

Research glossary

Research is a language of its own. Learn how to speak ‘research’ with this glossary. Whether you are a person affected by dementia or someone curious about this field, our glossary provides clear explanations to help you navigate through the complexities of research studies. Dive in and explore the world of dementia research with confidence!

Active / experimental group: Many clinical trial studies separate participants into at least two groups: the active (or “experimental”) group will receive the intervention being examined (for example, a new drug), while the other “control” group receives a placebo.

Biomedical research: A type of research that focuses on understanding the causes, treatments and possible cures for diseases. For example, biomedical research might focus on determining the safety of a disease-modifying t for dementia.

Case study: Research that involves a very small number of participants who are studied in detail. This can be a starting point for a larger research study that would involve more participants, but generally cannot reveal anything about cause and effect.

Clinical trial: A research study focused on determining on how well a treatment, procedure, drug or care practice works on a specific group of people.

Cohort study: Research that tracks two or more groups over time to see how different factors impact their health and other experiences. For example, there might be two groups of people with similar characteristics except that one group is living with dementia and the other is not. A cohort study might examine how their experiences of growing older are similar and how they might be different over a two-year period.

Community-engaged research: When researchers and community members come together to address a problem or issue that community members have identified. People affected by the research issue, like people affected by dementia, are involved in planning, conducting and using the research findings.

Control group: A group in a clinical trial study that will be compared to the “active/experimental” group. The control group may receive a placebo (e.g., a sugar pill), the normal treatment for the condition being studied or no intervention at all. This group provides a comparison to determine whether changes in the experimental group are a result of the intervention itself (e.g., a drug) or due to other factors.

Correlation: This means there is a relationship between two variables, whereby when one variable changes, the other tends to change as well in a specific way. Importantly, this does not mean that one of them is the reason the other changes, only that the two variables are related in some way. Often more research is needed to explain the nature of the relationship. For example, when ice cream sales go up, so do sunburns. There is a correlation between ice cream sales and sunburns, however, it is sunny weather that is the real cause of both changes.

Dependent / independent variable: A dependent variable is what researchers measure to see the potential effects of the independent variable. An independent variable is the factor that researchers modify or control in a study to see how it impacts other variables.

Double-blind study: Using this research design, neither the participants nor the researchers know if a participant is in the active group or control group during the study. This ensures that the results aren't influenced by the researchers treating participants differently based on group.

Efficacy: Refers to how well a drug, treatment or intervention worked under controlled conditions, such as a clinical trial. It measures the degree to which the intervention causes the intended outcomes.

Inclusion / Exclusion criteria: The specific attributes or characteristics that determine who can participate (inclusion) and who cannot participate (exclusion) in a research study. These criteria help researchers select participants who best represent the population being studied and ensure the safety and integrity of the research.

Intervention study: A type of study where the focus is on determining whether a change or treatment is acceptable, feasible, and/or effective. For example, researchers might conduct an intervention study to determine whether engaging in cardio-focused exercises for 20 minutes a day, 4 days a week for 6 months improves cardiovascular health in women aged 60 years and older.

Informed consent: When participants receive clear information about a research study before deciding to either take part or decline participation. This includes understanding the purpose of the research, what will happen during the study, privacy and security measures, the ability to leave the study at any time for any reason, and the potential risks and benefits from participating. Participants will often document their informed consent by providing a signature and in some cases, verbal consent.

Like informed consent, **informed assent** is applicable in situations where a person living with a cognitive impairment is being invited to participate in a research study. Additional steps are taken to ensure that the person understands as much as possible about their potential

participation. Often times a family caregiver or substitute decision-maker will help to decide whether participation in research is in the person's best interest.

Knowledge mobilization: Sometimes referred to as “knowledge translation,” the process by which research findings are shared in such a way that it helps policymakers, practitioners, and the public understand and apply them.

Literature review: A published synthesis of all the important information that has been written on a specific topic, often during a specific period (e.g., literature published between 1990-present). By conducting and publishing a literature review, patterns and similarities across studies focused on the topic can be identified, helping to form evidence-based conclusions.

Meta-analysis: A research method whereby researchers combine the results from different studies examining the same topic. By analyzing all the data together, researchers can identify patterns and differences within diverse sample populations.

Meta-synthesis: Similar to a meta-analysis for quantitative research, a meta-synthesis. A summary of qualitative studies, that uses a rigorous process to draw conclusions from data gathered in multiple studies.

Methods: Used in research to refer to specific processes and strategies that direct a study. This includes how to frame the research questions, how to gather and analyze data, and how to interpret data. Certain fields of research tend to use certain types of methods to conduct research.

Open-label extension / study: A type of clinical trial study where both the researcher and research participants know which treatment or intervention is being given. Unlike “blind” or “double-blind” research studies, an open-label study is often used when it is either unethical or unavoidable to “blind” participants to the intervention. For example, if a research study was focused on an exercise program to help prevent falls among older adults, participants would know they are receiving the intervention.

Participatory action research (PAR): A research approach that prioritizes the experiences of those impacted most by a particular phenomenon. Often used within social justice and action-oriented research and initiatives, PAR works to build community and shared understanding of an issue to evoke emancipatory social change.

Patient-oriented research: A research approach that engages patients and their caregivers as co-collaborators to ensure that the outcomes produced from the research process are patient- and/or caregiver-focused.

Placebo: A substance or treatment that has no therapeutic effect. Researchers give some participants the treatment being studied, like a new medication, and others the placebo, which looks the same, but does nothing. By comparing people on the real treatment compared to those in the placebo, researchers can see if the treatment works.

Quality of life research: This type of research looks at how to improve quality of life for people living with dementia and their care partners through various interventions and strategies, including symptom management and health-care system research.

Qualitative research: A domain of researcher that gathers information about people's thoughts, feelings and experiences by talking to them, observing their behaviours and analyzing texts.

Quantitative research: A domain of research that collects and analyzes numerical data to find patterns, relationships and trends.

Quasi-experimental: A research design that aims to evaluate the effects of an intervention or treatment but does not randomly assign participants to an experimental or control group.

Randomized controlled trial (RCT): A research study designed to determine how well a new treatment or intervention works on a specific group of people. This type of research is considered the gold-standard because it randomly assigns people into two groups for comparison purposes: the active group and the control group. This way researcher can determine whether differences in the two groups were caused by the treatment or intervention.

Sample population: The small number of people from the population being studied that take part in the study. The sample is chosen to represent the larger population.

Statistical significance: A way for researchers to determine whether the results of their study are meaningful (e.g., correlation or causation is found between variable(s)) and not due to random chance. Importantly, while statistical significance is an important indicator and often leads to more research, it does not necessarily mean that an intervention works outside of the conditions of the research study.

Systematic reviews: A comprehensive summary of existing research on a particular topic, where researchers carefully gather and analyze all the available evidence from high-quality studies to draw conclusions about that topic. Systematic reviews follow specific guidelines and typically focus on research that has been published between a certain time frame (e.g., 1990-present).

Types of studies

When deciding which studies might be a good fit for your interests and experiences, it can be helpful to consider different types of studies.

