

Sensitive Data: How do you do yours?



Today's BoF Format

1. Panel Intros
2. Audience poll & Discussion



Panel

- Dr Frankie Stevens - AARNet
- Dr Steven McEachern - ADA
- Kate LeMay - ARDC
- Jeff Christiansen - QCIF
- Angela Gackle - TERN
- Ingrid Mason - AARNet

Frankie Stevens

- AARNet Australia's Research & Education Network - Research Engagement Strategist
- Research Background: Cancer Research
- eResearch Background: National, State and Institutional
- Interests: Open Research, Sensitive Data Storage and Sharing, Upskilling Researchers

Kate LeMay

- Australian Research Data Commons
- Skilled workforce team - events (face to face training, webinars, virtual training), guides, website resources
- Background: pharmacist and primary care medical research
- Interests: Ethics, governance, mediated access, de-identification, risk management e.g. Five Safes, F.A.I.R. data not open data, policy, (plus good data management in general)

Steve McEachern

- Australian Data Archive: <https://ada.edu.au>
- The Australian Data Archive (ADA) provides a national service for the collection and preservation of digital research data. ADA disseminates this data for secondary analysis by academic researchers and other users.
- Background: industrial relations and human resource management, social science, research data archiving, preservation and dissemination
- Interests: many and varied - in terms of research data, the safe and useful dissemination of data for research, policy and public use purposes and frameworks for achieving this (5 Safes, FAIR, etc.)

Angela Gackle

- TERN (Terrestrial Ecosystem Research Network)
- TERN publishes its own data and a range of high value legacy data sets
- Background: Science communication, partnership building
- Interests: Encourage collaboration and the use of ecological data for best outcomes for Australian environmental management; understanding problems and defining them



Jeff Christiansen

- Currently:

- QCIF Health and Life Sciences Program Manager
- EMBL-ABR and Australia Bioinformatics Commons



- Previously:

- Manager of med.data.edu.au (QCIF, Intersect, VicNode)
- Contractor for NSW Cancer Institute Biobanking Stakeholder Network
- Medical researcher



- Interests:

- Shared infrastructure for storing, describing, analysing and linking biological data (e.g. gene sequence, images, etc) and associated 'specimen' contextual information.
- Ensuring the above is suitable for human derived information
- Education around shared responsibilities for protecting information and minimising risk

Ingrid Mason

- AARNet Australia's Research & Education Network - Deployment Strategist
- Research Background: Digital cultural heritage, digital curation and archiving
- eResearch Background: National, State and Institutional
- Interests: Cultural protocols and societal conventions for collection of and access to documentary history and heritage materials

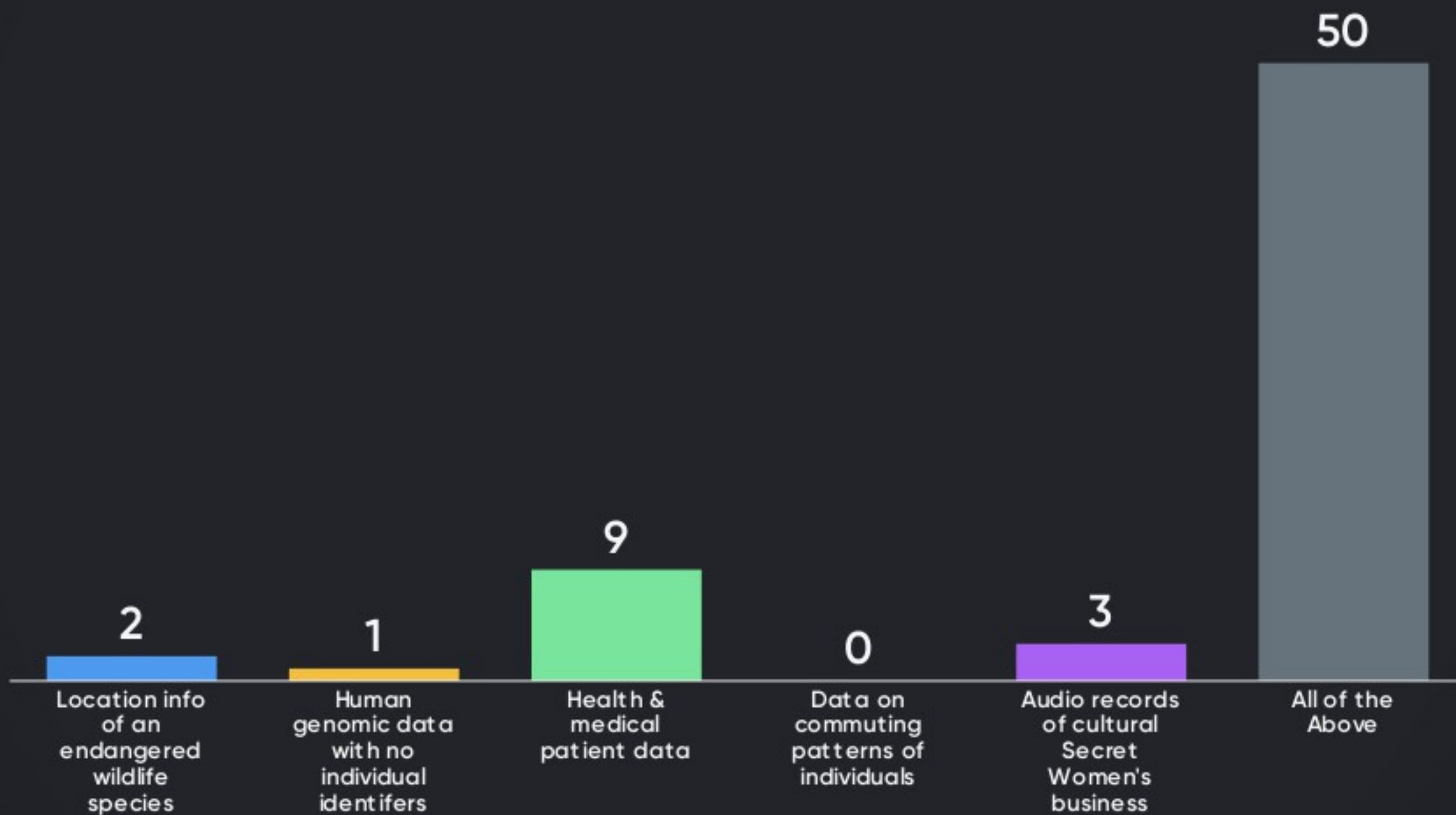
Sensitive Data Poll



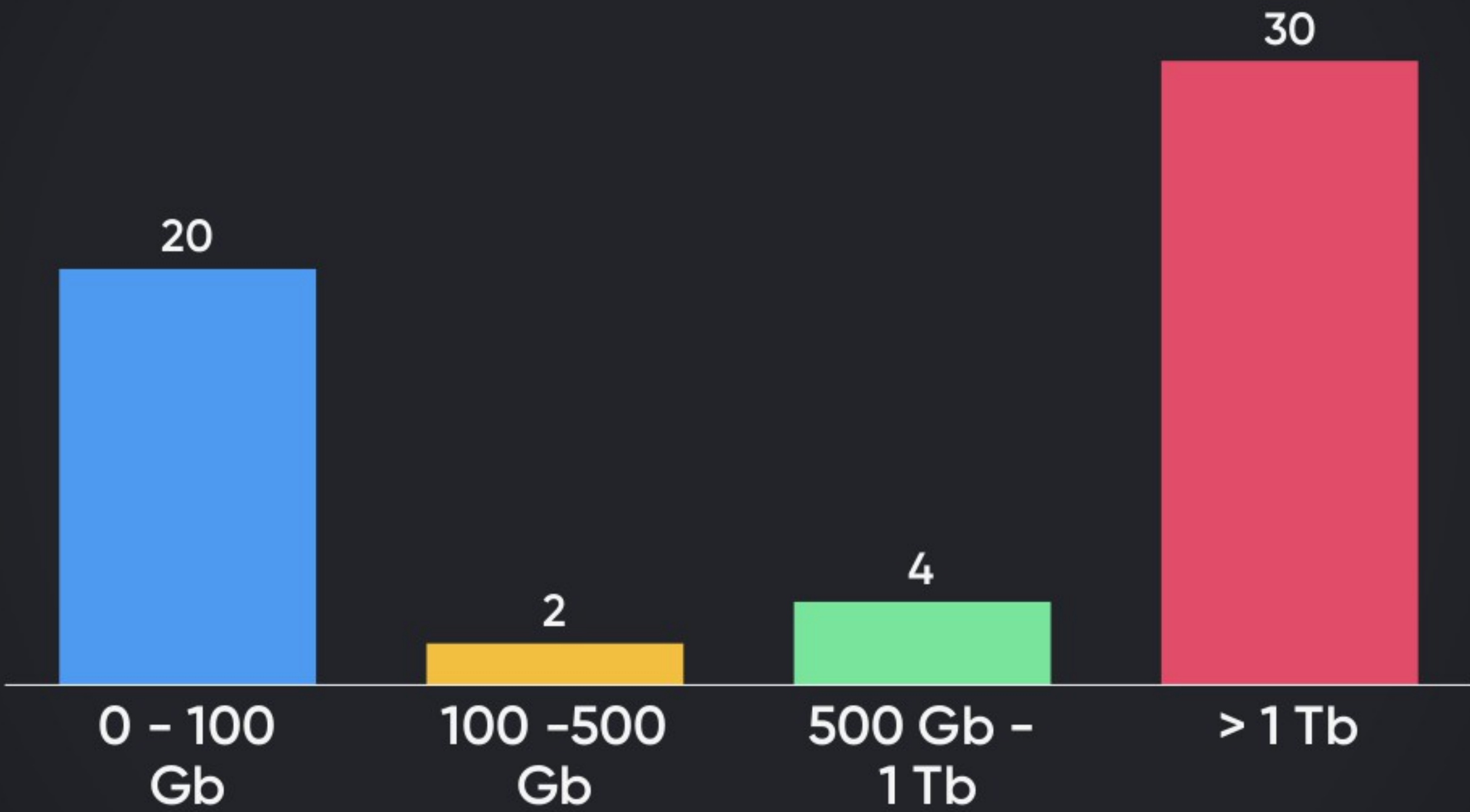
What do you associate with Sensitive Data?



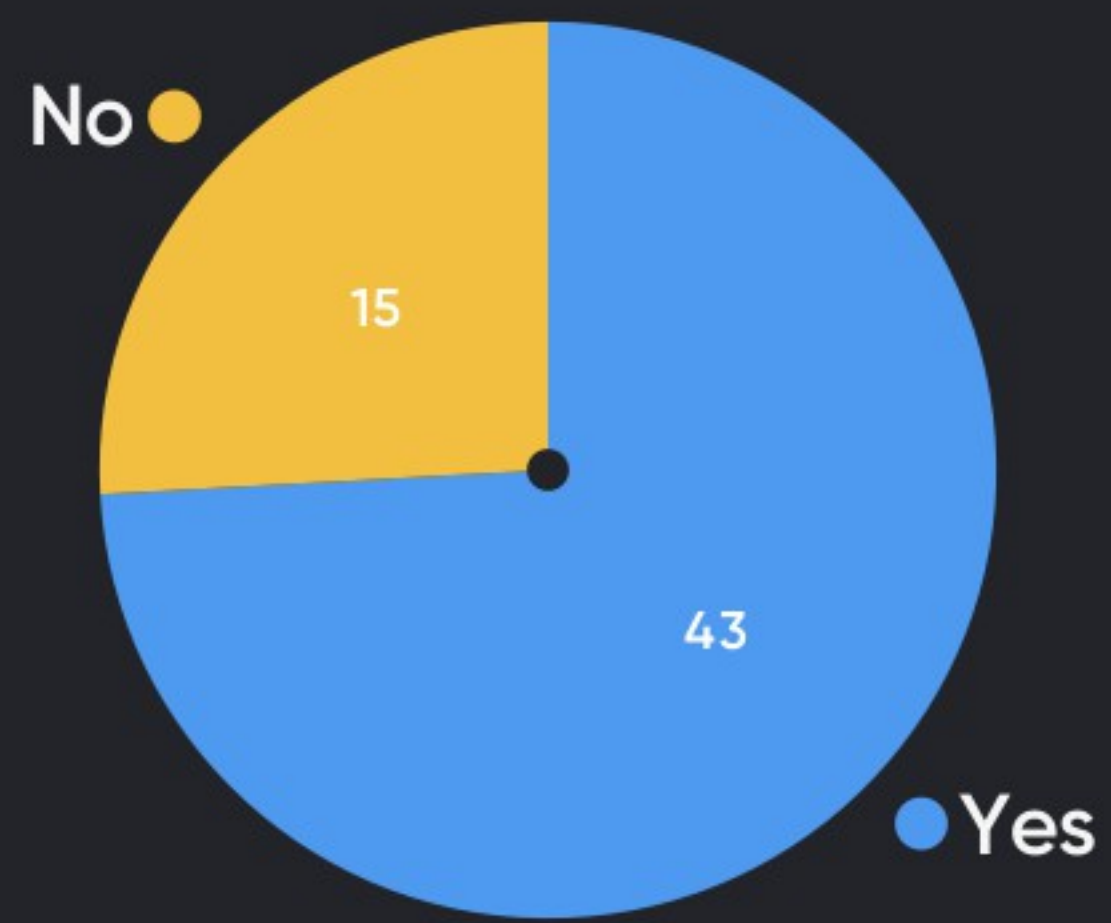
Which of these do you think are examples of Sensitive Data?



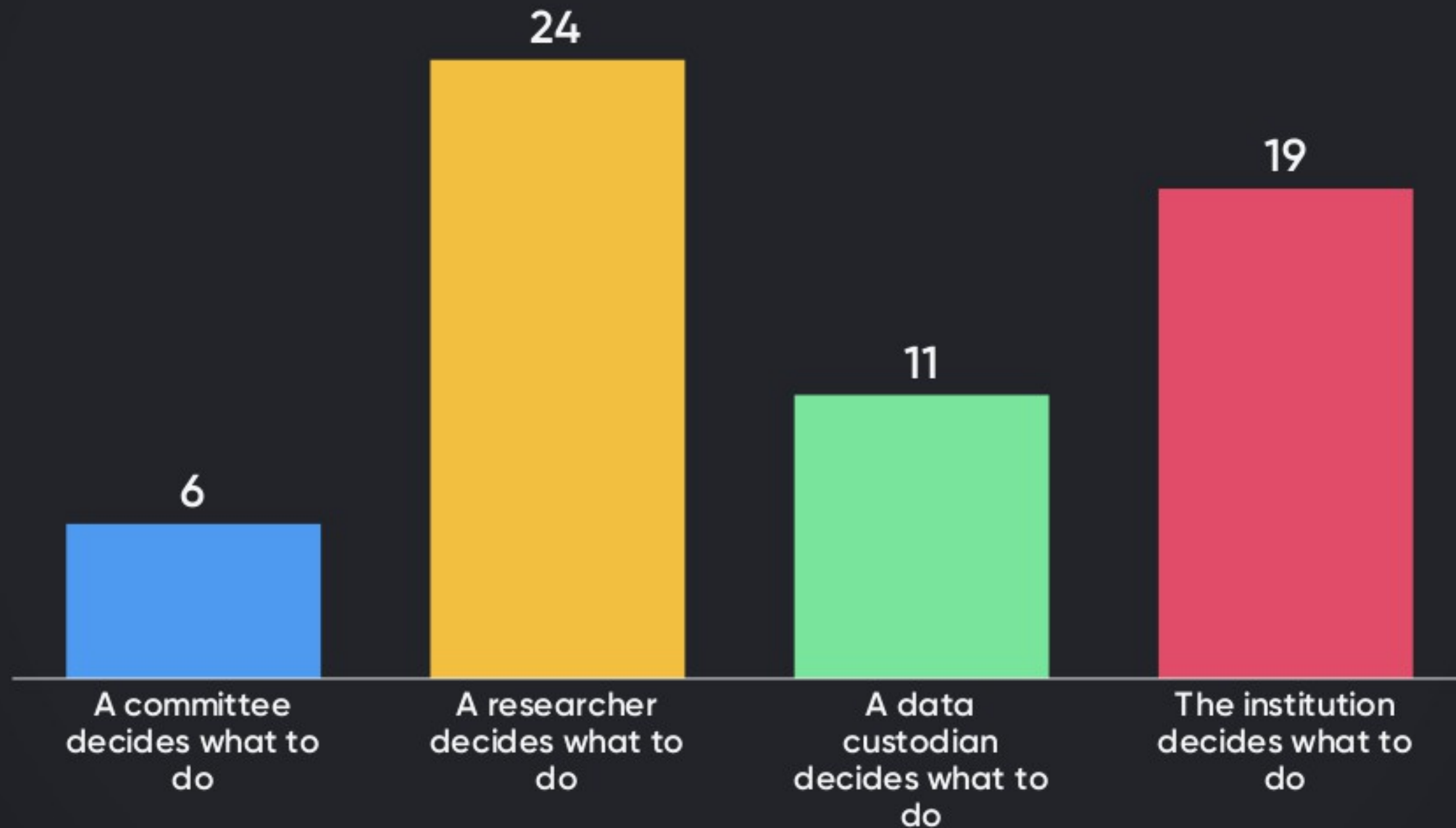
How much sensitive data do you have?



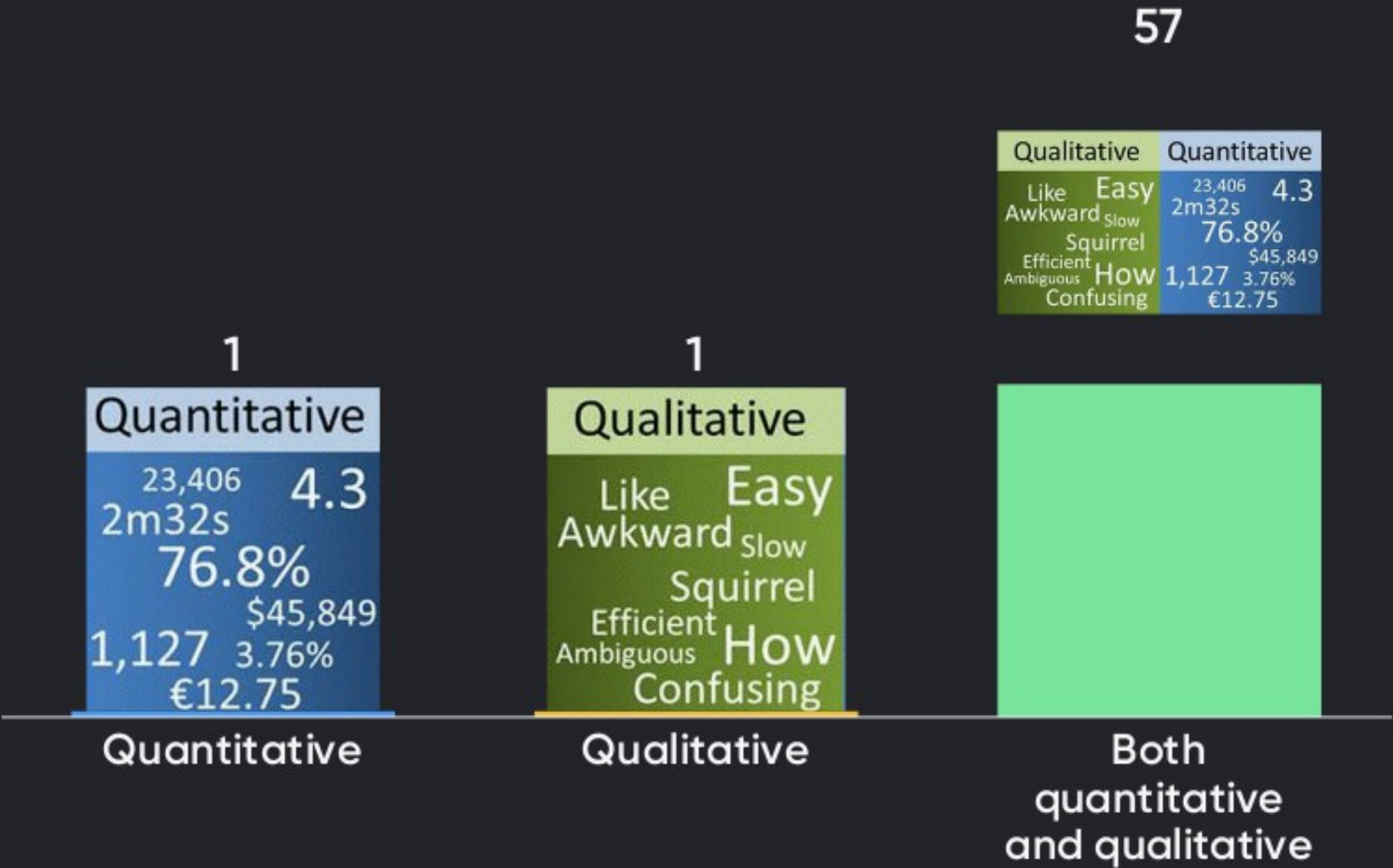
Are you aware the National Statement on the Ethical Conduct of Human Research has recently been revised?



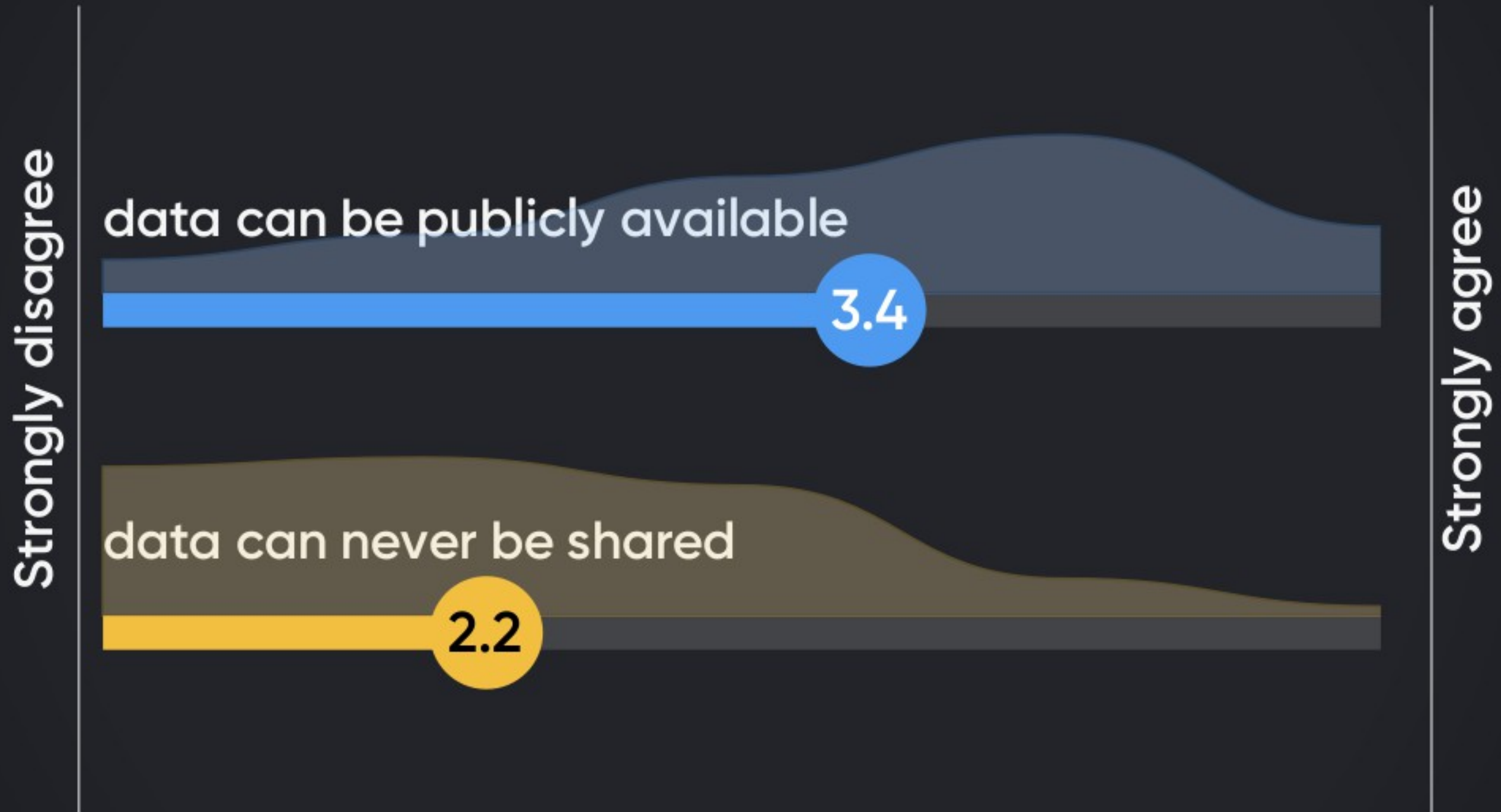
Who has responsibility around managing sensitive data risks?



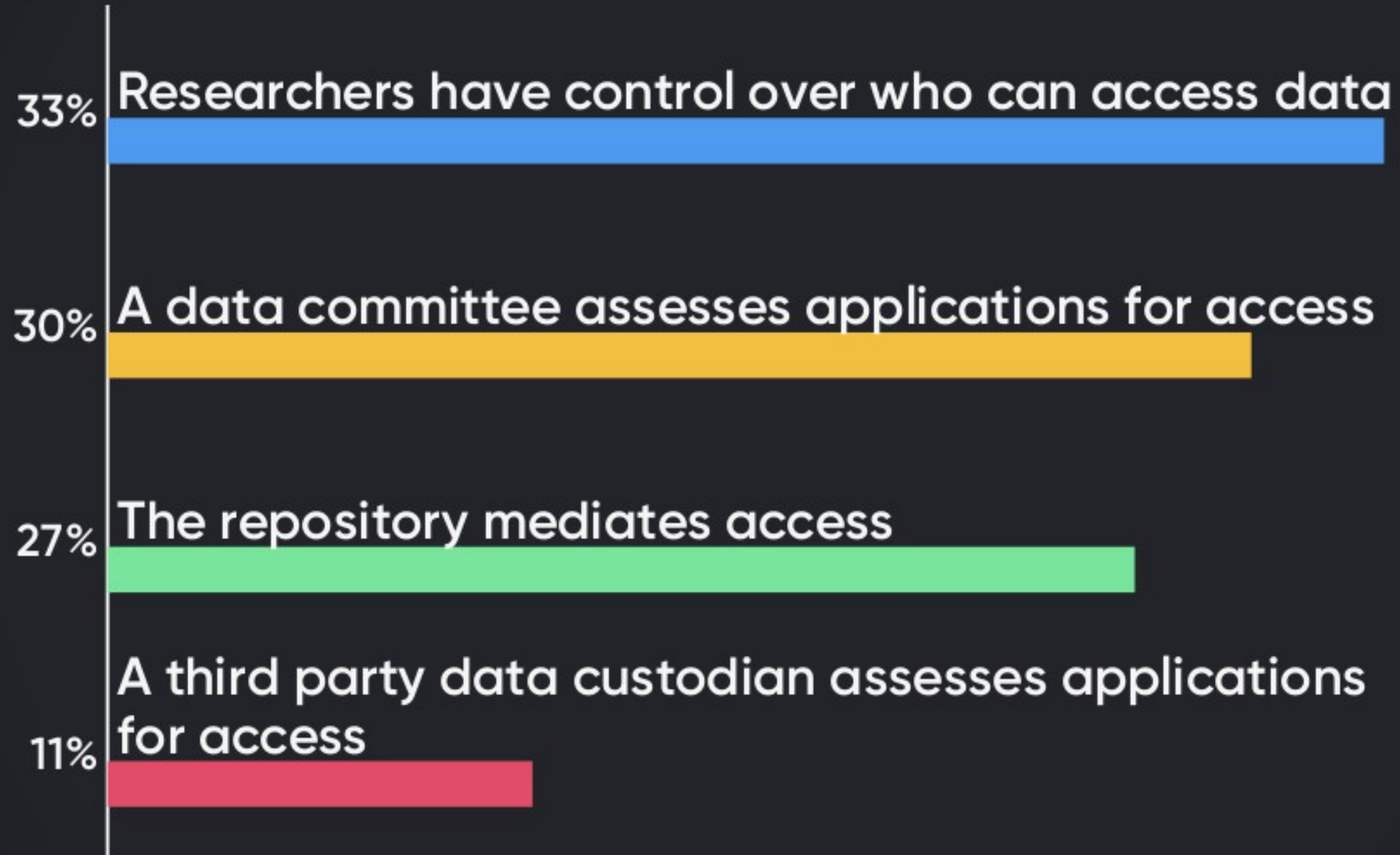
What types of data may need to be 'de-sensitised' before sharing?



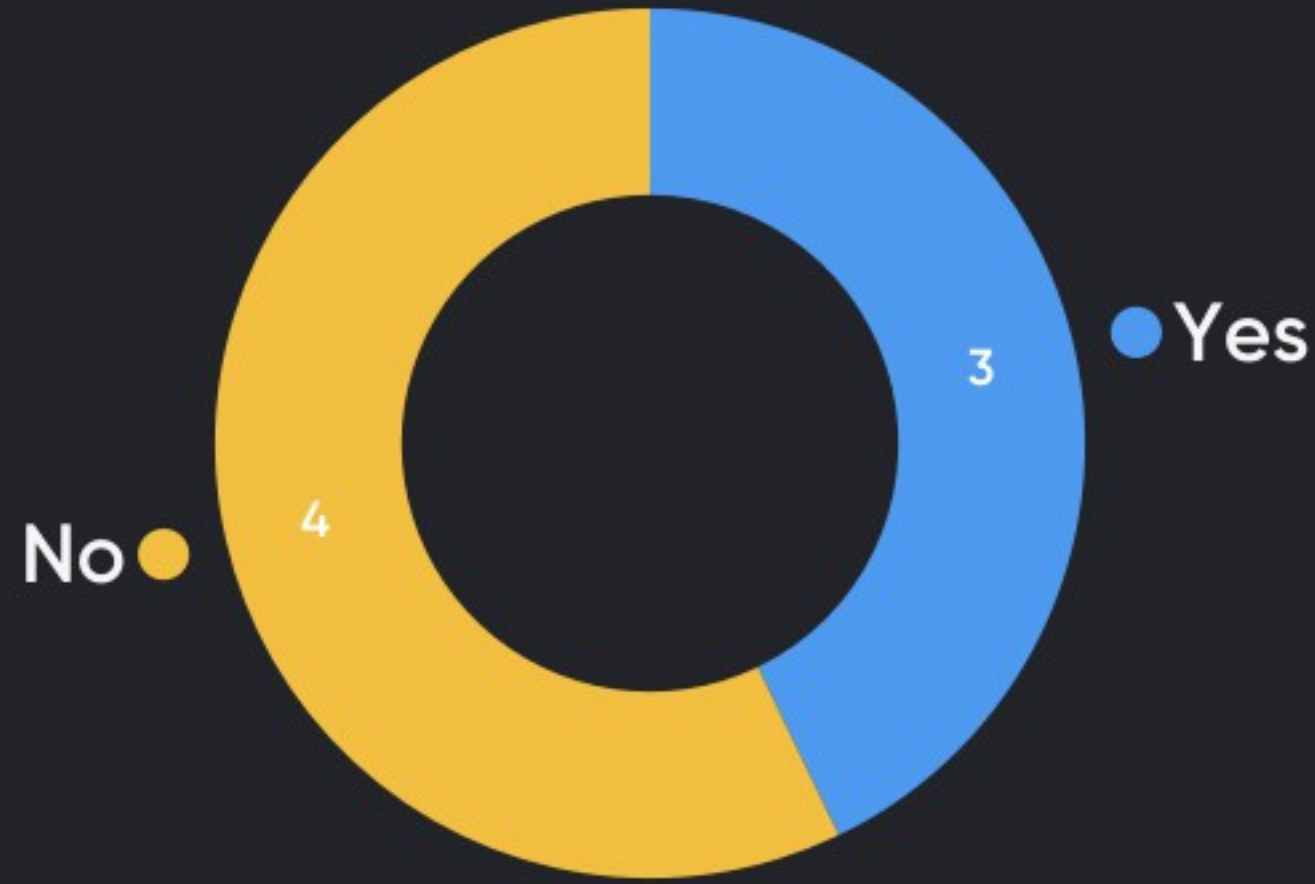
Sharing Sensitive Data



What would be the most preferable model for mediating access to a sensitive dataset?



Are you aware of the upcoming federal Data Sharing and Release Act?



How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

Form a community of practice cross disciplinary

Community of practice

Properly defining what is considered sensitive data and in what context

Work with University Ethics department Talk to researchers in different disciplines

ARDC should do it

That might be best decided on a per institution basis?

Researcher education

Community of practice

Ensuring metadata is attached.

How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

Openly and with candour!

ARDC

Wiki

Involve librarians!

Get common training

ARDC

Tackle this in training

Bof

Listen to lots of people –
subjects of research,
researchers, data custodians,
etc

How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

ARDC

ARDC

Ensure quality metadata

Community of practice

Community of practice / e-list
/ semi-regular discussions

ARDC

Don't let ICT/National
infrastructure back away from
storing it.

Continue the conversation
with all stakeholders

ARDC

How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

Sharing ideas and practices

ARDC

Wiki

Educating researchers Gathering/assimilating requirements Provider solutions/services to address requirements

Define scopes of what constitutes sensitive data in the realm of concern

Build on related efforts around FAIR principles with extra controls

Put Frankie in charge. But seriously, a pilot that the community can participate in would be good.

Shared description of current practices

Committee with representatives from all sectors / backgrounds including research participants

How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

Let's have afternoon tea

Examples of business rules

ARDC

Sharing our different approaches to handling sensitive data as organisations

Not just ARDC, the broader keeping community have a stake, gov, heriage

Shared approach to access conditions

Committee aligned to domain

Online forums, involve librarians and museums and researchers, HDR training

Involve the people who the data is actually about

How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

Hold a "National Conversation"

Keep it simple, where possible

I am happy to have tea with you

Research Data Alliance
Interest group on Ethics and
Social Aspects of Data

What Steven said

Get government support at
the ministerial level

Involve librarians to talk to
researchers about meta data
and ethics

CoPs are great and all, but it
needs a central coordinator.
Maybe ARDC?

Did anyone mention the
ARDC? :)

How can we all collaborate on identifying / describing / consolidating approaches to Sensitive Data?

Conference where all relevant folk come together to formulate and agree an approach

Take a national approach through something like ardc to try and build best practice and reference implementations, avoiding fragmentation within institutions and the complication that comes from letting enterprise IT manage the risk

Any questions for the panel?

How can we offer training on deidentification?

Why can't FAIR be reworked to FAIRER and include Ethical and Responsible?

Can you identify these questions to the user?

Research on hard stuff is still going to happen, can we shift from a compliance/policy to reduction of risk approach?

What's a good strategy for researchers who think sharing data is the same as completely open?

Thoughts on the Australian Government's My Health Record and its ramifications?

Suggestions for how data custodians might identify sensitive data where no metadata is available.

Can we turn up the air-con?

Working with indigenous populations: What if we gave the data back to the people we have gathered it from... is it really our data to manage? Then the decisions as to who can access and work with the data remains with the people it is about.

Any questions for the panel?

Understand risk adverse attitudes more fully

How can one safely collaborate across institutions?

If you were a subject in a research study, would you like your sensitive data to be shareable?

How many cases in Australia have there ever been of violation of sensitive data?? Maybe the numbers are too small to worry about it too much.

Can we find the identify of the person who wants the aircon turned up? It's freeeeeeezeing.

I am the air con

Is it reasonable for transfer of responsibility?

I think the person who wanted the aircon turned up was referring to increasing the temperature.

FCUK?