

# Rethinking Information Governance: 'Failures' and what we can learn from them

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# IG 'Failures'

The world of information governance (IG) in [insert discipline\*] research can often feel murky, shrouded in nuance and clouded by uncertainty. This is especially true for those who are new to research and learning how research governance requirements sit alongside IG rules.

*NHS HRA, **Blog: Information governance in research - an update on our work to improve assurances** 30 Jun 2025*  
*\*health and social care*

# What does Good IG look like?

Security

Effectiveness (the goal)

Efficiency

# Why is Information Governance (and Ethics) so hard?



# Activities

- In groups, discuss the real-world examples of IG failures
  - What went wrong?
  - What are the implications for TREs, researchers, the public?
  - What could be done differently in the future?



# Case Study 1 – University Ethics

A researcher sought University Ethics from their current department, a Business School. Their research used deception methodology (common in Psychology research). The ethics application was rejected because the Business Ethics panel stated that deception methodology was illegal and against GDPR.



## Case Study 2 – External Researchers

International research team had data application to TRE approved. After the project was approved, Information Governance team were involved to identify how the international team would connect to the TRE (i.e., who was responsible and what institution, if any, were managing laptops). This assessment took 8 months to progress.

During this 8-month period, the research team had changed; an amendment was submitted for the changed team as well as additional data since the research team realised the original data request wouldn't be sufficient to answer the research question.

The review panel then said the level of detail of the data was now disproportionate to risk (less safe data, less safe setting).



## Case Study 3 – Processes

A researcher was in a research team where a **project** was approved for both secure room and home working access via a TRE. However, the researcher themselves was marked as accessing the data via secure room access only. Subsequently, the researcher applied for homeworking, and received the confirmation of approval via email. The researcher then accessed the secure environment for several months via the home access method to undertake analysis.

After several months, their account was blocked via a failed login attempt. The researcher phoned the TRE asking to sort their login. However, the TRE stated that the researcher unlawfully accessed the secure environment and as a result blocked their account and logged an incident form – all without notifying the researcher.

The researcher then sent both the project homeworking approval, as well as their individual home access approval. The TRE responded that they had none of this on their system and couldn't access anything at their end because the person who sent it had left the team.

The researcher then had to fill in another form and get re-approval. However, the incident has caused them significant distress because they haven't received any indication of whether the incident log still reflects that they 'broke a rule' when they hadn't.





# Case Study 4 – Feedback on data request application

A researcher received the below feedback from a data access request to access microdata from a data provider:

*Thank you for summarising this section, however please write out acronyms in full when using them for the first time; keeping within the 100 word limit. Please also briefly describe your methodology, goal of this research and name the paper(s) you plan to publish in.*

A researcher received the below feedback from a data access request to access a COVID-19 dataset at the height of the pandemic from a data provider:

*Please could you also describe: - how you will carry out the regression modelling, e.g., which variables will you analyse? - any expected outcomes from your regression analysis.*

# Case Study 5 – Artificial Intelligence research

There has been increasing interest in AI/ML to a research permissions organisation, but only a few applications approved. These applications have received between 20-50 additional questions asked by the review panel, which has led to researcher frustrations, delays in progressing the research against funding grant deadlines.

Additional safeguards put in place prior to the projects going to the review panel:

- ensuring that a project technically feasible
- the proportionate volume of data is requested
- AI expertise are on the research team
- additional clauses added to the data access agreement
- penalties of misuse applied to both individual AND their organisation
- the data is handled safely within the secure research environment
- processes are in place for safe disclosure of outputs

## Case Study 6 – Incorrect data provided

TRE accidentally provided unapproved identifier (e.g., DOB) into TRE.

This error was identified when providing update of data 6 months later. Upon realisation, the TRE staff deleted entire TRE workspace, informed researcher new data (without identifier, but with updates) would be provided. Because the entire workspace was deleted, the researcher had lost whole PhD analysis.

Because of the impact on the student, the TRE had to retrieve the project workspace from backup (took 2 days), delete originally provided data and request researcher delete any copies and analysis that used this variable.



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# Thank you

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