

Enabling data flows in Greater Manchester Connected Health City

April 1st 2019

As part of [Connected Health Cities](#)¹ we have spent the last three years building a pilot learning health care system in Greater Manchester.

Actionable health intelligence is dependent on the timely flow of data. Setting up a new data flow can be convoluted. By sharing our learning we hope to speed up this process.

We report on the governance approach, the workforce involved in sharing data, and describe how data flowed for three projects – with the ‘take home message’ that health data flows are dependent on a wide base of skilled personnel.

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¹ This project was part of Connected Health Cities, a Northern Health Science Alliance led programme funded by the Department of Health and delivered by a consortium of academic and NHS organisations across the north of England. The work uses data provided by patients that was routinely collected by the NHS as part of their care and support. The views expressed are those of the author(s) and not necessarily those of the NHTA, NHS or the Department of Health and Social Care.

Governance through public engagement

Connected Health Cities developed an Information Governance framework informed by public views including two 3-day [citizens' juries](#). More than two-dozen safeguards were implemented to protect patient data including:

- Clearly describing the benefits and risk for patients and the public of each project
- Maintaining NHS information governance assurance
- Completing Privacy Impact Assessments for each project
- Specifying in data sharing agreements who has access to the data and for what purpose

We also built secure analytical facilities. The [Trustworthy Research Environment](#)² at The University of Manchester follows best practice in protecting health research data. We developed processes in line with [other safe settings in the UK](#)³ and [UK anonymisation guidance](#)⁴ to suit Greater Manchester Connected Health City (GM CHC) operations, including:

- [Project applications](#)⁵ signed by the principal investigator specify how long data should be stored for, and include evidence of ethical and information governance approval where applicable.
- Training portfolio for research users following the Office for National Statistics [Safe Researcher training](#)⁶ and bespoke Privacy by Design training for technical support staff⁷.
- Rigorous calendar of internal audits and external audits in an information security management system [certified to the international information security standard](#) ISO 27001⁸.
- Output checkers perform statistical disclosure control on all research outputs, for which a [handbook was published](#) in March⁹ and dedicated training was developed.
- Guidance for users on how to check that data meet the specification¹⁰.
- Communications were developed including leaflets about each project, and a GM CHC patient and public forum. For projects involving patients who could not easily communicate with words, some leaflets were designed specifically with pictures¹¹.

² <https://www.herc.ac.uk/tre/> Last accessed 16/05/2019

³ <https://securedatagroup.org/> Last accessed 16/05/2019

⁴ <https://ukanon.net/ukan-resources/ukan-decision-making-framework/> Last accessed 16/05/2019

⁵ <https://www.herc.ac.uk/wp-content/uploads/2018/09/FORM-002-TRE-Project-Application-Form.docx> Last accessed 16/05/2019

⁶ <https://www.ons.gov.uk/aboutus/whatwedo/statistics/requestingstatistics/approvedresearcherscheme> Last accessed 16/05/2019

⁷ <https://www.herc.ac.uk/tre/#training> Last accessed 19/04/2019

⁸ <https://www.herc.ac.uk/2018/10/15/keeping-health-data-secure-trustworthy-research-environment/> Last accessed 16/05/2019

⁹ <https://securedatagroup.org/guides-and-resources/> Last accessed 07/02/2019

¹⁰ <https://www.herc.ac.uk/wp-content/uploads/2018/09/ISMS-07-02-TRE-Data-Validation.docx> Last accessed 16/05/2019

¹¹ Leaflets and posters downloadable from <https://www.connectedhealthcities.org/research-projects/using-technology-data-improve-diagnosis-treatment-strokes/> Last accessed 16/05/2019. Aphasia friendly leaflet is also in the Appendix

Governance through teamwork

A diverse network of stakeholders put the information governance framework into action. GM CHC comprised an interdisciplinary, inter-organisational team from academia, industry and the NHS, coordinated by the University of Manchester. Data flows were only made possible by the contributions of hundreds of professionals working across the health sector; this team approach enabled anonymised extracts of routinely gathered patient data to be requested, prepared, shared, validated, and analysed for GM CHC projects.

The diagram below illustrates the human resource network and generic steps to be followed in a large organisation that provided data. Knowledge of the organisation's structure was assembled from enquiries about the nature, quality and governance of requested data, and about challenges in the flow of approved data, such as IT connectivity or governance queries.

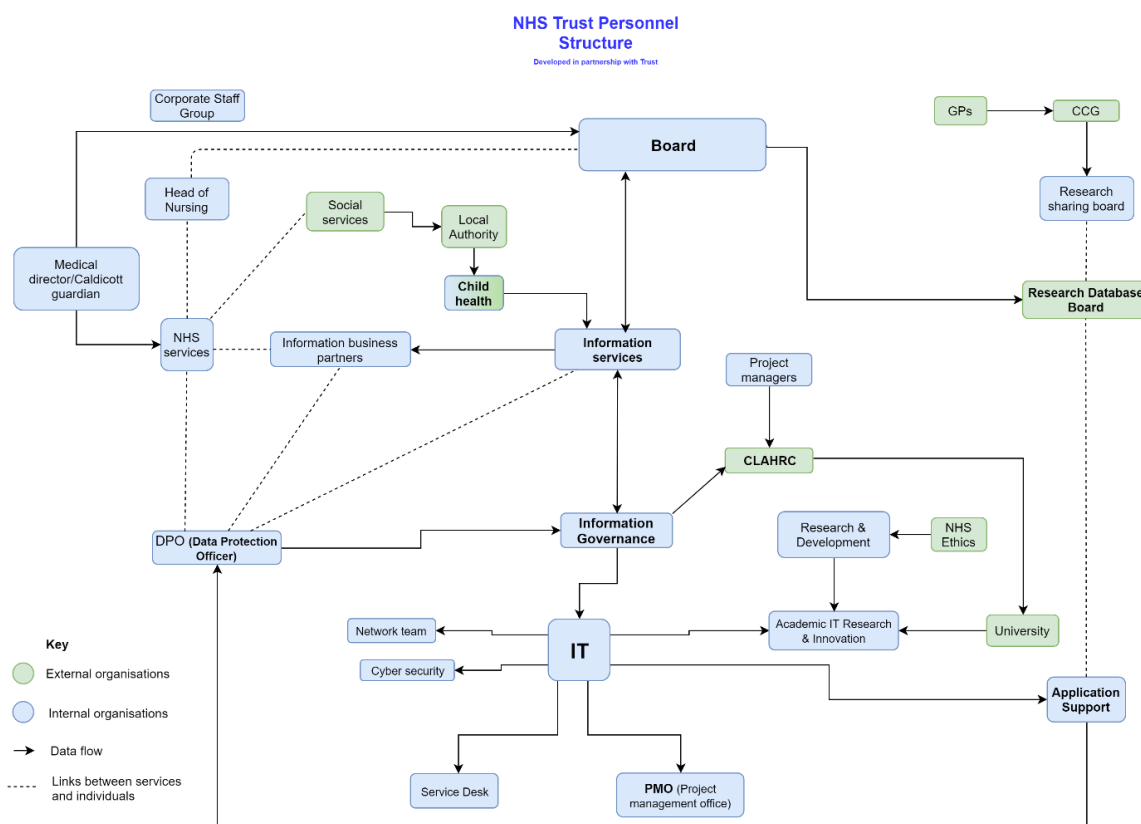


Figure 1 Diagram of collaboration and communication examples from departments and teams across an NHS Trust to enable data to flow for Greater Manchester Connected Health City projects. Designed with colleagues from the Trust. The structure of other organisations may differ.

Structures and processes in organisations receiving data can also be complex. Within The University of Manchester, GM CHC staff partnered with other departments to enable data to flow safely. For example, we worked with the Contracts Office to draft data sharing agreements; and with Estates and Facilities who ensured physical security around our Trustworthy Research Environment.

Staff reported that accessing data was a challenging process. In response, we developed an e-learning resource to help guide projects that wish to request use of routinely collected health data¹².

¹² E-learning tool for efficient health data journeys developed from Greater Manchester Connected Health City experiences and tailored to services at The University of Manchester <https://ispri.ng/RgNWM>

We also shared project documentation and assurance between organisations providing and receiving data via an online tool, the Information Sharing Gateway¹³.

Three Health Data Journeys

A technique developed at The University of Manchester for mapping the data journey was applied for GM CHC health research projects¹⁴. Below we present three data journey diagrams for: a single provider project, a multi-provider project, and a multi-provider integrated health and social care project.

1. Completed data journey (single data source)

One of the simpler data journeys involved inpatient data from a local NHS trust on episodes and adverse drug reactions (

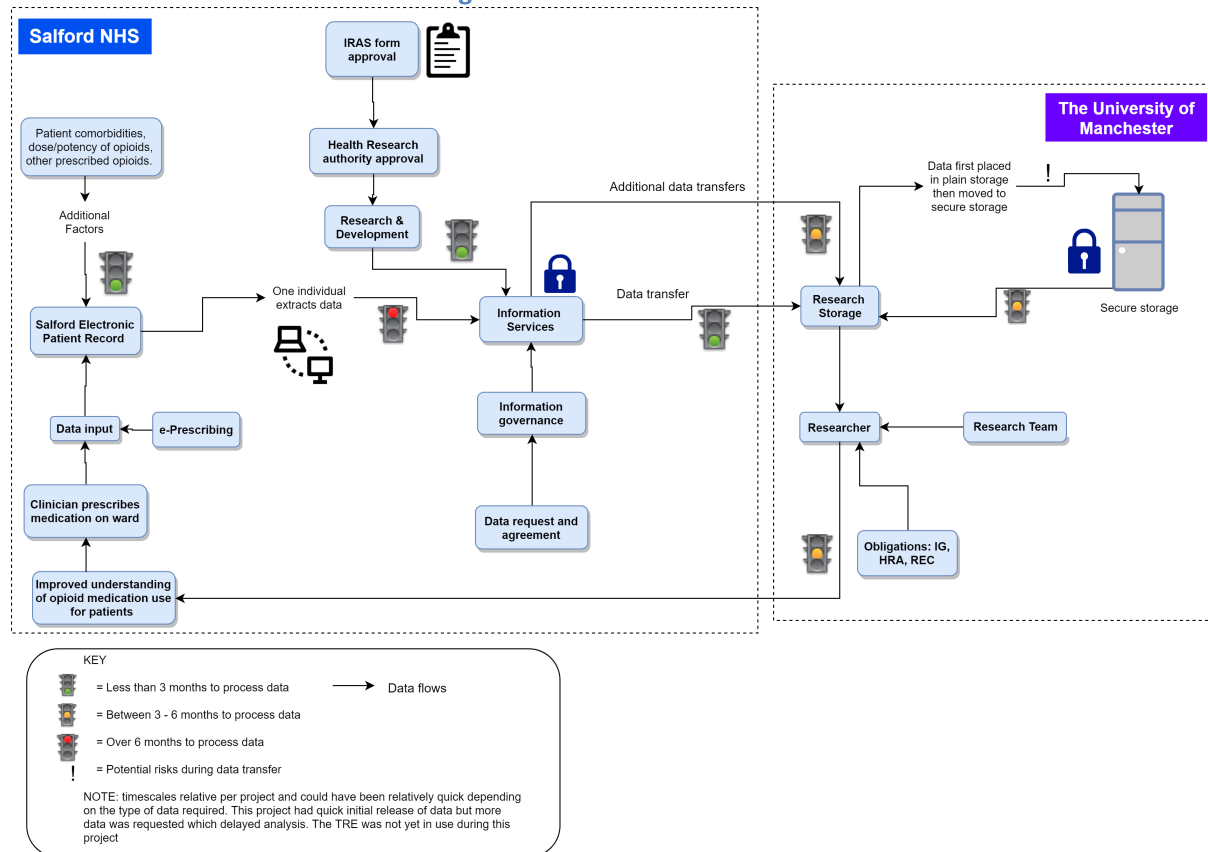


Figure 2). Medical codes, prescriptions, and demographic information were requested. Once approval was obtained from the Health Research Authority, the requested data were extracted from the patient record system at the Trust and transferred for analysis at The University of Manchester by a small, dedicated team of analysts. Organising and preparing the data for analysis took over a year, involving various iterative cycles of quality checks and seeking clarification from Information Services at the Trust. In response we produced guidance on validating flows of data⁹.

¹³ <https://www.informationsharinggateway.org.uk/> Last accessed 16/05/2019

¹⁴ <http://www.cs.man.ac.uk/~elefthi9/datajourney/> Last accessed 16/05/2019

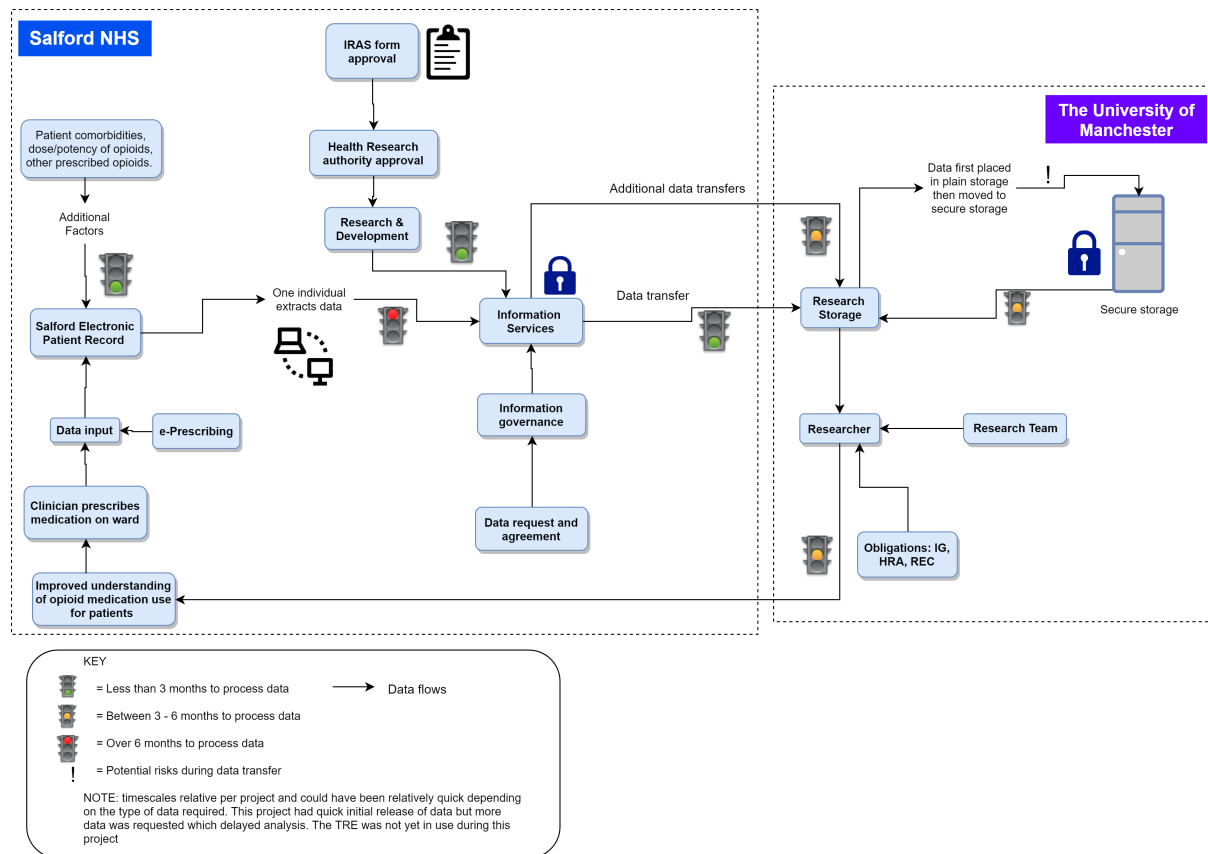


Figure 2 Data journey diagram for one project receiving inpatient data from one NHS Trust. For more details see the project website: <https://www.connectedhealthcities.org/research-projects/assessing-comparative-safety-opioid-medications-non-cancer-pain/> Traffic lights indicate the time to steps being completed from less than 3 months (green) to more than 6 months (red).

2. Recent data journey (two data sources)

More complex data flows involved multiple providers. An example is the stroke mimics project that sought ambulance and acute hospital data is shown in Figure 3. The project discovered that electronic data were not available directly from the ambulance service and scanned forms received by the acute Trust needed to be transcribed into electronic form. These transcribed data about patients brought by ambulance to the stroke unit, plus other information from the hospital system, were transferred under a data sharing agreement¹⁵.

¹⁵ <https://www.connectedhealthcities.org/wp-content/uploads/2016/08/Stroke-mimics-SRFT-DSA.pdf> Last accessed 16/05/2019

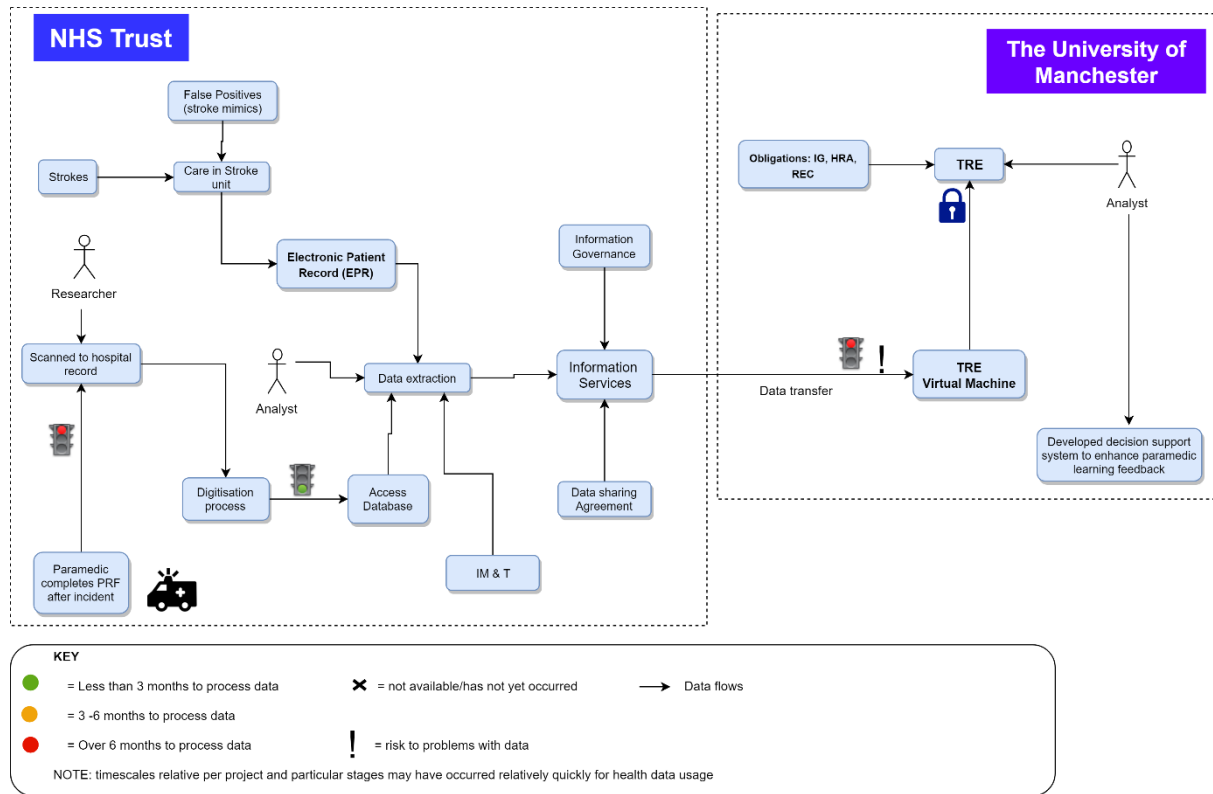


Figure 3 Data journey diagram for a project using ambulance and inpatient data from one NHS Trust. For more information see: <https://www.connectedhealthcities.org/research-projects/using-technology-data-improve-diagnosis-treatment-strokes/> Traffic lights indicate the time to steps being completed from less than 3 months (green) to more than 6 months (red).

3. Prospective data journey (multiple providers)

As part of an evaluation of the impact of devolution of the Health and Social Care budget in Greater Manchester, one project uses data from multiple care providers to estimate the burden of musculoskeletal disease among adults in the city. So far data have been shared from two outpatient units (

Figure 4), with on-going liaison from other potential providers.

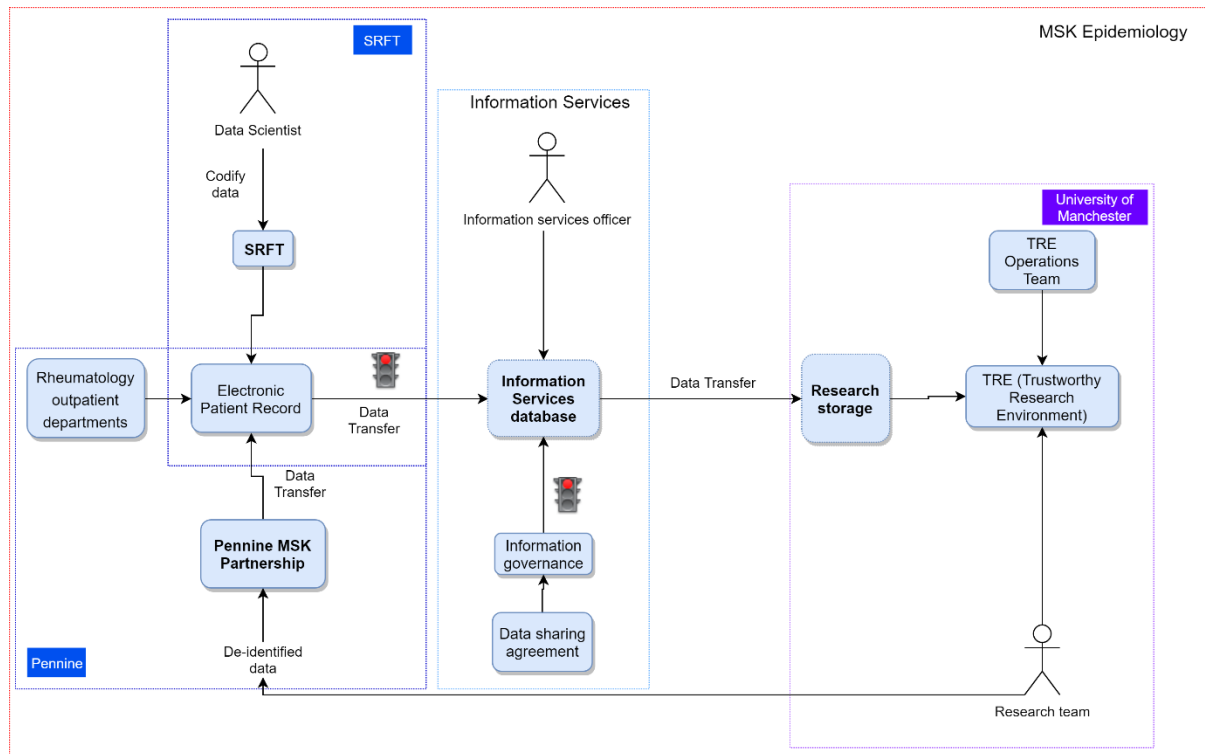


Figure 4 Data journey diagram for a project using outpatient data from two NHS providers. For more information see: <https://www.connectedhealthcities.org/research-projects/health-inequality-and-the-burden-of-musculoskeletal-disease/> Traffic lights indicate the time to steps being completed from less than 3 months (green) to more than 6 months (red).

Steps along the data journey

We have synthesised what should be done from the early stages of a project to ensure robust and efficient information governance (Figure 5). These stages are described for selected CHC projects in a series of four case studies (see Appendix). These served as material for two workshops for others involved in health research delivered in March 2019 in response to demand to understand new data protection legislation, regulations around health data, and to share Connected Health Cities' experiences. Despite the sequential questions in Figure 5, the workshop exercises demonstrated that data access is neither linear nor predictable.

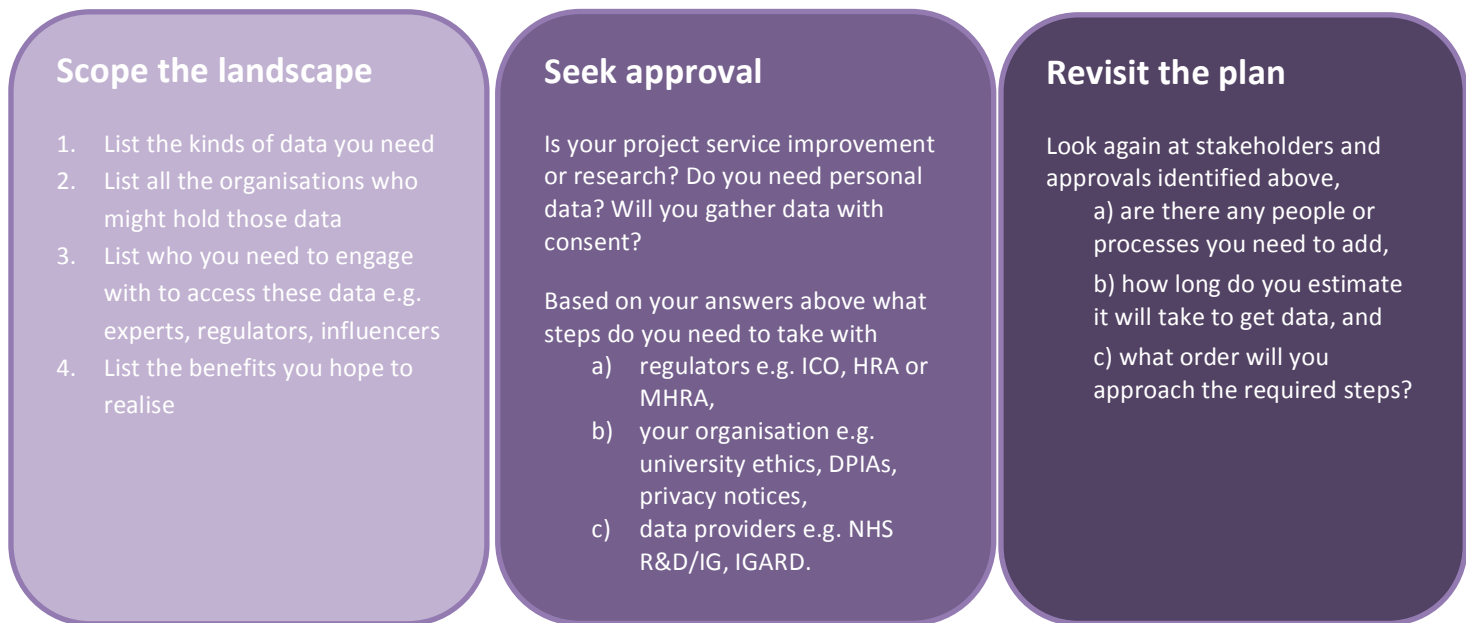
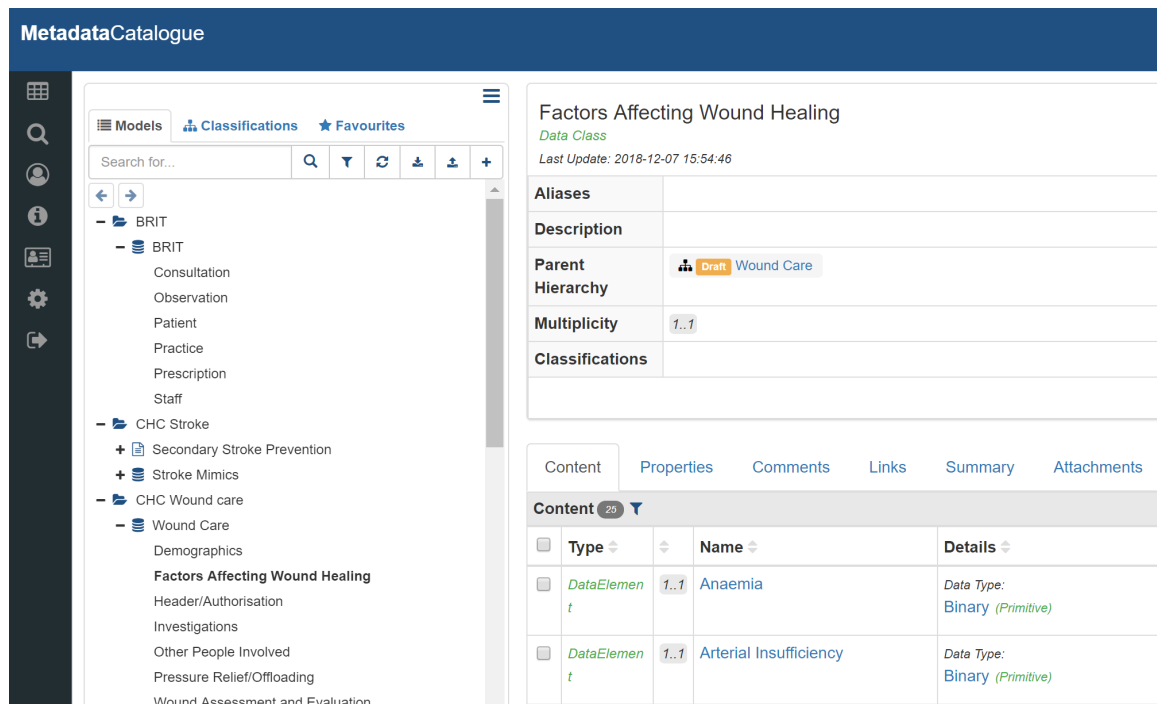


Figure 5 Steps for planning the information governance for a successful health data journey. For more guidance around each step, see this e-learning tool developed from Greater Manchester Connected Health City experiences and tailored to services at The University of Manchester <https://ispri.ng/RgNWM>

Development of an accredited research database

Given the substantial effort required to enable data flows there is a desire to generate maximum benefit for the data, for example through a secure archive that other researchers could apply to access. A Consortium was set up across all four CHC regions to consider issues around access to data by external researchers.

Building on this Consortium consultation, we are drafting an application to the Health Research Authority to form an approved research database in conjunction with the National Institute for Health Research Biomedical Research Centre in Manchester¹⁶. We are also collaborating on development of a metadata catalogue, which is now publicly available¹⁷. The catalogue fulfils transparency obligations, helps other researchers formulate requests for data, and can capture comments about data quality or processing methods. This arose out of a GM CHC project into how health researchers find data, and how data repositories are working to meet the 'Findability Principle, the first of the FAIR principles¹⁸ (paper in draft). We anticipate that the database and catalogue will provide a fruitful legacy from GM CHC that builds efficiencies for others seeking to access health data for research and innovation.



The screenshot shows the 'Metadata Catalogue' interface. On the left is a sidebar with a search bar and a tree view of categories: BRIT, CHC Stroke, CHC Wound care, and Wound Care. The main area displays details for 'Factors Affecting Wound Healing', including its aliases, description, parent hierarchy, multiplicity, and classifications. Below this is a table of content with columns for Type, Name, and Details.

Type	Name	Details
DataElement	Anaemia	Data Type: Binary (Primitive)
DataElement	Arterial Insufficiency	Data Type: Binary (Primitive)

Authorship & acknowledgments

This report was written by Emily Griffiths and Zoher Kapacee. We also acknowledge the contributions of many who supported the success of Connected Health Cities. In particular we wish to thank Mari Crotty and Iliada Eleftheriou (for developing the data journey diagrams), Clare Sanderson (for developing the CHC IG framework), Dipak Kalra (for leading the Data Access Consortium), and Niels Peek (for directing GM CHC and leading the development of the metadata catalogue). Please direct enquiries to emily.griffiths@manchester.ac.uk

¹⁶ <https://www.manchesterbrc.nihr.ac.uk/> Last accessed 16/05/2019

¹⁷ <https://modelcatalogue.cs.ox.ac.uk/chc/#/catalogue/search> Last accessed 16/05/2019

¹⁸ <https://fair.healthdata.be/fair-principles> Last accessed 16/05/2019