EFAMRO GDPR Guidance Checklist: *Informed Consent and Transparency Checklist*

The EU **General Data Protection Regulation** (GDPR) comes into effect across all EU Member States on 25 May 2018.

This Guide, prepared for EFAMRO member associations, sets out a checklist of steps to consider when seeking consent from research participants in a GDPR-compliant manner.

EFAMRO is providing this data protection guidance as general information for research practitioners. The GDPR also allows Member States to enact national positions in specific areas. National legislation should always be consulted for a complete picture on how data protection framework applies domestically.

This guidance is not legal advice and should not be relied upon as such. Specific legal advice should be taken in relation to any specific legal problems or matters.

Choosing to use consent

- ○ Ensure consent is the most appropriate lawful basis for processing the personal data
    - Is the personal data being collected directly from research participants?
    - Can participants actively and positively opt-in to the research?
    - Is another ground such as legitimate interests more appropriate?

- ○ Alternatively, if conducting research for private sector organisation, consider whether data collection can be conducted based on their legitimate interests (including commercial benefits)
    - Is the processing necessary to pursue the interests?
    - In balancing the interests of the organisation and participants are the fundamental rights and interests of the data subject adversely affected and how?

Asking for consent for research purposes

- ○ Allow participants to positively opt-in to provide consent e.g. signing a consent statement; providing oral confirmation; submitting a survey form

- ○ Use clear, plain language that is easy to understand

- ○ Obtain consent for each separate processing activity e.g. initial research; retention of details for re-contact; use of video, audio or photo images at a conference and ensure that participants do not have to consent to all to take part

- ○ Explicitly request consent to collect any sensitive personal data such as racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, genetic data, biometric data, data concerning health or data concerning a natural person's sex life or sexual orientation.

- ○ Check the suitability of the consent process for the individuals that will be using it.
    - For vulnerable adults – Have special arrangements been put in place? What steps will be taken to ensure appropriate level of participant understanding?
    - For children - Are there appropriate age=verification measures in place? Do you have suitable parental consent measures? Has the child consent form been written or communicated in a way that children can understand? Have separate information sheets been prepared for child and adult?
    - For visually impaired – Is the font size large enough? Can it be provided in a different format?

Asking for consent for scientific research purposes

- ○ Ensure the data processing meets scientific research purposes within the GDPR research regime such as technological development and demonstration, fundamental research, applied research or privately funded research.
- ○ Be as specific as possible in seeking consent (taking into account the state of knowledge about the research project at the time of starting data collection).
- ○ If possible, offer the opportunity to consent to certain areas of research or to parts of a research project

Asking for consent – Written

- ○ Make sure that written consent request is prominent and separate from any other terms and conditions to be provided to participants

Asking for consent – Verbal

- ○ Provide a clear script for interviewers, moderators and anyone else who may be seeking participant consent

Asking for consent – Digital/Online

- ○ Highlight prominently the digital/online consent request and ensure it is separate from other information provided to participants

Providing sufficient information to get consent

- ○ Provide (at the minimum) the following information to get informed consent:
    - data controller(s) identity and contact details – research agency and client where joint controllers and preferably allowing for different channels of communication (e.g. phone, email and postal address)
    - purpose of each processing activity that consent is being sought for
    - purpose of each processing activity that consent is being sought for
    - type of data to be collected and used
    - existence of the right to withdraw consent
    - information about the use of the data for decisions based on solely on automated processing, including profiling
    - possible risks of data transfers to third countries in absence of adequacy decision or appropriate safeguards

Communicating information transparently

- ○ Use effective layering and blending of the information to be provided to participants by
  - use of condensed notices supported by full notices so that some information is actively provided and some is made accessible to participants
  - use of different mechanisms to deliver information across both online and offline platforms such as videos, audios, infographics, icons, cartoons, emailed information, nominated individuals, FAQ's, information hubs

- ○ Actively provide participants with relevant names of those responsible for data collection and processing:
  - name of data controller(s) (could be both the research organisation collecting the data and the commissioning client)
  - name of client organisation (where personal data will be shared or they were the source of the personal data)
  - third parties who will rely on the consent

- ○ Actively provide participants with key required information including:
  - general subject of the data collection
  - purpose of the data collection
  - any sensitive data collection
  - whether the data will be recorded and/or observed
  - any guarantees on participant anonymity and/or confidentiality
  - length in minutes of data collection
  - costs likely to be incurred by the participant (if appropriate)
  - right to access data
  - right to withdraw consent

- right to object to processing
- re-contact details including when any re-contact will occur; the purpose and by whom
- possible risks details of any international data transfer to third countries in the absence of an adequacy decision and appropriate safeguards

○ Provide or make accessible other required information to participants including:

- who will administer any incentives, what it will be; when it will be received; any conditions attached
- generic contact details of data protection officer
- details of any data transfers
- retention period for data or criteria for retention
- right to lodge complaint with data protection authority
- right to port data (if automated data collection exercise)
- right to erasure of any personal data made public
- right to restrict processing
- right to rectify any data held

Recording consent

○ Keep a record to demonstrate when and how you got consent from research participants including:

- who consented (name of individual, or other identifier (e.g. online user name, session ID)
- when they consented (copy of dated document; online record with timestamp; note of time and date which was made at time of conversation)
- what they were told (master copy of document or data capture form containing consent statement used at time; record of scripts used in getting oral consent)

- how they consented (relevant document or data capture form; for online consent data submitted as well as timestamp to link to relevant version of data capture form; note of oral conversation but not necessarily a full record of conversation; audio recording of confirmation of the consent)
- whether they have withdrawn consent and if so when

Managing consent – general

- ○ Refresh existing consents if they do not meet the GDPR requirements or identify another legal basis for processing the data
- ○ Make it easy for individuals to withdraw their consent and provide details and publicise how to do so
- ○ Act on withdrawals of consent as soon as possible

Managing consent – panels

- ○ Put processes in place to refresh panel members consent at appropriate intervals, including parental/guardian consent for children
- ○ Provide panellists with access to privacy dashboards or other preference management tools
- ○ Provide clear terms and conditions including the conditions for collection of points or other incentives
- ○ Use appropriate recruitment processes for panellists with a separate opt-in for individual research projects

Founded in 1992, EFAMRO represents the interests of market, social and opinion research in Europe. Its members are national trade associations for research businesses.

For further information on EFAMRO and its activities, contact Dr Michelle Goddard, Director of Policy and Communication.

EFAMRO
Bastion Tower, level 20 Place du
Champ de Mars 5, B-1050 Brussels

T : +32 (0)2 550 3548

www.efamro.eu

F : +32 (0)2 550 3584

E : michelle.goddard@efamro.eu