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# A Qualitative Exploration of Patient and Staff Experiences of the Receipt and Delivery of Specialist Weight Management Services in the UK

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## Abstract

**Background** Addressing the increasing prevalence of obesity is a global public health priority. Severe obesity (body mass index > 40) reduces life expectancy, due to its association with people developing complications (e.g. diabetes, cancer, cardiovascular disease), and greatly impairs quality of life. The National Health Service (NHS) in the UK provides specialist weight management services (SWMS) for people with severe obesity, but key uncertainties remain around patient access to and engagement with weight management services, as well as pathways beyond the service.

**Methods** In this multiple methods study, using online forum data and semi-structured interviews, stakeholders' experiences of delivering and receiving SWMS were explored. Using the web search engine Google with keywords and web address (URL) identifiers, relevant public online platforms were sourced with snowball sampling and search strings used to identify threads related to people's experiences of accessing SWMS ( $n = 57$ ). Interviews were conducted with 24 participants (nine patients, 15 staff), and data from all sources were analysed thematically using the framework approach.

**Results** Six themes related to access to and engagement with SWMS emerged during data analysis: (1) making the first move, (2) uncertainty and confusion, (3) resource issues, (4) respect and understanding, (5) mode of delivery, and (6) desire for ongoing support.

**Conclusion** There is a mixed and varied picture of SWMS provision across the UK. The service offered is based on local clinical decision making and available resources, resulting in a range of patient experiences and perspectives. Whilst service capacity issues and patient anxiety were seen as barriers to accessing care, peer support and positive clinical and group interactions (connectedness between individuals) were considered to increase engagement.

## 1 Background

In 2019, the Health Survey for England found obesity prevalence (as estimated by body mass index [BMI]) was 27% for men and 29% for women, a 14% rise since 1993 [1, 2]. By 2035, 5 million people in the UK are predicted to have severe obesity ( $\text{BMI} > 40 \text{ kg m}^2$ ), which is more than double the prevalence observed in 2015 [3]. This prevalence rate poses significant problems for public health and healthcare

### Key Points

Patients would like to have more information on waiting times and understand why services prioritise those who are ready to make key lifestyle changes.

Patients turn to online forums to seek additional information and advice when they are uncertain about access to care and these forums provide a welcome community of support.

Both patients and healthcare staff recognised the importance of building rapport to reduce anxiety and increase engagement with services.

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services because not only does severe obesity account for 24–35% of all obesity-related costs [3], it can also reduce life expectancy by 10 years [4]. In addition, quality of life can also be affected by severe obesity, as the risk of type 2 diabetes, infertility, sleep apnoea, reduced mobility, cardiovascular disease, and some types of cancer increases [5].

In the UK, specialist weight management services (SWMS) support people who have severe obesity, providing structured programmes for behaviour change to address long-established habits and attitudes to food and physical (in)activity. National guidelines (National Institute for Health and Care Excellence [NICE] guidance for obesity identification and treatment) [6] advocate a multimodal approach involving a multidisciplinary team [MDT] to treat severe obesity [6, 7]; however, NICE guidance does not define how behavioural interventions should be delivered. Consequently, the few published evaluations of SWMS for people with severe obesity, also known as ‘Tier 3’ services (e.g. Logue et al. [8], Jennings et al. [9], Brown et al. [10], 11, Steele et al. [12], and Moffatt et al. [13]), show that programmes tend to be developed and implemented in isolation of one another, and also vary in their approach. A systematic review exploring the evidence base for Tier 3 weight management interventions for adults found variations in service provision and highlighted the need for further research on effective approaches [11].

To identify approaches that best address patients’ and service providers’ needs, a range of patient and other stakeholders views are required to fully understand the patient experience and any organisational or policy contexts impacting service provision [14]. A potentially rich source of information about patients and stakeholder views might come from online forums. We know that around 10% of internet users in the UK participate in online forums [15] to express their views, seek out information, and receive social support. Moreover, those living with obesity are more likely to search for and apply online health information and communicate virtually with clinicians than those with other chronic illnesses [16]. With this in mind, online forums had the potential to provide data that would contrast with patient interviews, as interviewees might represent a wider demographic.

The aim of the present study, therefore, was to explore how patients and staff experience the receipt and delivery of SWMS, using two different methods (semi-structured interviews and online forum data capture) to obtain a depth (probing detail in interviews) and breadth (drawing from a wide range of sources) of data. These insights will inform the refinement of PROGROUP, a novel, group-based Tier 3 intervention for people with severe obesity, which will be evaluated in a feasibility and subsequent effectiveness trial.

## 2 Methods

This qualitative study collected and synthesised data from online forums on which people shared experiences of SWMS across the UK, and semi-structured interviews with patients and staff responsible for delivery of these services in the South-West of England. The study was designed to capture a breadth of patient views from online forums juxtaposed with the in-depth patient and staff experiences of group-based programmes to build an understanding of SWMS across the UK.

### 2.1 Participants and Recruitment

#### 2.1.1 Online Forums for People with Severe Obesity

Online forums are defined as asynchronous communication platforms that offer users anonymity. Within these forums, threads or conversations are generated when one user creates the original post and other users respond around this topic. For posts to be included in this study, content had to contain an exchange between a minimum of two users, relate to UK Tier 3 SWMS, be publicly available, and have been posted within the last 10 years. To mitigate ethical concerns, closed groups or private (members only) forums were not accessed, and usernames or locations were removed from forum posts to preserve anonymity.

#### 2.1.2 Semi-structured Interviews with Patients with Severe Obesity, Healthcare Staff, and Service Commissioners

Healthcare staff were recruited by word of mouth through an extensive regional network of contacts known to the research team. Those who expressed interest in the study were sent a participant information sheet by email and invited to contact the research team if they wished to participate. Participants were purposively recruited to represent a variety of healthcare practitioners with different levels of expertise in supporting this population. The purposive sampling strategy also ensured that, collectively, participants represented those involved in designing (programme designers [PD]), delivering (service managers [SM] and facilitators [FA]), and commissioning SWMS (service commissioners [SC]), as well as those involved in training (trainers [TR]). Patient participants were recruited via independent support groups linked to a local regional service. These patient support groups comprised individuals who were either currently participating in a programme or had recently completed one. Potential participants made direct contact with the research team who provided them with a participant information sheet and answered any questions and confirmed eligibility, prior to taking consent. Informed consent was sought verbally and

documented electronically prior to each interview. After giving informed consent, each participant was assigned a unique reference number (e.g. P01). All interviews were conducted on a one-to-one basis. Recruitment and interviewing continued until the team agreed sufficient conceptual density/depth had been reached across all interview groups. This decision was based on the current evidence and discussions with our clinical and patient collaborators. Participant and forum details are presented in Table 1.

## 2.2 Data Collection Procedures

### 2.2.1 Online Forums

A variety of public forums used by people with severe obesity were sourced using the web search engine Google, with keywords and web address (URL) identifiers (Electronic Supplementary Material file 1). Within these forums snowball sampling (i.e. linked posts) and search strings were used to identify threads relevant to specialist weight management programme experiences ( $n = 57$ ) (Table 1). The searches and data collection were conducted between 24 September and 14 November 2021.

### 2.2.2 Semi-structured Interviews

Three researchers, with over 20 years combined postdoctoral experience in qualitative health services research and unknown to participants, undertook all interviews using Microsoft Teams between July 2021 and March 2022. The interviews lasted 45–60 min each. The three interviewers, RW, DS, and SM (one male, two female), had mixed health research backgrounds and had experience in working in weight management/severe obesity research. The interviews focussed on participants' experiences of developing, delivering, or attending weight management programmes, using topic guides developed with our Patient Advisory Group. The topic guide prompts (Electronic Supplementary Material file 2) underwent minor modifications in light of early interview data, consistent with an inductive approach [17]. Memos were taken during the interview process to enable the researchers to determine characteristics of participants and provide insight into potential themes. Interviews were audio recorded and underwent targeted transcription [18] to facilitate rapid identification of relevant issues for refining findings. Once transcribed, audio recordings were deleted. All consented participants provided complete interview data; there were no withdrawals.

**Table 1** Participant and online forum details

Interview participants	Sample size (initially specified)	Participant details
Programme designers (PD) (involved in designing or refining the SWMS programme)	7 (6–8)	Dietitians ( $n = 3$ ), psychologists ( $n = 2$ ), a nurse and a physiotherapist
Trainers (TR) (responsible for training SWMS facilitators)	3 (5)	Dietitians ( $n = 2$ ) and a psychologist
Facilitators (FA) (responsible for delivering programme sessions)	11 (10 or until saturation)	Dietitians ( $n = 5$ ), physiotherapists ( $n = 3$ ), psychologists ( $n = 2$ ), and a health improvement practitioner
Service managers (SM) (programme organisers and service delivery managers)	2 (5 or until saturation)	A nurse and a consultant
Service commissioners (SC) (who assess needs, plan, prioritise, and budget for SWMS)	2 (2–3)	Commissioners for two regions
Patient participants/service users	9 (15 or until saturation)	Age ranged from 36 to 63 years (35–44 [ $n = 4$ ], 45–54 [ $n = 1$ ], 55–64 [ $n = 4$ ]); gender (1 M, 8 F); carer ( $n = 5$ ), employed ( $n = 3$ ), retired, ( $n = 1$ ); all white British ethnicity
Forums	Sample size (initially identified)	Inclusion criteria for online content
Online platforms	13 (29)	All platforms related to UK Tier 3 services were publicly accessible without an account, and contained user generated content
Online threads	57 (64)	All threads referring to UK Tier 3 services were active within the last 10 years and publicly accessible
Online posts	307 (4382)	All posts selected for analysis related to UK Tier 3 services

F female, M male, SWMS specialist weight management services

## 2.3 Data Analysis

Transcripts were analysed thematically using NVivo software (QSR International; Version 12 Pro) to help organise, code, and explore the data. The analytic focus was to organise the data in a meaningful way according to the *a priori* aims of the study, and to allow identification of topics and issues of importance to participants. The first five transcripts were double-coded by a second researcher, and themes identified. Any differences in interpretation were discussed before an initial coding framework was developed [19]. Through the reading and re-reading of all transcripts across each interview group (RW), new and recurring themes were identified, the framework was refined (Electronic Supplementary Material file 3), and then these were coded by RW across all interviews. The themes and their names and explanations were continually refined through discussion between the researchers to ensure that they were distinct from other themes, internally coherent, and consistently applied.

Analysis of the online forum data was conducted by two researchers (RW and MA). Repeated reading and familiarisation with the forum data led to development of an initial set of codes. These codes were assimilated into the existing coding framework (developed from the interview transcripts), resulting in a unified coding framework agreed to by RW, MA, DS, and JL. Framework analysis allowed for data amalgamation to create key themes from all data sources [19].

## 3 Results

Searches within each of the identified platforms yielded 64 relevant online forums. Seven of these were excluded (pre-October 2011, referral to Tier 4 not Tier 3, one post with no reply), resulting in the inclusion of 57 forums for analysis, with a total of 4382 posts, 307 of which met the inclusion criteria and were included in the final analysis (Electronic Supplementary Material file 1).

Fifteen healthcare staff and nine patients took part in interviews. No repeat interviews were conducted. Amongst the healthcare staff were five dietitians, three physiotherapists, two psychologists, two commissioners, one nurse, and one consultant. In the context of Tier 3 service provision, eight of these healthcare staff could be described as PD, three as TR, 12 as FA, three as SM, and two as SC (Table 1). Patient participants are described demographically in Table 1. Illustrative quotes are denoted by a participant number (e.g. P01 [patient], S01 [staff]) as well as a primary role suffix for healthcare staff (e.g. S01FA). Online forum data are denoted by “OF” followed by a chronological number based on where they appear in Tables 1 and 2.

From the online forums and the semi-structured interviews, six themes were identified, three pertaining to accessing Tier 3 services (making the first move; uncertainty and confusion; resource issues) and three to engaging with Tier 3 services (respect and understanding; mode of delivery; desire for ongoing support). Each theme incorporated the perceptions of participants across the three participant groups (healthcare staff; patients who had recently attended a group-based programme for severe obesity [interview data]; people with severe obesity [online forum data]). Illustrative quotes relating to the themes are listed in Tables 2 and 3.

### 3.1 Accessing Specialist Weight Management Services

#### 3.1.1 Making the First Move

Initiating the conversation around accessing weight management support was associated with difficulties, and this was a prominent feature of online content (OF1, OF5). Forum users posted comments relating to how daunting it was to approach their general practitioner (GP), having not spoken about their weight with any healthcare professional for many years (OF2, OF3, OF5, OF9). This lack of contact resulted from negative past experiences such as feeling stigmatised by their interactions with healthcare professionals, coupled with not wanting to overburden an already stretched service and a resulting overall sense of “being failed” (OF6, OF7). One forum user described their GP as “fatphobic” (OF8), although, notably, other posters used the forum to express gratitude for the support of their GP—finding them to be sympathetic and doing as much as they could to help (OF3, OF9). From the patients’ perspective (forum users and interview participants), a health scare, recent diagnosis, or ongoing associated health issue (e.g. knee pain) prompted a desire to access Tier 3 services—and that addressing their weight-related issues was important, not only for their long-term health, but also for the future wellbeing of their family. Making this first move was seen as a way to take control of their situation (P04, P08, P02, OF10, OF11).

Once referred to Tier 3 services, healthcare staff at some sites discussed how they operated an informal opt-in system for patients—a final barrier to access, which was designed to help ensure that patients were prepared for (and committed to) programme attendance. This was orchestrated via initial one-to-one assessments, as well as via a group induction session or taster session in which a clinician(s) would explain the format of the programme, as distinct from other interventions that patients may have experienced. As well as preparing patients for their upcoming programme, this approach was designed to reduce patient attrition from services (S01FA, S04FA).

**Table 2** Illustrative quotes for access to specialist weight management services

Theme	First-order construct
Making the first move	<p>Online forums</p> <p>“After 15 + years of being overweight I finally took the plunge and approached my GP for help.” (OF1)</p> <p>“I am such a meek person I couldn’t formulate all the questions I had for my GP about referral for my weight. Perhaps someone here who has been through this can point me straight.” (OF2)</p> <p>“My sister-in-law said a friend had enquired about weight loss surgery with her doctor and I should look into it too.” (OF3)</p> <p>“Not been seen by tier 3. I’m afraid my GP may be gatekeeping a little too effectively.” (OF4)</p> <p>“I’m scared to call, I don’t want to hear them say no, I know I will fall off the wagon big time if that happens because “what’s the point?”” (OF5)</p> <p>“[I have] never tried NHS as my GP is monumentally unsympathetic in general and I didn’t want to wait, I’d spent long enough debating it with myself. [Private surgery] was affordable to me so went for it.” (OF6)</p> <p>“I had it in my head that he would take one look at me and say nah go away and try and lose it on your own ... so when I was accepted [for weight loss surgery] I was shocked, speechless, emotional and then I felt guilty (because [it’s] via the NHS and [it’s] not a cheap operation and the NHS are short on money)” (OF7)</p> <p>“My fatphobic GP gave incorrect treatment advice on trigger finger (weight loss doesn’t fix everything) and I can no longer fully bend that finger or grip in that hand. The same fatphobic GP dismissed my pleas for physio/investigation following a knee injury” (OF8)</p> <p>“I saw my GP expecting to be laughed at or simply told no. To my shock the GP was amazing and did everything she could really quickly” (OF9)</p> <p>“During this time I’ve had a family bereavement, losing my sister, and I’ve shed a few pounds, so I also hope that they don’t assume I can lose weight at a drop of a hat. [S]he was also very over weight, and it was a contributory factor in her death. It has made me even more positive and determined that I MUST get this surgery.” (OF10)</p> <p>“I need some help though I can’t go 3 or 4 months between appointments and I need to see the psychologist I think – now I just hope they will give me another chance – I so want to get healthier for my children!” (OF11)</p> <p>Interviewed patients</p> <p>“I got diagnosed with extremely high blood pressure, and for me it was going to be life changing. I’ve grandkids on the way, um, and it, I got to the stage where ... being overweight, getting help is just the same as having a smoking or a drinking habit.” (P04)</p> <p>“My gallbladder and I had a little spell in hospital because it flared up and then it was through the doctor advising about losing some weight and putting me erm in touch with the weight management.” (P08)</p> <p>“I didn’t even, and in all fairness if it wasn’t for my doctor, I never even knew this programme existed, and if I did then I would have done it years ago.” (P04)</p> <p>“Hadn’t heard of weight management until I’d actually had an injury and I was waiting for an x-ray and all of a sudden this lady come along, lovely lady, really friendly, asked me to follow her, I followed her and I ended up sitting in a group of people, and I thought, this is a bit strange for an x-ray, so I made a question and said excuse me but why am I here? Because I’m expecting an x-ray and she said, “[O]h my god, we’re really sorry, this is the weight management group.”” (P02)</p> <p>Interviewed healthcare staff</p> <p>“Hello, how are you? Who are you? What is it you want? Tell us about yourselves and you know, can we offer what you, what you want and what we need?” (S01FA)</p> <p>““This is not a diet, it’s a lifestyle change,” and, “It’s not a quick fix, it’s not going to happen overnight,” as well, you know, so um, managing people’s expectations as well.” (S04FA)</p> <p>“Do they know the difference between us and Slimming World? Us and Weight Watchers? Because everybody thinks it’s about eating less and moving more. We know it’s not, but at that point they don’t. Some people who’ve been referred by GPs didn’t even know they were coming to a group session.” (S01FA)</p>

**Table 2** (continued)

Theme	First-order construct
Uncertainty and confusion	Online forums
	“I’m so confused by all this information. I don’t think my GP knows what and who to refer to.” (OF12)
	“I have been referred for the Tier 3 NHS weight loss program – so thank you for the recommendation. My old GP never mentioned it as a possibility.” (OF13)
	“I don’t really know where in the process I am, I’ve done the Tier 3 thing (albeit without knowing it), so I don’t know what happens next which makes me a bit nervous!” (OF14)
	“I’m also a nurse and I’ve spoken to 5 different GPs at my surgery. The other 2 surgeries locally won’t accept me as I’m “not in their catchment area”. 2 referred me to the local weight loss hub who refused to help as I was beyond their limit. 1 told me to go to [S]limming [W]orld and the other 2 just told me to “eat less and move more.” (OF15)
	“It is very different all over the country, bit of a postcode lottery. Fingers crossed for you. Just be prepared to be patient.” (OF16)
	“In some places with a BMI of over 50 you do six rather than 12 months of tier 3. The trouble is everywhere does it differently so the only way to be absolutely sure about how it will work for you is to ask your weight loss surgery team to clarify that for you.” (OF17)
	Interviewed patients
	“I went to the GP and asked to be referred. I had a load of bloods taken and bits and pieces, and got referred, I thought, I know, I know there’s sort of restrictions and criteria, but it always seems a bit bizarre. That you almost have to wait to get a certain BMI before you’re allowed to access them. And reflecting back as well now, having seen what was on the course, and it, I, I don’t think you should have to wait until that level before you can access the service, because there’s an awful lot there that’s beneficial at any weight to be honest.” (P03)
	“I attended all my appointments and the sessions, but I just sometimes um, well I attended all of the group sessions, because if you didn’t then you get kicked off.” (P01)
	“I didn’t even, and in all fairness if it wasn’t for my doctor, I never even knew this programme existed, and if I did then I would have done it years ago.” (P04)
	“How many more times do I have to tell them, yes I really want to do this before I’m actually allowed on the course?” (P03)
	“You had to ring up, once you’d been at this information session, if you decided that that was the course, the, the, that you wanted to do, you had to then ring up and get booked on, um, basically booked on a course, um, and that, that, the information session I had was, I think it was like November, um, and I, I had a meeting with them in December, but didn’t actually start until the March.” (P05)
	“They actually did say that at the next session you’ve got to be a one hundred percent in this, no playing with your phones, answering phone calls or messages, texts.” (P09)
	Interviewed healthcare staff
	“There’s a bit of clinical decision making and discussing with the patient if it’s the right time, and we can take that to our MDT if need be, if you’re not sure or you’re worried that actually they, “Yeah, this person’s, there’s a mental health issue and you know, they’re not very stable at the minute, that sort of thing, does it need going back to the GP?”” (S02FA)
	“[I]s this the right thing for them at this present time, or if somebody’s gone through a significant bereavement then and actually, you know, there’s no way they’re going to be making these sorts of changes” (S02FA)
	“You know, they go to their GP and the GP just doesn’t know what to do, it’s too complex, can’t help” (S13SC)
	“The GP or healthcare professional will refer them to the service and we, we offered several stages for the patient to opt in, so not an opt out but an opt in. So, we’d write and say we’ve received your referral, if you want an appointment let us know. And there’d be a seven or a fourteen-day deadline ... if the clinician felt that the, the service matched the patient’s needs we would sign them up. But again, it was offering an opt in, so let us know if you want to join this group in June, or July, or August. Let us know which day of the week you want to opt in. So, it was very asking people always to keep reaffirming what they wanted.” (S01FA)
	“The major intervention that came out of that was our, what we call an induction. So, we used to waste a lot of time having offered appointments to patients to come for assessments who never turned up.” (S05SM)



**Table 2** (continued)

Theme	First-order construct
Resource issues	<p>Online forums</p> <p>“If anyone has just started on this journey, ... please bear in mind that this is likely to be a long and frustrating process with little information, and whatever information you are given is most likely to be incorrect.” (OF18)</p> <p>“The waiting is definitely the hardest part of this journey.” (OF19)</p> <p>“I got referred to tier 3 by my GP, but by the time they even got in touch for an initial phone call I’d already booked surgery privately. I’d been reading on lots of weight loss surgery groups about everything being pushed back so far due to Covid, so I just didn’t want to wait any longer. Like you, I didn’t feel I had any more life left to spend sat on the side-lines.” (OF20)</p> <p>Interviewed patients</p> <p>“I can understand, there’s going to be wait lists, everywhere you go, and you know, definitely with a programme like this.” (P04)</p> <p>“So I got referred in the August, I had to wait until the May to get started, so it was quite a long time and it felt like you still had to jump through a lot of hoops.” (P03)</p> <p>“Everything boils down to finance really you know she said you would benefit from some counselling, but of course I can understand you know with all the situations in the last couple of years there is a lot of people struggling big time and I’m not struggling in that way you know I’m not struggling in that I might harm myself or anything like that.” (P08)</p> <p>Interviewed healthcare staff</p> <p>“Funding is a huge, huge part of those decisions to what services, I have a, my budget is finite you know. I’m very limited as a commissioner in that respect of I can only work with what I’ve got, that plays a huge part.” (S14SC)</p> <p>“We have people who have actually no medical comorbidities, but their BMI is 70+, but then you get some people who have got a BMI of 35 but they’ve got everything, they’ve got high blood pressure, diabetes and that, so um, that’s why we do that screening at the start.” (S15FA)</p> <p>“So [after Covid] the service pretty much stopped completely for a long time, and that has left an ongoing problem with our waiting lists, and also slowed down our development of the online programme.” (S08PD)</p> <p>“I’m not supposed to use the pots of money across the two. It’s like, hello. And let alone tying in anything to do with type 2 diabetes, which most people understand is gonna cripple the NHS, but they seem to have overlooked the fact that obesity is what’s driving that.” (S05SM)</p> <p>“It can be quite tricky as a commissioner too, to really understand, what the options are out there, what are all the different models people are using and what outcomes they are having.” (S13SC)</p> <p>“We’re still picking up the pieces of recovery from Covid really, still with a view to moving forwards towards implementation of a policy, but in a context now that is a service under massive pressure.” (S13SC)</p> <p>“We’re also seeing a lot of younger patients with BMIs over 50, ... even in the last fifteen years, most of our patients with diabetes were over the age of fifty. You don’t bat an eyelid now at a twenty-year-old coming in with type 2 diabetes.” (S05SM)</p> <p>“One particular situation where a patient was hypertensive, we had to sit them out of the exercise because their blood pressure was a medical emergency, and then it was a case of, “You really need to speak to your GP and get this blood pressure under control, because this is going to be difficult for us to manage.”” (S03FA)</p>

*BMI* body mass index, *Covid* coronavirus disease (COVID), *FA* facilitator, *GP* general practitioner, *MDT* multi-disciplinary team, *NHS* National Health Service, *OF* online forum, *P* patient, *PD* programme designer, *S* staff, *SC* service commissioner, *SM* service manager

### 3.1.2 Uncertainty and Confusion

Uncertainty and confusion encompassed patients’ perceptions of the pathway to accessing a Tier 3 programme, including the uncertainty over the treatment available to

them and time to referral and programme initiation (OF14, OF15, OF16, OF17, P05). Some patients suggested that their GPs were unfamiliar with the weight management pathway and the requirements to access it (OF12, OF13). This resulted in frustration amongst patients and an increased sense of anxiety (P01, P03, OF14). It also prompted some

**Table 3** Illustrative quotes for engagement with specialist weight management services

Theme	First-order construct
Respect and understanding	Online forums
	“There are lots of hoops to jump through but, ... there is lots of support and advice from everyone on here.” (OF21)
	“The 2 people running it (husband and wife) are both diabetic (type 2) and he has been taken off the diabetic register by his GP. So, I thought “great, they must know what they are talking about.” (OF22)
	“My doctor I am registered with has never been supported I went to another doctor who referred me for tier 3 and surgery but she wasn't stick thin like my doctor!” (OF23)
	“The same GP who berated me for not having lost any weight on the weight management course even after I explained that while I'd been admitted they hadn't started the course yet due to a lack of psychologists – her response was to ask what I was doing to fix this!? Like I can fix the NHS recruitment issue!” (OF24)
	Interviewed patients
	“We would find ourselves saying that nobody can be sent to weight management. Just because your GP, your nurse, your consultant has ticked the box to say you should go – you need to want to be here.” (P01)
	“Everybody had been through a similar sort of experience to me, so that was very comforting.” (P02)
	“You know, they had like crutches and were like obese like I was, and nobody sort of had any, you know, you, you didn't see like stick thin people going, “Oh, this is what you should be eating.”” (P05)
	“You could resonate with the challenges around families, work, work-life-balance, not putting yourself first, not wanting to lose weight for the right reasons. How you feel about it, you know, how you feel people perceive you. I think there's an awful lot of similarities with everybody really.” (P03)
	“Everybody in there failed at home, and sometimes some of them will get a little bit down, or something like that, and we'd just be there to pick each other up really, you know, you, we're all in the same boat.” (P04)
	“I do have anxiety problems anyway, so I was a bit anxious obviously, so and that, you know, that didn't help us, but everyone was really friendly, and they were nice, obviously there's more people that are a bit more vocal than others.” (P01)
	Interviewed healthcare staff
	“There's help making sure people feel comfortable, have they got a chair, have they got something to look at, ... fun quizzes in it as well, we have buddies [peer supporters] with us, so it's not just clinical people talking to patients.” (S02FA)
	“And then you sort of point out the buddies, like these guys who are actually living it as well. Erm, and the buddies were normally the hit.” (S01FA)
	“I was almost seen as like the skinny one who didn't know what I was talking about, so we actually paused the group and we addressed that because it's a really good example to talk about weight stigma and kind of challenge some of their wonky thoughts about that.” (S10TR)
	“They all go round and scribble on words and that's quite an emotional session actually because you know it brings up all the stigma and internalised stigma that there is, so that's quite a powerful session.” (S10TR)
	“So we have paused a couple of people in the group and said, “We don't think you're ready to do this group at the moment.”” (S08PD)
	“So if you really get a group where people (are) engaged, keen, they ... can have a positive ripple effect. Likewise, a couple of mood hoovers who are not really wanting to change and it can have the opposite effect, but on the whole, peer support has a really positive effect.” (S09PD)

**Table 3** (continued)

Theme	First-order construct
Mode of delivery	<p>Online forums</p> <p>“The session was quite nice, I have some apps to sign up to today which are for keeping in contact with the group and dietitians. The sessions are every 3 weeks, and some of them are exercise based, not sure how that will work in my pokey living room but let’s see!” (OF25)</p> <p>“Basically I couldn’t do the programme they offered me because of my working hours. So, I’m hoping to get some one-to-one help from a dietitian and psychologist, but I’ve no idea when this will be.” (OF26)</p> <p>“The very best thing you can do now is to join your Tier 3 hospitals private Facebook group. It was invaluable to me. We all support each other along the pathway. Meet up. Do join a group and meet others who have been through it.” (OF27)</p> <p>Interviewed patients</p> <p>“It’s really important for you to make those friendships and to have that support, you kind of need to meet face-to-face.” (P05)</p> <p>“Because of Covid we could only meet remotely so it was on Zoom meetings and I didn’t find the group sessions to be particularly useful because it’s sort of artificial, and you didn’t really have chit chat that maybe you would, if you were meeting in a room before a meeting started.” (P07)</p> <p>“It was delivered via a link and it was alternating between some videos that we watched and then the next one would be an interaction – but sadly there was only a couple of people that actually came online as well which was a bit of a shame. In the end it was just myself and one other lady but – like I said in between you have videos that are sent – I think I’ve still got access to them though I haven’t looked this side of Christmas, but then they are there I think for you to refer back to.” (P08)</p> <p>“And online one week we had videos we had to watch and loads of reading and then the following it would be a discussion about the videos that we’d watched and the reading that we had done and they would just chat, did you find it helpful? how did you find it helpful? did you not find it helpful? and that was like five or six of us linked into a chartroom, you could see their face and that was about it.” (P09)</p> <p>Interviewed healthcare staff</p> <p>“You know “you alright Bill” chat, chat, chat “how’s your dog after his operation?” or whatever, you know, those little bonding conversations that aren’t directly related to the programme – we don’t get any of that online.” (S12FA)</p> <p>“You know, if you did it on a Tuesday evening, somebody wanted a Thursday evening, if you did it on a Friday morning, well you should be doing it on a Monday morning, so there was very much all that to consider. Erm, and the cost is quite prohibitive, a lot of our patients don’t have their own transport. So nobody wants to get public transport in the evenings. Getting across town at rush hour was very difficult.” (S01FA)</p> <p>“We do ask people to turn their cameras on if possible, but there’s still a debate over this because I don’t think we’re ever going to please everybody with cameras, because we’ve had feedback that people don’t like people having their cameras off so that’s why we do ask if everybody can turn their cameras on.” (S04FA)</p> <p>“I think what it has done is open up attendance for the people who would never have got to a group session cause they don’t have to go anywhere, and they don’t actually have to sit in a room with other people – they can do it virtually. So, I think it’s been a huge benefit for some and a massive drawback for others.” (S05SM)</p> <p>“So they don’t have to travel anywhere – they find that much more convenient being able to just sit at home and join in the group so there’s a, there’s a mixed bit of feedback really about it. Some people talk all the way, you know all the way, join in all the way through it, some people might not contribute at all. By about the third or fourth one we do try and bring them in by actually asking them perhaps a direct question.” (S04FA)</p> <p>“It’s always problematic, you’ve got to find the right place with access, where you keep the stuff. Bear in mind we’ve got special chairs so if you’ve got 12 chairs they take up a lot of space and you can’t just leave them out ... it costs a lot of money to rent venues.” (S07PD)</p> <p>“We had to leave one setting because there was quite a lot, there was a lot of youth activity happening at the same time and there was some inappropriate comments that happened. And there was another setting that we used um, in a [c]hurch hall that wasn’t really feasible long-term, access to the toilet wasn’t great.” (S08PD)</p> <p>“Adults do not want to be told what to do, they want to have a conversation about why, what’s in it for me and of course the video doesn’t necessarily lend itself to that.” (S01FA)</p>

**Table 3** (continued)

Theme	First-order construct
Desire for ongoing support	<p>Online forums</p> <p>“I’ve done my year in Tier 3 and have been referred on to the hospital but it’s not decided yet if I get surgery – I’m basically in no-man’s land at the moment! Very frustrating!” (OF28)</p> <p>“It’s really hard to keep the motivation going after the programme finishes. You’re expected to stick to the healthy changes, but that’s hard when there’s nobody to support you along the way.” (OF29)</p> <p>I have no idea what you’re supposed to do if you don’t want surgery. Basically, at [place name], you get 3 month[s] of classes and then you’re just left to your own devices.” (OF30)</p> <p>Interviewed patients</p> <p>“That’s the bit that was a little bit upsetting towards the end, because once you finished that all disappeared.” (P04)</p> <p>“I’ve still got a really long way to go, I don’t know where I’m going to be at this time next year, you know, things do happen, you do make mistakes still, you’re not, you’re only human, you know, and nothing’s perfect, it’s not a magic, it’s not a magic tool, you know, it literally is, it’s not a magic pill, it literally is just a tool that you have to work with.” (P01)</p> <p>“So I don’t know what other people at the end of the sessions, what, what they were offered, this is just, what I sort, I need to sort out I had an appointment already booked in with a consultant to go and see her again and say, “I’d done this now,” um, so yeah, I don’t, and then there was some talk about if I wanted to have support from um, dietitians and things like that, um, but there wasn’t any offer of further psychological support.” (P07)</p> <p>“It’s like a grey area when you’re kind of left on your own unless you know you can afford to go and have regular session, trying to sort of find out what’s going on in your head erm ... you are sort of a little bit abandoned in that respect.” (P08)</p> <p>“Even if it was a five minute phone call once a week or once a fortnight, just to say how you are doing, it just keeps it at the forefront of your mind.” (P08)</p> <p>“We have a buddies group and we meet once a month at the moment, online, for like a support meeting.” (P02)</p> <p>Interviewed healthcare staff</p> <p>“The whole idea from NICE and all of the commissioning documents about a weight intervention being a one-year intervention that you offer people, when overweight and obesity is a lifelong condition doesn’t sit right with any of us as a, a team.” (S08PD)</p> <p>“The commissioners were very clear that they only wanted us to see patients for a maximum of a year, and the patients either went for surgery or we had to discharge them completely.” (S06TR)</p> <p>“In my opinion and, there is a need for longer-term interventions and in my opinion as well, more longer-term social interventions, so people can have little top ups along the way, and better social input.” (S09PD)</p> <p>“I wish we didn’t have to measure weight I’d much rather measure all the other things like their quality of life, ability to move a bit better, get up the stairs faster” (S12FA)</p> <p>“[I]t’s really important to look into the other things like the confidence and quality of life and things like that.” (S15FA)</p> <p>“Absolutely, yeah, and it can change both ways. People who were never interested in surgery suddenly understand ooh actually, this might be of benefit.” (S01FA)</p> <p>“And in a way as a practitioner you do feel a little bit like, you get to know these people and then that’s it they’re gone and then you start new, a new lot, you know, and we don’t, we don’t really know how they go on so for us that, that, that’s a little bit um, demotivating for us.” (S04FA)</p>

*Covid* coronavirus disease (COVID), *FA* facilitator, *GP* general practitioner, *NHS* National Health Service, *NICE* National Institute for Health and Care Excellence, *OF* online forum, *P* patient, *PD* programme designer, *S* staff, *SM* service manager, *TR* trainer

patients to turn to online forums to share their experiences and enquire about the experiences of others (OF4, OF13, OF14, OF18).

The diversity of reported experiences on online forums was indicative of the fragmented and varied provision of Tier 3 services across regions and sites, including variability

with regards to approach, delivery methods, eligibility criteria, and waiting times (OF17, OF14). Data showed that programmes varied in length (6–12 months), although, according to some online comments, these could be up to 2 years duration. Eligibility also varied and was based on decisions made by local Clinical Commissioning groups (CCGs), who

chose a combination of factors such as BMI, catchment area, and patient co-morbidities to create criteria for inclusion. Some areas had no Tier 3 service, meaning that patients were referred to weight management services (WMS) in the community (Tier 2) or referred directly for bariatric surgery if eligibility criteria were met. These apparent service variations were highlighted in the staff interviews, where participants described slightly different approaches (S02FA, S13SC).

Healthcare staff also described how enrolment on a Tier 3 programme was contingent on a patient being perceived as ready to join (see S04FA in the previous section), and this required discussions with the MDT, all of which took time and resources. Perceived readiness to join a programme may not have been a factor considered by or communicated to patients, and this may have exacerbated a sense of frustration when they “had to jump through numerous hoops” to access a programme (P03, S01FA).

### 3.1.3 Resource Issues

Waiting times were an implicit consequence of services having limited resources. Healthcare staff described how a lack of resources and burgeoning demand had impacted their ability to deliver services, shaping the mode of delivery, the design of Tier 3 programmes, and the level of service that they could provide patients. It was acknowledged that the coronavirus disease (COVID) pandemic had exacerbated these capacity issues and delayed the evolution of services (S08PD, S13SC). SM reported that some of the issues with allocating funding to Tier 3 programmes overlapped (and competed with) other SWMS (e.g. Tier 2, diabetes programmes), highlighting a challenge of resource allocation (S05SM). The lack of clarity over funding allocation was echoed by SC (S14SC), who acknowledged the paucity of guidance. Forthcoming commissioning policy for SWMS to align with NICE guidance had reportedly been delayed by the COVID pandemic, which was widely considered to have aggravated the strain on an already over-stretched service.

Perceived pressure on the service was compounded by health complexities. Patients came into the service with a range of co-morbidities, including physical disabilities, sensory impairment, and increased anxiety, all of which had the potential to impact their ability to access and engage with Tier 3 programmes. Healthcare staff discussed the shifting profiles of patients, who were coming into the service with higher BMIs, at a younger age, and with a more complex array of co-morbidities. This posed clear challenges to the provision of a service to meet the complex needs of its patients (S15SA, S05SM).

Resource issues were also recognised by patients, adversely impacting waiting times, but also communication between service providers and patients (OF20).

However, there was a general acceptance that delays were to be expected given perceptions of an overstretched health service (P04). Moreover, patients interviewed about their experiences of attending Tier 3 group programmes were generally positive, indicating that the wait, however frustrating, was worth it.

## 3.2 Engaging with Specialist Weight Management Services

### 3.2.1 Respect and Understanding

Whilst awaiting access to services, some forum users sought advice from others and some drew on their experiences to provide emotional, social, or practical support for the challenges of living with obesity (OF21, OF22). Forums were perceived as an important space for people with severe obesity to discuss their health experiences, connect to others with similar experiences, and increase their knowledge of Tier 3 services (OF21). For patients already referred onto the weight management pathway, posts from service users provided clarity on the process and an opportunity to air their own frustration, helping them to stay on their pathway into the National Health Service (NHS) programme (OF24).

Once enrolled on a Tier 3 programme, both patients and healthcare staff discussed the importance of rapport building, particularly given the anxiety expressed by some patients at the prospect of joining a group and being evaluated and judged by others (P01, S10TR). Some WMS invited previous attendees (Tier 3 graduates) to taster sessions or programme inductions to help provide reassurance and integrate patients, with healthcare staff keen to draw on past participant experiences to engage new starters (S02FA, S01FA). Whilst empathy was implicit amongst previous attendees and patients, healthcare staff were not always perceived as empathetic or discerning given that they did not share the experience of living with obesity. One member of the healthcare staff recognised this perception and explained how they explicitly discussed weight stigma of all body sizes within their group to help individuals also reflect on their own preconceptions (S10TR).

Weight stigma was perceived as a unifying factor that helped to build rapport amongst patients and between patients and healthcare staff and, in so doing, helped to engage patients with the group-based programme. The process of reflecting on stigma during the programmes as a means of forging group bonds was recounted by healthcare staff (S10TR). Patients who were interviewed acknowledged the value of shared experience with their weight management group and recognised the acceptance, reassurance, and solace that could be found through membership (P02, P03). However, healthcare staff recognised that peer support was contingent on a well-functioning group where individuals

formed productive relationships, and that there was always the potential for some members to negatively affect the group dynamic, if not properly managed (S09PD).

### 3.2.2 Mode of Delivery

Tier 3 programmes were delivered in-person, online, or as a hybrid programme (i.e. with some material offered online and some provided in-person). Participants reported advantages and disadvantages with each mode of delivery. In-person group programmes were perceived to enhance group bonding, and it was widely acknowledged that face-to-face sessions enabled casual interactions, small talk, and the potential for friendships to be fostered as a result (P05, P07). However, the practical issues of in-person provision were also recognised by patients, who described the parking at hospital sites as a “nightmare”, and staff questioned the suitability of some settings, describing airless, windowless rooms and uncomfortable chairs—generic issues with in-person service provision (S07PD). Staff also described some of the logistical challenges of in-person delivery such as scheduling sessions at convenient times for patients and finding suitable venues to host sessions (S01FA).

Online delivery offered greater flexibility, giving patients the opportunity to access content at their convenience and then attend virtual group “catch up” sessions to discuss the topics covered. This enabled patients to view the information multiple times and revisit it if necessary. Online forum users also reported using service recommended apps to help manage their progress (OF25). Whilst this approach suited some patients, it was a barrier to engagement for others who valued the opportunity to discuss issues and share experiences with other patients in face-to-face sessions. Finally, whilst healthcare staff acknowledged the convenience of disseminating content via video (S01FA), the more didactic format was also perceived as a potential barrier to engagement (S12FA).

### 3.2.3 Desire for Ongoing Support

Online forum users reported mixed outcomes from Tier 3 programme attendance. On the one hand, users described how the psychological tools and support provided enabled them to make sustained positive behaviour changes. Other users described how the Tier 3 programme helped to prepare them for bariatric surgery, achieving the necessary weight loss ahead of surgery or laying the foundations for sustained lifestyle change post-surgery. However, users also lamented the lack of a clear pathway beyond Tier 3 and the opportunity of continued engagement with services (OF28, OF29).

In the interviews, this sentiment was echoed by healthcare staff, who described the finite provision of SWMS and the lack of long-term options for patients to stay engaged with

services (S08PD). Some patients described completing the Tier 3 programme as the “cliff-edge”, which was accompanied by a sense of isolation and abandonment (P08). Healthcare staff also expressed disappointment at not being able to follow up patients and monitor their progress over time, having seen them make progress on Tier 3 programmes, but having no awareness of long-term outcomes (S04FA). It was suggested that patients could benefit from maintenance doses, defined as short duration “top-up” interventions, or sustained intervention (S09PD). It was widely intimated that long-term engagement with SWMS was necessary to address the chronic nature of obesity, with a 6-month intervention deemed insufficient to tackle the implications of what can be a life-long challenge for most people (S08PD).

Healthcare staff and patients also acknowledged the wider benefits of participation in group-based programmes, beyond weight loss and/or maintenance (see P05 in the previous section). Both patients and healthcare staff described the positive impact that Tier 3 services could have on patients’ quality of life, including an enhanced ability to carry out functional day-to-day activities, improved self-efficacy and self-confidence, and greater involvement in social groups (S12FA, S15FA).

## 4 Discussion

This study identified six important themes related to access to and engagement with SWMS: (1) making the first move; (2) uncertainty and confusion; (3) resource issues; (4) respect and understanding; (5) mode of delivery; and (6) desire for ongoing support. Data from all sources informed each theme, although data from online forums fed predominantly into accessing SWMS, whereas interview data fed mainly into engaging with SWMS. The themes identified are dynamic, with multiple positive and negative feedback loops affecting patient experience. For example, how services are commissioned at individual sites impacts the resources available, thus influencing decisions about eligibility criteria, patient waiting times to access care, mode of delivery and session format (frequency/length), and ongoing patient support (both during and post-programme). Other research has found that factors such as stigma, low mood/depression, obesity not being considered as a serious disease, and disproportionate commissioning have hindered access, whilst improving healthcare staff communication with patients and broadening the number of staff that are able to refer to and deliver WMS may facilitate access and engagement [20].

Reflecting on the findings from this study in light of recent literature, a critical aspect to accessing care was the difficulty that patients had in starting discussions with their GPs about their weight. Many patients here delayed beginning the conversation at all, which is consistent with

recognised challenges in interactions between health professionals and patients with obesity [21, 22]. Evidence suggests that GPs can fear beginning these conversations with patients because of limited consultation time [23] or uncertainty about how best to raise the topic [24, 25]. Recent guidance highlights the need to acknowledge the difficulty on both sides of a weight loss conversation, and provides practical advice on appropriate language and its potential to alleviate stigma [21, 26, 27]. Broadly, our data support the previously evidenced view that more emphasis should be placed on improving awareness and engagement with weight management by primary care practitioners [28].

The patient experience of limited service availability, caused by service suspension and then adaptation in response to the COVID pandemic [29], came through strongly in the study findings. This was voiced as frustrations over waiting times and confusion around accessing services. Whilst online forum users expressed frustration over the postcode lottery of service provision and associated waiting times, interviewed patients were more accepting of the process, more sympathetic to the resource challenges experienced by the NHS, and cognisant of the potential value of Tier 3 programmes. This difference may be indicative of the sampling frame, with interviewees having pre-experience of care, whereas online forum users predominantly seek information whilst waiting to access services.

The move to remote and hybrid care delivery for people with severe obesity has widespread implications. In line with Dickins et al. [30] and Cliffe et al. [31], remote delivery increases access and engagement, offering protection and support in a safe space and reducing transport costs and other attendance difficulties. Stakeholders interviewed here held a range of opinions on these formats, broadly framed around the convenience and accessibility of online delivery versus the potential for in-person social connection development between patients. The importance ascribed to building social connections concurs with previous work where people enrolled on group-based programmes for severe obesity highlighted benefits for patients' engagement with, and progression through, programmes [32]. Our data also corroborate findings from earlier stages in the care pathway [22] and in other health services [33]. Other research on the delivery of remote healthcare services has cautioned that uptake may be lower amongst older adults, along with those with lower income and those with a lower educational level [33].

In addition to delivery formats, the wider literature also encourages greater flexibility to meet the needs of a diverse patient group, including preferences shaped by age, socioeconomic status, and geographic location, as well as personal preferences [33–35]. A recent critique of NHS England policy called for a more integrated system of weight management composed of two tiers, a tier for prevention and a tier for treatment, with the treatment tier (encompassing

current Tiers 2, 3, and 4) streamlining access to the necessary expertise and a range of treatment options to meet individuals' needs [36]. This approach may also mitigate the current uncertainty when a Tier 3 programme comes to an end, described as a “cliff-edge”, which constitutes a source of frustration amongst both patients and healthcare staff and an important gap in understanding. The issue of Tier 3 follow-up is also reflected in the wider literature, which cites the paucity of evidence on the effectiveness of Specialist Weight Management Programmes (SWMP) after 12 months [37] and how best to support patients to manage their weight once they have completed a programme. This lack of long-term data, and thus the necessary assumptions about weight regain, make economic modelling of SWMP very challenging [37]. However, recently published research reassures patients that the positive effects of SWMP, including improvements to quality of life, are not immediately reversed by rapid weight regain after programme end and are a cost-effective intervention for improving long-term weight management [38].

In tandem with increased flexibility, two ways in which SWMS could seek to expand capacity and increase reach are through remote (online) delivery and group rather than one-to-one delivery. Combining these approaches may further expand capacity. However, although remote delivery of obesity interventions has shown some promise [39, 40], research in the area is in its infancy. Regionally, services responded to COVID restrictions with rapid transfer online without time to consider how best to deliver such services. Preliminary evidence from Public Health England's report into how UK WMS adapted to COVID indicated that patient satisfaction with online delivery was high and there were reductions in attrition, but the effectiveness of this mode of delivery in supporting weight management and promoting healthy living is yet to be established [29]. Moreover, online provision may not be suitable for all [41]. Despite a wealth of research from other fields showing how establishing meaningful social connections supports wellbeing [42], there is very limited research on the effectiveness of group-based remote delivery [31, 43].

#### 4.1 Implications and Limitations

The findings demonstrate that patients turn to online forums when they are seeking additional information and advice, and there is some evidence that patients with chronic conditions can find solace in online communities [44]. Some services have already implemented supportive interventions; for example, closed Facebook groups have been set up to offer an informal level of support. It might be suggested that this type of platform could support patients both before and after Tier 3 programmes, initially advising on access and subsequently switching focus to help to sustain positive



behaviour change, recognising that part of having the skills to take forward patients' learning is being within a connected community [45, 46].

The current research also found that patient perceptions of waiting times did not necessarily reflect the referral protocols put in place by some SWMSs, which were designed to ensure patient suitability, thereby improving service provision and both clinical and patient-reported outcomes. Future services could consider clarifying the protocol for admission to Tier 3 programmes, including expectations of waiting times and why and how limited resources should be directed towards patients that are "ready for change". This study adopted a novel approach by contrasting the views and opinions of online forum users, providing a candid insight into the patients' experiences, with data obtained from the more conventional, in-depth interviews with patients and healthcare staff—thus providing a more contextualised understanding of service design and delivery, and its impact on patients trying to access services.

An obvious limitation of the study was the possibility of recall bias or completeness of recollection from interviewed patients, given the length of time since programme participation for some (five patients—2 years or more; four patients—5 years or more). Moreover, the study only represents active online users and staff and patients in a localised area of the South-West of England. For instance, although data saturation was reached within the recruited cohort, the variability of services and the complexity of treating and managing obesity manifests in considerable heterogeneity of experience. Additionally, the interviewed patients were predominantly female (8/9), middle-aged, and white British, and whilst this is a limitation, it is broadly representative of patients accessing SWMS [47] (therefore indicative of a limitation in the current research corpus rather than in this study).

## 5 Conclusion

This study explored how patients and staff perceive SWMS using online forums and interviews. The study findings illustrate a set of interconnected issues that are related to access to, and engagement with, services, with wide-ranging experiences reflective of disparate service provision. This heterogeneity is borne out of the challenges and complexity facing SWMS; on the one hand, there are rising numbers of referrals and limited resources, and on the other hand, there is a paucity of research about the optimum design and delivery of such interventions. Both these challenges can make commissioning decisions difficult. Of course, it is essential to find ways to overcome such challenges, and the current study offers insights into

the different perspectives and concerns that emerge across the pathway that can be informative in this regard.

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## Declarations

**Competing interests** The authors have no conflicts of interest that are directly relevant to the content of this article.

**Author contributions** This study was conceived and designed by Professor Jonathan Pinkney, Professor Mark Tarrant, Professor Rod Sheaff, Professor Sarah Dean, Dr Dawn Swancutt, and Dr Jenny Lloyd. Data collection and analysis were performed by Dr Ross Watkins, Dr Dawn Swancutt, Ms Mia Alexander, Dr Shokraneh Moghadam, and Dr Jenny Lloyd. The manuscript was drafted by Dr Ross Watkins, and all authors contributed to subsequent versions. All authors read and approved the final manuscript.

**Data availability** The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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**Ethics statement** The interview study was approved by the Camden and Kings Cross Ethics Committee on 1 June 2021 (21/PR/0679). Informed consent was sought verbally and documented electronically prior to each interview.

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