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
<table>
<thead>
<tr>
<th>GDPR terms</th>
<th>Research</th>
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<tbody>
<tr>
<td><strong>Data subject:</strong> persons whose personal data is collected, stored and used</td>
<td>Participants; Secondary data</td>
</tr>
<tr>
<td><strong>Personal data:</strong> identifiable data and info of data subjects</td>
<td>Participant personal information; participant identifier; non-anonymised participant data</td>
</tr>
<tr>
<td><strong>Anonymised data:</strong> non-identifiable data</td>
<td>Anonymised research data</td>
</tr>
<tr>
<td><strong>Special categories:</strong> sensitive personal data requiring additional safeguards</td>
<td>Info and data on ‘race’/ ethnicity, religion, TU membership, politics, biometrics/genetics, health, criminal records, sex life/ sexuality</td>
</tr>
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<tr>
<td><strong>Processing:</strong> collect, store, use or delete personal data</td>
<td>Collect, store, use and delete participant information; collect, store, analyse and delete participant data</td>
</tr>
<tr>
<td><strong>Legal basis:</strong> Lawful basis for processing which data subjects’ consent to and are informed of</td>
<td>‘necessary for a task in the public interest’ ‘collects and analyses sensitive data only necessary for research in the public interest’ (UREC)</td>
</tr>
<tr>
<td><strong>Data controller:</strong> organisation that determines purpose and means for processing</td>
<td>Usually ‘University of Sheffield’ although collaborations may have ‘joint controllers’ (with formal data sharing agreements) (UREC)</td>
</tr>
</tbody>
</table>
**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?