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### Professor John Ainsworth john.ainsworth@manchester.ac.uk NHS-HE Forum, November 2016

- 1. Valderas JM, et al. Defining comorbidity: implications for understanding health and health services. Annals of family medicine; 7(4):357–63.
- 2. Fortin M, et al. Randomized controlled trials: do they have external validity for patients with multiple comorbidities? Annals of family medicine 2006 Jan



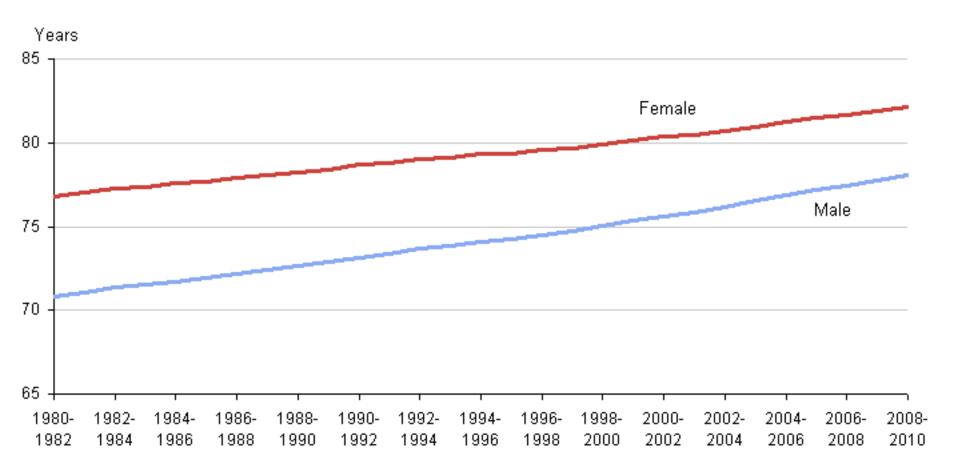




- Palm Tungsten
  - Discontinued!
  - 2<sup>nd</sup> hand from e-Bay?







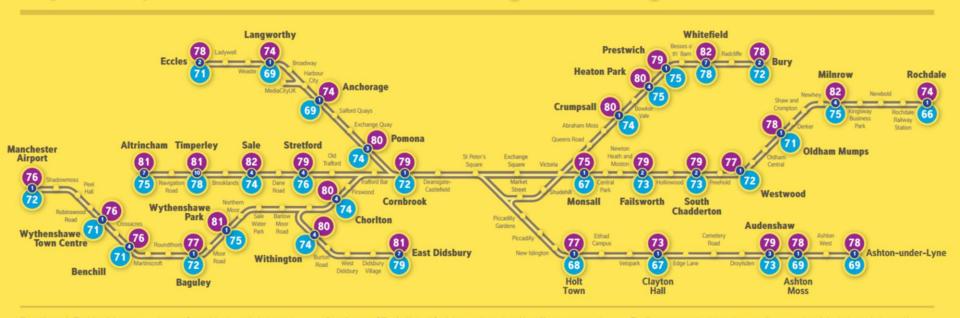
Life expectancy at birth, UK, 1980-82 to 2008-2010 from period life tables Source: ONS



### Life on the tram? Differences in life **expectancy across Greater Manchester**



Female life expectancy at birth (years) Male life expectancy at birth (years) IMD Decile (1 most deprived; 10 least deprived)

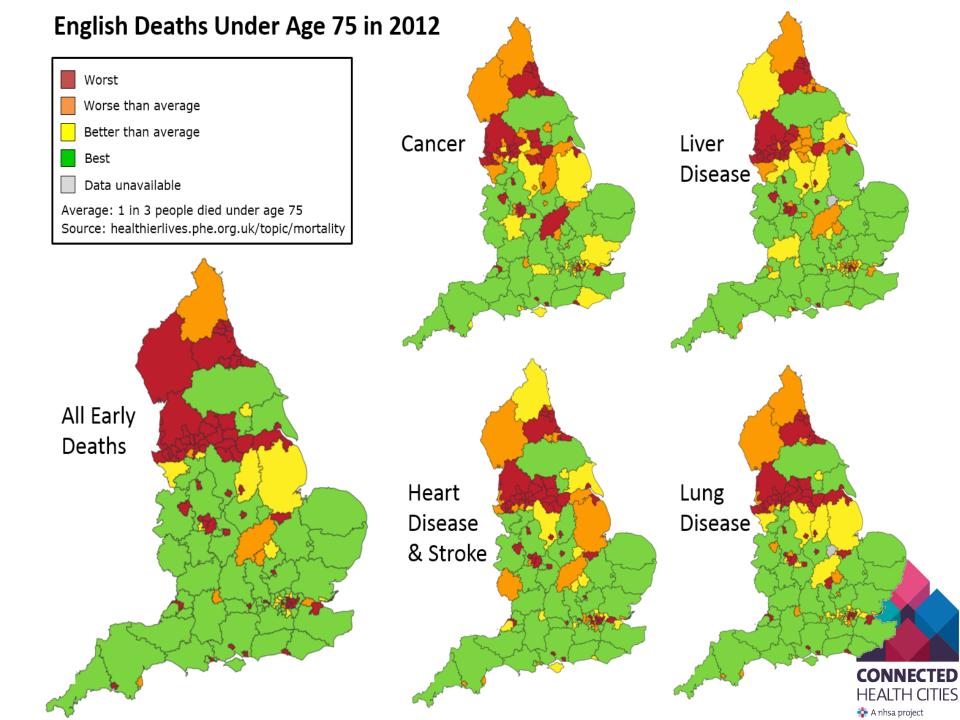


Tram Network: The Metrolink tram network across Greater Manchester includes nearly 100 kilometres of track and 93 stops. In 2015 there were around 33.4 million journeys (Metrolink 2015). The average journey time between tram stops is 2 minutes, but some stops are further apart.

Data Sources: Office for National Statistics experimental ward level life expectancy and health living life expectancy estimates (ONS 2006) linked to selected Greater Manchester Metrolink tram stops. The selection highlights some of the biggest differences between tram stops. We also include information on socio-economic deprivation at ward level from the Index of Multiple Deprivation.

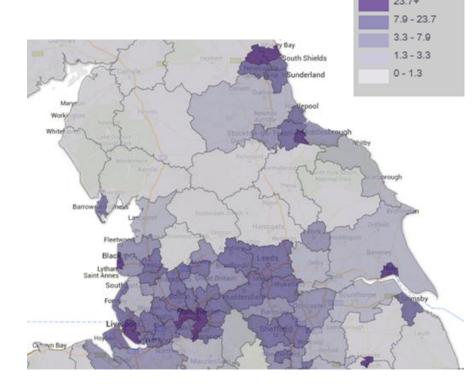
The life expectancy data is based on mortality among those living in the particular ward in 1999-2003. The estimates are not the exact number of years a baby born in the ward could actually expect to live, both because the death rates of the area are likely to change in the future, as is health care provision and because many of those people born in the ward will live elsewhere for at least some part of their lives.





## Health North: CHC pilots

- Hub and Spoke Model
- Four city regions
  - Greater Manchester
  - North West Coast
  - Yorkshire & Humber
  - North East and North Cumbria
- One hub (GM)
- ~2 pathways per region
- Start Jan 2016 3 years



Population densities: North England 2012



Population density (100s per km2)

### Three aims

1. To continually improve and optimise the health and social care system to deliver better care, more efficiently, by providing actionable information to inform decision making at all levels.



## Health(care) Evidence History



Scientific basis of medicine →

Evidence based care→

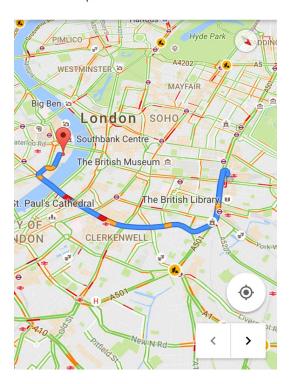
Learning health systems →

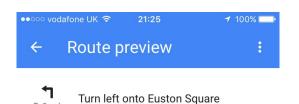


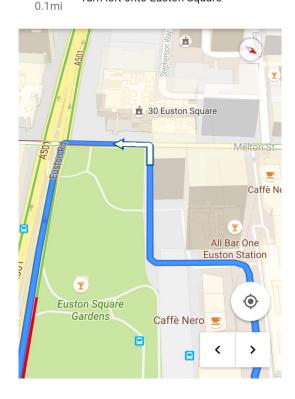
### Systems that learn: an analogy

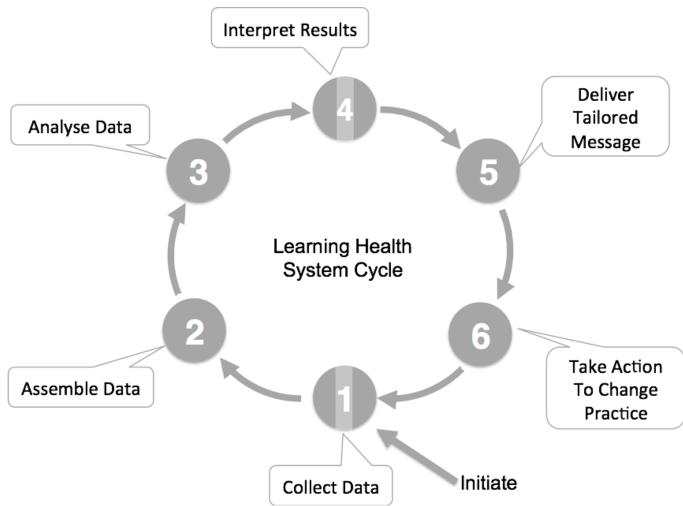


Head south-west towards Euston Square



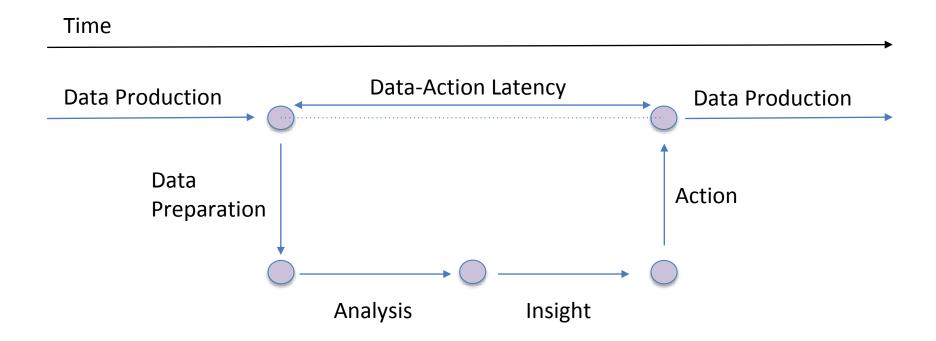






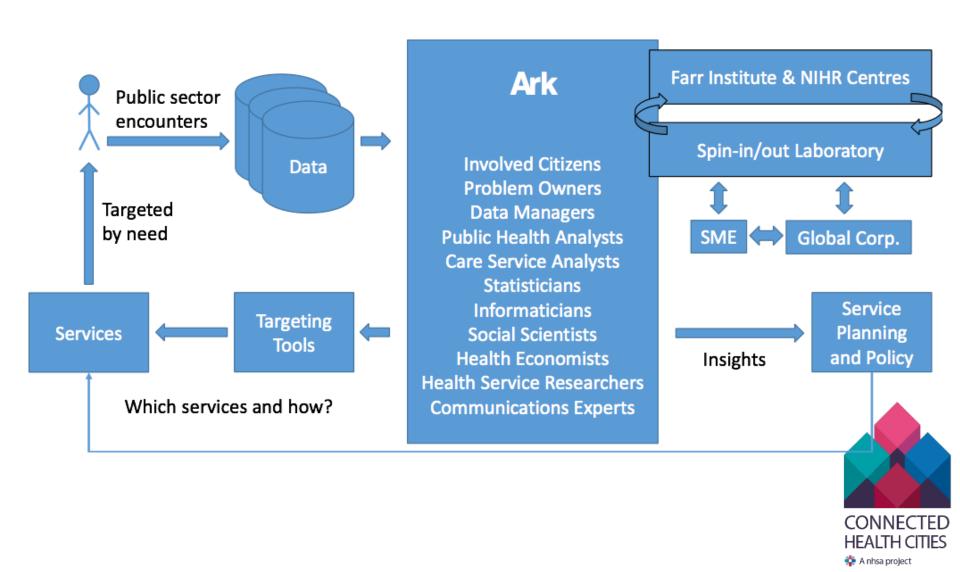
A health system organised to optimise the delivery of care based on the evidence produced through delivering care.

## **Data-Action Latency**

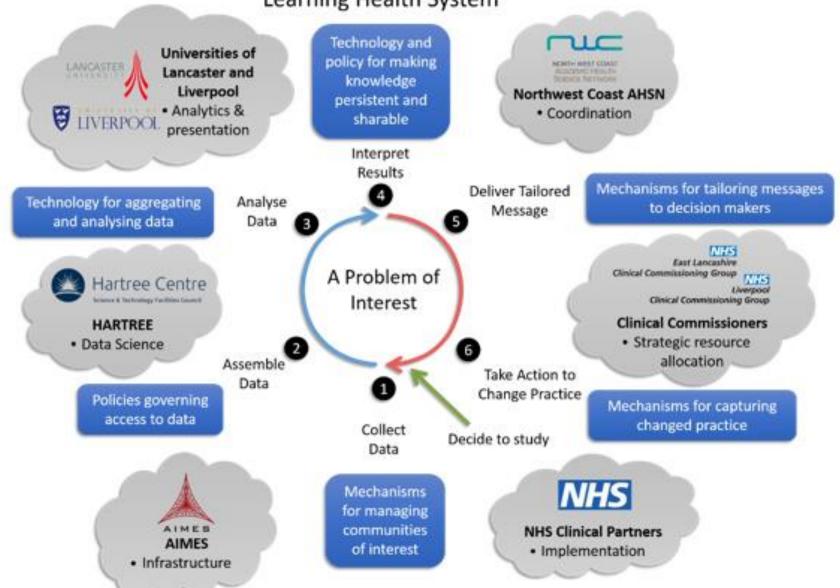




# Connected Health City: Ark-enhanced Information Flows



### North West Coast Learning Health System



### Three aims

- 1. To continually improve and optimise the health and social care system to deliver better care, more efficiently, by providing actionable information to inform decision making at all levels. This is known as a Learning Health System (LHS).
- 2. To establish a social contract with the population that gives license to use healthcare data for the public good.





### The social licence for research: why care.data ran into trouble

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#### **ABSTRACT**

In this article we draw on the concept of a social licence to explain public concern at the introduction of care. data, a recent English initiative designed to extract data from primary care medical records for commissioning and other purposes, including research. The concept of a social licence describes how the expectations of society regarding some activities may go beyond compliance with the requirements of formal regulation; those who do not fulfil the conditions for the social licence (even if formally compliant) may experience ongoing challenge and contestation. Previous work suggests that people's cooperation with specific research studies depends on their perceptions that their participation is voluntary and is governed by values of reciprocity, non-exploitation and service of the public good. When these conditions are not seen to obtain, threats to the social licence for research may emerge. We propose that care.data failed to adequately secure a social licence because of:

- (i) defects in the warrants of trust provided for care.data,
- (ii) the implied rupture in the traditional role,

Although care.data has numerous aims (box 1), we focus specifically on its research purposes. We begin by offering some brief background on the use and regulation of routine medical data before introducing the concept of a social licence.

#### THE USE AND REGULATION OF MEDICAL RECORDS FOR RESEARCH

Researchers have long relied on access to personal medical information routinely collected during the course of patient care in order to conduct studies, including clinical trials and epidemiological research. However, the repurposing of routinely collected data for research is not without risk to relevant values, 8 and measures such as anonymisation (even when possible) do not solve all ethical, legal and technical problems; people may, for example, have religious or moral objections to particular studies<sup>5</sup> or concerns about stigma and breaches of privacy.

Accordingly, researchers' access to, and use of,



## Data Sharing: Diameter of Trust



Population Audits/Realsters/Monit

Excellence provider
benchmarking e.g.
strokeaudit.org but no
learning across disease areas

Large enough for economy of scale

Small enough for a conversation with the citizenry about data sharing Actionable information for health system optimisation

Payer evidence, quality management, public health intelligence and research share data, infrastructure





www.herc.ac.uk/get-involved/citizens-jury/

## Public Engagement

- Citizens Juries
- http://www.herc.ac.uk/get-involved/citizens-jury/
- Nov 2016
- #datasaveslives







## Information Governance

Privacy Impact Assessment Data sharing Agreements



### Public Engagement

#datasaveslives Citizen Juries Data Donation



### Citizens Portal

Dynamic consent Data feedback



### Three aims

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- 2. To establish a social contract with the population that gives license to use healthcare data for the public good.
- 3. To accelerate business growth in the digital health sector for the benefit of the North of England.



## How will we drive economic growth

- Open innovation partnership with established IT companies to advance core infrastructure
- Spin-in laboratory to accelerate development of digital health technologies by SMEs
- Platform for delivering real-world evidence studies
- Scale to 15m population of North; internationally competitive

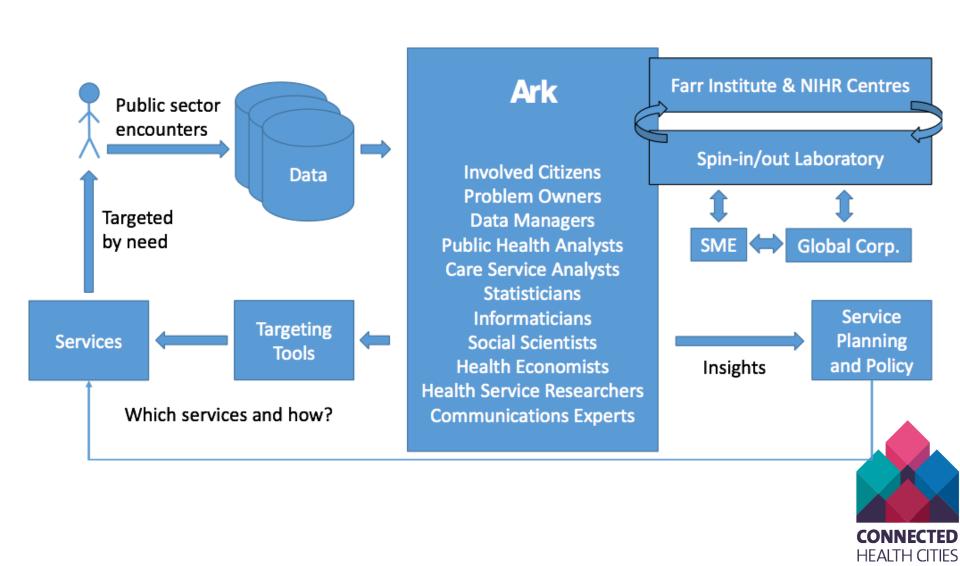


## Technology

- Data Access, Information Governance and Citizens Control
  - → Distributed Ledger Technology, Digital Economy
- Ark Design and Reference Architecture
  - → Real-time multimodal data analytics
- Knowledge Exchange and Reuse
  - → Digital asset: publication, discovery and reuse
- Data Federation, Virtualisation and Distributed Data Analysis
  - → Security: Trust, Identity; Semantics & Discovery



## Spin-in/out Laboratory



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### **CHC Outcomes**

- Civic partnerships
  - -Effective model for patient and public involvement
- Four pilot CHCs
  - —Blueprints and plans
- Federation of CHCs
  - Exchanging and reusing knowledge
- Test learning health system methodology
  - -Understand data needs
- Model for driving economic growth
  - Responsive to the needs of industry



## Summary

- 1. To continually improve and optimise the health and social care system to deliver better care, more efficiently, by providing actionable information to inform decision making at all levels.
- 2. To establish a social contract with the population that gives license to use healthcare data for the public good.
- 3. To accelerate business growth in the digital health sector for the benefit of the North of England.





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### Informatics for Health 2017

Joint meeting of MIE 2017 and The Farr Institute International Conference 2017

Venue: Manchester, UK

Date: 24th - 26th April 2017

Web: www.informaticsforhealth.org

