

# COLLABORATE GATHER SHARE



A Workbook towards dementia-friendly research

Alzheimer Society  
BRITISH COLUMBIA

Health  
Design  
Lab.  
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# Introduction

In dementia research, there is a growing emphasis on generating meaningful research collaborations with people with lived experience of dementia. Researchers are continually developing practices that engage participants with lived experiences using participatory methods to generate shared knowledge. This workbook brings attention to how these participatory practices have been realized by research practitioners, in order to extend our understanding of participation by considering how people with lived experience can contribute to research beyond their role as participants.

How current leaders in dementia research understand the role of participation informs not only how we engage in participatory practices but also how we make space for people with lived experience to take on roles as research leaders and collaborators. As such, this workbook hopes to foster a culture of collaboration over participation, whereby people with lived experiences are invited to join research teams as co-researchers, collaborators, leaders, and initiators to develop dementia-friendly practices.

## Dementia-friendly research

Dementia-friendly research recognizes the expertise that people with lived experiences bring to research to meaningfully engage people affected by dementia before and throughout a research study. The goals of a dementia-friendly research aims to collaborate with people living with dementia by:

- Collaboratively developing research goals and questions
- Inviting people with lived experience to take on advisory and co-researcher roles during the study
- Committing to accessible knowledge mobilization after the study is completed
- Ultimately resulting in better outcomes, services and resources for people living with dementia based on their needs and experiences.

In this workbook, **people with lived experiences** refers to those who have experience living with dementia as well as those who provide care to people living with dementia. People with lived experiences contribute unique knowledge, insights, and perspectives to a research project to the make the process sensitive to needs of research participants.

## How did we get here?

The content of this workbook is derived from a participatory research study (referred to as a workshop dialogue) that took place in collaboration with the Health Design Lab at Emily Carr University of Art + Design, the Alzheimer Society of B.C. and two researchers, Dr. Gloria Purveen (University of British Columbia) and Dr. Jodie Gawryluk (University of Victoria). A group of interdisciplinary researchers, practitioners and people with lived experiences were invited to this participatory study to share their experiences and together:

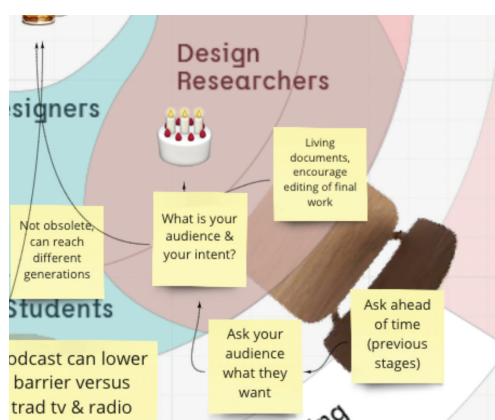
- 1) Explore existing interdisciplinary research practices, tools and strategies that promote partnerships with people with lived experience to amplify their knowledge and foster inclusivity in research.
- 2) Identify gaps and opportunities to further develop person-centered and collaborative research tools and practices.

Through this workbook we share insights and knowledge generated from this study to create an opportunity for you, our readers, to reflect on your own practices and find moments of collaboration towards mutual learning. Most importantly, we hope that you can recognize the value that people with lived experience bring and that they are the real experts in a research project.

### Workshop dialogue

The workshops that took place as part of a larger study to foster dementia-friendly research are part of an ongoing and generative dialogue that will be built throughout this project. In order to highlight its generative nature, this study will be referred as a **workshop dialogue** moving forward.

The workshop dialogue took place virtually as part of the Dementia Lab Conference in January, 2021. Thirty-eight participants gathered from different parts of the world to attend these sessions. The workshops were designed to invoke the feeling of a gathering around a table. This was represented by visual cues depicted on an interactive online platform and the use of prompts to encourage participants to share their experiences, expertise and knowledge.



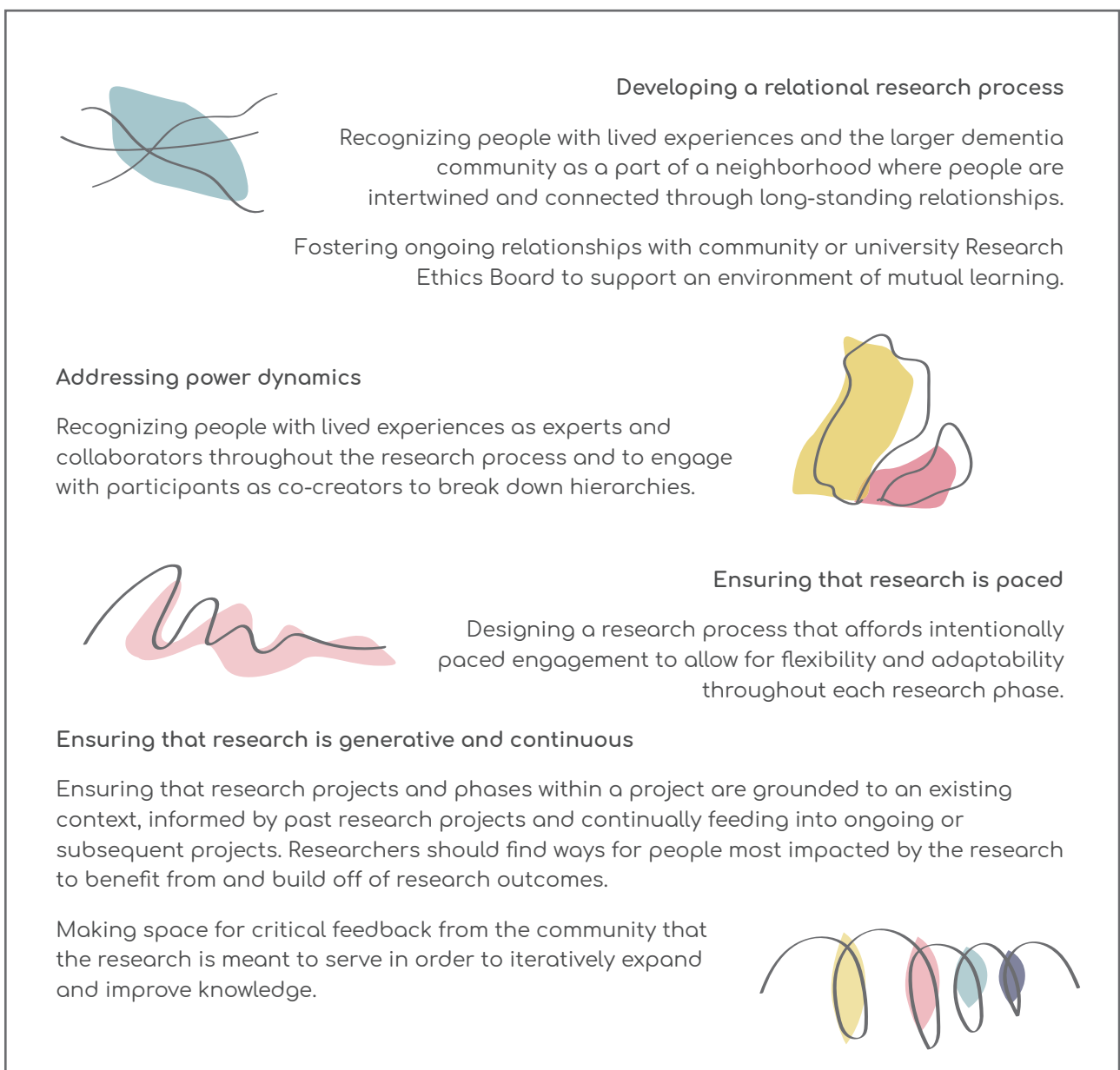
Miroboard created during the workshop sessions.



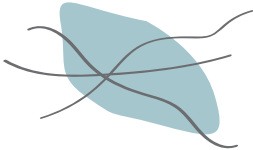
## Strategies towards dementia-friendly research

To bring context to this workbook, let's read through the most salient points that we learned from the workshop dialogue to guide our overall understanding of the workbook content.

Different perspectives and experiences shared during the workshop helped us identify some overarching strategies to foster collaborative and inclusive research engagement and outcomes. These strategies include:




**Developing a relational research process**



Recognizing people with lived experiences and the larger dementia community as a part of a neighborhood where people are intertwined and connected through long-standing relationships.


Fostering ongoing relationships with community or university Research Ethics Board to support an environment of mutual learning.

**Addressing power dynamics**




Recognizing people with lived experiences as experts and collaborators throughout the research process and to engage with participants as co-creators to break down hierarchies.

**Ensuring that research is paced**



Designing a research process that affords intentionally paced engagement to allow for flexibility and adaptability throughout each research phase.

**Ensuring that research is generative and continuous**



Ensuring that research projects and phases within a project are grounded to an existing context, informed by past research projects and continually feeding into ongoing or subsequent projects. Researchers should find ways for people most impacted by the research to benefit from and build off of research outcomes.

Making space for critical feedback from the community that the research is meant to serve in order to iteratively expand and improve knowledge.

These themes and strategies are carried out throughout the workbook with suggestions on how they can be adopted in different phases of research. We hope you find these insights valuable and can incorporate them in your research practice.

# About this workbook

## Purpose

The purpose of this workbook is to foster interdisciplinary and collaborative capacity in dementia research projects in order to transition from a culture of participation to collaboration. This workbook is intended to drive self-reflection amongst initiators and leaders of dementia related research projects to develop research practices that are grounded in collaboration and recognize people with lived experiences as experts.

## Who is the workbook intended for?

This workbook is intended for researchers that work in the field of dementia research. Through this workbook, we hope to promote the inclusion of people with lived experience as experts in research teams. This includes academic researchers as well as researchers who might describe their roles as initiators, leaders, co-researchers, partners, collaborators, etc., and those who contribute to the design and development of a research project. In short, the workbook welcomes any research practitioners who hope to work towards building a culture of dementia-friendly research in their practice and contributions to research projects.

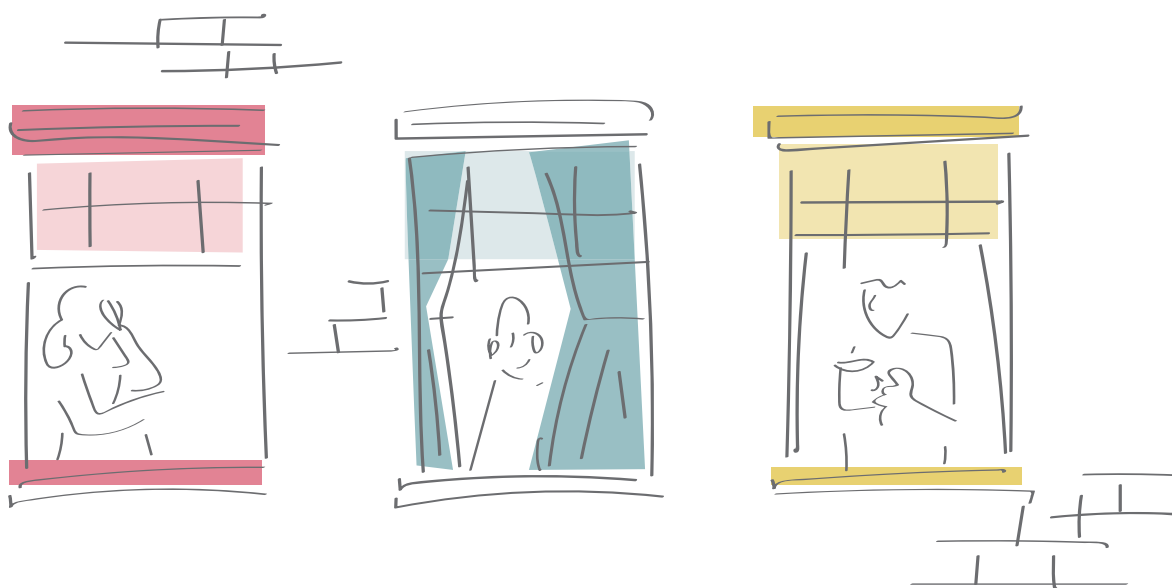
The dementia-friendly considerations outlined in this workbook are relevant for research studies as well as other health related projects. These considerations may be adopted for project activities related to evaluation, report quality improvement or design, amongst others.

### Participation through collaboration:

This workbook focuses on the inclusion of people with lived experience as collaborators in research projects. Participatory practices have been valuable in democratizing research; Space is made for participants of a research project to express their lived experiences by exercising their voice, without feeling like they are subjects of a study<sup>1</sup>.

However participatory practices can nonetheless be extractive and perpetuate attitudes that characterize participants as external agents of a study. This can take away the agency of the participants with lived experiences and how they contribute to, or experience, the benefits of a research project. On the other hand, a collaborative approach to research values people with lived experience as experts who bring value to a research project, not just as participants but as collaborators, initiators, leaders and/or co-researchers.

Collaborative projects leverage knowledge held by people with lived experience to drive research projects and to make valuable decisions on research methods and engagement practices, amongst other things. In this way, people with lived experience can move between roles throughout the project, from taking on advisory or leadership roles to contributing as research collaborators or participants, as needed, keeping in mind that each of these roles require thoughtful consideration and planning.



## Workbook organization

This workbook showcases dementia-friendly participatory practices for each different phase of the research process. Research phases are highlighted to emphasize the circular and continuous nature of the research process, whereby each research phase feeds into the other. Identifying the research phases brings attention to the value of collaborating with people with lived experience at every step of the way, driving dementia-friendly outcomes.

These phases include:

- Building teams and setting goals**
- Preparation and training**
- Data gathering and analysis**
- Sharing and communication of data**

Through each research phase, the workbook will take you through the challenges, successes and strategies that might emerge during a research project. This will be followed by a set of questions to prompt reflection on your own roles and assumptions in order to build collaborative and dementia-friendly approaches within your research projects.



Read the suggestions and consider how you can re-frame existing assumptions and concepts.



Reflect on how you collaborate in your day to day.



Reflect on how you can bring these tools of collaboration to your research projects

Share these collaborative tools and activities with your peers to foster an environment of trust and mutual learning!

## Workbook Theme

In this workbook, we will be using the analogy of holding a community gathering as a metaphor for dementia research. Organizing a gathering can be complex and requires a great deal of care and attention to the needs of those involved. Different stakeholders have their experiences and expertise that they contribute to a research project.

As a researcher, you are the host of the gathering. You are a leader, an initiator or a contributor to the gathering. Who do you share your organizing responsibilities with? You bring something valuable to the table, and you appreciate the diverse offerings that your neighbors contribute.

As you go through the workbook, consider the challenges that come up when developing dementia-friendly research by imagining what organizing and holding a community gathering might look like. Look to the suggestions presented in the workbook to explore how you might overcome these challenges.

- Reflect on how you make space for collaboration in your day to day interactions when gathering with people who you care for and respect.
- Think about aspects of your interactions with your peers that lead to non-hierarchical exchanges that foster mutual learning.
- How can you bring these strategies to a research project?

Starting from the beginning of a research project, at the 'Building teams and setting goals' phase of the study, consider how you initiate a project and how to invite collaboration.



## Dementia community as a neighbourhood

In this workbook we imagine a research project and the research team as a gathering of community members or neighbours. We see the larger research and dementia-care space as a community or a neighborhood. This idea of dementia community as a neighbourhood was shared during the research workshop by a person living with dementia who has participated in various research projects as a co-researcher.

Re-framing the research community as a neighborhood-like community brings attention to the value of community engagement and relationship building as an integral part of the research process by which research is non-hierarchical and participants are treated as peers, experts, or collaborators instead of subjects of a study. Supportive exchange, similar to moments of neighborly sharing and care, can bring valuable lived experience perspectives to a research project while empowering people with lived experiences to have voice and agency. As such, we have defined the theme of this workbook as a community or a neighbourhood gathering.

# Let's get started!



# Building teams and setting goals

If you imagine your research project as a community or a neighbourhood gathering, it all starts with the invitations — who are you inviting to the gathering? Who will be your co-organizers? Who you invite and how you invite them will set the tone for the entire gathering — this is the same for research projects.

A research project starts by initiating the recruitment process to invite project team members, collaborators and participants in order to set the goals and priorities of the project.

Inviting people with lived experience to project teams as collaborators can shape project goals and trajectory based on the lived context and experience of people living with dementia<sup>2</sup> and provide valuable insight that will further help develop recruitment strategies. Fostering these relationships to recruit participants will help ensure their engagement, carrying the process and their retention throughout the project.

## Challenges we heard

Let's make space to address some challenges that might come up as you embark on a research project and are looking to invite people with lived experiences as collaborators, co-researchers or participants:

It might be difficult for people with lived experience of dementia to imagine what roles they might take on a research project especially if they are new to the research process.

Researchers might find it challenging to balance their professional responsibilities as researchers while also developing relationships with participants and collaborators to develop meaningful exchanges and supportive outcomes.

Challenges in recruiting people with lived experience might include finding and establishing trust with people living with dementia that belong to diverse cultural, age and diagnosis groups.



## Recommended strategies

Consider the following suggestions to overcome some of the challenges listed in the previous page.

### Relationship building

- Foster long-lasting and ongoing relationships using community engagement strategies to recruit people with lived experiences as collaborators and participants for research projects. Consider assigning a community navigator or facilitator that is responsible for engaging with community stakeholders and experts (see case study box).
- Imagine the larger dementia community as part of a neighborhood, which means creating consistent opportunities for a meaningful exchange by engaging with the community and lending support.
- Develop cross-regional collaboration by reaching out to organizations and projects in other regions that resemble your mandates and goals to exchange ideas, support and resources.

### Being mindful of how a project is introduced

- When introducing a project, communicate the project as a part of a continuum or an iterative prototype, so that the context of the project is clearly stated in relation to the larger dementia research landscape.
- Introduce a project with transparency, sharing the effects and outcomes of similar previous research projects with new collaborators and participants.
- Introduce the research team's connection to the project as well as benefits of the project to participant groups.
- Express why the research project is relevant to the field and how it will impact the participants.

### Understanding the lived experiences of participants

- Prior to initiating a project, take the time to understand the collaborators and participants' needs and challenges, particularly how their dementia diagnosis may affect their participation in the project.
- Understand how diverse groups might relate to research projects and the varying roles they might want to play in research.
- Utilizing outcome measures that represent the lived experiences of those living with dementia.
- Validate outcome measures in relation to previous relevant work and build conversations with people with lived experience to ensure that these outcomes are considered as priorities.<sup>3</sup>



“The research  
community can be a  
part of our support  
system”

— Person with lived experiences

## Community engagement case studies

### Developing supplementary units and roles for community engagement

#### Community navigator and facilitator

Community Engagement (CE) Studio is a service provided by the Vanderbilt Institute for Clinical and Translational Research in Nashville, Tennessee. The service engages community members, patients, caregivers, community health providers, advocates and policy makers in research to enhance public participation in clinic research. The CE Studio is implemented by a team that includes a faculty researcher, a community navigator, who is responsible for community engagement, throughout the span of a research and a skilled facilitator to facilitate the engagement activities. Team members are knowledgeable about the research process and have experience engaging and maintaining relationships with diverse communities. As evident in this example, making space for designated roles and organizational structures that promote community engagement can make a research projects community focused and participatory<sup>4</sup>.

#### Memory clinic

In order to address the challenges of recruiting patients into early-phase trials of mild cognitive impairment (MCI) and Alzheimer's disease, a memory clinic was developed within the clinical trials unit of a bio pharmaceutical company. Facilitated by the Memory Clinic, the research team collaborated with local organizations to host community outreach events to raise awareness about Alzheimer's disease and the clinic services. Meanwhile, Memory Clinic patients were given free clinical evaluations and invited to possible research opportunities and referred to the early-phase unit for a screening visit.

"New referrals for research participation significantly increased from 12 patients diagnosed with MCI or Alzheimer's disease per protocol in 2016 and 3 enrolled, to 98 patients diagnosed and 16 enrolled. In addition, the physician referral network and collaborations with national nonprofit organizations also increased." This intentional community engagement strategy benefited local community members living with Alzheimer's disease as well as research projects that looked intentionally sought long lasting relationship building and community support<sup>5</sup>.

4- Israel, T., Farrow, H., Joosten, Y., & Vaughn, Y. (2021). Meharry-vanderbilt.org. Retrieved 1 September 2021, from [https://www.meharry-vanderbilt.org/sites/vumc.org/meharry-vanderbilt/files/public\\_files/CESToolkit%202.0.pdf](https://www.meharry-vanderbilt.org/sites/vumc.org/meharry-vanderbilt/files/public_files/CESToolkit%202.0.pdf)

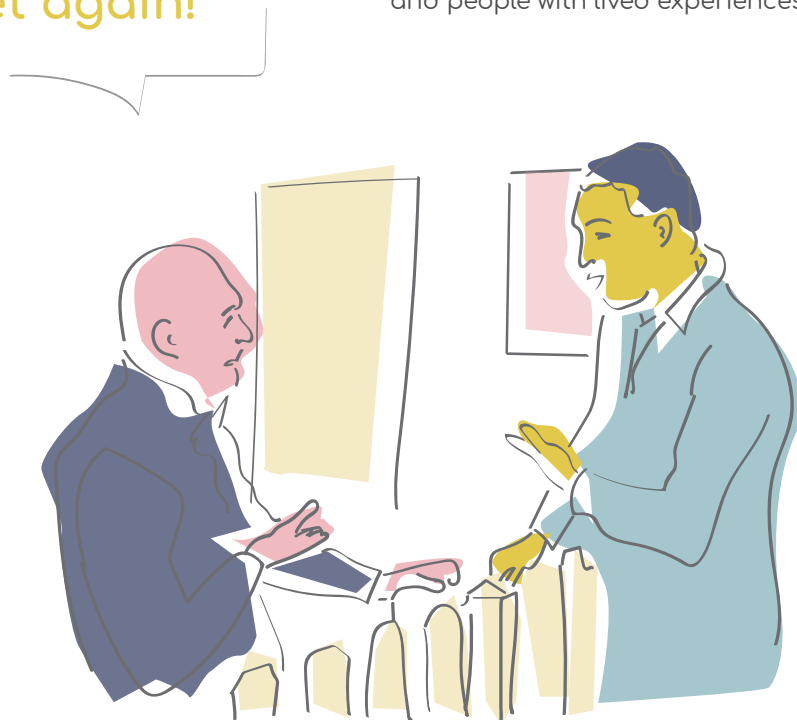
5 - Park, L., Kouhanim, C., Lee, S., Mendoza, Z., Patrick, K., & Gertsik, L. et al. (2019). IMPLEMENTING A MEMORY CLINIC MODEL TO FACILITATE RECRUITMENT INTO EARLY PHASE CLINICAL TRIALS FOR MILD COGNITIVE IMPAIRMENT AND ALZHEIMER'S DISEASE. The Journal Of Prevention Of Alzheimer's Disease, 1-4. <https://doi.org/10.14283/jpod.2019.8>

### Assessing assumptions and re-framing concepts

When initiating a project and undergoing the **Building teams and setting goals** phase, engaging people with lived experience early and often results in more engaged feedback and dementia-friendly outcomes. We encourage project researchers, leaders, and initiators to re-assess existing assumptions, concepts and practices in order to meaningfully collaborate with people with lived experiences. Consider the following when re-framing existing concepts and assumptions about the research process:

- Expertise in research can take on different forms. Lived experience is a valuable and integral expertise that is important in research projects.
- Moving between roles is natural and notions of professionalism can be pushed and extended. Each researcher and collaborator can play different roles during different research phases. Roles can shift from researcher to collaborator to facilitator, observer, knowledge-seeker and participant amongst others.
- “Research community can be a part of our support system.” Research projects are meant to generate knowledge, and they can also present opportunities for lending support and empowering a community of participants and people with lived experiences.

It's been so long since  
we've gathered!  
Lets meet again!



“I remember hearing from people with lived experiences that they wish researchers would take more time to sit and talk about the study.”

— Researcher

### Roles of people with lived experiences

People with lived experiences can take on multiple roles in a research study . They can act as leaders and collaborators to support the organization of the research project and participants in the study. When collaborators who have lived experience take on such dual roles, the research team should establish open and clear communication to ensure that shared information reflects its intended purpose. For example, it is important to be clear about which information shared by people with lived experience is intended to shape research protocol and which is shared as research data. <sup>7</sup>

### Case study

#### Creative Methods to Instill Confidence

#### Initiate. Collaborate<sup>6</sup>

Initiate Collaborate is a tool to build collaboration at the start of a project. The card game facilitates a set of interactive and creative activities that new teams can do together to understand diverse perspectives, develop effective relationships and highlight different expertise and ways of thinking to ensure that all team members can contribute to their best capacity while feeling supported.



6- initiate.collaborate. initiate.collaborate. (2019). Retrieved 1 September 2021, from <https://www.initiate-collaborate.com/>

7- BC Support Unit, Strategy for Patient Oriented Research. (2019, February). How Patient-Oriented is Your Research? British Columbia Academic Health Science Network. <https://www.bcahsn.ca/sites/default/files/2021-05/How%20patient%20oriented%20is%20your%20>

## Questions for self-reflection

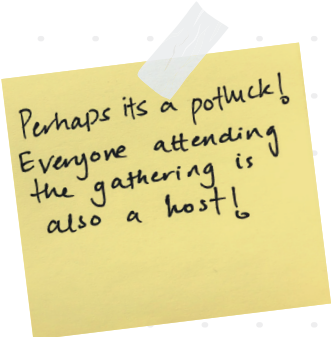
Now that you have read about the challenges of and the strategies used when building teams and setting goals for a research project, take time to reflect on your role and how you extend the invitations to people with lived experiences to collaborate or participate in research.

Imagine that you are organizing a community gathering. Consider the following questions

What types of roles do you take on when planning a community gathering?

Who would you lean on in your community to share responsibilities? Which characteristics of your community members make you feel like you can rely on them to collaborate or organize a gathering?

What do you offer to your community members in return for their contributions?



Perhaps its a potluck!  
Everyone attending  
the gathering is  
also a host!

How might you share the intention of your gathering with neighbors, friends or family to invite them to help organize the event?

Can you think of an instance when you made space for someone else to take the lead and took a back seat? What allowed you to do that? How did it make the other person feel?

## Plan your research

Take these reflections and apply them to your research project. Answer the following questions:

Why is this project important to you?

What is your role in this project? Are you best suited to perform this role?

What roles do you envision for people with lived experiences in your collaborative team?

What might be some anticipated challenges when collaborating with people with lived experiences who want to collaborate on or participate in this project? What supports and compensation can you offer to your collaborators?

What is your plan to develop a shared understanding of the goals of the project, keeping in mind that different collaborators value the project from different perspectives?

# Preparation and training

Going back to the metaphor of a community gathering, in the planning and preparation stages, consider who you are accountable to for a meaningful and safe event? How do you delegate tasks and make other collaborators feel confident in how and what they contribute? The preparation process for a gathering sets the stage and tone for how people will come together, collaborate and share.

Similarly, the preparation and training stage of a research project informs the strength of its next phases. People with lived experiences can contribute tremendously to the preparation phase by providing valuable insights for developing research questions and outcomes, as well as assisting with generating contextual knowledge about participants and drafting informed consent forms<sup>8</sup>. This can be vital when writing grant proposals or acquiring research ethics boards (REB) approvals.

Taking time to prepare and train collaborators who have lived experience can ensure that they feel confident in how they contribute to research and develop a good understanding of their roles and responsibilities throughout. These steps bring teams together to develop a shared positive experience so that everyone is on the same page. This is particularly important when we look to expand our teams to include people who may be new to research or academic contexts.

## Challenges we heard

Recognizing challenges allows us to identify opportunities for improvement! When setting up a research project, the **preparation and training** phase can bring about different stresses associated with different roles assumed by members of a research team. Instilling confidence in collaborators and participants can be integral in supporting dementia-friendly outcomes. Some of the challenges around preparation and training for research that we heard include:

- REB can lack awareness about participants' experiences. With their focus on safety and emphasis on risk and the vulnerability of participants, REB's may perpetuate a deficit-based narrative.
- People with lived experiences who want to contribute to the research team might not understand the role of the REB and might benefit from more training to understand the research ethics space and the dynamic process in acquiring ethics approval.
- Dementia diagnoses frequently leave people without confidence. People living with dementia may find it difficult to imagine how they could meaningfully contribute to a research project.

8- BC Support Unit (2018, October). Ensuring the Ethical Conduct of Patient-Oriented Research: A Guide for Researchers British Columbia Academic Health Science Network. [https://www.bcahsc.ca/sites/default/files/2021-05/POR%20Ethics\\_Researchers\\_20181025.pdf](https://www.bcahsc.ca/sites/default/files/2021-05/POR%20Ethics_Researchers_20181025.pdf)



## Recommended strategies

### Instilling confidence

- Find ways to instill confidence in people with lived experiences during the preparation and training sessions by highlighting their assets and strengths. This can be done using arts based and creative methods!
- Make space for mistakes to happen and allow collaborators to stumble as they learn about the project and their roles within it.
- Ensure that collaborators have the opportunity to ask questions and their questions are answered.

### Fostering relationships with your university or community's Research Ethics Board (REB)

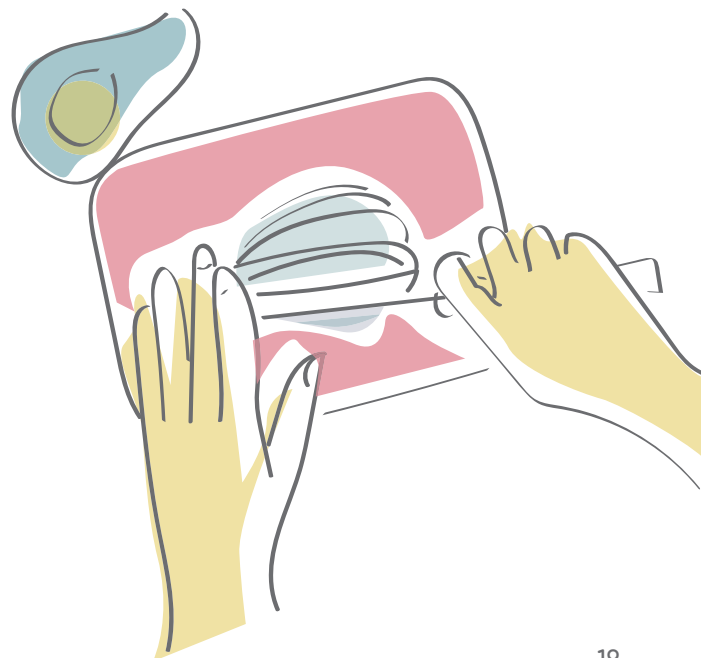
- Be in close communication and conversation with your REB through the lifetime of your project.
- Relationship with your REB can be viewed as a learning process that allows mutual learning to do more rigorous and respectful research.
- Request a meeting with the researcher, person with lived experience and the Research Ethics Board at the onset of the project. This is a great opportunity to educate the REB about the needs and context of your project, project team and participant group. This also allows a more robust and ethical research process in support of collaborators and participants with lived experiences.

### People with Lived Experiences as experts

- Bringing people with lived experiences on to the team early can allow for transfer of valuable knowledge. Use the [preparation and training](#) phase to learn from people with lived experiences. They have firsthand experience and will have valuable insights about the needs of participant groups.

### Making the Process Clear for People with Lived Experiences

- Ensure that entire research team is on the same page prior to engaging with participants. Allow everyone to understand the goals and objectives of the project at the onset of the research.
- Inform people with lived experiences who are contributing to the project about what the research process involves, including role of the REB and aspects of ethics approval that impacts their contribution in the project.
- Provide the team with meaningful literature and tool kits to understand the research process and get on the same page.



## Case study

### Flipping stigma

The project Flipping Stigma on its Ear Toolkit was developed “to recognize and respond to the stigma and discrimination” associated with a diagnosis of dementia. The toolkit contains a set of prompts and resources for people living with dementia, their care providers and researchers to reflect on their roles in perpetuating stigma and discrimination in order to combat discriminatory practices.

“Discrimination occurs when others act on assumptions in a way that leads to the person with dementia being treated as incapable, and feeling judged or deficient in some way.” As researchers, it is important for us to reflect on our discriminatory assumptions that cause an environment of stigma for people living with dementia. Do use this tool to further access resources!

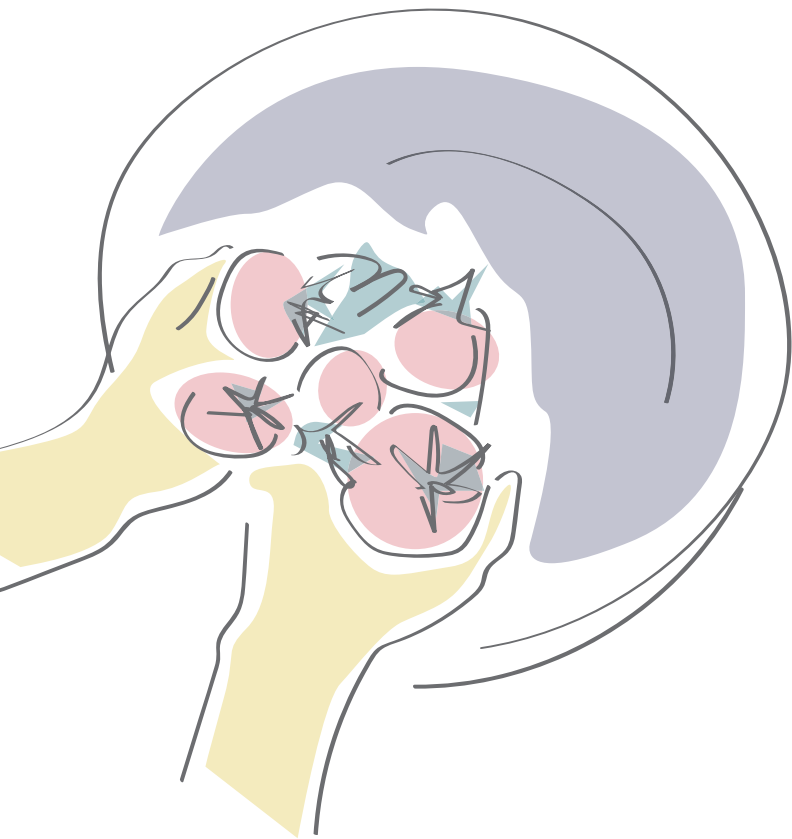
<https://www.flippingstigma.com>

Furthermore, this project is an example of research project that invites people living with dementia as leaders of research. The toolkit is a part of a research study where academic researchers and people with lived experiences of dementia worked together to develop the outcome using a Participatory Action Research methodology.



“I worked with researchers to help people understand the benefits of including people with lived experiences”

— Research advocate living with dementia



### Assessing assumptions and reframing concepts

- Do reconsider your relationship with your REB. While this might feel like a burden, take this opportunity to develop space for mutual learning.
- Remember to see people with lived experience on your team as advisors and experts, continually instilling creative confidence and making sure they have the necessary tools and support as the project continues.

### Questions for self-reflection

Going back to the community gathering metaphor, consider how you slow down and get to know your community members and co-organizers to foster strong collaboration through thoughtful preparation. Consider the following:

Can you think of an instance when you slowed down from your day-to-day routine to get to know a neighbor?

When preparing for your community gathering, how do you best understand the strengths and experiences that your co-organizers bring?

While organizing your gathering do you expect to adapt your expectations because of different needs of peers and community members? How might you adapt?

Can you draw a self-portrait of yourself when you feel the most confident? What are the characteristics of this self-confidence?

How do you make others- peers, neighbors or loved ones feel confident?

## Self-evaluate your project

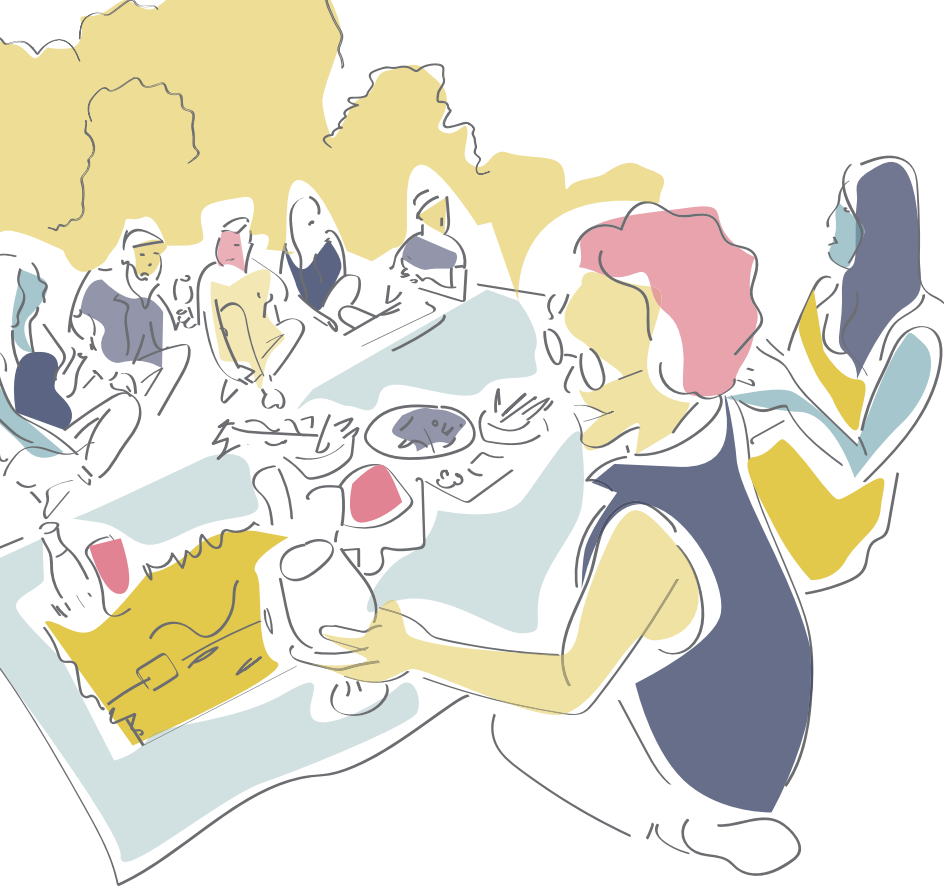
Applying these reflections to your research project, consider:

How can you instill confidence in your research team to allow them to exercise their voice and vocalize their needs throughout the duration of the project?

How can you pace the training and preparation of the project to give collaborators and co-researchers the time to familiarize themselves with the project and understand the role/s they want to take on?

What measures did you take to ensure that everyone on your team understands the research process?

How can you make space and leave time for team members to stumble and learn?



# Data gathering and analysis

When organizing a community gathering, how do you make your gathering creative, engaging and meaningful for those coming together? How do you create an environment so that people feel comfortable enough to converse and share with each other?

These same considerations come into play during the data gathering and analysis phases of a research project. Developing creative engagement methods that represent participants' lived experiences can create an environment for research that is also grounded in relationality and collaboration and makes participants feel safe, heard and cared for. To make data gathering more safe and engaging, people with lived experience on the research team can provide valuable insights when designing inclusive and collaborative data gathering methods and environment for research. They can also support facilitation of interviews and surveys, as well as interpretation of knowledge and the development of themes during data analysis by sharing lived experiences and contextual insights<sup>9</sup>.

## Challenges we heard

- Certain data gathering methods may be intimidating for people with lived experiences and make them feel uncomfortable.
- Research participants might feel as though they are subjects of a study which takes away their sense of agency and choice.

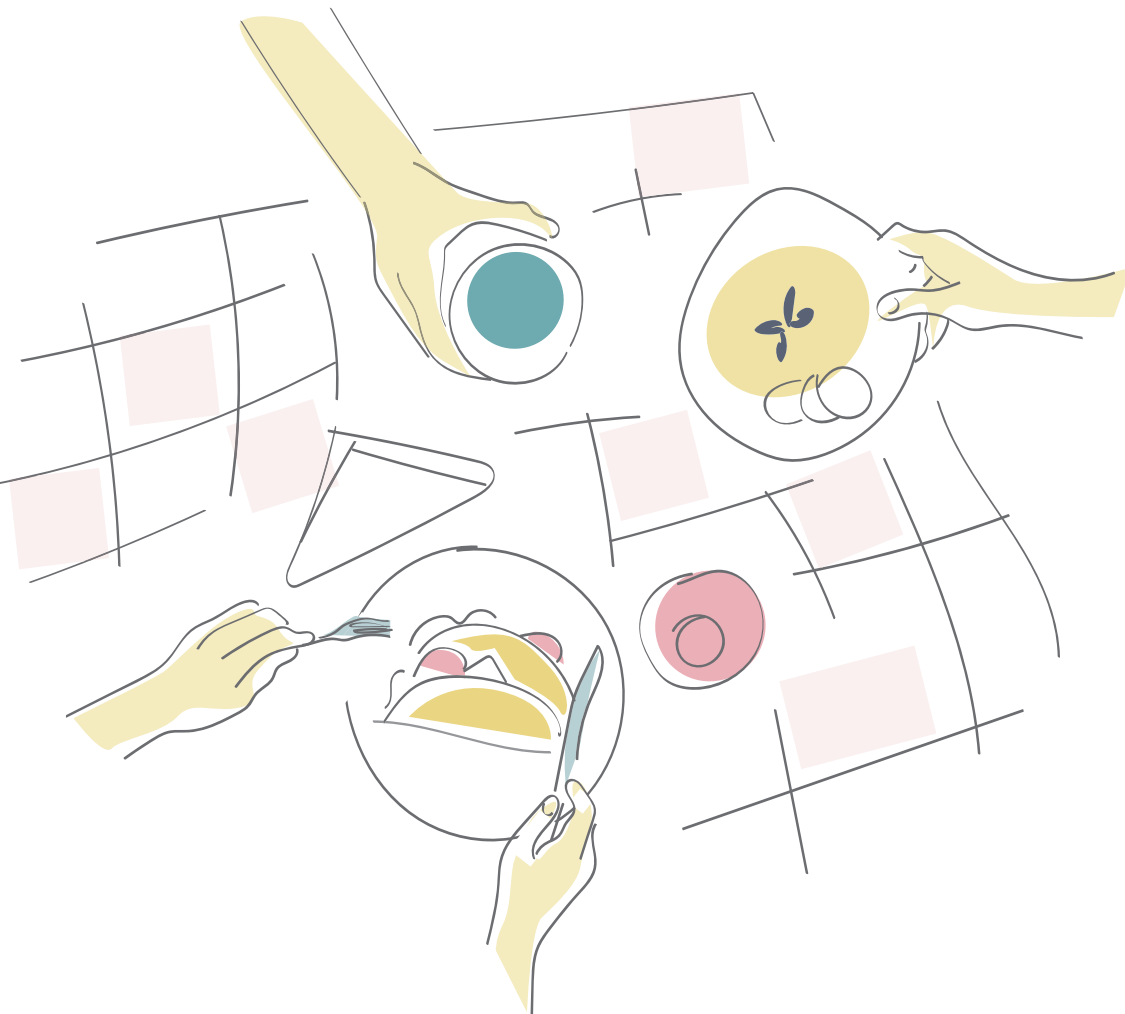
## Recommended strategies

### Learn from people with lived experiences

- Take insights from people with lived experiences when developing or choosing data gathering methods. For example, utilize outcome measures in data gathering that are important to people with lived experiences.
- Make space for people with lived experiences to contribute to the analysis phase of the research. Their interpretation of data can bring unique and relevant perspectives.

### When working with people living with dementia as participants, develop data gathering methods that are

- **Flexible** — Allow for adaptability when participant engagement presents unexpected needs or challenges.
- **Space-specific/relevant** — Create research spaces that ensure that participants feel at ease. Develop methods that are inspired by programs and activities that people with lived experience are familiar with as methods of expression in their spaces of comfort.
- **Interdisciplinary** — Take inspiration from different fields of practice including arts, design and theatre to develop rich set of inquiry methods.





Understanding how people with lived experiences experience the spatial dimensions of their day-to-day experiences can contribute to the development of data gathering methods that ensure safe, comfortable and expressive research engagement. Translating spatial and relational elements of their home environment that re-instate a sense of belonging, meaningfulness, safety, security and autonomy into research engagement methods can leverage participants' capacity and natural expression to generate meaningful knowledge. These elements can include fostering familiarity through physical cues or adopting activities of expression that people with lived experience participate in routinely. in their homes, amongst other things <sup>10</sup>.

### Assessing assumptions and re-framing concepts

Consider that when working with participants who are living with dementia, pace of a research is valued over the results. Flexible and adaptable research methods can make participants feel comfortable and supported.

Adopting creative and space-specific methods can generate valuable knowledge and insight in research by highlighting the capacity of participants living with dementia. This might mean immersing yourself in the dementia community to learn about spatial dimensions, activities and methods that encourage people with lived experiences to feel safe, expressive and confident.

## Case study

### Creative arts based methods for data gathering

#### In There, Out Here- Art Making Space

In this study, researchers focused on learning from people living with dementia and their care partners about what it means to live well with dementia to the end of life, including developing plans for health and social care. The research started out with face-to-face interviews with people living with dementia and their care partners and went into arts-based workshops that explored the question of what it means to live well. Workshops included mask-making, poetry, painting and collages. Participants were able to express their lived experiences through multi-sensory and creative methods to contribute to knowledge derived from the research. The art works were shared with the larger dementia community through a virtual exhibition and website as a way to amplify insights and perspectives of those with lived experiences as well as share the value of the research itself <sup>11</sup>.



(COLLAGES — Art Making Space, 2021)<sup>10</sup>

10- COLLAGES — Art Making Space. Art Making Space. (2021). Retrieved 1 September 2021, from <https://www.artmakingspace.com/artwork/collage>.

11- Portraying life with dementia in new light and colour. UBC Faculty of Medicine. (2021). Retrieved 1 September 2021, from <https://www.med.ubc.ca/news/portraying-life-with-dementia-in-new-light-and-colour/>.

### Questions for self-reflection

When organizing a community gathering how do you intend to create an environment that is comfortable, fun and engaging so everyone is excited to come together? Think about what makes you feel engaged, creative and safe. Consider the following:

How do you best express yourself? It could be verbally or written, through movement or song or any other way that allows you to share your thoughts, ideas and insights. What tools do you use?

Do you ever engage with your peers, neighbors or loved ones using creative methods or fun activities? What are these activities?

What are some spatial elements in your home or in your neighborhood that make you feel at ease or leave you with a sense of belonging?

Do you ever curate a space or create an environment to allow people to share and exchange ideas with ease? What are different elements that you introduce to the space to let conversation and mutual learning flow?



## Plan your research project

Take your reflections and apply it to the research project.

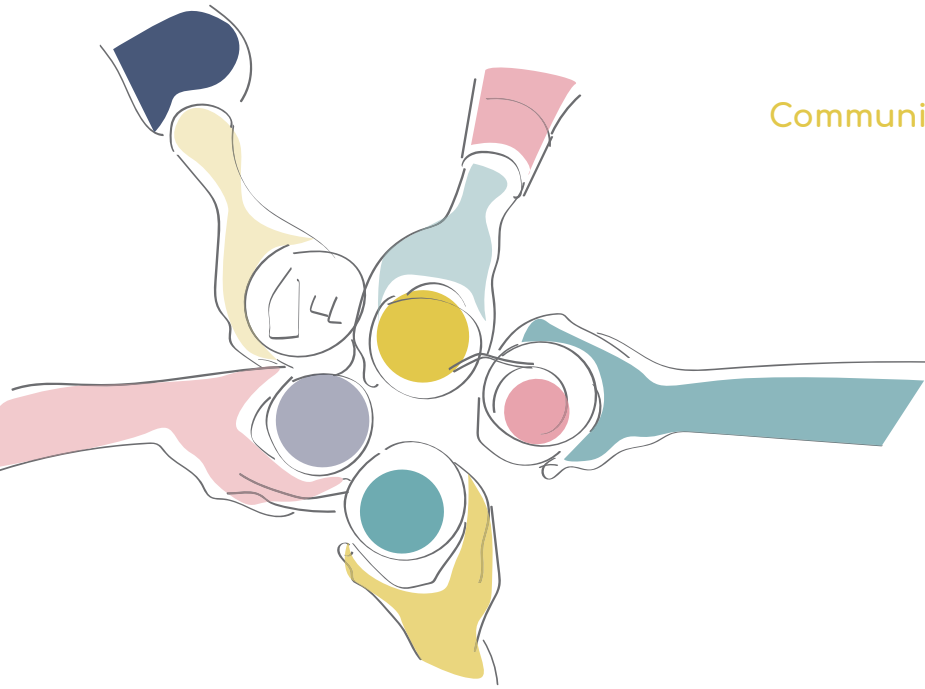
Does data gathering methods adopted in your research make your research participants feel empowered and endowed with voice?

If the data gathering methods adopted in your research make your research participants feel intimidated or uncomfortable, how can you alter your methods or create a safe environment to mitigate this discomfort?

How do you make sure that the participants of your research take the time to understand the research project and process so they can participate with continued consent?

What are your data gathering methods? Do they align with outcome measurement goals established in the early stages of the research?

How can people with lived experience contribute to the analysis of your data? What types of added value and perspectives could they bring to the interpretation of gathered data and knowledge?



# Communication and sharing knowledge

When someone in your community has accomplished something, how do you share and celebrate that accomplishment with your community? Do you toast those that have made the accomplishment possible and bring attention to their contributions? How do you continue to nurture these accomplishments?

These considerations are relevant to the Sharing and Communication phase of a research project where the impact of a research can be celebrated and shared with the community of knowledge contributors and users. Collaborating with people with lived experience to share and disseminate results of a research project can positively impact how new knowledge can support community of knowledge users. People with lived experiences can contribute by identifying local platforms for dissemination, co-authoring literature, jointly presenting findings, or sharing in informal networks.

Mobilizing knowledge to serve the community of people with lived experience can take place by keeping knowledge alive, dynamic and nurtured through methods of communication and dissemination that are community centered and engaging.

## Challenges we heard

- Once the data is gathered and analyzed, methods of disseminating can sometimes become static.
- Research frequently doesn't go back to the community of participants that generated the knowledge.
- Communication and sharing strategies can feel inaccessible to those outside of academic circles.

## Recommended strategies

Share knowledge in the voice of people with lived experiences

- Use the language of participants to describe research findings or key insights. This can empower people with lived experiences and the information will feel more relevant to the group it seeks to serve.

Employ methods of communication and sharing that are

- **Interdisciplinary** — Using arts and design methods to share research results to make them more accessible.
- **Community focused** — Sharing result of a research through community engagement to celebrate the project success with collaborators, participants and the larger dementia community. (see case study page 29)

Disseminate and share research in a way that keeps research alive

- This means sharing research results in a way that makes research relevant to the dementia community and,
- Developing dissemination strategies that leave space for critical feedback from those most impacted by the research.

## Assessing assumptions and re-framing concepts

- Disseminating research findings should be done in support of and collaboration with people with lived experiences of dementia.
- Sharing and communicating of research results can be an opportunity for further meaning making by validating results or acquiring critical feedback about research findings.



### Questions for self-reflection

Bringing people together over a shared experience can be deeply meaningful and transformative. How we make meaning of and hold on to shared experiences can keep memories alive and further enrich relationships. Consider how you might document a gathering of shared experiences and expand connections by embedding rituals of sharing and celebration to foster long lasting connections.

When was the last time you celebrated successful accomplishment? What did this celebration look like? Who did you invite?

How might you document a gathering to keep memories of shared experiences alive?

How do you share knowledge about something that you care deeply about that you've gathered through a shared experience? Do you share through conversation, writing, passing on literature or resources, etc.?

How do you welcome feedback to improve something you have accomplished? What types of questions do you ask?

## Plan your research

Bringing these reflections back into the context of your research project:

Can you define the purpose of sharing the results of your research?

Which communities will benefit most from the results of your research project? How do you intend to reach these communities when sharing the results of your research?

What methods of sharing research will keep the intention of your research alive?

How can you see the process of sharing your research as a way to celebrate shared experiences and accomplishments?



# Conclusion

Now that you have read through the different strategies of being in community with people living with dementia, we hope you have been able to look inward to reflect on your roles as researchers or project initiators and ways that you can make space for community relationships to foster. By building the theme of research practice as a community gathering, we acknowledge the value and affordances of community support networks that are very important to people living with dementia, as we have heard in their own words. Reciprocal support networks bringing comfort, community and confidence to people living with dementia.

Through this workbook, reframing research practice as a community gathering brings attention to the value of community engagement and relationship building as an integral part of the research process by which research participants with lived experience are recognized as peers, experts, or collaborators instead of subjects of a study. To augment patient-oriented research, it removes focus on deficits of patients towards their capacity and expertise as collaborators to ensure that people with lived experience of dementia have a say in how policies, systems, and services are tailored to meet their needs. A community-oriented framework thus reorients hierarchical dynamics in research to foster meaningful and reciprocal participation and contribution from people with lived experiences.

We hope that this workbook, that we imagine as a practice in reflection, allows you to reframe research as a community practice and rethink your own roles and assumptions. We hope that you can go forth and build meaningful relationships and research projects. We hope you experience what reciprocal joy can feel like!

This workbook is also supplemented with a pamphlet for people living with dementia who are new to research and would like to contribute to research as participants or collaborators. The pamphlet shares the value and challenges of

participating in research as leaders, collaborators, or participants as expressed by advocates living with dementia. The pamphlet demystifies the research process and dispels research myths. Do share the pamphlet with new contacts to kick-start a relationship built on thoughtful invitation.

## Key Resources

Strategy for Patient-Oriented Research - Patient Engagement Framework

<https://cihr-irsc.gc.ca/e/48413.html#a7>

Draft CIHR Ethics Guidance on Developing Research Partnerships with Patients: Public consultations

<https://cihr-irsc.gc.ca/e/51217.html>

Evidence-Informed Practices and Strategies for Patient-Oriented Research (POR): A 'Menu' for Research Teams

[https://www.bcahsn.ca/sites/default/files/2021-06/POR%20Menu\\_20191004.pdf](https://www.bcahsn.ca/sites/default/files/2021-06/POR%20Menu_20191004.pdf)

Resources for Engaging Patients

<https://www.ctontario.ca/patients-public/resources-for-engaging-patients/>

How Patient-Oriented is Your Research?

<https://www.bcahsn.ca/sites/default/files/2021-05/How%20patient%20oriented%20is%20your%20research.pdf>

This workbook was designed and authored in collaboration with Alzheimer Society of BC, The Health Design Lab at Emily Carr University of Art + Design, and researchers Dr. Gloria Purveen (UBC) and Dr. Jodie Gawryluk (University of Victoria).

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