
Panel discussion: NHS Digital and the emerging data access landscape for health research

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Our organisation: the UK Data Service

- **National service** for social and economic data
- Founded 1967 by ESRC as a 'Data Bank' for science science
- Over 50 years of curating and providing access to data for research and teaching
- A Trusted Digital Repository (TDR) and accredited to ISO27001 Info Security Management standard
- Work closely with research funders and key data producers /institutions, e.g. Office for National Statistics, NHS-D, government departments, British Library etc.



UK Data Service



UKDS: meeting data publishing requisites

✓ Findable – rich resource discovery

✓ Accessible – free at point of access

✓ Interoperable – standard metadata

✓ Re-usable – rich documentation

✓ Persistent identification of collections

Our strategy for enabling safe access to data

- ✓ **Protection of identities** when promised
- ✓ **Processing ground** for personal data
- ✓ **Regulated access** where needed (all or part of data) by group, use, time
- ✓ **Robust safeguards and security**



Open where possible, closed when necessary

Spectrum of Access: UK Data Service

Open

- No disclosure risk
- Licence: Open
- Controls: very few restrictions on reuse

Safeguarded

- Zero to low disclosure risk
- Licence: UKDS plus agreements
- Controls: Authentication, Authorisation, Auditing

Controlled

- Disclosure risk/personal data
- Controls: Five Safes: Authentication, Authorisation, Auditing, Project Approval, Training, Output vetting



Fives Safes Framework

Fives Safes enables **safe access to data** that meet the needs of **data protection** yet fulfils the demands for **open science and transparency**

- **Safe data** - treat data to protect confidentiality
- **Safe people** - educate researchers to use data safely
- **Safe projects** - research projects for 'public good'
- **Safe settings** – Secure Lab environment for personal data
- **Safe outputs** – Secure Lab projects outputs screened

[5 Safes Animation](#)



Effect of restrictive licenses on usage

Adult Psychiatric Morbidity Survey

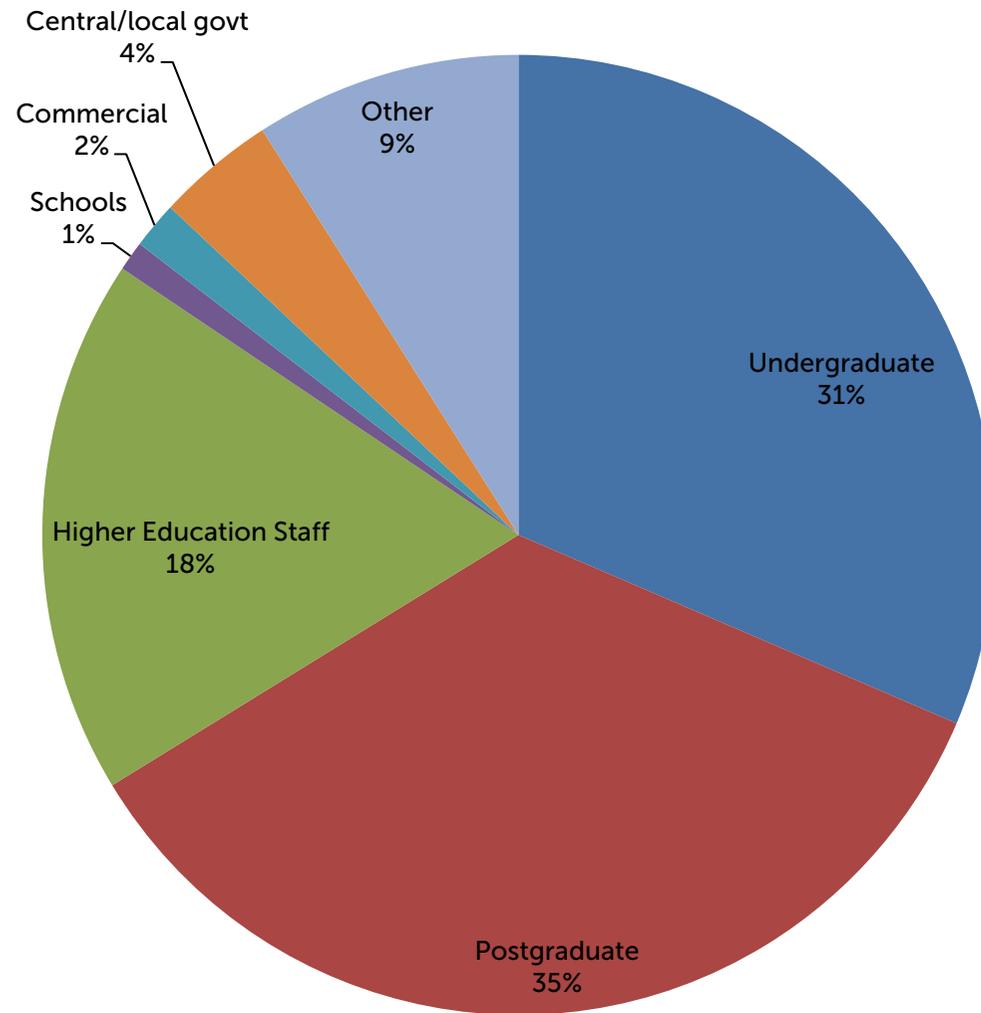
	Year	No. of downloads	% Undergrad Downloads	No. of Unique Users
End User Licence 2007	2018	107	27 (n=29)	85
	2019	52	25 (n=13)	40
Special Licence 2014	2018	28	0	12
	2019	10	0	10

Health Survey for England usage

Year	No. of Downloads	No. of Unique Users
2015	2374	678
2016	2795	726
2017	2312	709
2018	2855	821
2019	1451	405



User Types 2018 (% unique users) Health Survey for England– End User Licence



Summary of comments from UK Data Service

We welcome:

- more detailed/linked data under more restrictive conditions but....
 - restrict the barriers to access
 - has to be quick and easy
 - allow access for postgrads
 - future charges?
- retention of an End User Licence version with limited variables
 - consultation with users and analyses of usage types
 - utility - how many people will use this in reality?
 - retain Nesstar version
- retention of teaching datasets
 - End User Licence and open versions (perturbed versions?)
 - risk losing undergrads/ECRs as future users