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# Measuring older peoples' experiences of person-centred coordinated care: experience and methodological reflections from applying a patient reported experience measure in SUSTAIN

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1 **Title:** Measuring older peoples' experiences of person-centred coordinated care: experience and  
2 methodological reflections from applying a patient reported experience measure in SUSTAIN

3

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42

43 **Summary**

44 Introduction: While several evaluation studies on (cost-)effectiveness of integrated care have been  
45 conducted in recent years, more insight is deemed necessary into integrated care from the perspective  
46 of service users. In the context of a European project on integrated care for older people living at  
47 home (SUSTAIN), this paper shares the experience and methodological reflections from applying a  
48 Patient Reported Experience Measure (PREM) on person-centred coordinated care -the P3CEQ-  
49 among this population.

50

51 Methods: A combination of quantitative and qualitative data and analysis methods was used to assess  
52 the usability and the quality of applying a PREM among older people presenting complex care needs,  
53 using the P3CEQ delivery in SUSTAIN as a case study. 228 service users completed the P3CEQ and nine  
54 SUSTAIN researchers participated in a consultation about their experience administering the  
55 questionnaire. P3CEQ scores were analysed quantitatively using principal component analysis and  
56 multilevel linear regression. P3CEQ open responses and researcher notes collected when  
57 administering the questionnaire were thematically analysed.

58

59 Results: Service user inclusion was high and most P3CEQ items had low non-response rates.  
60 Quantitative analysis and researcher experience indicate the relevance of face-to-face administration  
61 for obtaining such an amount of data in this population group. The presence of a carer increased  
62 inclusion of more vulnerable respondents, such as the cognitively impaired, but posed a challenge in  
63 data interpretation. Although several P3CEQ items were generally understood as intended by  
64 questionnaire developers, the analysis of open responses highlights how questions can lead to  
65 diverging and sometimes narrow interpretations by respondents. Cognitive impairment and a higher  
66 educational attainment were associated with lower levels of perceived person-centredness of care.

67

68 Conclusion: This study shows essential preconditions to meaningfully collect and analyse PREM data  
69 on older peoples' experiences with integrated care: face-to-face administration away from care  
70 providers, collection of reasons for non-response and open comments providing nuances to answers,  
71 and multilevel modelling taking into account diversity in the target population. Several areas of  
72 improvement for future PREM use in this population have been identified: use of administration and  
73 coding guides, inclusion of clear and easy to understand definitions and examples illustrating what  
74 questions do and do not mean, measures of the expectations of person-centred coordinated care, and  
75 procedures ensuring sound ethical research. These methodological learnings can enhance future  
76 evaluation of integrated care from a service user perspective.

77

78 **Keywords**

79 Patient reported experience measures, integrated care, older people, person-centredness, care  
80 coordination, data quality, methods

81

## 82 INTRODUCTION

83 An increasing number of people with multiple health and social care needs live in their homes and  
84 communities until old age. Their complex care needs require multidisciplinary collaboration and  
85 coordination between care professionals from different organisations. Across Europe, numerous  
86 initiatives have been implemented to organise continuous and person-centred care for older people,  
87 often called integrated care [1-6]. Despite several evaluations, evidence for their (cost-)effectiveness  
88 is inconsistent [7-10]. This is partly due to diverse and often inappropriate outcome measures. These  
89 measures are often generic and health based (e.g. health status, physical functioning, quality of life)  
90 [8], thus failing to capture wellbeing, social participation and patient experience, arguably more  
91 appropriate for older people with complex needs [11, 12, 13]. Significant gaps in our ability to evaluate  
92 integrated care improvement from a service user's perspective remain [14].

93 Care coordination and care tailored to peoples' needs and preferences are principal characteristics of  
94 integrated care [15]. However, the multidimensionality and variety of values [16] attributed to  
95 integrated care hinders its measurement [17, 18]. The concept of person-centred coordinated care  
96 (P3C) explicitly recognises the multidimensional nature of care experiences. P3C places an emphasis  
97 on understanding the relationship between individuals and their capabilities and resources, also  
98 acknowledging that care and support should strive to be responsive and coordinated across sectors,  
99 irrespective of organisational structures and configurations [19]. P3C is particularly relevant to assess  
100 care delivery for people who require continuous care, ensuring that patients are viewed as people in  
101 a care encounter, not just passive recipients [20].

102  
103 Questionnaires can be useful tools to capture care experiences. There are a large number of tools  
104 exploring person-centred care [21, 22]. However, there is a lack of Patient Reported Experience  
105 Measures (PREMs) that probe both coordination and person-centredness in a co-dependent model.  
106 Most existing PREMs (cf. Patient Assessment of Chronic illness Care (PACIC) [23], Picker Patient  
107 Experience Questionnaire (PPE-15) [24], Patient assessment of integrated elderly care (PAEIC) [25], IC-  
108 PREM-Home [26]), focus on these constructs separately. Moreover, the complexity of P3C can lead to  
109 ill-defined and abstract items that are difficult to understand or translate. Different individuals, for  
110 example, will have different understandings of 'shared decision-making' or 'goal setting'. This  
111 difficulty is compounded for older people, who are more likely to suffer reduced cognitive function  
112 and sensory impairments, rendering questionnaire completion difficult. The testing of existing 'user  
113 experience' questionnaires with older people has sometimes found high respondent burden – with  
114 participation experienced as difficult, time consuming or emotionally stressful [27].

115

### 116 **Setting and aim**

117 A PREM to measure Person-Centred Coordinated Care (P3CEQ) was developed between 2017-2019 in  
118 the United Kingdom [28, 29] to address the growing priority of P3C for service users, carers,  
119 professionals and policymakers. Unlike pre-existing PREMs, the P3CEQ aims to jointly probe different  
120 aspects important in redesigning and integrating health and social care initiatives: person-  
121 centredness, care coordination, carer involvement and care planning [28]. The P3CEQ was used in a  
122 pan European project (SUSTAIN) between 2015-2019, aiming to generate evidence on how to improve  
123 integrated care for older people living at home with complex care needs [30]. SUSTAIN applied the  
124 P3CEQ as one of the instruments of a mixed-methods study design [31] to evaluate interventions in  
125 thirteen integrated care initiatives (details of SUSTAIN can be found elsewhere [32-41]).

126 The aim of this paper is to share the SUSTAIN experience and methodological reflections from applying  
127 the P3CEQ to explore care experiences of older people living at home with complex health and social  
128 care needs. The thirteen participating care initiatives were heterogeneous: from seven European  
129 countries, focused on different objectives and target groups, and providing different types of care and  
130 support services [33]. By sharing details of our data collection experiences, and analysing findings in  
131 relation to usability and quality of data, we hope to inform further development and use of PREMs to  
132 evaluate integrated care provided to (older) people with complex care needs.

133

134 The following research questions (RQ) guided our study:

135 RQ1. To what extent can older people with multi-morbidity and/or cognitive deterioration provide  
136 answers to a PREM exploring care coordination and person-centredness?

137 RQ2. What are the enabling and constraining factors for completing such a PREM instrument in  
138 this target group?

139 RQ3. Do service user characteristics or the administration mode have an impact on reported care  
140 experiences?

141

142

## 143 **METHODS**

144

### 145 **Study design: a case study on PREM use with older people**

146 The SUSTAIN experience administering the P3CEQ is treated here as a case study of PREM use in older  
147 people with complex care needs. Our study combined quantitative and qualitative data and analysis  
148 methods to assess both the usability and the quality of PREM use.

149

### 150 **Measures and data collection**

151 The P3CEQ is a valid and reliable 11-item measure of 'person-centred coordinated care' (Table 3) with  
152 strong face, construct and ecological validity [28]. In the P3CEQ validation study, a two factor measure  
153 was determined by principal component analysis: items 1-4 & 10 probe 'person-centredness'  
154 exclusively; items 6-7 probe 'care coordination', and items 5, 8 & 9 probe both constructs. Overall  
155 scalability was demonstrated by a Partial Credit Rasch analysis indicating good fit for each dimension.  
156 Furthermore, the P3CEQ showed longitudinal sensitivity to intervention change, which was confirmed  
157 by semi-structured interviews and ethnographic observation [29].

158

159 To enable its use in the SUSTAIN project, the P3CEQ was translated from the English-language version  
160 to six local languages (Catalan, Dutch, Estonian, German, Norwegian, Spanish) in collaboration with  
161 the original P3CEQ developers. This process was guided by principles of good practice for translation  
162 and cultural adaptation of patient reported outcome measures [42].

163

164 Subsequently, each integrated care initiative selected a convenience sample of service users following  
165 the minimum criteria defined by the SUSTAIN consortium (65+ years, living at home –unless  
166 temporarily admitted to a nursing home, with multiple health and social care needs as assessed by  
167 professional care teams, informed consent provided). Face-to-face administration was the preferred  
168 option to overcome possible limitations such as hearing, reading and writing difficulties. Researchers  
169 visited service users of ten initiatives at home, whereas three local research teams organised

170 appointments at care provider premises. In exceptional cases, researchers delivered the P3CEQ as a  
171 postal survey or by phone (Table 2).

172

173 The P3CEQ includes tick boxes (for scoring) and open boxes (for comments). This study analysed both  
174 scores and comments, as well as any observational notes taken by researchers during/after P3CEQ  
175 completion. In addition, the study used sociodemographic and health data collected during the  
176 SUSTAIN project (sex, age group, completed education, living situation, self-reported chronic  
177 conditions and functional impairments).

178

179 For the purpose of this paper, nine researchers who delivered the P3CEQ to SUSTAIN service users  
180 were consulted to verify details concerning local administration methods using a self-complete  
181 questionnaire. We specifically enquired about interviewer procedures concerning repetition or  
182 rewording of questionnaire items to identify any differences across research teams. We also checked  
183 how SUSTAIN researchers coded reasons for not scoring items (i.e. using researcher notes, using the  
184 open text box of the corresponding question, etc.), to consistently incorporate this information into  
185 the dataset.

186

### 187 **Data analysis**

188 Quantitative data analysis (QnA) consisted of four steps:

189 QnA1. Preliminary analysis described service user characteristics. From a list of eighteen individual  
190 health conditions, we created four categories of health characteristics that would be used in the  
191 multilevel analysis: hearing problems, visual problems, cognitive impairment and mental health  
192 problems (Table 1). Statistical descriptives were also calculated for P3CEQ context and  
193 administration mode variables.

194 QnA2. To address RQ1, we calculated the proportion of missing values for each P3CEQ item. Where  
195 this was higher than 10% [43, 44], we addressed RQ2 by analysing whether *not* answering the item  
196 was related to service user characteristics or administration mode, using multilevel analysis. We  
197 estimated a two-level logistic regression model (level 1: integrated care initiatives, level 2: service  
198 users) predicting whether the service user had a missing value on that item (dependent variable).  
199 We estimated the total variance at the level of the integrated care initiatives with the variance at  
200 the level of the service users fixed at 1 (model 0). Then we estimated model 1, including a  
201 characteristic of the service users or administration mode (predictor variable) and estimated its  
202 fixed effect. This model was estimated for each characteristic separately.

203 QnA3. As a preliminary step to addressing RQ3, we conducted principal component analysis (with  
204 Varimax rotation) and compared the dimensionality of the P3CEQ with the two-dimensional  
205 structure found in the original validation study [29] and calculated Cronbach's alpha. This was  
206 done to confirm we could construct two reliable scales ('person-centredness' and 'care  
207 coordination') for further analysis in QnA4.

208 QnA4. We conducted multilevel linear regression analysis to estimate the effect of the characteristics  
209 of service users and administration mode on the P3CEQ (scale) scores, thus addressing RQ3. As in  
210 QnA2, we estimated two two-level models: first a model 0, which included the two random  
211 coefficients (i.e. the variance components of each level) only, then model 1 in which we included  
212 a characteristic of the service users or administration mode as fixed coefficient (predictor  
213 variable). Model 1 was estimated for each characteristic separately, as the sample size did not  
214 allow multiple regression analysis. In QnA2 and QnA4, the regression coefficient and standard

215 error, and the P-value based on the resulting Z-statistic are reported for the fixed effect of the  
 216 characteristic included.

217

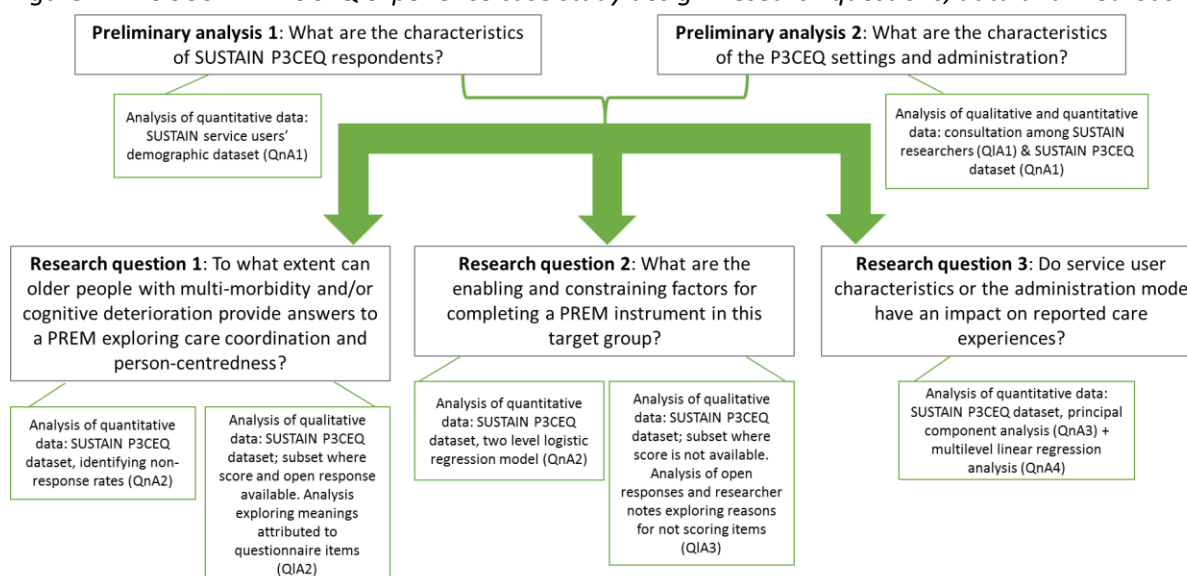
218 Analysis of qualitative data (QIA) consisted of three steps:

219 QIA1. Information obtained through the consultation with SUSTAIN researchers concerning  
 220 administration mode and data coding was used to recode variables ensuring we applied consistent  
 221 criteria in the use of each answer option in our final dataset.

222 QIA2. To provide a qualitative insight to RQ1, on the usability of this type of PREM by this target  
 223 group, for each P3CEQ item we selected a subset of data where respondents had provided a score  
 224 and an open response was available. We analysed these comments to identify how this subset of  
 225 respondents interpreted the items and related them to their own experiences, providing details  
 226 or examples of the meaning they attributed to each P3CEQ item.

227 QIA3. To address RQ2, for each P3CEQ item we selected the subset where a valid score was missing.  
 228 We analysed open responses provided by service users as well as researcher notes to examine  
 229 why the service user had not reported their experience using the corresponding scale.  
 230 Explanations were categorised into possible reasons for missing scores using inductive coding.  
 231

232 *Figure 1. The SUSTAIN P3CEQ experience case study design: research questions, data and methods*



233

234

235

236

## RESULTS

### 237 Characteristics of the study sample

238 SUSTAIN recruited service users in three iterations between 2016 and 2018. The majority completed  
 239 the P3CEQ (93.4%; N=228 of 244 total recruited service users [45]). Two thirds of the service users  
 240 were women; three quarters aged 75 years or older (Table 1). About half of all service users did not  
 241 complete any schooling or completed primary school only. Half of service users were living alone,  
 242 whereas approximately 30% lived at home with their spouse or partner. Approximately 8% of service  
 243 users were temporarily living at a home for older persons. The vast majority of service users suffered  
 244 from multi-morbidity [46], presenting on average five chronic conditions. Osteoarthritis, persistent

245 back pain and heart failure were reported most frequently. About 40% of the service users reported  
 246 visual problems and a similar proportion reported hearing problems. Almost a third of service users  
 247 reported mental health problems; 12% reported cognitive impairments.

248

249 *Table 1. Socio-demographic and health characteristics of the sample of service users (N=228)*

	N	M (SD)	n	%
<b>Socio-demographic characteristics</b>				
Sex: female	228		153	67.1
Age (in years):	228			
- 65 – 74 years			53	23.2
- 75 – 84 years			95	41.7
- 85 years and older			79	34.6
- Unknown			1	0.4
Education (completed):	228			
- No schooling/primary school			107	46.9
- Secondary school			48	21.1
- Advanced vocational training			48	21.1
- High professional / academic education			22	9.6
- Unknown			3	1.3
Living situation:	228			
- Living at home, alone			118	51.8
- Living at home, with spouse/partner			65	28.5
- Living at home, with family member(s)			20	8.8
- Living at home, with paid carer			2	0.9
- Assessed living / sheltered home			4	1.8
- Nursing or residential home for older persons			18	7.9
- Unknown			1	0.4
Marital status:	228			
- Married/cohabiting			78	34.2
- Divorced			26	11.4
- Widowed			105	46.1
- Single			16	7.0
- Unknown			2	0.9
<b>Health related characteristics (self-reported)*</b>				
Hearing problems:	226		92	40.7
Visual problems:	226		93	41.2
Cognitive impairments:	225		26	11.6
Mental health problems:	225		71	31.6
Number of chronic conditions**:	228	5.23 (2.47)		
- None			3	1.3
- One to three			60	26.3
- Four to six			101	44.3
- Seven or more			64	28.1
- Multi-morbid (2 or more chronic conditions***)			217	95.2
*The four categories of health characteristics were created from the list of eighteen individual health conditions collected with the demographic/health data sheet: hearing problems, visual problems, cognitive impairment (dementia including Alzheimers, loss of memory, traumatic brain injury, alone or in combination), and mental health problems (anxiety, panic disorders, depression, schizophrenia, alone or in combination).				
**Variable based on a count of conditions indicated to be present.				
***Multi-morbidity is calculated here as having two or more of the following conditions: hearing problems, problems with vision, dementia including Alzheimers, loss of memory, traumatic brain injury, anxiety - panic disorders, depression, breathing problems (asthma, chronic bronchitis, lung emphysema, or chronic obstructive pulmonary disease), cancer, diabetes, dizziness with falling, heart failure, stroke-cerebral haemorrhage, prostate symptoms, urine incontinence, broken hip, other broken bones, osteoarthritis, loss of bone tissue - osteoporosis, persistent back pain.				



250 **Characteristics of the P3CEQ administration**

251 Sample sizes across the seven countries ranged from seven (Austria) to 61 (Germany) (Table 2). All but  
 252 11 service users completed the P3CEQ in a face-to-face interview. 72.8% responded to the P3CEQ at  
 253 home; the others were interviewed at care provider premises (see methods). Seventeen percent of  
 254 the service users completed the questionnaire in the presence of a family member/carer. For service  
 255 users with cognitive impairment, this increased to 42.3%. Concerning the consultation among  
 256 SUSTAIN researchers who administered the P3CEQ, all teams expressed that when needed they used  
 257 additional agreed explanations/examples illustrating P3CEQ item meanings. Following SUSTAIN's  
 258 multi-method approach [32], a convenience sample of service users (N=87) also participated in a  
 259 qualitative interview during the same appointment.

260

261 *Table 2. Country and P3CEQ administration characteristics*

	N	n	%
<b>Country</b>	228		
- Austria		7	3.1
- Estonia		52	22.8
- Germany		61	26.8
- Netherlands		13	5.7
- Norway		40	17.5
- Spain (Catalonia)		32	14.0
- United Kingdom		23	10.1
<b>P3CEQ administration characteristics</b>			
Mode of administering:	228		
- Face to face		217	95.2
- By telephone		3	1.3
- By mail		8	3.5
Place of administration	228		
- At home (includes temporary nursing home)		166	72.8
- At care provider premises		62	27.2
In presence of a carer:	228	39	17.1
Service users with cognitive impairment: In presence of a carer	26	11	42.3
In combination with qualitative interview:	228		
- No		141	61.8
- Qualitative interview before P3CEQ		33	14.5
- Qualitative interview after P3CEQ		54	23.7

262

263

264 **RQ1: To what extent can older people with multi-morbidity and/or cognitive deterioration provide**  
 265 **answers to a PREM exploring care coordination and person-centredness**

266

267 *Quantitative analysis*

268 Among our sample, missing answers per P3CEQ item were low at between 2.2% (for Q6 *Person(s) in*  
 269 *charge of coordinating care*) and 18.9% (for Q11b *close ones involved in decisions as much as wanted*).  
 270 Besides Q11b, only one other item had more than 10% missing values: Q5 *care joined up in a way that*  
 271 *works* (12.3% missing values).

272

273 *Insight: qualitative analysis of meanings attributed to 'care coordination' and 'person-centredness'*  
 274 *construct items*

275 The face-to-face administration of the P3CEQ provided a unique opportunity to explore  
 276 understandings of different questionnaire items by older people, forming a *de facto* cognitive  
 277 interview similar to those used during development processes of most PREMs. Although SUSTAIN  
 278 researchers did not systematically collect understandings of all P3CEQ items for the complete sample,  
 279 the subset of open responses provides insight into meanings this target group attributed to the  
 280 questions.

281  
 282 Open responses were provided by 15-35% of respondents depending on the P3CEQ item: Q7 *care*  
 283 *planning* obtained the least open responses (N=34) and Q6 *professional coordinating care* obtained  
 284 the most (N=81). Open responses were coded as follows: ‘confirming’ (respondent recalls details or  
 285 identifies an occasion that confirms a positive experience); ‘disputing’ (respondent recalls details or  
 286 identifies an occasion indicating a less than positive experience); ‘neither’ (open response is not  
 287 directly relevant to the question/neither confirms nor disputes a positive experience); and ‘both’  
 288 (respondent specifically recalls having both positive and negative experiences concerning the  
 289 question).

290  
 291 Almost half of the open responses provided confirmed or explained a positive experience in relation  
 292 to the item; a quarter reported less than positive experiences and fifteen percent were comments  
 293 that neither confirmed nor disputed a positive experience. There were some particularities of P3CEQ  
 294 items. For instance, for Q10 *confidence to self-manage health*, half the open responses reported a less  
 295 than positive experience and frequently related this to the lack of personal autonomy.

296  
 297 Table 3 presents the most frequent concepts or meanings associated to each P3CEQ item, as identified  
 298 in QIA2. Although not generalizable to the whole sample, some items were understood practically the  
 299 same by most SUSTAIN respondents (e.g. Q4 *repeating information*, Q10 *confidence to self-manage*  
 300 *health*), and in line with the meaning intended by P3CEQ developers, while other items were  
 301 understood in a variety of ways, and not always coinciding with the intended meaning. Some concepts  
 302 were narrowly understood: Q1 *discussing what’s important with care professionals* and Q2 *being*  
 303 *involved in decisions* were frequently interpreted as having rather basic interactions with care  
 304 professionals (e.g. being told what to do, being given advice); Q5 *care joined up in a way that works*  
 305 was often related to how care professionals treat the respondents; and Q9 *receiving information to*  
 306 *self-manage health* was answered on several occasions taking into account how much information  
 307 was received in general.

308  
 309 *Table 3. Meanings attributed to P3CEQ items in open responses of service users who scored the*  
 310 *corresponding item. Ordered from more to less frequent*

	<b>Most frequent meaning / reaction</b>	<b>Other frequent meanings / reactions</b>	<b>Other meanings / reactions</b>
Q1. Discuss what’s important with care professionals	Recalling (lack of) conversation with specific professional(s) or at a specific time (e.g. first visit), and/or (lack of) solution	Recalling basic interactions with care professionals (e.g. receiving advice, information, medication checks, being told what to do)	Reporting delegation of discussions to family member/ friends  Qualifying professionals (e.g. being happy with care team, trust, lack of empathy)
Q2. Involved in decisions	Recalling (lack of) being involved in a decision with specific professional(s) or at a specific time (e.g. first visit), and/or (lack of) solution	Recalling basic interactions with care professionals (e.g. receiving explanations, being informed, complaints being listened to, following routines)	Reporting cognitive deterioration as a factor to be taken into account when seeking decisions

Q3. Considered 'whole person'	Recalling that care professionals (do / do not always or depending on the professional) treat them with e.g. caring attitude, compassion, respect, easy to understand language.		Referring to specific examples of how care professionals (did not) take whole situation into consideration (e.g. beyond clinical approach or criteria, beyond formal job duties)  Recalling basic interactions (e.g. being asked ones opinion, receiving advice, being able to access electronic records)
Q4. Repeating information	Recalling how care professionals are (not) aware of conditions and / or can (not) access information (e.g. in the computer, written documentation, when care professionals change).		Recalling details that are not directly relevant to the question.
Q5. Care joined up in a way that works	Recalling how care professionals were (not) communicating, coordinating and aware of different parts of the care process	Qualifying professionals or professional care (e.g. well treated, useful, smooth)  Referring to current health situation and (lack of) improved health outcomes	Referring to the existence of care plan that care professionals were following.  Giving specific examples of how the coordinated care does (not) work for them (e.g. being visited at home, being visited by the same professional, long waiting lists, timetable of cleaners, coordination between primary and specialist professionals).
Q6. (Single) professional coordinating care	Confirming there is (not) a specific professional or professionals who coordinate care. (e.g the GP, the nurse, the GP and the nurse, one for social and one for health)	Identifying a family/ friend as the person they were referring to as in charge of coordinating their care.	
Q7. Care planning (overall)	Describing the actions professionals and him/herself were applying as (not) part of a plan		Referring to medication plans or clinical records  Referring to different needs that they consider (un)attended
Q8. Support to self-manage	Explaining whether care provided meets their needs		Referring to specific examples when advice or instrumental aid to enhance self-management were (not) being provided  Qualifying professionals or professional care (e.g. well treated, helped when needed)
Q9. Information to self-manage	Recalling examples when (un)useful information for self-management was(not) received (e.g nutritional advice, medication adherence advice, overwhelming advice)	Refers to oneself or close persons as self-seeking information for self-management.  Refers to receiving information in general.	
Q10. Confidence to self-manage	Refers to level of autonomy (physical, cognitive) as explaining level of confidence	Recalls examples of support (not) received and how that impacts level of confidence	
Q11a. Wants close ones involved	Identifies the person(s) to be involved.  Identifies the person(s) to be involved, and specifies how or why		Explaining reasons for not wanting to involve others (e.g. self-capable, not wanting to be a burden, negative relation with family members)
Q11b. Close ones involved as much as wanted	Identifies persons or occasions when care team has/hasn't involved as much as wanted.	Identifies the person who has / hasn't been involved	Refers to basic relations between care professionals and close ones (e.g. calling them, having them accompany service users to health consultations)

311  
312  
313

314 **RQ2: What are the enabling and constraining factors for completing a PREM instrument on care**  
315 **experiences in this target group?**

316

317 *Quantitative analysis*

318 Analyses of the two items with non-response rates above 10% revealed that (non-)response could  
319 partly be explained by the integrated care initiative (intraclass coefficient of the null model was .26  
320 (se .16) for Q5 and .36 (se .15) for Q11b). However, most variance in (non-)response to these items  
321 existed at the level of the individual service users.

322

323 The (fixed) effects of the service user characteristics (added in model 1) demonstrated some  
324 statistically significant findings (Supplementary file, Table 4):

- 325 1. Experiencing mental health problems was associated with less missing values for Q5  
326 (coefficient -1.36, standard error 0.66,  $P=.04$ ), indicating that service users with mental health  
327 problems were more likely to answer this item. In contrast, experiencing mental health  
328 problems increased the likelihood of not answering Q11b (coefficient 1.37, standard error  
329 0.41,  $P=.001$ ).
- 330 2. Service users with no schooling or primary schooling only were less likely to answer Q11b  
331 than service users who had completed secondary school (coefficient -2.24, standard error  
332 0.83,  $P=.007$ ).

333

334 The effects of other service user characteristics on (non)responding to Q5 or Q11b did not reach  
335 significance (Supplementary file, Table 4). For the other P3CEQ items the number of non-responders  
336 was too low to conduct these analyses.

337

338 The multi-level analysis of model 1 also provided some insights in whether the administration mode  
339 of the P3CEQ enabled or constrained answering Q5 and Q11b. It was found that:

- 340 1. Administering the P3CEQ otherwise than face-to-face increased the likelihood of non-  
341 responses for Q5 (coefficient 1.95, standard error 0.93,  $P=.04$ ).
- 342 2. The presence of a carer during the interview decreased the likelihood of Q11b remaining  
343 unanswered (coefficient -1.36, standard error 0.62,  $P=.03$ ).

344

345 The administration of the P3CEQ in combination with a qualitative interview did not impact the  
346 response of Q5 and Q11b (Supplementary file, Table 4). Again, the number of non-responders on the  
347 other P3CEQ items was too low to conduct these analyses.

348

349 *Qualitative analysis*

350 Lack of understanding or applicability of questionnaire items can also represent constraining factors  
351 for data collection. We analysed the open responses and researcher notes for the subsets where  
352 scores had not been provided to explore the different reasons explaining missing scores of P3CEQ  
353 items. Inductive coding identified six categories (Supplementary file, Table 5).

354

355 The most prevalent reason for not scoring questionnaire items was lack of relevance. It was more  
356 frequent for Q5 *care being joined up in a way that works* ( $N=14$ ), and was usually related to the  
357 perceived low complexity of the care they received, e.g. 'I currently only receive care from one

358 service'. It was also the most frequent cited reason for not scoring Q1 *discussing what's important for*  
 359 *your health and wellbeing with care professionals* (N=12). In this case, three kinds of explanations were  
 360 provided: 1) considering that 'the care team knows best'; 2) considering that such discussions were  
 361 pointless; or 3) relating the lack of relevance to the low frequency of visits with care teams. Lack of  
 362 relevance was also the most frequent reason behind missing scores for Q2 *being involved in decisions*  
 363 (N=12) and was mostly related to the fact that the service user considered no decisions had been  
 364 made (N=9). Twelve cases considered Q9 *receiving useful information to self-manage* irrelevant, for  
 365 instance because the respondent was highly dependent on others, or because respondents  
 366 considered themselves self-sufficient, not needing such information from care teams.

367

368 **RQ3: Do service user characteristics or the administration mode have an impact on reported care**  
 369 **experiences?**

370

371 Our principal component analysis with Varimax rotation showed sufficient basis to calculate a person-  
 372 centredness scale score similar to the result of the original validation study (by summing scores of Q1,  
 373 Q2, Q3, Q4, Q5, Q8, Q9, and Q10), but not for calculating a care coordination scale score (Cronbach's  
 374 alpha .76 and .55 respectively) (Table 6, Supplementary file). Therefore, Q6 and Q7, which originally  
 375 contributed with Q5, Q8 and Q9 to a care coordination scale, were analysed separately, in addition to  
 376 Q11a and 11b, which were originally intended to be analysed separately.

377

378 Table 7 (Supplementary file) shows the mean scores of the service users on the P3CEQ person-  
 379 centredness scale and Q7 and Q11b, as well as the percentages of service users answering 'yes' to Q6  
 380 and Q11a. In general, subgroups did not differ regarding their scores, with some exceptions. Service  
 381 users aged 75 to 84 years were more positive about the care planning process (Q7) than the other age  
 382 groups. Higher educated service users were less positive about the person-centredness of the care  
 383 they received and the extent to which their carers were involved in decision-making about care  
 384 (Q11b).

385

386 As to the effects of the various characteristics of service users and administration mode on the P3CEQ  
 387 scores (Tables 8 and 9), the intraclass coefficient (ICC) of the null model for person-centredness was  
 388 .24 (se .09), indicating that a substantial proportion of variation in service users' scores related to the  
 389 integrated care initiative. This might be explained by specific characteristics of the integrated care  
 390 initiatives, but also by characteristics of health and social care systems where the initiatives had been  
 391 implemented. Furthermore, a high level of education was related with experiencing care as less  
 392 person-centred. In addition, experiencing cognitive problems related to experiencing less person-  
 393 centred care.

394

395 Regarding service users' experiences with care planning (Q7), the ICC of the null model was .04 (se  
 396 .03), which means that differences in service users' experiences with care planning were not related  
 397 to the integrated care initiative they received care from. Neither the service user characteristics nor  
 398 the way the P3CEQ was administered impacted on service user' care planning scores.

399

400 The extent to which service users experienced that their carers (family or friends) were involved in  
 401 decision-making about their care as much as they wanted (Q11b) related to the integrated care

402 initiative they received care from (ICC .22, se .09). In addition, a higher level of education related to  
 403 less positive experiences in this respect.

404

405 *Table 8. Fixed effects of characteristics of service users and administration mode on P3CEQ scale or*  
 406 *item scores; results of two-level mixed-effect linear regression model (N=13 integrated care initiatives,*  
 407 *N=183-225 service users); separate analyses for each characteristic*

	Person-centredness (scale)				Care planning overall (average Q7a-d)				Family/friends involved in decision-making as much as wanted (Q11b)			
	N	esti- mate	Se	P	N	esti- mate	Se	P	N	esti- mate	Se	P
<b>Fixed effect of service user characteristics</b>												
Gender: female (ref. male)	225	-0.20	0.60	.74	223	-0.08	0.15	.57	185	-0.15	0.15	.32
Age (ref. 65 to 74 years)	224				222				184			
- 75 to 84 years		-0.17	0.74	.82		0.34	0.18	.06		0.29	0.19	.12
- 85 years or older		0.71	0.74	.33		-0.11	0.18	.54		0.25	0.19	.19
Education (ref. no schooling or primary school)	222				220				183			
- secondary school		-0.81	0.79	.30		-0.21	0.18	.26		-0.33	0.19	.08
- advanced vocational training		-1.19	0.81	.14		-0.22	0.19	.25		<b>-0.46</b>	<b>0.22</b>	<b>.04</b>
- high professional/academic education		<b>-2.62</b>	<b>1.06</b>	<b>.01</b>		-0.25	0.25	.31		<b>-0.79</b>	<b>0.25</b>	<b>.002</b>
Hearing problems (ref. no)	223	-0.01	0.57	.99	221	-0.04	0.14	.79	184	0.13	0.14	.35
Visual problems (ref. no)	223	0.83	0.59	.16	221	-0.08	0.14	.56	184	-0.09	0.15	.54
Cognitive problems (ref. no)	222	<b>-2.43</b>	<b>0.86</b>	<b>.005</b>	220	-0.18	0.22	.40	183	-0.21	0.22	.35
Mental health problems (ref. no)	222	0.32	0.60	.60	220	0.09	0.15	.54	183	0.12	0.16	.45
<b>Fixed effect of administration characteristics</b>												
Mode of administering: other (ref. face-to-face)	225	2.82	1.61	.08	223	-0.29	0.37	.43	185	-0.26	0.40	.51
Carer: present (ref. not present)	225	-1.45	0.78	.07	223	-0.07	0.19	.73	185	0.17	0.20	.39
In combination with qualitative interview (ref. no)	225				223				185			
- interview before P3CEQ		-1.53	1.13	.17		-0.13	0.23	.57		0.25	0.28	.37
- interview after P3CEQ		-1.33	0.73	.07		-0.00	0.17	.98		-0.02	0.18	.90

408

409 Whether service users stated they had a (single) care coordinator (Q6) was substantially related with  
 410 the integrated care initiative they received care from (ICC .34, se .12). Service user characteristics and  
 411 the way the P3CEQ was administered did not influence their answers to this question (Table 9).

412

413 Finally, whether service users needed or wanted their carers involved in decision-making about their  
 414 care (Q11a) also related to the integrated care initiative they received care from (ICC .21, se .10).  
 415 Service user characteristics were not significantly related to their answers to this question. Service

416 users who had their carer present during the P3CEQ interview were more likely to confirm that they  
 417 wanted their carers involved in decision-making about their care.

418

419 *Table 9. Fixed effects of characteristics of service users and administration mode on P3CEQ*  
 420 *dichotomous item scores; results of two-level mixed-effect logistic regression model (N=13 integrated*  
 421 *care initiatives, N=214-223 service users); separate analyses for each characteristic*

	(Single) professional coordinating care (Q6)				Want friends/family involved in decision-making: yes (vs no/don't know) (Q11a)			
	N	esti- mate	Se	P	N	esti- mate	se	P
<b>Fixed effect of service user characteristics</b>								
Gender: female (ref. male)	223	0.02	0.35	.96	217	-0.19	0.35	.58
Age (ref. 65 to 74 years)	222				216			
- 75 to 84 years		-0.48	0.45	.28		0.46	0.42	.28
- 85 years or older		-0.14	0.45	.75		0.81	0.42	.06
Education (ref. no schooling or primary school)	220				215			
- secondary school		0.26	0.49	.59		0.66	0.47	.16
- advanced vocational training		0.42	0.49	.39		0.32	0.46	.49
- high professional/academic education		0.91	0.65	.16		-0.32	0.58	.58
Hearing problems (ref. no)	221	-0.40	0.33	.23	215	0.67	0.34	.05
Visual problems (ref. no)	221	0.04	0.34	.91	215	-0.31	0.34	.37
Cognitive problems (ref. no)	220	-0.51	0.51	.32	214	0.76	0.61	.21
Mental health problems (ref. no)	220	0.13	0.35	.71	214	-0.37	0.34	.28
<b>Fixed effect of administration characteristics</b>								
Mode of administering: other (ref. face-to-face)	223	0.06	0.97	.95	217	-1.01	0.96	.29
Carer: present (ref. not present)	223	-0.03	0.45	.95	217	<b>2.12</b>	<b>0.66</b>	<b>.001</b>
In combination with qualitative interview (ref. no)	223				217			
- interview before P3CEQ		0.35	0.63	.58		1.02	0.66	.12
- interview after P3CEQ		-0.51	0.44	.24		-0.10	0.41	.82

422

423

## 424 DISCUSSION SECTION

### 425 Main findings and implications

426 Older people's experiences with integrated care can be collected using a PREM instrument such as the  
 427 P3CEQ. The findings of this case study provide insight into what worked and what could be improved  
 428 when delivering a PREM with older and vulnerable populations and using data to assess integrated  
 429 care from a service user perspective.

430 Unlike previous studies [26], SUSTAIN obtained a high return rate applying a PREM to evaluate care  
 431 received by older people, reducing inclusion bias dramatically. All except two items of the P3CEQ had  
 432 low non-response rates. The only potential reason explaining non-response that appeared across most  
 433 items was a perceived lack of relevance of questions. Nevertheless, this lack of applicability was

434 marginal (occurring for 72 of the 2,736 total possible scores<sup>1</sup>). When answering RQ1, we must bear in  
435 mind that the usability of a PREM instrument is not just about how much data can be collected (i.e.  
436 return and response rates), but also the quality of data. A key aspect here is whether respondents  
437 understand questions and use tick boxes as intended. Our qualitative analysis provides insight on the  
438 possible shortcomings of the data obtained: while several P3CEQ items were generally understood as  
439 intended (e.g. Q4 *repeating information*, Q10 *confidence to self-manage health*), the analysis of open  
440 responses indicates how questions can lead to diverging interpretations by respondents. This  
441 highlights the difficulty of capturing data related to complex concepts quantitatively (particularly from  
442 populations like that in SUSTAIN), and also the importance of mixed methods and use of qualitative  
443 approaches such as in-depth interviewing to develop a nuanced understanding. PREMs such as the  
444 P3CEQ could be enhanced by including simple definitions with real-life examples illustrating each  
445 concept. This would help avoid narrow or misled interpretations such as understanding ‘being  
446 involved in decisions’ or ‘having discussed what is important’ as basic exchanges with care  
447 professionals; that ‘care joined up in a way that works’ is referring to the way care professionals treat  
448 service users; or that ‘support for self-management’ enquires about the extent to which support  
449 meets ones’ needs in general. If unidentified, these misinterpretations may lead to inaccurate  
450 assessments of experiences with integrated care.

451 Analysis of the enabling and constraining factors for questionnaire completion (RQ2) points to a key  
452 factor in this target group: face-to-face delivery. SUSTAIN researchers agreed that the high inclusion  
453 and response rates would unlikely have been feasible if the questionnaire had not been delivered face-  
454 to-face with service-users, at their own pace. After piloting the P3CEQ in the translation and cultural  
455 adaption process, SUSTAIN researchers opted for face-to-face interviews in order to maximize both  
456 quantity and quality of data. In fact, most SUSTAIN researchers expressed that they found themselves  
457 delivering the P3CEQ almost as a semi-structured interview guideline, providing additional  
458 explanations or examples to illustrate the meaning of items and facilitate understanding. In order to  
459 ensure data quality, researchers (and research funders) should be prepared for such a delivery,  
460 allowing sufficient time for each respondent to answer the questionnaire and adopting a facilitating  
461 role when needed. In this sense, researcher notes and paraphrasing of open responses are particularly  
462 relevant for data interpretability.

463 The presence of a carer while the questionnaire was delivered was another enabling factor. It had a  
464 significant impact on the level of response in one of the two questions with a non-response rate higher  
465 than 10% (Q11b), and became a more or less explicit requirement in cases presenting cognitive  
466 impairment. The option of using the carer as a proxy respondent enabled SUSTAIN’s research to be  
467 inclusive and provide learnings on care experiences of this particular target group, with carers  
468 commonly invited to participate in a qualitative interview [36]. However, presence of a carer  
469 introduced the possibility of bias. For instance, service users who had their carer present during the  
470 P3CEQ were more likely to confirm that they wanted their carers involved in decision-making about  
471 their care. Due to the collinearity between ‘existence of a carer’, ‘carer being present during  
472 questionnaire delivery’ and ‘cognitive impairment’ (when this applies), from a quantitative  
473 perspective we cannot make much of this data, and from a qualitative point of view we can only  
474 speculate the extent to which responses represented the carer’s or the service user’s wishes.

---

<sup>1</sup> 2,736 = 228 respondents per 12 P3CEQ items



475 Our third RQ, exploring if user characteristics or administration mode impact the perceived level of  
476 person-centred coordinated care, provides three additional findings (besides the above-mentioned  
477 impact of presence of a carer) that are of methodological relevance concerning PREM design and data  
478 analysis. First, from a statistical point of view, it was not possible to obtain one of the two constructs  
479 intended by the P3CEQ –care coordination. Our dimensionality analysis therefore indicates the need  
480 for further validation among older and vulnerable people.

481 Second, service users with cognitive problems experienced less person-centred care as measured by  
482 the P3CEQ. This is in line with previous literature finding that, even in interventions designed  
483 specifically for the cognitively impaired, aspects relevant for person-centredness, such as  
484 communication and collaboration between family members and care professionals, can be lacking  
485 [47]. In this sense, it has been argued that person-centredness needs to be more proactively promoted  
486 within interventions, and this can be achieved through the inclusion of important and enjoyable –or  
487 meaningful [48] activities, both from the service user and carer perspective [49].  
488

489 Third, service users with higher levels of education were less positive about the person-centredness  
490 of the care they received and about the extent to which their carers were involved in decisions. This  
491 coincides with previous studies exploring determinants of health care satisfaction and/or experiences  
492 [50, 51]. Education and age can be used as proxy measures of health expectations, given their  
493 correlation with satisfaction [52, 53]. Previously it has been hypothesised that older people may be  
494 more accepting and more reluctant to pass negative judgements with respect to their health care [52].  
495 Cohen found that dissatisfaction with aspects of hospital-based care decreased markedly with age,  
496 but called for further research in order to confirm the aforementioned hypothesis [53]. A later study  
497 on the Questionnaire for Patient Expectations of Health Care found that older age predicted higher  
498 met expectations of health care [54]. The interrelation between age, health status, education,  
499 expectations and care assessment is an ongoing research topic [i.e. 52, 53, 50, 55, 54], that highlights  
500 the need to apply multivariate analysis and multilevel modelling, adjusting scores for the  
501 characteristics of the population in order to avoid systematic misrepresentations in the assessment of  
502 care that assists particular patient groups [55]. Such is the case for integrated care, a main beneficiary  
503 of which are older people who require continuous support from a variety of care providers. It is  
504 important, however, to recognise the diversity amongst older people, avoiding stereotypes [56].  
505 Collecting and analysing user characteristics (e.g. physical functioning or autonomy, educational  
506 attainment, attitudes [50]) in relation to reported experiences with integrated care may help surface  
507 issues that are particularly relevant for specific subgroups. It would also be particularly useful to  
508 develop an instrument to collect expectations concerning the specific dimensions of person-centred  
509 coordinated care (e.g. discussions with care professionals, decision-making, self-management of  
510 health), as to improve the interpretation and use of data collected with PREM such as the P3CEQ.  
511

512 Finally, although open responses to P3CEQ items gathered by SUSTAIN did not provide rich narratives,  
513 we can use them as indications of the kind of reactions people had when they completed this PREM.  
514 Questions on ‘support for self-management’ and ‘confidence to self-manage health’ triggered  
515 reflection on functional or mental impairments that might be hard to accept, acknowledging  
516 dependence on others. Question 11, which defines the concept of ‘close ones’ and asks if such persons  
517 should be included in decisions on care options, implies asking respondents to consider if they do or  
518 do not have anybody they can consider close, and if so, state if they do or do not want them involved.

519 It is important to consider how questions in a tool like the P3CEQ might prompt discomfort amongst  
520 respondents, and make sure plans for limiting and dealing with such situations are in place to ensure  
521 sound ethical research. This is particularly relevant in cases where carers accompany service users  
522 when replying a PREM that includes questions enquiring about service user/carer relationship.

523

## 524 **Limitations**

525 SUSTAIN researchers delivered the P3CEQ tool almost in the form of a semi-structured interview  
526 providing additional explanations when needed, and this helped reduce non-scoring to acceptable  
527 levels. However, researchers may have had different understandings and criteria on how to code  
528 certain answers. A guide specifying administration and coding criteria would be highly recommended  
529 since individual researchers might deal differently with situations where, for example, a respondent  
530 indicates a score then provides evidence that is contradictory to that score. This is particularly relevant  
531 when carers support service users to complete the questionnaire, since this implies having two  
532 persons –interviewer and carer- between the question and the service user, increasing the chance of  
533 differing interpretations.

534

535 Open responses were only provided by 15-35% of respondents who scored a P3CEQ item, and  
536 therefore the findings concerning how they understood each item cannot be generalised to the whole  
537 sample. There may be a bias in researcher note-takings, perhaps tending to write down responses  
538 more that deviated from their understanding of the concept. Further work, such as cognitive  
539 interviews, among frail older service user groups to check understandings of questions, concepts and  
540 scores may be valuable.

541 Finally, this paper does not emphasise the perceived level of person-centredness and coordination of  
542 care of the older people participating in SUSTAIN and how this varies across European integrated care  
543 initiatives. Nor does it examine factors particularly relevant in each integrated care initiative to explain  
544 service user experiences. Such analyses would be of interest, but are not possible here due to the  
545 combination of relatively low sample sizes from each integrated care initiative (since SUSTAIN's  
546 multiple embedded case study design was characterised by the integration of evidence collected  
547 through a variety of instruments in order to identify patterns [57]), and the heterogeneity of the types  
548 of care and target groups of the thirteen initiatives involved in SUSTAIN.

549

## 550 **Conclusion**

551 This study shows essential preconditions to meaningfully collect and analyse PREM data on older  
552 peoples' experiences with integrated care: face-to-face administration away from care providers,  
553 collection of reasons for non-response and open comments providing nuances to answers, and  
554 multilevel modelling taking into account diversity in the target population. Several areas of  
555 improvement for future PREM use in this population have been identified: use of administration and  
556 coding guides, inclusion of clear and easy to understand definitions and examples illustrating what  
557 questions do and do not mean, measures of the expectations of person-centred coordinated care, and  
558 procedures ensuring sound ethical research. These methodological learnings can enhance future  
559 evaluation of integrated care from a service user perspective.

560

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