

Principles for Conducting Research in Family Carers Ireland

As an organisation that supports family carers, it is essential that the research work carried out by, on behalf of or in partnership with Family Carers Ireland does not cause harm or distress for any carer participating in a research study. Therefore, the following principles shall be applied to all research conducted by, on behalf or in partnership with the organisation:

- Respect
- Consent
- Anonymity, Confidentiality & Privacy
- Data Security
- Promoting involvement of carers
- Accessible

External researchers who wish to conduct research with carers in Family Carers Ireland's network reach must demonstrate how they will incorporate these principles into their own research projects.

Respect

Family Carers Ireland recognises that we have a responsibility to ensure the physical, social and psychological wellbeing of research participants or PPI contributors is not adversely affected by our research programme. We will strive to protect and respect the rights and dignity of those participating in research activities as well as their wellbeing and privacy. This includes avoiding the over-researching of members of Family Carers Ireland. We also strive to protect and respect the right to confidentiality of the person requiring care in all research activities.

Family Carers Ireland also tries to ensure that research methods, tools and research materials used are appropriate to the participants and are respectful of their needs, priorities and privacy.

Consent

Family Carers Ireland will ensure that the recruitment of research participants is based on freely given, informed consent and in line with GDPR requirements. Family Carers Ireland will explain, in appropriate detail and in terms meaningful to all potential research participants what the research is about, who is undertaking and financing it, why it is being undertaken and how it will be disseminated and used.

Family Carers Ireland recognises that research with children requires particular care. Where research involves young carers under the age of 18, the consent of a parent or responsible adult will be obtained for the participation of the child in a research study. The assent of the child will also be sought.

Research participants will be made aware of their right to refuse or withdraw their participation whenever and for whatever reason. Participants will be made aware that they are not obliged to take part and this includes the right to withhold answered a specific question or element of a questionnaire.

Anonymity, confidentiality and privacy

The anonymity and privacy of all those taking part in Family Carers Ireland research will be respected and personal information regarding research participants will be kept confidential. Family Carers Ireland has a duty of care to take steps to protect those taking part in any of our research studies or



another individual, if they are considered to be at risk of significant harm or danger. The limits of confidentiality should be outlined with all participants before the commencement of any research activity. This should also be explicitly stated in information sheets and consent forms given to all research participants.

Data security

Appropriate measures must be taken to ensure that all data is stored securely in line with Data Protection Legislation and Family Carers Ireland Privacy Policy. Family Carers Ireland has full regard for its obligations under Data Protection and GDPR legislation on the appropriate security measures to be taken against unauthorised access to or alteration, disclosure or destruction, of personal data.

Promoting involvement of carers in research

Patient and Public Involvement (PPI) is becoming increasingly important in how health research is conducted. While PPI activities can be empowering for individuals, there are tensions and risks, including exploitation and the burden and resource implications can be considerable. Family Carers Ireland will reflect on how to work with carers ethically, considering carer burden, equity and power, fair and respectful arrangements, confidentiality as well as processes and consequences of any data collected or stored.

Accessible

Family Carers Ireland recognises that our research outputs are relevant for a wide range of people. This includes the research participants, the wider carer and civic society community, service providers, stakeholders within the broader health and disability services sector and decision and policy makers at organisational, local and government levels. Family Carers Ireland will therefore endeavour to disseminate our research findings and recommendations in as wide of a variety of ways, across different formats, platforms and languages, where appropriate.