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Improving the quality of research in emergency surgery

### **Purpose of the engagement/involvement activity**

This main aim of this body of work is to find out how to improve the quality of research into emergency surgery. It is important to involve the public in the running of this work, as it may have a direct bearing of how patients and their care are studied in the NHS. I conducted a Patient and Public Involvement event on 12 January 2021. At this focus group, individuals with personal experience of unplanned surgery were invited to share their views on the collection of quality of life data in the emergency surgery setting. The participants included people of different genders and from diverse ethnic groups, and one participant identified herself as having an autistic spectrum condition. The purpose of the event was to determine the participants' opinions on collecting quality of life data after surgery. This was informed by the participants' experience of their own emergency surgeries. I was particularly interested to know whether participants would have been willing and/or able to provide quality of life information before and after their surgeries. This involved demonstrating a number of quality of life questionnaires to the participants in order to understand which research tools are the most appropriate in the emergency setting. In addition, two of the participants provided extra written feedback after reviewing questionnaires in more detail.

### **What benefits do you think the engagement/involvement activity had**

- 1) The involvement activity has reinforced the importance of the research question and has provided extra reasons to perform the research, and desirability for funders.
- 2) The research proposal will incorporate the participant's preferred quality of life questionnaires to enhance the recruitment and retention of future patients to the research study.
- 3) In response to the participants' feedback, the research proposal will now include engagement of the next of kin of the patient undergoing emergency surgery.
- 4) The participants also gave tips as to how to keep recruited patients in the study, and these engagement activities will be incorporated into the proposal.

### **What were your lessons learnt?**

The participants endorsed collecting quality of life data as an outcome measure in surgical studies. They emphasised the importance of ensuring that the data collection was not '*another ritual*' and that the information was used effectively; in particular, the potential use of the quality of life data to enhance the process of informed consent for future patients was encouraged.

It was generally felt that the process of consent for an emergency operation was a formality: *'I was given a very stark choice that the surgery would save my life, so there was no question about whether I wanted to opt for it or not.'* Despite this, the participants would still have valued a discussion about quality of life after their procedure.

Outcomes which the participants would have liked to be informed about at the time of consent for their emergency surgeries included *'mobility, self-care, the ability to walk, the ability to lift and carry, which otherwise create a dependence on someone else.'* In addition, they would have valued pre-operative information about pain, fatigue and *'psychological things such as body image, not being able to do the things that you want to do, becoming unemployable.'*

An unanticipated focus of the group's discussions was the importance of communicating potential changes to the patient's quality of life to their next of kin. One participant said,

*'You cannot discount the impact of a family member or carer being involved in this whole process. Because otherwise it can create a great deal of isolation and loneliness, so that family support is crucial after a major operation. They should be notified of some of these potential implications and complications that may happen post-surgery, and what to do about them if they do happen.'*

This was seen as particularly important in the emergency setting, where *'the patient's next of kin has a critical role to play...because if the patient isn't fully aware of what is going on, then you need that information shared with the supporter.'* The process of consent before emergency surgery was described as a *'black hole'* that engulfed all the information given to the patient. It was thought that patients' relatives would be more likely to absorb the information, especially if the patient is acutely unwell.

*'Once I got home, the fact that my wife had been fully brief on the consequences of what was happening, she was able to help me.'*

When asked about the feasibility of assessing patients' quality of life prior to emergency surgery, the participants were divided. Some drew on their own experiences to explain that the acutely unwell patient might not be able to provide quality of life information preoperatively: *'Once surgery became an option, I was too ill [to fill in a quality of life questionnaire], I wasn't really aware of much that was going on, and there was a period of about two weeks when I was so ill that I don't think I could have done anything.'* It was felt that this would be compounded by a simultaneous life-changing diagnosis, such as cancer, as the patients *'might need time to process that a bit more.'* Other participants felt that quality of life data could be collected preoperatively, but that clinicians and researchers should be flexible and, where possible, allow patients to fill out questionnaires *'at their own speed, not necessarily in the clinical environment and when they've had time to discuss it with their husband or wife.'*

The focus group participants were clear that quality of life should be collected for many months after surgery, in order to get an accurate idea of the longer-term impacts of the surgery.