

GUIDANCE NOTES FOR ETHICS IN RESEARCH

‘...the well-being of the human subject (sic) should take precedence over the interests of science and society’ World Medical Association Declaration of Helsinki, (2000); Article 5

The purpose of the ethics committee is to protect and safeguard the rights and interests of the service users

The researcher must respect the dignity, rights, safety and wellbeing of all services users and guard against any negative consequences of participation in the research

Ethical research principles are well documented in professional codes of ethics

*The research proposal must be submitted to the ethics committee **before recruitment commences.***

Consent to participate must be informed, voluntary and free from deception

*Consent should be obtained from the participant themselves in so far as possible and where this is not possible. Where the person is deemed ‘incapable’, **consent must be sought in addition from parent/guardian***

The right not to participate has to be made clear to the person and that it will not affect their level of service

People with intellectual disability are often an ‘overrepresented’ group in research so it is important that the same people are not constantly approached to participate in research projects.

It is incumbent on all researchers to be familiar with documentation on rights for individuals with disabilities and up to date data protection legislation

All researchers are required to have Garda clearance or equivalent from their course institute.

Central files on children or adults must only be accessed with permission from their immediate supervisor.

The foundation’s file policy must be consulted.

Note St Josephs Foundations holds the health and well being of it service users extremely highly. With this fact in mind St Josephs Foundation has developed a policy inhibiting the inclusion of service users regularly within surveys or studies. To this end a service user may not be included in a study if they have participated in one in the previous 2 years.