

# **Stronger Research, Together: a guide**

- video links and summaries for people with  
a living or lived experience of dementia

# Introduction to research

- + This training is designed to answer questions you might have about being research to help you decide whether you'd like to get involved in research in ways that inform how research is designed and implemented.
- + This training is set up as a series of videos that you can watch in any order and stop and start them as you wish.
- + People with a living or lived experience of dementia bring unique and essential insight to research.
- + Your involvement helps make research more practical, respectful, and real.
- + Dementia Australia and Dementia Australia Research Foundation support Dementia Advocates and researchers to meaningfully and successfully collaborate.

**Watch the full video →**



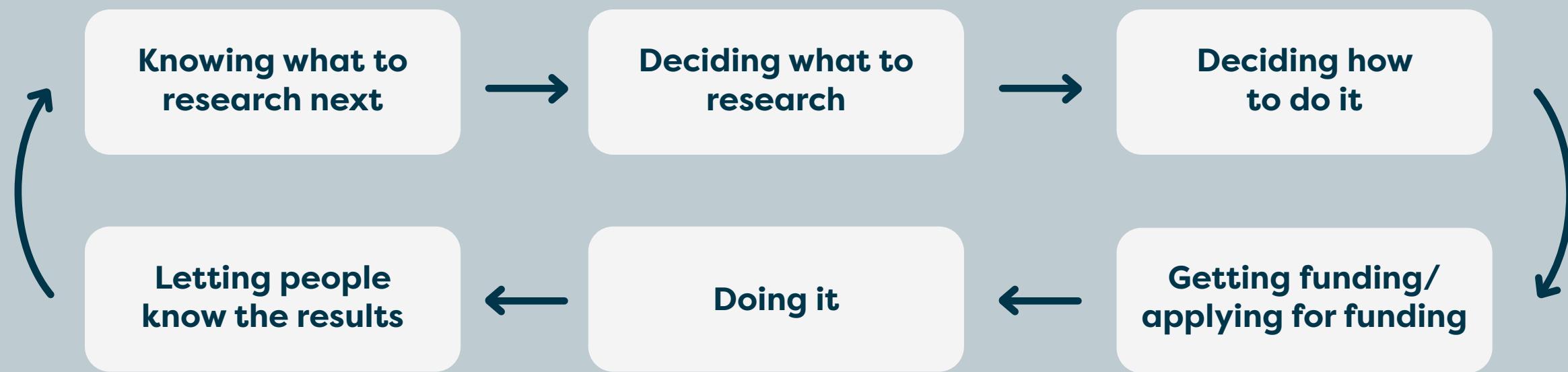
# Involvement in research

- + Being involved in research and participating in research are different.
- + Participating in research involves providing your data in some way (responding to a survey, providing a blood sample), but being involved in research means influencing what is researched, how it's researched and how to let people know about the results.
- + Your lived or living experience expertise brings purpose and practical insight to the research and helps researchers better understand what it is like for people living with dementia and their carers.
- + You don't need to be a research expert to be involved, your lived or living experience of dementia is your expertise.
- + Being part of a research team can be empowering.
- + It's your right to be included in decisions that affect you and your community.

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# Understanding the research cycle



- + Research is a cycle, and your perspectives are important at every stage.
- + All contributions – big or small – help make research more meaningful and effective.
- + Your insights help shape a project from the very beginning and can strengthen funding applications and study design.
- + Your involvement in how research is done, can make the experience better for those who participate in research studies.
- + You can ensure that important study findings are accessible to people who aren't scientists.

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# Different research roles

- + The role you play in the research will be based on the type of research project or the stage of the project. It might also be based on your interests and specific the living or lived experience you bring.
- + Some of the tasks that you might do in a research role include;
  - + being part of discussions that help decide research priorities
  - + identifying aspects of a study design that aren't practical
  - + providing feedback on a plain language summary for a funding application
  - + being a member of an Advisory panel or Steering committee
  - + improving clarity and accessibility of research documents
  - + co-designing resources or tools
  - + co-presenting findings at conferences
  - + being an Associate or Chief investigator

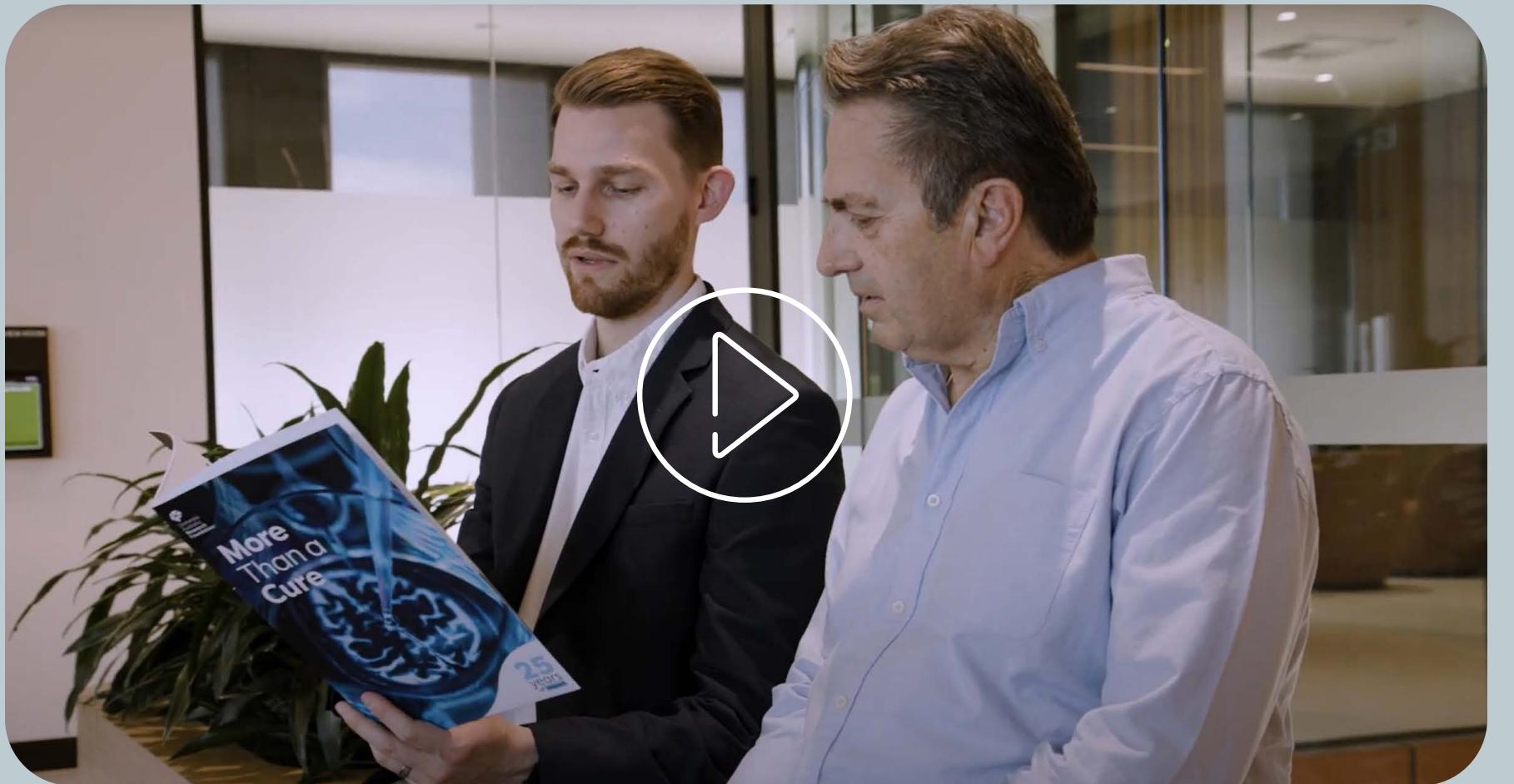
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# Getting started

- + Dementia Australia are always there to support you and can connect you with researchers.
- + It is good to choose projects that align with your interests, values, or personal experiences.
- + Think carefully about the topic, time commitment, and the role you're being asked to take on.
- + It's okay to say no to any invitation, change your mind at any time or walk away from projects that don't feel right or respectful.
- + Researchers should take time to build a relationship with you so they can find out how best to communicate and support your involvement.
- + Researchers should be clear about what stage their research project is at and what sort of lived or living or experience involvement they are looking for.
- + Preparation helps all those involved: you might need to review agendas, notes, and past minutes before any meetings.

**Watch the full video →**



# Support and advice

- + Stay informed: ask questions if you're unsure about your role or project updates.
- + Researchers should clearly explain your role, time commitment, and any payment or recognition.
- + Be upfront about your needs, availability, and preferred level of involvement and honest about your strengths, interests, and limitations.
- + Dementia Australia are always there to support you if you need to discuss something about the research or need to have a difficult conversation with a researcher.
- + Choose roles that fit your life, energy, and priorities; you don't need to say yes to everything and it's okay to step back if the commitment becomes too much.
- + Recognition matters: this can include acknowledgements in publications, gift cards, or covering expenses.
- + Value your own expertise: your lived experience shapes and strengthens research.

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