

digitalhealth

REWIRE
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Headline Sponsors:



Big Data, Patients & Public Consent

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Outline

- Opportunities from analysis of routinely collected data
- *Assembling the Data Jigsaw* research programme
- Approach to public trust within Jigsaw

Electronic health record (EHR) research

- Health data supports clinical care, with additional opportunities to support research and more



Electronic health record (EHR) research

- Health data supports clinical care, with additional opportunities to support research and more
- Limitations, however, come from the availability and quality of data
- Musculoskeletal research exemplifies many health data problems:

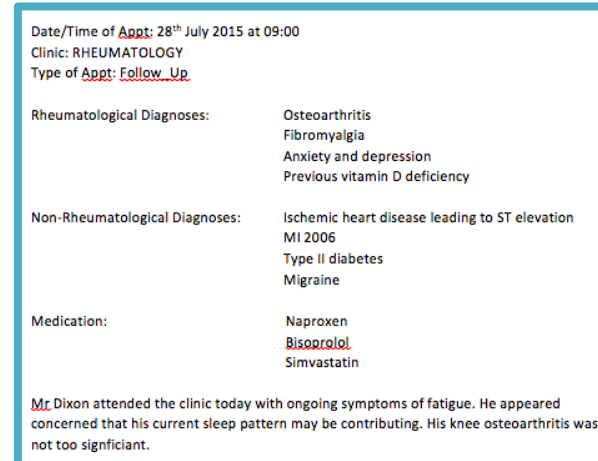
1. Absent



2. Inaccurate

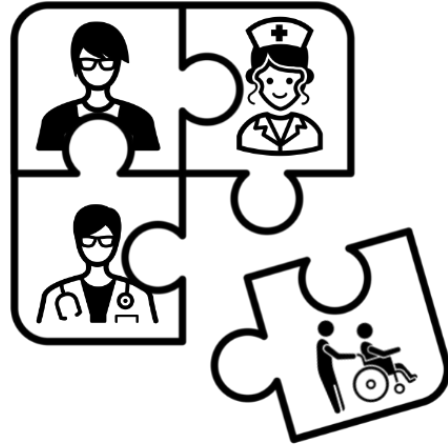


3. Unstructured



4. Siloed





Assembling the Data Jigsaw

Powering robust population research in MSK disease

2021-2024

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EPIDEMIOLOGY
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ARTHRITIS**

Assembling the Data Jigsaw



- A 'local data integration pilot' that

1. Pilots **novel data collection, extraction and integration** in rheumatology,

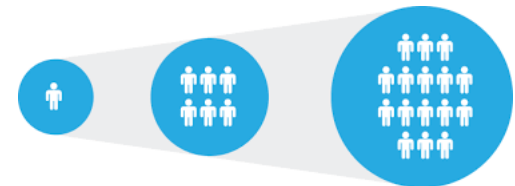
in order to...

2. Answer **important research questions**,



and designed to...

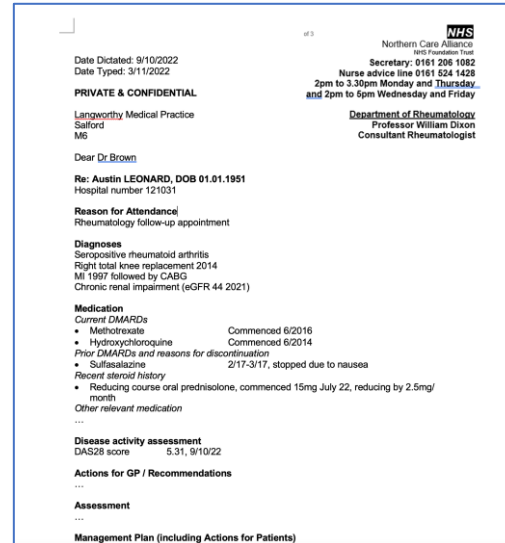
3. **Maintain public trust**, and for **sustainability and scalability** beyond the pilot



Data sources



Primary care EHR



Hospital letters



Inpatient EHR



Web-based surveys



Social care data



Interviews and focus groups

Steps towards trustworthy research

1. Patient and public involvement in developing the research questions
2. Holding a public consultation workshop for linked data
3. Completion of ethics and governance approvals (x6)
4. Excluding data from people who have opted out of data sharing
5. Accessing only deidentified data within a Secure Data Environment
6. Public notification of research
 - Benefits of addressing the research questions
 - How we have involved patients and the public
 - Data sources
 - How we keep data safe including video re SDEs

Developing public communication materials

Research
Team



Patient &
Public
Involvement

Patient &
Public
Involvement

Qualitative
Research:
Design

- Including sessions at
- Loaves and Fishes
 - AgeUK

Comms
Agency



**Comms Strategy
and Materials**

Awareness and
Understanding

Channels and messaging

Value proposition x4



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MANCHESTER
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Posters

including
Bus stops



Your health data could transform arthritis care in Salford.

The Data Jigsaw is a new initiative researching muscle and joint conditions to lead to better future treatment. Understanding more about the people already living with these conditions can answer our biggest questions, all unlocked by analysing patient data.

To find out more visit:
thedatajigsaw.co.uk

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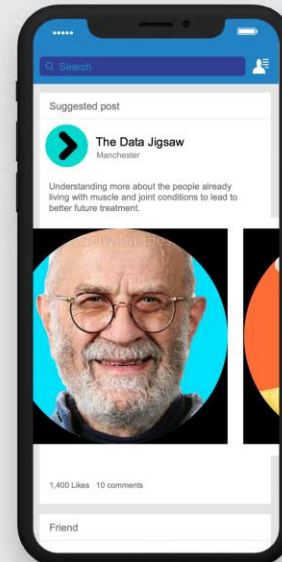
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Digital Ads
 eg MCR Evening News

Social Media

To find out more visit:
thedatajigsaw.co.uk





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[About us](#) [Our research](#) [How we collect data](#) [Keeping your data safe](#)

Your health data could improve arthritis care.

[View our explainer film](#)

[View film](#)



[About us](#)

**Muscle and joint problems need new solutions.
Salford patient records can provide the answers.**

Website including Videos

- [Jigsaw overview](#)
- [SDE](#)



Secure Data Environment video



Developing public communication materials

Research
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Patient &
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Patient &
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Qualitative
Research:
Design

Qualitative
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Value proposition x4

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