

Are HRECs our sensitive data advocates?

How working with HRECs can improve research data management outcomes

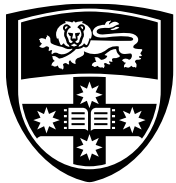
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THE UNIVERSITY OF
SYDNEY



Introduction

All researchers conducting human research must abide by the *National Statement* and the *Research Code*. Both require research data to be appropriately managed.

At Sydney University our policy specifies that researchers must use university-managed platforms to store and manage their research data.

*“Researchers should develop a data management plan that addresses their intentions related to generation, collection, access, use, analysis, disclosure, storage, retention, disposal, sharing and re-use of data and information, the risks associated with these activities and any strategies for minimising those risks.” - **National Statement on Ethical Conduct in Human Research***

*“The responsibilities of researchers with respect to management of data and information in research should be clear from the beginning of a research project. The development of a data management plan for this purpose is strongly encouraged.” - **Australian Code for the Responsible Conduct of Research***

Human Research Ethics

All research involving humans must receive ethics approval or exemption from a Human Research Ethics Committee.

At Sydney this may involve review by a Human Research Ethics Committee (HREC) or a low risk committee.

Ethics Officers assist our three HRECs.



Human Research Ethics Committee

HRECs must have a minimum of 8 people (roughly equal number of men and women, and 1/3 from outside of the institution) including

- Chairperson
- 2x lay people (one man, one woman, not involved with the institution)
- 1x person with current professional care experience (nurse, allied health)
- 1x person in a pastoral care posting in the community (Aboriginal elder, minister of religion)
- 1x Lawyer (not involved with the institution)
- 2x people with current research experience

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**NO GUARANTEED DATA
MANAGEMENT
KNOWLEDGE**

Research Data Management (RDM) related questions

Researchers provide details of their data management plans as part of our human ethics applications.

Question 236 – Constraints for surveys

“If your project involves online surveys, state where the surveys will be hosted and comment on any security, data ownership and privacy constraints associated with this survey host.”

Question 353 – Storage during the project

“Describe where study materials will be stored DURING the project (including electronic and hard copy files, consent forms, audio recordings, questionnaires, interview transcripts, video recordings, photographs etc). Please include building and room numbers for hard copy materials.”

Question 354 – Storage on completion of the project

“Describe where study materials will be stored upon COMPLETION of the project (including electronic and hardcopy files, consent forms, audio recordings, questionnaires, interview transcripts, video recordings, photographs etc). Please include building and room numbers for hardcopy materials. Note that on conclusion of the project a copy of all materials must be kept in an accessible and secure location on University premises.”

Question 355 – Security measures

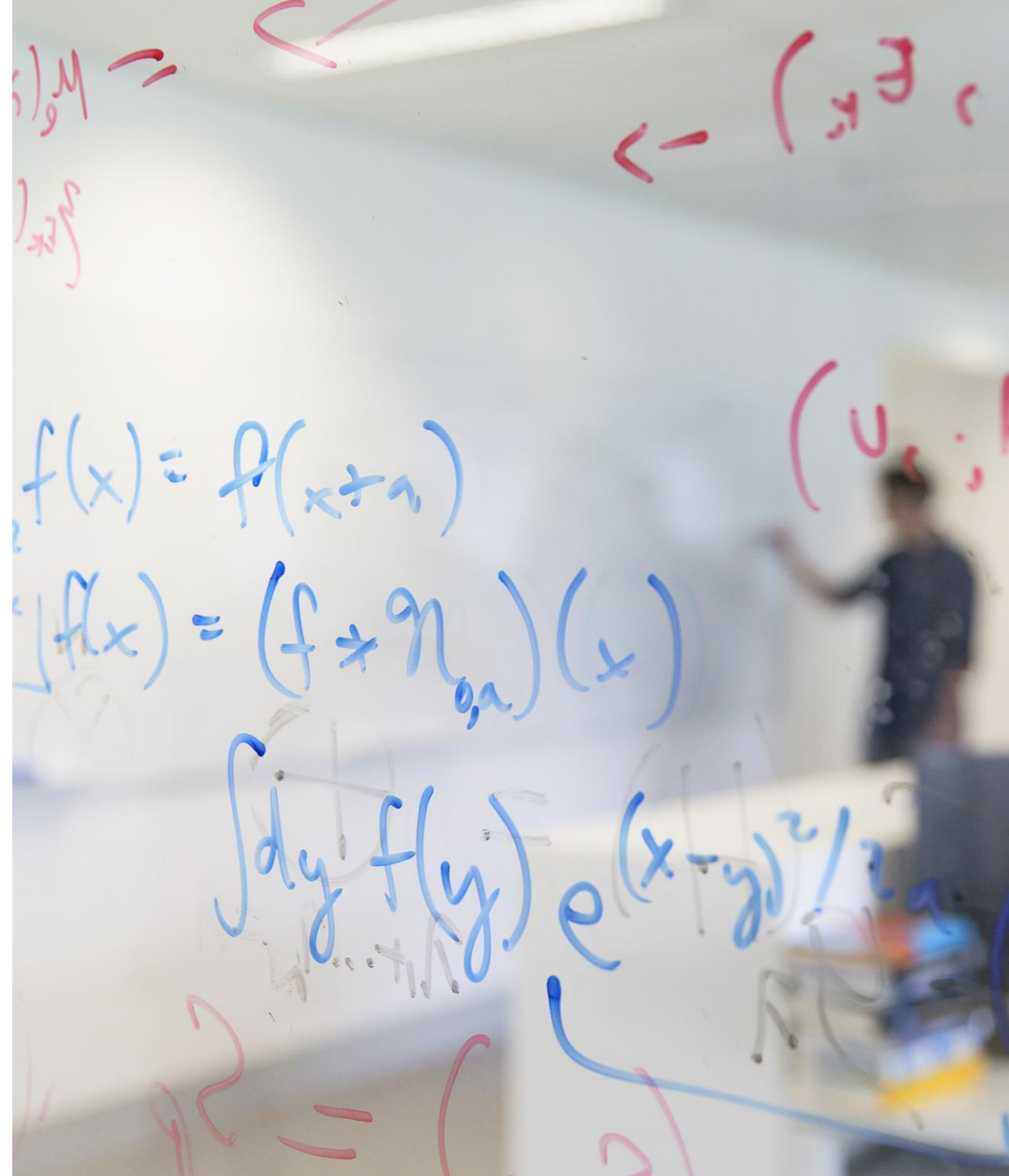
“Outline the security measures that will be used to protect study materials from misuse, loss or unauthorised access during and after the project (e.g. removal of identifiers, secure storage, restriction of access to appropriate personnel etc).”

HRECs are key advocates for responsible research data management and facilitate collaboration with data management consultants!

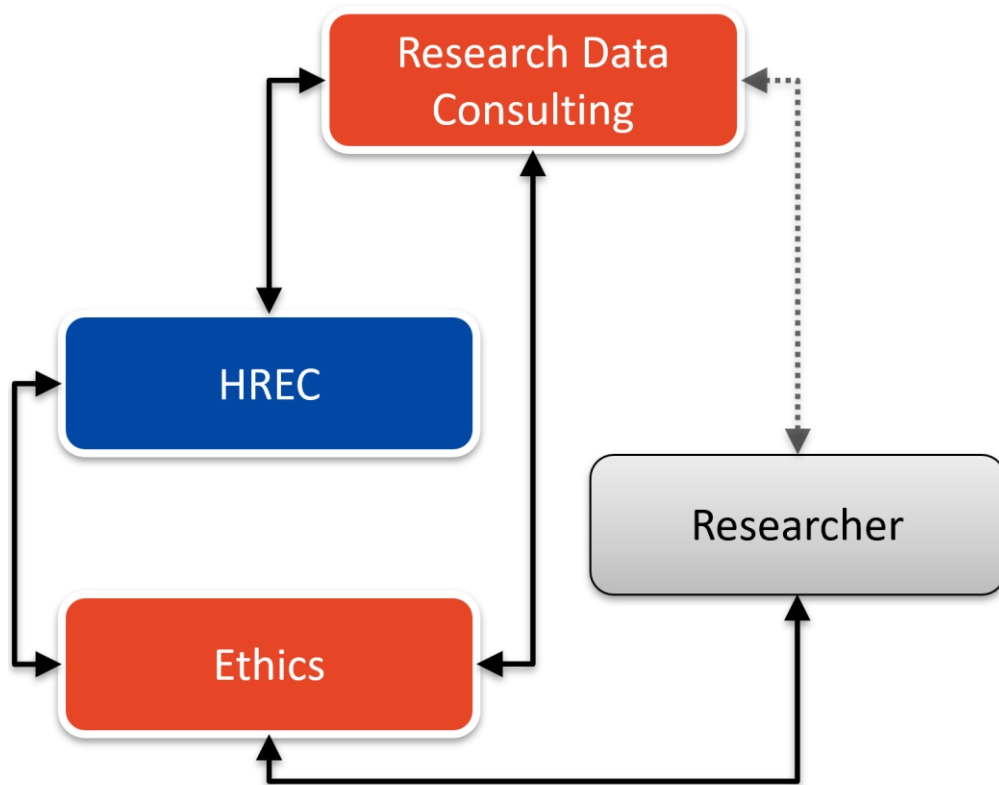
Method

By attending and observing HREC meetings throughout 2020, the Research Data Consultants (RDC):

1. identified how researchers were planning to manage their research data
2. observed how the HRECs approached these questions
3. provided materials and training to the HREC and the ethics administration team to identify research data management problems, knowledge gaps, provide advice, and/or direct researchers to our team



Method



This involved working with different groups

- Ethics administration officers, who:
 - collate the applications, and prepare them for committee meetings (i.e. checking for completeness)
 - can advise researchers to come to RDC for advice
- HREC (especially the chairs) who:
 - review the merits and ethics of applications and approval
 - know what to look for, what the standard should be
 - know what conditions must be applied for an approval
- Researchers, who:
 - Are required to meet ethical and RDM requirements

Results

Initially we observed:

- Poorly answered RDM questions
- Non-compliant RDM practices in some applications
- Some level of identification of RDM issues by HREC members and ethics administration team



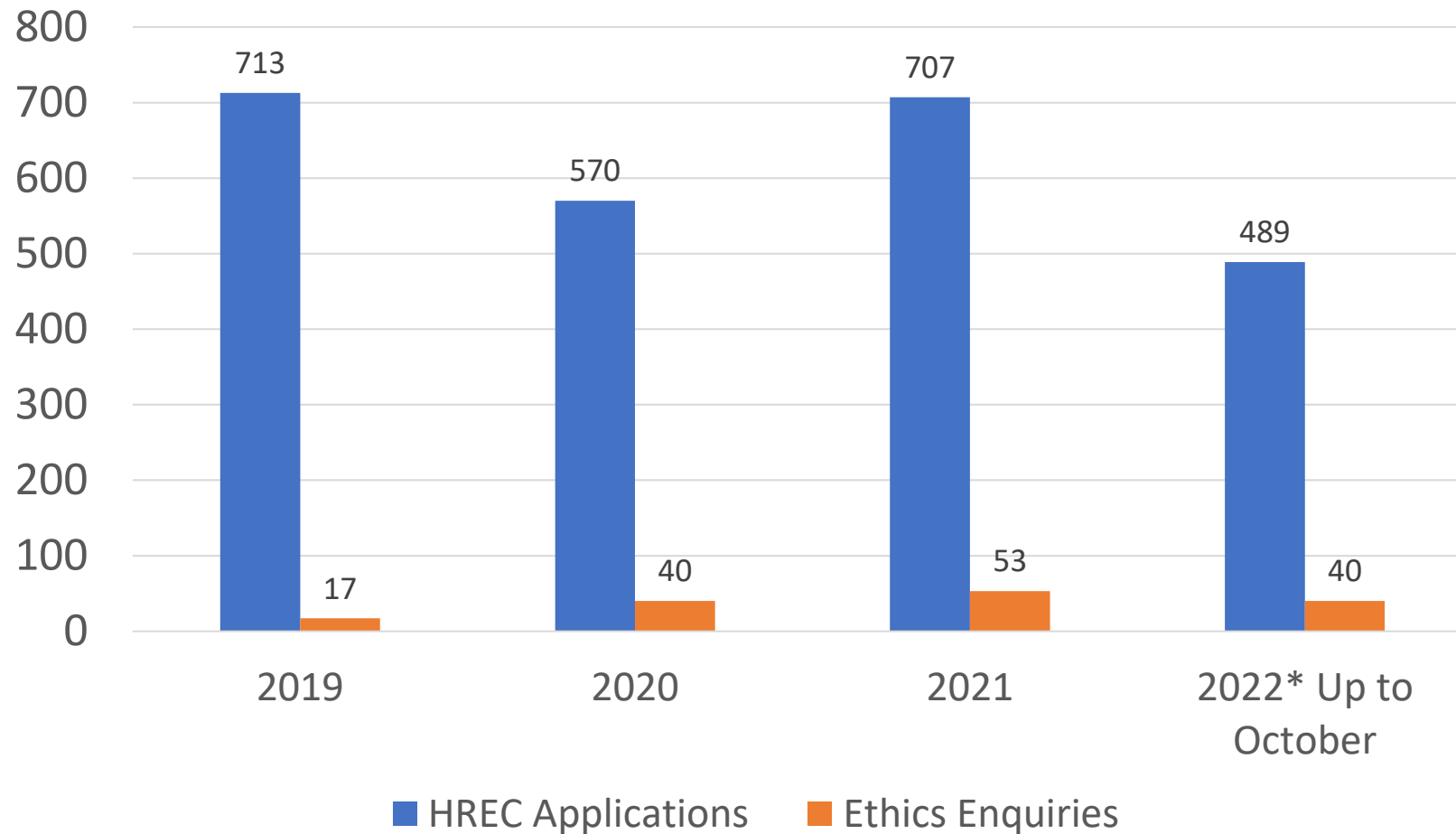
Results



We then:

- Provided some RDM advice to our ethics officers
- created, updated, revised resources for our HRECs, ethics officers and researchers
- identified gaps in our suite of platforms and tools e.g. transcription

Support enquiries from the ethics administration team



- 2019 baseline
- 2020 observing HREC meetings
- 2021 “new normal”

Human Ethics Applications vs Enquiries

Examining our support log data for the time period we saw:

- An increase in enquiries from the ethics administration team
- Similar number of HREC applications (COVID dip in 2020)

Note:

- Ethics enquiries represent <1% of total support enquiries
- Ethics enquires in the “RDM General” category represent 5-10% of total number of all “RDM General” enquiries

Support data - Caveats



Support data is derived from the RDC service log so there are some limitations

- only support enquiries coming from an ethics officer can be attributed to “research ethics”
 - Cannot discern enquiries from researchers who have been referred by ethics officers
 - Likely underestimates the total impact of this work with HREC and the ethics officers

Bigger picture

Observing HREC meetings allowed us to:

- assess the current state of RDM in research
- highlight capability gaps
- identify what/where resources are most needed



Bigger picture

Working with Ethics and HRECs enabled us to:

- develop a deeper understanding of how each team works
- build strong working relationships
- develop and provide better resources, support and training

HREC members and ethics officers are now:

- more aware and better able to make informed decisions about acceptable RDM practices
- able to make researchers aware of RDM issues, provide resources
- advise researchers to seek consultations



Conclusions

Positive outcomes for EVERYONE involved

- Compliant transcription tool project!!!
- RDC joining Ethics under the “Research Integrity & Ethics Administration” umbrella
- Better awareness
- Better resources
- Better advocacy for the research community

Does this translate to better outcomes?



Thank you!

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