisfactory (0.932 and p<0.05, respectively).

Exploratory factor analysis identified four factors with an Eigenvalue ≥1. Stepwise refinement of the structure excluded a single item with cross-loading >0.4 (“I was asked how I would like to be addressed”) and two items with a communality of <0.4 (“I could easily read name badges” and “the temperature was about right”).

A subsequent factor structure comprising 25 items distributed across four factors was established, explaining 65.4% of the total variance. The scree plot supported the retention of all four factors (Supplementary Material SM10.4). All items demonstrated loadings >0.4 onto a single factor; average communality was 0.6. Patterns of loading of items indicate that the scales measure (i) relational care, (ii) the ED environment, (iii) staying informed, and (iv) pain assessment. Internal consistency of each of the scales was good—excellent (Cronbach’s alpha 0.944—0.786; mean 0.870) (Supplementary Material 10.5)

10.5.6 Test-Retest Reliability

One hundred sixty-one retest surveys were issued, of which 52 were returned within 7—10 days (32.3%). Missing data (16.7%) were also imputed using E-M (Supplementary Material SM10.6). The overall ICC for the 25 items and four subscales was 0.670 (95% CI 0.632-0.704), indicating good test-retest reliability (Supplementary Material SM10.7).

10.5.7 Criterion Validity

The average correlation between PREM-ED 65 items and the FFTQ was fair (r=0.397). The strongest positive correlation was for the item "A&E met my expectations" (r= 0.592). (Supplementary Table 10.8)

10.6 Finalised instrument

The finalised, 25-item version of PREM-ED 65 retains user-friendly design features established with stakeholders, and the concise length is appropriate for routine administration to ED patients. This version may be reproduced and copied under the Creative Commons Licence (Figure 9.3; overleaf).

PReM- ED 65

Measuring, Informing and Improving Older Peoples' experiences of emergency department care

[Institution Logo Here]

Please tell us about your experience in A&E today.

This questionnaire asks you about your experience in the A&E department today. It is two pages long and consists of twenty- five questions. It will normally take about 5 minutes to complete.

You can ask a friend or relative to help you complete the questionnaire, but the views expressed must be your own.

Please answer all questions that apply to you.

Your answers will be used to identify areas where we can improve care for older adults attending this A&E department in the future.

Thank you!

Details about your visit.

So that we can better understand your answers, please tell us about yourself and the reasons for your visit here:

Gender ☐ Male ☐ Female ☐ non-Binary ☐ Prefer not to say.

Age Range ☐ 65—74 years ☐ 75—84 years ☐ 85 years and above

Ethnic Group ☐ White ☐ Mixed/ Multiple ☐ Asian ☐ Black ☐ Another ethnic group

Arrival Transport ☐ Private Transport ☐ Ambulance ☐ Public Transport ☐ Prefer not to say.

Reason for today's visit ☐ A medical condition ☐ An injury ☐ Unsure ☐ Prefer not to say

Do you have an accompanying relative or friend? ☐ Yes ☐ No ☐ Prefer not to say

How well have we looked after you today?

Relational care looks at how well our staff have communicated and cared for you as an individual. Please tell us about your experience of receiving **relational care** in the A&E department today, by indicating with a ✓ how much you agree or disagree with the following statements:

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	Cannot answer
Staff thoroughly assessed my condition	☐	☐	☐	☐	☐
I understood why tests were needed	☐	☐	☐	☐	☐
Staff could locate the right equipment	☐	☐	☐	☐	☐
I was treated like I mattered during my A&E stay	☐	☐	☐	☐	☐
Staff explained what was going to happen	☐	☐	☐	☐	☐
Staff checked I understood what was said	☐	☐	☐	☐	☐
I felt able to ask questions	☐	☐	☐	☐	☐
Staff introduced themselves by name	☐	☐	☐	☐	☐
A&E met my expectations	☐	☐	☐	☐	☐
I felt ready to cope at home	☐	☐	☐	☐	☐
Staff asked my permission before treating me	☐	☐	☐	☐	☐
I was told when I was ready for discharge home	☐	☐	☐	☐	☐

Figure 10.3 Finalised Version of PREM-ED 65

PReM- ED 65

Measuring, Informing and **Improving** Older Peoples' experiences of emergency department care

[Institution Logo Here]

What has it been like visiting our A&E department today?

Please tell us about your experience of the **A&E environment** today, by indicating with a ✓ how much you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Cannot answer
It was easy to find and use the toilets	☐	☐	☐	☐	☐
I could go to the toilet in dignity	☐	☐	☐	☐	☐
The A&E department was clean and tidy	☐	☐	☐	☐	☐
I felt safe whilst I was waiting	☐	☐	☐	☐	☐
I could get help if I needed it	☐	☐	☐	☐	☐
I was able to find a seat or bed	☐	☐	☐	☐	☐
My seat or bed was comfortable	☐	☐	☐	☐	☐
I felt cared for whilst I was waiting	☐	☐	☐	☐	☐

Have we kept you informed today?

Please tell us about your experience of **staying informed** in A&E today, by indicating how much you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Cannot answer
I was given updates whilst waiting	☐	☐	☐	☐	☐
I was informed about waiting times	☐	☐	☐	☐	☐
I was informed whether I could eat or drink	☐	☐	☐	☐	☐

Have we assessed your pain?

Please tell us about your experience of **receiving pain assessment** in A&E today, by indicating how much you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Agree	Strongly Agree	Cannot answer
I was asked how much pain I was in	☐	☐	☐	☐	☐
I was asked how much pain I was in more than once	☐	☐	☐	☐	☐

About PREM-ED 65

PREM- ED is a patient reported experience measure originally developed by Blair Graham, Jason E Smith, Pamela Nelmes, Jos M Latour, in association with the University of Plymouth, University Hospitals Plymouth NHS Trust, and supported by the Royal College of Emergency Medicine (UK).

Cite: Graham B et al, 2023.

For further information including associated publications, see https://premedstudy.wordpress.com/

Images: openclipart.org, no attribution required.

Figure 10.3: Finalised Version of PREM-ED 65 (Page 2 of 2)

10.7 Discussion

This study aimed to provide initial psychometric validation for PREM-ED 65.

The resulting 25-item PREM-ED 65 captures essential aspects of the care experience for older adults discharged from the ED, including relational care with providers, the ED environment, information provision, and pain assessment. The resulting structure meets predetermined psychometric and interpretability criteria and is intended to follow COSMIN standards for content validity, structural validity, and internal consistency.(19)

Whilst participants mainly reported a positive ED experience, several items with higher proportions of negative responses related to waiting experience (e.g., “I was given updates whilst waiting), physical comfort (e.g., the seat or bed was comfortable), and provision of refreshments (“e.g., I was able to get food or drink if needed”). These findings may indicate areas where real-world quality improvement may be indicated and beneficial.

Common barriers to adopting patient-reported measures in the ED, including timing of administration, development of relevant measures, and accommodating differing patient priorities,(25) have been addressed throughout the development of PREM-ED 65. The high test-retest reliability suggests that PREM-ED 65 is suitable for administration after an ED attendance or up to 10 days post-attendance.

Eliminating items with low engagement is intended to facilitate ease of survey administration and limit respondent fatigue, acquiescence bias, and satisficing,

all of which may adversely affect response rate and instrument reliability.(26) Hierarchical item reduction excluded items with low response rates relating to the reception area, presence of disability, sensory disturbance, non-pain symptomatology, and interpretation requirements. Excluding items with significant differential validity aims to ensure that survey results are not inadvertently biased towards a certain sub-population; in the case of PREM-ED 65, such items were limited to providing blankets/ pillows, shared decision-making, and communication of uncertainty.

Whilst eliminating unnecessary items is essential for creating PREMs that are user-friendly for the general patient population, exclusion may not diminish their potential value for select subgroups. We advocate the development of supplementary scales for future iterations of PREM-ED 65 to ensure the experiences of minority, underrepresented, and very old/ frail adult populations are captured. This is especially pertinent as implicit bias within healthcare may negatively impact patient experience, health outcomes, and patient safety.(27) For example, the significant differential validity observed for “I was involved in decisions about my care” may indicate that very old adults are less involved in shared decision-making.

In keeping with similar literature, our findings revealed only a fair correlation with the FFTQ, suggesting that PREM-ED 65 provides a more comprehensive measure of patient experience, extending beyond the likelihood of recommending care.(28)

10.7.1 Limitations

Although opportunistic sampling precluded the calculation of a precise capture rate, using the sampling matrix resulted in a representative distribution of participants. Characteristics of the study sample generally align with UK ED attendance patterns. The lower-than-expected proportion of ambulance arrivals was likely due to excluding high-acuity and admitted patients. Although we did not include patients with known or suspected SARS-CoV-2, pandemic precautions restricted the presence of accompanying persons and may have broadly impacted waiting times and ambulance conveyance rates.

Whilst the age-related inclusion criterion for PREM-ED 65 has been adopted for simplicity, chronological definitions of older age are imperfect due to heterogeneity of ageing.(29) Further work is required to ensure PREM-ED 65 captures the needs of very old adults, those living with frailty, or other long-term conditions. Validation amongst older adults hospitalised from the ED should be a priority, as this group may be especially vulnerable to shortcomings in care processes. Different approaches may be required to ensure perceptions of experience amongst older adults with cognitive impairment are represented.

Whilst PREM-ED 65 demonstrates promising psychometric properties, confirmatory factor analysis with additional data is desirable to confirm the stability of the four measurement scales. Separate cross-cultural adaptation will ensure applicability to patients from minority ethnic and non-English speaking backgrounds. Future studies may also explore the effect of characteristics such as education, health literacy, and socioeconomic status on ED patient

experiences. Finally, while comparing PREM-ED 65 scores to the FFTQ provides a preliminary test of criterion validity, the FFTQ does not represent a 'gold standard' test of patient experience with limitations relating to question construct, comprehension, and differential validity.(30) Therefore, a comparative analysis of PREM-ED 65 with other ED-specific PREMs or satisfaction surveys is desirable.

10.8 Conclusion

The 25-item PREM-ED 65 is suitable for administration to older adults up to ten days following ED discharge. Findings may be used to assess the quality of ED services from older adults' perspectives, identify areas for impactful quality improvement, and monitor service quality over time. Future priorities should include validating PREM-ED 65 in those hospitalised from the ED and developing supplementary scales to capture the experiences of under-represented patient groups fully. Further studies employing confirmatory factor analysis are desirable to ensure stability, relevance, and sensitivity, particularly amongst very old adults and those living with frailty.

Post Publication Addendum

Contribution to the PREM-ED 65 Study

This study represents the final stage in the current research programme, resulting in a 25-item PREM-ED 65 that demonstrates suitable validity and reliability for administration to older adults following ED discharge.

Next, the penultimate chapter of this thesis presents a process evaluation that considers the validation study from student collaborators' perspectives.

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Supplementary Material

SM 10.1 Draft Instrument

PREM ED 65 Validation Study

The PReM-ED Study

Please tell us about your experience in A&E

Thank you for taking part!

This questionnaire is part of a research project looking at experiences of older adults when they attend the emergency department (A&E).

Please make sure you read the information leaflet and sign the consent form before completing the questionnaire.

The questionnaire will take about 20 minutes to complete.

Remember to ask if you would prefer a member of the research team to help you complete the questionnaire.

We are very grateful for your help with this project, which will help us to measure and improve emergency care for people aged over 65.

University Hospitals Plymouth NHS | UNIVERSITY OF PLYMOUTH | The Royal College of Emergency Medicine

PREM ED 65 Validation Study

A few details about me and my A&E visit

I am...

☐ A man
☐ A woman
☐ I would prefer not to say

My age, in years, is...

_____ Years
☐ I would prefer not to say

I attended A&E because of...

☐ An illness or medical complaint
☐ An injury or accident
☐ Another problem
☐ I would prefer not to say

I arrived in A&E by...

☐ Ambulance
☐ Private Transport
☐ Public Transport
☐ I would prefer not to say

I spent roughly the following amount of time in A&E...

_____ Hours _____ Minutes
☐ I cannot remember
☐ I would prefer not to say

Did any friends, family or carers accompany you to A&E?

☐ Yes
☐ No
☐ I would prefer not to say

I belong to the following ethnic group...

PREM ED 65 Validation Study

Choose one option that best describes your ethnic group or background

☐ White
☐ Irish Traveller

Mixed/Multiple ethnic groups

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed/Multiple ethnic background, please describe

_____

Asian/Asian British

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, please describe

_____

Black/African/Caribbean/Black British

☐ African
☐ Caribbean
☐ Any other Black/African/Caribbean background, please describe

_____

Other ethnic group

☐ Arab
☐ Any other ethnic group, please describe

☐ **I would prefer not to say**

PREM ED 65 Validation Study

How to fill out this questionnaire

This questionnaire contains statements which relate to a different aspect of your experience in A&E. An example of a statement might be:

"My cup of tea was nice and warm"

We would like you to indicate your level of agreement with each statement from 'strongly disagree' to 'strongly agree' by ticking the matching box.

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
My cup of tea was nice and warm	☐	☐	✓	☐	☐

Your judgement should be based on your experience of A&E care. Please give your most honest opinion. **It is ok to be critical**, as this helps us improve care for others.

Sometimes a statement may not apply to you, or you may not be able to remember. In this case, simply tick the 'I cannot answer' box.

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
My cup of tea was nice and warm	☐	☐	☐	☐	✓

Please feel free to complete the questionnaire at your own pace.

Do ask your research assistant if you would like help to complete the questionnaire. They can help by reading the questions to you and ticking the boxes for you.

If you have any other questions, please speak to the research assistant.

Thank you again for taking part in this research project, which will help us to better care for people like you in the future.

Part 1: My experience of arriving and waiting in A&E

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
The signs in A&E were easy to follow	☐	☐	☐	☐	☐
The reception desk was easy to find	☐	☐	☐	☐	☐
The receptionist was kind	☐	☐	☐	☐	☐
The waiting room was pleasant	☐	☐	☐	☐	☐
I felt safe whilst I was waiting	☐	☐	☐	☐	☐
I felt cared for whilst I was waiting	☐	☐	☐	☐	☐
I was informed about waiting times	☐	☐	☐	☐	☐
I was given updates whilst I was waiting	☐	☐	☐	☐	☐
I felt like I could get help if I needed it	☐	☐	☐	☐	☐
I was offered a seat or a bed	☐	☐	☐	☐	☐
The seat or bed was comfortable	☐	☐	☐	☐	☐
I was told whether I was allowed to eat or drink	☐	☐	☐	☐	☐
I was able to get food or drink if needed	☐	☐	☐	☐	☐
The temperature in A&E was about right	☐	☐	☐	☐	☐
I had enough access to blankets and pillows	☐	☐	☐	☐	☐
The department was clean and tidy	☐	☐	☐	☐	☐
It was easy to find and use the toilets	☐	☐	☐	☐	☐
I could go to the toilet in a dignified way	☐	☐	☐	☐	☐

Part 2: My initial symptoms

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
I was asked how much pain I was in	☐	☐	☐	☐	☐
I was asked about pain more than once	☐	☐	☐	☐	☐
Pain medicine arrived quickly	☐	☐	☐	☐	☐
Pain medicine worked well	☐	☐	☐	☐	☐
I received relief for shortness of breath	☐	☐	☐	☐	☐
I received relief for other symptoms	☐	☐	☐	☐	☐

Part 3: My Unique Needs

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
My disability was recognised	☐	☐	☐	☐	☐
Staff were considerate of my mobility issues	☐	☐	☐	☐	☐
Staff were considerate of my hearing loss	☐	☐	☐	☐	☐
Staff were considerate of my visual loss	☐	☐	☐	☐	☐
Staff respected my language needs	☐	☐	☐	☐	☐
Staff understood my cultural needs	☐	☐	☐	☐	☐
I was offered an interpreter when needed	☐	☐	☐	☐	☐
My age did not get in the way of my care	☐	☐	☐	☐	☐

Part 4: My experience of care in A&E

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
Staff asked my permission before treating me	☐	☐	☐	☐	☐
I understood the possible risks of treatments	☐	☐	☐	☐	☐
Staff explained what was going to happen	☐	☐	☐	☐	☐
I was told when something might be painful	☐	☐	☐	☐	☐
I understood why tests were required	☐	☐	☐	☐	☐
I was told why I needed medication	☐	☐	☐	☐	☐
I was told about possible side effects of new medication	☐	☐	☐	☐	☐
I was given a choice whether to take new medication or not	☐	☐	☐	☐	☐
I was able to take my usual medication	☐	☐	☐	☐	☐
I was involved in decisions about my care	☐	☐	☐	☐	☐
I felt able to ask questions	☐	☐	☐	☐	☐
The answers to my questions were clear	☐	☐	☐	☐	☐
Everything was explained to me in a way that I could understand	☐	☐	☐	☐	☐
Staff told me if they were unsure about anything	☐	☐	☐	☐	☐
Staff told me what was likely to be wrong	☐	☐	☐	☐	☐
My skin was assessed for damage	☐	☐	☐	☐	☐
Staff were able to locate the right equipment	☐	☐	☐	☐	☐
My condition was assessed thoroughly	☐	☐	☐	☐	☐
I had confidence in the care provided	☐	☐	☐	☐	☐

Part 5: My discharge experience

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
Staff informed me when I was going to be sent home	☐	☐	☐	☐	☐
I felt safe to be discharged	☐	☐	☐	☐	☐
I was told what to do if things got worse	☐	☐	☐	☐	☐
My pain was under control after being discharged	☐	☐	☐	☐	☐
I felt ready to cope at home	☐	☐	☐	☐	☐

Part 6: My views on the A&E team

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
The Staff looking after me…					
…introduced themselves to me	☐	☐	☐	☐	☐
…told me their name	☐	☐	☐	☐	☐
…asked how I would like to be addressed	☐	☐	☐	☐	☐
…checked that I understood what they had said	☐	☐	☐	☐	☐
…spent enough time speaking with me	☐	☐	☐	☐	☐
…were concerned about my wellbeing	☐	☐	☐	☐	☐
…responded to my needs	☐	☐	☐	☐	☐
"Taken as a whole, I think that the A&E team was…"					
…kind	☐	☐	☐	☐	☐
…caring	☐	☐	☐	☐	☐
…respectful	☐	☐	☐	☐	☐
…helpful	☐	☐	☐	☐	☐
…competent	☐	☐	☐	☐	☐
I could easily read name badges	☐	☐	☐	☐	☐
Junior staff seemed well supervised	☐	☐	☐	☐	☐
The porters were kind	☐	☐	☐	☐	☐
The cleaners and housekeepers were kind	☐	☐	☐	☐	☐

Part 7: My general thoughts about A&E

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
"During my A&E stay…"					
…I was treated like I mattered	☐	☐	☐	☐	☐
…my privacy was respected	☐	☐	☐	☐	☐
…my dignity was respected	☐	☐	☐	☐	☐
…I did not feel vulnerable	☐	☐	☐	☐	☐
…I did not feel alone	☐	☐	☐	☐	☐
"Family members or friends accompanying me…"					
…were treated respectfully	☐	☐	☐	☐	☐
…were involved in my care as much as I wanted	☐	☐	☐	☐	☐
…did not get in the way of my care	☐	☐	☐	☐	☐
A&E met my expectations	☐	☐	☐	☐	☐
My journey through A&E felt efficient	☐	☐	☐	☐	☐

Part 8: My final recommendation

Please tick (✓) one option per statement	Strongly Disagree	Disagree	Agree	Strongly Agree	I cannot answer
I would recommend this A&E to my friends or family members if they were in a similar situation	☐	☐	☐	☐	☐
I would like to attend this A&E again if I were to have an emergency in the future	☐	☐	☐	☐	☐

Making a formal compliment or complaint about your care

If you would like to make a formal complaint or compliment about your care, please speak with your research assistant. Your local **Patient Advice and Liaison Service (PALS)** will also be able to help:

[Name of PALS Contact Here]

[Telephone Number of PALS Contact Here]

Please still return this questionnaire, even if you would like to make a formal compliment or complaint.

Returning this questionnaire

You can return this questionnaire by the following means.

	Hand Back to your research assistant. They can provide you with an envelope to seal your questionnaire in.
	Post the questionnaire using the self-addressed envelope provided, or to the following address: **PREM-ED Study, c/o Dr Blair Graham, Level 4 Nancy Astor Building, University of Plymouth, Plymouth, PL4 8AA.**

Thank you for taking part!

PEM10d: Initial Questionnaire ELECTRONIC VERSION

The PREM-ED Study

PREM-ED 65+ Survey (Electronic Version 1.1 Updated 14 April 2021)

Please tell us about your experience in A&E

SM 10.2 Per Item Proportion of Responses

Item	Value Descriptor	1 Strongly Disagree		2 Disagree		3 Agree		4 Strongly Agree		Distribution of responses Skew*	Mean (95%CI)	Median (IQR)	Missing Total Missing		Cannot Answer		Blank	
	Participants	Proportion of Responses																
	N	N	%	N	%	N	%	N	%				N	%	N	%	N	%
The signs were easy to follow	510	5	1.0	19	3.7	255	50	120	23.5	-0.47	3.23 (3.17-3.29)	3 (1)	111	21.8	102	20.0	9	1.8
The reception desk was easy to find	510	2	0.4	5	1.0	205	40.2	148	29.0	-0.30	3.39 (3.33-3.44)	3 (1)	150	29.4	142	27.8	8	1.6
The receptionist was kind	510	3	0.6	4	0.8	191	37.5	162	31.8	-0.59	3.42 (3.36-3.48)	3 (1)	150	29.4	137	26.9	13	2.5
The waiting room was pleasant	510	2	0.4	34	6.7	244	47.8	97	19.0	-0.20	3.16 (3.10-3.22)	3 (1)	133	26.1	124	24.3	9	1.8
I felt safe whilst I was waiting	510	3	0.6	11	2.2	262	51.4	189	37.1	-0.57	3.37 (3.32-3.42)	3 (1)	45	8.8	34	6.7	11	2.2
I felt cared for during my A&E visit	510	6	1.2	35	6.9	264	51.8	145	28.4	-0.53	3.22 (3.16-3.18)	3 (1)	60	11.8	49	9.6	11	2.2
I was informed about waiting times	510	45	8.8	168	32.9	132	25.9	70	13.7	-0.78	2.93 (2.86-2.63)	2 (1)	95	18.6	83	16.3	12	2.4
I was given updates whilst I was waiting	510	47	9.2	165	32.4	154	30.2	61	12.0	-0.04	2.54 (2.45-2.62)	3 (1)	83	16.3	67	13.1	16	3.1
I felt like I could get help if I needed it	510	10	2.0	24	4.7	286	56.1	150	31.0	-0.78	3.24 (3.18-3.30)	3 (1)	32	6.3	21	4.1	11	2.2
I was offered a seat or a bed	510	10	2.0	17	3.3	274	53.7	177	34.7	-0.83	3.29 (3.24-3.35)	3 (1)	32	6.3	22	4.3	10	2.0
The seat or bed was comfortable	510	10	2.0	56	11.0	266	52.2	135	26.5	-0.56	3.13 (3.06-3.19)	3 (1)	43	8.4	27	5.3	16	3.1
I was told whether I was allowed to eat or drink	510	54	10.6	172	33.7	121	23.7	74	14.5	-0.15	2.51 (2.42-2.60)	2 (1)	89	17.5	73	14.3	16	3.1
I was able to get food or drink if needed	510	19	3.7	64	12.5	208	40.8	112	22.0	-0.62	3.02 (2.95-3.10)	3 (1)	107	21.0	94	18.4	13	2.5
The temperature in A&E was about right	510	11	2.2	38	7.5	288	56.4	137	26.9	-0.67	3.16 (3.10-3.22)	3 (1)	26	5.1	15	2.9	11	2.2
I had enough access to blankets and pillows	510	17	3.3	49	9.6	149	29.2	99	19.4	-0.67	3.05 (2.96-3.14)	3 (1)	196	38.4	173	33.9	23	4.5
The department was clean and tidy	510	5	1.0	10	2.0	275	53.9	198	38.8	-0.58	3.36 (3.31-3.42)	3 (1)	22	4.3	11	2.2	11	2.2
It was easy to find and use the toilets	510	11	2.2	21	4.1	233	45.7	156	30.6	-0.90	3.27 (3.20-3.33)	3 (1)	89	17.5	79	15.5	10	2.0
I could go to the toilet in a dignified way	510	7	1.4	13	2.5	231	45.3	170	33.3	-0.81	3.34 (3.28-3.40)	3 (1)	89	17.5	75	14.7	14	2.7
I was asked how much pain I was in	510	9	1.8	47	9.2	261	51.2	160	31.4	-0.63	3.20 (3.14-3.26)	3 (1)	33	6.5	22	4.3	11	2.2
I was asked about pain more than once	510	17	3.3	68	13.3	230	45.1	142	27.8	-0.63	3.09 (3.02-3.16)	3 (1)	53	10.4	39	7.6	14	2.7
Pain medicine arrived quickly	510	12	2.4	37	7.3	96	17.3	52	10.2	-0.53	2.95 (2.83-3.07)	3 (2)	321	62.9	293	57.5	28	5.5
Pain medicine worked well	510	6	1.2	23	4.5	95	18.2	48	9.4	-0.64	3.08 (2.96-3.19)	3 (1)	340	66.7	316	62.0	24	4.7
I received relief for shortness of breath	510	10	2.0	21	4.1	29	5.7	23	4.5	-0.32	2.78 (2.57-3.00)	3 (2)	427	83.7	396	77.6	31	6.1
I received relief for other symptoms	510	9	1.8	28	5.5	74	14.5	45	8.8	-0.39	2.99 (2.86-3.13)	3 (1)	354	69.4	327	64.1	27	5.3
My disability was recognised	510	3	0.6	13	2.5	147	28.8	76	14.9	-0.31	3.24 (3.16-3.32)	3 (1)	271	53.1	247	48.4	24	4.7
Staff were considerate of my mobility issues	510	3	0.6	12	2.4	156	30.6	120	23.5	-0.65	3.35 (3.28-3.42)	3 (1)	219	42.9	200	39.2	19	3.7
Staff were considerate of my hearing loss	510	4	0.8	12	2.4	84	16.5	47	9.2	-0.76	3.18 (3.07-3.30)	3 (1)	363	71.2	335	65.7	28	5.5
Staff were considerate of my visual loss	510	4	0.8	11	2.2	67	13.1	19	3.7	-0.79	3.00 (2.87-3.13)	3 (1)	409	80.2	380	74.5	29	5.7
Staff respected my language needs	510	2	0.4	2	0.4	32	6.3	18	3.5	-1.04	3.22 (3.03-3.41)	3 (1)	456	89.4	424	83.1	32	6.3
Staff understood my cultural needs	510	4	0.8	0	0.0	42	8.2	20	3.9	-1.30	3.18 (3-3.36)	3 (1)	444	87.1	412	80.8	32	6.3
I was offered an interpreter when needed	510	2	0.4	0	0.0	8	1.6	3	0.6	-1.18	2.92 (2.35-3.50)	3 (1)	497	97.5	463	90.8	34	6.7
My age did not get in the way of my care	510	5	1.0	7	1.4	168	36.9	179	39.3	-0.89	3.34 (3.27-3.40)	3 (1)	131	25.6	115	22.5	16	3.1
Staff asked my permission before treating me	510	2	0.4	26	5.1	271	53.1	149	29.2	-0.25	3.27 (3.21-3.33)	3 (1)	62	12.2	47	9.2	15	2.9
I understood the possible risks of treatments	510	1	0.2	25	4.9	205	40.2	101	19.8	-0.18	3.22 (3.16-3.29)	3 (1)	178	34.9	154	30.2	24	4.7
Staff explained what was going to happen	510	4	0.8	18	3.5	277	54.3	173	33.9	-0.43	3.31 (3.26-3.36)	3 (1)	38	7.5	21	4.1	17	3.3
I was told when something might be painful	510	3	0.6	35	6.9	215	42.2	127	24.9	-0.42	3.23 (.316-3.29)	3 (1)	130	25.5	110	21.6	20	3.9
I understood why tests were required	510	2	0.4	8	1.6	260	51.0	179	35.1	-0.23	3.37 (3.32-3.42)	3 (1)	61	12.0	43	8.4	18	3.5
I was told why I needed medication	510	4	0.8	11	2.2	165	32.4	105	20.6	-0.65	3.20 (3.23-3.37)	3 (1)	225	44.1	199	39.0	26	5.1
I was told about possible side effects of new medication	510	2	0.4	39	7.6	81	15.9	57	11.2	-0.29	3.08 (2.97-3.19)	3 (1)	331	64.9	300	58.8	31	6.1
I was given a choice whether to take new medication or not	510	2	0.4	34	6.7	87	17.1	56	11.0	-0.33	3.10 (2.99-3.21)	3 (1)	331	64.9	300	58.8	31	6.1
I was able to take my usual medication	510	6	1.2	27	5.3	159	31.2	91	17.8	-0.65	3.18 (3.10-3.26)	3 (1)	227	44.5	198	38.8	29	5.7
I was involved in decisions about my care	510	10	2.0	32	6.3	226	44.3	125	24.5	-0.74	3.19 (3.12-3.25)	3 (1)	117	22.9	87	17.1	30	5.9
I felt able to ask questions	510	1	0.2	7	1.4	270	52.9	203	39.8	-0.11	3.40 (3.36-3.45)	3 (1)	29	5.7	14	2.7	15	2.9
The answers to my questions were clear	510	2	0.4	4	0.8	265	52.0	202	39.6	-0.23	3.41 (3.36-3.46)	3 (1)	37	7.3	21	4.1	16	3.1
Everything was explained to me in a way that I could understand	510	2	0.4	2	0.4	278	54.5	203	39.8	-0.14	3.41 (3.36-3.45)	3 (1)	25	4.9	11	2.2	14	2.7
Staff told me if they were unsure about anything	510	8	1.6	26	5.1	192	37.6	109	21.4	-0.73	3.20 (3.13- 3.23)	3 (1)	175	34.3	153	30.0	22	4.3
Staff told me what was likely to be wrong	510	10	2.0	38	7.5	218	42.7	131	25.7	-0.71	3.18 (3.11-3.25)	3 (1)	113	22.2	90	17.6	23	4.5
My skin was assessed for damage	510	16	3.1	58	11.4	125	24.5	78	15.3	-0.49	2.96 (2.86-3.06)	3 (2)	233	45.7	204	40.0	29	5.7
Staff were able to locate the right equipment	510	1	0.2	8	1.6	243	47.6	157	30.8	-0.05	3.36 (3.31- 3.41)	3 (1)	101	19.8	78	15.3	23	4.5
My condition was assessed thoroughly	510	2	0.4	15	2.9	247	49.4	216	42.4	-0.47	3.41 (3.36-3.46)	3 (1)	30	5.9	19	3.7	11	2.2
I had confidence in the care provided	510	1	0.2	5	1.0	240	47.1	244	47.8	-0.34	3.48 (3.44-3.53)	3 (1)	20	3.9	8	1.6	12	2.4
Staff informed me when I was going to be sent home	510	8	1.6	26	5.1	235	46.1	151	29.6	-0.74	3.26 (3.20-3.32)	3 (1)	90	17.6	62	12.2	28	5.5
I felt safe to be discharged	510	1	0.2	10	2.0	250	49.0	177	34.7	-0.14	3.38 (3.33-3.43)	3 (1)	72	14.1	46	9.0	26	5.1
I was told what to do if things get worse	510	9	1.8	40	7.8	214	42.0	133	26.1	-0.68	3.19 (3.12-3.26)	3 (1)	114	22.4	81	15.9	33	6.5
My pain was under control after being discharged	510	3	0.6	24	4.7	183	35.9	111	21.8	-0.48	3.25 (3.18-3.32)	3 (1)	189	37.1	156	30.6	33	6.5
I felt ready to cope at home	510	4	0.8	6	1.2	255	50.0	160	32.9	-0.45	3.36 (3.30- 3.41)	3 (1)	77	15.1	51	10.0	26	5.1
Staff Introduced themselves	510	2	0.4	8	1.6	255	50.0	219	42.9	-0.38	3.45 (3.38-3.48)	3 (1)	28	5.1	6	1.2	20	3.9
Staff Told me their name	510	3	0.6	12	2.4	253	49.6	211	41.4	-0.32	3.40 (3.35-3.45)	3 (1)	31	6.1	11	2.2	20	3.9
Staff asked how I would like to be addressed	510	16	3.1	110	21.6	177	34.7	124	24.3	-0.30	2.96 (2.88-3.04)	3 (1)	83	16.3	53	10.4	30	5.9
Staff checked that I understood what they had said	510	3	0.6	31	6.1	266	52.2	163	32.0	-0.40	3.27 (3.22-3.33)	3 (1)	47	9.2	23	4.5	24	4.7
Staff spent enough time speaking with me	510	1	0.2	13	2.5	272	53.3	196	38.4	-0.18	3.38 (3.33-3.42)	3 (1)	28	5.5	7	1.4	21	4.1
Staff were concerned about my wellbeing	510	4	0.8	7	1.4	270	52.9	194	38.0	-0.47	3.38 (3.33-3.43)	3 (1)	35	6.9	13	2.5	22	4.3
Staff responded to my needs	510	2	0.4	7	1.4	271	53.1	201	39.4	-0.25	3.40 (3.35-3.44)	3 (1)	29	5.7	8	1.6	21	4.1
Staff were kind	510	4	0.8	2	0.4	211	41.4	264	51.8	-0.92	3.53 (3.48-3.58)	4 (1)	29	5.7	5	1.0	24	4.7
Staff were caring	510	3	0.6	6	1.2	206	40.4	267	52.4	-0.87	3.53 (3.48-3.58)	4 (1)	28	5.5	4	0.8	24	4.7
Staff were respectful	510	4	0.8	2	0.4	212	41.6	264	51.8	-0.91	3.53 (3.48-3.58)	4 (1)	28	5.5	2	0.4	26	5.1
Staff were helpful	510	3	0.6	7	1.4	207	40.6	265	52.0	-0.86	3.52 (3.47-3.57)	4 (1)	28	5.5	3	0.6	25	4.9
Staff were competent	510	4	0.8	2	0.4	203	39.8	271	53.1	-0.99	3.54 (3.49- 3.58)	4 (1)	30	5.9	3	0.6	27	5.3
I could easily read name badges	510	15	2.9	58	11.4	207	40.6	148	29.0	-0.70	3.14 (3.07-3.21)	3 (1)	82	16.1	60	11.8	22	4.3
Junior staff seemed well supervised	510	0	0.0	8	1.6	220	43.1	133	26.1	-0.97	3.35 (3.29-3.4)	3 (1)	149	29.2	129	25.3	20	3.9
The porters were kind	510	0	0.0	1	0.2	164	32.2	111	21.8	-0.33	3.40 (3.34-3.46)	3 (1)	234	45.9	208	40.8	26	5.1
The cleaners were kind	510	0	0.0	3	0.6	144	28.2	96	18.8	-0.20	3.38 (3.32-3.45)	3 (1)	267	52.4	241	47.3	26	5.1
I was treated like I mattered during my A&E stay	510	1	0.2	9	1.8	258	50.6	208	40.8	-0.21	3.41 (3.37-3.46)	3 (1)	34	6.7	11	2.2	23	4.5
My privacy was respected during my A&E stay	510	1	0.2	4	0.8	267	52.4	210	41.2	-0.08	3.42 (3.38-3.47)	3 (1)	28	5.5	9	1.8	19	3.7
My dignity was respected during my A&E stay	510	1	0.2	0	0.0	261	51.2	220	43.1	-0.04	3.43 (3.41-3.50)	3 (1)	28	5.5	8	1.6	20	3.9
I did not feel vulnerable during my A&E stay	510	1	0.2	6	1.2	262	51.4	213	41.8	-0.16	3.43 (3.38-3.47)	3 (1)	28	5.5	9	1.8	19	3.7
I did not feel alone during my A&E stay	510	1	0.2	15	2.9	263	51.6	203	39.8	-0.26	3.39 (3.34-3.44)	3 (1)	28	5.5	11	2.2	17	3.3
My relatives were treated respectfully	510	2	0.4	0	0.0	77	15.1	62	12.2	-0.80	3.41 (3.32-3.51)	3 (1)	369	72.4	332	65.1	37	7.3
My relatives were involved in my care	510	1	0.2	3	0.6	76	14.9	59	11.6	-0.50	3.39 (3.29-3.48)	3 (1)	371	72.7	331	64.9	40	7.8
My relatives did not get in the way	510	1	0.2	1	0.2	75	14.3	61	12.0	-0.31	3.43 (3.33-3.52)	3 (1)	374	73.3	329	64.5	45	8.8
A&E met my expectations	510	6	1.2	9	1.8	219	42.9	227	44.5	-0.95	3.45 (3.39-3.50)	3 (1)	49	9.6	11	2.2	38	7.5
My journey through A&E felt efficient	510	7	1.4	14	2.7	224	43.9	232	45.5	-0.99	3.43 (3.37-3.48)	3 (1)	31	6.5	4	0.8	29	5.7
Total, n	510	93	-	2048	-	16226	-	11628	-	-	-	-	139	-	117		22	-
Median, %	-	-	0.8	-	2.5	-	42.5	-	28.7	-	-	-	-	17.5	-	13.7	-	4.3
Minimum, %	-	-	0.0	-	0.0	-	1.6	-	0.4	-	-	-	-	3.9	-	0.4	-	1.6
Maximum, %	-	-	10.6	-	33.7	-	58.4	-	53.1	-	-	-	-	97.5	-	90.8	-	8.8
IQR, %	-	-	1.2	-	5.0	-	20.8	-	19.9	-	-	-	-	33.5	-	24.8	-	2.5

*Shapiro Wilk Statistic

SM 10.3 Hierarchical Item Reduction Results

a: Items meeting exclusion criteria for Non- Engagement

	"I cannot answer" Or "Not applicable"		Blank		Combined	
Excluded Item (n=33)	N	%	N	%	N	%
I was able to get food or drink if needed	94	18.4	12	2.5	106	20.9
The signs were easy to follow	102	20	8	1.8	110	21.8
Staff told me what was likely to be wrong	90	17.6	23	4.5	113	22.1
I was told what to do if things got worse	81	15.9	33	6.5	114	22.4
My age did not get in the way of my care	100	19.4	16	3.1	116	22.6
I was told when something might be painful	110	21.6	20	3.9	130	25.5
The waiting room was pleasant	124	24.1	9	1.8	133	25.9
Junior staff seemed well supervised	129	25.3	20	3.9	149	29.2
The receptionist was kind	137	26.9	13	2.5	150	29.4
The reception desk was easy to find	142	27.8	9	1.8	151	29.6
I understood the possible risks of treatment	154	30.2	24	4.7	178	34.9
My pain was under control after being discharged	156	30.6	33	6.5	189	37.1
Staff were considerate of my mobility issues	200	39.3	19	3.7	219	43
I was told why I needed medication	199	39	26	5.1	225	44.1
I was able to take my usual medication	198	38.9	29	5.7	227	44.6
My skin was assessed for damage	204	40	29	5.7	233	45.7
The cleaners and housekeepers were kind	241	47.3	26	5.1	267	52.4
My disability was recognised	247	38.8	24	4.7	271	53.1
Pain medicine arrived quickly	293	38.8	28	5.5	321	63
I was given a choice whether to take new medication or not	300	38.8	31	6.1	331	64.9
I was told about the possible side effects of new medication	300	58.9	31	6.1	331	65
Pain medicine worked well	316	38.8	24	4.7	340	66.7
The porters were kind	208	40.8	26	5.1	345	67.7
Staff were considerate of my hearing loss	335	38.8	28	5.5	363	71.1
Relatives were involved in my care as much as I wanted	331	38.8	40	7.8	371	72.7
Relatives did not get in the way of my care	329	38.8	45	8.8	374	73.3
I received relief for other symptoms	327	38.8	27	5.3	354	74.4
Staff were considerate of my visual loss	380	38.8	29	5.7	409	80.3
I received relief for shortness of breath	396	38.8	31	6.1	427	83.7
My relatives/ accompanying persons were treated respectfully	332	65.1	37	7.3	431	84.6
Staff understood my cultural needs	412	80.1	32	6.3	444	86.4
Staff respected my language needs	424	83.2	32	6.3	456	89.5
I was offered an interpreter when required	463	90.9	34	6.7	497	97.6

b: Items meeting exclusion criteria for ceiling effects

Excluded Item (n=5)	Proportion of "Strongly Agree" responses	
	N	%
Staff were kind	264	51.8
Staff were respectful	264	51.8
Staff were helpful	265	52.0
Staff were caring	267	52.4
Staff were competent	271	53.1

c: Items meeting exclusion criteria for differential validity based on gender/ age group/ mode of arrival

Excluded Item (n=3)	Gender[1a]	Age Group[2b]	Mode of Arrival[1c]
	p Value		
I had enough access to blankets and pillows	0.66	0.004†	0.21
I was involved in decisions about my care	0.85	0.012†	0.41
Staff told me if they were unsure about anything	0.62	0.99	0.01†

†p≤0.05

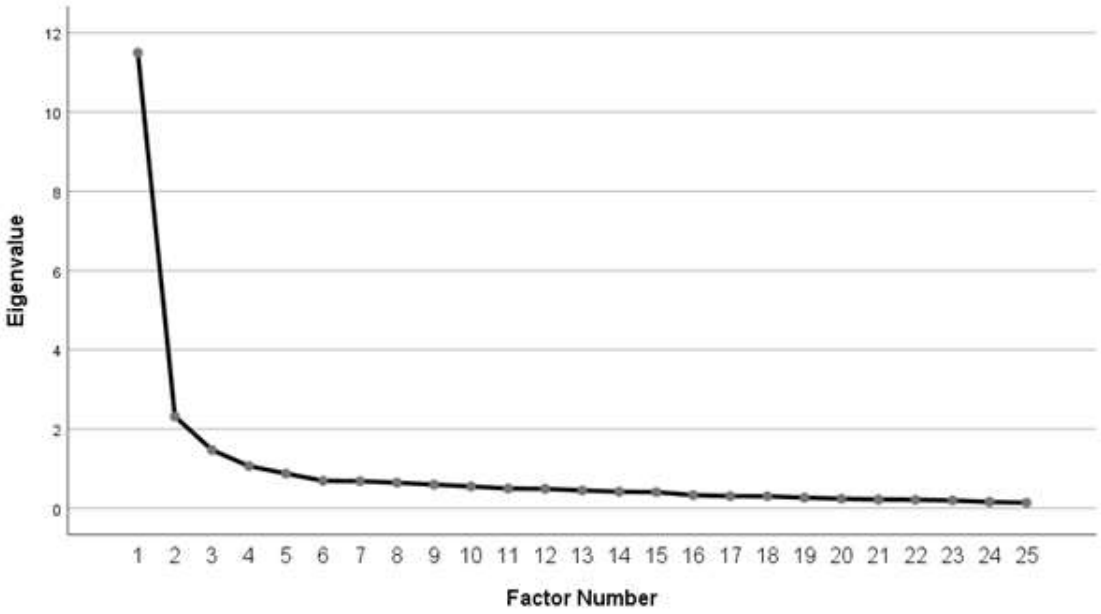
1 Kruskall Wallis Test, 2 Mann Whitney U Test

a 65–74y, 75–84y, >85y b Male, Female c Ambulance, Private Transport, Public Transport

d: Items meeting exclusion criteria for excessive inter-item correlation

Excluded Item (n=12)	r	**Retained Item (n=6)**
The answers to my questions were clear	0.73	I felt able to ask questions
Everything was explained to me in a way I could understand	0.77	
I had confidence in the care provided	0.8	My condition was assessed thoroughly
I felt safe to be discharged	0.78	Staff informed me when I was going to be sent home
Staff told me their name	0.82	
Staff spent enough time speaking with me	0.86	Staff introduced themselves
Staff responded to my needs	0.73	
My privacy was respected during my A&E stay	0.84	I was treated like I mattered during my A&E stay
My dignity was respected during my A&E stay	0.83	
I did not feel vulnerable during my A&E stay	0.80	
I did not feel alone during my A&E stay	0.81	
My journey through A&E felt efficient	0.71	A&E met my expectations

SM 10.4 Scree Plot



SM 10.5 Rotated Factor Matrix

	Factor				
	1	2	3	4	
	Relational Care	The ED Environment	Staying Informed	Pain Assessment	Communality
Eigenvalue	11.49	2.31	1.47	1.06	-
% Variance	46.00	9.26	5.89	4.26	-
Item					
Staff thoroughly assessed my condition	**0.854**				0.711
I understood why tests were needed	**0.845**				0.666
Staff could locate the right equipment	**0.840**				0.744
I felt like I mattered	**0.820**				0.637
Staff explained what was going to happen	**0.806**				0.623
Staff checked I understood what was said	**0.786**				0.570
I felt able to ask questions	**0.740**				0.654
Staff introduced themselves by name	**0.736**				0.563
A&E met my expectations	**0.682**				0.543
I felt ready to cope at home	**0.643**				0.578
Staff asked my permission before treating me	**0.570**				0.503
I was told when I was ready for discharge home	**0.569**				0.481
It was easy to find and use the toilets		**0.812**			0.633
I could go to the toilet in dignity		**0.756**			0.651
The A&E department was clean and tidy		**0.737**			0.584
I felt safe		**0.728**			0.502
I could get help if I needed it		**0.656**			0.604
My seat or bed was comfortable		**0.619**			0.417
I was able to find a seat or bed		**0.612**			0.510
I felt cared for		**0.594**			0.460
I was given updates whilst waiting			**0.828**		0.729
I was informed of the waiting times			**0.763**		0.563
I was informed whether I could eat or drink			**0.595**		0.420
My pain was assessed more than once				**0.966**	0.894
My pain was assessed				**0.705**	0.638
Cronbach's Alpha	**0.944**	**0.901**	**0.786**	**0.849**	-
				Average Communality	0.595

a. Rotated Factor Matrix. Principal Axis Factoring with Promax Rotation using Kaiser Normalisation

SM 10.6 Proportions of Missing Data

Item			Complete		Missing	
	Participants	N	%	N	%
Staff thoroughly assessed my condition					
Retest	52	48	92.3	4	7.7
Case- Matched Initial Responses	52	48	92.3	4	7.7
I understood why tests were needed					
Retest	52	37	71.2	15	28.8
Case- Matched Initial Responses	52	39	75.0	13	25
Staff could locate the right equipment					
Retest	52	35	67.3	17	32.7
Case- Matched initial responses	52	30	57.7	22	42.3
I was treated like I mattered during my A&E stay					
Retest	52	47	90.4	5	9.6
Case- Matched initial responses	52	45	86.5	7	13.5
Staff explained what was going to happen					
Retest	52	46	88.5	6	11.5
Case- Matched initial responses	52	43	82.7	9	17.3
Staff checked I understood what was said					
Retest	52	43	82.7	9	17.3
Case- Matched initial responses	52	41	78.8	11	21.2
I felt able to ask questions					
Retest	52	48	92.3	4	7.7
Case- Matched initial responses	52	44	84.6	8	15.4
Staff introduced themselves by name					
Retest	52	49	94.2	3	5.8
Case- Matched initial responses	52	47	90.4	5	9.6
A&E met my expectations					
Retest	52	44	84.6	8	15.4
Case- Matched initial responses	52	42	80.8	10	19.2
I felt ready to cope at home					
Retest	52	43	82.7	9	17.3
Case- Matched initial responses	52	41	78.8	11	21.2
Staff asked my permission before treating me					
Retest	52	43	82.7	9	17.3
Case- Matched initial responses	52	43	82.7	9	17.3
I was told when I was ready for discharge home					
Retest	52	43	82.7	9	17.3
Case- Matched initial responses	52	45	86.5	7	13.5
It was easy to find and use the toilets					
Retest	52	45	86.5	7	13.5
Case- Matched initial responses	52	42	80.8	10	19.2
I could go to the toilet in dignity					
Retest	52	44	84.6	8	15.4
Case- Matched initial responses	52	42	80.8	10	19.2
The A&E department was clean and tidy					
Retest	52	47	90.4	5	9.6
Case- Matched initial responses	52	47	90.4	5	9.6
I felt safe whilst I was waiting					
Retest	52	45	86.5	7	13.5
Case- Matched initial responses	52	44	84.6	8	15.4
I could get help if I needed it					
Retest	52	48	92.3	4	7.7
Case- Matched initial responses	52	47	90.4	5	9.6
My seat or bed was comfortable					
Retest	52	47	90.4	5	9.6
Case- Matched Initial Responses	52	47	90.4	5	9.6
I was able to find a seat or bed					
Retest	52	46	88.5	6	11.5
Case- Matched initial responses	52	46	88.5	6	11.5
I felt cared for whilst I was waiting					
Retest	52	45	86.5	7	13.5
Case- Matched initial responses	52	44	84.6	8	15.4
I was given updates whilst waiting					
Retest	52	38	73.1	14	26.9
Case- Matched initial responses	52	43	82.7	9	17.3
I was informed of the waiting times					
Retest	52	39	75.0	13	25
Case- Matched initial responses	52	39	75.0	13	25
I was informed whether I could eat or drink					
Retest	52	39	75.0	13	25
Case- Matched initial responses	52	36	69.2	16	30.8
My pain was assessed more than once					
Retest	52	40	76.9	12	23.1
Case- Matched initial responses	52	43	82.7	9	17.3
My pain was assessed					
Retest	52	45	86.5	7	13.5
Case- Matched initial responses	52	45	86.5	7	13.5

SM 10.7 Test-Retest Reliability Results

Item	ICC (95%CI)
Staff thoroughly assessed my condition	.463 (.033--.528)*
I understood why tests were required	.403 (-.040--.657)NS
Staff could locate the right equipment	.395 (-0.55--.484)NS
I was treated like I mattered during my A&E stay	.591 (.288-.765)**
Staff explained what was going to happen	.343 (-1.44--.623)NS
Staff checked I understood what was said	.599 (.302--.770)**
I felt able to ask questions	.635 (.364--.790)**
Staff introduced themselves by name	.804 (.658--.887)**
A&E met my expectations	.364 (-1.08--.635)NS
I felt ready to cope at home	.864 (.762--.922)**
Staff asked my permission before treating me	.418 (-.014--.666)NS
I was told when I was ready for discharge home	.766 (.592--.866)**
Total Factor 1	**.533 (.452--.602)****
It was easy to find and use the toilets	.617 (.333--.780)**
I could go to the toilet in a dignified way	.714 (.501--.836)**
The A&E department was clean and tidy	.518 (.160--.723)*
I felt safe during whilst I was waiting	.399 (-.047--.655)NS
I could get help if I needed it	.805 (.659--.888)**
My seat or bed was comfortable	.709 (.493--.833)**
I was able to find a seat or bed	.726 (.522--.843)**
I felt cared for during whilst I was waiting	.613 (.326--.778)**
Total Factor 2	**.675 (.605--.732)****
I was given updates whilst waiting	.884 (.798--.933)**
I was informed of the waiting time	.736 (.540--.848)**
I was informed whether I could eat or drink	.494 (.118--.709)*
Total Factor 3	**.675 (.555-.763)****
I was asked how much pain I was in more than once	.735 (.539--.848)**
I was asked how much pain I was in	.581 (.269--.759)**
Total Factor 4	**.675 (.517--.781)****
Total for PREM- ED 65	**.670 (.632--.704)****

Average Measures are presented. Two Way fixed effects model with absolute agreement.
NS= Not Significant; * p<0.05; **p=<0.01

SM 10.8 Criterion Validity Results

Item	FFTQ[a] *r*
Staff thoroughly assessed my condition	0.517
I understood why tests were required	0.466
Staff could locate the right equipment	0.484
I was treated like I mattered during my A&E stay	0.506
Staff explained what was going to happen	0.504
Staff checked I understood what was said	0.450
I felt able to ask questions	0.458
Staff introduced themselves by name	0.499
A&E met my expectations	0.592
I felt ready to cope at home	0.421
Staff asked my permission before treating me	0.388
I was told when I was ready for discharge home	0.392
It was easy to find and use the toilets	0.430
I could go to the toilet in a dignified way	0.474
The A&E department was clean and tidy	0.452
I felt safe whilst I was waiting	0.361
I could get help if I needed it	0.412
My seat or bed was comfortable	0.299
I was able to find a seat or bed	0.378
I felt cared for during whilst I was waiting	0.324
I was given updates whilst waiting	0.196
I was informed of the waiting time	0.132
I was informed whether I could eat or drink	0.101
I was asked how much pain I was in more than once	0.314
I was asked how much pain I was in	0.380
Average (Mean)	**0.397**

[a]Friends and Families Test Question (FFTQ):
"I would recommend this A&E department to my friends or family if they were in a similar situation".

Chapter 11 Process Evaluation

Authorship
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Contributor Statement
Blair Graham (BG) conceived the study and led the development, study design, recruitment of student researchers, data collection, analysis, and writing of the first draft of the manuscript and all subsequent versions.

Jason Smith (JES) and Jos Latour (JML) contributed to the study design, data collection and analysis and reviewed the first draft of the manuscript and all subsequent versions.

The agreed approximated percentage contributions toward the production of this research are: BG 95%, JES 2.5%, JML 2.5%.

Conflict of Interest Statement
None of the authors have any conflicts of interest to declare.

Publication Status
This chapter has not been submitted for publication as of May 2024. However, the lead author intends to submit a short report to a relevant medical education journal.

What this chapter adds.

This chapter:

- Provides proof-of-concept that undergraduate medical students may be recruited and trained as study investigators for observational emergency care research.
- Reports students' perceptions of involvement in the PREM-ED 65 study related to research awareness and the likelihood of considering research involvement and future academic careers.
- Provides practical insights into facilitators and barriers to administering PREMs within the ED clinical environment, which may inform administration strategies for the finalised version of PREM-ED 65.

Medical Students' Experiences as co-researchers in the PREM-ED 65 Validation Study: A Process Evaluation

11.1 Abstract

Background

Collaborative research involves more than one party working towards a research aim and is becoming a common approach to encourage research amongst UK postgraduate medical trainees. Medical students face multiple potential barriers to research participation, including inexperience and lack of access to professional networks. As such, undergraduate research collaboratives may help improve access to research training and participation among medical students.

Aim

This process evaluation aims to report students' involvement in the final development and validation study for a patient-reported measure for older adults attending the emergency department (PREM-ED 65).

Methods

Students studying on an intercalated degree programme in emergency care (University of Plymouth, UK) were invited to participate in the PREM-ED 65 validation study. A registered clinician provided site-level supervision. Students were involved in patient screening, recruitment, survey administration, and data entry.

Following the study, students received a 30-item electronic survey to evaluate their experience of involvement.

Descriptive statistics, including per-item responses, are presented.

Findings

Twenty-one students out of fifty students volunteered to participate (54%). Seventeen returned a completed process evaluation survey (capture rate 80.9%). Students' motivation to participate included research experience, publication opportunities and career progression. All reported that preparatory training was useful, and self-reported confidence across nine research skills areas significantly increased post-involvement ($p=<0.01$). Sixteen students (94.1%) stated that they were more likely to become involved in research in the future, and nearly one-third (5/17; 29.4%) were more likely to consider a clinical academic career.

Perceptions of PREM-ED 65 administration to patients were positive, with most students recruiting over 50% of patients screened; barriers to patient completion included survey length, risk of respondent fatigue and difficulty with the electronic version.

Conclusion

With appropriate training, all student collaborators successfully recruited participants for the PREM-ED 65 study. Students reported positive perceptions of involvement and that the draft version of PREM-ED 65 was generally well-received by study participants. Barriers to completion the instrument, including survey length and formatting, should be addressed in the final version.

11.2 Introduction

Collaborative research involves more than one party working together to achieve a research aim. In recent years, the proliferation of trainee research collaboratives has been described as a ‘coordinated movement’ with collaboratives being established across anaesthesia, medical, and surgical specialities.(1, 2) Initially motivated to help trainees meet the research requirements of postgraduate training programmes,(3) other advantages of the trainee collaborative model include promoting research awareness and training among early career doctors, enabling a more flexible approach to research involvement, and empowering the formation of higher-quality, multi-site research.(4, 5) In the longer term, research collaboratives may increase the proportion of senior doctors who are trained and experienced to lead future projects.

Within emergency care, the UK Trainee Emergency Research Network (TERN)(6) has successfully published research focusing on diverse topics, including the need for recovery of emergency physicians,(7) the psychological impact of emergency physicians responding to COVID-19,(8) external validation of clinical decision rule for subarachnoid haemorrhage,(9) and an evaluation of electronic scooter injuries.(10) These studies have demonstrated the feasibility of engaging trainee emergency physicians—many of whom have little prior clinical research experience—in various stages of research, including patient recruitment, data collection, and data entry. By harnessing the collective effort of many collaborators, this approach has demonstrated the potential to recruit large numbers of participants in a geographically wide area over a short period of time.

For medical undergraduates, the UK General Medical Council stipulates that all new medical graduates should be aware of research, including research methodology and governance.(11) Yet, a recent national cross-sectional survey of UK students from 40 medical schools (n=1,771) revealed frequent barriers to research participation, including inadequate signposting to opportunities, time constraints, difficulty balancing research with clinical training, and insufficient opportunities to network with researchers.(12) Since many of these barriers are like those experienced by early career doctors, developing undergraduate research collaboratives may provide a solution, enabling medical students to contribute to real-world research. However, whilst recognised as potentially beneficial for students,(13) Prior to the PREM-ED 65 study, the feasibility, benefits, and potential drawbacks of undergraduate research collaboratives were unknown.

The BSc (Hons) Urgent & Emergency Care Programme at the University of Plymouth (UK) is a one-year programme open to medical students across the UK. Students must undergo a 9-month longitudinal clinical placement in one of thirty EDs within the UK.(14) A previous cross-sectional survey focusing on student and mentor perceptions of this programme indicated that intercalated students desired greater involvement in research.(15) Additional research focusing on intercalated degrees highlights that research involvement and subsequent progression to clinical academic careers are discrete benefits of intercalation during medical school.(16, 17)

This paper reports intercalated medical students' self-reported evaluation of involvement in field testing and validation of the Patient-Reported Experience Measure for adults over 65 attending the Emergency Department (PREM-ED

65). Findings are presented as a process evaluation, focused on students' own experiences, the effect of involvement on motivations to pursue research in the future, and perceptions related to administering PREM-ED 65 to older adults in the ED.

11.3 Aims

This process evaluation aims to:

1. Evaluate student experience of participation in the PREM-ED 65 study.
2. Evaluate student perceptions of PREM-65 administration in the ED setting, including facilitators and barriers to completion by older adults.

11.4 Methods

Process evaluation using an electronic cross- sectional survey.

11.4.1 Study Population

Medical students enrolled in the BSc (Hons) Urgent and Emergency Care programme at the University of Plymouth during the 2020/21 academic year.

11.4.2 Validation Study Overview

The 82-item draft PREM-ED 65 instrument was developed using a mixed-methods approach. Validation of PREM-ED 65 in a real-world setting was recognised as essential to confirm its validity and reliability. Therefore, a national multi-site validation study to include UK EDs was designed and planned, with a target of recruiting between 300-700 patients nationally.

Rationale for the Student Collaboration

The chief investigator for the PREM-ED study (BG) helped establish the UK TERN collaborative and is a lecturer for the BSc (Hons) Urgent & Emergency Care (Intercalated) Programme. Having realised the potential benefits of the

collaborative approach for fostering research awareness, the involvement of intercalated students was planned from the outset.

11.4.3 Recruitment

From September 2018, students were invited to volunteer as site investigators. Volunteers were provided with training before study commencement, including *Good Clinical Practice* training aligned to national standards,(18) and separate instruction on the research protocol and study procedures. These sessions lasted about 60 minutes each and were mandatory for students to attend.

Local approval was arranged for each ED site, and supervision was provided by a registered clinician acting as the site Principal Investigator (PI). The PI retained responsibility for overall conduct. Student responsibilities included screening, participant recruitment and consent, data collection, and data entry.

The local PI and research department supported students. In addition, the WhatsApp software (Menlo Park, CA) was used to facilitate encrypted instant messaging communication between students and the study team (BG and JML). This allowed for open sharing of queries and rapid troubleshooting between the study team and student collaborators, also reducing burden on PIs. During the study period, weekly email newsletters were issued to all members of the research team including students and PIs (Supplementary Material SM11.1).

In recognition of their contribution, students received a certificate and were named as study collaborators in resulting presentations and publications. No additional incentives were provided.

11.4.4 Evaluation Questionnaire

A 30-item closed electronic survey (SurveyMonkey, San Mateo, CA) was emailed to all student researchers at the end of the PREM-ED 65 validation study in August 2021. The voluntary survey aimed to capture the perceptions of student researchers involved in the study. Items explored (i) motivations to participate in the study, (ii) prior preparation for research, (iii) Quality of training and support provided, (iv) learning through participation, (v) experiences of involvement in the research team, (vi) general perceptions of involvement in research, and (vi) experience of administering PREM-ED 65.

Written information was provided, and informed consent was obtained before the survey was completed. The survey was fully anonymised, and no personal details, including the respondent's IP address, were recorded.

The Checklist of Reporting Results of Internet E-Surveys (CHERRIES) has been used to support the reporting of the process evaluation.(19)

11.4.5 Data Analysis

Basic descriptive statistics, including per-item proportions of responses, are presented. Differences in students' self-reported confidence pre- and post-study involvement are reported across nine discrete research competency areas, with the significance of change assessed using a paired student's t-test. Selected free-text responses are also presented.

11.4.6 Ethical considerations

Ethical approval was not required for this process evaluation. However, general ethical principles, including informed consent, the right to refuse participation and withdraw, confidentiality, and data protection, were followed. The survey was distributed after students' academic commitments for the year had finished.

11.5 Results

The PREM-ED 65 study was conducted across 18 EDs in England. Recruitment was exclusively student-led in 13 sites, supported by ED research clinicians in two additional sites, and led exclusively by research clinicians in three sites.

Students recruited 276 participants for the initial survey (mean=15.3 per student) and 64 participants for the retest survey (capture=23.1% of total recruitment).

11.5.1 Participant Characteristics

Twenty-one out of fifty eligible cohort members were recruited as study collaborators (54%). Before intercalation, all students had three (n=2) or four (n=19) years of study experience on their primary medical degree.

Seventeen of the twenty-one participating students completed the follow-up questionnaire (capture rate = 80.9%).

11.5.2 Prior experience in research

Before their involvement, only a single student (5.9%) had prior experience in the design or delivery of research and three students (17.9%) had received some previous instruction on research methods. Twelve of the students (70.6%) did not feel adequately prepared to undertake research, prior to enrolment as investigators.

11.5.3 Motivations to join as a site investigator.

Students were asked to assign all potential motivations to join the PREM-ED 65 collaboration against a list of twelve options assigned by the lead investigator. All students were assigned multiple motivations against this list (mean motivators per student= 6.9; SD 2.82). The most prevalent motivations for involvement in the study were ‘the opportunity to participate in research’ (n=16,

94.1%) and ‘the opportunity for a taster in research’ (n=12, 70.5%). This was followed by ‘to be part of the research team’, ‘opportunity to get published’ and ‘existing interest in research (n=10, 55.6%). Only three students reported a specific interest in geriatric emergency care (n=3, 17.6%). The full breakdown of motivations to join the PREM-ED 65 study is listed in Table 11.1.

Table 11.1 Student motivators for joining the validation study

Motivator	n (%)
Existing interest in geriatric emergency care	3 (17.6)
Existing interest in patient experience	8 (47.0)
Existing interest in research	10 (58.9)
Opportunity to participate in research	16 (94.1)
Opportunity to get published	10 (58.9)
Opportunity for research training	9 (52.9)
Potential to enhance foundation application	12 (70.5)
To benefit future career	8 (47.0)
To be part of the ED research team	10 (58.9)
To help assist the ED research team	7 (38.9)
Opportunity for a taster in research	12 (70.5)
To benefit own academic progression	9 (52.9)

When asked to justify their motivations, students emphasised the opportunities posed by getting involved in the project within the free-text comments:

> *“We get limited access to research participation at medical school, and generally, we must go out of our way to organise it ourselves with a specific consultant or department. This means that we get little support from the university. This was a well-supported project, so I thought it would be a good opportunity to get research experience in a more supportive setting. The department I was in is also very research- focused”.*
>
> Student Respondent (Anon.)

Four of the students also cited additional motivators in an accompanying free-text response option:

> *"It seemed like a 'good deal' for work that needed to be done. It is beneficial for my development/progression without being too burdensome."*
>
> Student Respondent (Anon.)

> *"I had no experience of research, and it was important to me to gain this from this degree"*
>
> Student Respondent (Anon.)

> *"Never been part of a research project before and wanted to explore this area of medicine".*
>
> Student Respondent (Anon.)

11.5.4 Experiences as a Site Investigator

All seventeen respondents reported that the site investigator training was helpful (100% 'agree'/ 'strongly agree'). Involvement in the study introduced students to new members of the multidisciplinary team, including research administrators (13/17, 76.4%), other research active physicians (9/17, 52.9%) and research nurses (8/17, 47.1%). All student researchers gained increased familiarity with the roles of the clinical research team following their involvement (100% agree/ strongly agree), and the majority reported that involvement in the study was an overall 'useful' experience (16/17, 94.1%). Reasons for this stated within the free-text responses were focused on developing an understanding of the research process:

> *It was useful to see every stage of the process and explain what each bit did and why we were doing it. I hope to apply for an academic foundation job next year and I now have a much better understanding of what research is and that I enjoy it!*

Student Respondent (Anon.)

Disadvantages to involvement were reported by three students (17.6%) and were related to balancing their research and clinical placement commitments:

> *Data collection was relatively time-consuming and required full days of placement time to recruit patients and administer surveys as it was challenging to engage in clinical work (e.g. clerking patients and assisting with procedures) whilst collecting data. This came at a time when we had very little practical time remaining on our intercalation course following assessments.*

Student Respondent (Anon.)

As a result of their involvement, most students reported that they were 'more likely' to get involved in clinical research in the future (16/17, 94.1%), and nearly a third were more likely to consider a clinical-academic career path because of involvement (5/17, 29.4%). Respondent opinions on whether collaborative research should be a mandatory component of undergraduate training were mixed (4/17, 23.5% 'Yes' and 'Unsure', respectively; 9/17, 52.9% 'No'). One student in support of mandatory exposure reflected the generic relevance of basic research competence:

> *Although not everyone is a fan of research, it is useful to gain a baseline knowledge of research design. This could also lead to some students developing a research interest.*

Student Respondent (Anon.)

Conversely, another student felt making research involvement mandatory at an undergraduate level could paradoxically reduce engagement amongst disinterested students:

> *There are plenty of mandatory elements to undergraduate training already which are not useful. For students who*

> *have no interest in research, mandatory inclusion will likely discourage them further. Students should participate in research because they want to and are interested in it, not because they are forced to.*
>
> Student Respondent (Anon.)

Effect of involvement on self-perceived confidence in a research role

Using visual analogue scales (0—100; 0 'Not confident at all', 50 'Somewhat Confident', 100 'Completely Confident'), students were asked to rate their perceived confidence against nine discrete research skills before and after involvement in the PREM-ED 65 study.

Skills assessed included understanding research design, ethics approval, participant screening, obtaining patient consent for research, maintaining research records, understanding data protection requirements, and the role of local and national research regulators.

A highly statistically significant increase ($p<0.01$) in self-perceived confidence was observed across all these domains (average increase in VAS following involvement= +34.6/domain) (Table 11.2, overleaf).

Table 11.2 Self-perceived research confidence pre- and post- study

Domain	VAS Rating (SD)
Understanding of research design	
Before PREM-ED 65	33.2 (20.1)
After PREM-ED 65	67.4 (11.5)
Difference	+34.2 (15.6)*
Understanding of how ethics approval is obtained for research	
Before PREM-ED 65	27.6 (21.2)
After PREM-ED 65	56.9 (11.6)
Difference	+29.3 (16.9)*
Ability to screen and identify patients for clinical research	
Before PREM-ED 65	34,6 (25.1)
After PREM-ED 65	77.9 (12.1)
Difference	+43.3 (24.3)*
Ability to obtain patient consent for clinical research	
Before PREM-ED 65	35.9 (22.4)
After PREM-ED 65	76.4 (13.3)
Difference	+40.6 (21.4)*
Ability to maintain records for clinical research	
Before PREM-ED 65	37.9 (22)
After PREM-ED 65	75.3 (14.3)
Difference	+37.4 (24.2)*
Understanding of data protection requirements for research	
Before PREM-ED 65	45.8 (21.4)
After PREM-ED 65	73.9 (14.7)
Difference	+28.1 (20.1)*
Ability to record and input research data	
Before PREM-ED 65	39.6 (22.5)
After PREM-ED 65	76.5 (11.1)
Difference	+36.9 (23.2)*
Understanding of the Role of the Health Research Authority	
Before PREM-ED 65	26.6 (21.2)
After PREM-ED 65	49.4 (19.7)
Difference	+22.8 (20.3)*

Table 11.2 (continued)

Domain	VAS Rating (SD)
Understanding of the role of local research and development departments	
Before PREM-ED 65	31.4 (18.7)
After PREM-ED 65	70.1 (20.2)
Difference	+38.7 (16.4)*

Legend: VAS= Visual Analogue Scale; * p<0.01

11.5.5 Facilitators to patient recruitment

Concerning ease of survey administration of PREM-ED 65, fifteen students (88.2%) agreed that the instrument was intuitive for participants to follow. They reported that patients they approached were enthusiastic to be involved in the research (16/17, 94.1%). Students indicated that the proportion of eligible patients who agreed to consent to involvement in the study was favourable overall, with over half (52.9%) of students reporting that they recruited 75%--100% of the patients they approached. For a minority of students (n=4, 23.5%), the reported recruitment rate was lower than 50%.

Recruitment to the retest survey was more challenging, with 13 respondents (72.2%) recruiting less than 50% of study participants. This data is summarised in Figure 11.1 (overleaf).

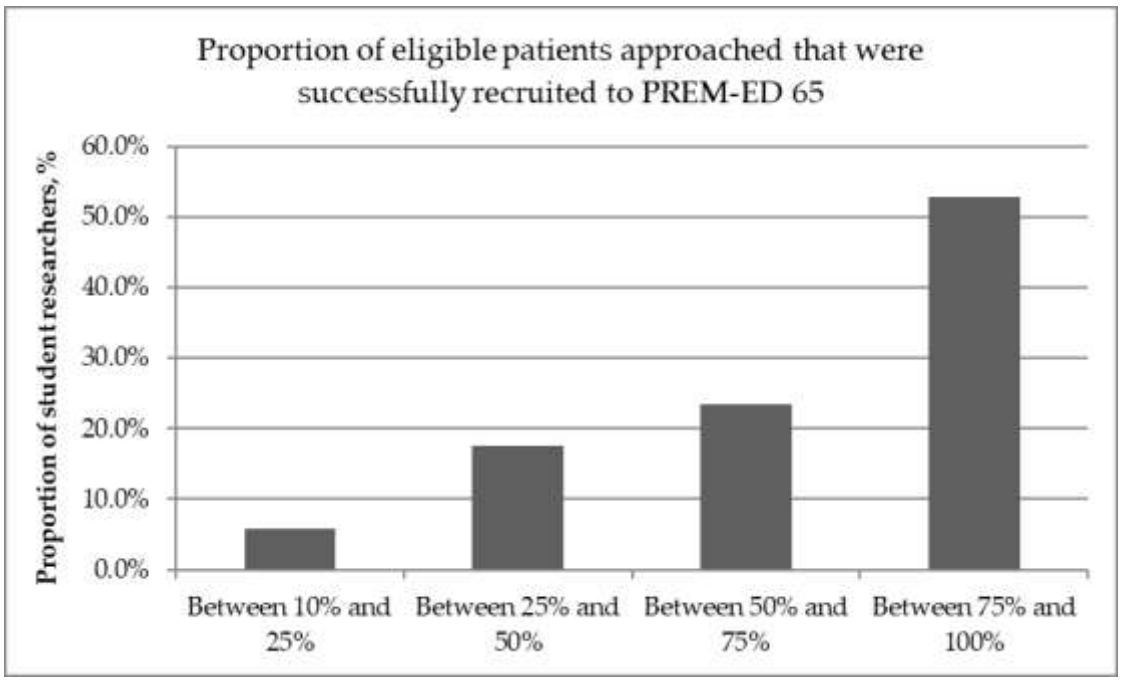

Figure 11.1 Estimated conversion to recruitment for the validation study

11.5.6 Barriers to Patient Recruitment

Barriers to patient recruitment and survey completion were reported against eleven pre-defined domains. Students indicated the subjective frequency with which they encountered each barrier against a five-point frequency scale (Never/ Infrequently/ Somewhat Frequently/ Frequently/ Always).

The most prevalent barriers encountered were ‘unwillingness to complete—patient wanted to go home’ (‘somewhat frequent’ or ‘very frequent’ occurrence n=13, 72.2%), difficulty reading text due to visual impairment (‘somewhat frequent’ or ‘very frequent’ occurrence n=11, 61.1%) and ‘Difficulty engaging with electronic version’ (always n=3, 16.7%; ‘somewhat frequent’ or ‘very frequent’ occurrence n=7, 38.9%) (Fig 4).

Approximately half of the students reported that participants experienced difficulty comprehending the survey items and/or the Likert response scale

(‘somewhat frequent’ or ‘very frequent’ occurrence n=9, 50% and n=8, 44.4% respectively)

Conversely, difficulty comprehending patient information or consent forms was infrequently encountered (‘somewhat frequent’ or ‘very frequent’ occurrence n=3, 16.7% each). The frequency of barriers to completion is summarised in Figure 11.2 (overleaf).

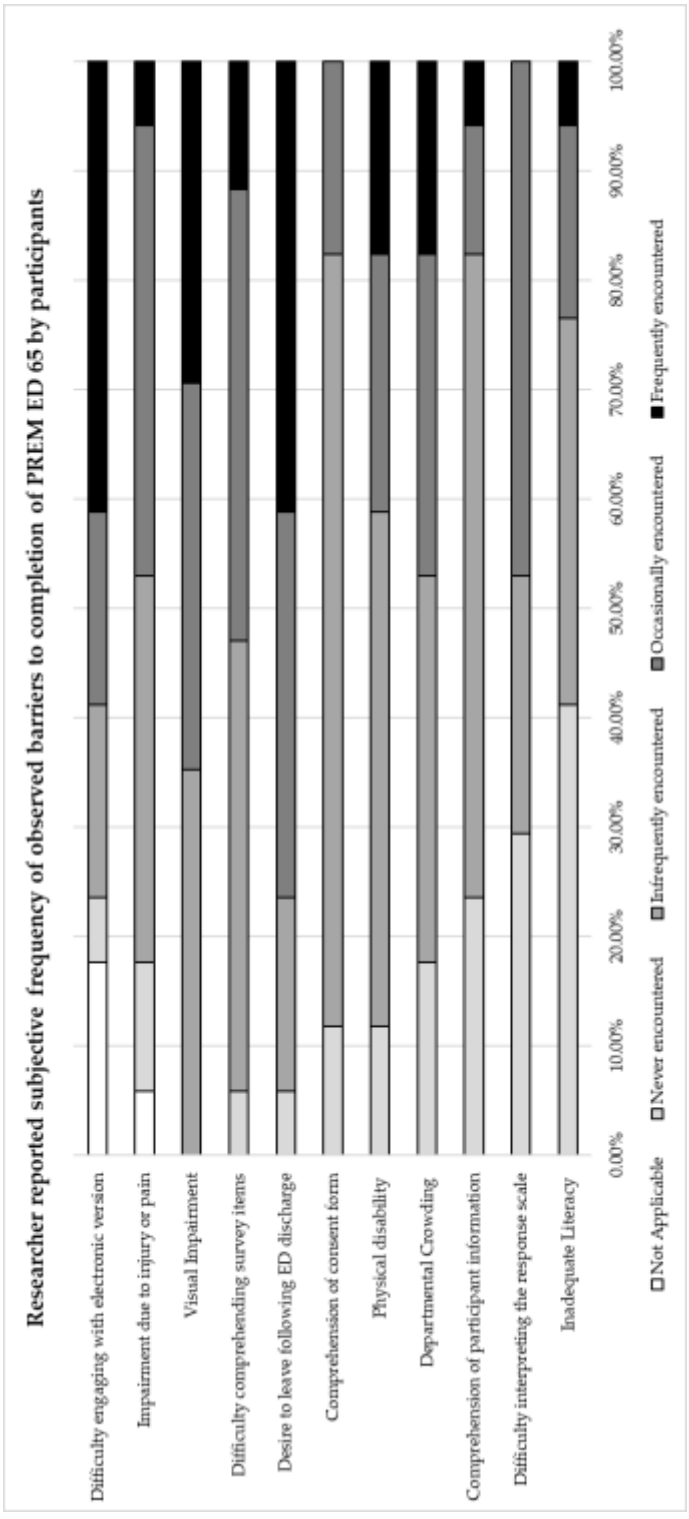

Figure 11.2 Estimated occurrence of barriers to PREM-ED 65 completion.

Two additional barriers were reported in the free-text responses. These were related to the influence of family members and the unwillingness of participants to voice strong opinions:

> *"It was difficult to avoid family members filling out the survey on behalf of the patient if they were visually impaired or feeling unwell- this required a more hands-on approach and communication skills to say that the patient must fill out the survey. I think this was because the family were equally as keen to help and fill out the survey as the patients were."*
>
> Student Respondent (Anon.)

> *Many patients were inclined to just say agree or disagree rather than voice any strong opinions.*
>
> Student Respondent (Anon.)

11.6 Discussion

The process evaluation aimed to describe student investigators' experiences as collaborators in the PREM-ED 65 validation study and determine facilitators and barriers to the instrument's completion by older adults in the ED.

Student collaborators recruited over half of all study participants to the validation study, helping reach the desired sample size and successfully validate a final version of the PREM-ED 65 instrument. Findings from the post-study evaluation survey demonstrate students' high levels of motivation to engage in research collaboration and recognition that involvement may help overcome barriers to research participation, including inexperience and lack of established personal networks. Students also recognised the potential value of collaboration in offering insight into the research process, enabling them to function as part of an academic team and enhance publication and future career prospects. However, survey findings indicate that, despite their enthusiasm,

most students had no prior training in research methodology or governance. Providing appropriate training should be considered essential for students assuming a research collaborator role. For PREM-ED 65, bespoke training aligned to UK national standards for research governance (18) and separate instruction on the validation study protocol and procedures was provided. Survey feedback indicates that this was useful and was well received. No adverse events occurred during the study period, and students had high overall satisfaction following their involvement. In particular, students' confidence in a range of research skills domains increased significantly as a result of involvement. Confidence following involvement was lowest in understanding regulatory functions such as the role of the HRA and ethics approval process. This may, therefore, be a useful focus of training in future collaborative studies.

The main single barrier to student participation was related to demands placed on their time. This is also reflected in an international survey (n=1625) exploring medical students' perceptions of research.(20) As with the PREM-ED 65 study, ensuring that expectations are agreed upon with student collaborators before the study period and offering a flexible approach to involvement may mitigate such conflicts.

An important additional objective of the process evaluation was to establish perceptions of administering PREM-ED 65 within the ED setting, specifically focusing on facilitators and barriers to participant recruitment. Whilst the precise recruitment rate was not measured, most students reported successfully recruiting more than 50% of the eligible participants they approached. Although frequently encountered barriers to administration did not impede the overall administration of the survey, these findings confirm the importance of timing

PREM administration appropriately during the patient journey, reducing respondent fatigue, and adapting to the needs of specific patient populations. In the case of older adults, this may include providing ‘large print’ formats suitable for those with visual impairment and following cognitive design principles.(21, 22) Despite efforts through stakeholder engagement to optimise usability and limit the potential for response biases within the draft version of PREM-ED 65, some responses indicate the potential for effects such as acquiescence bias to be persistent among some participants. Therefore, ongoing monitoring and consideration of response biases is important in future administrations of the finalised instrument.

Finally, the administration of PREM-ED 65 by proxies has not been investigated as part of the validation study. Still, it could provide a compelling means of increasing inclusivity—for example, amongst those with sensory and cognitive impairments. Evidence suggests that caregivers may approximate older adults’ self-reported opinions across various domains.(23, 24)

11.6.1 Strengths and Limitations

This process evaluation has evaluated medical student participation in a national research collaborative. Overall, the findings support the potential for student collaboratives to overcome many of the traditional research barriers undergraduates encounter. However, this process evaluation is not easily generalisable due to the small sample of self-selecting students from a single UK-based intercalated programme. As part of selection to the intercalated BSc programme, students must demonstrate sound academic ability before enrolment. As such, intercalated students may be more inclined to do research than the general population of students. Additionally, students enrolled on the programme have a declared pre-existing interest in emergency care and may

be particularly motivated by research opportunities. Whilst the apparent increase in students' confidence in key research skills because of their participation is highly encouraging, confirmation using more objective measures is highly desirable. This paper highlights students' ability to perform observational research and administer a cross-sectional survey within the ED environment. Whether students may contribute as collaborators to interventional studies is likely to be more complex and may not be feasible for regulatory reasons.

Ongoing evaluation of future student research collaboratives is essential to confirm these findings and further investigate enablers and barriers to involvement. In addition, recruiting students from a broader range of backgrounds for example nursing and the allied health professions, may further increase the reach and impact of student collaborative research, and foster interprofessional working at an undergraduate level.

In terms of PREM-ED 65 administration, this evaluation provides only estimates of the response rate. Although deemed to intensive for the student investigators, maintaining a screening log including reasons for non-recruitment may be insightful in future studies, and help identify where sampling biases may occur. The barriers to completion of the draft version of PREM-ED 65 are insightful, but it is possible that additional barriers encountered that were not present on the predefined list may have been missed.

11.7 Conclusion

With appropriate training, all student collaborators successfully recruited participants for the PREM-ED 65 study. Students reported predominantly positive perceptions of involvement, increased their overall research

awareness, and some were more likely to participate in future research and plan academic careers as a result. Student feedback indicates that the draft version of PREM-ED 65 was generally well received by study participants. However, students' feedback indicates that barriers to completion, including survey length and formatting, should be addressed in the final version.

Addendum

Contribution to the PREM-ED 65 study

This chapter has evaluated student involvement in the multi-centre validation study and confirms the feasibility of undergraduate student collaboration in emergency care research. Discrete benefits for students from the study included increased awareness and understanding of the research process, enhanced knowledge of research ethics and governance, and informing academic career options. It is anticipated that these findings will be helpful in justifying, enabling and expanding future student collaborative research,

Students reported high levels of participant conversion from screening to recruitment, yet an important function of the survey was reporting potential barriers to completion. These included survey length, readability, and difficulties experienced by patients when engaging with the electronic version. Although the shortened final instrument should help remedy some of these barriers, this knowledge may inform future implementation of PREM ED-65 and the optimisation of electronic health measurement platforms for older adults.

Publication Strategy

This chapter is being prepared for submission to a relevant medical education journal.

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Supplementary Material

SM 11.1 Email recruitment update, August 2021.

Dear colleague,

PREM ED Recruitment Update 17/09/21—including finalised study end date (10th September 2021).

I hope that this finds you well and that you don't mind me writing a brief update regarding the status of PREM ED 65+ recruitment.

To date, we have achieved **378** accruals. Together, through our collaborative approach, we have comfortably exceeded the minimum acceptable sample of 300, which is impressive in itself. However, the *optimal* sample size is 500, and I am confident we can get *towards* this number over the remaining few weeks.

'How so confident?' you ask. Well, we still have a critical mass of enthusiastic participating centres, with recruitment ongoing at the following sites:

-
-
-
-
-

In addition, aim to commence shortly.

Therefore, **if you can, please continue to push recruitment until 10th September.** Following this date, we will close your site and I will leave you alone (I promise!). I appreciate many of you have other studies and commitments to attend to, and your efforts during the time remaining are especially appreciated.

As a final point, please continue to prioritise the issue of retest surveys where a patient is willing to participate.

If you need to contact me please don't hesitate to email) **OR** if you require an immediate response, you are most welcome to message via WhatsApp (

Thank you so much once again for your help!
With best wishes

Blair

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Chief Investigator, PREM-ED 65+ Study

Chapter 12 Discussion and Conclusion

What this chapter adds.

This chapter:

- Summarises research leading to forming the finalised 25-item version of PREM-ED 65.
- Considers the role of PREM-ED 65 in the context of increasing challenges facing the UK Health Service and ongoing deterioration in ED performance.
- Critically reflects upon the methodological approach used to develop PREM-ED 65. This includes methodological integrity, strengths and limitations of the research methods, and the resulting psychometric properties of the instrument.
- Proposes applications of PREM-ED 65 and clinical practice, health services, and future research.
- Considers potential unintended consequences of PREM administration, such as overreliance on survey data, perpetuation of structural inequality, and the generation of perverse incentives.

12.1 Outline

This integrative discussion chapter aims to consolidate previous content and expand upon the discussions already made within the individual chapters in this thesis. This chapter summarises the research and considers the utility of PREM-ED 65 in the context of current challenges facing UK emergency care,

arguing that capturing patient experience is critical when health systems are most vulnerable. Following this, reflections on the study methodology aim to highlight the strengths of the research, how challenges were overcome, and the original contributions made to emergency care and patient-reported outcomes research. The chapter then confronts the limitations of PREM-ED 65 and provides some key recommendations for future development. Implications regarding clinical practice, health services, and research are considered, along with a discussion of potential unintended consequences of implementing PREM-ED 65 in practice.

12.2 Summary of the Research

The PREM-ED 65 study has resulted in a 25-item validated instrument designed with the involvement of multiple stakeholders. This new instrument is suitable for administration to older adults up to 10 days following ED discharge. Importantly, PREM-ED 65 demonstrates satisfactory psychometric characteristics and is intended to meet COSMIN criteria for content validity, structural validity, and internal consistency.(1)

To begin the research, an initial exploration of ED patient experience was performed by undertaking a systematic meta-synthesis of qualitative literature on patient experiences in the ED.(2) This enabled the development of an original conceptual framework focused on patient needs that has since contributed to understanding within this area. Recognition of the relevance of this review and the framework to knowledge is indicated by the high citation score and social media interest assigned to the published manuscript, the latter of which is within the top five per cent of all published research.(3) Besides advancing the academic understanding of ED patient experience, the

framework's accompanying recommendations mean it is relevant to real-world ED quality improvement. Moving forward, this framework conceptually underpinned the onward development of PREM-ED 65.

The requirement for a PREM specifically evaluating the experiences of older adults attending the ED was confirmed by the scoping review of existing PROMs, PREMs and HRQOL instruments. This highlighted the growing interest in patient-reported outcomes and experience measurement within emergency care, with the identified measures designed for administration to the general ED population, such as PROM-ED,(4) and patients with defined acute conditions, including asthma,(5) acute heart failure,(6) and sickle cell disease.(7) The dimensionality of each instrument was compared to the needs-based framework to assess applicability to patient experience measurement, and psychometric characteristics were appraised using COSMIN criteria. From a practical perspective, this review has implications for informing providers who may wish to select appropriate PREMs, PROMs, or HRQOL measures to assess ED care and support quality improvement activity. For the PREM-ED 65 study, the scoping review confirmed the need for a rigorously developed and validated PREM to assess older adults' experiences in the ED, thus further reinforcing the study rationale and delivering valuable insight into desirable characteristics for ED patient-reported measures, including content validity, structural validity, and reliability.

The qualitative phase of PREM-ED 65 consisted of patient interviews and focus groups with staff.(8, 9) Interviews with patients were administered within the ED, and the face validity of the needs-based framework for older adults was confirmed. The interview participants emphasised the importance of high-quality

clinical care, information provision and a safe waiting environment as determinants of their ED experience. In addition, the importance of staff professionalism and team behaviours was interpreted as an additional analytical theme supported by external evidence demonstrating an association between staff behaviours and patient experience.(10) Using a similar question schedule, focus groups highlighted the high priority that staff assigned to providing person-centred care for older people, including ensuring comfort, meeting fundamental needs such as toileting and hydration, and preserving patients' privacy and dignity. Staff shared the experience of caring for older adults in suboptimal, crowded environments. Concern related not only to the effect on patients' experience and clinical outcomes but also personal and professional well-being. Accordingly, staff recognised the potential value of PREM-ED 65 for improving patient care and satisfaction. This enthusiasm spurred the onward development of PREM-ED 65.

Findings from the meta-synthesis, interviews and focus groups were triangulated to propose draft items, which multiple stakeholders assessed during a one-day prioritisation exercise.(11) Whilst ambitious within the confines of a single-day event, results from the nominal group technique demonstrated that priorities relating to care needs were consistently ranked highly—interpreted by the participants as 'must haves'—whereas comforts offered by the physical environment were comparatively deprioritised, perhaps best viewed as 'nice to haves'. As the take-home message, these findings highlight older adults' expectations of high-quality clinical care and achieving optimal outcomes during an ED encounter.

After cognitive interviews that led to further refinement of the draft instrument content and design, an 82-item version of PREM-ED 65 underwent validation across 18 EDs in England.(12) Analysis comprising hierarchical item reduction and exploratory factor analysis resulted in the current 25-item finalised version of PREM-ED 65. This consists of four measurement scales assessing older adults' experience of relational care, the physical ED environment, waiting, and pain assessment. This final version of PREM-ED 65 is proposed to represent a concise, valid, and reliable measure for administration to older adults discharged from the ED.

12.3 Six years on—is PREM-ED 65 still relevant?

> *"Urgent intervention is needed to put people first. Patients and staff should not bear the consequences of insufficient funding and under-resourcing. We cannot continue to face inequalities in care, avoidable delays, and death."*
>
> Dr Adrian Boyle, President of RCEM, 1st April 2024 (13)

Since the study was conceived, the NHS has faced significant challenges, and the performance of the ED services has seen progressive deterioration.(14, 15) Policy decisions and events that have contributed include economic austerity and increasing poverty,(16-18) Britain's exit from the European Union ('BREXIT'),(19) the COVID-19 pandemic,(20) reduced primary care access,(21) and poor industrial relations between doctors and the current government.(22) Consequently, EDs and their staff are at the forefront of a crisis facing unscheduled care in the UK, which has been reported to the public through the increasing prevalence of prolonged ED wait times and ambulance handoff delays. (Figure 12.1, overleaf)

Figure 12.1 "Third World A&E": A selection of newspaper headlines.

(Source: National Health Executive).

Such assertions are supported by national data that demonstrates the average proportion of patients seen and treated within four hours of ED arrival has progressively decreased, from 84.4% in 2016 to 57.6% in 2023.(23) (Figure 12.2; overleaf) This has led to significant real-world harms, with the Royal College of Emergency Medicine estimating excess mortality exceeding 250 patients per week directly attributable to prolonged ED length of stay.(24, 25)

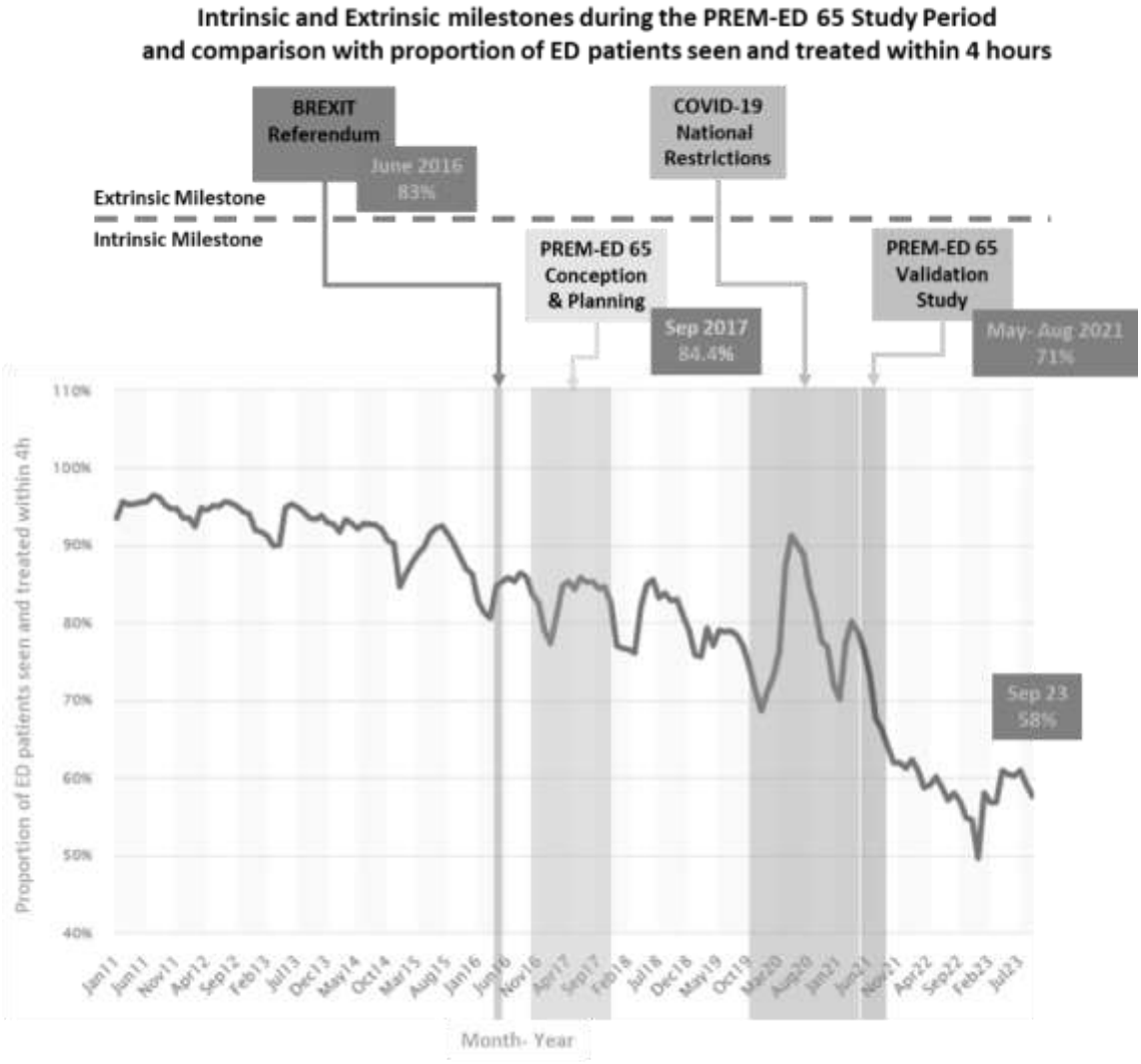

Figure 12.2 ED performance 2011-2023 with study milestones.

Image Source: Statista

Emergency department patient experience has also declined. This is demonstrated within the most recent British Social Attitudes Survey, which suggests that public satisfaction with ED services is currently 37%, compared with 52% in 2017.(26) Of particular concern is that older adults are likely to be more vulnerable to the adverse effects of the current health service and suffer disproportionately as a result (Quote 1, overleaf).

> *"While the current crisis in the NHS affects us all, older people are bearing the brunt. It is predominantly older people who are stuck in ambulances outside emergency departments, on trolleys in hospital corridors, and waiting in hospital for care packages before they can be discharged."*

Professor Adam Gordon, President of the British Geriatrics Society (27)

The continued relevance of PREM-ED 65 despite these changes can be argued through key findings presented within this thesis, which helps us understand how the deterioration in ED performance may negatively impact older adults' experiences. For example, waiting time and waiting experience were prominent determinants of older peoples' experiences during in-situ interviews. Patients also emphasised the importance of privacy and dignity, which is directly threatened by the proliferation of ED crowding and the normalisation of corridor care for older adults in many UK EDs. (Quote 2). (28, 29)

> *"For staff, there is consistent evidence that [corridor care] leads to lower morale and poorer mental health outcomes in the workplace… For patients and their families, the experience can be traumatising."*

Heather Wilson, Health Foundation (28)

As already mentioned, the emotional burden of working in an environment where suboptimal care frequently occurred was sufficiently marked during focus groups that 'staff distress' was identified as a supplementary theme. In a recent editorial, the GP educator John Launer makes a case for "… looking directly at every patient we pass and at least nodding politely to acknowledge their existence, if not saying hello in every case".(30) An emergency medicine consultant's rebuke to this article within its rapid response section challenges this by arguing that "in this [ED] environment, every consultation becomes a source of shame and is started with an apology." This latter sentiment directly

echoes focus group discussions in this study, which powerfully highlighted how working in crowded EDs is morally injurious for staff. Additionally, whilst not the primary aim of the validation study, results imply some areas where participants' experience may already be most vulnerable, including the provision of drinks and food, information whilst waiting, and serial pain assessment.

These links, drawn between the research and the current context of emergency care, do not diminish but rather reinforce the continued face validity of PREM-ED 65. As no floor effects were identified for any item during validation, there is a considerable margin for PREM-ED 65 to maintain measurement sensitivity in the setting of less positive patient experience than was reported during initial validation. The test-retest reliability characteristics of PREM-ED 65 mean that the instrument may be administered retrospectively up to 10 days following ED attendance. Hence, patients need not necessarily occupy space at the end of their stay to provide views on their experience.

Empowering patients to participate in their care is vital to clinical outcomes, the establishment and maintenance of a safety culture, and ensuring an optimal experience. Yet, the patient's voice risks being lost when services are most stretched, with providers compelled to prioritise efficiency and patient flow above individual preferences.(31, 32) This is problematic as—has been highlighted many times in this thesis—patient experience, clinical outcomes, and patient safety are not mutually exclusive.(33) Therefore, listening to patients when services are weakest should be a priority. To this end, administering well-validated PREMs may present a time-, resource, and cost-effective means of reliably measuring patient experience.

In summary, whilst UK standards of ED care have indeed quantifiably deteriorated since PREM-ED 65 was first conceived, the instrument retains validity, relevance, and reliability. The administration of PREM-ED 65 to older adults discharged from the ED remains justified. The instrument should be welcomed as a timely and welcome addition to monitoring the quality of ED services for older adults.

12.4 The impact of COVID-19

The World Health Organisation declared the COVID-19 pandemic on 11 March 2020, leading the UK government to implement its first-ever public lockdown.(34) The impact of the pandemic, unprecedented in modern times and leading to over 200,000 UK deaths up until 2022,(35) deserves mention due to its effect on the study's progress.

Public reticence to attend hospitals meant that ED attendance for non-COVID-related complaints unexpectedly decreased by about one-third during the initial months of the pandemic.(36) In response to the COVID-19 threat, the UK Health Research Authority and NHS Trusts prioritised research to assist the pandemic response, and non-COVID-19 studies were suspended.(37) Because of the unprecedented change to attendance patterns (with the potential to seriously impact sample representativeness and the validity of psychometric assessment) and the new regulatory constraints, the commencement of the validation study was delayed until May 2021, once ED attendance patterns had somewhat normalised. Whilst suspected or known COVID-19 patients were excluded from the validation study, pandemic precautions likely still affected these participants' experience somewhat. For example, fewer than expected had an accompanying person, and wait times were comparatively low, probably

due to increased ED resourcing and residual hospital surge capacity.(38) The pandemic also saw a surge in public support for health workers,(39) potentially resulting in positivity bias amongst participants and inflating the ratings assigned to PREM-ED 65 items.

Despite the real challenges posed by the COVID-19 pandemic, the development of PREM-ED 65 continued. With the right timing, some creative adaptations such as virtual hosting of cognitive interviews, cooperation of host NHS trusts, and the dedication of participating clinicians and students, the draft instrument was successfully administered to over 500 participants.

12.5 Reflections on the methodological approach

This section critically evaluates the methodological approach for developing and validating PREM-ED 65. First, justification is provided for selecting a mixed-methods approach, which is revisited. Then, the importance of stakeholder engagement is emphasised and approaches to ensuring the quality of the research are considered. Finally, the researchers' experience implementing some of the patient-facing aspects of the study, including pitfalls encountered, is reported.

12.5.1 A Mixed Methods Approach to PREM Development

Underpinned by a pragmatist epistemology, the PREM-ED 65 instrument was developed using a mixed methods approach, defined as research employing two or more research strategies to meet a project's aims.(40) The benefits of mixed-methods research include obtaining a comprehensive understanding of an issue or finding, validating and corroborating findings using more than one approach, and obtaining richer data than possible using a single-method

approach. When undertaking mixed methods research, caution is required to ensure all methodologies are rigorously applied and reported.(41, 42)

The mixed methods approach to developing and validating PREM-ED 65 allowed for a combination of inductive and deductive approaches, beginning with an inductive conceptualisation of older peoples' ED experiences that facilitated the creation and validation of a novel conceptual framework for patient experience in the ED. Methodological triangulation (43) of data from meta-synthesis, interviews, and focus groups deduced a comprehensive list of draft items. Subsequent derivation and validation of the draft measure utilised a deductive approach involving consensus generation and cross-sectional field testing to establish item response characteristics, structural validity, and reliability. The mixed methods approach was instrumental in producing a patient-centred measure that meaningfully captures elements of experience that matter the most to older people attending the ED.

12.5.2 Stakeholder, Patient and Public Involvement

Central to the design of PREM-ED 65, and enabled by adopting a mixed methods approach, was the prospective involvement of a wide range of stakeholders, including patients, the public, healthcare professionals and organisations advocating for older adults. From the outset of the study, stakeholders were involved when the initial proposal for PREM-ED 65 was presented to members of the Sheffield Emergency Care Forum in 2017.(44) Following this, recruiting a representative sample of patients and professionals directly informed draft item generation through interviews and focus groups.

Patient-public involvement is increasingly recognised as essential to developing patient-reported measures and has been demonstrated to positively influence

comprehension, response rates, validity, and reliability of patient-reported measures.(45) The contributions of stakeholders in design is therefore proposed as a key strength of PREM-ED 65.

12.5.3 Methodological Integrity

Consideration of reflexivity, rigour, and quality were essential to ensuring methodological integrity throughout the study's design and implementation. Optimising the integrity of the research helped ensure that PREM-ED 65 was valid and reliable and that the risk of systemic bias was minimised.

Reflexivity

Reflexivity describes the process of ‘looking inward’ and, in the context of research, refers to acknowledging researcher biases, being aware of how external factors may influence research, and communicating issues transparently. To this end, the practice of reflexivity consists of three aspects that are (i) thinking about thinking, (ii) observing one’s own emotions, boundaries and power dynamic, and (iii) exploration of perceptual experiences.(46) In considering reflexivity specific to health research, Huttlinger remarks that reflexivity “considers the reciprocal influence of the researcher and what is being researched”.(47) Olmos-Vega suggests that reflexivity extends beyond the individual researcher to consider interpersonal, methodological, and contextual issues in the research.(48)

The chief investigator’s role as an emergency physician was a vital issue concerning reflexivity. It was recognised that this could influence the conduct and analysis of the qualitative research, not least as the interviews were conducted in the researchers’ usual clinical work setting. To mitigate the potential for the Hawthorne effect(49) occurring during the interviews, staff were

prospectively briefed regarding the purpose of the study and reassured regarding confidentiality and data governance arrangements. When conducting patient interviews in the ED, the researcher wore non-clinical attire to differentiate themselves from the ED team and did not participate in direct clinical care during these sessions. Similar steps were taken during focus groups with staff, who were assured that their anonymity would be respected and that Chatham House rules followed the sessions.(50) On a positive note, it is also possible that the researcher's relationship with EDs participating in the focus groups assisted recruitment, particularly amongst emergency physicians. In addition to the measures described, field notes and post-interview/ focus group observations were recorded to assist future reflection, inform debriefing with supervisors, and contextualise data analysis.

Periods of self-reflection, maintenance of reflexive notes, and regular debriefing meetings with supervisors and the wider research team promoted a reflexive approach to qualitative data analysis. A beneficial function of debriefing meetings was to identify challenge assumptions, ensuring that the patient-centred focus of the study was maintained. The broader research and supervisory team assisted in coding data and assigning themes for the meta-synthesis, interviews and focus groups, and informed usability assessment of existing instruments within the scoping review. Sweeney et al. confirms that collaborative data analysis enhances reflexivity by inviting multiple perspectives and building stronger consensus around the generation of themes.(51)

Rigour and quality

Within health measure development, rigour involves the meticulous and systematic application of research methodologies throughout instrument development and validation.(52) In the context of PREM development, rigour

ensures the development of a high-quality instrument with appropriate measurement properties. Therefore, issues concerning rigour and quality were considered at each stage of the PREM-ED 65 study.

The Enhancing Quality and Transparency of Health Research (EQUATOR) network is an international consortium founded in 2006 to improve the adoption of good research practices and the quality of reporting.(53) The EQUATOR guidelines assist in standardising research processes, promoting transparency in reporting, and ensuring replicability. As such, the selection and reporting of methodology for some elements of PREM-ED 65 have been informed by guidelines to help ensure rigour. This includes Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA),(54) Consolidated criteria for reporting qualitative research (COREQ)(55) and the Consensus-based standards for selecting health measurement instruments (COSMIN).(56) Using a reflexive diary and field notes helped continuously assess positionality during the qualitative elements of the study and maintain a reflexive approach.

As discussed further in the next section, specific training was provided to research-naïve student investigators, including research governance.(57) From a quality perspective, this ensured that all students understood appropriate regulations and study procedures. As an additional quality measure, the students' experiences were captured in the post-study questionnaire, and the presence of significant barriers to recruitment or completion of the draft instrument were excluded.

12.5.4 Practical Implementation of the research

Careful implementation stages of the PREM-ED 65 study were necessary to ensure the validity of individual findings and the finalised version of the

instrument; challenges included sampling to promote representativeness of the study population, constructively managing discussion and interpersonal conflict, and administering the draft survey instrument to participants during the validation study.

Thoughtful employment of appropriate sampling strategies optimised the study population's representativeness and increased the external validity of PREM-ED 65. For example, purposive sampling was employed for interviews and focus groups to ensure that a representative cross-section of older adults and health professionals was selected. Due to the participants' required time commitment and the high level of engagement for the nominal group technique, a convenience sample of participants was recruited for the stakeholder prioritisation meeting that likely limited the overall diversity of the group, perhaps most of all involvement from older adults within lower socioeconomic groups. Nonetheless, a range of organisations was approached to maximise recruitment of a broad cross-section of stakeholders and ensure advocates for underrepresented groups were present at the meeting. For the validation study, site researchers were guided by a sampling matrix and captured a representative sample based on age, gender, and type of presentation.

A range of approaches was used to engage participants effectively in the research. In-situ recording of patients was performed to maximise ecological validity and minimise recall bias, but this had to be balanced against the need for confidentiality and privacy within the ED. Using noise-cancelling technology and lapel microphones enabled effective recording within clinical settings, including the ‘majors’ area. Even so, it became apparent that private settings

within the ED—such as the relatives' or seminar room—were desirable to minimise interruptions from patients and other team members.

The mixed, interdisciplinary focus groups proved a highly effective engagement method for professionals that leveraged the flattened hierarchy that ED staff are familiar with to stimulate discussion from various perspectives. These discussions were universally constructive, and as expected of professional registrants, participants had no problem self-regulating behaviour and negotiating differences of opinion, with no need for facilitator intervention to manage conflict at any point. The involvement of multiple stakeholders in prioritising the candidate items allowed participants from a broad range of backgrounds to contribute opinions using a standardised, inclusive, and democratic process. To enable constructive discussions, stakeholder meeting participants were divided into smaller focus groups, each facilitated by a research team member who was formally briefed on the study protocol and procedure for managing group interactions.(58) Feedback was sought from participants and facilitators to confirm adequate group interaction throughout the workshop.

Practical implementation of the validation study presented a logistical challenge due to the number of investigators and study sites involved. Following a request for volunteers among students enrolled on the BSc (Hons) Urgent & Emergency Care programme at the University of Plymouth, site investigators were provided with induction, including remote training on *NIHR good clinical practice* principles, which is a prerequisite for clinical investigators in the UK setting.(59) Additional protocol-specific training was delivered to ensure students had a working knowledge of screening, recruitment, and data handling procedures.

Local research departments provided research governance oversight, from whom prospective approval also had to be obtained, and registered clinicians were nominated as Principal Investigators.(60) Before the study period, packs containing all necessary study documentation, paper-based versions of the draft instrument, and a tablet computer to enable completion of the electronic version were distributed. Data input was managed and fed back to the research team electronically during the study period using the *SurveyMonkey* platform per General Data Protection Regulations (GDPR).(61) Using instant messaging via the encrypted *WhatsApp* platform enabled the research team to be responsive to investigator queries and operational issues. The follow-up survey, presented in the previous chapter, ensured investigators' satisfaction with study training, preparation, and implementation.

Whilst the practical implementation of some aspects was challenging, various creative approaches were taken to engage stakeholders and investigators during the study. Prospectively identifying and overcoming the challenges associated with implementing the research has assisted in producing an instrument with optimal face validity that measures what matters most to older people attending the ED.

12.5.5 Original Contributions to Knowledge

A core purpose of doctoral research is to provide original contributions to knowledge which may relate to the research approach, methodology, findings, or new theory.(62) This section will first discuss the contributions made by this research programme to knowledge in emergency care and health measurement methodology, respectively. It will then consider the end contribution offered by PREM-ED 65 as a new instrument.

Contributions to knowledge in emergency care

Broader contributions that the PREM-ED 65 study has made to knowledge in emergency care include the derivation of determinants of patient experience specific to the ED, a novel 'needs-based' conceptual framework for patient experience (Figure 12.3), generation of practical recommendations to improve patient experience, and providing original insights into older adults' experiences in the ED obtained during in-situ interviews. In addition to further expanding on data from the literature and the interviews, focus groups with staff revealed professional challenges associated with caring for older adults in the ED. Specifically, the focus groups highlighted the distress experienced by staff when desired standards of care could not be met.

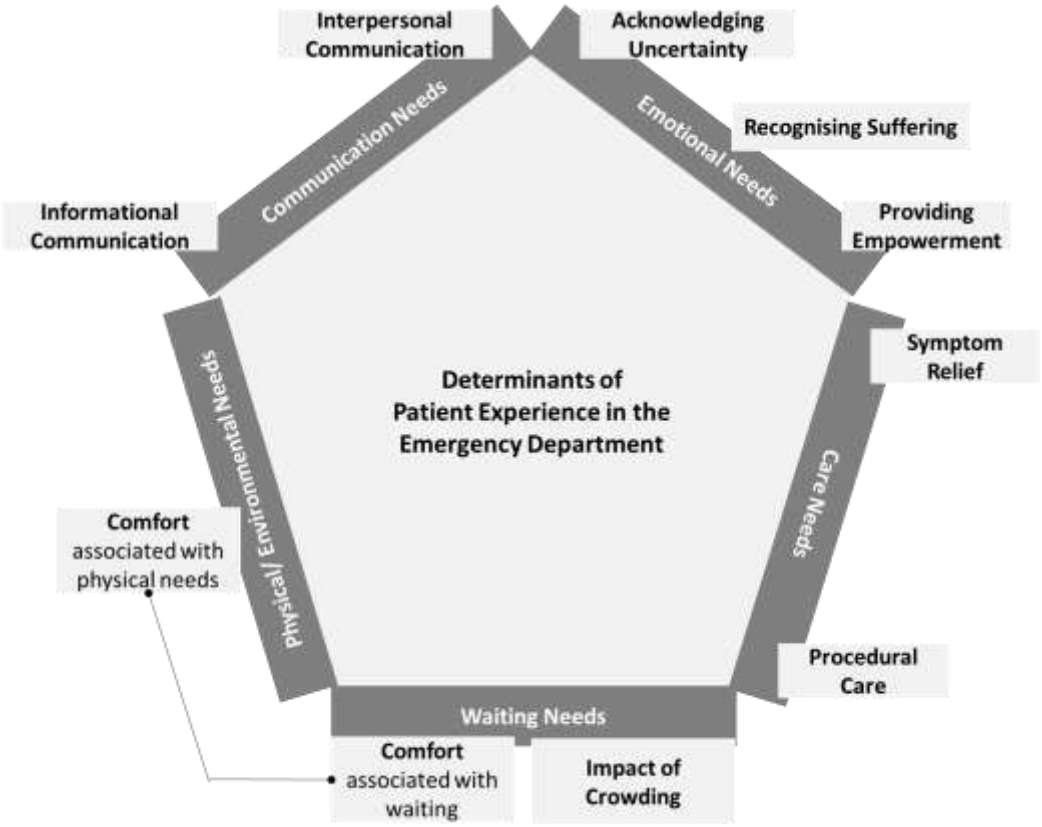

Figure 12.3 Conceptual Framework

(See Figure 4.3 for practical recommendations)

An additional original contribution to knowledge in emergency care is the scoping review of available instruments. Not only did this support the rationale for the study, but from a practical perspective, it should provide clinicians and healthcare organisations with an accessible guide to currently available health measurement instruments applicable to ED care. Once published, this important piece of work is envisaged to help inform the evidence-based selection of outcome measures for ED based research and quality improvement activity.

Contributions to knowledge in health measurement methodology

The PREM-ED 65 study's methodological contributions include the use of qualitative meta-synthesis as a technique to identify determinants of patient experience. The study has demonstrated how conceptualising a patient group's needs may guide research progress and directly inform the development of new health measures. In the case of PREM-ED 65, this included the adoption of framework analysis, using the analytical themes of the original conceptual framework, for both in-situ interviews and focus groups with staff, ultimately resulting in the generation of a comprehensive list of draft items.

The successful application of in-situ interviews with a population of older adults in the ED setting has demonstrated the value of this approach in exploring perceptions of care in near 'real-time' with patients as they attend the ED. In-situ interviews potentially reduce sampling bias and, in the context of the ED, may eliminate recency and recall biases, which are important considerations given the short length of ED encounters. Furthermore, the study has demonstrated the value of gaining staff opinions on patient experience for comprehensiveness and inclusivity. Staff may provide insights into patient care through a more critical lens, assisting in identifying vulnerabilities in service provision and processes.

An additional contribution is the involvement of multiple stakeholders, including older adults, in assessing item comprehensibility and priority during the one-day nominal group exercise. This workshop format demonstrated the feasibility of engaging a wide audience to prioritise candidate items and ensure the comprehensibility and comprehensiveness of the final item list.

Finally, adopting a collaborative research model for the validation study demonstrates the value of this method for recruiting participants across multiple centres. The positive perceptions of involvement reported by the student researchers demonstrate that this approach provides the added benefit of providing research training, increasing research awareness, and informing academic careers among novice researchers.

Contribution of PREM-ED 65 as a new ED health measure

Grounded by recognition of the globally ageing population, acknowledgement of the challenges in providing emergency care for older adults, and the lack of existing measures for evaluating their ED experiences, PREM-ED 65 offers an original addition to currently available health measures within the ED setting. The assessed psychometric characteristics of PREM-ED 65 mean that it meets the COSMIN study design criteria (63) for acceptable structural validity, internal consistency and test-retest reliability. The result is a valid and reliable tool for assessing older adults' experiences of relational care, the ED environment, information provision, and pain assessment. Furthermore, the formatting and length of the finalised instrument are designed to facilitate ease of administration within the ED and promote completion by older adults, aiming to maximise patient and staff engagement and minimise the potential for non-response bias. Although development was mindful of the need for brevity, data derived from PREM-ED 65 should be detailed enough to empower clinicians

and healthcare organisations to effect change and implement meaningful improvements for older adults attending the ED. Meeting the future research priorities (Section 12.7) is anticipated to enhance the contribution of PREM-ED 65 further to include additional populations of ED patients.

12.6 Study Limitations

The prior research chapters within this thesis consider the nuanced limitations of the PREM-ED 65 study's different elements. This section will summarise the study's overarching limitations regarding selection bias, sampling bias, survey biases, and psychometric characteristics.

12.6.1 Selection Limitations

Several general selection limitations are pertinent to the PREM-ED 65 study. These include the use of chronological age as inclusion criteria, the instrument's global applicability, its applicability to other groups of ED patients, and cognitive impairment.

Chronological Age as a selection criterion

The chronological definition of older age as the primary inclusion criteria for PREM-ED 65 is based on international definitions. It is intended to facilitate an inclusive approach to assessing older adults' ED experience. As discussed within the introductory chapters of this thesis, features familiar to older adults, such as increased incidence of atypical acute presentations, multimorbidity, polypharmacy and odds of increased length of ED stay, provide a rationale for measuring the experiences of older adults as a single group.(64, 65) From a pragmatic perspective, the straightforward age-based criterion facilitates administration within the busy ED setting. However, a single age-based inclusion criterion is arguably simplistic. Indeed, it does not account for the wide

variation in health trajectory encountered at similar ages in the older adult population, known as heterogeneity of ageing.(66) Additionally, health services increasingly view older adults living with frailty as a distinct group for whom the development of bespoke emergency care pathways is becoming more commonplace. Concerning patient-reported measures for this group, Van Oppen and colleagues have recently developed PROM specifically aimed at frail older adults in acute care (PROM-OPAC).(67) Having been carefully developed and validated, this instrument represents a significant development and has potential to complement PREM-ED 65 (and vice-versa) in the specific assessment of frail older adults' ED experiences and outcomes.

While it seems intuitive that the ED care needs and expectations of individual older adults may differ, available evidence suggests that the fundamental determinants of ED patient experience may be somewhat similar, irrespective of ageing or clinical frailty status. For example, qualitative interviews with twenty-eight frail older adults during PROM-OPAC development revealed key themes of staff care and attitudes, information and communication, environment and personal comfort, and time waiting in ED.(68) Indeed, these align very closely with the needs-based framework underpinning PREM-ED 65. Commonality in experience is also supported by the negligible differential validity observed based on gender, age, or reason for presentation during the PREM-ED 65 validation study.

Therefore, whilst it is acknowledged that PREM-ED 65 does not directly account for the heterogeneity of ageing or clinical frailty, the instrument is nonetheless expected to measure important aspects of the patient experience for most older adults. Even so, further validation of the instrument using confirmatory factor

analysis amongst very old adults or those with moderate/severe frailty is desirable to confirm. As will be discussed in detail later, the development of additional scales may be beneficial in capturing the nuanced expectations of subgroups such as those living with sensory impairment or disability.

Global applicability

Care of the ageing population is an international concern beyond the UK, with over two-thirds of the global population of older adults residing in low—and middle-income settings.(69) Differences in cultural perceptions, economic and social factors, and life expectancy mean that the absolute chronological inclusion criteria of >65 years may not be relevant worldwide.(70) Hence, rather than being viewed as an absolute inclusion criterion, the age-based definition of 65 may need to be adjusted to reflect norms in the local target population if applied within global settings.

Applicability of PREM-ED 65 to other groups of ED patients

A separate limitation of the current instrument is that its administration during the validation study was limited to patients discharged from the ED. Validation in patients admitted to the hospital from the ED must now be a priority. This is particularly important as it is this patient group is most vulnerable to the effects of ED crowding, increased ED LOS, and excess morbidity and mortality.(24)

Applicability of PREM-ED 65 in cognitive impairment

Finally, PREM-ED 65 is not validated among older adults with cognitive impairment. Given the substantial and increasing prevalence of dementia in the over-65 population (7.1% as of 2013), finding ways to capture the experiences of this group effectively should be a research priority.(71, 72) As measures requiring information recall may be less effective, approaches including provider

self-assessment, enhanced regulatory inspection, proxy measures, and real-time reporting of experience have been suggested.(73)

12.6.2 Study Design Limitations

As previously described in this discussion, the methodology selected for developing PREM-ED 65 has been designed to maximise the finalised instrument's content validity, structural validity, and reliability. Despite this, existing design limitations include sampling participants from a single geographic region of the UK during the development phases of the study. Even though the South West region has the highest proportion of over-65s in the UK, other differences his may limit external validity, especially given regional differences in ethnicity and health outcomes.(74, 75) Whilst within recommendations for qualitative research and meeting criteria for thematic saturation,(76) sample sizes were reasonably small within the study's interview and focus group elements. A broad range of perspectives were sought from older adults and professionals. Even so, the sample may not be fully representative. As described, the stakeholder workshop sample was non-representative of those from lower socioeconomic groups. General limitations of the nominal group process, including respondent fatigue and the concept of ‘rosy retrospection’ related to previous healthcare encounters, may affect the validity of the results.(77) The national, multi-centre design of the validation study aimed to mitigate some of these prior limitations and did result in selecting a broader cross-section of the older adult population; however, ongoing validation is required to confirm structural validity and inclusivity of PREM-ED 65 amongst underrepresented groups. Proposed approaches to ongoing validation are further detailed within this discussion section's psychometric limitations and future research priorities.

12.6.3 Sampling Limitations

Obtaining a truly representative sample of older adults in the emergency setting is challenging due to limitations in electronic health records, staff engagement in research, difficulty screening for eligible patients, the presence of acute illness, delirium, cognitive impairment, and sensory and communication issues.(78)

To help mitigate this, purposive sampling was applied to the qualitative phase of the study. This resulted in a broadly representative sample based on characteristics including gender, acuity, and mode of ED arrival. Likewise, convenience sampling assisted by a matrix facilitated representativeness amongst the validation study participants. However, fewer than the expected proportion of patients lived with severe levels of frailty or were from ethnic minority backgrounds.

A non-representative sample may occur due to non-participation bias. Reasons for non-participation may include refusal, inability to participate, or not being screened by researchers. Whilst a precise response rate was not calculated for the validation study, 76% of student respondents to the follow-up survey estimated a conversion rate of >50% of screened participants during the study period.

As will be explored later when considering unintended consequences of PREM implementation, the under-representation of patients from minority backgrounds is a significant limitation because of health inequalities that are known to result in worse patient experiences and outcomes for patients from underrepresented groups.(79-83) Therefore, confirmation of validity amongst minority groups and cross-cultural validation is a priority for onward research. In addition, the development of sub-scales may be required to ensure the experiences unique

to other underrepresented groups are captured, including older adults living with severe frailty, disabilities, or sensory impairment. In addition to the items within the original comprehensive list, this may also be informed by specific instruments targeted at these groups, for example, in hearing loss (84) or physical disability.(85)

12.6.4 Response Limitations

Response biases relevant to PREM-ED 65 include older adults' increased tendency to agree with statements, acquiescence bias, and social desirability bias.(86) Responding to interview questions or survey items within healthcare settings may lead to a tendency for positive care ratings. Information provided on participant information sheets encouraged participants to give honest feedback and provided reassurance regarding their anonymity and the impartiality of researchers.

12.6.5 Psychometric Limitations

As already stated, the proposed version of PREM-ED 65 is intended to meet COSMIN criteria for content validity, structural validity, and internal consistency. As has been conducted in similar studies,(87, 88) future validation studies involving PREM-ED 65 should utilise Confirmatory Factor Analysis or Rasch analysis to confirm structural validity and gain further insights into per-item performance.(89, 90)

Whilst test-retest reliability at 7—10 days post-administration was adequate, missingness for retest data was relatively high at about 17%. The imputation of a large amount of missing data can potentially adversely affect the Intraclass Correlation Coefficient, and as such, a repeat assessment of Test-Retest reliability is desirable. Additionally, utilisation of the NHS friends' and families'

test as a measure of criterion validity is imperfect as this is not an established 'gold standard'.(91) Therefore, comparing either ED-specific instruments, such as ED-PREM, (92) or those aimed at older adult inpatients, such as RIGHTPREM™,(93) may provide more detailed insights into psychometric properties.

As already mentioned, assessing the cross-cultural validity of PREM-ED 65 is also necessary, particularly as additional determinants of ED patient experience may be present among non-English-speaking populations.(82) Further validation studies purposefully sampling populations of interest, as has been attempted with other PREMs, may accomplish this.(94) Besides formal validation, Roberts et al. describe a pragmatic process for cross-cultural adaptation of Vaillancourt et al.'s PROM-ED from a Canadian to a UK population.(95) This latter process is time- and resource-efficient and may apply to PREM-ED 65. UK residents speak a range of languages besides English, including Welsh, Polish, Romanian, Panjabi, and Urdu.(96) To maximise PREM-ED 65's inclusivity, translation to widely spoken languages is desirable but should follow appropriate COSMIN guidelines. These include independent translation by more than one reviewer, procedures to resolve differences between original and translated versions, and a pilot study amongst the intended population. This ensures that the meaning of items and psychometric properties are preserved and not 'lost in translation'.(97)12.7

Future Research Priorities

As a result of the identified limitations, four key priorities to guide the onward development of PREM-ED 65 are proposed. Meeting these priorities will help

ensure that PREM-ED is optimally inclusive and effective for measuring older adults' experiences of ED care:

Priority 1: Ensure the suitability of PREM-ED 65 to assess the experiences of patients admitted to the hospital from the ED.

Priority 2: Perform cross-cultural adaptation and validation of PREM-ED 65 to ensure the instrument effectively measures the experiences of older people from underrepresented groups, including ethnic minorities. This may include translating PREM-ED 65 to other languages.

Priority 3: Consider the development of additional scales to measure the nuanced experiences of patients living with (e.g.,) disabilities, sensory impairments, or specific cultural or spiritual needs.

Priority 4: Further optimise the psychometric characteristics of PREM-ED 65 using further validation samples and repeat assessment of test-retest reliability against an ED-specific patient experience measure.

12.8 Implementing PREM-ED 65

Encouraging EDs to adopt PREM-ED 65 for routine administration requires considerate implementation at a local level if it is to be successful. A systematic review of twenty qualitative studies identified barriers to PREM implementation, including health professional concerns relating to the use of data in complaints investigation and individual performance management, limitations in quantitative data to identify areas for improvement, the time cost associated with administration, and the potential for PREMs to raise false expectations amongst patients. Conversely, proposed facilitators to staff adoption of PREMs included training on the purpose and administration of adopted PREMs, open discussion of results, staff involvement in subsequent quality improvement processes, and

proactively using positive experience data to identify team strengths and commend good practice.(98) In the ED setting, specific barriers to measuring patient outcomes include the actionability of data given the time-limited and periodic nature of patient encounters, the timing of administration within the ED patient journey, and the perceived risk of patient response biases, including recall bias.(99) As the implementation of PREMs is likely to be context-dependent and governed by the clinical setting, Stover et al. recommend that approaches based on implementation science be used when adopting a new PREM.(100) Similarly, Benson advocates a Plan-Do-Study-Act (PDSA) approach to PREM implementation.(101) Following the implementation of a PREM, providing timely and interpretable data is essential to ensure responsiveness of services, engage staff, and provide improvements at a local level.(102)

12.9 Study Implications

The PREM-ED 65 instrument aims to provide specific and detailed measurements into older adults' experiences of ED care compared to currently available methods, including the NHS friends' and families' test. Although implementation must be conducted thoughtfully to ensure acceptance of the instrument, the survey is intended to be straightforward enough for routine administration to most of those over 65 who are discharged from the ED. It should give older adults a means of reporting their ED experience, encourage their opinions to be reported, and involve ED patients meaningfully in quality assurance and improvement. Along with definitions provided in a recent review, it is proposed that data from PREM-ED may be utilised at an individual (*micro*-), institutional (*meso*-), and national (-macro) level.(103) In addition, PREM-ED 65

may support future research on health services for older adults and the delivery of value-based healthcare.

12.9.1 Implications at the individual, institutional and national level

At the individual level, clinicians or teams may use PREM-ED 65 to assess their performance for appraisal, professional revalidation, or a measure of care quality before regulatory inspection. Patient experience or satisfaction is infrequently covered in postgraduate curricula, and PREM data may be used to facilitate clinician training in person-centred care.(104)

At the institutional level, PREM-ED 65 provides a valuable quality assurance mechanism and may indicate strengths and weaknesses in care.(105) By doing so, PREM-ED 65 may act as a vehicle for change that helps ensure that quality improvement activities to improve the patient experience are appropriately targeted, efficient, and cost-effective. Repeat administration of PREM-ED 65, following implementation of an intervention or innovative change, may provide comparative data enabling impact assessment during subsequent quality improvement cycles. The utility of patient-reported data for facilitating quality improvement activity had been previously demonstrated for improving patient flow(106), enhancing communication in acute care(107), and improving pain management in the ED.(108)

At the national level, data from instruments such as PREM-ED 55 may be used to compare the quality of patient experience delivered to older adults across institutions. This may identify where systemic areas of excellence or inadequate services exist and—if published—enable older adults or their carers informed choice over where to best seek emergency care.

As discussed within the introductory chapter of the thesis, national ED performance metrics are predominantly process-focused and do not presently include patient-reported experience or outcomes data. This contrasts with surgery, where a National Patient Reported Measures programme exists both in the UK and internationally and is used to direct post-operative rehabilitation, commissioning of services, best practice tariffs and enable patient choice.(109) It is proposed that a similar data-driven approach may be utilised in emergency care to set performance standards to replace or supplement the existing metrics. Select items or an aggregate score from well-validated instruments, including PREM-ED 65, may provide a reliable means of achieving this.

Is there a role for PREM-ED 55 in value-based emergency care?

Value-based healthcare (VBHC) expands the traditional notion of quality to assess how health systems improve patient outcomes on an individual and population level and the cost required to achieve this. A core aim of value-based health is to improve patient-centredness whilst limiting unnecessary utilisation of healthcare resources and expenditure.(110) VBHC is assessed through a health system performance assessment. In defining the dimensions of value-based healthcare, the American College of Physicians expands on the Donabedian model of healthcare quality by adding access, patient experience, and value of care.(111) In the ED context, VBHC may reduce the fragmented nature of emergency care by promoting integration with primary and secondary care, improving efficiency and patient flow, and avoiding admissions through increased utilisation of ambulatory emergency care pathways.(112) There is increasing interest in VBHC in UK settings, including national implementation in Wales.(113, 114) Although not yet commonly utilised within VBHC, PREMs may provide a valuable means of measuring performance as part of a VBHC system.

They can provide more detailed insights into patient expectations and care preferences than satisfaction measures alone.(115)

12.9.3 Implications for Research

Finally, PREMs have a potential role in supporting and evaluating future research activity. By identifying vulnerabilities in care processes, patient-reported data may be used to generate research questions and hypotheses. The inclusion of PREM data may objectively demonstrate the consideration of patient views in research proposals and grant applications.(116)

For research implementation, PREM-ED 65 may be used as a patient-centred outcome for health services research aimed at innovating or improving care pathways and ED services for older people. Specific examples may include implementing and evaluating ED-based frailty services, ambulatory/same-day emergency care pathways, or geriatrician-led comprehensive assessment.

Additional applications for PREM-ED 65 in the research process may include its ability to provide a participant feedback loop, where the utility of data for improving quality is presented to participants and may increase subsequent engagement.(117) Finally, there may be a role for the adoption of PREMs in health economic evaluations by enabling the incorporation of patient preferences and experience data to evaluate the value of interventions robustly.(118)

12.10 Unintended Consequences

Implementing PREMs within the healthcare setting may give rise to potentially serious unintended consequences. The final section of this discussion explores some possible repercussions arising from PREM administration, including the potential for overreliance on survey data, the perpetuation of structural

inequality, and PREM data to generate perverse incentives that may harm patients.

12.10.1 Overreliance on survey data

> *"Not all that counts can be counted.*
> *Not everything that can be counted counts."*
>
> William Cameron, 1963(119)

The ED is a highly complex care environment. Due to its undifferentiated clinical caseload, heterogeneous patient group, and multi-professional care delivery model, defining absolute outcomes or determinants of experience for ED patients is challenging. This is likely to explain the relative lack of PREMs, PROMs, and HRQOL instruments in emergency care compared to more predictable clinical settings or long-term conditions.

This thesis has described, in detail, the comprehensive approach to derive, assess, prioritise, and test items that now enable the measurement of older adults' ED experiences. But no matter how rigorously developed or well validated, survey instruments provide data that is limited in depth and vulnerable to response bias and temporal effects.(120, 121) Whilst the role of PREMs in identifying and driving quality improvement is clear, overreliance on data may include the generation of misassumptions regarding quality of care, which may be especially true for underrepresented groups within the survey population. Therefore, clarifying and further expanding vulnerabilities identified because of survey administration is encouraged to provide nuance and a deeper understanding of identified issues. This may be achieved using qualitative methods such as those reported within this thesis, content or sentiment analysis of free-text comments where provided,(122, 123) analysis of e-mail or telephone follow-up with patients,(124) or through patient-public

initiatives such as user groups.(125) When performing quality improvement informed by PREM data, providing a feedback loop and, where possible, actively involving service users and other stakeholders in processes such as action research or experience-based co-design is likely to be highly beneficial.(126, 127) A novel ‘PREM observatory’, developed in Italy, provided a means of delivering responsive and meaningful feedback derived from PREMs to clinicians.(128) Finally, it is essential to remember that although patient experience is an important determinant of healthcare quality, this must not be at the expense of measuring other quality dimensions, including clinical outcomes and patient safety.

12.10.2 Perpetuation of Structural Inequality

Structural inequality is increasingly recognised as a determinant of mortality and poorer health outcomes amongst some discrete groups within society, including but not limited to lower socioeconomic status (SES), females, people of colour and those living with learning disabilities.(79, 129) The presence of structural inequality has been recognised within emergency and acute healthcare, for example, in the suboptimal diagnosis and poorer outcomes of women with acute coronary syndromes,(130) racial bias in ED management of patients with sickle cell disease,(131) clinical management and increased mortality in COVID-19 patients with intellectual disability,(80) and increased risk of hospital admission for older adults attending the ED from low SES.(132)

Appropriately validated PREMs and PROMs have the potential to mitigate health inequality and promote population health.(133) However, inconsiderate design, inadequate validation, sampling biases or population-level disengagement with health services may mean that the experiences of underrepresented communities are inadequately captured.(83) In the worst

case, PREM data may conceivably amplify the opinions of a non-representative sample, perpetuating confirmation bias among providers and paradoxically worsening structural inequalities. As such, it is essential to ensure proper instrument validation amongst underrepresented groups and make efforts to ensure these groups are adequately represented in the subsequent administration of the instrument.(134, 135) As already recommended within this chapter, the future evolution of PREM-ED 65 must include direct engagement of underrepresented groups, formal cross-cultural validation and adaptation, and the development of appropriate additional measurement scales.

12.10.3 Generation of perverse incentives

Whilst applying patient-reported data to monitor the performance of individuals and health services is attractive and may complement existing ED process metrics, care must be taken to ensure that doing so does not result in perverse incentives at the expense of other aspects of care delivery, leading to patient harm. A striking example of where patient-reported data has led to worse outcomes relates to the opioid crisis in the United States, which is responsible for over 100,000 deaths per year. Although not a single causative factor, concern has been raised that overprescribing may have occurred to prevent inadequate satisfaction ratings and financial penalties for pain-related items.(136) A similar link has been reported with over-requesting medical imaging and interventional spinal procedures.(137) Value-based healthcare may perpetuate this effect as, particularly in some US settings, patient satisfaction is heavily linked to remuneration. Whilst this specific scenario is unlikely to directly translate to the UK setting at present, these examples provide a stark reminder of the necessity to employ effective balancing

measures when assessing discrete dimensions of quality of care, including patient experience.

12.11 Summary of Discussion

This chapter has summarised the PREM-ED 65 project and offered reflections on challenges encountered, methodological choices, steps taken to optimise quality and rigour, and practical implementation aspects. Aside from the successful development of the validated 25-item PREM-ED 65 survey, original contributions of this study include the conceptualisation of a ‘needs-based’ framework for patient experience, the application of interviews conducted with older adults during their acute ED visits, and the multiple stakeholder prioritisation exercises to determine items for the draft instrument.

Existing limitations of PREM-65 include the lack of validation among older adults admitted to the hospital from the ED, the need for broader cross-cultural validation, and consideration of additional needs of underrepresented groups. Explicit recommendations made within this chapter should ensure these limitations are mitigated in the future.

Whilst PREM-ED 65's impact may extend beyond individual healthcare teams and institutions to enable benchmarking and performance monitoring of ED services for older adults, evaluation of VBHC systems, and outcomes measurement for future health services research, care must be taken to monitor for and avoid unintended negative consequences, including the use of appropriate safeguards and balancing metrics.

12.12 Conclusion

This research programme aimed to produce a patient-reported experience measure for older adults over 65 who are attending the ED. The resulting 25-

item PREM-ED 65 instrument has been developed using mixed methods and validated within a multi-centre national study. The involvement of patients, carers, members of the public and other stakeholders throughout the development process ensures excellent content validity for administration to the general older adult population in the UK context. In addition, PREM-ED 65 demonstrates good psychometric characteristics, including structural validity, internal consistency, and test-retest reliability. The adoption of PREM-ED 65 is encouraged to help assess individual and departmental standards of care for older people, identify areas for meaningful quality improvement, and facilitate benchmarking and comparison of ED services for older adults. Careful adoption of person-centred ED performance criteria derived from PREMs may augment current process- and outcome-driven metrics and drive quality improvement, innovation, and the provision of value-based emergency care for older adults.

External validation of PREM-65 is now required to confirm its properties. In addition, further validation of the instrument among older adults admitted to the hospital from the ED and those with different cultural or language needs is needed. To optimise inclusivity, developing or integrating existing scales to measure the nuanced experiences of older adults with disabilities or sensory impairments is desirable.

12.13 Personal Reflections

12.13.1 Lessons Learned

Throughout this research, I encountered academic and practical challenges requiring reflection and adaptation. Adopting a broad-based, multiple-methods approach presented the challenge of learning and seeking training across qualitative and quantitative methodologies. An early lesson encountered was to seek advice and collaboration from other methodologists, including fellow

clinical academics with qualitative research experience and medical statisticians. On a personal level, this has equipped me with a broad research skillset and heightened my awareness of roles within the multidisciplinary research team. Specific to the PREM-ED 65 study, broad training and collaboration has enabled the production of a comprehensive, valid, and reliable instrument for use in the ED. As I have progressed, I have learned to maintain a flexible approach and anticipate likely problems before they occur. Although the study has taken longer than initially envisaged, flexibility and adopting a proactive approach to problem-solving have enabled me to complete the study despite challenges including the COVID-19 pandemic and the competing demands of my clinical and educator roles. As such, I have matured as a clinical academic, and my project management skills have improved. Specifically, I recognise the importance of generating realistic and achievable project timelines and formulating specific short-term objectives. Doing so has helped maintain my motivation and momentum. A particularly challenging aspect of the project was coordinating the multi-centre validation study. I have learned that multi-centre research necessitates clear communication with clinicians and research staff at each site. I learned the importance of building rapport with institutional stakeholders and research departments and being responsive to queries. In practical terms, this assisted in obtaining confirmation of capacity and capability within host trusts, which enabled local approval for data collection to commence within the data collection window, which was constrained by student researchers' academic year. I have also learned how different institutions prioritise and administer clinical research. Reflecting on the research programme, an overarching lesson has been to embrace a team

approach, whether by involving lay and expert stakeholders in research design or institutions and professionals in assisting research delivery.

Some currently unresolved limitations also provide important lessons. For example, the lower-than-expected proportion of minority participants within the validation study highlights the importance of purposeful sampling from groups often underrepresented in research. Although I hope to overcome this limitation in my postdoctoral work, I recognise that prospectively making a deliberate effort to engage more diverse participants may have obviated this requirement.

In addition to broadening my academic and research skillset, conducting this research has led to some relevant clinical insights and lessons. Notably, my appreciation of the variation in needs and expectations between older people is much deeper than previously. As highlighted by the priorities from the stakeholder workshop, this includes the importance of delivering high-quality, compassionate, and relational care and extends to identifying and meeting patient expectations for clinical and technical care. This highlights the necessity of individualised care for older people based on personal values, beliefs, and expectations and will positively influence my clinical practice moving forward.

Overall, leading this project and reflecting on the lessons learned have enhanced my academic, leadership, and clinical skills, which I plan to continue developing as a clinical academic into the future.

12.13.2 Epilogue

As a newly graduated foundation doctor, I remember meeting a prominent emergency medicine professor to explore getting involved in some research. The first question they asked me was, “What is your ‘ology?’”. I clearly remember that this question dumbfounded me. I had some idea of the topic

areas that interested me, but I had failed to give any thought to the expertise I would require to generate and address research questions meaningfully! Little did I know that developing a credible answer to this most fundamental question would take years to develop.

As I end my doctoral studies, my confidence and competence to function as a mature and independent researcher have hugely developed since those early days. I end this thesis fascinated by qualitative research, and I am aware of the potential for qualitative methods to provide insight into complex healthcare issues and uncertainties. I have become an advocate of person-centred health research and have experienced the benefit of bringing patients, colleagues, and others along on the research journey. I have learned much about developing a valid and reliable questionnaire and the strengths and limitations of patient-reported outcomes. Despite operational challenges affecting emergency medicine and the impact of COVID, leading a collaborative of motivated medical students to deliver a national NIHR portfolio study was a definite highlight, and I hope it has encouraged some others to embark upon their own research path. Perhaps most importantly, I hope PREM-ED 65 will help maintain and improve standards for older adults accessing emergency care. I remain determined to continue developing my academic skills and use the expertise I have gained from this project for the benefit of the patients. Although my choice of clinical speciality has recently changed, I remain motivated to contribute effectively to health services and patient-centred research in unscheduled care. I see great opportunity to supervise emergency clinicians and share my expertise, whilst also transferring my research skills to interventional and emergency radiology settings, which play an increasingly prominent role in the care of acutely unwell and injured patients.

To close, I will rely on the words of Winston Churchill: This is not the end. But it is, perhaps, the end of the beginning.

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Appendices

Appendix 1: Scoping Review Data Extraction Tool

Part 1: Study Characteristics	
Journal	
Study Title	
DOI	
Author(s)	
Country	
ED Properties *Including ED type, urban vs. rural, numbers of patients/yr*	
Patient Characteristics *Including gender proportions, age, presenting complaint, etc*	
Part 2: Scale Content	
Name of Scale	
Category ***PROM/ PREM/ Safety Reporting Measure/ Other (State)***	
Purpose	
Domains	
Number of Items	
Type of Response Scale	
Scoring	
Time to complete	
Part 3: Mode of Administration	
Type of Administration	
Format (e.g. electronic vs. paper based)	
Language Options	
Other accessibility options (e.g. large print, braille, etc)	
Part 4: Quality Assessment **Use COSMIN Checklist, rate each domain as 1=Poor; 2=Fair; 3=Good or 4=Excellent.**	
Internal Consistency	
Reliability	
Measurement Error	
Content Validity	
Structural Validity	
Hypothesis Testing	
Cross Cultural Validity	
Criterion Validity	
Responsiveness	
Part 5: Usability	
Does the study have external validity/ generalisability?	
Does the study have utility for improving the quality of ED care delivery?	
Part 6: Conclusion	
Reviewer conclusion	

Appendix 2: Consent Form used for in-situ interviews.

PReM-ED 65
Patient Reported Measure for Emergency Department patients aged 65 and over

IRN: PREMED65/INT/01/PN_____

Informed Consent (Interviews)

Patient Addressograph

Study Title: Interviews with patients to develop a list of outcomes for older adults attending the emergency department.

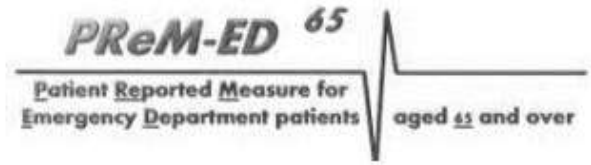
Thank you for reading the information sheet about this study. If you are happy to participate then please complete and sign the form below. Please initial the boxes below to confirm that you agree with each statement:

	Initials
I confirm that I have read and understood both the participant information sheet and the supplementary information about GDPR regulations (both dated 18th July 2018) and have had the opportunity to ask questions.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and will not be identified or identifiable in the report or reports that result from the research. Information which could be used to identify me will be destroyed after the study is complete.	☐
I understand that if the interview reveals information that highlights concerns regarding my immediate safety or wellbeing, the researcher will inform the senior attending clinician looking after me.	☐
I agree for this interview to be audio- recorded. I understand that the recording will be used only for analysis and that quotations from the interview, from which I would not be personally identified, may be used in any conference presentation, report or journal article developed as a result of the research. I understand that no other use will be made of the audio recording without my written permission.	☐
I agree that my anonymised data will be kept for future research purposes such as publications related to this study after the completion of the study.	☐
I agree to take part.	☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Investigator	Date	Signature

Document Version 2 Date: 18/07/2018

Appendix 3: Participant Information used for in-situ interviews.



Supported by

The Royal College of Emergency Medicine · University of Plymouth · NHS University Hospitals Plymouth

Participant Information Sheet: Interview Study

Project Title: Initial development and pre-testing of a Patient Reported Measure for Emergency Department patients aged 65 and over.

Thank you for considering participating in this research project. This leaflet provides some more detailed information. It takes a few minutes to read and will guide you through the study

Take the time you need to read this leaflet carefully.

Please ask any questions you have.

1. Why have I been asked to take part?

You are an unwell adult aged 65 years or over who has attended A&E today or have been admitted through A&E.

2. What is the purpose of the study?

This study will explore how you feel about being looked after in A&E by asking for your views and opinions using a set list of questions. This is known as a *semi- structured* interview. You will be asked questions about what you think makes a good experience in A&E, what care you would like to receive as a result of attending A&E, and what helps you to feel safe being cared for in A&E.

Results will be used to inform the design of a questionnaire to measure patient experiences of A&E care

3. What will happen if I take part?

You will be invited to participate in a face-to-face interview lasting about **45 minutes**. Any questions will be answered and you will complete a short

consent form. You will be taken to a private area for your interview. Your relatives may attend but won't be directly involved. The researcher will go through a list of questions, and your responses will be recorded on a microphone. The research team will identify how your views compare with those of other patients.

4. Do I have to take part ?

No. Please let us know if you do not wish to take part, would like to withdraw your involvement, or would like to decline to ask a specific question at any point. You do not have to justify this with a reason.

5. Will participation affect my usual care

No. You will receive usual care.

6. I'm too unwell to participate now. Could I take part later?

If you are admitted to hospital, it might be possible to approach you again in 24 hours or so. Please do let us know if you would like to participate at a later date.

7. Are there any potential benefits or risks of taking part?

This study will help inform how we measure patient experience in the future. This is very important as it helps us to identify where we can improve the care provided and compare quality of care amongst A&E.

We understand that talking through your experiences might sometimes be upsetting. If this is the case, let us know and we can help advise sources of support. Likewise, the interview might identify that you wish to make a compliment or complaint.

8. What if I wish to make a compliment or complain about the standard of care I have received in A&E?

If your interview reveals that you would like to provide a compliment, we can help you do this. If your interview highlights a complaint, we will advise you how to pursue it. In the unlikely instance that your care appears unsafe, we will let you know and take this forward with your consent.

9. **Who is involved in this study?**

This study is being conducted as part of a PhD project by Dr Blair Graham. Funding support has been obtained from the Royal College of Emergency Medicine, Plymouth University and Plymouth Hospitals Charity.

10. **How will you protect my data and confidentiality?**

Protecting your data and confidentiality is very important to us. This study complies with all current data protection rules and regulations. See below for a detailed explanation, and ask a member of the research team if you have any questions.

The University of Plymouth is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Plymouth will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

We will not be looking at your medical records as part of this study.

University Hospitals Plymouth will keep your name and contact details confidential and will not pass this information to Plymouth University. University Hospitals Plymouth will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Plymouth University and regulatory organisations may look at your research records to check the accuracy of the research study. Plymouth University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

University Hospitals Plymouth will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how we use your information by contacting the Lead Researcher whose contact details are at the end of this leaflet.

11. What if something goes wrong?

It is very unlikely that anything will go wrong. If you feel it does, please do let the researcher know or contact us using the details at the end of this leaflet.

12. Has this study received approval?

This study has received NHS and University Approval.

13. How may I contact the research team in the future?

If you would like to register or have further questions, contact Dr Blair Graham (Principal Investigator) by telephone (01752) or email (@plymouth.ac.uk).

14. Can I view the final study results?

Yes. Please let us know if you would like to be sent a copy of the final research report.

15. What if I wish to complain about this study?

Please contact Plymouth Hospitals Patient Advice and Liaison Service (PALS) on 01752

Thank You

Appendix 4: Interview Question Schedule

In Situ Interview Schedule

Study Title: Interviews with patients to develop a list of outcomes for older adults attending the emergency department.

IRN: PREMED65/INT/01/PN_____

Date:_____/_____/_____

Interviewer:_____ Co- Investigator:_____

Location: _____

Pre- Interview Actions:

Ensure Interview Screening Form **Completed in full** ☐

Ensure Patient Information Sheet **Has Been Issued** ☐

- ✓ Introduce self by name and role
- ✓ Personally thank participant for involvement
- ✓ Explain the purpose of the interview- clarify PIS- invite questions
- ✓ Explain purpose of recording, recording device and confidentiality
- ✓ Clarify right to withdraw

Ensure Consent Form **Completed & Initialled** ☐

Ensure Interview Baseline Characterstics **Proforma Completed** ☐

Start Recording (Time ____:_____) ☐

Question Schedule:

1. Perceptions of Experience

   Firstly, we're going to explore your perceptions of experience in A&E.

   What do you feel has affected your experience of visiting the A&E Department today?

   Probes shall relate to exploration of (i) Likes and Dislikes of Care,(ii) Areas for Improvement, (iii) Communication, (iv) Personal anxiety/ suffering, (v) Technical Competence of Staff (perceived), (vi) Teamwork, (vii) Waiting.

   [Notes].....

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2. Perceptions of Clinical Outcomes

   Thank you sharing your views on your experience with me.

   Is there anything else relating to what we've just discussed that you would like to mention?

If not, we will move on to look at your views on the sort of clinical outcomes you would like from your A&E stay—In other words, could you tell me what you expect from your A&E visit today?

Probes shall relate to (i) Understanding of symptoms, (ii) Need for reassurance regarding clinical condition, (iii) Need for medication/ symptom relief, (iv) onward care planning.

[Notes]……

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3. Perceptions of Safety

Thank you sharing those views with me.

Is there anything else relating to what we've just discussed that you would like to mention?

For this question, I'd like it if you could tell me about how safe did you have felt during your time in A&E today?

Probes shall include (i) vulnerability, (ii) experience of mistakes, (iii) medication safety, (iv) speaking up.

[Notes]……

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4. Proposing solutions

Thank you sharing those views with me.

Is there anything else relating to what we've just discussed that you would like to mention?

Finally then, We're now going to try a thought exercise. If money or time were no object, what would you suggest we do to improve your experience of care in the A&E department today?

[Notes]……

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5. Questions

Those are all of the questions that I have to ask you right now. Do you have any questions for me, or is there anything further you would like to add?

[Notes].....

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Stop Recording (Time_____:_____) ☐

Post- Interview Actions:

- ✓ Verbalise that recording has stopped
- ✓ Thank participant
- ✓ Encourage the participant to retain a copy of the PIS

Would the participant like a copy of the study report? **Y ☐ N ☐**

[Additional Notes/ Observations].....

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Appendix 5: Focus Groups Question Schedule

Focus Groups Guide

Study Title: Focus Groups with Staff to develop a list of outcomes for older adults attending the emergency department.

Site (Circle): Plymouth Taunton Exeter

Location: _____

Date: _____/_____/_____ **Focus Group #** _____

Interviewer:_____ **Co- Investigator:**_____

Participant 1: IRN: PREMED65/FG/01/PN_____ **Participant 5: IRN: PREMED65/FG/01/PN**_____

Participant 2: IRN: PREMED65/FG/01/PN_____ **Participant 6: IRN: PREMED65/FG/01/PN**_____

Participant 3: IRN: PREMED65/FG/01/PN_____ **Participant 7: IRN: PREMED65/FG/01/PN**_____

Participant 4: IRN: PREMED65/FG/01/PN_____ **Participant 8: IRN: PREMED65/FG/01/PN**_____

Pre- Interview Actions:

Ensure Patient Information Sheet **Has Been Issued to ALL participants** ☐

- ✓ Introduce self by name and role
- ✓ Personally thank all participants for involvement
- ✓ Housekeeping points (Toilets, Fire Exit, Refreshments)
- ✓ Introduce focus group 'ground rules'
  - Emphasise the need to speak, one at a time
  - Emphasise that there are no 'right or wrong' answers
  - Encourage active and respectful listening to all participants' views
  - Stipulate the requirement for confidentiality—'what is said in the room, stays in the room'
- ✓ Explain the purpose of the interview- clarify PIS- invite questions
- ✓ Explain purpose of recording, recording device and confidentiality
- ✓ Clarify right to withdraw

Ensure Consent Form **Completed & Initialled from ALL participants** ☐

Ensure Focus Group Individual Characterstics **Proforma Completed by ALL particpants** ☐

Start Recording (Time ____:_____) ☐

Turn Over

Question Schedule:

1. **Perceptions of Experience**

   Firstly, we're going to explore your perceptions of older adults' experiences in A&E. Please try to focus your opinions on patients aged 65 years or older.

   What do you feel has the potential to affect the experience of older adults aged 65 or over when visiting the A&E Department?

   Probes shall relate to exploration of (i) Likes and Dislikes of Care,(ii) Areas for improvement, (iii) Communication, (iv) Personal anxiety/ suffering, (v) Technical Competence of Staff (perceived), (vi) Teamwork, (vii) Waiting.

   [Notes].....

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2. **Perceptions of Clinical Outcomes**

   Thank you sharing your views on patient experience with me.

   Is there anything else relating to what we've just discussed that you would like to mention?

   If not, we will move on to look at your views on the sort of clinical outcomes you feel older adults should expect from their A&E stay. What do you think are desirable clinical outcomes for older adults in A&E?

   Probes shall relate to (i) Understanding of symptoms, (ii) Need for reassurance regarding clinical condition, (iii) Need for medication/ symptom relief, (iv) onward care planning.

   [Notes].....

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3. **Perceptions of Safety**

Thank you sharing those views with me.

Is there anything else relating to what we've just discussed that you would like to mention?

For this question, I'd like it if you could tell me what influences patient safety for older adults aged 65 years and over?

Probes shall include (i) vulnerability, (ii) experience of mistakes, (iii) medication safety, (iv) speaking up.

[Notes]……

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4. **Proposing solutions**

Thank you sharing those views with me.

Is there anything else relating to what we've just discussed that you would like to mention?

Finally then, We're now going to try a thought exercise. If money or time were no object, what would you suggest we do to improve your experience of care specifically for older adults attending A&E?

[Notes]……

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5. Questions

Those are all of the questions that I have to ask you right now.

We have discussed older adults' perceptions of experience, clinical outcomes a patient safety in ED to quite a lot of detail. Do you think there is anything else th is relevant but we have not discussed here today?

Do you have any questions for me, or is there anything further you would like to add?

[Notes]……

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Stop Recording (Time_____:_____) ☐

Post- Interview Actions:

- ✓ Verbalise that recording has stopped
- ✓ Thank participant
- ✓ Encourage the participants to retain a copy of the PIS

Would the participant like a copy of the study report? (Place *Asterisk beside IRN on page 1)

[Additional Notes/ Observations]……

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Appendix 6: NHS Health Research Authority Approval for PREM-ED 65 Qualitative Study (18/LO/1194)

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Blair Graham
Royal College of Emergency Medicine
Doctoral Research Fellow
UniversityHospitals Plymouth NHS Trust
Emergency Department
Derriford Hospital
Plymouth
PL6 8DH

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

20 July 2018

Dear Dr Graham

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Development and testing of a Patient Reported Measure for Emergency Department patients aged 65 and over (PREM-ED 65+).Phase One: Interviews with patients and Focus Groups with healthcare professionals to develop a list of outcomes for older adults attending the emergency department.**
IRAS project ID:	**243771**
Protocol number:	**FHHS-243771-BG-0216**
REC reference:	**18/LO/1194**
Sponsor	**Plymouth University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site

initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Professor Jonathan Marsden
Tel: 01752587590
Email: jonathan.marsden@plymouth.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **243771**. Please quote this on all correspondence.

Yours sincerely

Isobel Lyle | Senior Assessor
Health Research Authority
T: 0207 972 2496
HRA, Holland Dr, Newcastle upon Tyne NE2 4NQ
Hra.approval@nhs.net or Isobel.lyle@nhs.net
www.hra.nhs.uk

Copy to: *Professor Jonathan Marsden, Sponsor contact, Plymouth University*
Dr Helen Neilens, University Hospitals Plymouth NHS Trust

Appendix 7: Institutional Approval for PREM-ED 65 Qualitative Study (17/18-973)

UNIVERSITY OF PLYMOUTH

24th July 2018

CONFIDENTIAL

Blair Graham
Rm 102, 8 Portland Villas
Faculty of Health & Human Sciences
University of Plymouth
Drake Circus
Plymouth
PL4 8AA

Dear Blair,

Application for Approval by Faculty Research Ethics and Integrity Committee

Reference Number: **17/18-973**
Application Title: **Initial development and pre-testing of a Patient Reported Measure for Emergency Department patients aged 65 and over. Qualitative Study (Part A): *In situ interviews with patients* in the Emergency Department.**

I am pleased to inform you that the Committee has granted approval to you to conduct this research.

Please note that this approval is for three years, after which you will be required to seek extension of existing approval.

Please note that should any MAJOR changes to your research design occur which effect the ethics of procedures involved you must inform the Committee. Please contact the Faculty Research Administrator, Maurice Bottomley (email hhsethics@plymouth.ac.uk).

Yours sincerely

Professor Paul H Artes, PhD MCOptom
Professor of Eye and Vision Sciences
Co-Chair, Research Ethics and Integrity Committee -
Faculty of Health & Human Sciences and
Faculty of Medicine & Dentistry

Professor Paul H Artes, PhD Co-Chair, Faculty of Health & Human Sciences Research Ethics and Integrity Committee,
4th Floor Rolle Building, University of Plymouth, Drake Circus, Devon PL4 8AA
T +44(0)1752 586662 E hhsethics@plymouth.ac.uk W www.plymouth.ac.uk

Appendix 8: Institutional Approval for Multi-Stakeholder Consensus Meeting (19/20-1173)

UNIVERSITY OF PLYMOUTH

1st November 2019

Blair Graham
School of Nursing and Midwifery
Faculty of Health: Medicine, Dentistry & Human Sciences
University of Plymouth
Room 102, 8 Portland Villas
Drake Circus
Plymouth
PL4 8AA

Dear Blair,

Application for Approval by Faculty Research Ethics and Integrity Committee

Reference Number: **19/20-1173**
Application Title: **A multi- stakeholder consensus meeting to develop the Patient Reported Measure for Emergency Department Patients aged 65 year and over (PREM- ED 65+)**

The Committee has granted ethical approval to conduct this research.

This approval is for 12 months (i.e. until 31 October 2020). If you wish to continue beyond this date, you will need to seek an extension.

Please note that if you wish to make any MAJOR changes to your research you must inform the Committee. Please contact the Faculty Research Administrator, Maurice Bottomley (email hhsethics@plymouth.ac.uk).

Yours sincerely

Professor Paul H Artes, PhD MCOptom
Professor of Eye and Vision Sciences
Co-Chair, Research Ethics and Integrity Committee -
Faculty of Health: Medicine, Dentistry & Human Sciences

Appendix 9: NHS Health Research Authority Approval for Final Development and Validation Study (21/PR/0458)

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Blair Graham
Lecturer in Urgent & Emergency Care
University of Plymouth
Rm.102 6 Portland Villas
University of Plymouth
PL4 8AA

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

22 April 2021

Dear Dr Graham

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Validation of a new patient experience survey for patients aged 65 years or above attending the emergency department.**
IRAS project ID:	**292424**
Protocol number:	**N/A**
REC reference:	**21/PR/0458**
Sponsor	**University Hospitals Plymouth NHS Trust**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **292424**. Please quote this on all correspondence.

Yours sincerely,

Katherine Ashley
Approvals Specialist

Email: approvals@hra.nhs.uk
Copy to: Dr Christopher Rollinson (sponsor contact)

Appendix 10: Institutional Approval for final development and initial validation study (2021-2527-1758)

UNIVERSITY OF PLYMOUTH

26/04/2021

Confidential

Dr Blair Graham

Dear Dr Blair Graham

Research Ethics Application Approval - Faculty Research Ethics and Integrity Committee:

2527

Validation of a new patient experience survey for patients aged 65 years or above attending the emergency department.

The committee has considered your application and has granted ethical approval to conduct this research.

Approval is for the duration of the project. If you wish to continue beyond this date, you will need to seek an extension.

Please note that if you wish to make any minor changes to your research, you must complete an amendment form or major changes you will need to resubmit an application.

Yours sincerely

Professor Sarah Neill

Chair, Faculty of Health Staff Research Ethics and Integrity Committee

Appendix 11: Recruitment Poster, Multi-stakeholder workshop

Appendix 12: Sampling Matrix for Validation Study

The PReM-ED Study

Sampling Matrix. Sheet Number ______ of _______

This matrix is intended as a *guide* to help you ensure that you recruit a representative cross- section of patients for the PREM-ED Study, based on age group, patient gender and category of presenting complaint. Please also refer to study flow chart and inclusion/ exclusion criteria when selecting patients.

	Age	65—75 years				75 years +			
	Gender	Male		Female		Male		Female	
Sampling Strata	Primary Presentation	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐
		Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐	Injury ☐	Illness ☐

Examples of Injury:

- Fractures
- Dislocations
- Sprains and Strains
- Head Injury
- Chest wall injuries
- Cuts and wounds
- Bites and stings

Examples of Illness:

- Any non- traumatic complaint

If unsure, try to base judgment on primary presenting complaint/ reason for attending the ED.

For example—a presentation for a wrist injury which transpires to be due to a collapse can be listed as *injury*, whereas chest wall injury discovered during work up for a collapse can be listed as *illness*.

Intentionally Blank