

## GDPR and research



**GDPR IS COMING**

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**DON'T PANIC**



## GDPR and research ethics

1. GDPR terms and principles
2. Generic research ethics implications
3. UREC ethics policy/review changes, updates and guidance
4. GDPR and approved research-in-progress
5. GDPR – General advice (Daniel)
6. GDPR – PGR and research (Lorna)
7. Q&A

GDPR terms	Research
<b>Data subject:</b> persons whose personal data is collected, stored and used	Participants; Secondary data
<b>Personal data:</b> identifiable data and info of data subjects	Participant personal information; participant identifier; non-anonymised participant data
<b>Anonymised data:</b> non-identifiable data	Anonymised research data
<b>Special categories:</b> sensitive personal data requiring additional safeguards	Info and data on 'race'/ ethnicity, religion, TU membership, politics, biometrics/genetics, health, criminal records, sex life/ sexuality

GDPR terms	Research
<b>Processing:</b> collect, store, use or delete personal data	Collect, store, use and delete participant information; collect, store, analyse and delete participant data
<b>Legal basis:</b> Lawful basis for processing which data subjects' consent to and are informed of	'necessary for a task in the public interest' 'collects and analyses sensitive data only necessary for research in the public interest' (UREC)
<b>Data controller:</b> organisation that determines purpose and means for processing	Usually 'University of Sheffield' although collaborations may have 'joint controllers' (with formal data sharing agreements) (UREC)

## GDPR principles

### Personal data collected/processed must be...

- Fairly and lawfully processed
- Processed for limited purposes
- Adequate, relevant and not excessive
- Accurate and up to date
- Not kept for longer than necessary
- Stored securely
- Not transferred to another country without adequate protections

## Generic research ethics implications

- Inform participants of legal basis for use of personal data and who the data controller is/joint controllers are
- Inform participants of why personal data is being collected/processed and what will happen to personal data
- Inform participants of right to complain about (mis)handling of personal data
- Only collect personal data where necessary for research
- Anonymise/ pseudonymise personal data where possible/appropriate
- Ensure data security when stored
- Undertake timely deletion of personal data not needed post-project
- Have collaboration/data sharing agreements in place where needed (Research Services provide assistance)

*Following intro of GDPR - UREC has revised research ethics policy/review processes, guidance and resources (including example information sheets/consent forms)...relevant links and info can be found at...*

### \*\*\*UREC GDPR webpages\*\*\*

<https://sites.google.com/a/sheffield.ac.uk/gdpr/>

- GDPR and research ethics briefing videos/slides
- Summary of GDPR terms and changes
- Revised guidance and documents:
  - Anonymity, confidentiality and data protection
  - Compiling an information sheet and informing ongoing participants of additional GDPR info
  - Example info sheet and consent form
- Guidance on revised ethics review forms/online system
- Information about and links to Health and Social Care research governance GDPR related updates (HRA)
- FAQs and links to external 'GDPR and research' guidance



## Additional key research ethics info and guidance

- Research Services 'ethics and integrity' webpage  
<https://www.sheffield.ac.uk/rs/ethicsandintegrity>
- Guidance for applications and reviews via the online ethics review system:  
<https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/educationresources/onlinesystem>
- Health and social care research governance policies, processes and guidance:  
<https://www.sheffield.ac.uk/rs/ethicsandintegrity/governance>

## GDPR and approved research-in-progress (UREC 2018)

- **If data collection is complete:** no need for participant re-contact or re-consent but do anonymise/pseudonymise data where planned/appropriate and ensure data security
- **If data collection is not complete:** inform participants of required information at next opportunity (see UREC GDPR changes guidance). If you are as yet to provide info sheets and complete consent forms – use/adapt the new forms. If these are the only changes - no need for new ethical approval (but inform Ethics Lead and Administrator of the changes in info/consent forms). Process personal data in line with GDPR.

**\*\*\*NB: HRA Health and Social Care research ethics governance includes some differences\*\*\***

## GDPR General Advice

- Reduce the storage of personal data
- Online course about Personal and Data Information.
- Check that your laptops are encrypted.
- What are you storing in a USB? Are you using University Server Storage?
- Use of tablets/iPads.
- WiFi and use of VPN.

## Homework

- Mailing List
  - Privacy statement,  
<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>
  - Record interactions
- Third party – Data Processors

## PhD Students

### 3 Key Stages/Checks

- **Confirmation Review**, advise students:
  - on the new forms and how to use/adapt
- **If data collection is not complete**, ensure students:
  - inform participants of required GDPR info at next opportunity
  - use/adapt the new forms if they are yet to provide info sheets and complete consent forms
  - process personal data in line with GDPR
- **If data collection is complete**, ensure students:
  - anonymise/ pseudonymise data appropriately
  - comply with data security



**Comments and Questions?**