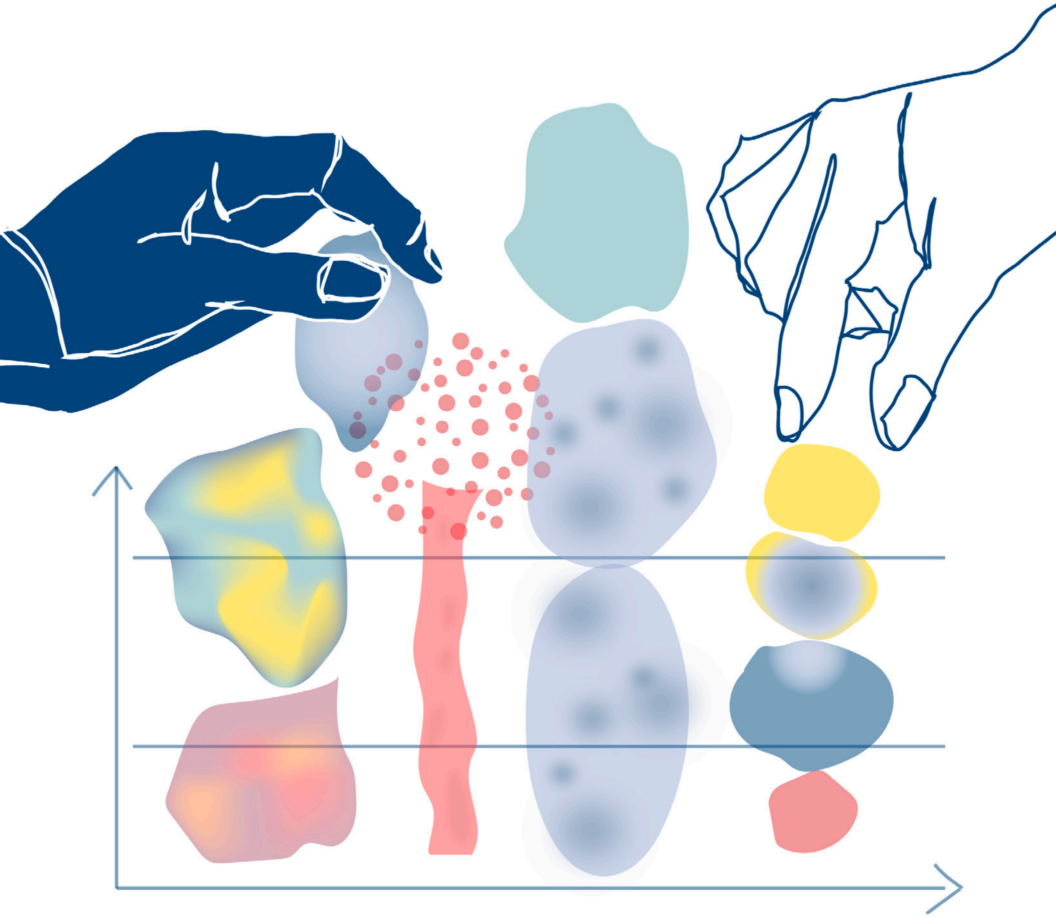
Collaborative minds

Shaping biomedical research with your lived experience of dementia



Acknowledgements

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Who is this guide for?

This guide is for people living with dementia and care partners who are curious about contributing to biomedical research beyond being a study participant. It explores how you can take on a collaborative role in research by sharing your expertise as someone with lived experience to help shape research projects.

Research plays an important role in improving the lives of people affected by dementia. Sharing your perspectives can help research better reflect outcomes that will matter to people like you. You don’t need a background in science to contribute meaningfully to research; your insights and experiences make your contributions valuable.

What is dementia-inclusive research?

Dementia-inclusive research engages people with lived experience as collaborators and advisors, offering opportunities for shared decision-making throughout the research process.

Dementia-inclusive research:

- Values your experience, knowledge and perspective.
- Offers opportunities to contribute in different ways.
- Recognizes that your capacity may change over the course of a research project and adapts accordingly.

What is biomedical research?

Biomedical research investigates the causes of dementia, as well as ways to reduce risk, slow disease progression and develop potential treatments. Researchers may work with people, animals or cells. Questions biomedical research might try to answer include:

- How does the brain change in the early stages of dementia?
- Can a blood test detect dementia earlier and make diagnosis more accessible?
- How do sleep-related changes influence brain health?

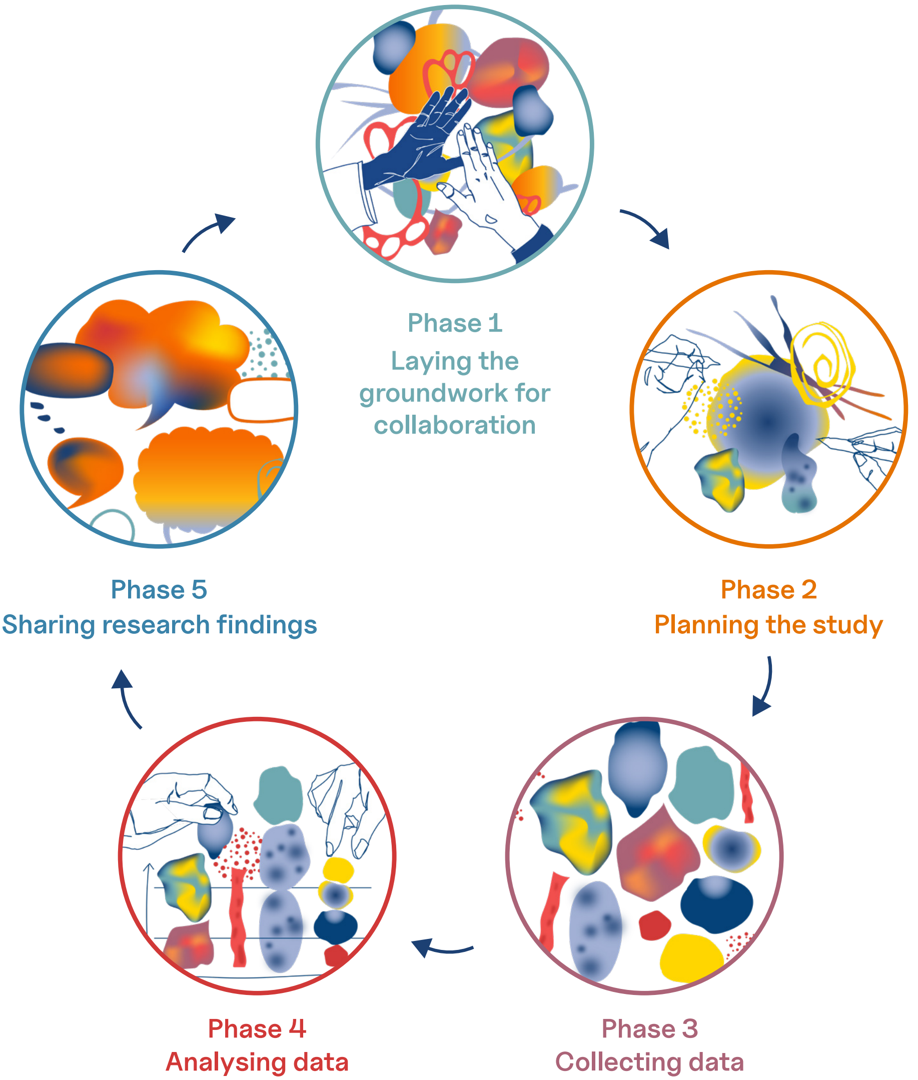
How to use this guide

This guide identifies five key phases of the biomedical research process. Each phase highlights ways you might get involved and things to consider along the way. You don't have to take part in every phase — ichoose what feels right for you.

Researchers are also working to support your involvement. This is one of two companion resources — ithe other is designed to guide biomedical researchers on how to meaningfully include people affected by dementia in their projects.

> **"I do not think there is any part of [the research] timeline...where a person with lived experience would not provide value."**
>
> - Researcher

Biomedical research lifecycle



The information in this guide is organized by phases, where each one informs the next and outlines how you can make meaningful contributions at every point in the research process.

PHASE 1

Laying the groundwork for collaboration

This is a time to explore your interest in biomedical dementia research. You don't need to decide right away to join a project. Instead, this phase is about fostering your curiosity, building relationships and learning what types of projects might interest you.

If you are curious, you might:

- Learn about different ways people with lived experience collaborate in research. Explore examples on our resources webpage linked below.
- Find opportunities to engage with research, such as open labs, public talks, newsletters or webinars.

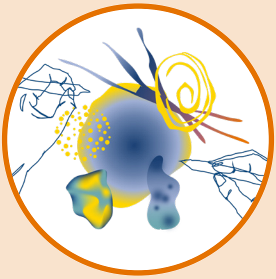
Things to consider:

- What areas of biomedical research spark my interest?
- What do I need to know before deciding whether collaboration feels right for me?
- What can I share with researchers so they understand the level of involvement that feels right for me or the person I support?

Don't know where to get started? Scan to learn more. You can also visit alzbc.org/cmle or call 1-800-667-3742.

PHASE 2

Planning the study



This phase includes deciding what questions to explore and what methods and resources are needed. Researchers then prepare a funding proposal, which may take several months to be evaluated. If successful, researchers submit their study to an ethics board, a group that helps protect the rights, safety and well-being of participants.

You might:

- Share perspectives on research questions.
- Identify ethical, practical or cultural considerations.
- Review materials to ensure they are easy to understand.
- Support recruitment through personal networks.

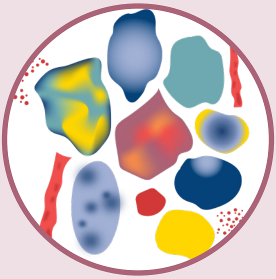
Things to consider:

- Do I understand my role and what's expected of me?
- How would I like to be compensated for my time (for example, an honourarium)?
- Have I shared when and how it's best for me to meet?
- Am I comfortable with the technology being used and do I have the support I need to take part?
- Do I understand how expenses — including transportation or respite caregiving — will be covered?

It's always OK to ask questions or adjust your involvement as needed. Just let the team know!

PHASE 3

Collecting data



In this phase, researchers run experiments and gather data to answer their research questions. In human studies, data collection can take months and even years. In non-human studies, such as those using animals or cells in a lab, the research team determines the procedures and timelines can vary.

You might:

- Review materials for study participants, such as instructions, consent forms or questionnaires, for clarity and ease of use.
- Advise on how the data collection experience could be improved for incoming study participants.
- Learn about non-human laboratory methods.

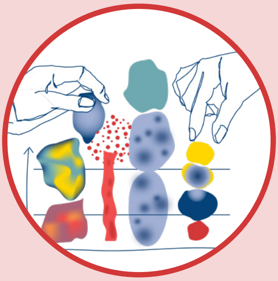
Things to consider:

- How can I use my experience of dementia to help the researchers understand how study participants will feel about the process?
- Do I have questions about the data collection methods being used?

The research team should keep you informed about timelines and progress.

PHASE 4

Analysing data



Researchers organize and review the data to look for patterns and understand the results. It may take time to gather enough data before results can be shared and interpreted meaningfully. When ready, the research team can discuss the findings in accessible ways and answer questions so you feel comfortable sharing your perspective.

You might:

- Reflect on what the results might mean for people affected by dementia, such as whether the findings connect with real-world experiences, priorities or needs.
- Identify what feels surprising, unclear or incomplete and suggest where more explanation might help.
- Suggest new questions or directions for future research.

Things to consider:

- Do I understand the findings well enough to share my perspective or do I need more information and support from the research team?
- How does my lived experience help me understand or interpret the results?

> **"Insight comes from the perspective of individuals, and you don't know that perspective until you sit together and talk."**
>
> \- Person living with dementia

PHASE 5

Sharing research findings

In this phase, researchers share what they have learned with the broader community. This can be through infographics, webinars, conference presentations and other forms of knowledge sharing. Your lived experience can help shape how findings are communicated so they are clear, relevant and accessible to people affected by dementia.

You might:

- Help identify key messages that matter.
- Co-develop or review accessible, non-technical research summaries or visuals to support understanding.
- Help decide where and how findings are shared.
- Co-present at conferences or public forums.

Things to consider:

- Which audiences most need to see this research?
- How would I prefer to take part in sharing findings?
- How would I like to be recognized or acknowledged?

> **“There’s a lot of people who don’t know anything about research, like I didn’t before, who might like it and become involved.”**
>
> - Person living with dementia

Your voice matters

However you choose to collaborate in research, your perspective is valuable. Lived experience offers insights that data alone can't provide, helping researchers stay focused on what matters most.

Contact us

🌐 alzheimerbc.org

✉ research@alzheimerbc.org

☎ 1-800-667-3742

📍 Alzheimer Society of BC and Yukon
300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

Scan to view the researcher guidebook and other *Collaborative minds* resources or visit: alzbc.org/collabminds

First Link® Dementia Helpline

If you are living with dementia or have questions about the disease, call the First Link® Dementia Helpline at 1-800-936-6033. The Helpline is available Monday to Friday, 9 a.m. to 8 p.m.

Call 1-833-674-5003 for support in Punjabi, Hindi or Urdu and call 1-833-674-5007 for support in Cantonese or Mandarin (both available Monday to Friday, from 9 a.m. until 4 p.m.). For support in the Yukon, call 1-888-852-2579 (Monday to Friday, 10 a.m. to 8 p.m.).

Learn more: alzbc.org/fldhl

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