

digitalhealth

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NATIONAL DATA GUARDIAN
FOR HEALTH AND SOCIAL CARE

This presentation will cover

1. Brief summary of what the National Data Guardian does

- Mission
- Strategic objectives

2. Learning over the last year in role

- 'Data Saves Lives' – what are the conditions for trustworthy data use?
- What themes have emerged more broadly?

What the National Data Guardian does

- **Statutory role** appointed by the Secretary of State for Health and Social Care
- **Acts as an independent advisor** to government and the health and care system on all matters concerning people's confidential information across health and adult social care in England
- Works with and through a small office team and panel of experts who meet regularly to provide **advice, guidance and challenge** to government and the health and care system

What the National Data Guardian does

Mission: to maintain trust in a confidential health and care system

Why this matters:

- We want the benefits of data to be realised - for our own care and treatment as individuals now, and for our shared future public benefit through health research, planning and innovation
- For this to happen, the health and care system needs to be **demonstrably trustworthy** to us all, as patients, service users, professionals and the public
- Because trust is essential both for **public confidence** in sharing confidential information at the point of care and subsequently, and **professional engagement** with its collection and use

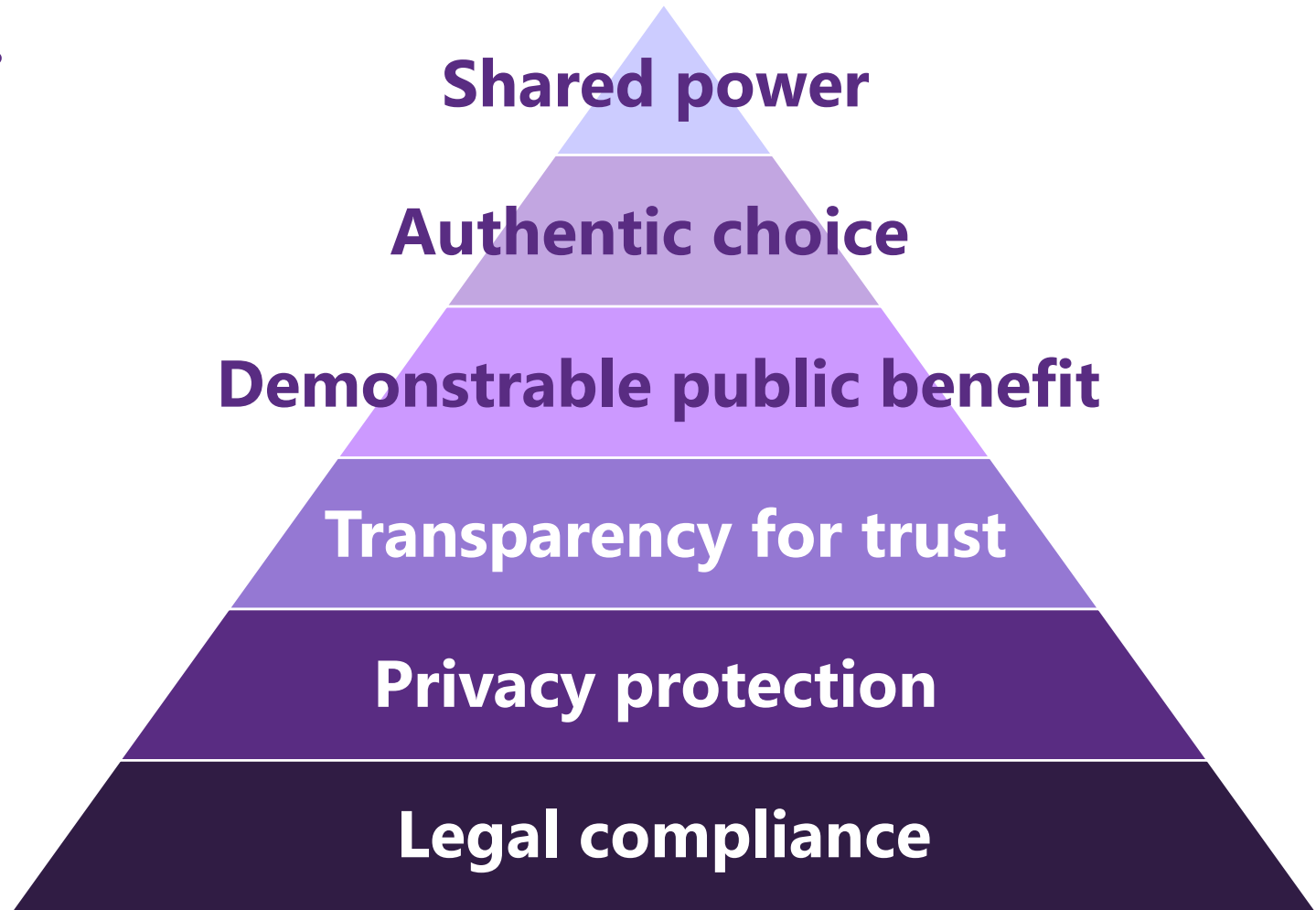
Strategic objectives

The NDG's mission is supported by **four long-term strategic objectives**:

1. Safeguard trust in the confidentiality of our health and social care system
2. Encourage safe and appropriate information sharing for individual care
3. Support understanding and engagement about how and why data is used
4. Encourage the safe, appropriate, and ethical use of data in system planning, research and innovation that benefits the public

Learning from *Data Saves Lives:*

What conditions
need to be met to
demonstrate
trustworthiness?



Learning from *Data Saves Lives*:

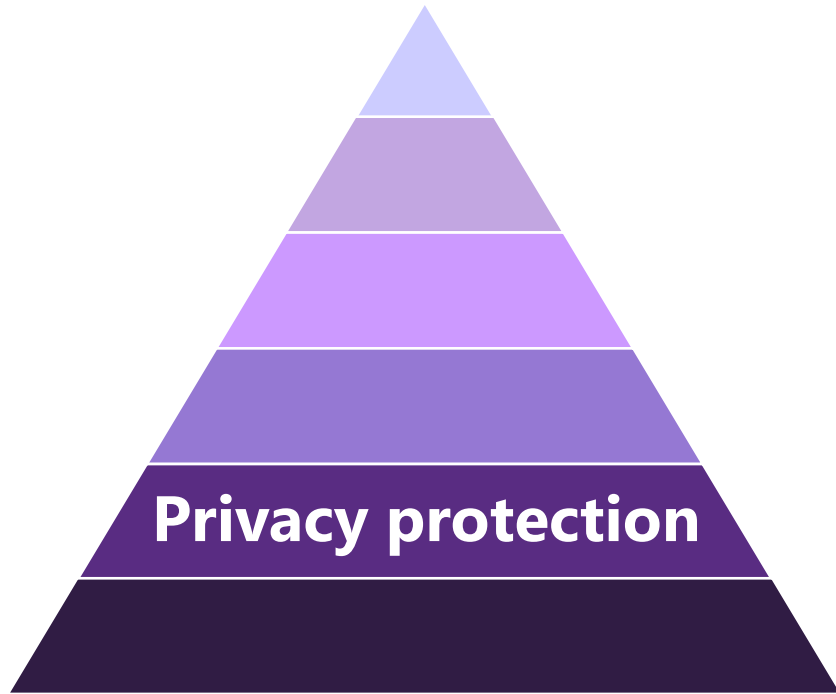
What conditions need to be met to demonstrate trustworthiness?



- All data use must comply with the law
- Just because something doesn't break the law it doesn't make it right in the public mind (GDPR)
- Foundational and necessary, but insufficient, condition for public and professional trust

Learning from *Data Saves Lives*:

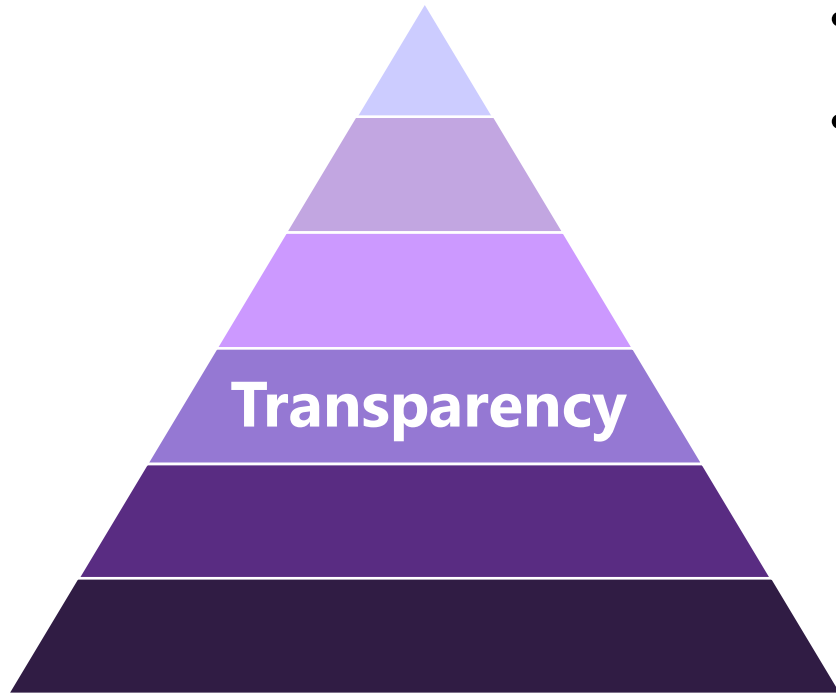
What conditions need to be met to demonstrate trustworthiness?



- Human error
- Intrusive curiosity
- Unanticipated use by public or commercial organisations
- Cyber attack by malicious actors

Learning from *Data Saves Lives*:

What conditions need to be met to demonstrate trustworthiness?

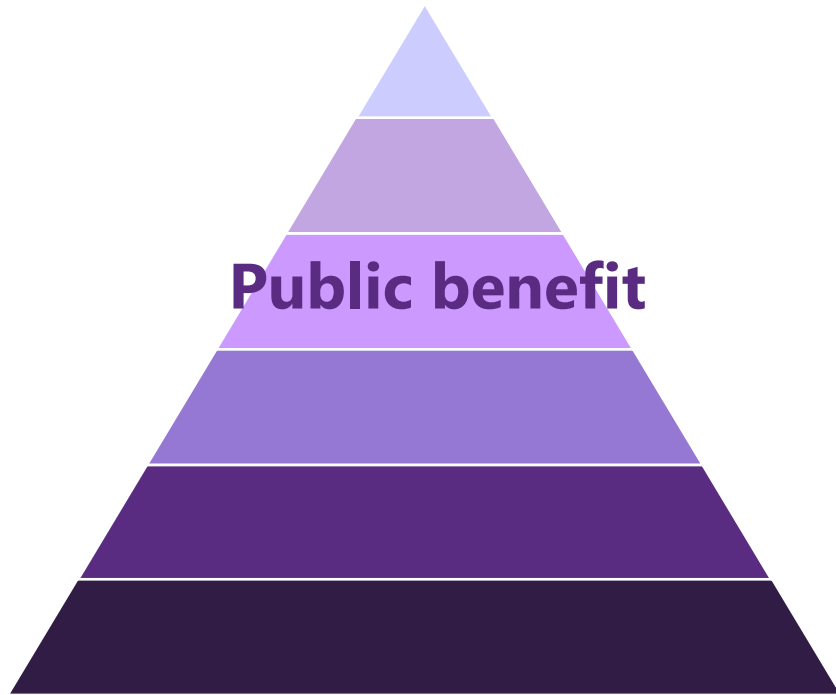


- Transparency to serve trust, rather than legal obligation
- **use MY data – ‘Say what you do, do what you say’**
 - Accessible
 - Understandable
 - Relevant
 - Useable
 - Assessable
 - Being as pro-active with ‘bad news’ as ‘good news’
 - Being timely with communication

Bland ‘PR’ statements tell the audience nothing

Learning from *Data Saves Lives*:

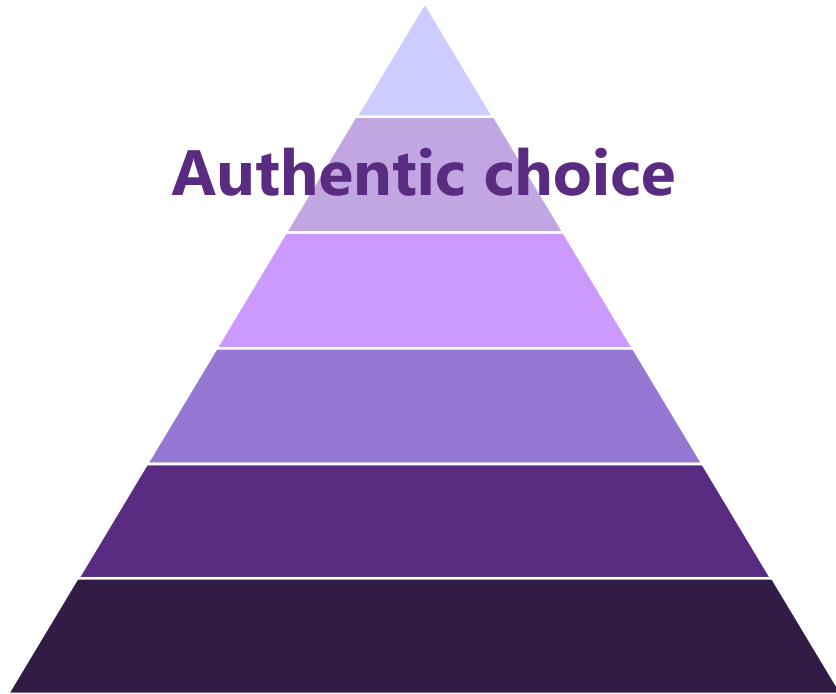
What conditions need to be met to demonstrate trustworthiness?



- **Guidance:** Evaluating public benefit when health and adult social care data is used for purposes beyond individual care
- Public benefit requires:
 - **Benefit:** balance in favour of benefits over risks
 - Benefits: Public are ambitious for data use, with broad, flexible interpretation
 - Risks of use: privacy; equity; safety; security; prioritisation of profit
 - Risks of not using data: consequences (safety, outcomes, equity)
 - **Public:**
 - Transparency about use, across the data cycle
 - Involvement in decision making

Learning from *Data Saves Lives*:

What conditions need to be met to demonstrate trustworthiness?

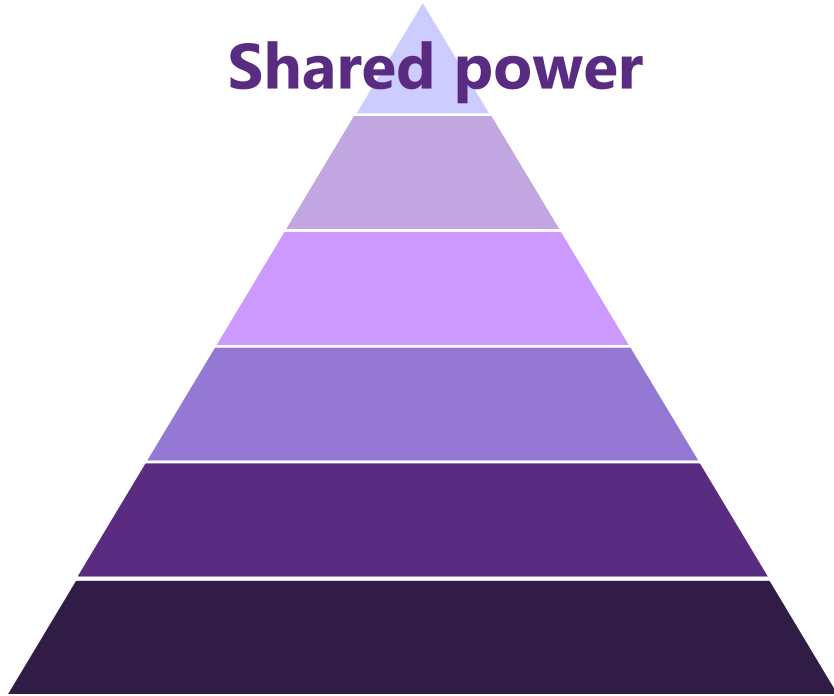


- Within health and care, opt-out achieves 'best balance' between meeting people's expectations about data use, whilst providing choice (*NDG's Review of data security, consent and opt outs, 2016*)
- Choices need to be **clear, coherent, simple to action**
- Any opt-out **needs to do what people expect it to do**

Learning from *Data Saves Lives*:

What conditions need to be met to demonstrate trustworthiness?

Shared power




- Organisational confidence to engage, listen and respond to what it hears in a two-way dialogue with the public
- Independent scrutiny and challenge – the public are actively involved in decisions about data use
- ‘Group think’ is actively surfaced and challenged
- A diversity of views and experience are actively sought, including from seldom-heard groups



Learning from the last year:

What themes have emerged more broadly?

The importance of:

- Keeping it real
 - Context
 - Coherence
 - Integrity
- 

1. Keeping it real

Initiatives must be anchored in the real world - as experienced by patients, staff and public

System leaders need to:

- Challenge any 'corporate reality gap' or performative virtue in policy, strategy or comms
- Metabolise the anxiety generated by complexity:
 - recognise individuals, technology, strategies and policies sometimes fail
 - accept people will disagree about the right thing to do
- Avoid action paralysis – getting stuck 'admiring the problem' or seeking perfection, including perfect consensus

Above all - be straight with the public and make expectations realistic.

2. Context

Data embeds [multidimensional] relationships

'The data we talk about is not an abstract thing: there is an individual, a person, a name behind each piece of data'. ('Data Saves Lives'). *Equally*:

The data we talk about is not a detached thing: there are relationships embedded in each piece of data

Individual - clinician – organisation - ICS – NHSE - DHSC - wider government - UK society - beyond
Individual - family - fellow citizens - future generations



System leaders need to:

- Understand data within its relational + social context – what it is, *and* what it represents and thereby means
- Recognise people may feel a strong connection with their ongoing representation in a data set - even when that data is anonymised - throughout the lifecycle of its use
- Actively engage with tension between individual and collective interest
- Surface trade-offs and resist 'cake and eat it' rhetoric

3. Coherence

Data delivery occurs through programmes, but each programme has a life (people; solution; 'politics') of its own, risking duplication and confusing communications that serve the programme rather than its aim.

Putting data, digital and tech at the heart of transforming the NHS (Wade-Gery, 2001), recommendation 1:

Commit to a patient and citizen centred organising principle for future service transformation

System leaders need to:

- Hold the big picture in mind - and be able to clearly communicate it
- Value institutional memory (seek it out if new) to retain learning and avoid wheel reinvention
- Interrogate how different initiatives fit together for patients, staff and the public e.g., in their ambition, proposed solutions or ask of people to do things differently
- Orientate their organisation towards intended outcomes, not internal processes or programmes

4. Integrity

Intention matters. Internal motivation is communicated, consciously or otherwise, and permeates results.

e.g. is 'transparency' or 'engagement' a means to a (tick-box) end, or understood as inherently valuable?

System leaders need to:

- **Consider the exercise of power within their organisation** – *who gets to decide; who has a veto; does the least powerful person in the room have a voice?* – **and how power is experienced, both by those working within it, and those impacted by its functioning**
- Surface, and be able to talk about, potential **conflicts of interests**, or perceptions of same:
 - Financial – either from 'the new', or personal investment in the status quo
 - Professional allegiances; personal alliances
 - Future career opportunities

National Data Guardian contact information

Website

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