Specialty COPD care during COVID-19: patient and clinician perspectives on remote delivery

Frances Wu,1 Jenni Burt,1 Teena Chowdhury,2 Raymond Fitzpatrick,3 Graham Martin,1 Jan W van der Scheer,1 John R Hurst4

ABSTRACT

Introduction The COVID-19 pandemic has impacted specialty chronic obstructive pulmonary disease (COPD) care. We examined the degree to which care has moved to remote approaches, eliciting clinician and patient perspectives on what is appropriate for ongoing remote delivery.

Methods Using an online research platform, we conducted a survey and consensus-building process involving clinicians and patients with COPD.

Results Fifty-five clinicians and 19 patients responded. The majority of clinicians felt able to assess symptom severity (n=52, 95%), reinforce smoking cessation (n=46, 84%) and signpost to other healthcare resources (n=44, 80%). Patients reported that assessing COPD severity and starting new medications were being addressed through remote care. Forty-three and 31 respondents participated in the first and second consensus-building rounds, respectively. When asked to rate the appropriateness of using remote delivery for specific care activities, respondents reached consensus on 5 of 14 items: collecting information about COPD and overall health status (77%), providing COPD education and developing a self-management plan (74%), reinforcing smoking cessation (81%), deciding whether patients should seek in-person care (72%) and initiating a rescue pack (76%).

Conclusion Adoption of remote care delivery appears high, with many care activities partially or completely delivered remotely. Our work identifies strengths and limitations of remote care delivery.

INTRODUCTION

The COVID-19 pandemic has greatly impacted patient care across many settings.1 For people living with chronic obstructive pulmonary disease (COPD) in the UK, the pandemic led to limitations in planned and unplanned access to specialist care, in both hospital and community settings. Such limitations are of particular concern for those with severe COPD who are considered to be ‘clinically extremely vulnerable’.2 The degree to which specialty care for COPD has been able to continue given the risks associated with face-to-face contact, as well as pressures on NHS staffing and organisations, is not known; anecdotal evidence suggests that rapid adoption of remote care delivery has enabled some continuity.

Telehealth is ‘the means by which technologies and related services concerned with health and well-being are accessed by people or provided for them irrespective of location’.3 Telemedicine (a subset of telehealth) typically refers to services delivered by healthcare professionals.3-5 There is mixed evidence on the provision and impact of telehealth in specialist COPD care, in part due to the diversity of services and outcomes evaluated.6,7 Aspects of telehealth may significantly reduce emergency department attendances and hospitalisations,7,8 but there is little evidence for its effect on mortality.7,8 Outpatient visits10 or length of stay.8 The impact of telehealth on quality of life in people with COPD is uncertain.9

While the UK has been historically slow to adopt digital technologies and telehealth,10 including in COPD,11 the current pandemic trajectory suggests that telehealth will have an important role for the foreseeable future. Recent rapid guidelines set out by National Institute for Health and Care Excellence (NICE) for COPD care include specific modifications to usual care to reduce patient...
exposure to COVID-19, including switching to telemedicine for routine annual review.\textsuperscript{12} The guidance leaves much room for organisations to determine appropriate local policy accounting for their patient population and resources. There is little clarity on what good remote COPD care should look like, both to substitute and to supplement in-person care, and questions remain on what can and cannot be effectively and safely delivered remotely to maximise high-quality care at a distance. Both short-term and long-term changes are needed to support and sustain such new care models.\textsuperscript{13,14}

In this study, we sought to better understand the extent to which care has moved to using telehealth approaches for COPD under specialist community and secondary care services in the UK. Our objectives were to conduct a survey to understand what is currently happening with remote provision of specialty COPD care (eg, telephone, video calls and e-mail), to develop consensus among clinicians and patients on what aspects of COPD care are appropriate for remote approaches, and to understand their perspectives on actions needed to improve ongoing remote specialty care delivery. We focus on the remote delivery of acute and planned care that would ordinarily have been delivered face-to-face, rather than remote monitoring of symptoms and physiological variables which in this context can best be considered an ‘add-on’ to usual care and which has generally not been shown to be cost-effective.\textsuperscript{15,16}

\section*{METHODS}

Our work involved two sequential components: a survey of current practices and a consensus-building process.

\subsection*{Survey of current practices}

We developed two questionnaires—one for clinicians providing specialty COPD care in community and secondary care services, and one for patients with COPD. The surveys were hosted using Thiscovery (www.thiscovery.org), a secure online platform developed by THIS Institute, which allows members of the public, including patients, carers, healthcare professionals and others, to engage in research. Both versions of the questionnaire included similar closed-ended questions about respondents’ experience of remote specialty care, including the mode and content of consultations. We also asked open-ended questions covering what worked well and improvements that might be made with regard to remote care delivery. The clinician questionnaire included additional questions to understand the scope of and support for remote care delivery. Questionnaire development drew on accepted approaches to design, item construction and survey procedures.\textsuperscript{16,17} In an iterative process, we undertook successive drafting of questions within the research team, informed by pretesting with small advisory groups of three patients and three clinicians, before finalising the survey instrument. We did not undertake formal piloting, but in keeping with questionnaire design principles,\textsuperscript{16,17} we used the development process to maximise clarity of questions and to ensure that ambiguities were removed.

Questions regarding the scope of current care were based on requirements set out in NICE standards for the provision of specialty support for people with COPD\textsuperscript{12} including both routine and urgent care. These were categorised by a clinically qualified member of the research team, and developed further in consultation with the advisory groups. Based on these discussions, the phrasing of each question was tailored for clinician and patient versions of the survey (eg, clinicians were asked whether they used remote care to ‘reinforce appropriate oxygen therapy in the community for patients with COPD’, while patients were asked whether remote care was used in ‘supporting your oxygen treatment’), and only clinicians were asked whether they used remote care for urgent care tasks. Both groups were asked about their use of remote care since the onset of the COVID-19 pandemic. Clinicians were also asked questions regarding the extent of their use of remote care, the modalities used and the existence of standard protocols on their units. In each case, categorical responses were provided based on consultation within the team and with advisory groups, with an ‘other’ category and associated free-text box to ensure that unanticipated responses were accounted for. Both groups were asked to state what had worked well and less well in their experience of remote care, again with slightly different question forms based on consultation with the advisory groups, using free-text response boxes. Questions were also asked regarding participants’ demographic characteristics (sex, age and ethnicity), using Office for National Statistics categories for ethnicity. See online supplemental appendices 1 and 2 for the questionnaires.

We sought responses from clinicians who provided specialty care for patients with COPD, including those who were part of respiratory care teams or other relevant specialties such as palliative care. For patients, eligibility criteria included that they (1) were 18 years or older, (2) had been diagnosed with COPD and (3) had accessed specialty COPD care in the last 3 months. In both cases, participation was limited to UK-based respondents. Because of restrictions on accessing NHS or professional organisations for research collaboration during the COVID-19 pandemic, recruitment primarily took place through social media. For clinicians, the British Thoracic Society (BTS), the Royal College of Physicians (RCP), the National Asthma and COPD Audit Programme (NACAP), the Association of Respiratory Nurse Specialists and the Association of Chartered Physiotherapists in Respiratory Care advertised the survey from their Twitter accounts. In addition, BTS, RCP and NACAP advertised through their electronic newsletters. For patients, the British Lung Foundation posted on Facebook and HealthUnlocked, an online forum for people living with various health conditions, including COPD.

Univariate summary statistics were calculated for closed-ended questions. For open-ended responses, one
researcher developed a coding framework based on the data and thematically coded all responses; a second independently coded 10% (n=13) of the responses according to this framework. There was a high degree of agreement between the two researchers. Analysis was conducted in R (closed-end questions) and Microsoft Excel, 2016 (open-ended questions).

Consensus-building process
In the second stage of the project, we undertook a consensus-building process to gain understanding of what care activities patients and clinicians consider appropriate for remote delivery. As with the survey, the process was hosted online using Thiscovery. We produced a briefing document summarising current evidence from 24 studies on the effectiveness of remote care in COPD, to which participants in the consensus-building process were given access as they participated. The briefing document was informed by a rapid literature review which followed recommended methods for searching, screening, data extraction and synthesis. In the first round, participants were asked to rate the appropriateness of delivering various COPD-related care activities remotely, again based on NICE standards, using a 9-point scale, from 1 (not at all appropriate) to 9 (highly appropriate). Care activities related to both planned and unplanned specialty care (table 1). In the second round, for care activities where consensus was not reached in the first round, we asked participants to review and rerate each item. In this round, we provided additional information: (1) group-level information (clinicians and patients) on how other respondents rated that item in the first round; and (2) for a subset of care activities, a summary of the evidence (based on the briefing document) with regard to the effectiveness of remote provision. This two-round consensus-building process was broadly based on Delphi consensus-development methodology, adapted for online administration and for involvement from potentially larger and more diverse groups of stakeholders.

We defined consensus as at least 70% agreement—that is, at least 70% of respondents rating an item 1, 2 or 3 (consensus on the item being not appropriate) or 7, 8 or 9 (consensus on the item being appropriate). Finally, during the second round, we asked participants for their views on what should be prioritised to improve remote communication for specialty COPD care, using a 5-point scale from ‘not at all urgent’ to ‘very urgent’.

For the two consensus development rounds, summary statistics were calculated for each item rated. In addition, we calculated the frequencies of the ratings and grouped frequencies for ratings 1–3, 4–6 and 7–9. Analysis was conducted in R.

Patient and public involvement
Patients or the public were not involved in the design, conduct, reporting or dissemination plans of our research.

RESULTS
Participants
Fifty-five clinicians responded to the survey. Fifty-one patients initiated the questionnaire, but several had not accessed specialty COPD care in the last 3 months; 19 patients met the eligibility criteria and completed

<table>
<thead>
<tr>
<th>Type of care</th>
<th>Care activity description</th>
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<tbody>
<tr>
<td>Routine</td>
<td>Collecting information about a patient’s COPD and overall health status by asking questions (eg, assessing symptoms, understanding recent hospital admissions and assessing needs for various services)</td>
</tr>
<tr>
<td></td>
<td>Performing a lung function test (breathing into a spirometer)</td>
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<tr>
<td></td>
<td>Measuring oxygen levels using a finger probe (pulse oximetry)</td>
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<tr>
<td></td>
<td>Assessing how far a patient can walk by doing a walking test (performing an exercise test)</td>
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<tr>
<td></td>
<td>Checking inhalers are used properly</td>
</tr>
<tr>
<td></td>
<td>Providing education about COPD or COPD treatment and developing a self-management plan</td>
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<tr>
<td></td>
<td>Supporting a patient to stop smoking (smoking cessation support)</td>
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<tr>
<td></td>
<td>Starting a patient on a new medication</td>
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<tr>
<td></td>
<td>Providing an exercise and education programme (pulmonary rehabilitation)</td>
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<tr>
<td></td>
<td>Having a healthcare professional teach how best to clear sputum/phlegm (airway clearance support)</td>
</tr>
<tr>
<td></td>
<td>Having a healthcare professional teach new breathing techniques (breathing training)</td>
</tr>
<tr>
<td></td>
<td>Helping a patient make plans around death and dying (advance care planning)</td>
</tr>
<tr>
<td>Urgent/unplanned</td>
<td>Making a decision on whether a patient needs to see a healthcare professional face-to-face</td>
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<tr>
<td></td>
<td>Helping a patient make a decision on whether to use extra treatment, often called a ‘rescue pack’</td>
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COPD, chronic obstructive pulmonary disease.
the consent and questionnaire. Table 2 provides demographic details.

Clinician respondents provided care in community (n=26, 47%), secondary care (n=20, 36%) or integrated settings (n=9, 16%). Respondents were mostly nurses (n=22, 40%), doctors (n=15, 27%) or physiotherapists (n=15, 27%).

Survey results

Most patients reported remote consultation by phone only (n=15, 79%), compared with other forms of communication, including by video only (n=2, 11%), by phone and video (n=1, 5%), or by text or online messaging (n=1, 5%). Remote consultations were typically concerned with COPD severity (eg, assessing symptoms, exacerbations, lung function and oximetry; n=11, 58%); patients also reported discussions concerning starting medication for COPD (n=6, 32%) (table 3). A majority of patients found remote communication to be helpful or quite helpful (n=11, 58%, and n=4, 21%, respectively).

Remote alternatives to routine face-to-face contacts were most commonly by phone (n=40, 73%), with 13 (24%) clinicians reporting most communication by video or by both phone and video.

Using remote communication, most clinicians reported that they were able to assess symptom severity (n=52, 95%), reinforce smoking cessation (n=46, 84%), signpost to other healthcare resources such as self-management support (n=44, 80%), and reinforce appropriate oxygen therapy (n=40, 80%) (table 3). Most clinicians also used remote communication for aspects of unplanned care, including determining a patient’s need for hospital assessment during an exacerbation (n=34, 62%) or initiating the use of rescue packs (n=39, 71%). Finally, a few clinicians reported using remote communication to liaise with other clinicians, such as the patient’s primary care or inpatient medical team.

Almost half of clinician respondents reported that they used a standard tool to assess and record disease severity during remote communication (n=23, 45%), and only 10 (18%) reported regularly using remote physiological monitoring of patients at home (table 4). Less than half of clinician respondents (n=24, 44%) reported that standard procedures were in place to support remote communication in their organisations, and eight (15%) were unsure whether any were in place. Finally, the majority of clinicians either reported that no protocol was in place for hard-to-reach patients, including patients unable to use technology (n=30, 55%) or were unsure whether such a protocol existed (n=11, 20%).

Answers to open-ended questions indicated that clinicians saw many benefits to remote approaches, including a way of communicating that avoided the perceived risks...
of coming to the clinic during the pandemic and the possibility of prompt, flexible and ongoing contact with patients. A few noted how quickly adoption had occurred and expressed surprise that a reasonable amount of patient needs could be addressed over phone and video. However, they expressed a high level of concern about patients with limited information technology access and the possibility of missing the more nuanced communication that goes with face-to-face contact, particularly in relation to telephone (as opposed to video) contact. The majority of patients found remote communication to be helpful but, in a few cases, felt they waited a long time to get their appointment and were disappointed by the limited nature of the communication (table 5).

**Consensus building**

For the first round of the consensus-building process, we invited respondents who had registered for the initial survey (n=106). For the second round, we invited only those respondents who participated in the first round (n=43).

For the first round, participants were asked to rate 14 items on their appropriateness for remote approaches. Twenty-three clinicians and 20 patients participated. There was consensus that 5 of the 14 items were appropriate for remote approaches, meaning that 70% or more of respondents gave a rating of 7, 8 or 9. These five items were: collecting information about a patient’s COPD and overall health status by asking questions (77%); providing education about COPD or COPD treatment and developing a self-management plan (74%); supporting a patient to stop smoking (81%); making a decision on whether a patient needs to see a healthcare professional face-to-face (72%); and helping a patient decide whether to use a rescue pack (76%) (table 6). For no item was there consensus that remote approaches were inappropriate (70% or more of respondents giving a rating of 1, 2 or 3). Comparison by group showed that there were some differences in rating between clinicians and patients. For example, clinicians had high agreement that collecting information on patients’ COPD and health status was appropriate (85% of clinicians rated it 7, 8 or 9 compared with 68% of patients). Notably, patients had high agreement that performing a lung function test (using spirometer) was not appropriate (73% of patients rated it either 1, 2 or 3 compared with 50% of clinicians).

**Table 4** Remote care delivery practices, number of clinicians responding yes

<table>
<thead>
<tr>
<th>Activities related to remote care delivery</th>
<th>Clinicians (n=55)</th>
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<tbody>
<tr>
<td>Unit has standard procedures to support remote communication with patients with COPD.</td>
<td>25 (45%)</td>
</tr>
<tr>
<td>Unit has protocol for hard to reach patients or patients unable to use technology.</td>
<td>14 (25%)</td>
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<tr>
<td>Actively helps patients in contacting clinicians by phone/video/text message outside of regular scheduled appointments</td>
<td>42 (76%)</td>
</tr>
<tr>
<td>Uses a standard tool to assess and record disease severity of COPD in remote communication</td>
<td>25 (45%)</td>
</tr>
<tr>
<td>Routinely uses remote physiological monitoring of patients at home with COPD</td>
<td>10 (18%)</td>
</tr>
<tr>
<td>Engages with carers of patients with COPD by remote communication</td>
<td>26 (47%)</td>
</tr>
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</table>

COPD, chronic obstructive pulmonary disease.

**Table 5** Quotations from open-ended responses

<table>
<thead>
<tr>
<th>Positive aspects of remote care</th>
<th>Concerns about remote care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinicians</td>
<td></td>
</tr>
<tr>
<td>‘We are still able to support patients at home and encourage them to keep active despite most of them having to shield.</td>
<td>‘Mostly by phone so parts of assessment it is difficult to complete, there is more feedback from face-to-face assessment via video’.</td>
</tr>
<tr>
<td>We can also ensure their oxygen requirements are catered for and if necessary decide to do a home visit’.</td>
<td>‘Our health Trust is very rural and wifi/technology signals are poor. Our older age population is not technologically minded which will discriminate against their ability to link in via video’.</td>
</tr>
<tr>
<td>‘Almost all aspects of care can be achieved by video, except hands on breathing techniques. Patients really appreciate the</td>
<td></td>
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<tr>
<td>contact, without having to risk infection from face-to-face care’.</td>
<td></td>
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<tr>
<td>Patients</td>
<td></td>
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<tr>
<td>‘It was very relaxing and the lady made me feel at ease. She was very helpful in explaining fully the medication I am on and the correct way of taking it. The video call was at the precise time as arranged’.</td>
<td>‘Doctor could have listened more to ongoing problem’.</td>
</tr>
<tr>
<td>‘I was given advice and medication to help with an exacerbation of my COPD. This was also followed up regularly to check on my condition’.</td>
<td>‘I doubt you could make remote care as good as face to face meetings, but they can fill a need for discussion and possible change of medication if necessary’.</td>
</tr>
</tbody>
</table>

COPD, chronic obstructive pulmonary disease.
The nine items for which consensus was not reached were included in the second round of consensus building, in which 31 of 43 respondents participated (72%), including 15 clinicians and 16 patients. None of the items reached consensus after a second round of rating. Subgroup analysis again showed rating differences between clinician and patient respondents. Whereas patients did not achieve consensus on any of the nine items, clinicians reached consensus that five items were appropriate for remote approaches: checking inhaler technique (75%), starting new medication (85%), delivering pulmonary rehabilitation (85%), providing education on airway clearance support (83%) and providing breathing training (77%).

Five activities were highlighted by respondents as immediate priorities for improving remote communication for specialty COPD (ratings of urgent or very urgent): establishing direct telephone access for urgent questions (87%); developing new or highlighting existing online education on how best to deliver remote consultations (81%); expanding video consultation availability for healthcare professionals and patients, including training and support (87%); providing or loaning pulse oximeters for at-home measurement of blood oxygen levels (83%); and developing standard guidelines for remote consultation (80%).

**DISCUSSION**

Our survey findings suggest that widespread adoption of remote care delivery for COPD occurred rapidly in response to the COVID-19 pandemic. In the absence of national guidance, these innovations were led by clinicians and varied in response to local circumstances. For some clinical participants, the ability to at least partially address many planned and urgent COPD care activities remotely was unexpected. Perceived benefits from remote approaches included the ability to provide some type of care continuity in a safe manner, especially for patients who were shielding. Activities requiring monitoring equipment limited the extent to which specialty care could be delivered over the phone or by video call, given the major changes in resourcing and organisation of care required. In terms of consensus on what activities are appropriate for ongoing remote care delivery, respondents agreed that there are planned activities
(gathering patient information on COPD and health status, providing counselling on smoking cessation, and providing education on COPD or developing a self-management plan) and urgent care activities (triaging patients for face-to-face care and initiating use of rescue packs) appropriate for remote provision. Subsequent rounds of consensus building did not result in agreement on other items.

Rating differences were found between clinician and patient respondents in sensitivity analyses. While the numbers are small, the findings suggest that clinicians and patients may have differing views with regard to appropriateness of remote care delivery for specialty COPD care, reflecting underlying differences in perspectives on and preferences for remote healthcare in general. In the second round of consensus building, a high proportion of clinicians felt various activities involving remote instruction or education were appropriate—checking inhaler technique, providing breathing training and providing education on airway clearance, for example. Lower ratings by patients suggest that they do not share the same level of comfort about the appropriateness of these activities, or prefer to receive this type of care in-person. These differences should be examined more closely in future planning and development of remote COPD care, including the impact of the medium of remote care (eg, video vs telephone contact).

Our findings provide some indication of the level of care being provided remotely in the UK and help to identify practical next steps to systematically build on and sustain current remote practice. Though adoption of remote communication was quick and widespread, limited provision of equipment, such as pulse oximeters and spirometers, for in-home monitoring is a barrier to more fully realising benefits of remote care delivery. The predominant reliance on telephone-only contact, and more limited uptake of video-based technology, may also act as a barrier, particularly given the limitations of telephone-based consultation identified by some participants.

Findings may help to elaborate on NICE COVID-19 COPD guidelines to describe what new models of remote care delivery should look like as NHS organisations need to move from reacting to the pandemic to considering the broader role of digital technologies in providing care of COPD in systems where capacity for face-to-face care may be limited for some time. Our study complements BTS provision of rapid guidance by providing both clinician and patient perspectives. Further work is required to more fully understand the degree to which both planned and unplanned care activities can safely be carried out remotely in a way acceptable to patients and clinicians, what kind of hybrid models can be implemented based on patient preferences, new workflows that need to be established to coordinate between clinicians and across care settings, and critical organisational investments needed to develop telehealth in meaningful ways.

We identified several potential limitations to the study. Given that the survey was online and advertising for our survey was primarily through social media channels, the responses may not be representative of specialty clinicians caring for patients with COPD, or (particularly) of patients with COPD themselves, given COPD’s higher prevalence among older and socioeconomically disadvantaged populations whose access to social media may be more limited. Notably, 100% of patient participants in the survey gave their ethnicity as ‘white’. We advertised the survey through organisations that reach a breadth of clinicians and consulted British Lung Foundation (BLF) on other avenues through which to reach hard-to-reach patient groups. In addition, we experienced attrition through the course of the project. Although only 43 of 106 invited participants took part in the first round of the consensus-building exercise (41%), there was 72% retention between consensus-building rounds. The number of participants is not large in relation to the sensitivity analysis, and so results must be interpreted with appropriate caution. A qualitative study of patients’ and clinicians’ views would add complementary information.

In this study, we collected data from clinicians and patients with COPD using a questionnaire on current practice and through a consensus-building process. Given constraints arising from the COVID-19 pandemic, we used an online research platform rapidly and pragmatically to identify strengths and limitations of current remote care delivery for specialty COPD care. Our findings add evidence on the acceptability of various components of remote care delivery, from the perspective of both patients and clinicians to existing evidence of impact of telehealth in COPD. Suggestions for improving remote care are likely to be of importance even when the current pandemic recedes.

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Contributors All authors jointly conceived the study, contributed to interpretation and approved the final version of the paper. Data collection was led by FW, with support from JB, TC, RF, GM and JRH. Data analysis was led by FW, with support from JvdS. FW led drafting of the paper, with critical input from all the other authors.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval The patient survey received approval from the University of Cambridge Psychology Research Ethics Committee. The clinician survey was considered to fall outside the scope of ethical review. Both patients and clinicians were required to provide consent to Thickeys’ terms and conditions regarding data storage, and both groups were provided with participant information about the survey and consensus-development process. For clinicians, participation in the survey was taken to imply consent; patients were additionally asked to confirm that they understood that participation was voluntary and would not impact the healthcare they received prior to accessing the questionnaire.
REFERENCES


