Sharing data responsibly: international, interdisciplinary and intersectoral entanglements

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Data sharing cultures

- Data are foundational to contemporary science
- International data sharing is complex
  - Legal and regulatory context
  - Methodological challenges – big data doesn't always travel easily
  - But it is the **peopled** nature of data sharing introduces the greatest complexity
- Data ethics in practice

Data sharing cultures

Shifting values in science - data Sharing

- 2004: OECD *Declaration on Access to Research Data from Public Funding*
  "The value of data lies in their use. Full and open access to scientific data should be adopted as the international norm for the exchange of scientific data derived from publicly funded research."

  Principles and Guidelines for the *Declaration, 2007*

- Underpinned by other values in science
  - Knowledge translation and the impact agenda
  - Responsible Research and Innovation
  - Open Science

Data sharing cultures

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But human data are different

- Sensitivity
  - Personal
  - Identifiable
  - And not only when human's are the subject of research/data processing – e.g. geographical data
- Identity
  - More than name and address
  - The right to choose when and what to disclose
  - Even when actively engaged in science
  - And especially when not

Data sharing cultures

- Interdisciplinarity
  - Different epistemic cultures
- Intersectionality
  - Different practice cultures
- Public engagement
- = Entanglements
  - Not so ‘spooky action at a distance’

Data ethics in practice

- Framework for responsible data sharing
  - Global Alliance for Genomics & Health (GA4GH)
- New Technologies meet old governance
  - DataSHIELD – “taking the analysis to the data not the data to the analysis”
- Fairness, transparency & citizen expectations
  - EU General Data Protection Regulation (GDPR)
- Participant involvement in data access governance
  - METADAC
  - Great North Care Record

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Great North Care Record

Responsible data sharing: GA4GH

Global Alliance for Genomics and Health

- 44 countries
- 500+ organisations
- Government, Industry, Third Sector, Patients & Publics
- policy-framing and sociotechnical standards-setting

GA4GH *Framework for Responsible Sharing of Genomic and Health-Related Data:* http://bit.ly/2tOsrJq

- Current frameworks are founded on the principle of protection from harm. In contrast…
- GA4GH Framework aims to activate the right to science and the right to recognition for scientific production by promoting responsible data sharing

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Global Alliance for Genomics & Health

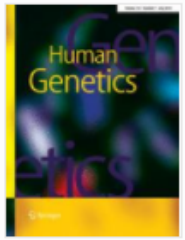
Responsible data sharing: GA4GH

The HUGO Journal
December 2014, 8:3 | Cite as

Framework for responsible sharing of genomic and health-related data

Authors | Authors and affiliations

Bartha Maria Knoppers



Human Genetics
July 2014, Volume 133, Issue 7, pp 895–903 | Cite as

A human rights approach to an international code of conduct for genomic and clinical data sharing

Authors | Authors and affiliations

Bartha M. Knoppers, Jennifer R. Harris, Isabelle Budin-Ljøsne, Edward S. Dove

Responsible data sharing: GA4GH

Universal Declaration of Human Rights, (1948)

27(1) "The Right to Science"

"Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits."

"The Right to Recognition" **27(2)**

"Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author."

29(1) "Duties to the community"

Everyone has duties to the community in which alone the free and full development of [their] personality is possible.

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Global Alliance for Genomics & Health

Responsible data sharing: GA4GH

Foundational Principles for Responsible Sharing of Genomic and Health-Related Data

- Respect Individuals, Families and Communities
- Advance Research and Scientific Knowledge
- Promote Health, Wellbeing and the Fair Distribution of Benefits
- Foster Trust, Integrity and Reciprocity

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Responsible data sharing: GA4GH

Core Elements for Responsible Data Sharing

- Transparency
- Accountability
- Data Quality and Security
- Privacy, Data Protection and Confidentiality
- Risk-Benefit Analysis
- Recognition and Attribution
- Sustainability
- Education and Training
- Accessibility and Dissemination

GDPR data processing principles

- Fair and lawful
- Purpose limitation
- Data minimisation
- Rules of further processing
- Data retention
- Data accuracy
- accountability

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Global Alliance for Genomics & Health

Sociotechnical solutions: DataSHIELD

DataSHIELD: taking the analysis to the data, not the data to the analysis

Amadou Gaye, Yannick Marcon, Julia Isaeva, Philippe LaFlamme, Andrew Turner, Elinor M Jones, Joel Minion, Andrew W Boyd, Christopher J Newby, Marja-Liisa Nuotio Rebecca Wilson, Oliver Butters, Barnaby Murtagh, Ipek Demir, Dany Doiron, Lisette Giepmans, Susan E Wallace, Isabelle Budin-Ljøsne, Carsten Oliver Schmidt, Paolo Boffetta, Mathieu Boniol, Maria Bota, Kim W Carter, Nick deKlerk, Chris Dibben, Richard W Francis, Tero Hiekkalinna, Kristian Hveem, Kirsti Kvaløy, Sean Millar, Ivan J Perry, Annette Peters, Catherine M Phillips, Frank Popham, Gillian Raab, Eva Reischl, Nuala Sheehan, Melanie Waldenberger, Markus Perola, Edwin van den Heuvel, John Macleod, Bartha M Knoppers, Ronald P Stolk, Isabel Fortier, Jennifer R Harris, Bruce HR Woffenbuttel, Madeleine J Murtagh, Vincent Ferretti, Paul R Burton

Volume 43, Issue 6
December 2014

International Journal of Epidemiology, Volume 43, Issue 6, 1 December 2014, Pages 1929–1944,
https://doi.org/10.1093/ije/dyu188

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DataSHIELD
Secure Bioscience Collaboration

Sociotechnical solutions: DataSHIELD

- BioSHaRE: European/North American collaboration
- DataSHIELD: “taking the analysis to the data not the data to the analysis”
- Leaves the data to be analysed on local servers behind the firewalls where they usually reside
- Analytic processing - *and options for disclosure control* - located with the data
- Multiple data sources
  - The analysis centre *co-ordinates* parallelised analyses in all studies simultaneously
  - Tie analyses together with non-disclosive information: (i) non-disclosive statistics (ideally *sufficient statistics*); (ii) encrypted information that can be decrypted as a final step of processing

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DataSHIELD Secure Bioscience Collaboration

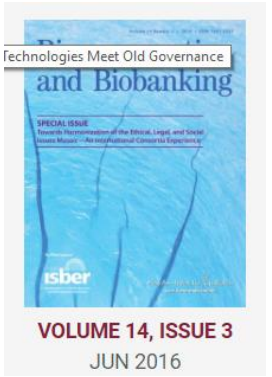
Sociotechnical solutions: DataSHIELD

Biopreservation and Biobanking, Vol. 14, No. 3 | Original Articles

International Data Sharing in Practice: New Technologies Meet Old Governance

Murtagh Madeleine J., Turner Andrew, Minion Joel T., Fay Michaela, and Burton Paul R.

Published Online: 1 Jun 2016 | https://doi.org/10.1089/bio.2016.0002



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bbmri-lpc
BBMRI – Large Prospective Cohorts

BioSHaRE.eu

DataSHIELD
Secure Bioscience Collaboration

Sociotechnical solutions: DataSHIELD

"I think that the very big hurdles in science are human hurdles, human relationships. Problems that have nothing to do with science."

Tensions

- Competition and collaboration
- Open science vs the profession of science

Protecting participants

Ensuring the tenets of participant consents are upheld

Managing emerging ethical considerations

Protecting the study

Managing the potential for reputational damage

Supporting participant trust in the studies

Protecting researchers

Recognition of research contributions and IP

DataSHIELD
Secure Bioscience Collaboration

Fairness and transparency: GDPR

- Legal basis for data sharing under GDPR
  - 9(2)(j) – Processing is necessary for archiving purposes in the **public interest**, or **scientific** and historical **research purposes or statistical purposes** in accordance with Article 89(1)
  - Interpretation/guidance still emergent
- Obligations under GDPR - **transparency**, **fairness** and actions commensurate with **citizen expectations** (UK Common Law Duty of Confidentiality)
- How?
  - Understand citizen expectations, including those of the marginalised and hard to reach
  - Communication and education
  - Engage with citizens – involve them in governance decisions to ensure those expectations are met

Citizen decision-makers: METADAC

Managing Ethico-social, Technical and Administrative issues in Data Access (METADAC) - www.metadac.ac.uk

- Managing access to UK longitudinal research projects
  - Decades of phenotypic and genotypic data and samples collection
  - Consent for sharing - but with constraints and expectations
- METADAC Access Committee
  - Assesses sensitive data and sample applications
  - Governance of complex data requires **expertise from across domains and disciplines**, including that of **study participants**
  - **Human-mediated decision making** central to ensuring achievable, reasoned and responsible decisions

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METADAC

Citizen decision-makers: METADAC

Better governance, better access: practising responsible data sharing in the METADAC governance infrastructure

M.J. Murtagh, M.T. Blell, O.W. Butters, L. Cowley, E.S. Dove, A. Goodman, R.C. Griggs, A. Hall, N. Hallowell, M. Kumari, M. Mangino, B. Maughan, M.C. Mills, J.T. Minion, T. Murphy, G. Prior, M. Suderman, S.M. Ring, N.T. Rogers, S.J. Roberts, C. Van der Straeten, W. Viney, D. Wiltshire, A. Wong, N. Walker, P.R. Burton.

(forthcoming)

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METADAC

Citizen decision-makers: METADAC

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  - **Human-mediated decision making** central to ensuring achievable, reasoned and responsible decisions
- Assessment criteria for data access - http://bit.ly/2HDOjJG

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METADAC

The Great North Care Record (GNCR)

Information and data sharing in health and social care: opportunities and challenges

Tejal Shah, Louise Wilson, Sarah Ashcroft, Tracy Best, Nick Booth, Ian Briggs, Olly Butters, Annette Chambers, Kathryn Common, Wendy Leanne Craig, Tim Goodship, Ian Lowry, Joe McDonald, Denis Martin, Mike Martin, Joel T Minion, Stephanie Mulrine, Seamus O'Neill, Heather Parker, Mark Westwood, Mark Walsh, Paul R Burton, Madeleine J Murtagh

(forthcoming)

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Great North Care Record

The Great North Care Record (GNCR)

The Great North Care Record makes information appropriately accessible for individual healthcare, service planning and **research**

CONNECTED HEALTH CITIES

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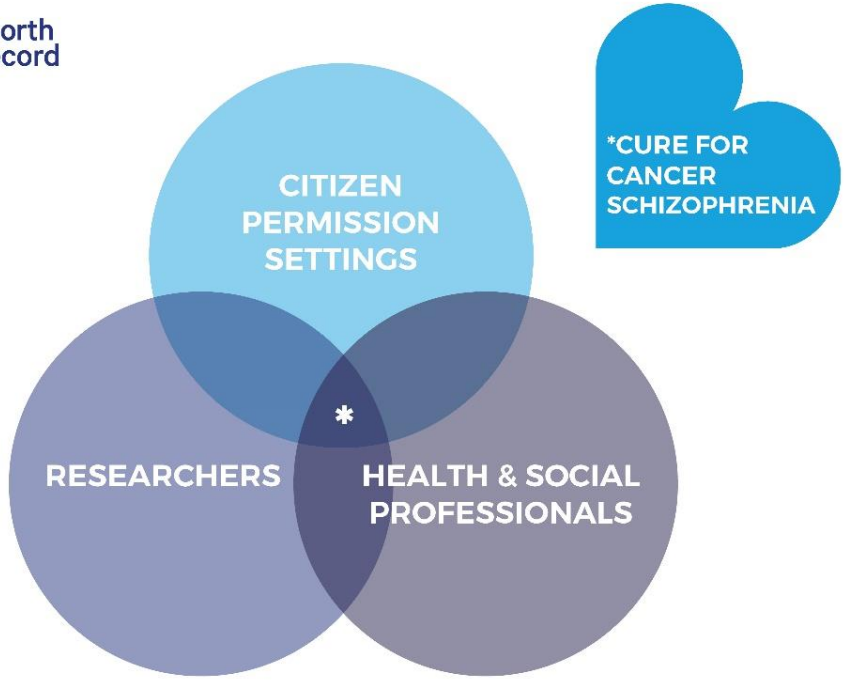
Great North Care Record

The GNCR vision

Great North Care Record



Safer care and better information for health and social care professionals at the point of need.
Better information for service planning.
A rich data analytics research environment

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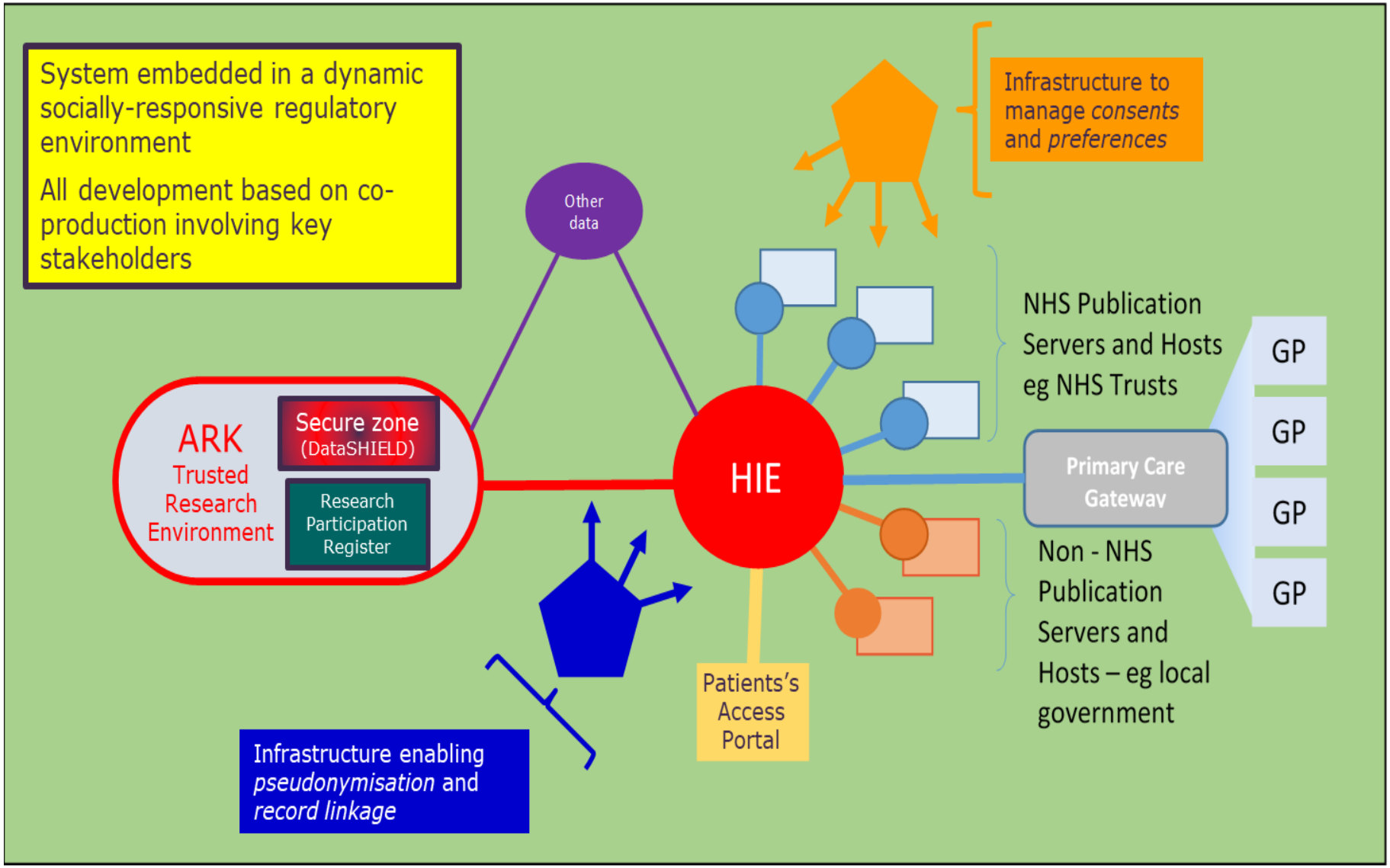
The GNCR vision: ARCHIE



Fairness and transparency in the GNCR

Transparency, fairness and actions commensurate with citizen expectations – obligations under GDPR

- **How?**
  - Understand citizen expectations, including those of the marginalised and hard to reach
    - Focus groups, interviews, ECOUTER
  - Engage with citizens
    - involve them in governance decisions to ensure those expectations are met
    - Co-producing the technical and governance systems for data sharing
  - Communication and education

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Sharing Data Responsibly

Is not simply made up of, but requires:

- Interdisciplinarity
- Intersectionality
- Public engagement
- Entanglements

THANK YOU FOR LISTENING

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Global Alliance for Genomics & Health

SEVENTH FRAMEWORK

wellcome

MRC Medical Research Council

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL