



use MY data - using our voice - How our Members are encouraging the use of health data to benefit others

Questions raised during the webinar

Note: Some questions were asked direct to the speakers and some were asked via the 'chat' box.

Your examples all covered health data. Does your remit cover social care data?

I think the update I gave reflected that health data is more widely recorded, shared and linked. Social care data is less well coordinated, but I think it's part of our overall health, so would be in scope.

What does X stand for in NHSX?

NHSX was set up as a "technology" arm of the NHS national bodies. It was actually meant to stand for "user experience".... But it's now moving into NHS England.

Diabetes PPIE links: "give your opinions on the use of your data in research"

<https://www.diabetes.org.uk/research/take-part-in-research/steadfast>

Do you have any specific examples of implementing Arnstein's Ladder of Citizen Partnership that you can share?

Arnstein's ladder is a model for understanding how the degree of citizen participation in government can affect public perceptions of legitimacy, authority and good governance. It presents different levels of public participation, with the 'most desirable' forms of participation found the higher you move up the ladder.

When you use the ladder it is sometimes is hard to reach the top of the ladder on smaller projects- is it better to consult than not do any form of PPI on a data project?

The ladder is a valuable tool. You should always 'get in' at the most practical level, then evolve the nature of the involvement. 'Consult' works if you can develop engagement from there as a base.

Link to the ladder <https://i2s.anu.edu.au/resources/stakeholder-participation-arnsteins-ladder> amongst many other links.

I have a rare cancer and see no one making an effort to collect the wealth of data and experience that I see in what is an international Facebook community. How do you get clinicians interested in this data?

In the UK, every new primary cancer is always registered by the cancer registry. In recent years this has included much more clinical information, such as surgery, radiotherapy and chemotherapy. So rare cancers are captured in the cancer registry. Helen's presentation showed the work that she had done with the national registry in England to get more of these statistics published in a safe and useful manner. The best way to get the interest of clinicians is to highlight this to them, or perhaps to ask them what statistics they have.

However, the cancer registry does not routinely gather information about day to day living events (experience), which are often reported in social media platforms such as Facebook.

Invitation to all patients involved in use MY data to sign up as patient reviewers for the BMJ

www.bmj.com/campaign/patient-partnership

Bob White and Helen Bulbeck – maybe you might consider writing a BMJ Opinion on what you do and why? Same for all the patient speakers here. This is the series

<https://blogs.bmj.com/bmj/category/patient-perspectives>

BMJ would welcome BMJ Opinion on the challenge of data cleaning for researchers.

Are Flatiron a commercial company? Are they the same as DATA-CAN?

How does the mission of Flatiron differ from DATA -CAN? What kind of company/organisation is Flatiron? Is it profit making?

Flatiron and DATA-CAN are different organisations. DATA-CAN is a research collaboration funded by the government through a grant from the Industrial Strategy Challenge Fund. They have a specific focus on bridging the gap between NHS data and commercial organisations, and they undertook some work with Flatiron some months ago to help shape the model for Flatiron in the UK.

Flatiron is a commercial company that specialises in improving the quality of the health data in an NHS Trust, so that the data becomes usable for research. They have recently launched their UK website, "with all thanks to Bob, Helen, Linda, Lesley and our whole Patient Voices Panel for working with us to develop and sign-off the website. You can learn more here: <https://flatironhealth.co.uk/> "

How many Members of use MY data are there?

196 Members (patients, relatives, carers)

145 Associate Members

341 in total

The recent statement led by the Health Research Authority and shared by a dozen public sector organisations on patient involvement in research, is clearly sympathetic to use MY data principles. How can we ensure that the deeper issues of data transparency etc. are pushed forward in this context?

We all have a responsibility to do what we can to push this agenda. As a movement use MY data engages with a wide range of organisations about transparency, including recently about the GDPR programme and the NHS COVID-19 Data Store. Our Members have also produced a Position Statement about transparency, which is [available here](#) for our Members to use in their own work.

Around 10 million people in the UK can see all their records via the Electronic Health Record (EHR) vendor "Patients Know Best (PKB)". I have full access via [my GP Practice] Patient Access portal but it does not work.

And a related question:

What are the patients' rights in terms of having access to read our own health records?

We have Position Statements which are very relevant to this topic, which are on our website: https://www.usemydata.org/page_db.php?page=Position_Statements and we hosted a webinar **Show me my data!** in which Patients Know Best took part, which can be watched here: <https://www.usemydata.org/webinars.php?webinar=2021-03-03>

The British Medical Journal (BMJ) ran a series of webinars on access to Electronic Health Records (EHRs) and has a collection of articles on this to show global progress.

There is no streamlined common process to correct EHRs - and there needs to be

We published a Call to Action "My access to my health records" on this subject, following the **Show me my data!** webinar.

The Call to Action is [available here](#) on the use MY data website.

How do you manage groups when they say that everything that is said here is 'confidential' ???

This can be a tricky area, but common-sense should apply. If you asked to maintain confidentiality in conversations or meetings, there should always be a clear reason why. In some cases it will be clear, in which case if you want to take part, you should respect that. If you don't think there is a valid reason then you should challenge that, and if you're not happy with the response, you can simply not take part.

How are use MY data ensuring diversity amongst their Members and what are you doing to include the voices of underserved groups or lesser heard communities?

Since use MY data began, it has grown organically and has always been open to Members from all backgrounds. We are a movement that concerns itself with inclusion and seeks to emphasise the

voice of patients to understand aspirations and concerns around the use of data in delivery, service improvement, and in research.

As an open movement, we had never asked our Members to provide any details about themselves, such as age, ethnicity or gender. However, to help meet our aim, we needed to understand the breadth of our Members' experiences and backgrounds. We wanted to do this to understand whose voices were missing or under-represented. We could then begin work to remedy this.

Working with our Advisory Group, the Secretariat produced a census to collect this information from our Members. The first part of the census was about personal characteristics and the second part was about engagement activities. The census was anonymous.

The analysis of the census results is [published here](#).

We mapped our results against the UK's general population and the patient population. The results show that we have good representation amongst our Members in most areas. The area where there is under-representation is in disease/health conditions other than cancer. We need the help of our Members to increase the voices of patients, relatives and carers in this area. To do this, the Advisory Group and Secretariat have identified a set of actions for our Members and for the Secretariat.

Does use MY data work with the James Lind Alliance on priority setting partnerships?

Not to date, though some of our Members have in their wider work, but we'd love to follow this up with you.

How useful are the trusted research environments to researchers?

We've done a few webinars related to Trusted Research Environments (TREs) and indeed the related topic of synthetic data. TREs could address some significant difficulties in research access, but there are some practical things that need to be in place to ensure that patients are actively involved in the governance, decision making, access, etc. But this is a very active area, that we might want to revisit...

How does the ethnicity/belief/views of staff have an impact - is this data collected?

We haven't come across anything that looked at this, though we are aware of a recent survey which looked at attitudes of staff in primary care about data sharing.

<https://understandingpatientdata.org.uk/sites/default/files/2022-03/Primary%20care%20professionals%27%20attitudes%20to%20data%20use%20.pdf>

Are you able to help us, the patients with data analysis?

use MY data doesn't hold any data and it does not analyse data. But we do run educational sessions on data for Members, and we could do something on data analysis, if that would be useful.

Research which uses patient data can often also involve the collection and use of human biosamples. Has this combination of using patient data with human biosamples for research ever been explored with the use MY data Membership?

We previously worked with a range of organisations to understand the issues around the low utilisation of tissue samples for research. Our report, [The Issue with Tissue](#), include a range of recommendations which have been take into national and international conversations. Details of the project are also [on our website here](#).