What do Londoners think? A snapshot of public expectations concerning access to health and care data.

ONE LONDON

Public expectations for access to identifiable health and care data for direct care purposes: to support care at the time patients need it

Data should be available on a need-to-know basis to those caring for a patient to enable the provision of safe and efficient care.

There should be background checks for staff being given direct access, mandatory training and additional safeguards in place such as confidentiality agreements, passwords to enter databases and audit trails in place.

There should be serious consequences for anyone who misuses data and sanctions in place to deter this from happening.

Public expectations for access to deidentified health and care data for secondary purposes: to support planning and prevention to improve research

Data controllers should make accurate data available within a secure data environment (SDE) that complies with the five safes framework, and it should be de-identified when used for planning and research.

Data to be accessed for an agreed purpose, for an agreed timescale and only access to relevant data should be given.

Patients should have the option to opt-out of their data being used for secondary purposes and opt back in if they change their mind.

RED LINES

Data must never be shared with or sold to insurance companies or for marketing purposes.

Data should not be used for reasons which are not in the public's interest and there should be severe punishments for misuse.

Access rules

Independent data access committees made up of NHS clinicians, researchers, lay members of the public, patients, data protection and legal experts should use the following rules in deciding who has access to health and care data for secondary purposes.

The request should demonstrate **a clear public benefit**.

There must be **a clear rationale as to why London's population data is necessary** or beneficial to the project.

No access should be given to organisations who are not already part of the London secure data environment **who cannot cover their costs**.

Existing health inequalities should not be exacerbated through the work, and n**o groups should be negatively impacted or harmed**.

RED LINE

The **police should not be given direct access** to health data in the London secure data environment.

PRICE LIST

The London SDE should operate tiered pricing for access to data, based on profit making and turnover. Benefits arising from data use should be shared across the NHS, starting with London.

Profit-making companies should pay the most ..... £££

Charities, local authorities and universities should pay somewhere in the middle ..... ££

Organisations part of the London SDE should pay the least for access to data ..... £

UK companies should pay less

Non-UK companies should pay more

Discounts for...

- Projects that can save the NHS money
- Projects that can benefit the NHS
- Projects that are aligned with the NHS priorities in London
- Projects that have the potential to deliver exceptional patient benefits

Additional charges

- Projects that require more support from the NHS secure data environment operators
- Projects that require access to data for a longer period of time
- Projects that require access to large amounts of data and/or more sensitive data.

To reassure people and engender trust, the public should be informed and educated about...

- how the NHS uses health and care data, and the benefits of this
- who is accessing health and care data, for what purposes
- their rights concerning the national data opt out for research and planning

References:

Public-deliberation-in-the-use-of-health-and-care-data.pdf (onelondon.online) Citizens Advisory Group | Discover Now (discover-now.co.uk) London Health Data Strategy Deliberation (onelondon.online) Ipsos report (onelondon.online) OneLondon-Citizens-Advisory-Group-Report-1-page-summary.pdf

This infographic was formed from five public deliberations that have taken place in London since 2020 and involved 301 participants reflective of our diverse population.

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