Bristol Health Partners

University of BRISTOL
Elizabeth Blackwell Institute for Health Research

Improving health through better use of data

Tuesday 19 September 2017

Workshop report

Introduction

On 19 September 2017, ninety-five delegates attended a workshop about improving health through better use of data. We focused on a project to create a 'health data inventory' and how it could be advanced.

The day began with three information sessions:

- An update from Professor Jeremy Tavaré about the story of the inventory's development so far.
- A video which outlined what 'version 1' of the inventory looks like and how it might be used.
- Dr Julian Walker gave three case studies of health data projects in action, and what he learned through them.

This report summarises delegates' discussions from the workshop. The resources section gives links to some of the projects and tools mentioned on the day. Recommendations from the workshop will be shared with the Local Digital Health R&D Group and Bristol Health Partners Board.

For more information about the work, please get in touch through hello@bristolhealthpartners.org.uk

Ambitions for a health data inventory

The health data inventory presented at the workshop was at an early stage of development. The project team was keen to make sure the inventory is progressed in a way that meets the ambitions of the people that will use it.

We invited delegates to tell us what potential they thought the inventory had. There was a spectrum of ambition from creating a secure, unified data-set to releasing process efficiencies.

A summary of emerging themes is provided below:

- A tool which supports developments and new ideas to **improve health outcomes**.
- Improved **collaboration** between unlinked data sources, groups, people and organisations.
- More **efficient data collection, sharing and use**. Delegates thought the inventory has potential to reduce the number of duplicate data collections both between and within organisations. By giving information about data sources in a single place, delegates suggested the burden on data controllers to field multiple queries should reduce. If the project increased transparency, delegates suggested barriers and vested interests that have previously blocked data sharing may be broken down. There was also a potential benefit in the inventory encouraging

greater consistency in the data sources organisations used. This would improve comparability of information across the system.
- More **locally applicable** research that can inform decisions. By connecting researchers with the local data sources and data controllers, there was an opportunity to answer the research questions that matter to local people and our system's context. Delegates felt this might also increase data controllers' engagement in research and service planning projects.
- Empowering people to control their own health and to make health and social care services more **accountable.**
- Enabling a **local integrated data set** to be created. Several delegates felt that the main ambition should be to develop a secure platform which would be a single point of access where local data could be linked and extracted in anonymised form for research and service planning.

The project team was encouraged to develop a 'roadmap' which articulates the overall vision for the inventory, and the steps required to get to that point.

Following this discussion, we will:
- Work with the Local Digital Health R&D Group to draft a vision statement for the health data inventory. This will be shared with delegates and other stakeholders (including patients and members of the public) for review and development.

Improving a health data inventory

We collected recommendations for how the inventory should be developed to meet the ambitions above:

- Include more **public health** data-sources.
- Add more **information about the structure and content of data sources** to improve the usefulness and searchability of the inventory.
- Include the **voluntary sector** in developing and adding to the inventory.
- **Map not only data sources, but also expertise**. Add details of those that are experts in the data sources listed. There should also be information about data scientists and others that can help with linking, anonymising and using data.
- Add **data sources from non-health sectors** (e.g. crime sources, education sources)
- Consider including **literature review and grey literature** repositories.
- Add a mechanism for people to **add their own data sources** and identify missing information.
- Ensure the inventory is accompanied by **data sharing agreements** between the organisations involved.
- Allow a **comments feature** for people to share experiences on using data sources.

- Add **national and international data-sets** which can be sliced to give information about our region.
- Label all data sources to show whether they can reveal **information by certain variables** (e.g. can you analyse by postcode, age, gender, ethnicity)
- Design the inventory to help **answer the critical questions** that the system wants to ask now.
- Consider **overlaying socio-economic data** (e.g. Acorn and MOSAIC) onto the data sources in the inventory.
- Develop **synthetic data sets** which contain 'dummy' data that correspond to the sources listed.
- Make data accessible through the **Open Data Platform.**
- Learn from **other regional initiatives** (see resources section).

Following this discussion, we will:

- Work with the Local Digital Health R&D Group to agree the scope of sectors and information types to be included in the inventory for the next phase.
- Contact other regional initiatives to share experience.
- Discuss opportunities to align with the Open Data Platform.

Challenges

Delegates shared their views on the challenges that the project will face:

- **Governance and political issues** need to be resolved at a high level.
- Need to show **cost savings** to convince management.
- **Mixture** of easily accessible information and that which has complex access requirements.
- **Quality assurance** of the data sources described in the inventory and the inventory itself. At present, there is no hierarchy of evidence within the inventory. Ensuring the information in the inventory is current.
- Determining whether it should be a **'catalogue' or 'resource centre'.**
- There is a **risk averse culture** and different organisations have different understandings of information governance.
- **Resources and time.**
- **Public engagement**. Providing both reassurance and proactive contact about the project need to be balanced. It's possible that service users may be happy to share data where organisations are not
- People will want to use this data **- applications to use data will increase.** Will this need to be funded?
- **Enabling** people to use the data sources listed in the inventory.
- **Making it work for all interested parties.**
- Without **buy-in from data owners**, the project risks encouraging protectionism/reducing openness.
- Ensuring that the project is not **reinventing the wheel.**

- Negotiating **commercial interests** and ensuring that public benefit is primary focus.

Following this discussion, we will reflect on these challenges with the Local Digital Health R&D Group to inform plans for the next phase of the project.

Project ideas

Throughout the day, we collated project ideas which might benefit from the inventory or make the most of local data sources.

Some broad project areas were raised:

- Homelessness and health
- Economic inequalities
- Health literacy
- Routes into / through / out of care
- Children in care health outcomes
- Cancer care / self-management / support
- Mortality among people with disabilities
- Neighbourhood design / physical activity
- Diabetes misdiagnosis - what are the causes of diabetes? (e.g. virus/infections)
- Linking Hospital Episodes Statistics data to primary and social care data

Delegates also provided some more specific suggestions:

- **Understanding self-harm patient pathways** (prior to health services, access to health services, admission to health services, after health services) and the relationship between self-harm and domestic violence. This could draw upon several sources: University Hospitals Bristol NHS Foundation Trust self-harm register, domestic violence register in A&E department, Council database - surveys of school children, Police database - MARAC, soft intelligence and primary care database. The project would help identify related problems, enable targeted support
- **Young people with eating disorders' experience of primary care**. Research to date has suggested that differing views on eating disorders in primary care (between GPs, patients and carers) may affect care. Through linking GP databases with Hospital Episodes Statistics and population databases (such as ALSPAC) a project could help identify whether there is a delay to assessment/treatment/ access to secondary services.
- Exploring **experiences of the dementia care pathway for black and minority ethnic (BME) communities**.
- Use researchers to go to individual organisations to **review asset registers** and help with their informatics strategy- what could be consolidated? What could be linked?
- **Enhancing Council data** – Joint Strategic Needs Assessment

- Locally, how **do patients progress through their diabetes**? A project that would look at incidence and experience of diabetes in areas of deprivation (using postcode data) and linking with primary care systems (EMIS), acute data, the renal register, patient reported outcomes and information through the diabetes digital testbed.
- The One Care Consortium may be interested in linking GP and secondary care data to evaluate the **impact of e-consultations.**

Following this discussion, we will work with the Local Digital Health R&D Group to discuss how these ideas might best be taken forward.

Support

To advance work in the region to make better use of data, the following support was requested:

- Help with **data governance -** data navigators/linkage experts would help (flow-charts, how to guides [including time scales])
- Having a **single point of access** for researchers
- **Exemplar queries**
- **Access to other data users** and their experience
- **Education and training**
- **Anonymising** data records
- A **network** for 'area of interest' to join researchers and data providers
- **Contact details** for data source owners
- Service to **support using the inventory** to ask a specific questions (online) - for example, enter clinical question - response: can the inventory help them, how?

Following this discussion, we will:

- Review the support that we are able to provide for the community with the Local Digital Health R&D Group.

Other outcomes

Through the event, we were notified of new connections being made to work on project opportunities. In addition, people reported finding out about new data sources that could help them with their work. Occasionally, these were sources within delegates' own organisations of which they were not aware.

Evaluation summary

Delegates were asked for feedback on the day. 58 responses were received – a response rate of 61 per cent.

The following feedback was received on how well the workshop met its aims:

Aim	Very well	Fairly well	Not well	Not at all well
Tell the story so far of developing the inventory	43%	55%	2%	0%
Explore the potential of the inventory and define its boundaries	12%	64%	24%	0%
Explore the practical implications of using the inventory to design projects	12%	47%	36%	5%
Help to Build New Networks and Collaborations	28%	51%	10%	2%

The full evaluation report is accessible here.

Next steps

We will progress the recommendations above with the Local Digital Health R&D Group, Bristol Health Partners Board and Elizabeth Blackwell Institute Executive Board.

We will stay in touch with delegates as the project progresses.

Thank you to everyone who contributed.

Annex: Selected resources mentioned on the day

- Born in Bradford – city wide sharing agreement for all GP practices https://borninbradford.nhs.uk/about-us/
- Connected Health Cities: www.connectedhealthcities.org
- Hampshire Health Record Analytics: www.graphnethealth.com/customers-case-studies/case-studies/hampshire-health-record/
- Health data finder for research: www.hdf.nihr.ac.uk
- Join Dementia Research register (for identifying patients interested in research opportunities: www.joindementiaresearch.nihr.ac.uk
- Open Data Bristol: https://opendata.bristol.gov.uk/pages/home/
- SAIL Databank: https://saildatabank.com/
- Understanding Patient Data initiative: https://understandingpatientdata.org.uk/