COHESIVE interim results of Round 1 Delphi survey

-PATIENTS AND PUBLIC-

Summary

The aim of COHESIVE (Core Outcomes for early pHasE Surgical Innovation and deVicES") is to develop reporting guidelines and a core outcome set (COS) for new surgical procedures and devices. A COS is an agreed minimum set of outcomes that are measured and reported in all new surgeries. Before new medicines can be introduced into clinical practice, they undergo rigorous testing and this process is highly regulated. New medical devices are also regulated before they can be widely used, though ways of assessing their safety and performance vary, and standardisation of what is reported is also lacking. New surgical procedures are, however, even less regulated. There is uncertainty and inconsistency around what outcomes should be monitored and reported to evaluate them, which can compromise patient safety and lead to inefficiencies.

A vital part of this project is a multi-stakeholder Delphi survey, consisting of two rounds of online questionnaires. Patients, the public and healthcare professionals around the world were invited to take part in Round 1 of the survey. This brief report summarises the response profile of participants self-identified as surgical patients or member of the public with (henceforth referred to as 'patients').

Recruitment and response rate

The COHESIVE Delphi survey Round 1 was conducted between 11th July and 16th September 2019. Patients with experience of surgery (surgical patients, patient representatives, carers and family members) were asked to respond to an online survey about outcomes across four different stages of surgical innovation (as proposed by IDEAL). Respondents were asked to rate the importance of 32 outcomes.

Recruitment relied on word-of-mouth and snowballing. Members of the COHESIVE Study Steering Group and the research team had identified contacts in their network to distribute the link to. Study promotion through PPI (patient and public involvement) leads and the recruitment through organisations such as Bowel Cancer UK, Digestive Cancers Europe, Edge Hill Service User and Carer Group and The National Cancer Research Institute (NCRI) have been of particular value. This is demonstrated by the fact that most patients/members of the public responded to recruitment calls sent via email by partner organisations (55%; see Figure 1). This is followed by "Other" channels (17%), of which electronic newsletter (e.g. NCRI, University of Bristol) was the most frequently mentioned source. Hard copies of flyers were the least effective recruitment method (2%).

Social media was successful in recruiting at least 20 patients (16%). During the study period of 71 days, the COHESIVE study Twitter account totalled 50.8K impressions, achieving 268 clicks to the weblink where the survey was hosted. In total, 197 likes and 162 retweets were made by patients and healthcare, totalling an average engagement rate of 1.8% per post.
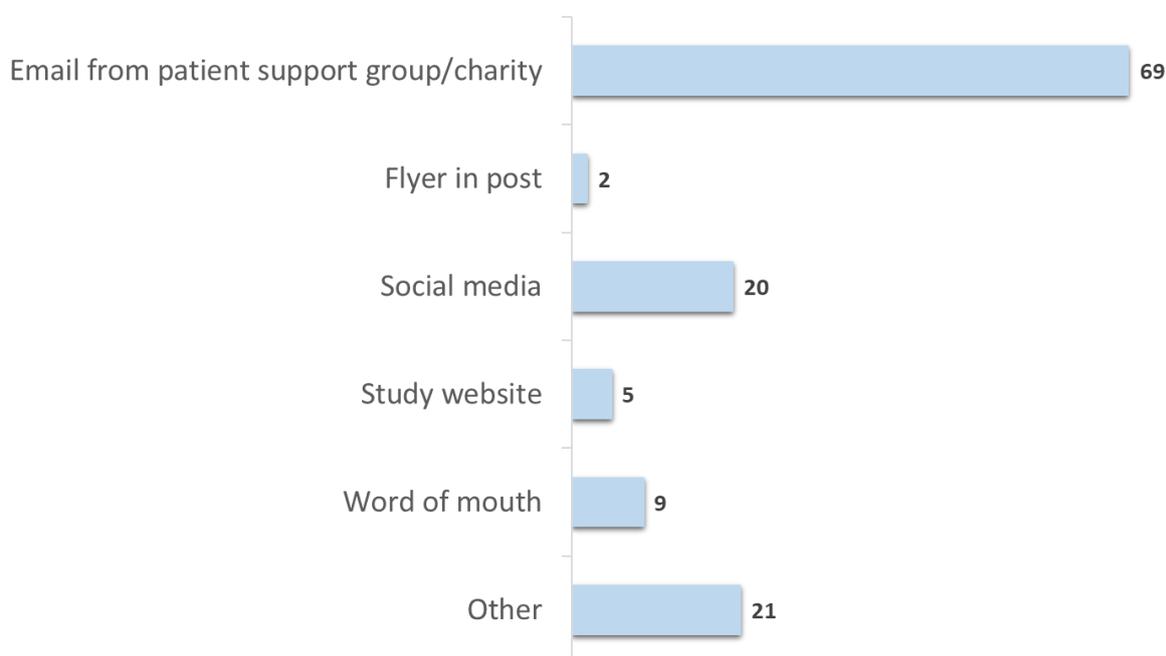
Figure 1 Distribution of recruitment channels, n=126 *(Question: How did you hear about the study?)*

In total, 319 patients/members of the public have attempted the COHESIVE Round 1 Delphi survey. Considering healthcare professionals, this is just under half of the total responses (45%). Of those, 131 responses were fully and 60 partially completed which resulted in 191 responses to be eligible to be invited to complete Round 2 of the Delphi. A summary of response rates for the patient survey can be found below.

|	*N*	Total Round 1 (%)	Total patients/public (%)	% Round 2 eligible (%)
Total attempts	319	45.4	100	-
not completed	128	59.5	40.1	-
Completed & partially completed (R2 eligible)	**191**	39.2	59.9	100
partially completed	60	38.7	18.8	31.4
completed responses	131	39.3	41.1	68.6

Table 1 Summary of responses and drop-outs

Demographic details

The study aimed to recruit a diverse sample of international patients. A good distribution in terms of age range and educational status was achieved (Figures 2 and 3). The majority of participants were over the age of 60 (58%) which broadly support the trends of an increased need of surgery in older age. Figures 4 and 5 show that there was a higher representation of female participants (60%) and a large majority of respondents live in the UK (94%). This is likely to be due to the recruitment strategy but also a possible consequence of language restrictions which require a good command of English to complete the survey.
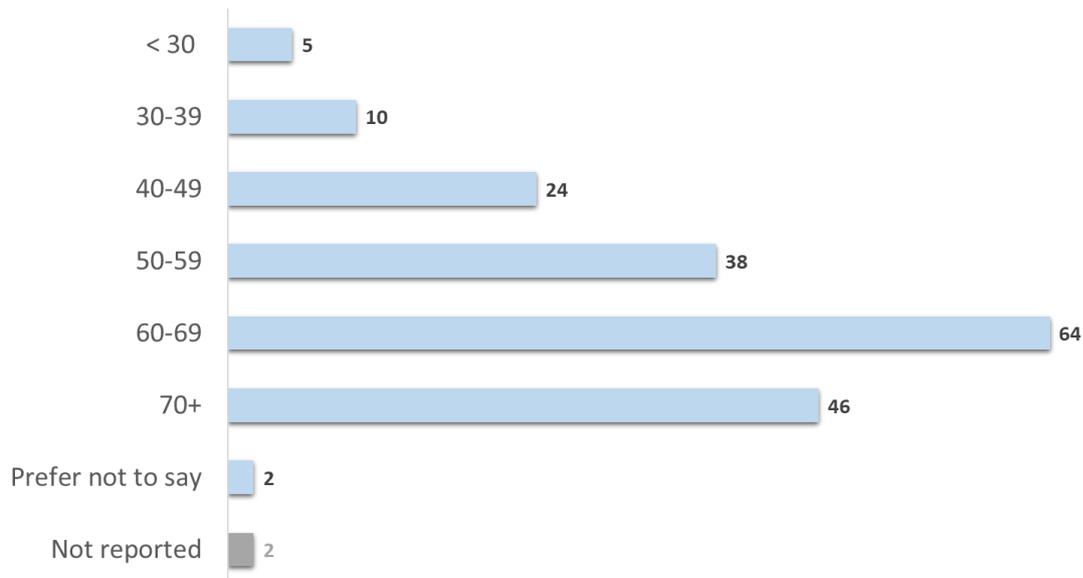
Figure 2 Age range distribution, n=191 (Question: How old are you?)
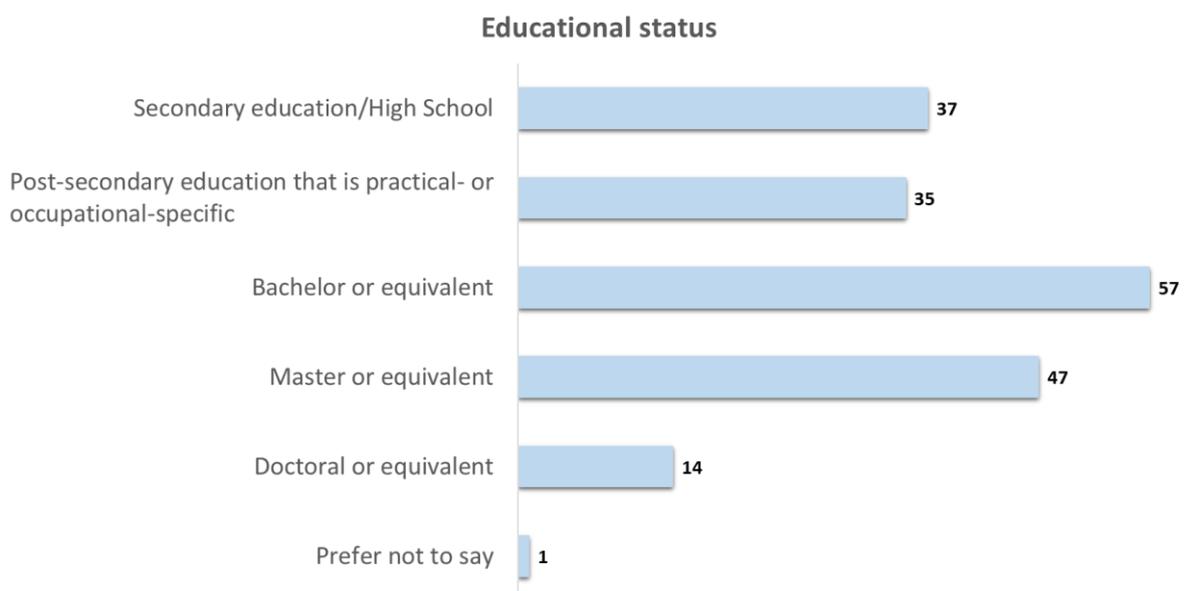
Figure 3 Educational status, n=191 *(Question: What is your highest education level?)*
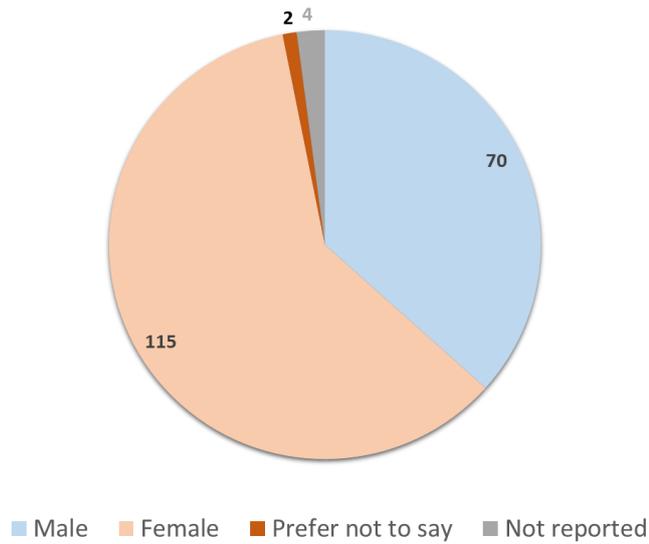
**Figure 4** Gender split, n=191 *(Question: Are you?)*

Figure 5 Country of residence, n=191 *(Question: In what country/region do you live?)*

Surgery-specific details

Nearly all participants were patients with experience of surgery (99.5%). About two-thirds (62%) of the participants underwent a procedure in the last 5 years. Bowel surgery (36%) was the most frequent surgery reported, followed by cancer surgery (33%)[1].

**Figure 6** Time of surgery, n=191 *(Question: When did you have your surgery?)*

- Less than 5 years ago
- 5 or more years ago
- Not reported
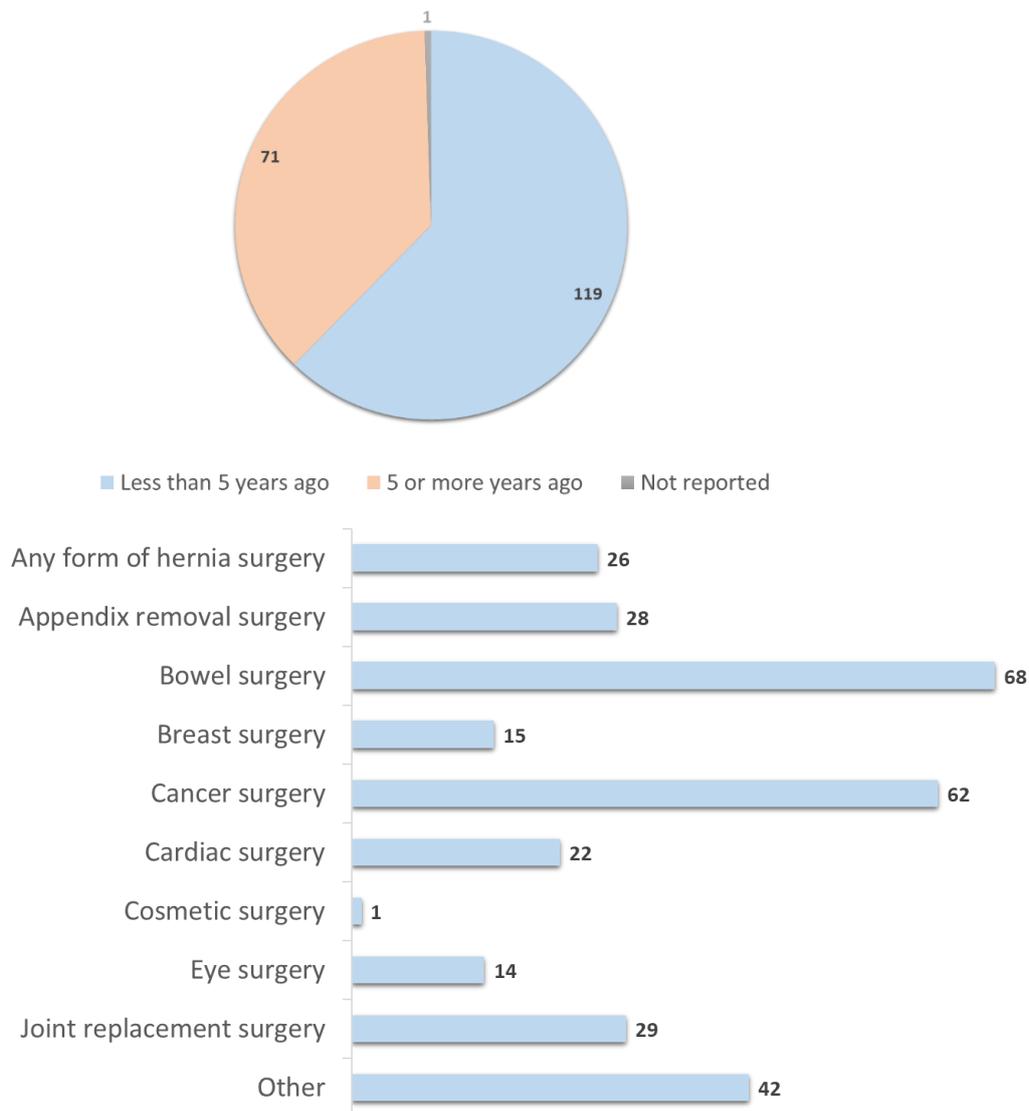
Figure 7 Types of surgery, n=307 *(Question: Below are some common types of operations. Have you ever had any of these procedures/operations?)*

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[1] Question answer options for "type of surgery" included some of the most common operations. The list intended to provide a manageable selection of different types of operations and did not aim to be exclusive. Rather, results illustrate how representative the sample is of some of the most frequently performed procedures.

Figure 8 below shows that most patients (86%) stayed in the hospital for at least one night. This may suggest a large part of procedures were invasive. The majority of respondents underwent a planned operation (87%) and most did not require a medical device to be implanted (61%).
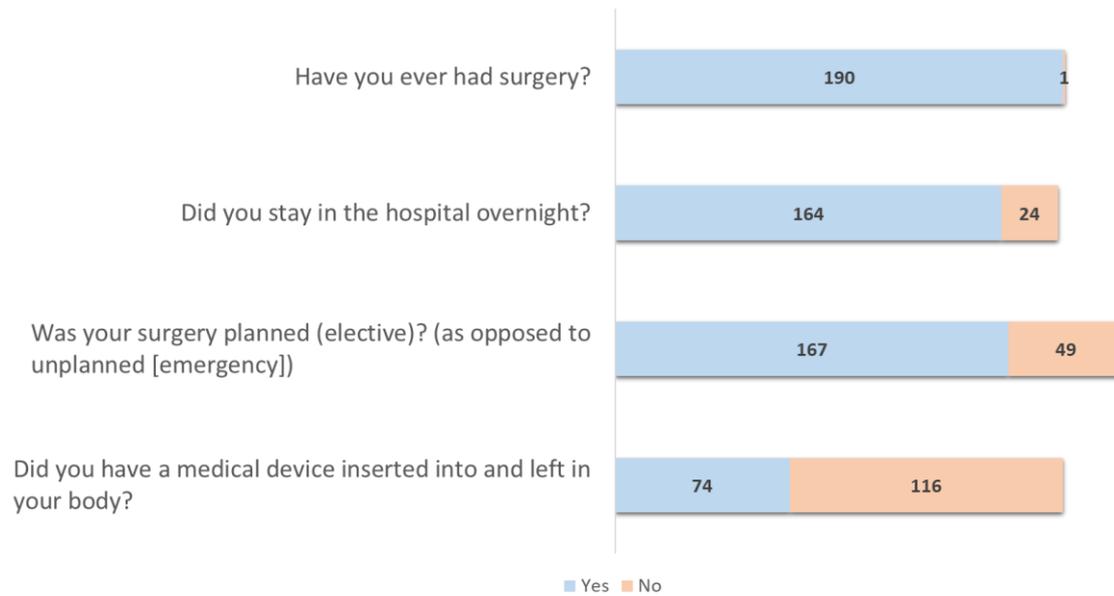
Figure 8 Details of respondents' surgical experience

Most participants had undergone between one and four procedures (61%) overall. Three (19%) and eight (3%) surgeries were reported the most and least frequent number of surgeries, respectively. There was also a high number of participants (10%) who have had more than 10 procedures in their life.
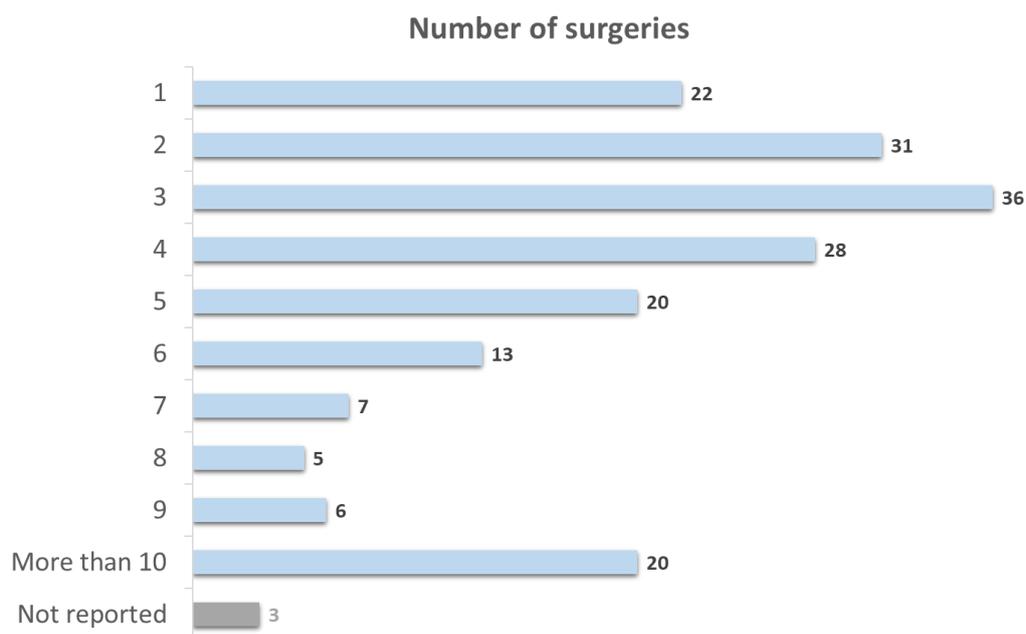
Figure 9 Number of surgeries, n=191 *(Question: How many times have you had surgery?)*

Acknowledgements

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If you have any queries, please get in touch with us using the contact information below.

Dr. Kerry Avery, Ms. Shelley Potter & Prof. Jane Blazeby

NIHR Bristol Biomedical Research Centre
Bristol Medical School, University of Bristol
39 Whatley Road, Bristol, BS8 2PS

Kerry.Avery@bristol.ac.uk and Shelley.Potter@bristol.ac.uk