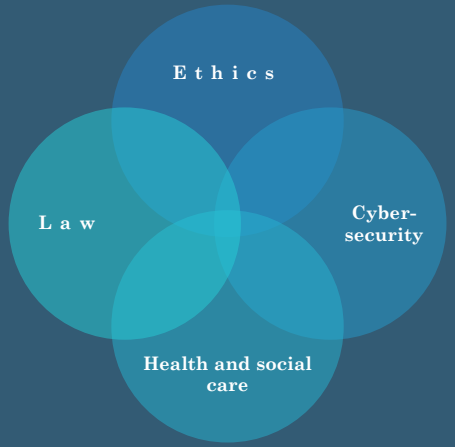
Social Data Foundation
for Health and Social Care

May 2022

Joined Up Data Equals Better Care

Presented by Prof. Dame Wendy Hall



Boniface, M., Carmichael, L., Hall, W., Pickering, B., Stalla-Bourdillon, S. & Taylor, S.
Interdisciplinary Centre for Law, Internet & Culture (iCLIC) | IT Innovation | Web Science Institute (WSI)

University of Southampton

NHS University Hospital Southampton NHS Foundation Trust

Southampton City Council

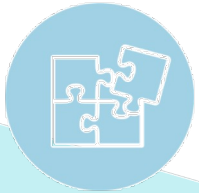
Joined Up Data Equals Better Care

Turning the wealth of health and social data into ***insights for better public health and personalised care*** is critically important for society

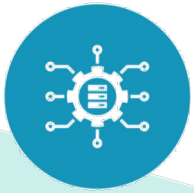
Yet ***data access and insights are hampered*** by slow, manual governance processes that are error-prone, time consuming and not easy to repeat

With increasing data volumes, complexity, and need for fast collaborative solutions, ***new approaches to data governance*** must be found

A Social Data Foundation



We are establishing a Social Data Foundation that aims to improve health and social care by ***accelerated access to linked data*** from citizens, local authorities and healthcare providers



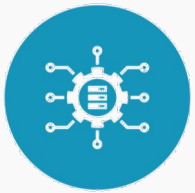
We will deliver a ***smart data management platform*** that helps automate legally compliant and ethical governance between health and social care data providers and analysts

We are a ***partnership between UoS, UHS and SCC*** to oversee the creation of the platform and the Foundation itself

Driven by Unmet Care Needs

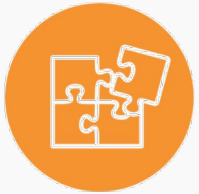
Users

- Seamless patient journey
- Digital divides, health inequalities and literacy
- Co-creation and social licence from citizens
- Co-creation and acceptance by healthcare workers



Systems

- Progressive digitisation of systems through IoT and Twins
- Advancing medical interventions and pathway configuration
- Continuously evolving collaborative governance
- Sustainability and performance



Data

- Data silos and lack of discoverability (clinical, social, environment, operational)
- Slow access to data
- Lack of assurance over data-related risks
- Disconnection from citizens

Exemplar Use Cases

Rapid provisioning of complex care services

Management of multiple long-term conditions

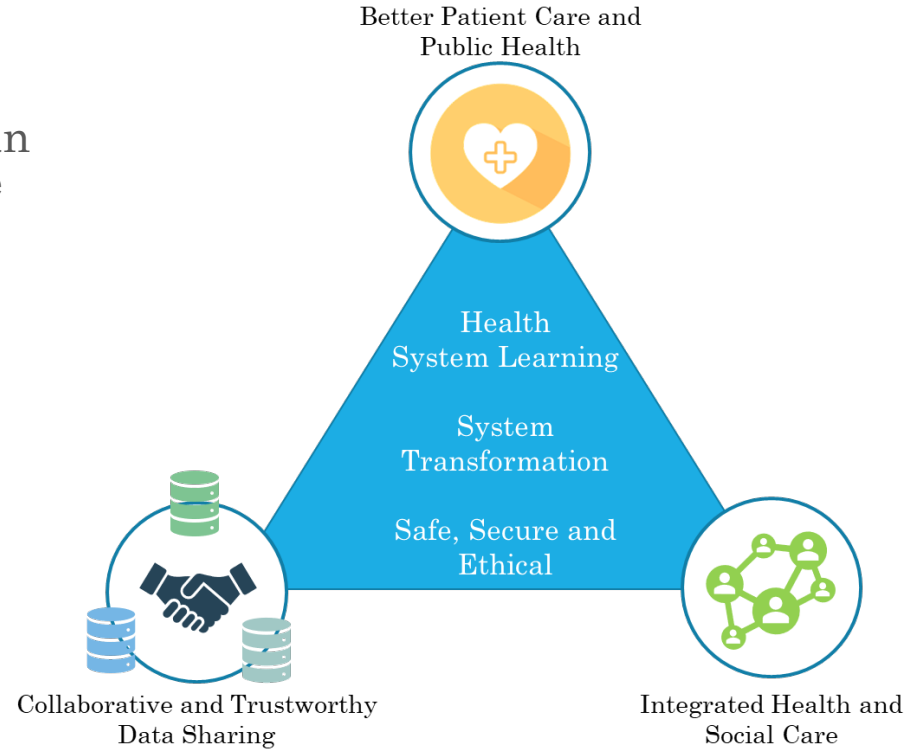
Integrated care planning and optimisation

COVID-19 intelligence

Positive and sustainable health and social care transformation

Facilitate **trustworthy multi-party data sharing** as part of an integrated health and social care system for stakeholder communities

A federation of stakeholders operating within a ***diameter of trust***



Governance and architecture

Solution: A Data Foundation

A new **data institution** for multi-party data sharing between the Council, Hospital, University called the

Social Data Foundation

- that builds on the data foundations framework for good data governance together with strong citizen representation and contract law

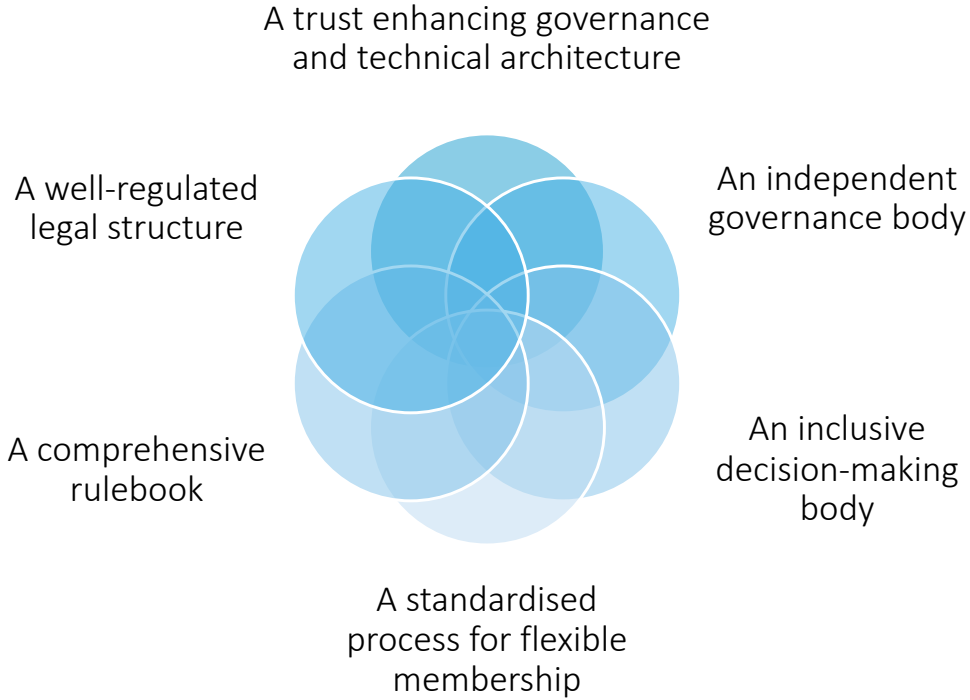
'Data institution' describes:

"organisations whose purpose involves stewarding data on behalf of others, often towards public, educational or charitable aims",

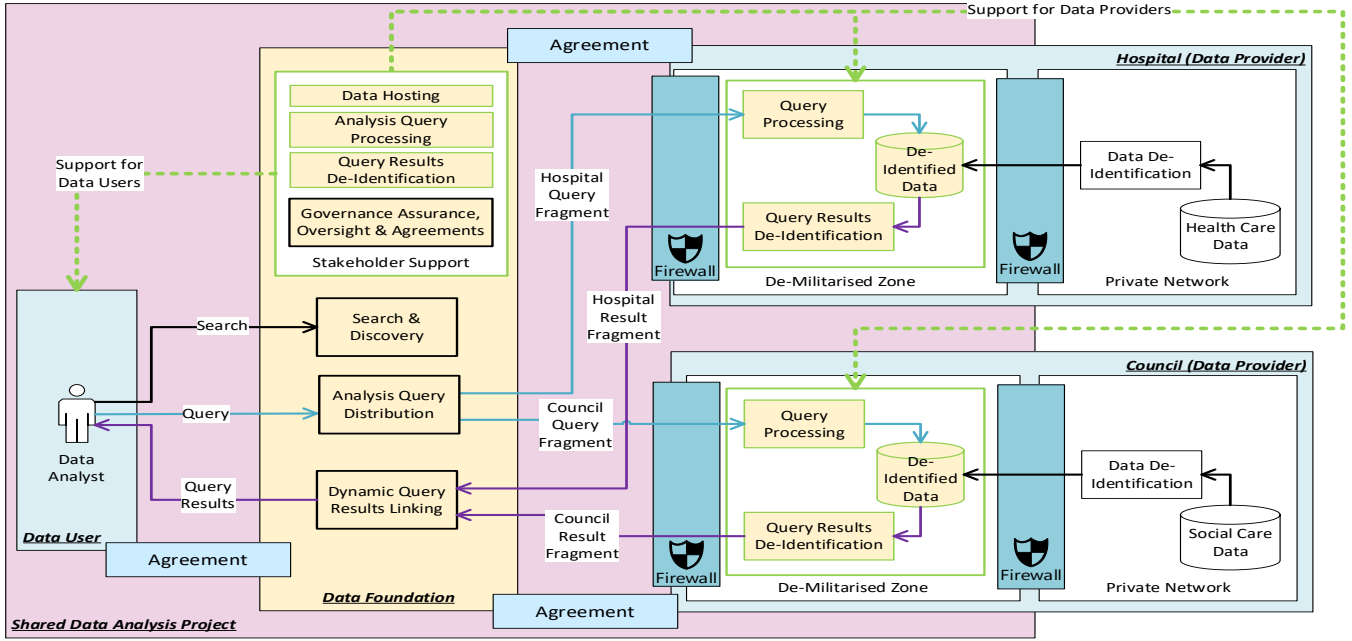
source Open Data Institute, UK

The data foundations framework

Six components for good data governance



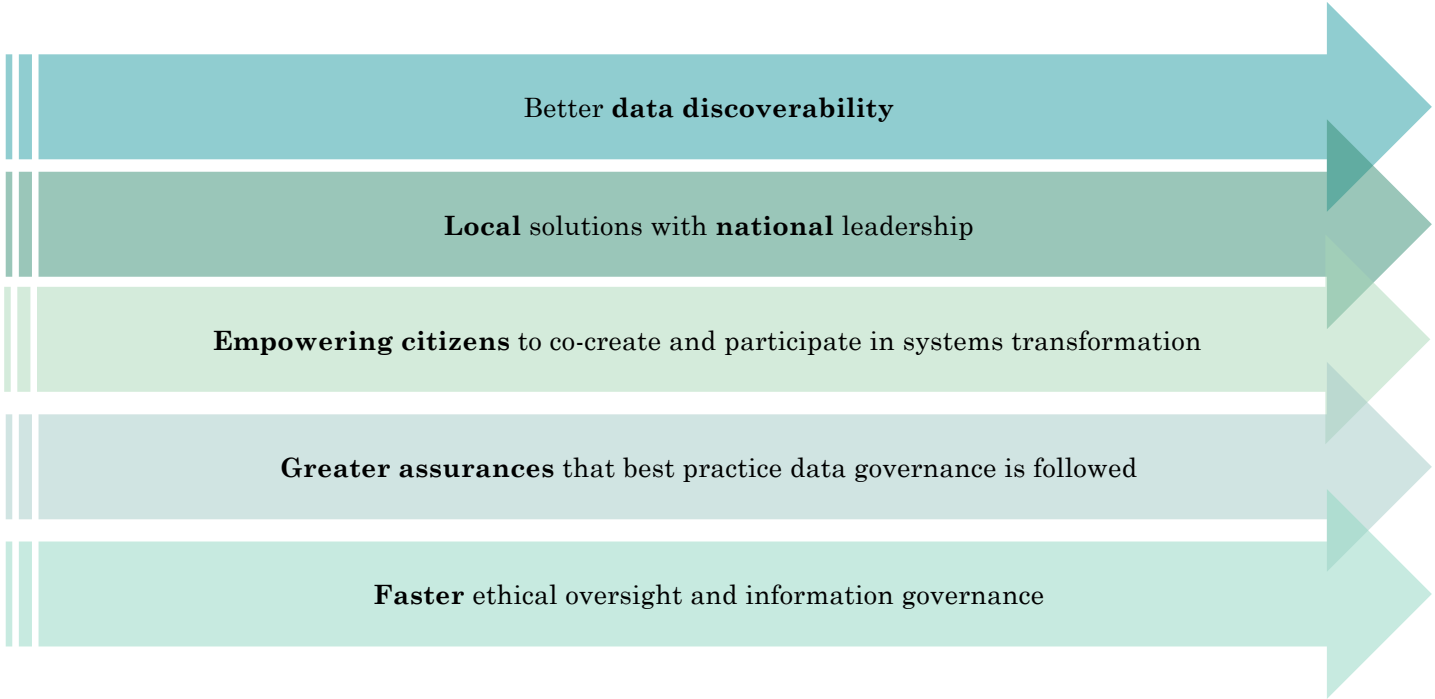
Better Policy, Compliance + Smart Governance Technologies



Data Foundation Architecture (distribution of function)

Automated risk management
Ownership and rights management
Security and privacy controls
Dynamic data linking

The principal ways the Data Foundation could accelerate data sharing



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A blueprint for a social data foundation: Accelerating trustworthy and collaborative data sharing for health and social care transformation

Boniface, Michael, Carmichael, Laura, Hall, Wendy, Pickering, Brian, Stalla-Bourdillon, Sophie and Taylor, Steve (2020) *A blueprint for a social data foundation: Accelerating trustworthy and collaborative data sharing for health and social care transformation* (Web Science Institute White Papers, 4) Southampton. University of Southampton 46pp. (doi:10.5258/SOTON/WSI-WP004).

Record type: **Monograph (Project Report)**

Abstract

Text
WSI white paper 4 social data foundations

Social Data Foundation agreement signed by Southampton University, City Council and Hospital, May 2021

First project – complex discharge from hospital into community

Further reading

- https://www.adalovelaceinstitute.org/report/legal-mechanisms-data-stewardship/Legal Mechanisms

- https://www.cambridge.org/core/journals/data-and-policy/article/social-data-foundation-model-facilitating-health-and-social-care-transformation-through-datatrust-services/CD882977DA412B4020945C3FFE8725A0

Thanks for listening…

Any questions?

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