



NHS

England

The social life of data

Designing for data using a
life-course approach

Presented by:

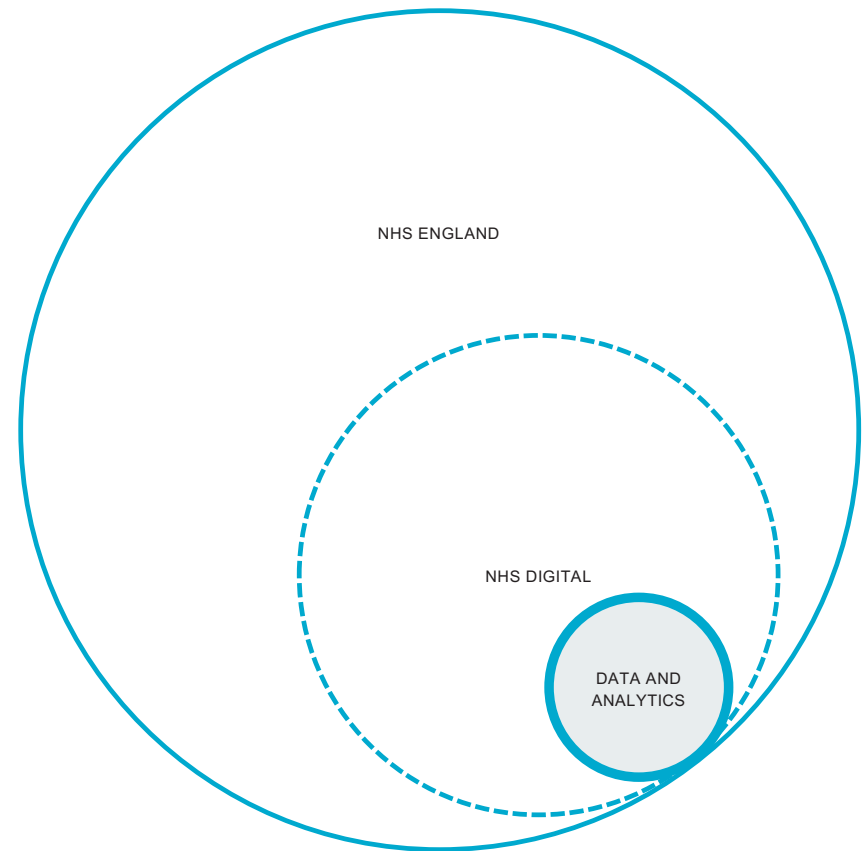
[Chiara Garattini](#) and [Danila Lalli](#)



Today's talk

- About health data and being a data custodian
- About how we started working in data services as user-centred design team and the approach we took
- Some of the implications of following the data instead of people when designing services

**“We are the
custodian for health
data in England”**





Data

What do we mean by data?

Information, especially **facts** or **numbers**, collected to be examined and considered and used to help decision-making, or information in an **electronic form** that can be stored and used by a computer. ([Cambridge Dictionary](#))



Data

What is the power of data?

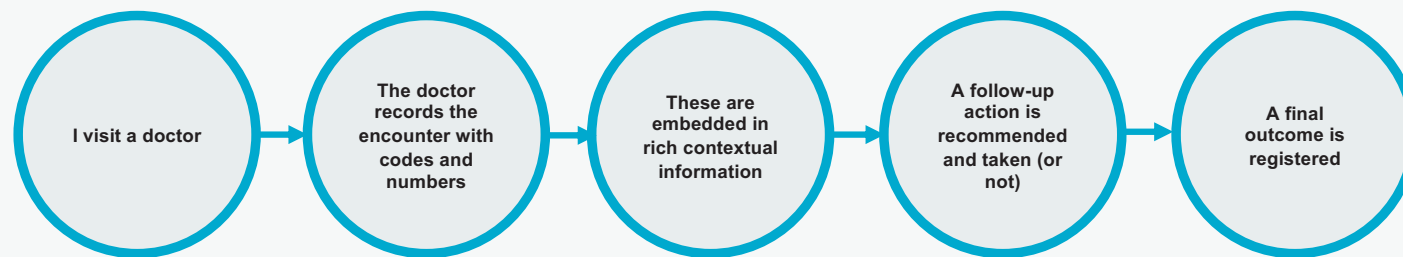
Social scientists have spoken of the **tyranny of numbers**,* highlighting how numerical and codified information (data) about people are often **interpreted and used as absolute, rigid representation of the truth** instead of the nuanced, sophisticated artefact that they are.



**An Anthropology of Biomedicine* by M. Lock and V.-K. Nguyen, John Wiley & Sons, 2010.

Health (data)

How do we make health numerical?



Custodian (of health data)

What does it mean to hold health data?

Data are collected in the real world for a reason (primary use), and then some of them are used to understand trends and the wider impact on people and the system (secondary use).

These data are **messy**, **complex**, **rich** and extremely **valuable**.



Understanding the context

The custodian for health data for England



NHS England has a duty to collect, protect and share health data for the benefit of the public and of the system



England has some of the best health data in the world in terms of population coverage, size and longitudinal records



Data are often collected for direct care and operational reasons and then used to understand areas of greatest needs



Requesting and providing access to health data is legally and technically very complex



The demand to access health data has increased exponentially in recent years, testing the ability to respond at scale



Who are the users of health data?

“Everyone.”

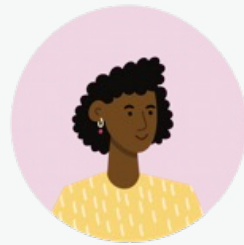
“Everyone who has a legal basis to use them.”

“Everyone who has a role in providing or using health data for the benefits of the public and the health and care system.”

Where do they work and what do they do?



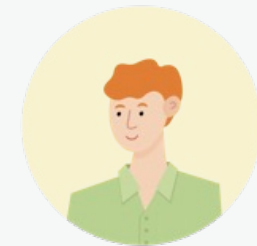
Frontline
clinical and
clerical staff



Analysts
and data
specialists



Policy and
service
decision
makers



Technology
and data
infrastructure
specialists

**Icons created by Emily Lodge.*



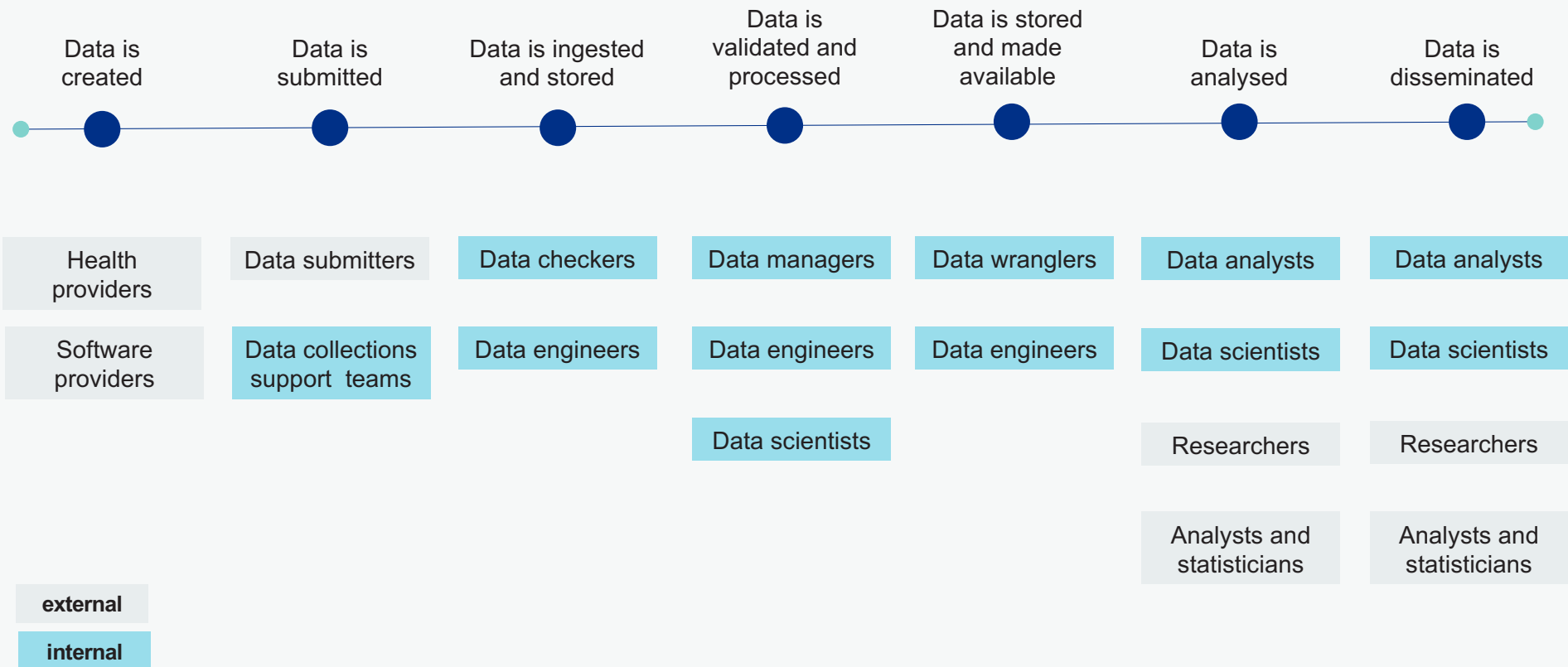
What about following data as non-human actor instead?

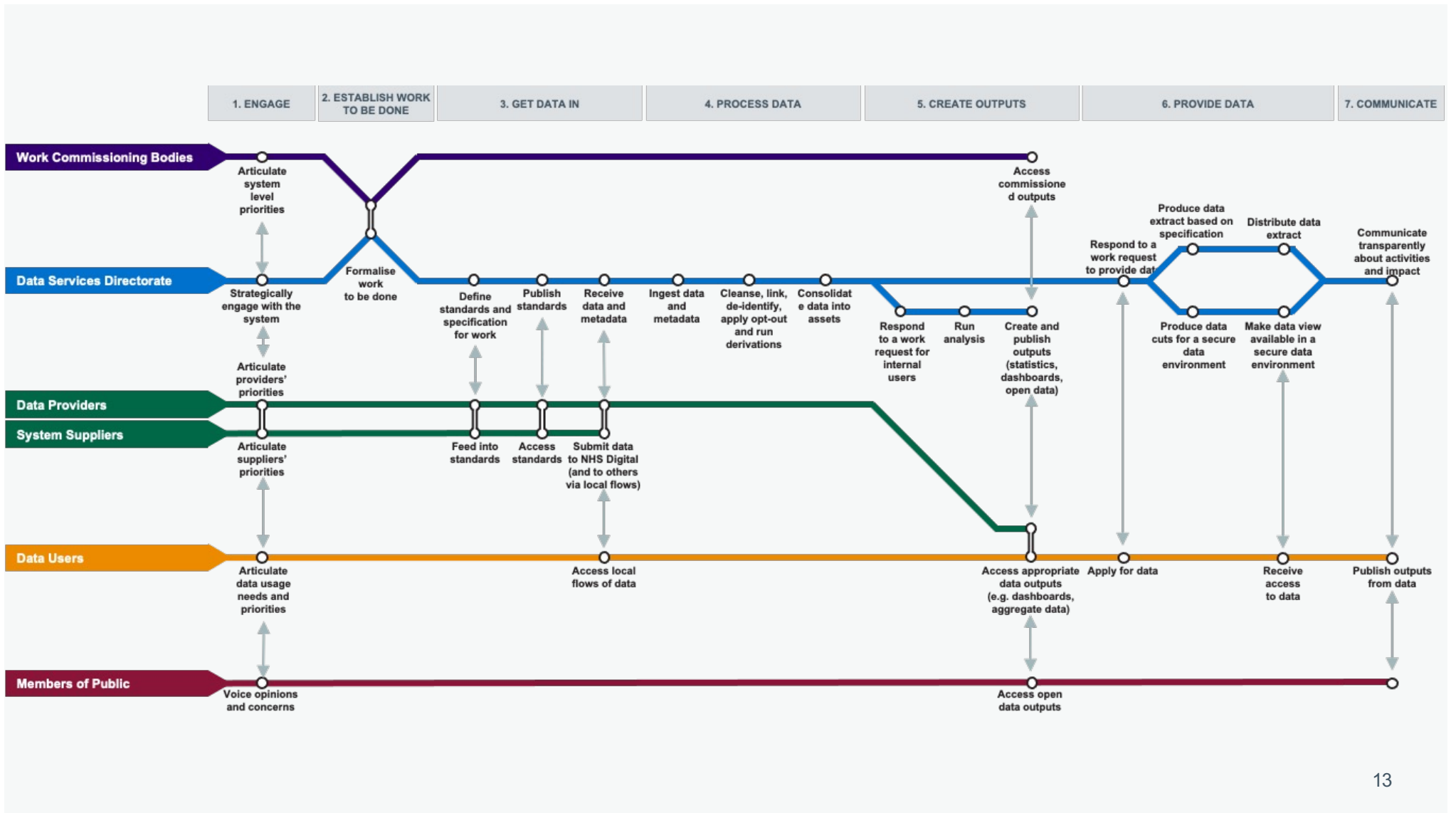
The social life of things*

We started capturing **what data went through**, what they experienced as they passed through our organisation. We did so by identifying the stages of the data during their life cycle and map the user groups involved at each stage.

**The Social Life of Things* by A. Appadurai (ed.), Cambridge University Press, 1988.

Following the data and its users







Examples

Research for clinical and population health
Commissioning for the health and care system
Political and policy decisions

[Coronavirus Vaccinations](#), NHS Digital, September 2023.

[Data Saves Lives](#), DHSC Policy Paper, June 2022.

[How data is supporting COVID response](#), NHS England Transformation Directorate, October 2021.

[Using data to track the virus](#), UKHSA, April 2020.

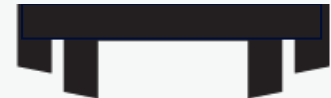


What are the implications for giving primacy to data?

Social agency and moral consequences

Thinking of things as people, as non-human actors*, has important implications. Things do not have a moral compass in themselves, but they are not morality-free. Rather, **they have morality and agency by design.**

Focusing on things always carries the risk of giving them primacy over people, hence designing for the former rather than the latter.



**The Berlin key or how to do words with things* by Bruno Latour, Routledge, 1993.



Conclusion

Working and designing for and with health data is **hard**.

But user-centred design approaches and ways of working are **necessary** to deliver the best that health data can offer.

Thank You

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