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# Patient experiences of Cytosponge: a qualitative study

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## ABSTRACT

**Objective** Cytosponge is a novel technology for oesophageal pathology diagnosis. Uses include diagnosis of Barrett's oesophagus and as a triage tool to prioritise upper gastrointestinal endoscopy. Patient experience is a key component of quality care. Previous work has developed endoscopy patient-reported experience measures. An appropriate tool to measure patient experience of Cytosponge is required. The aim of this work was to describe the patient experience of Cytosponge.

**Design/Method** Individuals aged 18 years or over, who had undergone Cytosponge from September 2020 to March 2021, were invited to participate in a semi-structured interview. Interviews were audio-recorded, transcribed verbatim and anonymised. Thematic analysis was undertaken. Themes were organised into two overarching areas relating to patient experiences and patient perceptions of the test.

**Results** 19 patients underwent interview (aged 37–80 years, 13 male). In terms of patient experiences of Cytosponge, five themes were identified: emotional reaction; expectations; environment and physical process; sensory experience; communication and information. All themes were present across all procedural phases, aside from sensory experience which was only present during the test. With regard to perception of the test, two major themes were identified: test novelty (encompassing patient awareness of the test and reaction to the new test) and trusting the test results.

**Conclusion** Patients must remain central to novel technologies such as Cytosponge. Measuring patient experience is essential to achieve that. This study demonstrates five major themes which describe the patient experience of this procedure. These have been used to adapt the Newcastle ENDOPREM for use in Cytosponge.

## INTRODUCTION

Cytosponge is a novel technology for the diagnosis of oesophageal pathology.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Cytosponge is a novel technology to aid diagnosis of oesophageal pathology.
- ⇒ Patient experience is a crucial component of quality care and must remain central to novel technologies.

## WHAT THIS STUDY ADDS

- ⇒ We demonstrate five key themes which describe patient experiences of Cytosponge.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The results of this study have been used to adapt the Newcastle ENDOPREM for Cytosponge, meaning patient experience can be measured.

Patients swallow a gelatine capsule attached to a string. As the capsule dissolves in the stomach, a sponge expands. The sponge collects cells from the oesophagus as it is removed, with immunohistochemistry later performed.

Cytosponge can be used for Barrett's oesophagus (BE) diagnosis with specificity of >92% and sensitivity of 80%.<sup>1</sup> A cluster-randomised controlled trial demonstrated that offering Cytosponge to individuals with chronic reflux increased Barrett's diagnoses by >10 times compared with usual care.<sup>2</sup> Cytosponge may also be used for triage to define urgency of upper gastrointestinal (UGI) endoscopy with high sensitivity and specificity for high-grade dysplasia and early cancer.<sup>3,4</sup> A major advantage of the Cytosponge is that it takes a short time to administer. Additionally, it may be more acceptable to some patients than UGI endoscopy.<sup>5</sup> The benefits of Cytosponge, along with the need to reduce the burden on endoscopy services (exacerbated by the COVID-19 pandemic), have expedited

the pilot implementation of Cytosponge into UK national care pathways.

Patient experience is a key component of high-quality care, encompassing what occurs during a healthcare episode and to what degree patient needs have been met.<sup>6</sup> This contrasts with patient satisfaction, which measures how content a patient is with overall care. Patient experience should be measured using patient-reported experience measures (PREM), which have been developed with patient input, capturing aspects of care prioritised by patients. Historically, there were no validated PREMs to measure patient experience of GI endoscopy. The Newcastle ENDOPREM was derived from in-depth patient interviews about their endoscopy experience with a bank of questions developed and iteratively refined with patients.<sup>7</sup> The instrument has been validated for UGI endoscopy, colonoscopy and CT colonography (CTC).<sup>8</sup> It can be used to measure detailed patient experience allowing care to be improved or additionally as a research tool for endoscopy studies.

A previous qualitative study among adults suffering from gastro-oesophageal reflux disease, but who had not undergone the Cytosponge procedure, found that the Cytosponge concept was acceptable to the majority of patients, although some expressed concerns regarding the physical experience.<sup>9</sup> One study assessed patient experience of Cytosponge using mixed-methods, namely questionnaire and qualitative interviews within the setting of a larger study.<sup>10</sup> It was found that the procedure was acceptable to patients, comparing favourably to endoscopy, however interviews highlighted that not all aspects of the procedure were equally acceptable.

As Cytosponge use broadens, an appropriate tool to measure patient experience of the procedure is required. This study described patient experience of Cytosponge, enabling us to adapt the ENDOPREM.<sup>11</sup>

## METHODS

Participants were recruited from the DELTA Innovate UK study evaluating Cytosponge in patients with dyspepsia or undergoing BE surveillance.

Individuals aged  $\geq 18$  years who had undergone Cytosponge testing were invited to participate in a semi-structured interview, conducted by an experienced qualitative researcher. Interviews were conducted by telephone or video-call, according to participant preference. A sealed copy of the Newcastle ENDOPREM was sent to participants ahead of interview with a request that the envelope was not opened in advance. Each interview comprised two phases: phase I followed a topic guide developed from literature review and expert opinion. This was used flexibly to allow participants to talk about their experience of Cytosponge, while ensuring all steps of the procedure were covered. Areas of interest arising in one interview were iteratively added to the topic guide for

subsequent interviews. Phase II involved participants completing the Newcastle ENDOPREM with encouragement to ‘talk aloud’ as they did so (questerview). Participants were asked views on questions and their relevance to undergoing a Cytosponge procedure and any areas not covered by the PREM or those felt to be redundant. Interviews continued until saturation was achieved. Pragmatic saturation as defined by Low was applied, where the researcher decides that there is enough data based on the analysis.<sup>12</sup>

Interviews were audio-recorded, transcribed verbatim and anonymised. Thematic analysis of both interview phases was undertaken. The transcripts were reviewed and reread for familiarisation, then coded and codes combined into themes producing a detailed account of the data. The data were initially analysed at a ‘semantic’ level, meaning that codes were applied as a description of what was said by the participant.<sup>13</sup> These codes were then organised into broad themes. The themes were organised into two overarching areas relating to patient experiences of the test and patient perceptions of the test. The themes within patient experiences were explored to determine if they were present across different phases of the procedural process—before the test, during the test and after the test. NVivo (V.12, QSR International, Australia) was used to organise the codes. Three interviews were double coded (by JD) to strengthen the analysis integrity. Discussion between the researcher undertaking the analysis (HG) and other authors (LJN, LS, JD) enhanced analysis validity and reliability. Illustrative quotes are provided to supplement narrative descriptions.

## RESULTS

Patients were recruited from Cambridge University Hospitals, from September 2020 to March 2021, 75 were sent an invitation to participate with semi-structured interviews undertaken in 19. The main reason for non-participation was inability to recontact patients. Age ranged from 37 to 80 years (mean 63) and 13 participants (68%) were male. One patient was of Indian ethnicity, two were non-British white and the remainder were white British. Interviews lasted between 27 and 71 min (mean 47).

### Patient experiences of Cytosponge

Five themes were identified: emotional reactions; expectations; environment and physical process; sensory experience; communication and information. All themes were present across all phases of the procedural process (before test; during test; after test), aside from sensory experience which was only present during the test and environment and physical process which were not present after the test. [Table 1](#) summarises areas encompassed in the themes with illustrative quotes.

**Table 1** Overview of themes with illustrative quotes

| Theme                            | Area   | Illustrative quote (ID number, sex)   |
|----------------------------------|--|---|
| Emotional reaction               | Anticipation of the test                     | "My main concern was that I could actually get it swallowed". C6, M   |
|                                  | Effects of personality and coping strategies | "The less information you have, the less there is to worry about, I guess?" C5, M<br>"That's usually the way I approach these things. I try not to think about it". C13, F  |
|                                  | Location                                     | "it was more about the setup if something went wrong, it felt safer at the hospital than you would in the GP". C11, M   |
|                                  | Effect of previous experience                | Interviewer: "Was the second experience easier for you after having had it the first time?"<br>Participant: "Yes. I was a lot less worried. As I say, not worried, but I knew what I was expecting". C15, M   |
|                                  | Embarrassment                                | "I didn't feel like there was any kind of humiliation or embarrassment". C6, M  |
|                                  | Anxiety about the results                    | "I was feeling anxious that I might have—because at the top of the letter it said something like, I don't know, the cancer clinic, and that made me very anxious". C13, F   |
| Expectations                     | Referral process                             | "I got in really, within the week. I was quite surprised how quick they were". C9, M  |
|                                  | Anticipation of the test                     | "The experience with Cytosponge, it was better than what I expected because I think initially when you see something is going to be pulled out from your gut, it does feel a bit grim, but the experience wasn't that bad. It was better than expected, as I said". C10, M  |
|                                  | Information before the test                  | "The procedure went exactly as it had been written it would be. So, no, I can't really think of anything else that needed to be done, to be perfectly frank with you". C8, M  |
|                                  | Anticipated physical experience              | "I'd expected to feel a bit of pain when they were bringing the sponge back up". C2, M  |
|                                  | Results and follow-up                        | "They came through fairly quickly afterwards, you know, the details. I presume that they cannot tell you the exact details of it compared to an endoscopy, because they can find out a lot more from that, you know, from the condition I have got. I suppose it is a bit limited what you can tell from the sponge". C11, M  |
| Environment and physical process | Location                                     | "I had been caught up in the traffic. So I was getting panicky and I come downstairs and someone said, 'No', and I spoke to some guy and he said, 'No, it's back upstairs again', and I said, 'No, it's not', and they eventually told me where the place was, which was around the front". C9, M   |
|                                  | Preparation                                  | "It's a very basic room. There are lots of dispensers, and a lady who sits there and takes your details. Then you just sit and wait. Did I need any more comfort? No". C16, M   |
|                                  | Referral process                             | "They told me that if you want to amend your date, please give us a call at that number. So, but I carried on because the time, actually, that suited me was morning". C2, M  |
|                                  | Medication                                   | "I do remember... I don't know if I read about it in the information I was given, or whether they actually offered it, but I certainly didn't have it". C6, M   |
|                                  | Effect of staff                              | "I felt that the person who did the test had done the test many times before, so was experienced". C4, M  |
| Sensory experience               | Physical sensation of the test               | "I wouldn't say it was discomfort. It was something like a weird sensation, but yeah, around the cord side, with the gag reflex, you have to just gulp it down, but yeah, I felt a bit of discomfort that could last, I would say, 1 second or half a second, I would say". C10, M<br>"It is not painful, it is just uncomfortable. You would not say being sick is painful, but it is more akin to that". C11, M<br>"From my memories, I can't remember anything that I felt uncomfortable". C3, F   |
|                                  | Recovery                                     | "There was a sensation in the throat which probably did last longer, actually, maybe hours, but it wasn't painful. It was just a sensation that something had happened, but yes, it wasn't soreness. The hoarseness dissipated and stopped after about 15 minutes, but there was certainly a sensation in the throat for, maybe, hours". C6, M  |
| Communication and information    | Information about the test                   | "I had a leaflet come through, which explained everything very carefully". C18, M<br>"Yes, got to the hospital. They didn't really explain what they were going to do because I already knew because of the video I watched". C13, F  |
|                                  | Staff involved in the test                   | "That would be nice to know exactly what they are looking for, you know, and what they can get from it". C11, M   |
|                                  | Results and follow-up                        | "it was a relatively short letter to say everything came back clear, and there will be no need for taking further steps and stuff. And that was about the long and short of it. As long as it was good, I'm not sure I was looking for any other info, really, to be fair. Because I'm not sure what else I'd be looking for, really". C18, M<br>"One thing to point out is that receiving the result was actually in the form of a telephone call, saying that the test had shown some inflammation and that an endoscopy was recommended. So, I mean, that was the limit of the results. I do not know if that is, in any way, limited or not". C7, M |

F, female; M, male.

**Emotional reaction**

This describes patients' emotional reactions to the test. Before the test, patients described anticipation and concerns or lack thereof. Some patients were concerned about 'gagging' during the test or worrying about the size of the 'pill' they had to swallow. Patients described coping strategies while anticipating the test and spoke about the important role of information. Some patients admitted that they would 'try not to think about it' and said that "the less information you have, the less there is to worry about", whereas others preferred more pretest information.

There was diversity in terms of whether patients had previously undergone the Cytosponge test. Previous experience impacted how patients dealt with the prospect of the procedure. Often previous experience of Cytosponge made patients less anxious; these patients said they were 'a lot less worried' as "I knew what I was expecting". Patients compared the Cytosponge favourably with endoscopy which was seen as more burdensome.

During the procedure, most patients denied negative emotions; one said they 'didn't feel like there was any kind of humiliation or embarrassment about it'.

Two patients acknowledged removing the Cytosponge caused gagging and retching and were embarrassed by this. Another recalled the procedure felt informal and commented that the *'relaxed nature'* helped them feel calm.

After the test, patients described anxiety regarding results and consequences (eg, treatment they might need). Patients did not receive results at the time of the test and described this waiting period as *'stressful'*.

### Expectations

Patients gave various examples of how expectations affected experience. Regarding the process of being referred, having Cytosponge and receiving results, some patients were *'surprised how quick'* it was, where others mentioned that it *'wasn't a quick process'*. Those who felt the process took longer than they expected felt that this delayed their symptom management.

Regarding expectations of the test itself, patients had differing expectations of what it would involve and whether they would experience pain or discomfort. Patients often did not know what size the Cytosponge would be, with a few mentioning it was *"larger than I imagined"*; another described it *'like a sausage in a blanket'*. Other patients *'thought it was going to be a massive, big pill'* and were pleasantly surprised when it was not. Some patients expected to feel discomfort after the test, however, the majority did not.

Time to results varied, with some patients not knowing how or when they would receive results. This caused anxiety with one patient calling the hospital for results. Others felt results *'came through fairly quickly afterwards'*.

### Environment and physical process

Before attending, some patients described difficulty in locating the hospital department. One patient who had Cytosponge in both primary care and hospital noted that test location affected their experience, explaining they *"felt safer at the hospital than you would in the GP"* because *"if the cord broke or something got stuck... you could get more immediate attention"*. Another patient noted that endoscopy felt invasive, whereas *"I was just sitting in a chair for the sponge... it's more of a medical setting for the endoscopy. Whereas the Cytosponge was less medical"*.

This study's referral pathway was unique as it took place as part of a larger study evaluating Cytosponge. Despite this, patients described the ability to change appointment if required and reported being satisfied with the time between referral and appointment. Some patients described being initially referred for endoscopy and offered the Cytosponge instead, sometimes due to long endoscopy waits. Once in the department, patients described a waiting area with staff who *"started preparing me for it, telling me what was going to happen"*.

During the test, some patients described an *'anaesthetic spray'* while others reported not being offered this. Patients described those doing the test positively using terms like *'experienced'* and *'friendly'*.

### Sensory experience

Sensory experience of Cytosponge related to the feeling both during insertion and removal and how patients felt during recovery. Some described Cytosponge as *'uncomfortable'*, but none described pain. Most patients had no difficulty swallowing Cytosponge; however, one patient explained that they *"had a small problem initially in swallowing it, but I sorted that out myself, rather than listening to the nurse. And after that, absolutely no problems whatsoever"*.

After the capsule was swallowed, many patients were unaware of it, however, several commented on the discomfort of the string remaining in the mouth. One was unsure initially if the sponge had *'gone down'* and described feeling *"there's something in your mouth and you think it's still there, but you have actually swallowed it"*.

Patients described various sensations as Cytosponge was removed. The majority described this as *'uncomfortable'* and described *'gagging'* or *'retching'* as it was removed. A few described the feeling of the Cytosponge removal as *'rough'*, likening it to a *'metal pan scourer...it was rough coming out, and that made me gag'*.

After the test, some patients described a sore throat lasting up to a few days *'but it wasn't painful. It was just a sensation that something had happened'*.

### Communication and information

Patients described the importance of communication and information at all stages of the Cytosponge test. Some described watching a video pretest, while others were given written information *'going through the procedure, what to do, where to go and how to get there'*. One patient noted that *"on the video, I thought I was going to suffer a lot of pain while taking the sponge out. It was so quick; I didn't feel any pain"*.

Some patients described being given information about medication to numb the throat. Some were given verbal information about what the test was looking for whereas others felt they would have liked more information to tell them *'what the sponge was actually looking for'*. Patients described being talked through the test and one noted that having someone speak to them as they waited for the Cytosponge to be removed distracted them and made the experience easier. Another felt that while waiting for the Cytosponge to be removed they *'had to sit there like a prune'*.

Patients were not given results at the time of the test and described different modes of receiving results. Some received a letter explaining results and next steps while others were contacted by telephone to discuss findings and further investigations or medication.

**Table 2** Patient perceptions of Cytosponge

| Overarching theme     | Area                      | Illustrative quotes (ID number, sex)  |
|-----------------------|---------------------------|---|
| Novel test            | Awareness                 | "At that time, there was more in the newspapers and the national press about Cytosponges than there'd ever been before, so a relatively new procedure". C16, M<br>"I had no knowledge of anybody else who had had the test". C8, M  |
|                       | Reaction to novel test    | "The result of that test has led on to a new test, which is not an endoscopy, again, which is great. I hope that this new test will, perhaps, provide the answers I need, at least to the severity of what my symptoms are about and what level of medication is actually right for me". C6, M<br>"Psychologically, I suppose, yes. I think, because it was that department that they were doing tests like that quite a lot, therefore it was a newish thing in a doctor's surgery and they, perhaps, had less experience". C5, M  |
| Trusting test results | Trust in technique        | Interviewer: "Did you trust the findings from the Cytosponge?"<br>Participant: "Absolutely, I did because I can see that a sponge coming up through your oesophagus is going to sample cells from all round. From the stomach, right the way up through your oesophagus all the way round". C19, F  |
|                       | Comparison with endoscopy | "I think the endoscopy gives, of course, better details, but I know the cost-benefit analysis as well, but I would say that, yeah, I would want to have both, more regularly a sponge test than endoscopy, because endoscopy has got the and painful side effects afterwards. Say, after a year or two, or a year and a half, then I would go for the endoscopy as well, as a backup plan". C2, M<br>"Whereas, the consultant who did the endoscopy, he told me he was a trainee, I thought, 'When you have the camera down, is he really looking carefully all round?' It felt to me it was less likely to be missed, any cancer cells, than if somebody had been looking, just looking. Yes, I felt better about it". C19, F<br>"It's not fool-proof, but it's certainly a strong indicator and is massively preferable to the endoscopy, which is obviously quite invasive, and unpleasant, and painful and all of that. So, I was glad that I didn't have to go through that procedure and that this procedure was reasonably effective at giving an indicator of what's going on". C6, M |

F, female; M, male.

### Perception of the test

There were two themes relating to patient perceptions of Cytosponge: test novelty and trusting test results (table 2).

#### Test novelty

##### Patient awareness

Patients recognised Cytosponge as a new procedure, and many had heard about it through the media. One 'had no knowledge of anybody else who had had the test'. Some noted the procedure is 'still being researched' but were satisfied information made this clear. Patients said they were told by the study team that this was a new test.

##### Reaction to the new test

Some patients described relief that this test was available, meaning they did not need an endoscopy. Others described being nervous about a new test and some expressed that they would have liked to have spoken to someone who had previously had the test.

##### Trusting the test results

Patients were mostly positive when describing their trust in the test and results. One said "I can see that a sponge coming up through your oesophagus is going to sample cells from all round".

Many compared Cytosponge with endoscopy. Some felt endoscopy would give greater detail but appreciated that Cytosponge had less 'side effects' and that they might prefer to have this if repeat tests were required over time. One mentioned they felt the Cytosponge might be more reliable as they felt cancerous cells were less likely to be missed with Cytosponge,

compared with the potential for human error with endoscopy. In contrast, another patient spoke about the Cytosponge results being limited compared with endoscopy.

## DISCUSSION

In this study of adults who had undergone the Cytosponge procedure, five key themes relating to patient experience were identified: emotional reaction; expectations; environment and physical process; sensory experience; communication and information. Participants had few concerns regarding a novel test; they described trust in the procedure and compared it, mostly favourably, with endoscopy.

Cytosponge has a strong evidence-base and is now used extensively in the UK, with growing use internationally. Patient experience of Cytosponge should be measured comprehensively encompassing all aspects of the procedure. By exploring patient experience in detail and mapping experience into themes, we are able to consider how patient experience maybe improved.

As far as we are aware, this is the first in-depth qualitative study assessing all aspects of patient experience of Cytosponge. Two previous studies focused on test acceptability in Cytosponge-naïve patients and a further study explored social media comments to assess public perception in Cytosponge-naïve patients.<sup>9 14</sup> Both studies were hypothetical as participants had not undergone the procedure. The latter study found a theme around 'anticipation of the physical experience'. This was reflected in our work, with patients describing expectations of the test and different pretest coping mechanisms. A further study undertook

semi-structured interviews with patients who had undergone Cytosponge, focusing on practical aspects of the test.<sup>10</sup> The findings were similar to the current study; information about the test was important, as was comfort and sensation of the test. The current study provides detail on patient views of the physical sensation, with most describing mild discomfort. Cytosponge-naïve patients and patients who had the test previously were included in our work, meaning experiences from both perspectives were described.

Previous studies described hypothetical anticipated difficulties with swallowing the Cytosponge string, concerns about it snapping and some patients described physical difficulty swallowing the string. While some patients in the current study anticipated difficulty with this prior to the procedure, none experienced difficulty. This is an important message to convey in patient information, to reduce preprocedural anxiety.

Previous studies described acceptability of the Cytosponge procedure. Our study demonstrated that the majority trusted the test, both as a novel technology, and in terms of the results they received. Some patients felt endoscopy would be more thorough and one patient noted likely cost-effectiveness of Cytosponge. Overall, our findings are reassuring given the rapid adoption of Cytosponge into clinical practice.

Many of the themes identified here were similar to those identified in our previous study exploring patient experience of endoscopy and CTC.<sup>7</sup> Patients described anxiety about what procedures would involve, in addition to stressing the importance of information and communication at all stages. Similar to the experiences of Cytosponge patients, those who underwent oesophago-gastro-duodenoscopy (OGD) did not describe pain, but described gagging and retching. Patients described discomfort due to air insufflation during endoscopy which does not occur during Cytosponge. A major difference between OGD and Cytosponge was that patients undergoing the latter did not describe embarrassment during the procedure. The current study aligns with our previous conclusions that when assessing patient experience of endoscopic procedures, many areas are common to different endoscopic modalities. However, there are some (although fewer) procedural-specific issues, and these are also important to consider to provide a full picture of experience.

The findings of the current study were used to adapt the Newcastle ENDOPREM for the Cytosponge population, which has been published elsewhere.<sup>11</sup> Redundant questions were removed and some questions specific to Cytosponge have been added, however the 'core' of the questionnaire is common across procedures.

A limitation of this work was that all participants were recruited from an ongoing study undertaken by an experienced team. It is, therefore, possible that patient experiences in this context may differ from

routine clinical practice. Further research should explore this, and also whether experiences differ when the test is delivered in primary care. One aim of such work might be to identify areas which could be improved, such as communication and information. Furthermore, although there was heterogeneity of participants in terms of age and sex, there was little ethnic diversity; a consistent finding in patient experience work is that those from non-white ethnic groups tend to report worse experiences.<sup>15 16</sup> Future qualitative research exploring experiences in more diverse populations and, in particular, ethnic minority and socio-economically deprived patients, would be a valuable addition to the evidence-base; the current study can provide a useful 'comparator'. Further work should also focus on capturing experience across a more diverse group of referral indications.

## CONCLUSION

Novel technologies such as Cytosponge have the potential to revolutionise reflux and Barrett's pathways. It is crucial that patients remain central to innovation and development and measuring experience is essential to achieve that. Procedures can then be adapted to optimise patient experience. This study demonstrates five major themes which describe the patient experience of Cytosponge. These have been used to adapt the Newcastle ENDOPREM for use in Cytosponge, both in a research and clinical setting.

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**Contributors** CR, RCF, LS and LJN conceived and designed the study. ID-B and JD undertook participant recruitment. JD undertook qualitative interviews. HG undertook qualitative analysis with supervision and input from LS, LJN and JD. JD, LS, LJN and CR adapted PREM according to analysis. All authors contributed to this manuscript. LJN is the guarantor for this work.

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**Patient consent for publication** Not applicable.

**Ethics approval** This study was approved by Cambridge East Research Ethics Committee (REC reference: 20/EE/0141, IRAS number 283505). Informed consent was obtained prior to interview.

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**Data availability statement** No data are available.

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