ESORT COVID 19 PPI Workshops 10th and 11th May 2022

Attendees:
ESORT C19 team: Richard Grieve (10th), Claire Snowdon, Paul Charlton, Clem Taft, Beth Silver (10th) Andrew Hutchings (11th)

Clinicians: Ravi Vohra (10th) Susan Moug (11th)

PPI panelists:
10th: Oliver, Emma, Katherine, Nicola, Sudhir and Fola.
11th: Stella, Sue, Brian, Stephen, Sue and Nicola.

Apologies:
Alan and Jay

Workshops were held on Tuesday 10th and Wednesday 11th May 2022. 6 panelists attended on Tuesday and 6 attended on Wednesday, most joining slightly before the start-time for an informal conversation. The format was identical for both workshops.

Panelists were provided with bespoke preparatory material in advance to ensure accessibility for all and provide necessary information on what had been done previously and how progression had been made to the current project.

1. Welcome and Housekeeping

CS opened each workshop by welcoming all and thanking them for support of the projects. She gave tips for the session and summarised the 3 tasks that that the panelists would be asked to complete during the session, focussing on the new study, looking at our findings and working out the value of them. She gave an extra summary for new panelists.

PC then led the introductions of both panelists and the study team, demonstrating a mix of new and previous panel members with a range of experience from both patient and medical profession sides. CT then started recording the session.

2. Reminder of ESORT Study Findings

RG (10th) and AH (11th) gave a reminder of the ESORT study – looking at the benefits of emergency surgery (ES) vs. a 'watch and wait' strategy. e.g. with appendicitis, antibiotics could be a better approach than surgery. The study looked at 2 alternatives and found that overall outcomes, death or days out of hospital, were similar but that outcomes were much worse following ES for frail patients. Conversely, for those who were fairly fit when they arrived, it was better to have surgery in a quick timespan rather than 'watching and waiting'.

3. What is the ESORT COVID 19 study

RG / AH went on to summarise the ESORT Covid 19 study

- looking at routine data on emergency admissions for the same 5 conditions: appendicitis, gallstones, diverticular disease, abdominal wall hernia and intestinal obstruction.
- Focus on people coming in for ES and what happened in the 1st lockdown period: mid-March to mid-May 2020 compared with outcomes from the same time period in 2019.
- Examining and comparing the number of emergency admissions, how many patients had emergency surgery or alternatives, whether patients were readmitted and how many deaths or days in hospital.

Findings:

- Strong themes emerged – much fewer emergency admissions 20 v 19; would expect subtle differences normally year on year but saw roughly 1/3 reduction for each of 5 conditions.
- Smaller proportion admitted actually had ES. More had alternatives e.g. antibiotics or delayed surgery.
- Higher number of emergency readmissions, decrease in planned or elective readmissions. Most worrying was higher death rates before 90 days.

PPI sessions will focus on 2 of the conditions: appendicitis and gallstones: key differences but also common findings.

- Appendicitis: more had watch & wait e.g. antibiotics with a higher proportion of readmissions compared to 2019. If they had surgery, less difference year on year.
- Gallstones: if they had ES more likely to come back to hospital. Increase in number who died.

4. <u>Task 1 – What do our data tell us:</u>

CS then asked for the panelists' views on the main results from the 1st wave of COVID-19, which were:

- Big reductions in emergency admissions during first wave
- Big reductions in numbers having emergency surgery (e.g. appendicitis)
- Big increases in numbers of emergency readmissions (e.g. gallstone patients who had emergency surgery)
- Big drops in numbers who had later (elective) surgery
- Increases in numbers of patients who died

Q: increase in deaths, specifically gallstone deaths or Covid?
RG: we were able to separate those who had been diagnosed with Covid and remove from analysis which slightly reduced excess death, but it didn't go away. As we know, the measures of Covid weren't perfect then as there was much less testing so we cannot be completely sure of the causes of death, however we can see that there was an excess death rate even without Covid deaths.

Q: was the drop in numbers because of those who had elective surgery?
RG: substantial reduction in planned surgery for gallstones. Can't say whether it was postponed beyond 90 days. About to analyse data for up to a year. Massive shock on system and push on waiting lists was an issue.

RG: death rate a concern – is it because people aren't getting ES but then coming in as emergency admissions?
RV: prior to Covid, we were treating the mix of ill and relatively ok in the same way but then the system became so stretched they had to discharge some patients who should have been operated on, but then came back in.

Q: did level of complications increase?
RV – massive reduction of people coming into hospital. Were those in hospital only those with severe pain / infection? In appendicitis: which didn't disappear, saw a drop in people coming into hospital. Suggesting it's a self-limiting disease. For a proportion of people, it just settled down.

Q: re. the wording: 'big reductions in numbers having ES' - is that actual number of people or in percentage?

RG: Percentage. Absolute number was a 1/3 down. Of those that came in, smaller proportion had surgery. People who came in were very sick but it wasn't always possible for them to have ES due to covid limitations.

Q: is there specific information regarding why a patient died e.g. specifically gallbladder or Covid?
AH: we don't have the data at the moment so whilst it looks more like Covid, we haven't seen 'cause of death' data yet.

Q: pandemic showed us that diet is vital to good health. For those who were at home, did they have loads of antibiotics, medicine etc?. OR were they advised to have better, healthy lifestyles? Should we consider studies to look at those with poor health and how they get the diseases so that focus could come onto looking at how good health helps people?

RG: yes, study throws up ideas for further studies. People were discharged far faster so onus on them to help themselves to recover. But higher proportion came back into hospital.
Were support services sufficient to help those who were discharged early?

Panel shared experience of emergency admission during 1st lockdown – those who were shielding were at great fear of going in, so by the time they did, were really sick and/or in severe pain.
Then discharged very early which led to being readmitted, some several times either due to illness or not having been able to have the surgery at the time. Personal fear as well as anxiety amongst health staff. Not just fear to self and others but also awareness of how difficult it was on the system at the time. Some patients went in when pain was so bad they had no choice. Would have gone to another external site to be assessed if it had been possible but there was no other choice than A&E.

Surgeons couldn't plan surgery due to risks of Covid and lack of theatre staff.

RV: First 3 waves were horrific - the type of disease it was and mortality. General feeling now is that Covid has changed to something more endemic and priority is for healthcare system to try to find some sort of normality and sort out waiting lists - as disease changing, dangers have shifted. Vaccination helps as can have Covid and still function now.

Q: How do we support patients in a pandemic e.g. virtual ward? Lack of outpatient support was an issue. Was too much placed on risk of Covid?

CS: there seem to have been 2 sides of patients: those who supressed the need to go and those who were at their limit of suffering. Are there certain situations when people are more able to 'deal with' their situation at home?

RV: Options available to clinicians changed significantly, it was an unknown time. Some of the associations / colleges, didn't give as much due diligence to the advice they were putting out. Operations surgeons were advised to do because of Covid, may not have been the right decisions. Medical community need to be more careful about what messages are being put out there. Decision making not necessarily poor but guidance possibly ill advised. Clinicians responded to what was available.

CS: was it poor decision making or a situation that was extremely challenged and constrained e.g. many pressures during the 1st lockdown, the fear in the messages for those shielding, challenges for those making decisions. Very hard for clinicians to know what best to do for their patients.

RV: cancer patients all still shield and don't want to mix as much as they did.
CS: we don't hear it as much anymore compared to messaging that there were those that absolutely could and should not go out at all. So would not go to ICU.
Interesting weighting by patients of risk v pain.

AH: what we don't know is who was really ill but didn't go in versus who delayed and then had to have more severe, emergency admission at a later stage.

SM: we have a window of opportunity with messaging now, going forward, there can be other pathways e.g. antibiotics for appendicitis and Gallstones better dealt with by fast surgery.

Q: what's happened to waiting lists?
SM: operations cancelled at start of lockdown, have since had to prioritise (P1 cancer, P2 urgent, then P3, P4) and a pool of waiting list that they still can't catch up on. Some patients happy to be low on waiting list as fearful of going into hospital, others happy to go in now as keen for surgery and feel hospitals safe now.

PANEL COMMENT: one patient knew that her health situation was key to her condition; feels that if it had been communicated that helping her own health and weight would help the pain and her mortality, would have pushed her to help herself. Onus could and should be on patient to help themselves – but only if messaging is better / other options, are communicated.

Break – Claire invited panelists to take a short break.

5. <u>Task 2 – What are the most important messages to convey:</u>

What should we say to the outside world about this data? Suggestions:

1 – Importance of clinicians, where possible, sticking to usual referral and care pathways.
2 – Patients need to be aware of importance not to delay going to hospital.

Thoughts from the panel:

PC: concerning frailty that was heavily discussed in first ESORT study, what were frailty outcomes during covid?

RG: We didn't have enough people to analyse frailty in first wave, but currently have a much larger set of data so will now analyse this. Also, putting 2 ESORT studies together, if we find out that people who are frail are better off not having ES, would it free up capacity for those who would benefit from ES? Appendicitis non-ES strategies have been worked up but not so much for other conditions. Should this change?

Q: wording 'usual referral and care pathways', is this under normal circumstances? If we get another winter wave it will be difficult to stick to normal pathway, so will we end up in same situation? Recommendations for clinicians to stick to usual referral but is that possible and what does it mean?

CS: we have a new normal from pre-covid, is it time to create new pathways?

RV: difficult to try to handle winter pressures in general whether Covid or other, always difficult to follow normal pathways. Elective services always really badly affected. More problematic with Covid as airborne pathogen. Emergency pathways are intertwined with what is happening.
Idea could be to disassociate elective and emergency – hospitals for each. So if there are pandemics can divide the two. But no political appetite to do that.
However, for patients and medical professionals who have been in hospitals that did this during the pandemic, they felt a far safer environment and worked extremely well. But is it practical?

AH – with regards to prioritising; which aspects of the health system need to be maintained to function as they largely do at all times and which parts have more flexibility to amend or deal with

Covid, so that overall impact minimised? What can we learn from experience and from data as to how to proceed?

SM – old school pathways don't stand up during pandemic but nor does shutting everything down. Separate access could work – elective v emergency hospitals. Keeping them separate so that people could get through safely and quickly.

GENGERAL COMMENT: changing pathway a positive not negative, should always be trying to improve.

PANEL COMMENT:
From a patient perspective, during lockdown, far too much social media so messaging was that hospitals were not a safe place. So much anxiety given through messaging. How do we get information out to people in an accurate way?

RV: messaging is so important as is leadership – the Covid landscape changed minute by minute and England did not manage it well. Social media makes it very difficult to dispel untruths.

CS: what do we now say to our patients about what to do? Using pandemic data to work out what to say in the future.

Q: re clinicians sticking to referral pathways, post-Covid, do we know what they are? GP's differ in their approach.
Long-Covid: does that influence clinicians sticking to referral pathways?
SM: yes, challenging as patients with different needs now e.g. rural links, public transport.
PANEL COMMENT: 2 sides: what are the messages now and what could / should there be if we are in another pandemic situation?

6. <u>Task 3 – How might we use these data?</u>

- How do we use the data?
- What happens when the system is squeezed and patients are nervous? e.g. winter pressures? Future pandemics?
- How relevant are our findings to future challenges?

Q: will data be communicated out to GP's so they know the importance of face to face?

RG: not immediately – paper will be published in various journals but GP's are an audience that we need to reach. This might be what we need to do for a future paper. Haven't yet had enough data to look deeper, but with what is coming now, will be able to improve analysis.

PC: significance of messaging is so important to the public health aspect of pandemic management. Would it be worth having a conversation with public health groups re this data?

RG: Yes - we have spoken to NHS England, who are interested in key messages.

CS: what lessons can be learnt about what might stop people going to hospital if there is another pandemic / wave?
SM: possible change of mindset of people to not instantly go to hospital unless severe, could help ease pressure on NHS.

RV: Covid has provided to be ultimate 'stress test' for the health system. Normal winter pressures do not apply this level of stress to healthcare system, but it does give us an indication of where

breaking point is. Major learning point for healthcare system is how we can better manage these when they occur.

CS: what about situations in local hospitals like outbreak of a bug, which might make people more reluctant to turn up to A&E?
Our slide is looking at stressful situations but maybe value is in the routine situations. Getting people out of habit of thinking hospital is not the right place to go. Maybe it's the mundane and ordinary we should be thinking about. During pandemic, did we change expectations? We couldn't speak to GP so we just 'got on' as had no other choice.

General discussion:

PANEL: change in practice between GP's and hospital-based doctors, entire system should be connected but is fragmented in approach post-Covid. Also – 111, what adjustments did they make during Covid and have they made post-waves? Decision making process involves the advice you're given. Even post-advice from 111 would still seek advice from other family, friends & professionals and unsure on correct action.

PC: considering the sincerity, intensity and value of what has been said, how do these discussions influence the studies?

RG: the comments are exciting from a research viewpoint as communicating with people from across the UK, adding valuable insight. This project is very big from a data perspective, so PPI allows us to get a more personal view.
AH: key for us to understand what is important and less-important to you. As well as understanding experiences of healthcare and how we could / would do things in different situations. Also to think about what sort of questions we want to ask when looking at future data.
CS: Also, an extremely valuable result of PPI endorsement is that it helped LSHTM to get funding for further research.

Q: will there be funding to continue after July end date?
RG: we have funding for a multi-morbidity study; an extra 6 months to look at people with these conditions and the pressure placed on the NHS.

PANEL COMMENT: important point about family support as reason for delaying presentation. Parental pressures for instance, can delay presentation at hospital due to concerns of infection and we all personal need for help.

CS: dominant message was to not put pressure on other family or on NHS so many people did not want to go into A&E.

PANEL COMMENT: pre-reading pitched perfectly. Enough detail, clear language and obvious effort.

Claire thanked everybody for their feedback, engagement in pre-reading and involvement in the tasks, especially to those who had worked with us over all the sessions.

Meeting Close
Paul closed the meeting by thanking everyone for their involvement and especially the ESORT team for their work on this subject. He reiterated that they have been great sessions and LSHTM had clarified the value of these conversations. Great uncertainly over what contribution we can make to research, but personal experiences really do matter.