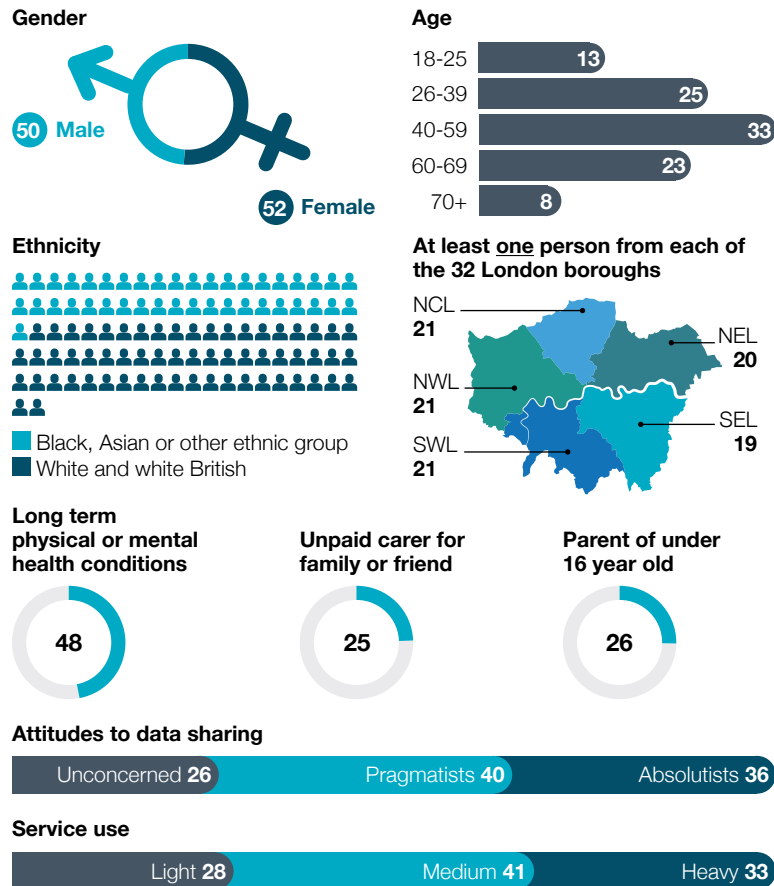


London Citizens Advisory Group

Summary of recommendations from 3-day deliberation in June and July 2023 on access to and charging for London's Secure Data Environment

The London Citizens Advisory Group (CAG) is a critical part of the ongoing governance of the London Data programme. In its inaugural 3-day deliberation in Summer 2023 the CAG explored **access criteria** and **charging models**. The process included plenary sessions, table discussions and recommendation forming, concluding in voting.

The 102 members of the CAG are a diverse cohort



Access criteria

What criteria should Independent Information Access Group/s use when deciding to permit direct access to deidentified data, including for non-member organisations?

Access

- Clear and **demonstrable public benefit** – estimated according to:
 - Breadth of the benefit (volume of people)
 - Depth of the benefit (lifesaving or lifechanging)
 - Benefits for underserved groups
- Project will create broader benefits e.g. new understanding/information/treatments
- **Health inequalities** will not be exacerbated, and no groups will be negatively impacted/ harmed

Prioritisation

- Demonstrate **broader benefits** e.g. reduce burden on NHS, or quicker to deliver impact
- **NHS priority area** as determined by health experts
- Clear **impact for London or the UK**
- Willing to **publish their findings**

General

- Vetting process' for all organisations
- Additional checks for longer-term projects, international organisations and projects that use more sensitive data e.g. mental health data

Red lines

- No access for insurance companies or marketing agencies.
- No direct access for Police to health data
- No access to non-member organisations that cannot cover costs

Charging criteria

What criteria should drive decisions about charging, and what are the principles that underpin more complex interdisciplinary partnerships?

Charging

- Costs should be **different for different types of organisation** (profit making pay most, NHS pay least, charities, local authorities and universities in between)
- UK based organisations should pay less than non-UK organisations
- If multi-disciplinary e.g. NHS and commercial organisations, charges should be applied **based on funding organisation**
- **Additional charges if:**
 - Require more intense support from Secure Data Environment team
 - Longer term access (more than 6 months)
 - Large amounts of data
 - More sensitive data

Discounts

- Measurable benefit for NHS (including cost savings)
- Aligned with NHS priorities in London
- Exceptional benefits for patients

General

- Other value exchange models (beyond fee for access) to be considered to maximise value for the NHS e.g. profit share, discounted products
- Opportunities for longer term strategic partnerships should be explored

We will use the recommendations to create London's access request process as well as the charging model and commercial principles.