Follow us @BoneJointOpen

Freely available online OPEN ACCESS

BJO

GENERAL ORTHOPAEDICS

What can we learn from the experiences and expectations of patients on growing waiting lists for planned care in the COVID-19 pandemic?

K. Kulkarni,
R. Shah,
M. Armaou,
P. Leighton,
J. Mangwani,
J. Dias

From University Hospitals of Leicester NHS Trust, Leicester, UK

Aims

COVID-19 has compounded a growing waiting list problem, with over 4.5 million patients now waiting for planned elective care in the UK. Views of patients on waiting lists are rarely considered in prioritization. Our primary aim was to understand how to support patients on waiting lists by hearing their experiences, concerns, and expectations. The secondary aim was to capture objective change in disability and coping mechanisms.

Methods

A minimum representative sample of 824 patients was required for quantitative analysis to provide a 3% margin of error. Sampling was stratified by body region (upper/lower limb, spine) and duration on the waiting list. Questionnaires were sent to a random sample of elective orthopaedic waiting list patients with their planned intervention paused due to COVID-19. Analyzed parameters included baseline health, change in physical/mental health status, challenges and coping strategies, preferences/concerns regarding treatment, and objective quality of life (EuroQol five-dimension questionnaire (EQ-5D), Generalized Anxiety Disorder 2-item scale (GAD-2)). Qualitative analysis was performed via the Normalization Process Theory.

Results

A total of 888 patients responded. Better health, pain, and mood scores were reported by upper limb patients. The longest waiters reported better health but poorer mood and anxiety scores. Overall, 82% had tried self-help measures to ease symptoms; 94% wished to proceed with their intervention; and 21% were prepared to tolerate deferral. Qualitative analysis highlighted the overall patient mood to be represented by the terms ‘understandable’, ‘frustrated’, ‘pain’, ‘disappointed’, and ‘not happy/depressed’. COVID-19-mandated health and safety measures and technology solutions were felt to be implemented well. However, patients struggled with access to doctors and pain management, quality of life (physical and psychosocial) deterioration, and delay updates.

Conclusion

This is the largest study to hear the views of this ‘hidden’ cohort. Our findings are widely relevant to ensure provision of better ongoing support and communication, mostly within the constraints of current resources. In response, we developed a reproducible local action plan to address highlighted issues.

Cite this article: *Bone Jt Open* 2021;2-8:583–593.

Keywords: COVID-19, Waiting list, Patient, Communication, Self-help

Correspondence should be sent to Kunal Kulkarni; email: kunalkulkarni@doctors.org.uk

doi: 10.1302/2633-1462.28.BJO-2021-0056.R1

Bone Jt Open 2021;2-8:583–593.

Introduction

The COVID-19 pandemic has had a profound impact upon all aspects of already stretched healthcare provision. Since 2020, directives have been implemented to delay non-urgent hospital treatments to prevent NHS services from being overwhelmed. Consequently, as of February 2021, over 380,000 patients had been on waiting lists for over 52 weeks, with over 4.7 million waiting for consultant-led elective care.[1,2] The Royal College of Surgeons (RCS) of England has described the 'calamitous impact' upon elective waiting lists, although the problem is certainly not isolated to the surgical specialties.[3]

For as long as activity lags demand, the problem is compounded. Attempts to address this backlog often focus on modelling approaches to streamline the flow of patients through a constrained system, with cases prioritized according to objective factors such as the severity and duration of the underlying problem, alongside resource availability.[4,5] The views of patients may not always be considered.

In between first booking patients for a planned treatment and the procedure taking place, patients have little contact with healthcare services – akin to hitting a 'pause' button on their care.[6] With the underlying problem still impacting their day-to-day life, each individual adopts different coping mechanisms to live with their condition until the proposed treatment hopefully provides relief. With a patient's life focused upon the planned intervention, delays may present significant psychological and physical challenges – elements that prioritization models fail to address.[7] Basic support systems to help patients cope are usually ad hoc, uncoordinated, and in some cases altogether absent. This may in part be due to resource constraints, although in the main is likely due to a lack of recognition and acknowledgement of this as an issue that needs to be addressed.

Prolonged waiting lists due to COVID-19 are certain to provide an enduring challenge. It is therefore now more important than ever to adopt a patient-centred support framework, based on the experiences of the very patients whose procedures have been further delayed, to ensure appropriate support is provided while patients await their delayed surgery. The primary aim of this study was to understand where patients on waiting lists required further support by hearing their experiences, concerns, and expectations. The secondary aim was to capture objective changes in levels of disability as a result of the delay, alongside mechanisms of coping.

Methods

Setting. This cross-sectional study was conducted at a single UK NHS university teaching hospital with institutional approval. The UK's first COVID-19 lockdown period began on 23 March 2020. At its outset 3,929 adult (age ≥ 16 years) patients were identified on the elective orthopaedic waiting list. After 312 exclusions, 3,617 were included.

Sample size calculation. Figure 1 highlights our patient selection criteria and sample size calculation. With no existing data on this topic, a priori assumption could not be made; to maximize variability and ensure the largest and most representative sample size, we therefore assumed that at least 50% of patients were still symptomatic. We undertook a sample size calculation, which required us to survey 824 patients to provide a 3% margin of error (MOE) and confidence interval of 95% (95% CI) for quantitative analysis.[8] We therefore estimated that we needed to sample 1,380 patients, with a predicted response rate of 60%. A total of 888 responded, 64 more than the minimum required for a representative sample.

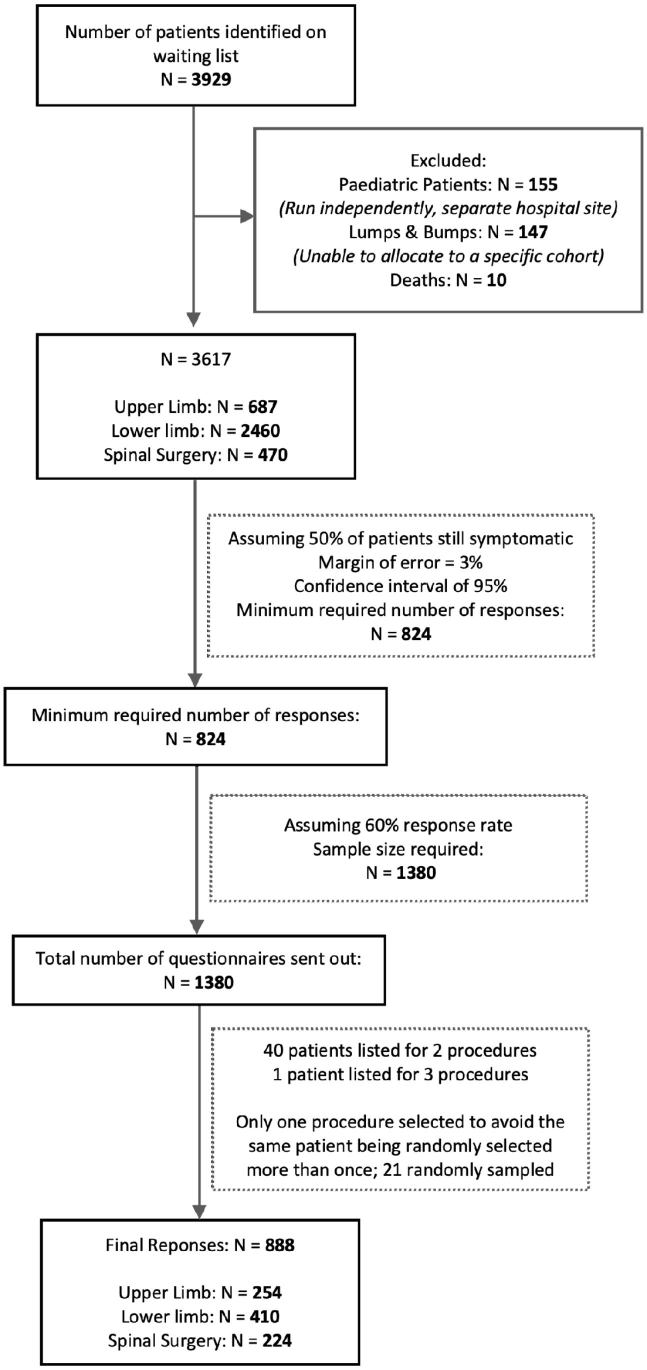

Fig. 1

Patient numbers and questionnaire responses.

Sampling was stratified by two factors: body region (upper limb, spine, and lower limb) and duration already on the waiting list at the time of the first lockdown in tertiles (longest, middle, and shortest time in weeks on the waiting list). Stratification by body region was performed ensuring that the sample drawn permitted at least a 5% MOE for sub-group analysis and accounting for a 60% response rate. Of 687 patients waiting for an upper limb procedure, we required 247 responses and sampled 430; of 470 patients waiting for a spine procedure, 212 were required and we sampled 370; and of 2,460 waiting for a lower limb procedure, 332 were required and we sampled 580.

The mean time the 3,617 patients had already spent on the waiting list at the beginning of the first lockdown was 27.6 weeks (standard deviation (SD) 13.8). Those in the shortest tertile were on the list for 12.8 weeks (SD 5.4), middle third 27.2 weeks (SD 3.8), and longest third for 43.8 weeks (SD 6.3). We adjusted our sampling stratified for duration on the waiting list, with 540 in the shortest, 440 in the middle, and 400 in the longest tertile, to ensure samples were balanced for time on the waiting list.

Patient involvement: questionnaire. Patient experiences, concerns, and opinions were sought via a postal questionnaire, sent out in September 2020 (between the easing of the first national COVID-19 lockdown measures and the start of the second national lockdown in November 2020). This was designed as a simple, cognitively undemanding questionnaire, with questions constructed by the authors to capture key aspects of patients' health. We used objective, validated patient-reported outcomes measures (PROMs). We also provided descriptive, open-ended, free-text sections to capture the more qualitative elements of health-related quality of life. Questions included baseline demographic details (supplemented with data extracted from our waiting list database), duration of symptoms, variation in pain (linear visual analogue scale (VAS) from 1 (least) to 10 (most) pain), activity ('active' defined as an average of ≥ 150 minutes of moderate activity (e.g. running, cycling) per week, 'inactive' defined as < 150 minutes, and 'sedentary' being minimal average activity), mood (linear scale from 1 (best) to 10 (worst)), overall health state (linear scale from 0 (worst) to 100 (best) imaginable health), treatments tried to alleviate symptoms, new symptoms since added to waiting list, and feelings/anxiety about attending hospital during the pandemic. Objective (quantitative) measurement of current health status was done using the EuroQol five-dimension (EQ-5D) and Generalized Anxiety Disorder 2-item (GAD-2) questionnaires.[4,5] EQ-5D enables patients to rate their overall health status based upon five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). GAD-2 is an anxiety screening tool based upon whether patients have experienced anxiety related symptoms over the past two weeks.[9,10]

Open-ended questions were incorporated to triangulate data as they can successfully elicit critical comments about patients' experiences and satisfaction with healthcare services that cannot easily be assessed purely with quantitative methods.[11,12] In particular, as they offer the opportunity for respondents to provide written feedback on their survey responses, they can assist in the validation of responses among satisfied and dissatisfied participants.[13,14] However, evidence shows that patients who feel more inclined to complete open-ended questions in the first place may be among the most and least satisfied patients.[15] This means that qualitative data can illustrate specific facets of patient experience, and complement observed quantitative trends to widen our understanding of factors that determine patient views to shape our action plan. Mixing quantitative and qualitative methods allows deeper understanding of multifaceted phenomena.[16,17]

Analysis. Descriptive statistics were presented as means and SD as data were normally distributed. Qualitative analysis of participants' survey responses explored their perceptions of the COVID-19-mandated changes enacted and, more specifically, the perceived impact of procedure delays and patient views on elements of those changes that required further improvement. Coding was performed using simple tabulation and NVivo (QSR International) software. Questionnaires with incomplete or missing responses were excluded. Based on Normalisation Process Theory (NPT), qualitative analysis explored elements of how changes were enacted ('collective action' - what was handled well and what should be done in the future) and how their effects were appraised ('reflexive monitoring' - key factors and experiences that drive judgements on how changes were handled).[18] The sentiments echoed in participants' responses to two main questions were analyzed: 1) *"what are your feelings about procedure delays?"* and 2) *"how can we in the hospital help you cope while waiting?"*

Results

Demographic details and baseline scores. Out of 888 respondents, 254, 410, and 224 were in the upper limb, lower limb, and spinal surgery cohorts, respectively. Table I summarizes the responses. There were no differences in baseline demographic data and mood scores between the three cohorts. The upper limb cohort reported the best health score, lowest average pain scores, and had the most active patients. In contrast, the spinal surgery cohort had the poorest overall health score, and the least active patients.

Self-help measures. Overall, 82% (727/888) had tried a basic intervention themselves to cope with their symptoms while awaiting surgery (Table II). These included medication (44%, n = 394), rest (39%, n = 346), exercise (37%, n = 331), ice/heat packs (26%, n

Table I. Patient demographic data and responses to subjective measures.

Characteristic	Upper limb	Spine	Lower limb	Total
Patients, n	254	224	410	888
Sex, n (%)				
Female	118 (47)	118 (53)	210 (51)	446 (50)
Male	136 (54)	106 (47)	200 (49)	442 (50)
Mean age, yrs (SD)	62.09 (13.36)	61.88 (13.81)	64.36 (14.26)	63.09 (13.93)
Mean pain scale (SD)	5.30 (2.89)	6.67 (2.23)	6.62 (2.22)	6.26 (2.50)
Mean mood (SD)	4.43 (2.84)	5.50 (2.62)	5.30 (2.64)	5.09 (2.73)
Mean health VAS (SD)	62.82 (25.13)	50.43 (24.74)	54.68 (33.89)	55.91 (29.73)
Activity level, n (%)				
Active	152 (62)	73 (34)	143 (37)	368 (43)
Inactive	61 (25)	91 (42)	163 (42)	315 (37)
Sedentary	32 (13)	51 (24)	86 (22)	169 (20)
Mean GAD2 (SD)	1.75 (2.11)	2.53 (2.20)	2.29 (2.27)	2.20 (2.22)

The total 888 respondents exceeded our minimum required response target by over 5%. Upper limb, lower limb, and spinal cohort numbers all met minimum targets for sub-group analysis.
GAD2, Generalized Anxiety Disorder 2-item scale; SD, standard deviation; VAS, visual analogue scale.

Table III. Patient opinions regarding attending for their proposed surgical intervention.

Variable	Upper limb	Spine	Lower limb	Total
Patients, n	254	224	410	
Mean symptom duration, mths (SD)	68.3 (130.75)	82.2 (124.66)	69.8 (114.14)	72.5 (121.76)
Mean EQ-5D score (SD)	0.6 (0.30)	0.42 (0.31)	0.46 (0.31)	0.5 (0.32)
Proceed with operation? n (%)				
No	13 (6)	17 (8)	16 (4.2)	46 (6)
Yes	223 (95)	187 (92)	365 (96)	775 (94)
Delay operation? n (%)				
No	163 (74)	160 (81)	301 (81)	624 (79)
Yes	58 (26)	37 (19)	69 (19)	164 (21)
GAD category, n (%)				
Not anxious	156 (72)	110 (55)	229 (65)	495 (64)
Anxious	62 (28)	89 (45)	125 (35)	276 (36)

A GAD score of ≥ 3 was used as a cut off for 'anxious' vs 'not 'anxious.' [9,10]
EQ-5D, EuroQol five-dimension questionnaire; GAD, Generalized Anxiety Disorder scale; SD, standard deviation.

= 230), or something else (12%, n = 108). Fewest in the upper limb cohort (74%, n = 188) had tried home remedies, in comparison to spine (85.7%, n = 192) or lower limb (85%, n = 347). This is consistent with upper limb patients having the highest overall health scores and lowest overall pain scores.

Table II. Patient responses to the question "what have you tried at home to improve your symptoms?"

Response	Upper limb	Spine	Lower limb	Total
Patients, n	254	224	410	888
Nothing, n (%)				
No	188 (74)	192 (86)	347 (85)	727 (82)
Yes	66 (26)	32 (14)	63 (15)	161 (18)
Medication, n (%)				
No	166 (65)	109 (45)	219 (53)	494 (56)
Yes	88 (35)	115 (51)	191 (47)	394 (44)
Ice/heat, n (%)				
No	193 (76)	165 (74)	300 (73)	658 (74)
Yes	61 (24)	59 (26)	110 (27)	230 (26)
Exercise, n (%)				
No	166 (65)	126 (56)	265 (65)	557 (63)
Yes	88 (35)	98 (44)	145 (35)	331 (37)
Rest, n (%)				
No	180 (71)	118 (53)	244 (60)	542 (61)
Yes	74 (29)	106 (47)	166 (41)	346 (39)
Other, n (%)				
No	228 (90)	195 (87)	357 (87)	780 (88)
Yes	26 (10)	29 (13)	53 (13)	108 (12)

Proceeding with proposed intervention. Table III and Supplementary Material 4 highlight patient responses with regard to their proposed intervention. The vast majority in all cohorts remained symptomatic and wished to proceed with their designated operation (94%, 774/888). In contrast, 21% (164/888) were prepared to tolerate deferral. The questionnaire was viewed by many patients as the only communication they had received to voice their concerns to their treating team while waiting.

Impact of time on waiting list. Subanalysis of the sample stratified by duration on the waiting list found that best overall health (mean 58.4/100 health VAS) was reported in the longest waiting group, although this cohort also reported the lowest overall mood (4.8/10, with 0 representing best and 10 being worst mood). With respect to GAD 2 anxiety categories, the middle waiters had a slightly higher percentage of patients who were more anxious overall (39%) compared to the shortest (35%) and longest (34%) waiting cohorts. For many patients, the growing anxiety levels reflected in the GAD 2 scores were secondary to a combination of their progressive symptoms, ongoing impact upon their quality of life, and worries about further delays. “Just get the job done”, “I really need it to be sorted ASAP”, “I would attend regardless of the COVID-19 risk”, and “the longer I wait for surgery the more concerned I feel about getting a good outcome” were some of the sentiments of the long waiters, with a desire to “have my operation as soon as possible” echoed by a notable number. Detailed analysis is presented in Supplementary Material 1.

Fig. 2

Word cloud based on sentiments expressed in response to the question, "what are your feelings about procedure delays?"

'What are your feelings about procedure delays?'. A word cloud was generated based upon patient qualitative responses (Figure 2). The most frequently used terms included '*understandable*', '*frustrated*', '*pain*', '*disappointed*', and '*not happy/depressed*'. Responses that included these (or similar) terms were further examined as the first step in understanding patient perceptions about implemented changes. The themes that emerged were tabulated with all responses to this question, with three main themes emerging: 1) understanding disruption was caused by COVID-19, but nonetheless disappointed; 2) impact on personal health as a direct consequence of surgical delay (e.g. deterioration of underlying condition, worsening pain); and 3) distress and mental health complaints as an impact of delaying treatment.

Two patients reported suicidal intent on their questionnaires. These were taken seriously, adopting a pre-agreed protocol to maintain patient safety including arranging for the responsible clinician to perform an urgent telephone consultation, and discussion with the general practitioner (GP). In both instances, these sentiments were expressed in the context of known underlying mental health problems under community treatment, and further safety-netting was arranged.

'How can we, in the hospital, help you cope?'. Responses to this question were analyzed with thematic codes tabulating participant views on what should be done in the future. The initial key codes generated included 1) access to doctor/pain management; 2) access to lifestyle management and psychosocial support; 3) more information, including updates about the delayed surgery; 4) a point of contact; and 5) clear messaging and better communication between hospital and patient.

Coding was subsequently refined with patient responses to other open-ended survey questions (e.g. details regarding pain management, anxiety issues, and self-care comments). The final coding was reorganized in two categories - elements of change that were either perceived to have been handled well, or poorly (Figure 3).

Two themes - procedures required for health and safety (COVID-19 prevention measures) and technology-based solutions (including virtual consultations and text message updates) - were identified as handled 'well' and were not perceived to be problematic. Four themes were perceived to have been negatively handled, encompassing

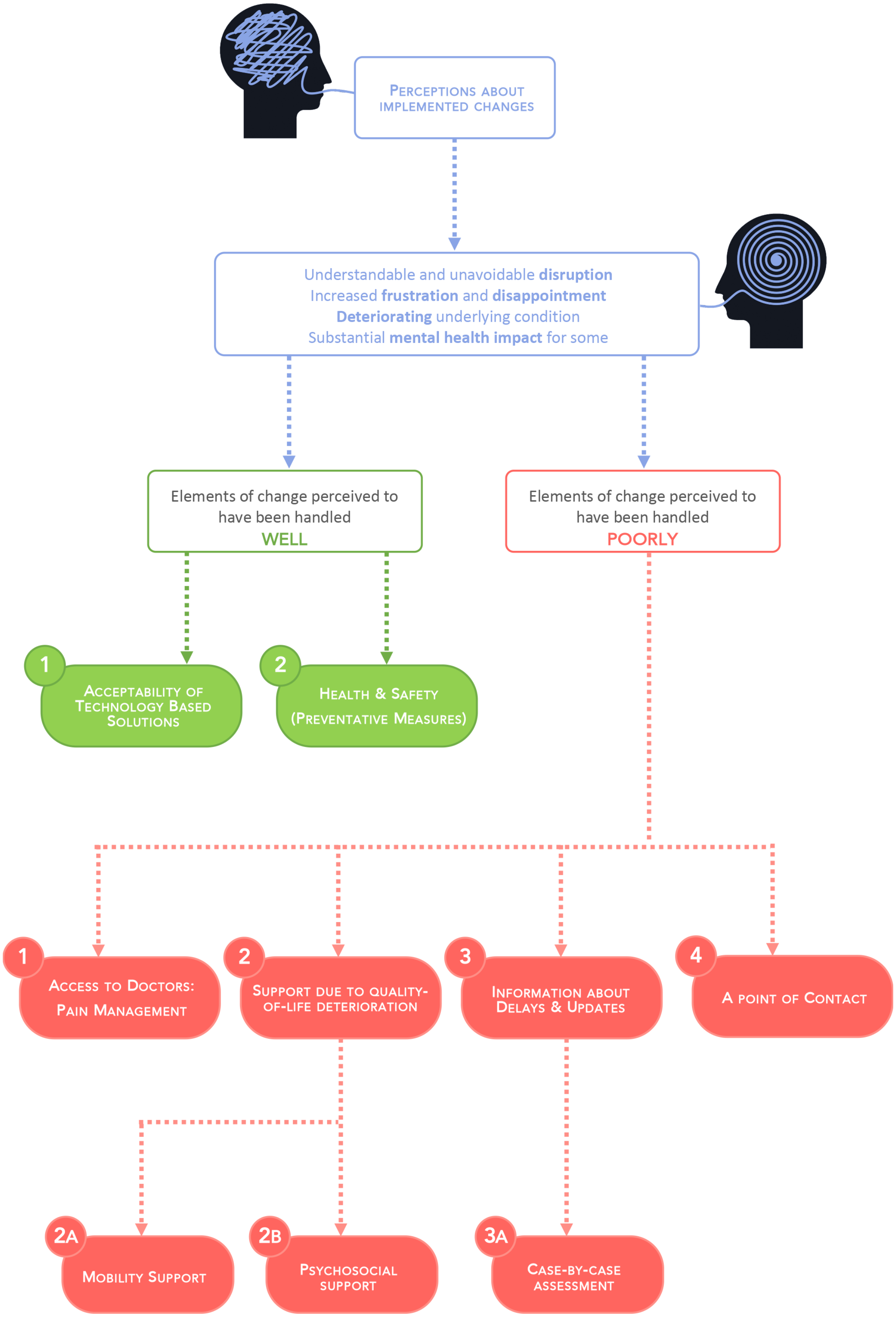

Fig. 3

Key themes emerging from patient perceptions about implemented changes in response to COVID-19.

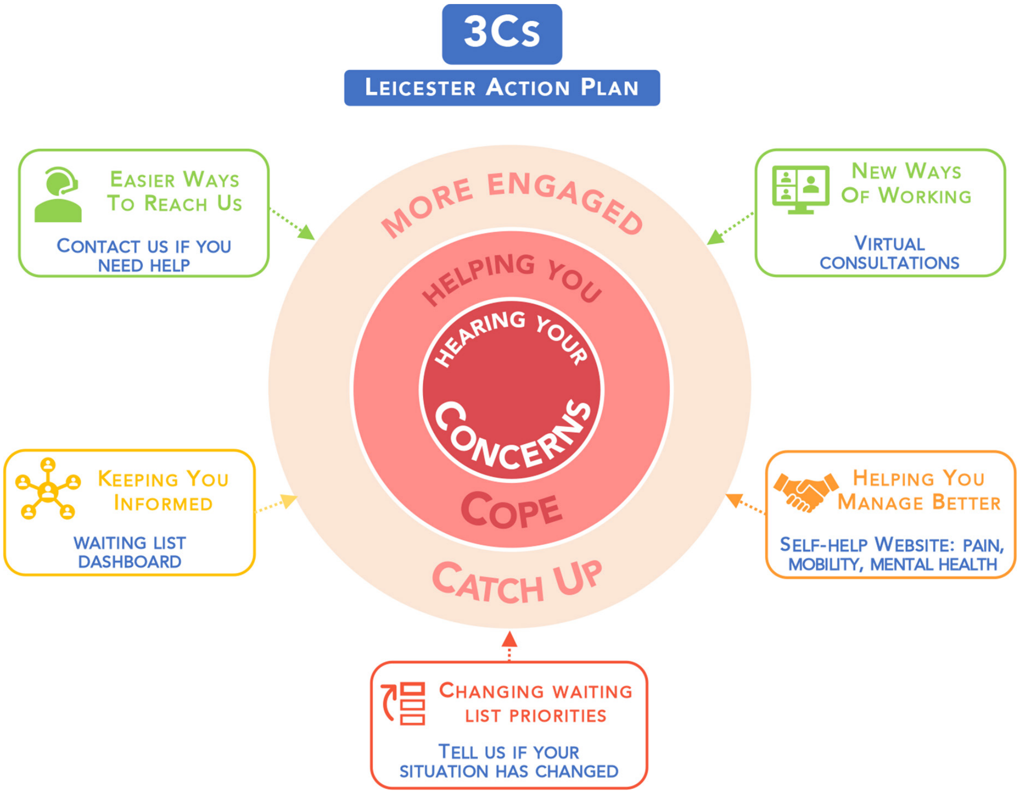

Fig. 5

3Cs action plan to address each of the patient highlighted key themes.

challenges with the ability to voice concerns (a point of contact), cope with ongoing or progressive symptoms (pain management), catch up with their treating teams (for information regarding delays and updates), and general support due to quality of life deterioration as a consequence of surgical delay (Figure 3).

Discussion

To our knowledge, this is the largest and most contemporaneous study to specifically seek the experiences, concerns, and expectations of patients on waiting lists for planned care. The majority of patients in all cohorts continued to struggle and had attempted some intervention to ease their symptoms while waiting. Over 90% still wished to proceed with planned surgery, and only a fifth would consider deferral. Overall patient mood was most frequently represented via the terms ‘understandable’, ‘frustrated’, ‘pain’, ‘disappointed’, and ‘not happy/ depressed’.

Patients expressed concerns about the length of delays they experienced and particularly the uncertainty around not knowing when their surgery would occur. Many patients felt that having the surgery prior to another lockdown would enable them to recuperate during the lockdown itself. The urgency of wanting surgery appeared to reflect their deteriorating quality of life. As a consequence, there was a substantial impact upon the mental health of some patients, with uncertainty about how and where they could seek psychosocial support to help them cope. Interestingly, our longest waiting cohort recorded the best health scores, suggesting that they had developed better coping mechanisms through necessity than their shorter waiting peers.

Patients generally felt that the health and safety measures and technology-based solutions we had implemented in response to COVID-19 were both necessary and implemented well. These included additional precautions for hospital visits (e.g. enforcement of social distancing, masks, and hand-washing in all clinical settings), as well as novel methods for communication (e.g. virtual consultations). These findings are consistent with others.[19] Four key themes where patients sought improved action included access to clinicians, pain management, support for quality of life deterioration (physical and psychosocial), and improved communication.

We achieved a response rate that exceeded sample size calculations for sub-group analysis. Our robust patient sampling and qualitative analysis methodology allowed us to confidently ascertain the holistic themes that dominated the patient perspective of being on a long waiting list, including the physical and emotional challenges that ensued. While results of this study represent elective orthopaedic patients, the findings and action plan are readily extrapolated and applicable to all specialties with patients on waiting lists for planned treatment.

Reducing inequality in access to healthcare services is an ongoing concern.[20] In line with other publicly funded health systems, NHS planned care waiting lists provide a ‘buffer’ between care demand and the rationing of limited supply. Previous studies have identified that standardized measures are required to fairly assess patients’ relative priority for services with waiting lists, with current systems often lacking either clear definitions to ascertain the true extent of individual patients’ suffering, or consideration of non-clinical factors that matter to patients, such as impact upon their livelihood.[21,22] Ultimately, current waiting list prioritization strategies are based upon mortality, with those at highest risk (e.g. patients with cancer) in a higher tier than those with significant morbidity and disability but no direct threat to life (e.g. patients with advanced osteoarthritis) prioritized lower.

The additional delays incurred through the ongoing deferral of planned procedures during COVID-19 have been unprecedented, and place further challenges upon an already stretched service, widening the gap between service demand and resource constraints, and further failing to meet patient expectations. With predictive models of the pandemic forecasting recurring cycles, with sustained delays to delivery of planned care, it is estimated that waiting lists could grow to exceed ten million.[2] With NHS staff increasingly redeployed to support the pandemic efforts, our already limited communication with waiting list patients is likely to be further constrained. It is therefore more important than ever to ensure that the growing number of patients on waiting lists are not inadvertently abandoned, and that they are provided with pragmatic channels of support to help them cope, and to raise concerns. While reducing the numbers and duration on waiting lists are unrealistic options for improving waiting list management, other strategies include improving the health of those already on waiting lists alongside ensuring quickest access for those with the greatest need.[23]

Where surgical waiting lists are concerned, NHS England and NHS Improvement advocate tools for “clinical validation” based upon checking the patient’s condition, additional risk factors, establishing patient wishes regarding treatment, communicating effectively with the patient and their carer/GP, and offering patients the option to defer surgery but remain on the waiting list. One of the principles of these strategies is to offer support to vulnerable patients, for example those with mental health problems. Results from our qualitative analysis revealed a subset of patients in whom a combination of deteriorating symptoms coupled with the emotional burden of delayed surgery has resulted in lower mood and, in some cases, even suicidal ideation. We suspect we have identified only the tip of the iceberg, and there are likely to be far more ‘silent sufferers’ who remain unaccounted for and increasingly struggling at home with fewer avenues for support while they wait for their planned treatment.

An earlier study similarly identified the concept of ‘progress’, through both the healthcare system and any change in their health status, to be central to patient beliefs.[6] When placed onto a waiting list, patients enter a ‘limbo’ period where they are offered hope of resolution of their problem, albeit with the waiting period currently unspecified. However, they may become largely invisible as individuals to healthcare providers, without any specific actions considered regarding their care until they are ready to transition to the next phase (i.e. their planned treatment). An important theme identified was that patients were provided inadequate information during the ‘limbo’ period, with patients expressing the uncertainty and helplessness they experienced when they felt their care was not progressing, for example when passing between two stages of care. For providers, while prioritization is clinically necessary to balance resource and demand, the radio silence during this period of ‘limbo’ must be addressed, with care proactively delivered during this worrying and often helpless time for patients. With adequate resources unlikely to become available to meet demand, the NHS needs to adopt more flexible and innovative ways of working.[19] Vigilance is particularly required to flexibly increase prioritization in response to changes in parameters that may result in the proposed intervention either being increasingly complex or redundant, and yielding a permanent and unacceptable quality of life reduction for patients (e.g. a failing hip arthroplasty that results in a periprosthetic femoral fracture or an unreconstructible acetabular defect).[24]

With constrained resources, this study has enabled us to focus on a workable solution to the specific challenges that concern patients on waiting lists. Having highlighted the challenges we attempted to develop a pragmatic, resource-undemanding, and rapidly reproducible local solution. To operationalize tangible interventions to effect rapid change to waiting list patient care, we propose a simple, progressive ladder of interventions, with the ultimate aim at each stage to determine whether the intervention priority needs to be adjusted (i.e. deferred or expedited) (Figure 4). To ensure that the key themes highlighted by patients were addressed, we developed a structured local ‘3 C’ action plan. (Figure 5; Table IV; Supplementary Material 2). This is based upon a three-tiered approach to providing support, including better ways to hear patients’ *Concerns,* providing simple tools to help them *Cope*, and improved two-way engagement to *Catch up* while they remain in ‘limbo’ on their waiting list, including through developing an elective wating list dashboard. This follows a similar model to other industries with consumer waiting (e.g. airline, customer service),

Table IV. Qualitative analysis - addressing "what patients want" while on a long waiting list.

Category	The need to hear and allay patient concerns is paramount.
Concerns	Means of access, providing information, and two-way communication were key. Making direct telephone links to the waiting list team more visible on communications is a simple way to achieve this. Patients want improved channels of communication with clinicians, facilitated via better access to technology (including provision of improved telephones and webcams for video consultations). More flexible clinic booking slots to provide a more readily accessible triage and support service in between formal clinical encounters.
Coping	We identified a clear gap in resources to help patients manage symptoms themselves, for example: 1) signposting to relevant self-help resources (such as websites); 2) providing access to support services (such as community pain management or physiotherapy). Deterioration in mental health was often secondary to anxiety, exacerbated by a variety of reasons. Providing access to urgent support services is paramount. Additionally, information provision to address patient concerns and/or reassure, helps maintain patient safety. We addressed this via establishing a new website for waiting list patients with links to resources (including urgent mental health support numbers), provided by one of our regional clinical psychologists. To bridge the gap between self-help and more interactive professional-led support, we are developing a programme of group therapy sessions for similar cohorts of patients highlighted as needing additional support, for example deteriorating patients with knee osteoarthritis awaiting arthroplasty.
Catch-up	Technology is the driver to facilitate many pathway improvements, including one of the most important factors that patients requested – better engagement in their care journey on the waiting list and being kept up to date. We are working with our management and IT teams to develop a patient-facing dashboard to present live updates on our website, with holding SMS reminders to be provided to all patients at periodic intervals, including with links to events and resources to help them cope better.

The goal of our 3 C model is to ensure that a change in a patient's status with regard to the proposed intervention is addressed, with appropriate adjustment of priority enacted in response.

We therefore developed a SOP for non-clinicians (administrative team, personal assistants) to triage patient requests as either:

- 'Green' (general solvable queries – see 'Concerns')
- 'Amber' (increased concerns/anxiety and difficulty coping, requiring directing to self-help resources – see 'Coping')
- 'Red' (potential clinical deterioration - escalate to responsible healthcare professional including therapist or clinician, for consideration of remote consultation to decide if the priority of planned intervention needs to be adjusted)

SMS, short message service; SOP, standard operating practice.

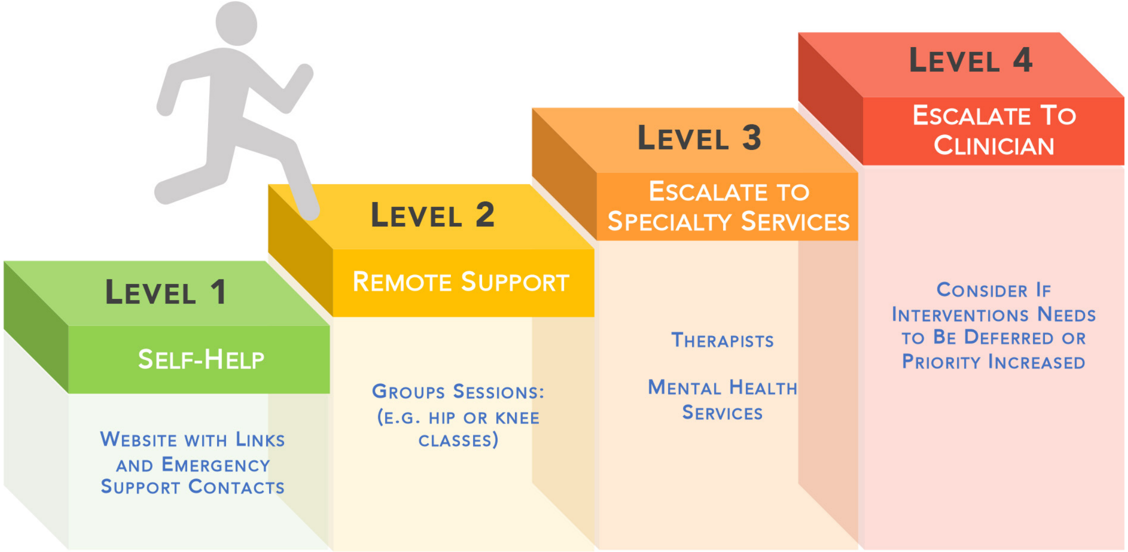

Fig. 4

Proposed ladder of interventions to provide patients with greater support as care needs increase.

and aims to strike a balance between keeping patients up to date with a realistic indicator of time (and therefore better able to plan their commitments around their intervention) and not providing false hope, notwithstanding the fact that waiting times understandably differ based upon individual clinical need.[25] To ensure actions were fed back to all participants, we developed an infographic (Supplementary Material 3). Patients on the waiting list were directed to view this on our dedicated support web site via a text message update containing a weblink.

Our study has several limitations. NHS England is currently driving a 'command and control' strategy for all communications, so our ability to implement some facets of our action plan (e.g. live dashboard) are limited until local Trusts regain control and the COVID-19 second wave subsides, so that patients are not provided with unrealistic expectations at a time when it remains unclear when normal services will resume. Our cohort were all elective orthopaedic patients, although the common themes that have emerged are generic and applicable to all planned care. The response rate met our sample size but was lower than our expectation and consistent with the mean response rate from patient surveys reported in the literature.[26] As others have highlighted, non-responders are potentially more ill, less satisfied with their care, or less frequent users of healthcare services; while it is therefore possible that we have not fully captured the views of this group of patients, we are confident that our findings are representative of the majority as we exceeded our robust calculated sample size requirements.[27–29] While we were able to accurately capture objective measures of current health status at the time of sending out the questionnaires, baseline data from the time of patients being initially placed onto the waiting list were not available for direct comparison. With no published literature on this topic we did not know what proportion of patients would still be symptomatic, and therefore assumed at least 50% so as to maximize our sample size; however, this estimate is consistent with a recent study reporting just over 50% of patients on elective waiting lists wanted to continue with planned surgical care at the earliest possibility.[30] Finally, we have not yet had the opportunity to evaluate the impact of our solutions on our patients; as planned care resumes, our aim is to re-assess patient experiences to ensure that we have made a positive difference to our waiting list patient experience. With a growing waiting list challenge in the years to come, a logical next step would be for further research into the optimal method of prioritizing patients awaiting planned care where life-saving or prolonging are not the objectives.

This unique study has revealed important insights into the feelings of our growing number of patients on NHS waiting lists for planned care. This cohort has unfortunately been ‘out of sight, out of mind’ and ignored, particularly due to the growing demands upon our healthcare system. With the need to do more with less, we hope that we can encourage other units to adopt such simple measures to improve the care of patients while they remain on waiting lists, by allowing them to better manage their problems, and more readily seek help when required, therefore improving the safety and quality of care that we deliver.

Take home message

- This is the largest study to seek the experiences, concerns, and expectations of patients on waiting lists for planned interventions.

- Primary patient concerns include difficulty coping with the physical and psychosocial aspects of the deterioration in quality of life caused by their symptoms, alongside challenges in contacting healthcare services and getting updates while they remain in limbo on a waiting list.

Twitter

Follow K. Kulkarni @doktor_kk
Follow J. Mangwani @jitmangwani

Supplementary material

Patient questionnaire data stratified by duration on the waiting list; detailed 3C local action plan; STROBE statement; patient infographic.

References

1. **O’Dowd A**. NHS Waiting list hits 14 year record high of 4.7 million people. *BMJ*. 2021;373:n995.
2. **Garner T**, **Fraser C**, **Peytrignet S**, **The Health Foundation**. Elective Care in England: Assessing the Impact of COVID-19 and Where next. 2020. https://www.health.org.uk/publications/long-reads/elective-care-in-england-assessing-the-impact-of-covid-19-and-where-next (date last accessed 19 July 2021).
3. **RCS**. Record number of people on hospital waiting lists. https://www.rcseng.ac.uk/news-and-events/media-centre/press-releases/record-number-of-people-on-waiting-lists/ (date last accessed 7 July 2021).
4. **Kroenke K**, **Spitzer RL**, **Williams JB**, **Löwe B**. The patient health questionnaire somatic, anxiety, and depressive symptom scales: A systematic review. *Gen Hosp Psychiatry*. 2010;32(4):345–359.
5. **Herdman M**, **Gudex C**, **Lloyd A**. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res. 2011;20(10):1727–1736.
6. **Preston C**, **Cheater F**, **Baker R**, **Hearnshaw H**. Left in limbo: patients’ views on care across the primary/secondary interface. *Qual Health Care*. 1999;8(1):16–21.
7. **Morris JA**, **Super J**, **Huntley D**, **Ashdown T**, **Harland W**, **Anakwe R**. Waiting lists for symptomatic joint arthritis are not benign: prioritizing patients for surgery in the setting of COVID-19. *Bone Jt Open*. 2020;1(8):508–511.
8. **Arya R**, **Antonisamy B**, **Kumar S**. Sample size estimation in prevalence studies. *Indian J Pediatr*. 2012;79(11):1482–1488.
9. **Sapra A**, **Bhandari P**, **Sharma S**, **Chanpura T**, **Lopp L**. Using generalized anxiety disorder-2 (GAD-2) and GAD-7 in a primary care setting. *Cureus*. 2020;12(5):e8224.
10. **Plummer F**, **Manea L**, **Trepel D**, **McMillan D**. Screening for anxiety disorders with the GAD-7 and GAD-2: a systematic review and diagnostic metaanalysis. *Gen Hosp Psychiatry*. 2016;39:24–31.
11. **Bruster S**, **Jarman B**, **Bosanquet N**, **Weston D**, **Erens R**, **Delbanco TL**. National survey of hospital patients. *BMJ*. 1994;309(6968):1542–1546.
12. **Milberg A**, **Strang P**. Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions. *Palliat Med*. 2000;14(6):533–534.
13. **Santuzzi NR**, **Brodnik MS**, **Rinehart-Thompson L**, **Klatt M**. Patient satisfaction: how do qualitative comments relate to quantitative scores on a satisfaction survey. *Qual Manag Health Care*. 2009;18(1):3–18.
14. **Iversen HH**, **Bjertnæs OA**, **Skudal KE**. Patient evaluation of hospital outcomes: An analysis of open-ended comments from extreme clusters in a national survey. *BMJ Open*. 2014;4(5):e004848.
15. **Riiskjær E**, **Ammentorp J**, **Kofoed PE**. The value of open-ended questions in surveys on patient experience: number of comments and perceived usefulness from a hospital perspective. *Int J Qual Health Care*. 2012;24(5):509–516.
16. **Greene JC**, **Caracelli VJ**, **Graham WF**. Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis: American Educational Research Association*. 1989;11(3):255–274.
17. **Clark VLP**, **Ivankova NV**. Mixed Methods Research: A Guide to the Field. California, USA: SAGE Publications. 2016.
18. **Murray E**, **Treweek S**, **Pope C**. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Med*. 2010;8:63.
19. **Carr A**, **Smith JA**, **Camaradou J**, **Prieto-Alhambra D**. Growing backlog of planned surgery due to covid-19. *BMJ*. 2AD;372:n339.

20. **Ford J**, **Gimson A**, **Toh C-. H**. Clinical validation of waiting lists - we need to avoid worsening health inequalities. 2020. https://blogs.bmj.com/bmj/2020/10/28/clinical-validation-of-waiting-lists-we-need-to-avoid-worsening-health-inequalities/ (date last accessed 7 July 2021).
21. **Hadorn DC**. Setting priorities for waiting lists: defining our terms. Steering Committee of the Western Canada Waiting List Project. *CMAJ*. 2000;163(7):857–860.
22. **Curtis AJ**, **Russell CO**, **Stoelwinder JU**, **McNeil JJ**. Waiting lists and elective surgery: ordering the queue. *Med J Aust*. 2010;192(4):217–220.
23. **Derrett S**, **Paul C**, **Herbison P**, **Williams H**. Evaluation of explicit prioritisation for elective surgery: a prospective study. *J Health Serv Res Policy*. 2002;7(Suppl 1):S14-22.
24. **Scott CEH**, **MacDonald DJ**, **Howie CR**. 'Worse than death' and waiting for a joint arthroplasty. *Bone Joint J*. 2019;101-B(8):941–950.
25. **Davis M**, **Heineke J**. Understanding the Roles of the Customer and the Operation for Better Queue Management. *Int Jrnl of Op & Prod Mnagemnt*. 1994;14(5):21–34.
26. **Asch DA**, **Jedrziewski MK**, **Christakis NA**. Response rates to mail surveys published in medical journals. *J Clin Epidemiol*. 1997;50(10):1129–1136.
27. **Rubin HR**. Can patients evaluate the quality of hospital care? *Med Care Rev*. 1990;47(3):267–326.
28. **Etter JF**, **Perneger TV**. Analysis of non-response bias in a mailed health survey. *J Clin Epidemiol*. 1997;50(10):1123–1128.
29. **Wensing M**, **Elwyn G**. Methods for incorporating patients' views in health care. *BMJ*. 2003;326(7394):877–879.
30. **Chang J**, **Wignadasan W**, **Kontoghiorghe C**. Restarting elective orthopaedic services during the COVID-19 pandemic: Do patients want to have surgery. *Bone Jt Open*. 2020;1(6):267–271.

Author information:

- K. Kulkarni, BMBCh, MA (Oxon), MSc, FRCS (Tr&Orth), Specialty Registrar in Trauma and Orthopaedics & Honorary Fellow (University of Leicester)
- R. Shah, BMedSci, BMBS, MScSEM, MRCS, Specialty Registrar in Trauma and Orthopaedics
- M. Armaou, PhD, Qualitative Research Assistant
- J. Mangwani, MBBS, MS (Orth), MRCS (Ed), FRCS (Tr&Orth), Consultant in Trauma and Orthopaedics & Honorary Fellow (University of Leicester)
- J. Dias, MBBS, FRCS, MD, Professor of Hand and Orthopaedic Surgery AToMS-Academic Team of Musculoskeletal Surgery, Undercroft, University Hospitals of Leicester NHS Trust, Leicester, UK.
- P. Leighton, BA (Hons), MA, PhD, Associate Professor of Applied Health Research, School of Medicine, University of Nottingham, Nottingham, UK.

Author contributions:

- K. Kulkarni: Conceptualization, Investigation, Formal analysis, Writing - original draft, Writing - review & editing.
- R. Shah: Conceptualization, Investigation, Formal analysis, Writing - original draft, Writing - review & editing.
- M. Armaou: Investigation, Conceptualization, Formal analysis, Writing - review & editing.
- P. Leighton: Investigation, Conceptualization, Formal analysis, Writing - review & editing.
- J. Mangwani: Conceptualization, Investigation, Formal analysis, Writing - original draft, Writing - review & editing, Supervision.
- J. Dias: Conceptualization, Investigation, Formal analysis, Writing - original draft, Writing - review & editing, Supervision.

- J. Mangwani and J. Dias are joint senior authors.

Funding statement:

- This study was funded by AToMS-Academic Team of Musculoskeletal Surgery research funds. In addition, staff volunteered their time above and beyond their own roles. No benefits in any form have been received or will be received from a commercial party related directly or indirectly to the subject of this article.

Acknowledgements:

- AToMS (Academic Team of Musculoskeletal Surgery) & Leicester Arthroplasty Remote Clinic (LARC) team: Elaine James (Team Leader, AToMS), Chris Bunce (Research Assistant, SWIFFT & DISC), Sarah Caswell (Project Support Lead, LARC), Herjit Heer (LARC Administrator), Mustakim Karim (LARC Administrator), Judy Jones (Research Administrator DISC). Sally Le-Good (General Manager for Elective Orthopaedics). Omar Gabbar and Aamer Ullah (Consultant Orthopaedic Surgeons, University Hospitals of Leicester NHS Trust).

Ethical review statement:

- This study was approved and registered with our clinical audit department (no. 10738). Separate formal ethical approval was not required.