Questions posted by delegates during the webinars on Trusted Research Environments:

(Note the questions are as typed by delegates)

- Do commercial users have the same rights of access to a TRE as public sector or academic users?
- How easy is it for someone to be able to find out what uses had been made of a TRE?
- Clarity is needed about costs of access to TREs. Is there a standard model, or are TREs going to become competitive? Lowest cost might not always be in the patient interest
- We seem to have a number of TREs run by different groups. What is the strategy to link or coordinate between them so we have a national service rather than separate TREs?
- Does research suffer by being limited to databases within the home nations rather than being truly national - i.e. whole UK?
- Will TREs do away with the need for all data releases?
- What are the different models for patient involvement in existing and developing TREs - contrast GEL, SAIL and NHSD
- How is HDR-UK bringing to bear what we know about public attitudes towards third parties accessing health data (even if de-personalised) that is routinely collected?
- Most data in TREs will be routinely collected, and not consented. GEL is the exception. How will TREs deal with the problems of using non-consented data?
- Who is responsible for data completeness in TREs?
- How safe are TREs to cyber attack?
- What is the difference between GP data in SAIL, NHS Digital and CPRD?
- How representative is the Welsh panel of the population whose data is held and used? Are there any sceptics on the panel?
- What are the reservations around the use of free-text data and what are the solutions?
- What is the average time from date of request to data access being made available to researchers? How does this compare with average access times for non-TRE data requests to NHSD?
- What work is done to make sure the data in the TRE is correct? Patient data has been coded correctly etc. How are updates passed through? Is there an active link through to the original data, or is the data stored at fixed time points, so that researchers can work on different versions?

- Rather than focussing on who gets the data (big bad commercial companies) and how they get it, should we not be focused on what it is used for (new vaccines for example).
- Is the legal basis for sharing data between TRE suppliers sound? I think NHSD have struggled with this in the past? Who would give data to whom to link?
- Was that a suggestion of a national standard of using ONS accreditation? MIght be a good idea, but could they cope with the demand?
- Need to separate justification for use of data (ethics, IG etc) and the assessment that a specific TRE provider is suitable. So back to some framework of trusted providers? And one size should not fit all, because flexibility (over data movements etc) can be justified *if* the risk of data (disclosure etc) is lower say. Hence ATI risk framework idea.
- Airlocks - perfect example! Should data exports have independent referee? ATI says yes, for highest risk (identifiable and sensitive), but no for pseudonymised - let researchers handle this themselves. This seems to make sense, and would encourage de-identification be design.
- TRE standards might help getting standard idea of costing too, based on storage/computer power x duration, and maybe possibly risk tier. Many smaller projects though cannot afford premium TREs.
- Biggest disincentive =cost.
- Security of access point is very important, and again can be directed by risk tier. Safe room, secure shared office, home, COSTA etc...
- Consent is a legal-ethical issue. GDPR would require proportionate security, so back to risk tiers again?
- Is there a security audit process for TREs to ensure that security procedures and technologies are adequate (including third party penetration testing)? You might start with TREs needing IS027001, compliance with NHSD DSPT and cloud best practice, and then bolt on the ATI risk tiering-security controls framework.
- My data isn't used enough for my own care never mind anybody else's.
- I think the panel are in danger of overcomplicating what for many (?most) ordinary people is a simple issue; fix my illness and use my data to do it and get on with it. And yes, if my data helps my hospital or the NHS then get on and do it. And if it helps researchers

help other patients, get on and do it. All these rules and regulations; too many fingers in too many siloed and soiled pies. Too many lawyers.

- The risk benefit is far too skewed.
- As an aside, opting out of health research strikes me as immoral!
- Technical standards are all well and good as long as they are implemented correctly and O/Ss kept up to dates and patched etc
- Do we then engage patients on research priorities for the sort of research TREs should facilitate, including what is not currently possible?
- Opt out should be a human right, and certainly is wrt research
- ...and yet, the tremendous benefit that comes from the output of research is just assumed. I would like to see this narrative switched.
- Fully anonymised data is usually free from the need to consent. But it is often hard to use anonymous data. There is usually some need to link, and some risk, but hopefully offset from the output - the vaccine, the new chemo...