Bristol Health Partners

Developing a Health Data Source Inventory.

Lessons learned report

1. Background

This report describes the lessons learned through building a 'Health Data Source Inventory' (HDSI) for Bristol, North Somerset and South Gloucestershire.

The project aimed to describe the data sources in the region's NHS, local authority and academic organisations that could be used for research and service planning. This would become a first version of a joint 'information asset register'.

The HDSI project arose from the shared interests of Bristol Health Partners and the Elizabeth Blackwell Institute, University of Bristol in making better use of local data sources. Both organisations recognised that there wasn't a way to understand what information people might be able to work with in our region, and where it's held.

Our work to create the HDSI was overseen by a Local Digital Health R&D Group[1], with membership from local organisations and informatics initiatives.

The intention was to:

a) Collect and collate meta-data about the data sources in our region
b) Do more detailed investigation of a sub-set of the data sources
c) Initiate 'exemplar projects' which would use the information in the inventory to help design new informatics and research projects

The project sought to serve our emerging Sustainability and Transformation Partnership in their work on the local digital roadmap for Bristol, North Somerset and South Gloucestershire. It was collecting only 'information about information' – it did not seek to collate data held in the data sources it listed. A flyer about the project is available at **Annex A.**

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[1] The Local Digital Health R&D Group is hosted by Bristol Health Partners and brings together academics, patient representatives and professionals from NHS organisations and local authorities in Bristol, North Somerset and South Gloucestershire with an interest in health informatics. Find out more here: www.bristolhealthpartners.org.uk/about-us/local-digital-health-research-development-group/

2. What did we do?

2.1. Data gathering

In January 2017, we contracted consultants with backgrounds in health informatics to begin collating a list of the data sources held in health, academic and local authority organisations. We sent a letter to all lead organisational contacts, inviting them to contribute information to the project (see **Annex B**).

Initial information was gathered using the following methods:

- Directly including organisations' information asset registers (or equivalent documents) shared by organisational contacts.
- Transcribing information from interviews with lead organisational contacts about data sources held.

Approaches were made to the organisations that contribute to Bristol Health Partners[2], selected partners in our local Sustainability and Transformation Partnership[3] and key health informatics and research initiatives[4].

Following the initial data gathering (March 2017 - August 2017), we began to source publicly available descriptions of the data sources in the inventory. Rather than seeking this from project contacts, a Health Informatics Intern – Runa Begum – was recruited to refine the information in the HDSI.

A final round of data-gathering ran from October 2017 - August 2018. This sought to provide more detail about the data sources listed in the inventory. For example, labels giving the field structure of data-sets.

2.2. Patient and public engagement

Throughout the project, the views and priorities of patient contributors were sought. A meeting with the People in Health West of England Strategy Group helped shape the project's approach to communications, as did the contributions of our patient contributors on the Local Digital Health R&D Group.

On 26 July 2017, patient contributors attended a workshop to design the strategy for patient and public engagement in the HDSI project. This included reviewing engagement objectives, considering the audiences that might be interested in the project and influencing the methods of engagement. A report from this event is available at **Annex C**.

Following the workshop, we ran Digital Cities Bristol events in October 2017 to showcase a visualisation of the HDSI, and to have a broader conversation about how projects like the HDSI can be used to help understand Bristol's health stories.

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[2] Avon & Wiltshire Mental Health Partnership NHS Trust, BNSSG Clinical Commissioning Group, Bristol City Council, North Bristol Trust, University Hospitals Bristol NHS Foundation Trust, University of Bristol, University of the West of England

[3] Bristol Community Health, South West Ambulance Service NHS Foundation Trust

[4] Avon Longitudinal Study of Parents and Children, Connecting Care, South Central and West Commissioning Support Unit

2.3. Sharing with potential users

On 19 September 2017, ninety-five delegates attended a workshop about improving health through better use of data. This workshop was the first ‘launch’ of the HDSI and was designed to gather views on what delegates thought the inventory could help them do, and how it should be developed to meet their needs. The report from this event is available at **Annex D.** Delegates at the workshop used the inventory and their own knowledge of local data sources to suggest ideas for ‘exemplar projects’, which have since been developed through the Local Digital Health R&D Group. A small amount of funding was provided to create a visual interface for the HDSI. More information can be found in this video.

Several discussions have taken place about who can access the inventory and how they view it. The HDSI has been shared on request with individuals from contributing organisations. At the time of writing a more formal sharing policy is being finalised.

2.4. Connecting with national initiatives

In the course of developing the HDSI, we connected with colleagues from Understanding Patient Data, the Health Data Finder for Research and Health Research Authority. Understanding Patient Data provided advice on engaging with patients and members of the public about our project, and we used their materials in our communications. Colleagues at the University of Oxford developing the Health Data Finder for Research and associated ‘meta-data catalogue’ provided advice on approaches to meta-data collation and offered use of the catalogue for our project. We had support from Health Research Authority colleagues through attendance at workshops, and advice on the information governance approaches to meta-data sharing.

3. What did we find?

3.1. Summary of inventory contents

The current version of the inventory contains the names of 463 data sources from twelve organisations/initiatives[5]. The chart below gives a breakdown of these data sources by sector.

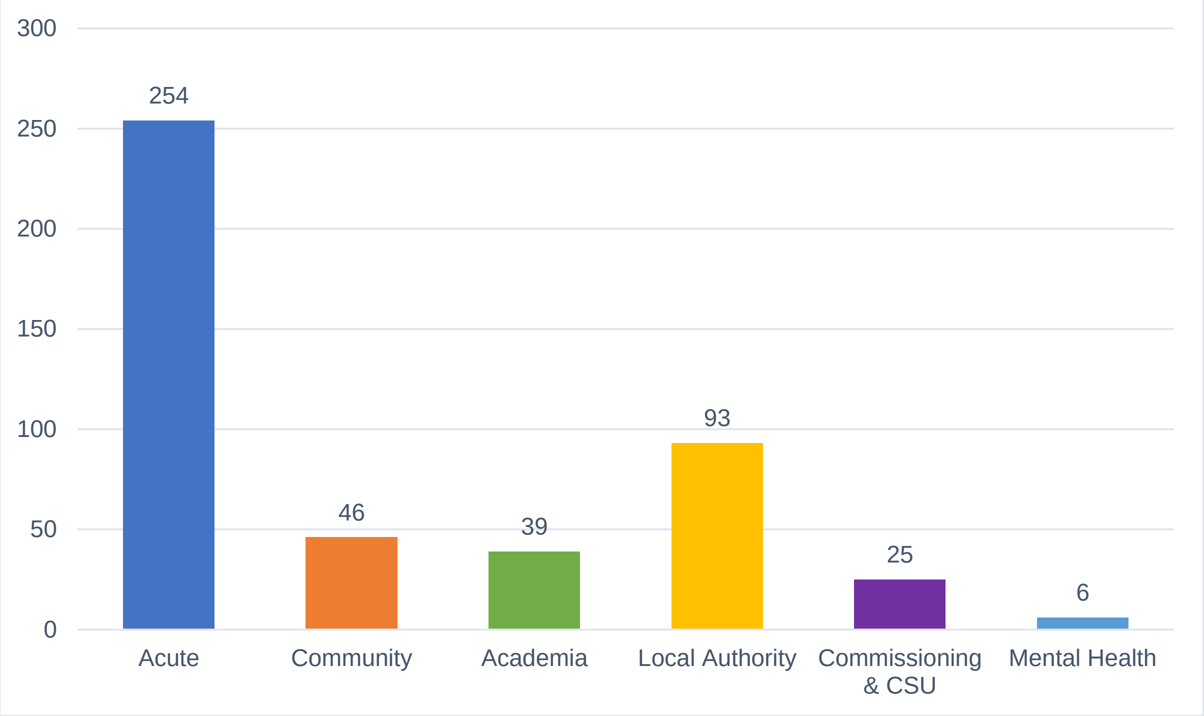

Figure 1: Breakdown of data sources in inventory by type of organisation

These data sources fall into the following broad types:

a) software

b) data-sets

c) hardware that produces data.

The lack of detail in descriptions of data sources means it is not possible to provide a breakdown of the inventory by type of data source.

The HDSI contains differing amount of detail for different organisations:

- Seven organisations/initiatives provided titles only of the data sources held.
- Five organisations/initiatives provided data constructs for some or all the data sources held.

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[5] Avon & Wiltshire Mental Health Partnership NHS Trust, Avon Longitudinal Study of Parents and Children, BNSSG Clinical Commissioning Group, Bristol City Council, Bristol Community Health, Connecting Care North Bristol Trust, South Central and West Commissioning Support Unit, South West Ambulance Service NHS Foundation Trust, University Hospitals Bristol NHS Foundation Trust, University of Bristol, University of the West of England

We found publicly available descriptions for 228 data sources. Only two data sources in the inventory matched the listings in the NHS Data Dictionary.

3.2. Data quality and coverage

Our work to develop the HDSI has produced a partial view of the data sources in our region. The lack of consistency in how information was provided and captured means that it forms only a starting point for a regional information asset register.

Main issues with data quality include:

- There is no agreed 'template' for an Information Asset Register, therefore different details about each data source are captured.
- Some organisations responded with the data sources that they thought would be of interest to the intended audience, others responded with their full information asset registers.
- Information included is only a 'snap-shot' and is likely to change on a frequent basis. During the project, several organisations were in the process of updating their own Information Asset Registers, so more detailed information may now be available.
- Organisations took different approaches to the level of detail they were willing to share. Some organisations shared system names and data structure, others giving only generic system 'themes'.
- The organisations listed on the HDSI do not make up the full Sustainability and Transformation Partnership membership. This was a pragmatic decision to involve those already in the Local Digital Health R&D Group with the intention to expand further in time. This lack of broad coverage may make the HDSI less useful.

3.3. Sharing information

Organisations involved in the project were at times reluctant to provide information for the HDSI. At times there was a lack of understanding about the project. There was often an initial misunderstanding that the project was seeking to collate the information *within* data sources. This meant that colleagues were at times reticent to engage in the project. Furthermore, several colleagues questioned the rationale for the project; seeing the effort of presenting collated 'information about information' as less useful than starting exemplar linked data research projects.

Producing the HDSI was reliant on networks and goodwill, as Bristol Health Partners does not have regulatory or financial levers to request information. This made the sharing process time consuming, and hard for organisations to prioritise. The lack of a coherent information sharing agreement for meta-data has meant that discussions about the uses of the inventory have been difficult to conclude.

The project took place before the introduction of the General Data Protection Regulation, which introduced a greater need for organisations to have a better understanding of the personal information they hold. Having this incentive at an earlier stage of the data collection process may have increased willingness to share information. For example, the University of

Bristol has now made its information asset register public[6] and others are working to improve their internal documentation.

3.4. Engagement

The project gained significant interest from our local academics, service planners and informatics leads. For example, the workshop to introduce the inventory had over 100 sign-ups. The work to compile the inventory has been a useful route to gaining an oversight of not just the data sources held locally, but the projects and professionals involved in health informatics in BNSSG. There has also been relatively high levels of interest in the project from national organisations.

Interest from patient and public stakeholders in this project has been limited, with relatively low numbers signing up for related workshops. Discussions with public contributors have indicated much greater interest in broader issues of data sharing for the public good. To an extent, the HDSI project was seen as a 'behind-the-scenes' and fairly technical exercise, that was of less interest than more direct uses of data. Despite this, the public contributors involved in the work were active and willing to contribute useful suggestions.

3.5. Impact

The project acted as informal audit of information asset registers, which had value for organisations ahead of GDPR. Anecdotal reports from contributing organisations have confirmed that being asked to provide information for the HDSI led to increased internal focus on quality assuring their information asset registers.

Carrying out the exercise has helped to expose the varied and multiple data sources that exist in our region, and some of the potential areas of duplication within BNSSG's digital estate. The HDSI has been shared with local service planners as a building block for work to improve how the local health and care system uses data.

The intention to produce exemplar projects from the information in the inventory has taken longer than expected. A small number of projects are being taken forward, but they have not yet begun data collection and analysis.

With time, the inventory and any potential successor should be a resource that will:

- Give a faster way of finding new sources for research projects
- Facilitate new research collaborations and informatics projects
- Provide new insights into data sources that could be used to enhance services
- Give greater transparency about data held by publicly funded organisations
- Improve oversight of the information held in local organisations
- Reduce duplicate data collections

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[6] www.bristol.ac.uk/secretary/data-protection/information-asset-register/

4. What next?

- **Making the current version of the HDSI available**: The Bristol Open Data Platform will be used to host and share the inventory. The version hosted will be a snapshot document, while further work is carried out to develop a more comprehensive document.

- **Supporting others in the ownership and development of a joint information asset register**: Bristol Health Partners will support Healthier Together and others to develop our local information asset management policy that includes a clear plan for ‘business as usual’ sharing of information asset registers.

Glossary

Data construct	The information about how a data-set is arranged. For example, in a spreadsheet it would be the names of column and row headings.
Data source	A source of facts and statistics that can be referred to or analysed. For the Health Data Source Inventory project, we use 'data source' as the overall description for any of the databases, software, hardware or other 'information assets' that an organisation can hold.
Data-set	A collection of related pieces of data.
General Data Protection Regulation	European Union legislation which governs the way in which data is handled across every sector. The regulation came into force on 25th May 2018. The regulation is implemented in UK law through the Data Protection Act 2018.
Hardware	The physical components of computers or other digital technology.
Health informatics	A discipline and profession that involves "the intelligent use of information and technology to provide better care for patients" More information is available here: www.healthcareers.nhs.uk/explore-roles/health-informatics
Information asset register	A formal list of the different information assets that an organisation is responsible for. These 'information assets' are systems, software or other sources of data. A briefing from the National Archives providers more detail.
Meta-data	Metadata is information about a data source that describes or helps you use it. It could be described as 'information about information'.
NHS Data Dictionary	The NHS Data Model and Dictionary provides a reference point for approved Information Standards Notices to support health care activities within the NHS in England. It has been developed for everyone who is actively involved in the collection of data and the management of information in the NHS.
Software	The programmes or other operating information used by a computer or other piece of digital technology.
Sustainability and Transformation Partnership	Local partnerships in every part of England to improve health and care in practical ways. More information is available here: www.england.nhs.uk/integratedcare/stps/

List of abbreviations

BNSSG	Bristol, North Somerset and South Gloucestershire
GDPR	General Data Protection Regulation
HDSI	Health Data Source Inventory
R&D	Research and Development

Annex A

BNSSG Health Data Source Inventory

What?

Researchers and service planners can use information collected by health, social care and academic organisations to improve health.

However, there isn't an easy way to understand what information people might be able to work with in our region, and where it's held.

We are creating an inventory of the data sources in NHS, local authority and academic organisations that could be used for research and service planning.

It won't include any identifiable information about individuals.

Who?

The inventory is being developed by Bristol Health Partners and the Elizabeth Blackwell Institute at the University of Bristol.

The work has been overseen by a Local Digital Health R&D Group.

Members include:
Patient contributors, Avon & Wiltshire Mental Health Partnership NHS Trust, Bristol City Council, Bristol Clinical Commissioning Group, Bristol Community Health, Connecting Care Partnership, University Hospitals Bristol NHS Foundation Trust, University of Bristol, University of West of England and West of England Academic Health Science Network.

Bristol Health Partners

University of BRISTOL

Elizabeth Blackwell Institute
for Health Research

Why?

For researchers

- Faster way of finding new sources for research projects
- New research collaborations and projects

For service planners

- New insights into data sources that could be used to enhance services
- Foundation for more advanced analysis at population level

For clinicians

- Access to wider picture of information to improve their own practice

For patients & members of the public

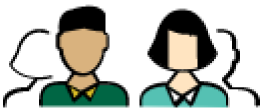
- Greater transparency about data held by publicly funded organisations
- More projects using local data to improve local services

For local organisations

- Improved oversight of the information held in their organisations in readiness for General Data Protection Regulation.
- Potential to reduce duplicate data collections that other organisations have already done.

Progress

- Built an overview of 464 data sources from 11 organisations.
- Convened a network of c.100 researchers, clinicians, commissioners, policy-makers with interest and expertise in health informatics, population health and data science
- Supporting two potential major funding bids
- Support from national health informatics initiatives



Inventory in action – case studies

1. An organisation taking part in the information gathering exercise to produce the first version of the Health Data Source Inventory confirmed to the project team that it had prompted internal work to improve the cataloguing of the information they held. The very act of collating this information improved their data stewardship.

2. A researcher attending our workshop was made aware of the Children of the 90s dataset for the first time. This was seen to be able to give information that had been missing from their work to date. Others attending the workshop were made aware of data sources at their own organisation that they had not come across before, but which they felt would be of great value to their work.

3. By viewing information in the current version of the inventory, a group of delegates from research, service planning, patient and clinician backgrounds devised a potential project which would draw upon several sources (self-harm register, A&E data on domestic violence, police data and local authority surveys of school children) to better understand the links between self-harm and domestic violence in our region.

What next?

- Improve the inventory with more information about data source structure
- Support local work-streams, such as Sustainability and Transformation Partnership Digital Theme

Find out more

✉ hello@bristolhealthpartners.org.uk

☎ 0117 903 7546

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Annex B

Bristol Health Partners

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From:
David Relph, Bristol Health Partners Director,
Professor Jeremy Tavaré, Elizabeth Blackwell Institute for Health Research Director

Date: 7 December 2016

,

Dear All

Re: Developing a regional information asset register

We are writing to let you know that Bristol Health Partners is working with the Elizabeth Blackwell Institute at the University of Bristol, on a work programme to map our local data assets in health and social care.

This initiative will fill the gaps in our region's knowledge about our health data sources. The aim is to develop a data asset map at the Bristol, North Somerset and South Gloucestershire (BNSSG) region level. This work came out of the Bristol Health Partners Local Digital Health Research and Development group.

It aims to look at how, by using information and data better, the health outcomes of the population could be improved, while also supporting improved service delivery and the STP. The programme could also attract research and other investment to the region.

Two consultants are doing this work on our behalf:

- David Thompson, IT Programme Manager, South West Academic Health Science Network
- John Kellas, freelance Community and Innovation Engagement Consultant

Work starts in December 2016 and will be in two phases. The first phase will identify information asset registers and key data sets held by the health and social care and academic sectors in the region, and will be completed by February 2017.

The second phase, between February and March 2017, will look at the identified data sets in more detail, to ascertain field labels only. **No individuals' personal information will be collected**. We will only be looking for details about the systems and type of information that are collected and used on a regular basis. We will also collate which organisation holds the information, who the owner of the data set is, whether it's complete and the information governance around the data.

We have specifically designed this project with due consideration for data governance. No personal data will need to be viewed by anyone outside of approved existing information governance frameworks.

The final map will show who holds what data assets, and what types and depth of information is contained within them. The team will produce a report presenting the findings. This will be taken back to the Bristol Health Partners Local Digital Health Research and Development group and all stakeholders/contributors, so that agreement on possible next steps can be made.

We hope that you will see this work as worthwhile and beneficial to your organisation. Dave and John will be contacting key staff from your organisation to begin this work. But if you have any questions at all, please get in touch with them via:

David.Thompson@swahsn.com and John@thisequals.net

With best regards

Relph

Jeremy Tavaré

David Relph
Director
Bristol Health Partners

Professor Jeremy Tavare
Director
Elizabeth Blackwell Institute

Using data to improve health, care and services through research

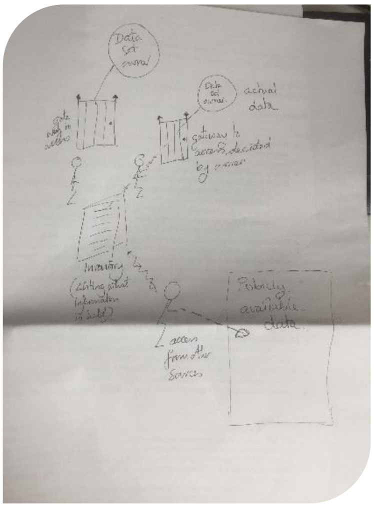
PPIE Workshop – 1.30pm – 4.30pm, 26 July 2017

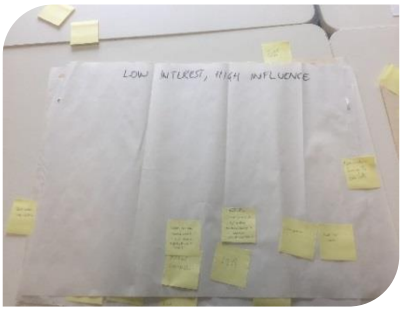
The Pavillion, The Pavilion, No1 Hannover Quay, Harbourside, Bristol, BS1 5JE

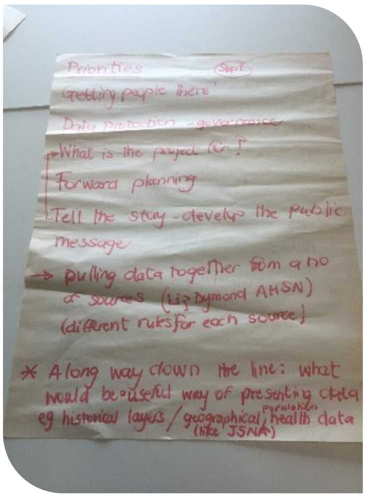
Bristol Health Partners

Better use of data

Involving and empowering patients







Priorities (Sept)

Getting people there'

Data protection - governance

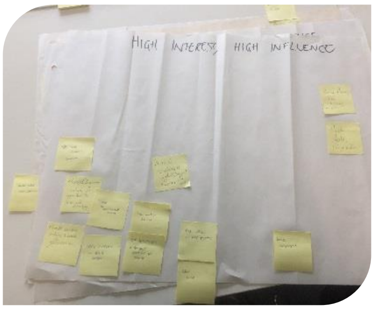
What is the project (c) ?

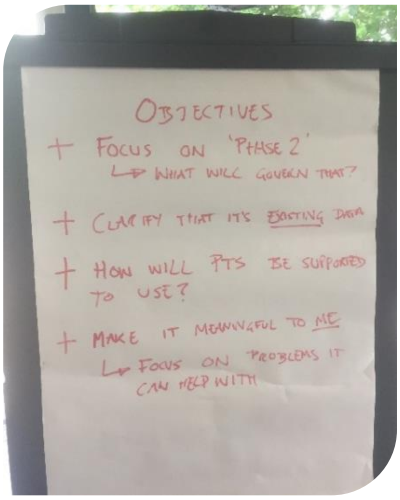
Forward planning

Tell the story - develops the public message

→ pulling data together from a no of sources (Liz Dymond AHSN) (different rules for each source)

* A long way down the line: what would be useful way of presenting data eg historical layers / geographical population health data (like JSNA)





OBJECTIVES

+ FOCUS ON 'PHASE 2'
  ↳ WHAT WILL GOVERN THAT?
+ CLARIFY THAT IT'S EXISTING DATA
+ HOW WILL PTS BE SUPPORTED TO USE?
+ MAKE IT MEANINGFUL TO ME
  ↳ FOCUS ON PROBLEMS IT CAN HELP WITH

Introduction

On 26 July 2017, patient and public contributors attended a workshop to discuss a project that seeks to make better use of data to improve health through research and service planning. They were joined by officers from local health organisations and a representative of Understanding Patient Data. Attendees are listed at **Annex A.**

Delegates discussed and shaped the strategy for patient and public engagement in the Health Data Inventory project. This included reviewing objectives, considering the audiences that might be interested in the project and influencing the methods of engagement. This report summarises the recommendations and suggestions made during the workshop, and through delegates' feedback forms.

PPIE Objectives

The group reviewed draft objectives for patient and public engagement in the project:

1. To encourage and harness members of the public and patients' curiosity for using their data for the public good.
2. To provide adequate opportunity for PPI in the emerging health informatics regional strategy.
3. To understand what reassurances members of the public and patients want in the governance and boundaries of the Local Digital Health R&D Group (/workstreams).
4. To ensure Local Digital Health R&D Group communications complement those of the Sustainability and Transformation Plan and national work on health data.

The following recommendations were made:

Engagement must distinguish between:

a) the purpose / use of the Health Data Inventory (research and project design, no sensitive information involved) and

b) what could be done with the data itself (research and service planning use, potentially more sensitive information used under strict controls).

It is important that both are covered when communicating about the project. Focusing only on the inventory itself is less likely to interest patients & the public. Indeed, it may cause confusion and suspicion to not describe what might result from the inventory's publication.

Objectives must recognise both the opportunity provided by the project and the reassurances that need to be given about the risks. Reassurances may need to include:

- That the information in the inventory is not linked to individuals
- That data is not being 'amassed' into a central and vulnerable location
- Clarification about who can access the inventory & how can they access it
- That all people who would like to access the data sources listed in the inventory for more in-depth/revealing information would be carefully vetted.
- More emphasis that the project is about labelling existing data.

Objectives should be clearer about what role the public and patients have in using the inventory (e.g. Is it about researchers' use of data, or members of the public's? Is transparency the main direct benefit for members of the public?).

Accessible and meaningful language should be used to describe the objectives.

It will be important to define what the public ‘end product’ should look like and be able to do.

Feedback forms completed by nine attendees, suggested that: five felt that the objectives were ‘about right’, two respondents thought that they were ‘missing anything’ and one replied ‘other’.

Following this discussion we will:

- Re-draft the PPIE objectives for this group to review (see Annex B for updated objectives)
- Reflect recommendations made about the approach to engagement in future communication materials.

Audience

Delegates were asked to map the patient and public groups that might be interested in this project. They then considered the levels of interest and influence that each group may have. Notes from this session are in the table below:

Audience group	Group name
High interest, high influence	Activists
	BME Groups – Chinese Womens Group, SARI etc
	Care forum
	City forums for groups with protected characteristics (for example, LGBT Forum, Bristol Older People’s Forum
	Health and wellbeing groups listed on WellAware
	Healthwatch
	NHS campaigners (e.g. Save our NHS)
	Patient groups
	Patient groups in GP surgeries
	PPI leads in NHS Trusts
	Privacy campaigners
	Third sector (e.g. umbrella bodies for third sector in Bristol, North Somerset and South Glos – particularly VOSCUR Health and Social Care Network)
High interest, low influence	AWP service user groups
	Citizen scientists
	Health Trust Patient Groups
	Organisations looking for partners to work with
	PPI partners in Health Integration Teams
	Schools
	Student organisations
	Students

	Tech 4 Good
	Vulnerable / disadvantaged groups
Low interest, high influence	38 degrees
	LA Councillors + LA public engagement leads
	Local news media
	MPs
Low interest, low influence	Members of the public who don't see the relevance
	National Cancer Research Institute – Panel members
	Patient / GP panel members

Following this discussion we will:

- Update our contacts lists with the new groups suggested
- Review whether bespoke communications can be created for different groups

Methods for engagement

Written materials and presentations about the Health Data Inventory

The following recommendations were made about how written materials and presentations about the inventory could be most effective:

- Be clear about the purpose…the problem you are solving & why is this a good way of resolving it.
- Provide examples of how it might be used by different audiences, and what the benefits are.
- Use meaningful analogies. For example, that the inventory is like a library catalogue or telephone directory.
- Create an infographic / diagram which explains how the Health Data Inventory works.
- Consider using language such as 'labels' (rather than meta-data) and 'data controller' that are more understandable than some of the current descriptions.

September workshop

On 19th September 2017, there will be a workshop to explore the Health Data Inventory with a wider audience of researchers, clinicians, service planners, policy makers and patients & members of the public. Delegates made the following suggestions about this design of this event:

- Include examples of successful research or service planning projects that have made use of existing data.

- Consider a workshop for patients and members of the public which provides a mock research design and application process.
- Invite feedback on the question - what data do you imagine is held about you?
- Explain how to access and navigate the inventory.
- Test the useability / accessibility of the inventory – potentially use a case study to do this.
- There will be a challenge in getting patients and members of the public to attend, consider what will get people there.
- Ensure that data protection and governance are covered.
- Use the event to refine messages about what is the project for – tell the story and develop the public message.
- Should there be approaches from private sector companies to attend, the criteria should be that they are working with the public sector to deliver a public good. The role and presence of private sector companies should be made transparent.

October public engagement event

In October 2017, BBC Bristol will be running 'Bristol Digital Week'. There is an opportunity during this week to present the Health Data Inventory, potentially using the 'Data Dome' or a large screen. The following suggestions for this event were made:

- Display the contents of a data source held in the inventory.
- Topics to explore through the inventory which might gain interest: type 2 diabetes – risks, prevention, self-care (digital coach); Mental health, stigma, interventions, Looked after children (through Children of the 90s data).
- Involve Health Integration Teams.
- 'Gaming' the data – get people to put together different types of data in the inventory and see what kind of research questions those datasets could answer.

Following this discussion we will:

- Produce an infographic which describes the Health Data Inventory and how it relates to existing data sources.
- Create a glossary which gives clear and understandable descriptions for the various aspects of the project. Ensure that terms are used consistently.
- Review programme for 19th September 2017 to ensure recommendations are accommodated.
- Consider recommendations for October public engagement event and share programme with this group.

Principles for using the inventory

Delegates reviewed a series of draft principles for how the data inventory is used, presented and updated. The following recommendations were made:

- Create a lay summary of the document, potentially in Question & Answer format.
- There should be openness and clarity about the role of private sector organisations in using the inventory.
- Direct edits to the document to suggest changes to language and grammar were made.

Following this discussion we will:

- Update the draft principles documents with the recommendations made above.
- Produce a lay summary of the principles.

Visual presentation of the inventory

A visual version of the inventory produced by Noomap was shared with the group for comment. Unfortunately, due to a lack of functioning wi-fi, it was not possible to share the full features of the site. However, the group provided feedback that it would be important for the published version to distinguish between information which is 'open access' and information that would only be accessible following existing data governance procedures. Indeed, it may be worthwhile considering taking out reference to information which would never be able to be accessed for research or service planning uses.

All but one respondent to the feedback forms suggested it was easy to follow the visual presentation of the inventory.

Following this discussion we will:

- Create labels which describe the accessibility level of the data sources named in the inventory.

Next steps

Attendees at the workshop and those who were unable to attend, but expressed an interest will be invited to stay involved in the project. All are invited to attend the event on 19th September. We will progress these hugely helpful recommendations.

Thanks to all who could attend and contribute to the workshop.

Annex A: Attendees

Name		Organisation / role
Natalie	Banner	Understanding Patient Data
Gill	Brookman	Bristol City Council
Jan	Connett	Bristol Health Partners
Hildegard	Dumper	People in Health West of England
Martin	Gregg	People in Health West of England / Bristol Health Partners
Trish	Harding	Bristol Health Partners
John	Kellas	Bristol Health Partners
Lisa	King	Bristol Health Partners / Elizabeth Blackwell Institute
Robert	Griffin	Movement Disorders Health Integration Team PPI
David	Relph	Bristol Health Partners
Ruth	Richardson	West of England Evaluation Steering Group PPI
Angela	Stagg	People in Health West of England / Bristol Health Partners
Jeremy	Tavare	Elizabeth Blackwell Institute
Louise	Ting	People in Health West of England
Sandra	Tweddell	People in Health West of England
Olly	Watson	Bristol Health Partners

Annex B: Updated Draft PPIE Objectives

Through our engagement with members of the public and patients about the health data inventory project we aim to:

- encourage and harness members of the public and patients’ curiosity about using data for the public good.
- provide the reassurances that members of the public and patients want in the governance and boundaries of the health data inventory, and the projects that might result from it.
- clarify how patients and members of the public can use the inventory and benefit from it.
- provide adequate opportunity for patient and public involvement in the emerging health informatics regional strategy.
- complement the Bristol, North Somerset and South Gloucestershire Sustainability and Transformation Partnership’s (STP) communications plan.

We will do this by:

- Running at least two events where patients and members of the public can learn more about the inventory and shape its development – by February 2018
- Provide support to patients and members of the public to develop and contribute to project proposals resulting from the inventory– by February 2018
- Produce accessible communications materials to explain the project for a lay audience – by September 2017
- Ensure continued patient and public representation on the Local Digital Health R&D Group (which oversees the health data inventory project) – ongoing
- Form a patient and public reference group for the project- by August 2017
- Share communications plans with STP colleagues at regular catch-up meetings – ongoing

Annex D

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/