

ESORT PPI Workshops – July 2020

Attendees:

ESORT team: Richard Grieve (Monday), Andrew Hutchings (Thursday), Claire Snowdon, Silvia Moler Zapata, Paul Charlton, Beth Silver

Clinicians: Ravi Vohra (Monday), Dale Vimalachandran and Frank McDermott (Thursday)

PPI panellists: Stella, Stephen, Debbie, Sue, Oliver, Emma, Fola (Monday); Alan, Brian, Jay, Katherine, Nicola, Raj, Sudhir (Thursday)

Workshops were held on Monday 6 and Thursday 9 July. 7 panelists attended each workshop, several joining slightly before the start-time to have an informal conversation. The format was identical for both workshops. Panelists were provided with bespoke preparatory material via Sway (a) in order to ensure accessibility, particularly because the panel included a visually impaired participant; and b) as we unable to hold a pre-discussion training session due to the pandemic.

1. Welcome and Housekeeping

Claire opened each workshop by welcoming participants and thanking them for joining.

2. Outline of the role of the panel and introductions

Claire explained that the panel was critical to the project as it enabled us to find out about people's real-life experiences - the 'lives behind the data'. She outlined the plan for the session and invited members to introduce themselves. She then noted that she would start recording the meeting.

3. Brief Outline of the ESORT Study

Richard (on Monday) / Andrew (Thursday) gave a quick overview of the study, explaining the aim was to understand for which patients emergency surgery is effective and cost-effective.

4. Tasks

Task 1 – HES Outcomes

Claire noted that we were using HES (Hospital Episode Statistics) data from people who had received care, so we can't change the outcomes which have already been tracked in HES. Claire reminded panelists of Helen and Amir from the pre-reading and the two different approaches with these two patients. (At this point, several panelists praised the quality of the materials provided). Claire flagged the HES outcomes being used from: whether readmitted within 30 days, whether alive at certain periods, and cost of care.

Panelists discussed these issues. Comments included:

- Pain – both post-op and beforehand (as a motivation to have the surgery)
- Psychological impact, including one patient whose PTSD was triggered by her experiences
- Recurrence of issues e.g. whether repeated trips to hospital
- Family obligations and ability to have a 'semi-elective' procedure a few days later
- Recovery time
- Impact of underlying conditions and comorbidities / low nutrition levels at point of surgery
- Type of surgery (e.g. whether keyhole) and impact this can have mentally, on recovery etc.
- Impact of swiftness of diagnosis and length of time in hospital before the operation
- Value of money: better to spend more if the outcome is better.
- Administrative efficacy i.e. are follow-ups happening as they should?
- Not just are you alive but "what are you alive with"?

Claire invited panellists to undertake a quality of life questionnaire and reconvene after a break.

Task 2 – Health-related Quality of Life (HRQoL) Outcomes

Claire reconvened the session to talk about quality of life outcomes. She noted that there were limitations to the data available. She explained that we could use HRQoL scales to understand how different people compare. Silvia then discussed HRQoL for the two conditions in more detail, noting that the questionnaire creates a score (from zero to 1) and that we can aggregate different patients' scores to see how they feel at different points in time.

Claire then invited panelists to discuss **appendicitis**. Comments included:

- The fact that appendicitis was an acute condition which could be dealt with in one go – not an underlying disease
- Mental element of *not* having surgery, worrying that the illness could recur. Also the mental element of having a planned procedure, which one could prepare for physically and psychologically. Gave me much more peace of mind to plan it
- The need to have choice and control where at possible.

Claire then invited panelists to discuss **diverticulitis**. Comments included:

- Variability amongst individuals: scores could differ significantly depending on how bouts are affecting you.
- Psychological assumptions that people can have e.g. assuming that they would not want a stoma, but many people find it changes their lives completely.
- Outcomes affected by age, body image, sexual behaviour etc (in context of stoma)
- Mood elements of the HRQoL would be really important.
- Issues such as wound infections and what quality of life people can have

Tasks 3 – How might coronavirus have affected decisions about care in 2020?

Richard (Monday) / Andrew (Thursday) explained that COVID-19 has had major implications for emergency surgery. We were hoping to expand the ESORT study to consider the COVID period, to help work out who should be having emergency surgery. They invited panelists' thoughts on emergency surgery during the Covid period. Comments included:

- Would have to consider prevalence of COVID in the community and risk of contracting it, vs. living with an acute condition via non-operative management.
- Trauma of treatment during Covid was discussed. Panelist who had had surgery said it was scary, given the 30% mortality rate post-op if you get COVID. Plus, very hard not having family to visit, and struggling to communicate with staff in full PPE. One panelist noted the possibility of PTSD being triggered, as she had had this experience with a traumatic surgery.
- Difficulty of making such individualised patient risk assessments where some people's mental states or learning / communication abilities may be very difficult. Massive risk of inequalities.
- Where surgery is not vital and quality of life manageable, several commented that they would wait for a procedure in the current environment

Richard invited panellists to join a subsequent panel focused on the Covid era and asked them to let Claire know if they were interested.

Claire and Paul formally thanked the panelists, noted that they would keep them updated on the progress of the study and closed the session.