



DARE UK



TREvolution

A DARE UK PROJECT

Public Attitudes Towards Sharing Sensitive Data

Judith Fisher

TR Evolution Public Involvement and Engagement Lead



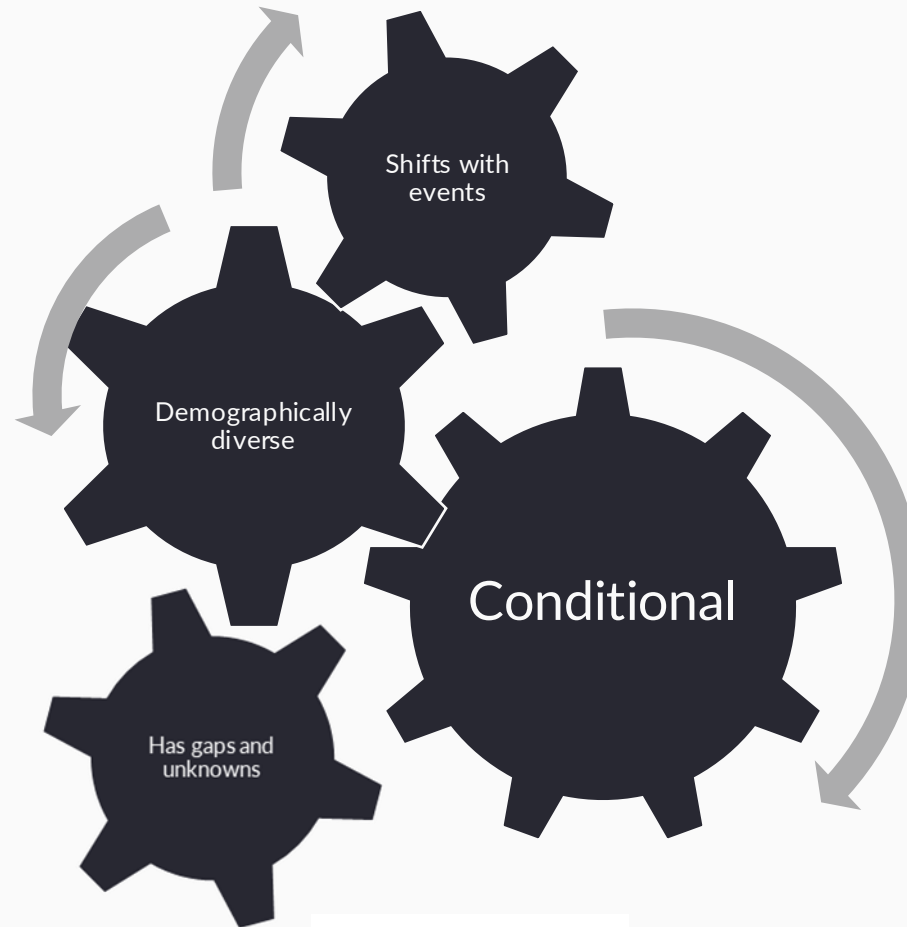
Public Attitudes Towards Sharing Sensitive Data

Research into public attitudes towards sharing sensitive data - both identifiable and de-identified - demonstrates consistent trends (HDR UK, 2025)

Existing research shows people are willing to share data when they know who is using it and why.

There is general support for use of sensitive data for both people's own and a wider societal benefit. (Sudlow Review, 2023)

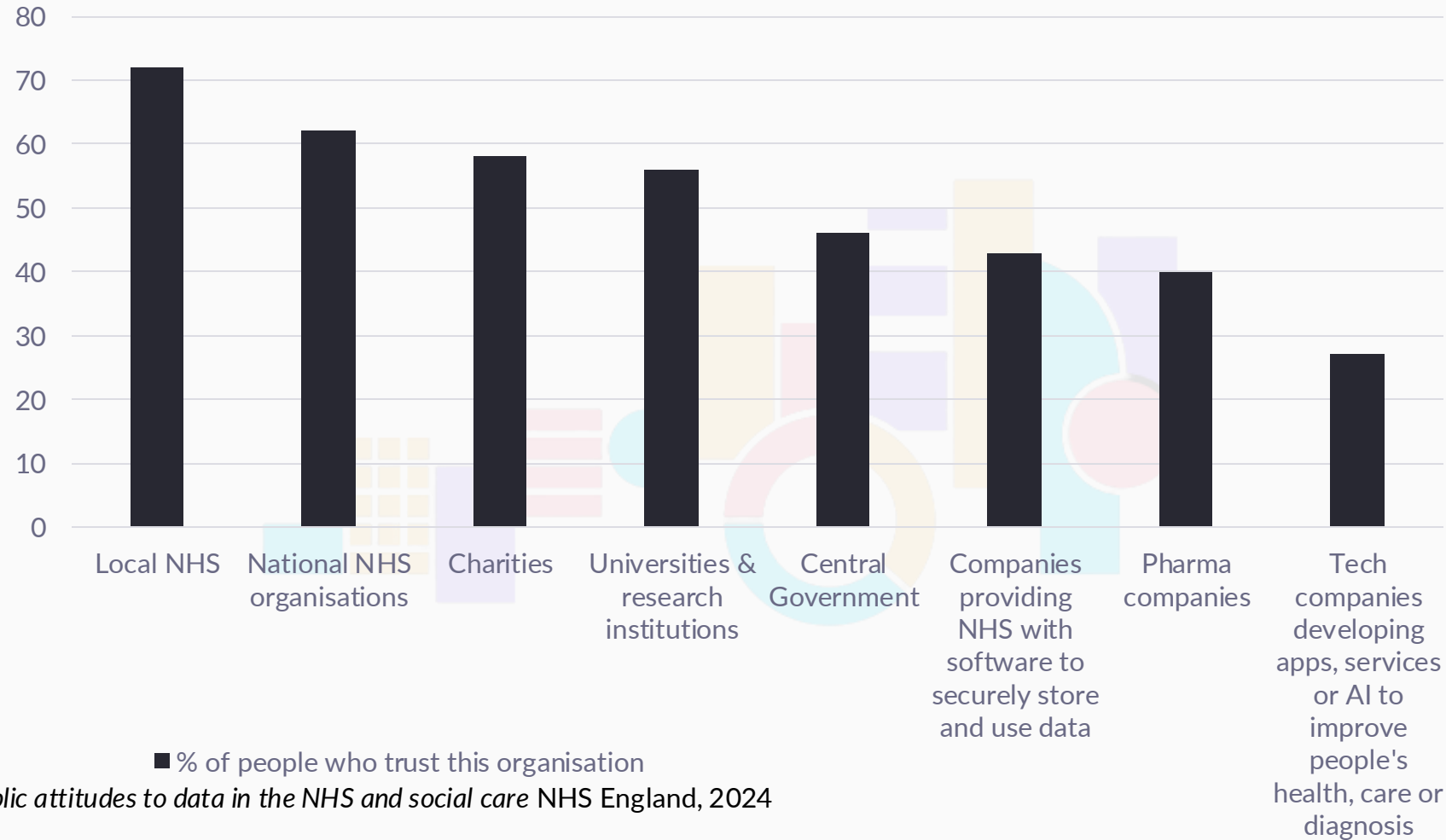
However, Public Support is...



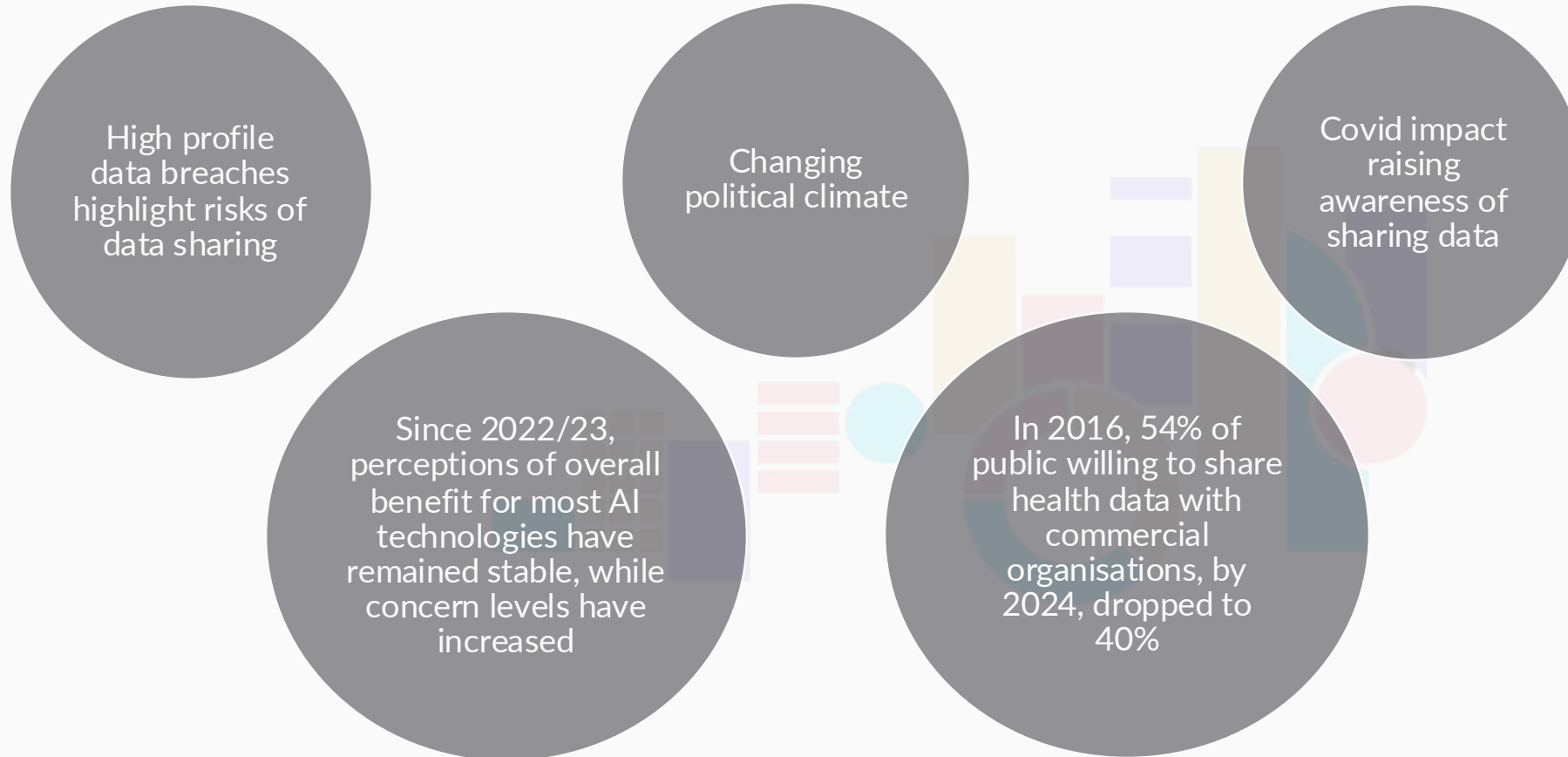
Conditional Public Support

- Willingness to share data dependent on who is using it and why (Sudlow Review, 2023)
- Value placed on transparency (DARE UK, 2022, BCG Centre for Growth, 2023)
- Open to research when it benefits society and has clear regulation (Gordon 2024, HDR UK, 2025)

Conditional Public Support– Who do the public trust with their data?

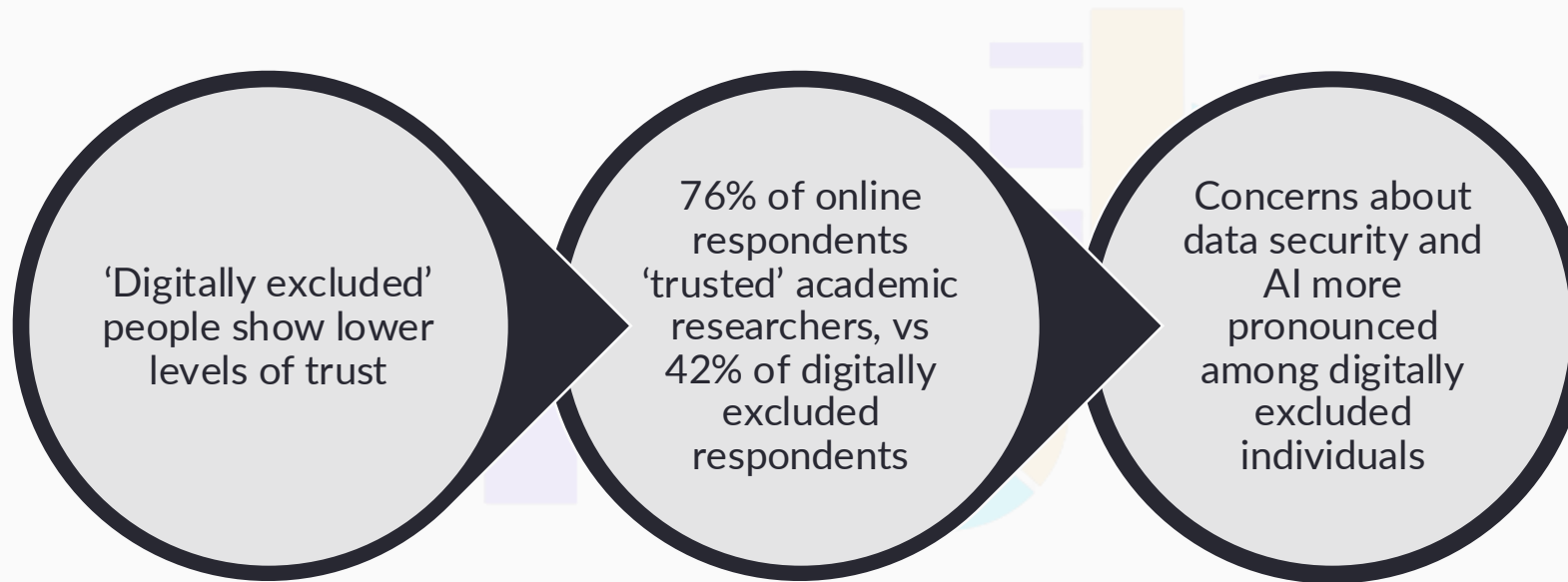


Shifts With Events



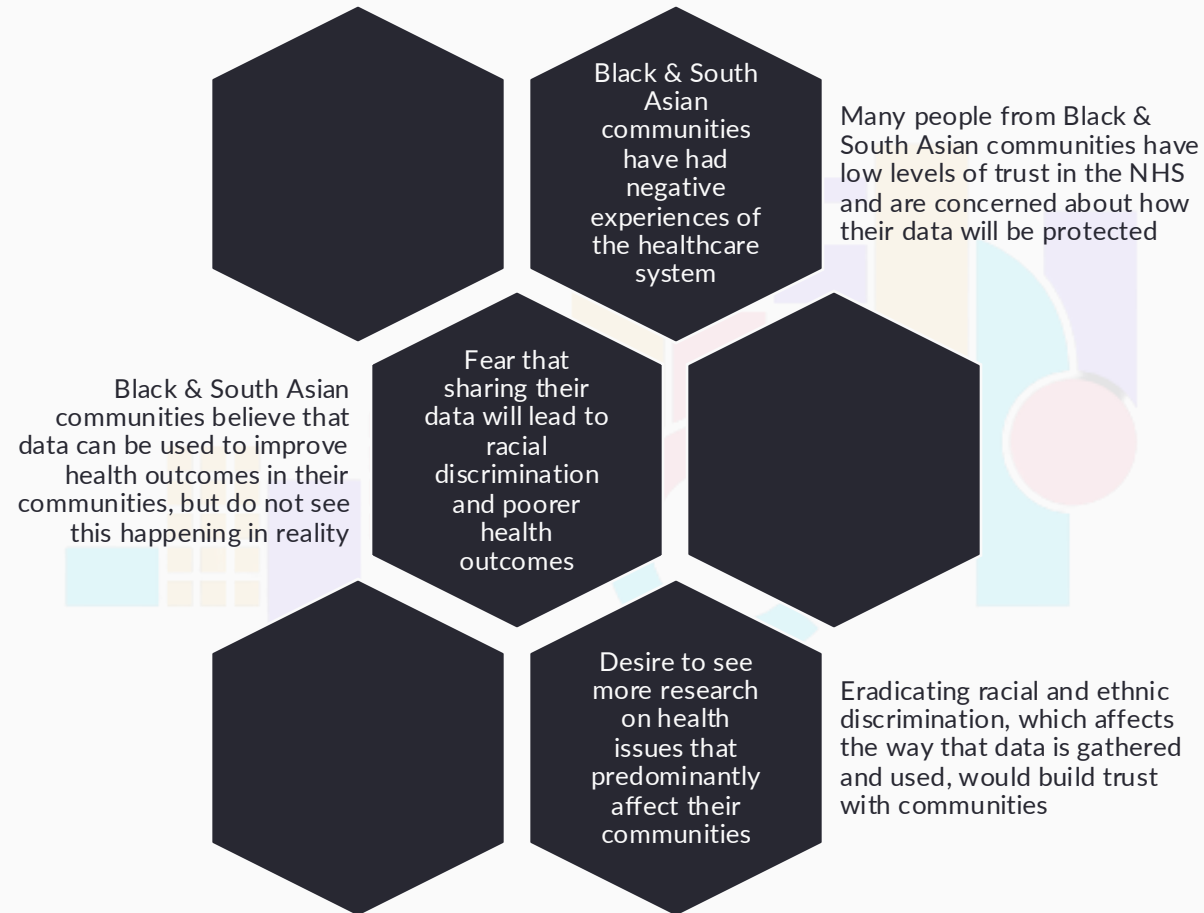
*Wellcome Trust, 2016
NHS England, 2024
The Ada Lovelace Institute and the
Alan Turing Institute, 2025*

Demographically Diverse



UK Government, 2024

Demographically Diverse



Understanding Patient Data, 2022

Gaps and Unknowns



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<https://attitudestoai.uk/findings-2025>

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<https://www.gov.uk/government/publications/public-attitudes-to-data-and-ai-tracker-survey-wave-4/public-attitudes-to-data-and-ai-tracker-survey-wave-4-report>

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<https://understandingpatientdata.org.uk/insights-black-south-asian-people-patient-data>



**East of
England**

SECURE DATA
ENVIRONMENT

Part of the
**NHS Research Secure Data
Environment Network**

Reflections as a Public Contributor

**Personal experiences
shaping research and PPIE**

Gareth Gault, Public Member of Core
Public Advisory Group at East of England
SDE

The Value of Lived Experience

Brings
perspectives
professionals
may not see

Grounds
decisions in
real-world
impact

Keeps research
relevant to
patients and the
public

Parity and Recognition

Lived experience has equal value to professional expertise

Barriers remain to being recognised as equal contributors

Need to build parity across PPIE professionals and public members

Co-Production



Beyond consultation → working with, not for



Encouraging a deeper ethos of shared ownership



Recognition co-applicants strengthens co-production

Transparency, Accountability & Trust



Public confidence depends on
openness



Accountability must be visible
and meaningful



Alignment with PEDRI
standards of good public
involvement

Personal Reflections



Moments where lived experience shaped outcomes



Positive and negative shifts in attitudes



Barriers faced and how to overcome them



Strengthening co-production and accountability

Closing Message

Trust grows when public voices shape decisions



Rights are respected



Contributions are valued as equal



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PPIE Professional Reflections

**Dr Elsie H Makachiya Senior
Public Involvement and
Inclusion Manager, Health
Innovation East**

TRE Conference PPIE Plenary 24th Sept
2025

Context & Purpose

Workshops held
Summer 2024 in
six East of England
locations

Partnered with 10
Healthwatch orgs

Part of wider PPIE
strategy for East of
England Secure
Data Environment

Explored NHS data
use, privacy, opt-
outs, and research
expectations

N=85 mostly 25–
75yrs; 12% Black
ethnicity; 10
LGBTQ+

Key Public Messages

01

Patient care first:
research valued only if
it improves NHS care

02

Concerns: breaches,
re-identification,
commercial misuse

03

Need for clear, simple
communication via
trusted NHS channels
(e.g., GPs)

04

Low awareness of
data opt-outs and
NHS data flows

05

Support is conditional
– enthusiasm mixed
with scepticism



Looking Ahead



Planning your Public Involvement & Engagement



P E D R I

PEDRI Standard	Explainer	What am I doing currently?	What can I aim to improve in six months?	What can I aim to improve in a year?
Equity, diversity & inclusion	Ensure representation of people from different backgrounds			
Data literacy & training	Empower the public to understand and contribute			
Two-way communication	Enable everyone to have open, honest, and clear conversations			
Transparency	Project information is freely accessible for discussions with the public			
Mutual benefit	There is benefit to everyone involved			
Effective involvement & engagement	There are clear tasks, purpose and impacts that are not tokenistic			
Creating a culture of involvement & engagement	Public involvement and engagement is embedded into ways of working			

