Assembling the Data Jigsaw

Advisory Group

Terms of Reference

Background

Routinely-collected health data, such as information held within electronic health records, are used primarily to support clinical care. Nonetheless, the secondary use of such data (having been deidentified) can also support population health research, such as understanding the burden of disease, or the effectiveness and safety of treatments. Limitations in this research can arise, however, due to the availability and quality of the data. Arthritis and musculoskeletal (MSK) research exemplifies many of these data problems, including data that are either siloed, missing completely or are unstructured.

Assembling the Data Jigsaw is a research programme, funded through the Nuffield Foundation in partnership with Versus Arthritis, which seeks to demonstrate the value of collecting, processing and linking datasets in order to answer important research questions. The programme will run from March 2021 – February 2024.

It aims to set up a local integration pilot in Salford, Greater Manchester, linking:

- Existing routine health data for research (primary care electronic health records and hospital episode statistics)
- Information that is automatically extracted from outpatient clinic letters
- New structured data collected from rheumatologists
- Data collected direct from patients
- Social care data

Researchers at the University of Manchester will use some of this data to:

- Estimate the incidence, prevalence and impact of common MSK disease
- Develop and validate a predictive algorithm to identify patients with undiagnosed ankylosing spondylitis and rheumatoid arthritis from primary care electronic health record data
- Examine the effectiveness and safety of analgesics

A third element of the programme will ensure that this is implemented whilst maintaining public trust, and producing guidance on how this approach can be scalable and sustainable.

Nuffield Foundation grant reference number: OBF/43995

Principal Investigator: Professor Will Dixon, University of Manchester.
Will.dixon@manchester.ac.uk

Nuffield Foundation contacts:
Programme Head / Director managing the grant: Catherine Dennison
cdennison@nuffieldfoundation.org
Grant Coordinator: Edmund McKiernan emckiernan@nuffieldfoundation.org

Overall Remit

The *Jigsaw* Advisory Group will provide advice and challenge to the research programme to help ensure it is robust, meets the needs of its stakeholders, is aware of existing and forthcoming relevant initiatives, and produces high quality outputs. Members of the Group will guide and support the successful dissemination of the research and other outputs from the programme, using their influence to amplify impact.

Specific Terms of Reference

The **terms of reference** of the *Jigsaw* Advisory Group include
1. to provide oversight, advice and challenge on the conduct of the research, including the methods and approaches used;
2. to highlight and discuss and, if possible, resolve, ethical considerations that emerge in the course of the research;
3. to comment on the suitability and quality of research instruments designed and/or used as part of the project;
4. to quality assure analytical approaches and interpretation;
5. to comment on and quality assure research outputs, including reports;
6. to help identify implications for policy and practice;
7. to help shape and advise on communication and dissemination of project outputs and findings;
8. to identify areas or issues on which the research team needs to seek external advice, whether that is from the Nuffield Foundation as funder, or from the research, policy or practice communities.

[Jigsaw-specific needs]

1. to refine our proposed work plans to meet stakeholder needs;
2. to support dissemination of results and learning through their networks;
3. to provide advice about existing or emerging national or international initiatives (horizon scanning); and

4. provide occasional *ad hoc* advice or review of quality

Note: The *Jigsaw* Advisory Group will be complemented by a second group comprised of senior representatives from local data custodians, along with local data users, patient/ carer representatives and governance experts ('the Spilsbury Group') to support the successful set-up of the local data integration pilot. The Spilsbury Group will meet quarterly for the first year of the programme to help guide and facilitate the successful assembly of the data jigsaw for this research programme.

For reference, draft terms of reference for the Spilsbury Group are as follows:

1. To help the research team understand barriers and enablers to establishing the local data integration pilot
2. To help facilitate successful access to data; and to navigate relevant governance
3. To provide a perspective about possible local benefits from the research, in terms of outputs and outcomes, helping ensure the research delivers for the local community
4. To help determine if we have met necessary quality standards

Composition

The group is composed of organisations who can provide expert advice on data standards and governance, and those who stand to benefit from *Jigsaw* research and data outputs.

Chair

Peter Lanyon	University of Nottingham

Members

Adam Steventon	Our Future Health
Aidan Peppin	Ada Lovelace Institute
Amanda Lucas	Imperial Health Partners
Andy Bennett	NHS England
Dale Webb	National Axial Spondyloarthritis Society
Harri Weeks	Understanding Patient Data
James Galloway	British Society for Rheumatology
Jose-Luis Fernandez	London School of Economics
Neha Issar-Brown	Versus Arthritis
Guy Lucchi	System C
Jane Brightman	NHS Transformation Directorate/NHS England

In attendance

Jigsaw team members

Will Dixon	Principal Investigator
John McBeth; Niels Peek; Caroline Sanders	Workstream Leads
Louise Cook	Programme Manager
Joyce Fox	PPIE Lead
Jane Taylor	Patient partner

Funders

Catherine Dennison	Nuffield Foundation
Michael Ly	Versus Arthritis

Mode of Working

Chaired by Peter Lanyon, the Advisory Group will meet every six months for the duration of the *Assembling the Data Jigsaw* programme (March 2021 – February 2024).

There may be some crossover with the implementation-focused Spilsbury Group, which will meet during the first year of the programme to help establish the data access and linkages.

Confidentiality

All advisory group members must treat as confidential any discussions at advisory group meetings, emails, and any documents that may be shared, including pre-publication copies of research reports.

Travel expenses

Members of the advisory group may claim reasonable travel costs incurred in attending formal meetings and should liaise with Louise Cook louise.cook@manchester.ac.uk.