Webinar: Uncharted territory – Using patient data to tackle COVID-19

Thursday 28 May, 2020 10:00 – 11:30

Questions recorded on the Chat function:

All questions are exactly as-posted. They are listed in the sequence in which they were asked

- Thanks for v clear intro Natalie. In your view, how much of current 'easier' access to data is streamlining that we would be happy to adopt permanently, or dropping of usual standards that we would not? Will (University of Leeds)

- Are panel members aware that those who wish to book a COVID-19 test online must have their identity confirmed by Trans Union, a UK subsidiary of a multi-billion dollar US credit reporting agency?

  Do they believe this is necessary?
  Is this seeming lack of transparency On Government's behalf justifiable as we are experiencing a 'public health crisis'?

- Natalie: What is your understanding of oversight mechanisms relating to release of Covid data, in particular for linked datasets combining, say, covid and cancer data.

- In terms of public trust in commercial use of data. NHSX and OLS were working on a commercial framework for the NHSX Centre for Expertise. Will something such as this be fast-tracked to ensure long-term safe use of patient data?

- there is a lot of information being garnered by charities now about what is happening to their patient groups ...any recommendations on what charities should be careful of when they're doing this; and secondly any suggested route for getting all this info together and using it well?

- Is the CPI only allowed to be used for COVID research?

- Much of the government's work on test and trace has been via focus groups. Do we know why they aren't publishing the various reports from these (which may well involve hard-to-hear groups) and indeed the discussion papers they are looking at?

- I'm absolutely committed to transparency - both as a citizen and as well as a charity - but how much transparency is useful? Raw data dump might lead actually to both misinterpretation and stun the general public (too much detail, too technical) so they stop bothering? How to balance that?

- is there any insight into what data is important to collect? Do we collect data from a patients point of view, what control do I have over inputting into my data. is it always done on my behalf?

- What is the Patient/Public Involvement in any of this? Or is that what Paul is going to look at?

- What does Natalie see as the key benefits that has arisen in terms of the timely access to data since COVID-19?

- Data quality and completeness in healthcare data is variable at best. Are there any risks in the use of poor quality, sometimes downright incorrect and patchy data? Patients often have great difficulty accessing and checking their own data and extreme difficulty in getting errors corrected. Any thoughts on that aspect?

- Has the C-19 response shown that actually we do not need all the obstacles created by Confidentiality Advisory Groups and others? We have sanctions readily available for people who break the rules; why have so any bodies all interpreting rules to their own advantage and not to ours?

- 3.7million plus patients are contributing to the Kings College / Zoe Covid-19 symptom study. Does this show that patients are prepared, for good reason, to share their personal health data (albeit a restricted set of data)?

- I'm interested in how we use the opportunity of the progress on data use that has been made rapidly in this crisis to enhance healthcare in future, while ensuring there is public understanding, confidence and support. I think there has been tolerance and acceptance of change in the eye of the storm, but that should not be taken for granted.

- Many government advisors disagree with government policy. Policy is always a political choice. "Led by science" is a red herring and always has been, not least because science hasn't yet found definitive answers to C-19 anywhere, not in stopping it, curing it, or preventing it.

- should all COVID 19 research that is looking for patient and public participation have meaningful PPI mandated as a condition of funding?

- I really agree with the two points that have been made on PPI. This is lacking in decision making and research around COVID. Some great examples and some great initiatives, some mentioned on this chat. However there is no system-wide PPI approach.

- The COVID problem is likely to return if the anticipated difficulties in creating a vaccine are realised. Will data be used to discover additional ways the public have helped themselves? The use of masks, supplements, more stringent hygiene procedures, physical distancing, etc. Are we asking what members of the public have done in addition? Or not done?

- I wonder how much data has already gone to USA in the premise of getting our tests analysed!

- "meaningful" PPI is itself open to question - relevant? effective? useful? to whom or to what - patients, funders, science? and who judges? PPI is always possible and usually desirable but in some cases it has been attempted with 24-hour deadlines;

is that useful (to whom?) or tokenistic and who is to say which? I have always thought that PPI should add value to the research; there is a danger that it may become a question of adding credence (eg NIHR's insistence that every study has PPI but making no systemic evaluation at all of what it was or what it added), and that opens a whole new can of worms.

- Completely agree re importance of PPI, as in all research - though it does need thinking about in this particular situation (some useful thinking on this done already by HRA and others) - not least defining who the potential PPI contributors are, given that we're all affected by this disease (some more than others, clearly). Probably an opportunity to do things in a different (/better) way than in research-as-normal. Definitely still seeing research waste and duplicated effort, and I'm sure PPI could help with that problem, amongst others.

- C-19 is likely to infect 95% of the population if unchecked, and will kill 2% at current rates. Cancer will affect 50% of the population (over a much longer period) and will kill half of those (eventually). Why do we delay and stall so much about using cancer data?

- Just to agree both with Lynn Laidlaw (with her shorthand) and Paul/Richard's wider points about the communication of data.

- More on PPI: if time is undoubtedly tight in getting new covid-19 studies set up, then PPI might be most practically and usefully embedded in the highest-level decisions about prioritising research questions rather than detail of research projects (if that's perceived to be more time-consuming) - and then at the other 'end', making sure results are made available and implemented into policy where needed (NB yes, all of this should be standard anyway!)

- As a wider point beyond research, it felt like there was negligible PPI in the early NICE/NHS E guidelines about (say) ITU Triage - and it wasn't surprising that that guidance had to be withdrawn.

- Yes, NICE hasn't involved any patients/ public in any of their rapid guidelines. There is a disconnect here, at a time we have been asked to share data/ participate in research more than ever there is less Involvement and Insight sought from patients and public.

- Hi Lynn; my point essentially is that simply summoning a focus group or having a chat online and calling that PPI isn't enough - but that DOES qualify for funding from some funders! We need to abolish the largely meaningless word "meaningful" and focus on what it is we mean - effective, relevant, informative etc. Stella's point about the NICE ITU Triage experience is very well made. PPI is a critical friend and too often the researchers or funders focus on the friendly bit and not on the critical bit. Grrrr.

- James is showing an excellent example but we need to remember that collection of and access to cancer data - including treatment data - are way ahead of most other conditions and their treatments; not all, but most.

- Richard is absolutely right. Should every project have a small report on PPI recording what PPI input was ignored and what was changed as a result?

- Excellent point about the potential for financial toxicity health insurance and its costs in other non-UK healthcare systems.

- Richard: is 'impactful' better than 'meaningful'?

- A q for the panel. What is the single change in use/accessibility/..... of data would each panel most want to retain for the future?

- I am not disagreeing with the points you make Richard, PPI critical friend function crucial to research and it isn't happening at the moment. It's only the funders that have the power to change this situation.

- Important to note that not all societies - even in the west - have citizen involvement the way we would see it. Denmark for example has very different attitude to Government holding and using data

- Are we still missing reliable data on some groups in particular circumstances similar to those in care homes - prisons, homeless hostels, asylum centres?

- Realtime data sharing as an early warning system (so to speak) for emergent areas of interest such as any impacts on pregnancy (different stages) or particular demographics or settings?
  A YouGov wing for patient experience? :) (wrt Paul Charlton)

- re "patients" agree, on the one hand we are all patients so patients = public, not all would identify as such, plus critical to integrate health and social care, and that is a different language - carers, service users etc. "people who use services" plus public?

- Terry Emery. My own hospitals PPI group has recognised that we have to adjust our own way of working. So we have reviewed protocols in a day instead of taking a week; many things like this allow involvement while still recognising the circumstances of an emergency.

- agree terminology is tricky but it's not the same as buying utilities etc. People rely on health and social care services

- People with "lived experience" is useful, but may seem to exclude those without LTCs who just use health and care services for more occasional interventions

- Agreed - the lack of good registries for so many diseases is such a barrier. It's what Swanson refers to as a knowledge necropolis - so much exists but it can't take on a useful life because it isn't accessible or analysable.

- Can the paper Natalie just mentioned be shared?

- how might we mobilise patients/service users/public to ask for more in relation to data and data use to make progress with public support, but not (unduly) scare the horses?

- Question for James: Are the other hubs working on COVID-19, similarly to DataCAN?

- Natalie says we have a plethora of bodies to regulate the use of data. True. Can this not be simplified?

- Terry Emery. If, as seems the case, 'data' is going to make an immense contribution to combatting the disease, how can this be best used to change the general attitude towards data use? Will 'data' be acknowledged for its effect or will the 'credit' be assigned to eg a hospital or a 'lab' or a 'scientist'?

- there is a lot of information being garnered by charities now about what is happening to their patient groups ...any recommendations on what charities should be careful of when they're doing this; and secondly any suggested route for getting all this info together and using it well?

- Hi Jane, let's talk! Think charities need to work in coalitions so in advocating for our respective constituencies we do not inadvertently appear to be challenging/competing with other needs. So many diverse needs out there.

- Data completeness: Very important. Also the right data. What data items are we using? Do we need to take account of lifestyle, nutrition, exercise etc. Not just the smoking and drinking?