



# The Future of People Powered Digital Health: making data and digital work for everyone

22nd May 2019

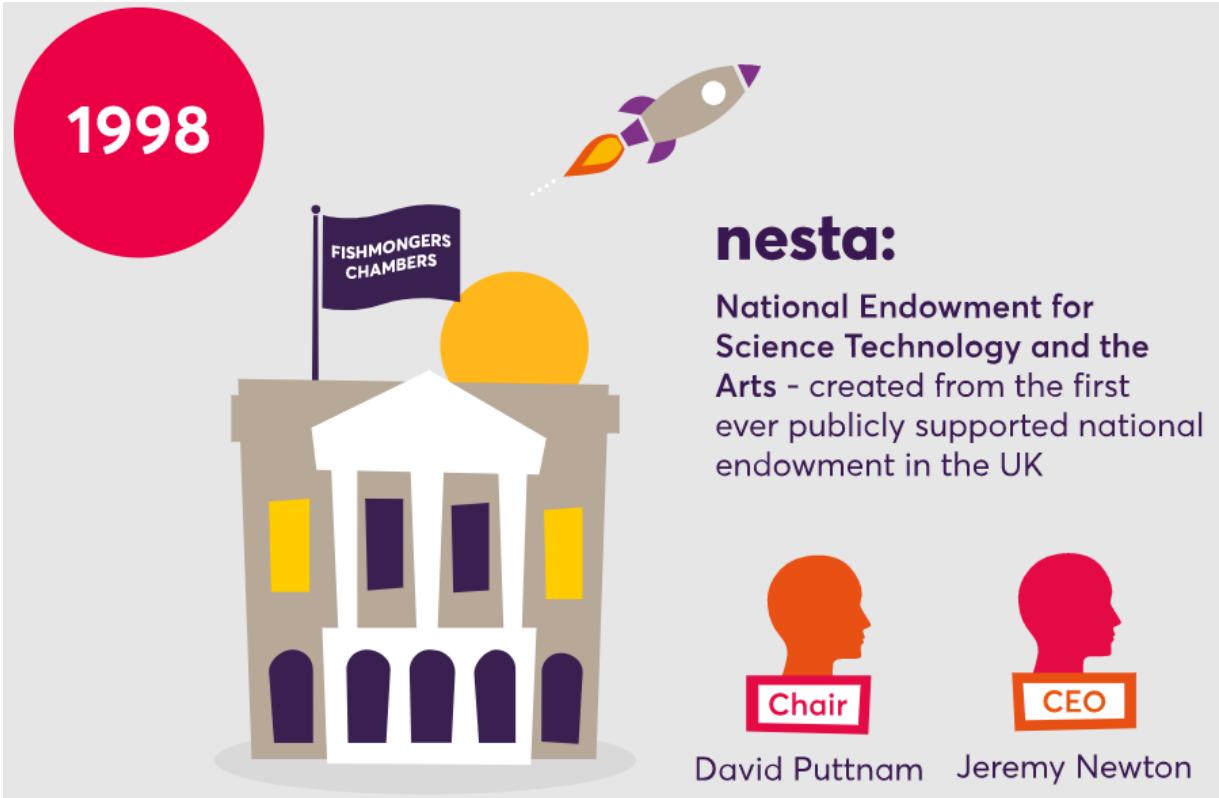
Sinead Mac Manus

Senior Programme Manager, Health Lab

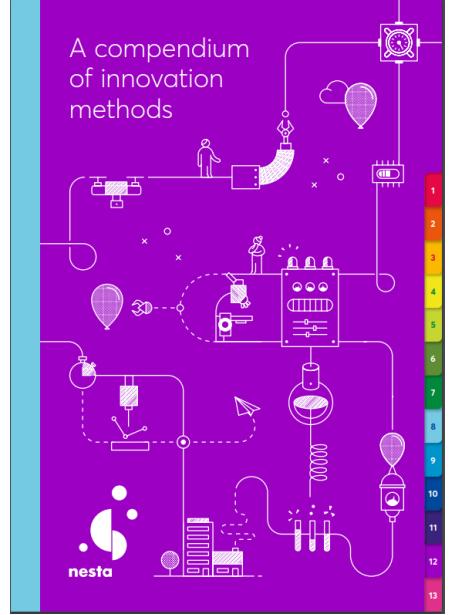
@nesta\_uk / @sineadmacmanus

# Who we are

Nesta is the UK's innovation foundation. We bring bold ideas to life to change the world for good



# How we work: our innovation spiral & innovation methods



In March we published a [compendium of Nesta's expertise in innovation](#) methods over the last decade. A rare publication spanning the breadth of Nesta's activities, it brings together methods from challenge prizes to crowdfunding to futures to grants and impact investment for scaling social ventures.

# Helene's story

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**Health Lab's vision is a people  
powered and data driven  
health and care system where  
technologies, relationships, and  
networks empower people to lead  
healthier and more independent  
lives**

# Our work in digital health: over the past 6 years we've ...

## Led digital health research



## Supported digital innovations through grants & investments



## Provided thought leadership on opportunities & challenges

A collage of thought leadership pieces and news articles, including:

- "Emerging innovation and our ageing society" (with photo of Siobhan Mac Manus, Senior Programme Manager, Health Lab)
- "Care Talk: The voice of excellence in social care"
- "Using big data in preventative healthcare" (with photo of Matt Hancock and text: "Advice for Matt Hancock as he announces that the 'predictive prevention' technology")
- "Good health tech needs citizens, as much as citizens need good health tech" (with photo of a person holding a sign that says "A.I.")
- "Latest Issue: Health Business" (with photo of a person holding a sign that says "A.I.")
- "Integrating technology in care is the future" (with photo of a person holding a sign that says "A.I.")
- "Using collective intelligence design to unlock new insights about cancer" (with British Council logo)

# Digital health needs to evolve ...

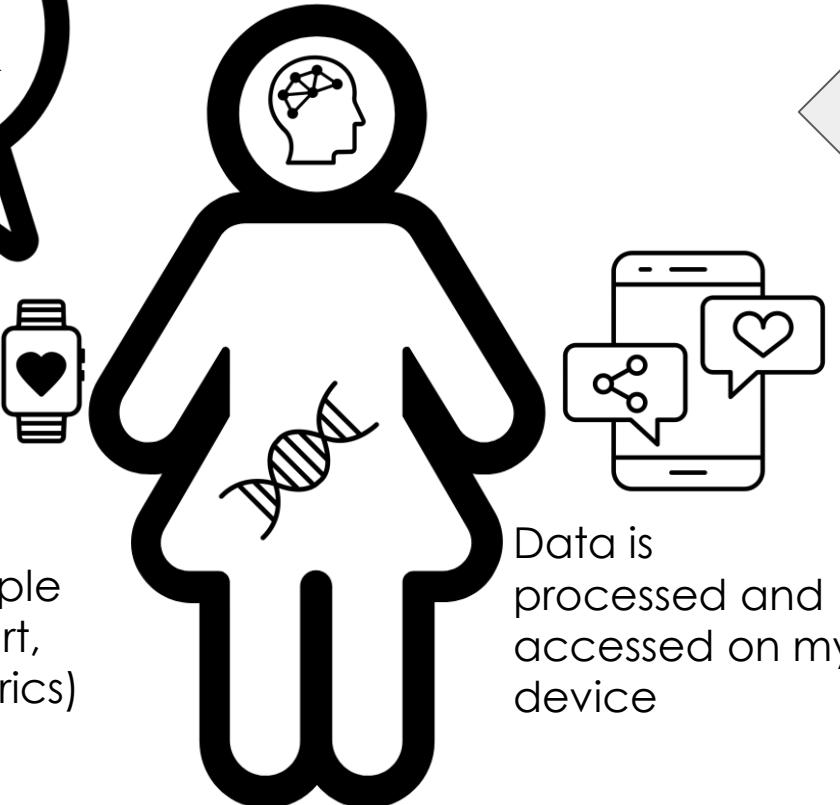
<b>Digital health today</b>	<b>Nesta's people powered digital health</b>
Done to	Done with
Standardised	Personalised
Biomedical	Whole person
Data subject	Data controller
Health data silos & data exploitation	Health data as a public good
Institution / system led	Citizen led
Focus on treatment & care	Moving to prevention & early intervention

# Our 2035 vision: The Connected Citizen

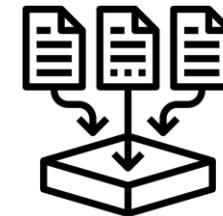
Data from multiple sources (search, social, lifestyle, housing, environment)



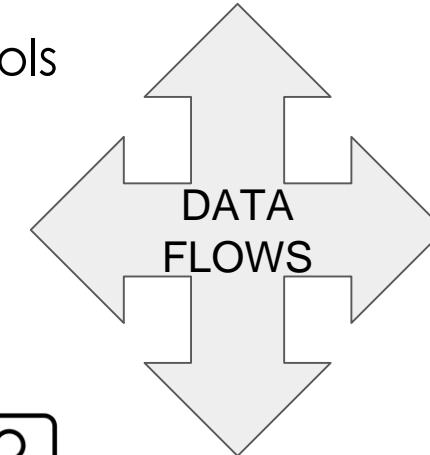
Qualitative data from my experiences & preferences



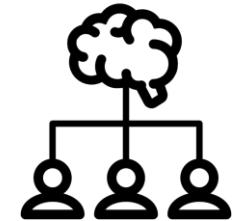
Biomedical & Social Research



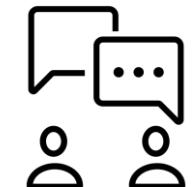
Data Pools



Health & Care system



Citizen-Led Collective Intelligence



Social support system

# Three challenges:

- 1.Trust
- 2.Knowledge
- 3.Power

# Trust

# Trust and transparency in how personal data is used is low



## Revealed: 50 million Facebook profiles harvested for Cambridge Analytica in major data breach

Whistleblower describes how firm linked to former Trump adviser Steve Bannon compiled user data to target American voters

- 'I made Steve Bannon's psychological warfare tool': meet the data war whistleblower
- Mark Zuckerberg breaks silence on Cambridge Analytica

Carole Cadwalladr and Emma Graham-Harrison

Sat 17 Mar 2018 22.03 GMT

198,045 484  
This article is over 8 months old



▶ 13:04



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Google

## Google 'betrays patient trust' with DeepMind Health move

Moving healthcare subsidiary into main company breaks pledge that 'data will not be connected to Google accounts'



▲ Google says the restructure is necessary to allow DeepMind's flagship health app Streams to scale up globally.  
Photograph: Stephen Lam/Reuters

Google has been accused of breaking promises to patients, after the company announced it would be moving a healthcare-focused subsidiary, DeepMind Health, into the main arm of the organisation.

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TRENDING

John Roberts Salmonella Outbreak Amazon Data Leak California Wildfires

SCIENCE

## Grindr Is Letting Other Companies See User HIV Status And Location Data

A data analysis conducted by an outside research firm, and independently verified by BuzzFeed News, shows that a popular gay dating app is sharing its users' HIV status with two other companies. (Update: Late on Monday Grindr said it would stop sharing this information.)



Azeen Ghorayshi  
BuzzFeed News Reporter



Sri Ray  
BuzzFeed Staff

Last updated on April 2, 2018, at 11:13 p.m. ET  
Posted on April 2, 2018, at 11:45 a.m. ET

# Dozens of AI ethical frameworks but very little real world application

## Uber halts self-driving car tests after death

© 20 March 2018

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Uber said it is suspending self-driving car tests in all North American cities after a fatal accident.

A 49-year-old woman was hit by a car and killed as she crossed the street in Tempe, Arizona.

## Google scraps AI ethics council after backlash: 'Back to the drawing board'

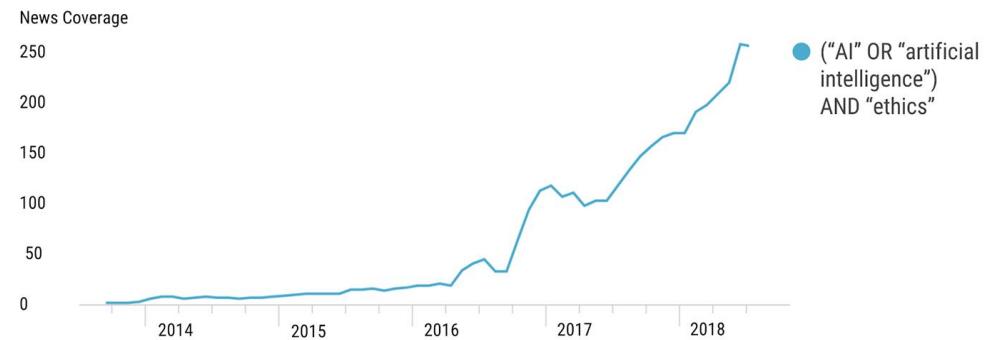
Decision comes after employees called for the removal of a rightwing thinktank leader from the council



▲ Google announced last week it had started a council dedicated to advising on ethical questions related to facial recognition and machine learning and consulting 'diverse perspectives' on its work. Photograph: Stephen Lam/Reuters

## Talk of AI and ethics is on the rise

Quarterly news mentions of ("AI OR artificial intelligence") AND "ethics" 2014 – Q3 2018



Source: cbinsights.com

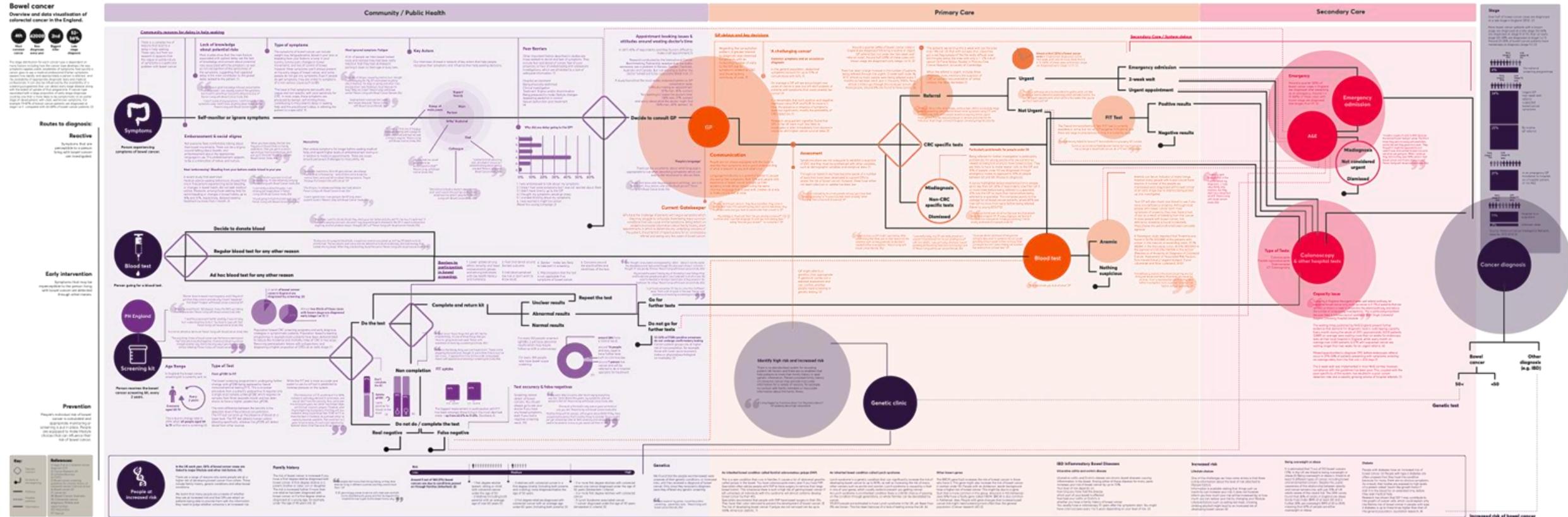
CB INSIGHTS

There are currently 70+ AI or automated decision making frameworks.

**Source: Algorithm Watch**

# Knowledge

## **“Health” data sits in silos across multiple areas of our lives ...**



Source: Designing for collective intelligence in cancer, Nesta

# ... and a “digital tsunami” of health data is coming



Created by Iconographer  
from Noun Project



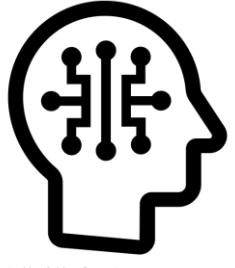
Created by Icon 54  
from Noun Project



Created by Philipp Petzka  
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Created by Mangop Leklai  
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Created by Adrien Coquet  
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There are 400,000+ smartphone apps in health and wellbeing

Biometrics, including physiological and behavioural characteristics, are beginning to be tracked

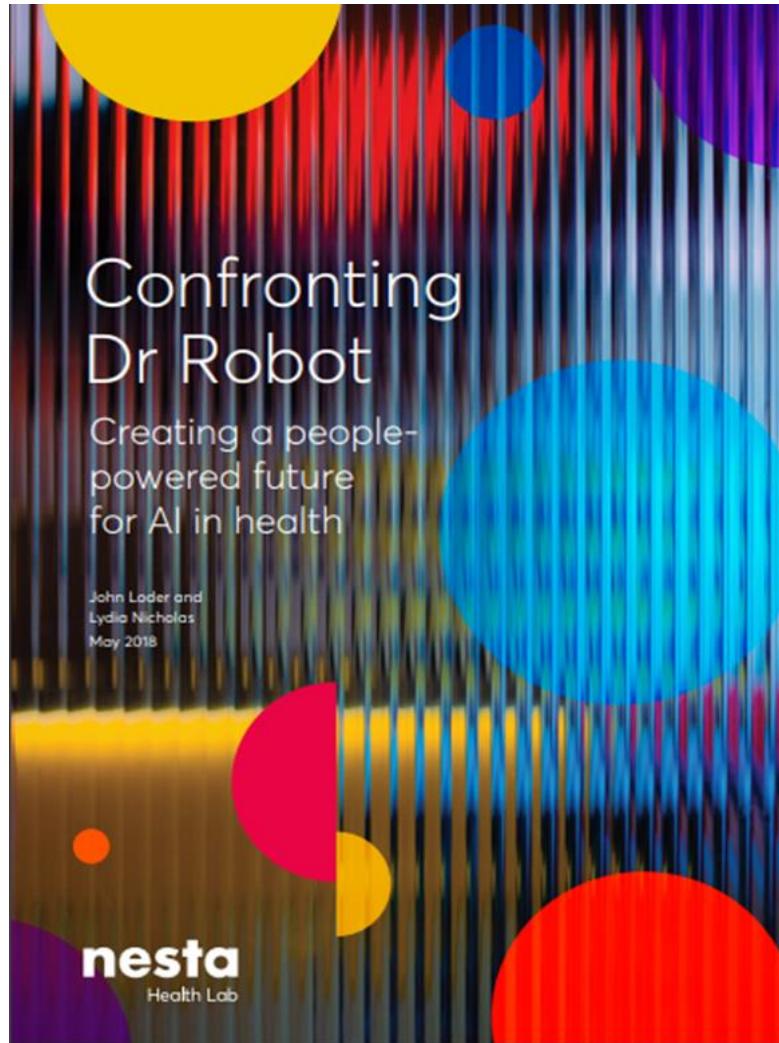
100,000 Genome Project completed in UK. Commitment to sequence 1 million more (then 5 million).

“One trillion new Internet of Things (IoT) devices (wearables, sensors) will be produced by 2035.” Arm Holdings

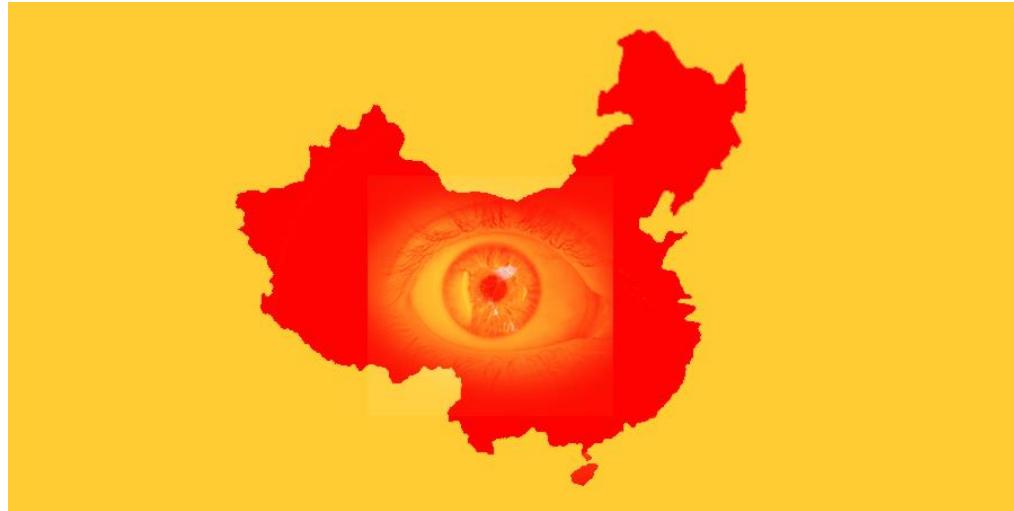
Data mining tools - artificial intelligence (AI), machine learning & Natural Language Processing are evolving

# Power

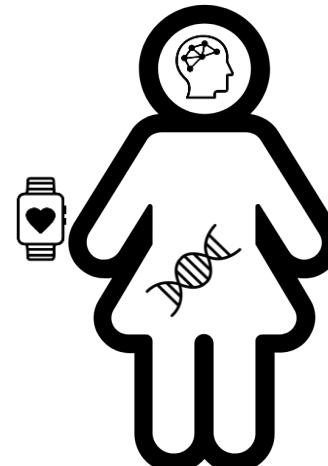
# Data & AI could increase health inequalities and create a two-tier system



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**Data rich /  
engaged**



v



**Data poor /  
disengaged**

# We don't ask people what they want

## HOW DOCTORS DIE

It's Not Like the Rest of Us, But It Should Be



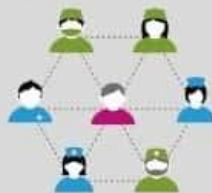
## REALISTIC MEDICINE

CAN WE:



CHANGE OUR STYLE TO  
SHARED DECISION-MAKING?

BUILD A PERSONALISED  
APPROACH TO CARE?



REDUCE HARM  
AND WASTE?

REDUCE UNNECESSARY  
VARIATION IN PRACTICE  
AND OUTCOMES?



MANAGE RISK BETTER?



BECOME IMPROVERS  
AND INNOVATORS?

Source: [Scottish Government](#)

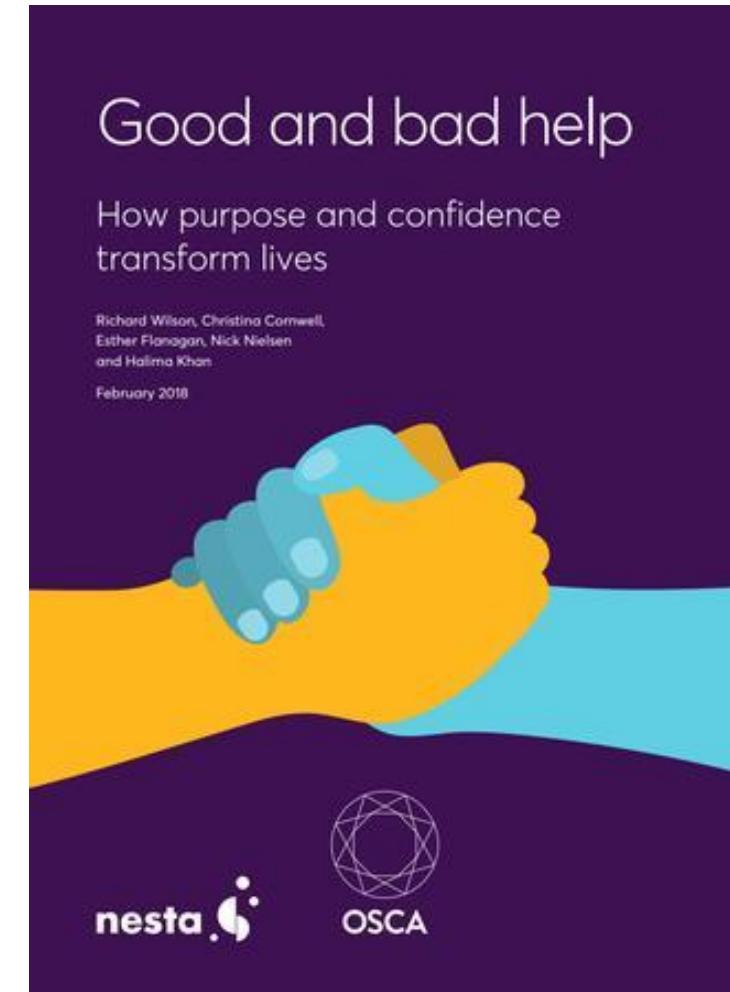
# How can we innovate to solve these challenges?



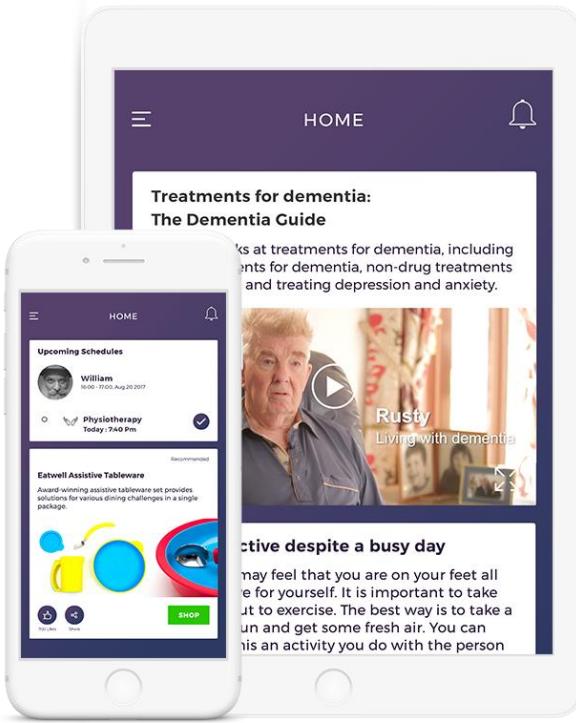
# Recognise people as actors in their own health & care



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# Codesign and involve people

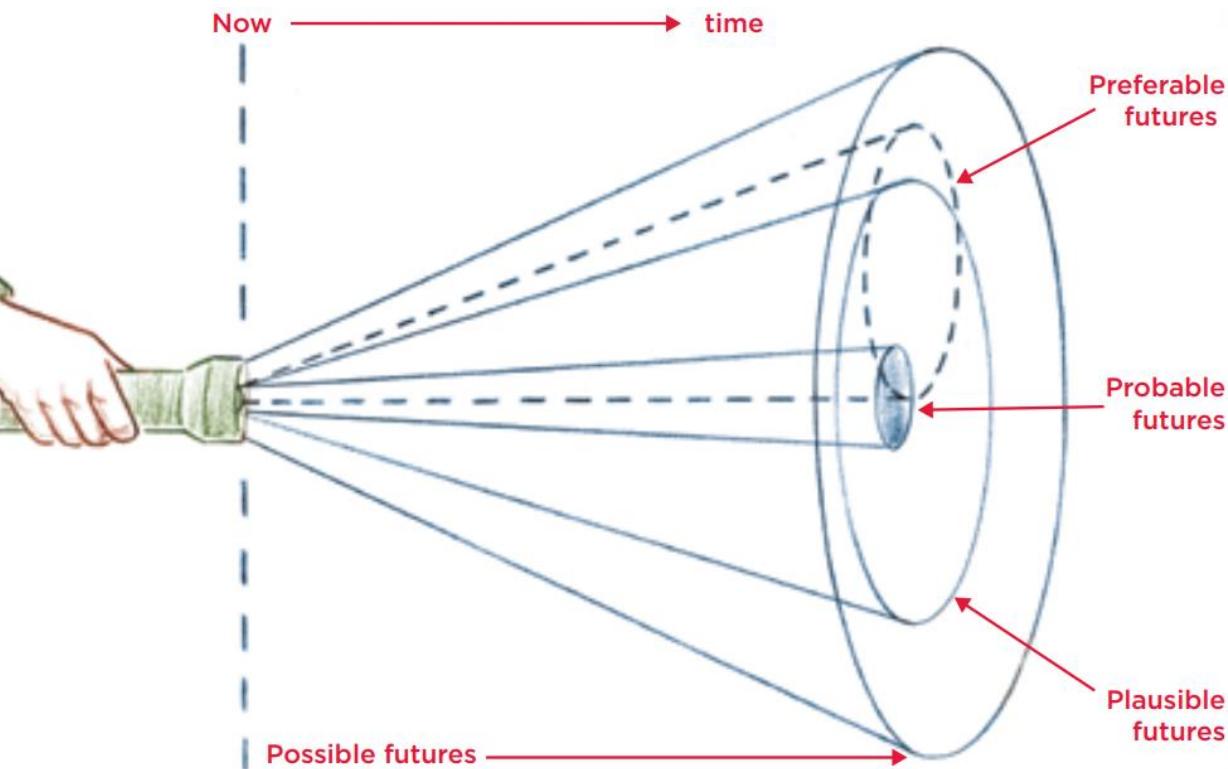


COGNIHEALTH

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# Engage people in conversations about health & care data

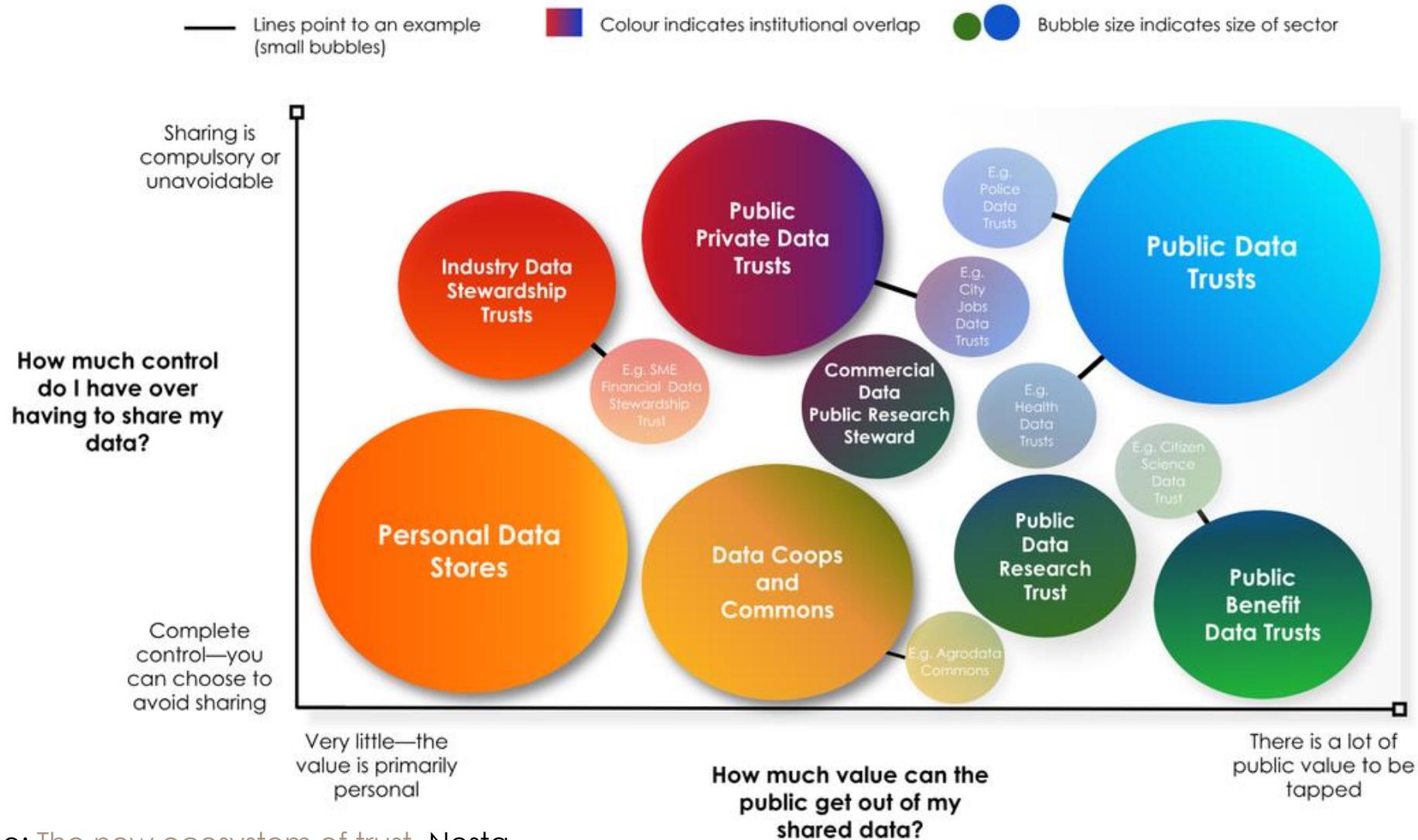


Source: [ShareTown](#), Nesta



# Experiment with new data models

## A new framework for data governance



# Nightingale Institute: using data and digital health to support social health

## NEWS

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**Scots' life expectancy falls for first time in 35 years**

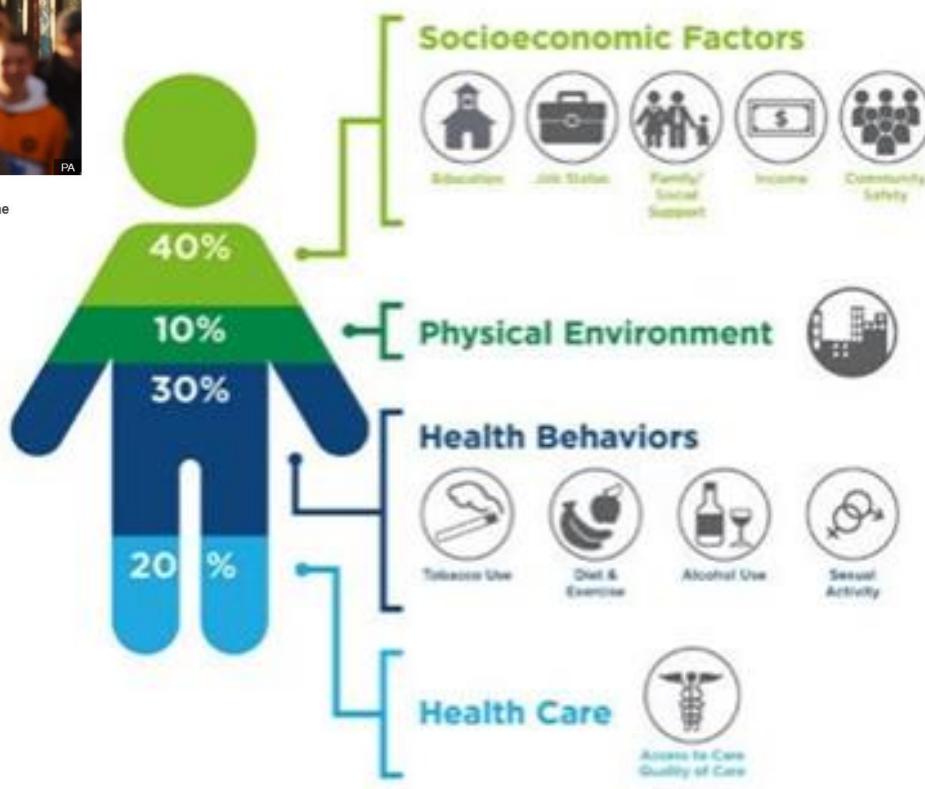
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25 September 2018

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How long men and women in Scotland can expect to live has fallen for the first time in 35 years.



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