

Public Advisory and Accountability Group Meeting summary - Feb 2025

Meaningful Engagement



Attendees - 6 members in attendance with 3 staff facilitators. Currently lacking young people who are a focus area for recruitment.



The PPIE report has been really well received. "I like the format". The exec summary is the most important thing to get right - "most people will skim"

The Opt-out infographic is a bit busy



"Can we make a podcast?" An idea that keeps surfacing.

Relentless focus on improving communications

"Closing the loop", "We don't get feedback", "we put a lot of effort in and then it drops off"

- A clear desire to have improved communications that follow up on what has happened rather than just moving on or getting lost in the hustle. Slow is steady and steady is smooth



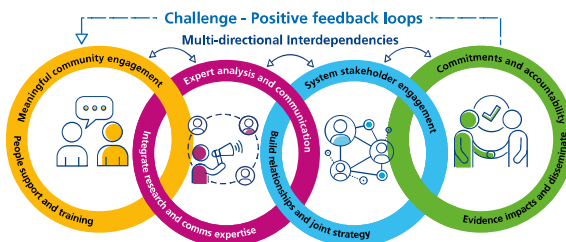
Actions - Infographic for Opt-out

Dale to make a clearer version - currently Ismael produced a more minimalist table for the website with written information to support. Asked to:

- Make de-identification clearer
- Remove summary care record info to reduce clutter
- Reduce techy words, focus on explanations



Action: Stephen suggested he may know someone involved with the Hospital Radio which could be a Podcast lead



Analysis and Communication

Exploring resources such as Google's Federated Learning comic - federated.withgoogle.com

Whilst the attempt to tell the story in comic was welcomed there was some distance to go.

- Dale and Stephen felt it was useful to explain things to a person with a decent level of technical expertise. Likely however, to complex for those with less expertise.
- This was echoed by the group and feedback
 - "Too techy" - Tech bro silicon valley type audience too - need to be more relatable
 - "too long for my attention span" - People play videos at 2x speed too
 - Would like more likeable characters - UK context
 - Need to get the information across in less frames (or a short "tiktokable" video)

"I feel the NHS is early in its public engagement journey, I do find the NHS is more defensive when I engage compared to other organisations"

- One of the more experienced members commented how we as a group and program are trying to operate noting that this type of openness doesn't seem to come as easily for the NHS

"We don't get feedback about how the money is spent"

- The group want more information about the commercial elements and how this is unfolding.
- This needs to balance openness without an expectation every pound and penny spent is itemised and justified. As the risk is staff are spending more time explaining themselves than actually working. Creating more bloat and bureaucracy. We can explore ideas like how money is spent based on themes (see image below for an example). And can start with getting our own house in order. How do we spend money in the PPIE workflow for example.

Action: Dale to continue exploration of how we make things transparent. Such as how the money is spent. This could look like a blend of pie charts, line charts, and tables. Focusing on spending themes, like staff costs, resources, technologies etc. See below

Stakeholder Engagement

Meeting attended by Dr Stephen Dobson, Director of OneLSC

Dr Dobson said "It's always a pleasure to hear our publics perspectives. The candid nature of the discussions cuts back to the core of what we are here to do. Helping ground our work to improve people's health and services. I look forward to both our website, engagement report and ongoing work in this space and encourage others to take the time to join our public forums."

We have one project so far focused on Prostate Cancer as a "national driver" project. Though recognise we need to improve how we communicate these projects, their aims and impacts.

BREAKING NEWS

Confidentiality Advisory Group Submission

- We are submitting our regions work for approval to enable data use for more than national care.



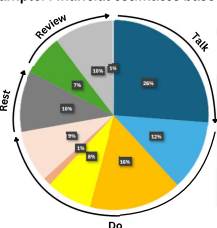
Actions: Dan/Dale - final updates for report and then critical review of exec summary by team. Making good progress.

Dale to sit down with Vishnu to move us closer to being on the same page

Recommendation: **Rethink... Medical Data** on BBC sounds <https://www.bbc.co.uk/programmes/m0027tx8>

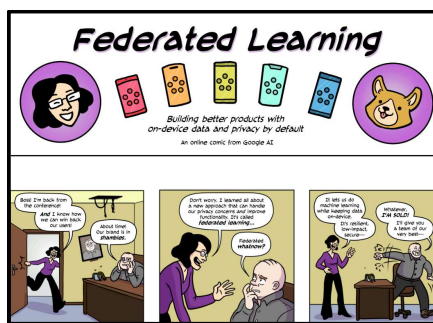
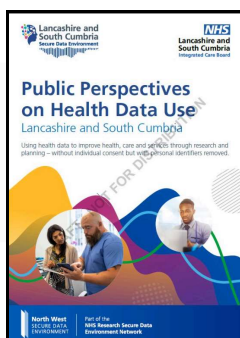
- Have a listen for food for thought

Example: Financial estimates based on proposed activities



- Meeting Coordination
- Project coordination
- Co-production
- Animation and Creative output support
- Report design
- Platform
- Annual Review
- Evaluation
- Flexible fund
- Remainder

Similar to a Plan-Do-Study-Act cycle. However, actions are being taken during the doing phase with feedback and co-design done in parallel.



Example: Financial breakdown based on Staff, public and external resource costs



Knowing your rights: Health data and data-opt out options



Examples

Health data use for individual care

GP shares a summary care record with the hospital

Hospitals shares data with you GP for direct care purposes

Health data use to support planning, population health and research

NHS managers can use the data to support planning of services.

Public health experts can use the data to do population health research

Research can access de-identified health data for discovery

Allow research data access

You are happy for doctors, researchers and service planners to access information to support the healthcare system and research. As well as your individual care.



National Opt-out

TYPE 1: GP data

Your GP data will only be used for your individual care. Not for planning or research

OR

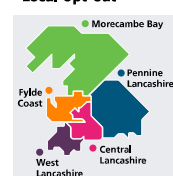
TYPE 2: All hospital and GP data

All your NHS data will only be used for individual care. Not for planning or research.



This GREY box represents health data usage which is "de-identified". Things like names, dates of birth, address and mobile numbers are removed. Protecting individual privacy and medical information.

Local Opt-out



You do not want your local health system or hospital using your health data for research or planning. Though still support use of your health data for national research and planning.



Please note that you can activate more type of opt-out depending on your preferences. National opt-out affects both national and local research and planning. Local opt-outs only affect use at a local research level. Not national planning and research level.



How to opt-out

No action required. To opt back in click [here](#)

Contact GP

Click [here](#)

Contact local organisation
01253953057