FAMILY ENGAGEMENT IN RESEARCH (FER): A GLOSSARY

This glossary is intended to support communication between researchers and family members that are partnering in research. It's normal for some family members to feel a bit lost in the jargon and slang researchers use regularly in their line of work. This document is not meant to be exhaustive or authoritative and some terms may require further explanation from a member of the research team. This glossary is just a starting point for partners to develop a shared language.

FER GLOSSARY

ETHICS

REB	A research ethics board (REB), Institutional Review Board (IRB), is an independent committee made up of medical and non-medical members, such as doctors, researchers, and community advocates. It ensures that a clinical trial is ethical and that the rights of study participants are protected.
INFORMED CONSENT	A process by which a participant or legal guardian voluntarily confirms his or her willingness to participate in a particular study, after having been informed of all aspects of the study that are relevant to the participant's decision to take part in the clinical trial. Informed consent is usually documented by means of a written, signed, and dated informed consent form, which has been approved by an REB/IRB (see above).
CONFIDENTIALITY	A research condition in which no one except the researcher(s) knows the identities of the participants in a study. It refers to the how the information that a participant has told to the researcher will be handled, with the expectation that it will not be revealed to others in ways that violate the original consent agreement, unless permission is granted by the participant.
ANONYMITY	A research condition in which no one, including the researcher, knows the identities of research participants.

FER GLOSSARY

ROLES

PI (PRINCIPAL INVESTIGATOR)	Person responsible for the management of the study conduct and subjects.
CRC (CLINICAL RESEARCH OR STUDY COORDINATOR)	The person that handles the administrative and day-to-day responsibilities of a clinical trial and acts as a liaison for the clinical site. This person may collect the data or review it before it is entered into a study database
PARTICIPANTS	Individuals who are the object of study in a research project.
PFAC (PATIENT AND FAMILY ADVISORY COUNCILS)	A productive way for patients and families to partner with a healthcare system to provide guidance on how to improve the patient and family experience.s.

FER GLOSSARY

DESIGN

QUALITATIVE	A research design in which the researcher explores relationships using experiences and words, rather than numbers. Examples include interviews, focus groups and observations..
QUANTITATIVE	A resarch design in which the researcher explores relationships using numeric data. Survey is generally considered a form of quantitative research.
MIXED METHODS	The use of a combination of research methods (e.g., both qualitative and quantitative methods) in a study. An example of mixed methods would be a study that included surveys, interviews, and observations. A common approach is to use qualitative methods (e.g., interviews with participants) to help explain quantitative results (e.g., numerical results from a survey).

FER GLOSSARY

METHODOLOGY

METHODOLOGY	A theory or analysis of how research does and should proceed.
POR **(PATIENT ORIENTED RESEARCH)**	A type of research in which patients play an vital role in the research team, is based on an understanding that people with lived experience of an illness usually have a good idea of what their health care needs are or how they would like to improve their quality of life.
PAR **(PARTICIPATORY ACTION RESEARCH)**	A type of research that differs from most other approaches to public health research because it is based on reflection, data collection, and action that aims to improve health and reduce health inequities through involving the participants who, in turn, take actions to improve their own health.
ASSUMPTIONS	Statements that are taken for granted or are considered true even though they have not been scientifically tested.
EMANCIPATORY RESEARCH	Research that is conducted on and with people from marginalized groups or communities. It is led by a researcher who is either an indigenous or external insider; and is done largely for the purpose of empowering members of that community and improving services for them. It also engages members of the community.
BIAS	A type of error in the use of research methods. It can appear in research via how the sampling was done or at other stages in research, such as while interviewing, in the design of questions, or in the way data are analyzed and presented. Bias means that the research findings will not be representative of, or generalizable to, a wider population.
TOKENISM	The practice of making superficial or symbolic efforts to engage communities or patients.

FER GLOSSARY

METHODS (1/4)

METHODS	Systematic approaches to how an operation or process is completed. It includes steps, procedures, application of techniques, amont other requirements, depending on the subject being studied.
CASE STUDY	The collection and presentation of detailed information about a particular participant or small group, frequently including data obtained from the people themselves.
FOCUS GROUPS	Small, roundtable discussion groups who look at specific topics or problems, including possible options or solutions. Focus groups usually consist of 4-12 participants, guided by moderators to keep the discussion flowing and to collect and report the results.
CLINICAL TRIAL	An investigation of a drug for use in humans that involves human subjects and that is meant to discover or verify the effects of the drug, identify any adverse events in respect of the drug, study how a human body processes the drug, or to discover the safety of the drug or how well it works.
PLACEBO	A drug or treatment that looks the same as the active drug but without the medicinal ingredient that is given to a group of trial subjects.

FER GLOSSARY

METHODS (2/4)

RANDOMIZED CONTROL TRIAL	A study in which the participants are divided by chance into separate groups that compare different treatments or other interventions.
CLUSTER ANALYSIS	A method of research where data that share a common trait are grouped together. The data is collected in a way that allows the data collector to group data according to certain characteristics.
COHORT ANALYSIS	A study that is based on groups. Group members share a particular characteristic [e.g., born in a given year] or a common experience [e.g., entering a college at a given time]..
AFFECTIVE MEASURES	Procedures or devices used to obtain measurable descriptions of an individual's feelings, emotional states, or personality.
HYPOTHESIS	A tentative explanation based on theory to predict a causal relationship between variables. Research questions often involve hypotheses that can be tested using an experimental design, such as a randomized control trial.

FER GLOSSARY

METHODS (3/4)

DOUBLE BLIND	A trial where both the investigators and the trial subjects don't know which treatment is given.
TREATMENT FIDELITY	The ongoing assessment, monitoring, and enhancement of the reliability and validity of a study.
SAMPLE	The population researched in a particular study. Usually, attempts are made to select a "sample population" that is considered representative of groups of people. For example, if the research has to do with a specific health condition, a portion of people with the health condition would be selected to be a part of the study.
ELIGIBILITY CRITERIA	List of characteristics that help decide which participants should be a part of the study. The characteristics describe both factors that include or exclude a participant (e.g. include participants must be between 55 and 85 years old; exclude those who took drug a certain medication three month prior to the study).
TREATMENT CONDITIONS	In experimental design, these are the different treatments received by each group involved in the study. For example, in an experiment examining the effects of four different drugs on dreaming, research participants or subjects would receive a different drug in each treatment condition.

FER GLOSSARY

METHODS (4/4)

CONTROL GROUPS	The group in an experimental design that receives either no treatment or a different treatment from the experimental group. This group can then be compared to the experimental group.
DATA	Measures, scales, questionnaires and surveys that collect information and that are recorded throughout a study. Data could also include other media such as video, audio, or written transcripts from interviews.
VARIABLE	Any characteristic or trait that can vary from one person to another [race, gender, academic major] or for one person over time [age, political beliefs].
PROTOCOL	A document that describes the objective(s), design, methodology, statistical methods, and organization of a trial.
PROTOCOL AMENDMENTS	A written description of a change or changes to a protocol.

FER GLOSSARY

RESULTS AND DISSEMINATION (1/2)

KNOWLEDGE TRANSLATION	A process that includes the summary, distribution, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system. More simply, it's taking knowlege and turning it into action.
OPEN ACCESS	In publishing, refers to freely available, digital, online information.
FACILITATION	A technique where a person makes things easier for others, by providing support to help them change their ways of thinking and working.
TARGET AUDIENCE	The group of people you want to reach with your message.
PEER REVIEW	The process in which the author of a book, article, or other type of publication submits his or her work to experts in the field to check for quality and importance, usually prior to publication. This is standard procedure in publishing scholarly research.
EFFICACY	Indication of whether a treatment is able to treat or prevent a given medical condition.
RELIABILITY	The degree to which a measure yields trustworthy results. If the measuring instrument [e.g., survey] is reliable, then administering it to similar groups would yield similar results. Reliability is required for validity.

FER GLOSSARY

RESULTS AND DISSEMINATION (2/2)

GENERALIZABILITY	The extent to which research results can be applied to the population at large (which includes those who weren't part of the study).
STATISTICAL SIGNIFICANCE	The probability that the difference between the results of the control and experimental group are great enough that it is unlikely due solely to chance.
EFFECT SIZE	The amount of change in an outcome variable that can be attributed to changes in the predictor variable. A large effect size exists when the value of the outcome variable is strongly influenced by the predictor variable.
PRACTICAL SIGNIFICANCE	While statistical significance tells us whether there is a relationship between variables, practical significance tells us the extent to which the effect of the relationship between variables is meaningful.
CAUSALITY	The relation between cause and effect.
CORRELATION	A non-cause and effect relationship between two variables.
CAUSAL RELATIONSHIP	The relationship that shows that a predictor variable, and nothing else, causes a change in an outcome variable. It also establishes how much of a change is shown in the outcome variable. In other words, it shows that one thing has caused the outcome and nothing else can explain the outcome.

FER GLOSSARY

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ACKNOWLEDGEMENTS

This glossary was compiled and designed in 2019 by Ariel Taylor, Marion Knutson, and Jeff McCrossin as a part of McMaster University's Family Engagement in Research Program, which brings together researchers and parents in the same course with the aim of increasing capacity for partnering together in research projects.

For more information:

https://www.canchild.ca/en/research-in-practice/current-studies/family-engagement-in-research-course