Forest Hill

Dementia Friendly Community

Report on the evaluation of the co-design process

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Dementia
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The Inner East Primary Care Partnership (IEPCP) is funded by the Victorian Government to support the health and wellbeing of the local community through collaboration and partnerships. The IEPCP catchment is four local government areas – Boroondara, Manningham, Monash and Whitehorse.

This report presents the findings of an evaluation of the co-design process for the Forest Hill Dementia Friendly Community (DFC) work in the Eastern suburbs of Melbourne.

Acknowledgements

Further Information

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1   EXECUTIVE SUMMARY

The Forest Hill Dementia Friendly Community Group was established in May 2018 and co-designed resources to help local businesses in Forest Hill Chase Shopping Centre become more dementia friendly. People living with dementia and their carers become isolated as community venues such as shopping centres are not aware of how best to respond to their needs.

The group used co-design principles developed by The Australian Centre for Social Inclusion (TACSI) and Community West as a guide. Co-design is a mindset and methodology that uses the skills of group members to develop solutions to complex issues.

Twelve months into their work the group evaluated its co-design process to find out the quality of the co-design process, benefits for participants and recommendations for future work. Fifteen surveys with qualitative and quantitative questions were distributed to current and past group members. Responses were received from 14 people, with 7 from community members and 7 from organisational members. 2 responses were from people who had recently left the group.

This evaluation showed a high level of satisfaction with the quality of the co-design process, a number of benefits to participants, some insights into how the process could be improved, and considerations for future co-design evaluation. Overall the co-design process used, aligned with the principles adopted by the group. Group members supported and encouraged each other, developed new friendships, skills and knowledge and had strong engagement with the project. Community and organisational members now have co-design skills that can be used to benefit the local community. The resources developed can be adapted to support other dementia friendly community work in other locations in the future.

This evaluation of the co-design process provides useful insights for community service practitioners to consider prior to embarking on a codesign project, and in establishing upfront evaluation. Key insights and recommendations were:

- Ensure adequate representation on the group by all stakeholders targeted - establish who should be involved so the process is more effective.
- Organisational support - engage all organisations in the work, provide orientation and information, and get senior level buy-in to provide appropriate recognition and resourcing.
- Acknowledge the time and commitment required to participate - provide clear information to all group members up front.
- Valuing contributions of group members - value and respect member's ideas and opinions and ensure their skills, knowledge and experience contribute.
- Match the pace of the work with the group's needs - be realistic about what can be achieved, develop an action plan with timelines and celebrate small achievements.
- Equalise power - implement strategies that ensure unequal power of group members is addressed and balanced as much as possible.
- Invest time on building and maintaining rapport, trust and group cohesion to ensure a positive and productive working environment.
- Ensure all group members understand what co-design is and jointly decide the co-design principles that will be used to guide the way the group works.
- Regularly reflect on the way the group is working together and make adjustments as you go.

Results showed that co-design can be a valuable and meaningful way to engage people with dementia and their carers to address issues of access and inclusion that people with dementia face every day in their local community.

I think it is important that there is more education about dementia. People with dementia should feel that they can go to the shops and feel safe and understood and welcomed (community member)

2 INTRODUCTION

This report presents the findings of an evaluation of the co-design process for the Forest Hill Dementia Friendly Community (DFC) work in the Eastern suburbs of Melbourne.

In 2016, a group of community service organisation representatives began to work together to improve the wellbeing and quality of life of people living with dementia within the Forest Hill area. After community consultation, the group expanded in 2018 to include community members living with dementia and their carers. In 2019 there were seven community members (1 person living with dementia and 6 carers) and six service providers in the Forest Hill DFC Group (the group). The DFC project was led by the Inner East Primary Care Partnership (IEPCP) and Whitehorse City Council (WCC).

Dementia describes a collection of symptoms caused by disorders that affect the brain. There are many different types of dementia. Dementia has physical, social and emotional consequences for the person with dementia, their family, friends and the community (Dementia Australia 2017).

While there is no one agreed definition of a **dementia friendly community**, it is generally accepted to be one where people with dementia are "included and respected" and barriers that stop people with dementia, and their family and friends, from participating in community life are removed (Davis et al 2009; Keenan 2014; Imogen Blood and Associates 2017).

The group focused their work on the suburb of Forest Hill in the Whitehorse City Council local government area. The aim was to **make Forest Hill a place where people living with dementia, and their family and friends, feel supported to participate in their community.** The group agreed to prioritize working with local businesses to build understanding about people with dementia and chose to direct their work to cafes at Forest Hill Chase shopping centre. The concept was to work with café management and staff to support them to become more dementia friendly so that anyone living with dementia would feel comfortable and welcome to visit the café at any time.

In July 2019, the group agreed that after more than 12 months working together, it was time to evaluate the process so far. The evaluation was conducted by the IEPCP with support from WCC.

2.1 Aim of the evaluation

The aim of the evaluation was to find out whether the co-design process was working well, what needed to be improved, and what were the impacts for members of the Forest Hill DFC group from May 2018 until July 2019.

...both through my work and personal life I have a strong connection to dementia.
I believe anything that assists those with dementia and their carers is extremely important
(organisation member)

3 CO-DESIGN

Co-design is a mindset and a methodology that focuses on building trust, respect and rapport, working together as equals, acknowledging and balancing power, sharing and exchanging information, using the skills of group members, and involving everyone in the process to test and evaluate solutions (TACSI 2017, Community West Inc 2016)

Having carers and people with dementia in the group gives an important voice to these people which is a great thing (organisational member)

In accordance with the underlying philosophy of DFC of **"nothing about us without us"** (Charlton 1998), the Forest Hill DFC group aimed to co-design its actions by including the voices of people with dementia and their carers to make Forest Hill more dementia friendly. The principles underlying co-design recognise that people have valuable knowledge about their own needs and are best placed to address issues that affect them, building on their strengths, and supporting their decision making and problem-solving skills (TACSI 2017). In the case of DFC work, it's about local people living with dementia and their family and friends being involved and making decisions on what in their local community could change to make their own lives better.

3.1 Principles of co-design

The group based its co-design process on The Australian Centre for Social Inclusion (TACSI) and Community West Inc principles of co-design. See Table 1 over the page.

Table 1: Co-design principles used for the co-design process (TACSI 2018; Community West Inc, 2016)

TACSI	Community West
Inclusive The process includes representatives from critical stakeholder groups who are involved in the co-design project from framing the issue to developing and testing solutions. It utilises feedback, advice and decisions from people with lived or work experience, and the knowledge, experience and skills of experts in the field.	**Principle 1** People are **assets**: the skills and strengths they bring are used in the process of **change**
Respectful All participants are seen as experts and their input is valued and has equal standing. Strategies are used to remove potential or perceived inequality. Partners manage their own and others' feelings in the interest of the process. Co-design requires everyone to negotiate personal and practical understandings at the expense of differences.	**Principle 2** People feel there is a **safe space** to speak up and be **listened** to
Participative The process itself is open, empathetic and responsive. Co-design uses a series of conversations and activities where dialogue and engagement generate new, shared meanings based on expert knowledge and lived experience. Major themes can be extracted and used as the basis for co-designed solutions. All participants are responsible for the effectiveness of the process.	**Principle 3** People are **equal partners** in the process, ensuring **accessibility** for everyone
	Principle 4 Everyone **commits to contributing** and **benefits** from being involved
Iterative Ideas and solutions are continually tested and evaluated with the participants. Changes and adaptations are a natural part of the process, trialling possibilities and insights as they emerge, taking risks and allowing for failure. This process is also used to fine-tune potential outcomes or solutions as it reaches fruition and can later be used to evaluate its effectiveness.	**Principle 5** Everyone is **involved in decision making** and it is **clear how decisions are made**

While the two sets of co-design principles are very similar, the language used by each is different. Having both sets as a guide provided a good cross check mechanism and reinforced the key aspects of co-design for implementation.

4 METHODOLOGY

4.1 Design

The methodology developed to evaluate the Forest Hill DFC co-design process was drawn from a number of sources including the evaluation expertise of the IEPCP (see Appendix A). The researchers considered:

- Evaluating co-design and participatory processes (Man et al, Scottish Health Council);
- Evaluating dementia friendly communities (Blood and Associates 2017);
- Evaluating process - sometimes called formative evaluation (Scottish Health Council 2013; WK Kellogg Foundation).
- Developmental evaluation (Patton, 2008; 2011; 2012).

As a result, the following **three key areas for exploration** were considered most important to evaluate the co-design process of the Forest Hill DFC work:

1. Quality of the co-design process
2. Benefits for participants
3. Insights and recommendations for future work

In addition, the researchers evaluated the co-design process with respect to the two sets of principles of co-design used by the group.

4.2 The Questionnaire

While face to face interviews provide a rich source of qualitative data, it was determined that a **written questionnaire** was the most appropriate method to use for this evaluation because:

- There was a short time frame
- There were limited resources to undertake and analyse interviews
- It provided a familiar and simple process
- It allowed for qualitative and quantitative data collection
- It provided for some standardised responses to questions from different people
- It simplified the analysis
- It is easy to repeat at regular intervals (NHS Health Scotland, 2006)

The survey questions were developed by IEPCP and WCC based on an internal review of evaluation and co-design literature.

All current and recently exited (within the current calendar year) group members were asked to complete the survey in August 2019, a total of 15 people. This included the IEPCP and WCC, acknowledging their important role in the co-design process and in alignment with accepted developmental evaluation practice (Patton 2011). The survey was completed anonymously, however given the small sample size, there was a risk of respondents adjusting their answers because they were concerned about confidentiality. It was hoped that the reassurance given, and high level of group rapport and trust developed at the time of the evaluation contributed to members' sense of freedom to be honest and open. One to one support was offered by IEPCP to assist group members to complete the survey and was taken up by one group member.

Questionnaires were emailed or printed for group members. Group members were encouraged to complete the questionnaire outside of the group meetings. The lead organisation distributed the questionnaires, collected completed questionnaires, and collated the de-identified data.

The questionnaire had closed and open-ended questions, collecting quantitative and qualitative data:

- 22 questions were multiple choice: The first 5 questions had response options of *yes, no or unsure*; The following 17 questions had responses options of *never, rarely, sometimes, most of the time, always or unsure*.
- Six open-ended questions asked participants to write their own responses.

See Appendix B for a copy of the questionnaire distributed.

4.3 Analysis

Questionnaire responses were de-identified and entered into an Excel spreadsheet. Responses were analysed based on the **three key areas for exploration** (quality of the co-design process, benefits for participants, insights and recommendations for future work) and **two sets of co-design principles** (TACSI and Community West).

Given the importance of community involvement in co-design, responses from community member and organisational members were analysed separately.

Analysis based on three key areas for exploration

To provide broad data on the quality of the co-design process, benefits for participants, and insights and recommendations for future work, the **quantitative multiple-choice question responses** were categorised as:

- **"doing well"** - where ALL responses from ALL surveys were either YES, ALWAYS, or MOST OF THE TIME
- **"room for improvement"** – where ONE OR MORE response from ALL surveys were either NO, UNSURE, SOMETIMES, RARELY, or NEVER

For the **qualitative questions**, responses were themed by the lead evaluator from IEPCP based on the three key areas for exploration.

Analysis based on co-design principles

The results were analysed for themes related to the two sets of **co-design principles** used to guide the group (see Table 1 on page 7).

Three people from IEPCP and WCC independently assessed which co-design principle was being measured by each **multiple-choice question**. Some questions measured more than one principle. Each person's allocation was reviewed with final determination made by IEPCP. Table 2 over the page provides the results of this mapping process. None of the questions measured the TACSI **iterative** principle.

Table 2: Mapping of co-design principles measured by the multiple-choice questions

TACSI	Survey questions that measure this principle	Number of questions that measure this principle	Community West	Survey questions that measure this principle	Number of questions that measure this principle
Inclusive	3, 7, 11, 12, 14, 15, 16, 17, 22	9	1 People are **assets**: the skills and strengths they bring are used in the process of **change**	15, 16, 17, 18, 20, 22	6
Participative	3, 4, 5, 6, 8, 9, 13, 17, 19	9	2 People feel there is a **safe space** to speak up and be **listened** to	9, 19, 20	3
			3 People are **equal partners** in the process, ensuring **accessibility** for everyone	3, 4, 5, 6, 7, 10, 21, 22	8
Respectful	6, 8, 9, 10, 11, 12, 18, 19, 20, 21, 22	11	4 Everyone **commits to contributing** and **benefits** from being involved	8, 17	2
			5 Everyone is **involved in decision making** and it is **clear how decisions are made**	7, 8, 9, 11, 12, 13, 14	7

The group was considered to have successfully implemented a co-design principle if 60% or more of the **quantitative** multiple-choice questions that measured that principle were rated as "doing well" (i.e. ALL respondents answered YES or ALWAYS/MOST OF THE TIME).

For example, if 6 of the 9 questions related to the **participative** principle were classified as "doing well", then an overall comment can be made that the group was successful in implementing the **participative** principle.

For the **qualitative questions**, individual responses were analysed based on whether they provided "evidence" of success or otherwise in implementing each of the co-design principles. Some responses provided evidence for more than one principle.

5 RESULTS

An overview of the questionnaires distributed and received is in table 3 below. Fifteen questionnaires were sent out and fourteen returned, a response rate of 93%. Seven from community members and seven from organisational members.

Table 3: Overview of questionnaires distributed and received

Questionnaires distributed	15	
Questionnaires completed	14	93%
Current group members	12	85.7%
Past group members	2	14.3%
Community members	7	50%
Organisational members	7	50%

5.1 Quantitative results

The overall results for the multiple-choice questions based on the categories of "**doing well**" or "**room for improvement**" are summarised in Table 4 below.

Table 4: Summary of multiple-choice questions by "doing well" and "room for improvement"

	Survey Responses	Community members	Organisational members
Doing Well (Strengths)	ALL respondents answered: • YES or • ALWAYS / MOST OF THE TIME	12 questions (60% of questions)	13 questions (65% of questions)
Room for improvement (Weaknesses)	ONE OR MORE of the respondents answered: • NO / UNSURE • SOMETIMES / RARELY / NEVER	8 questions (40% of questions)	7 questions (35% of questions)

Overall, the results were generally positive, with both community members and organisational members rating the group as "doing well" on 60% (12 out of 20) and 65% (13 out of 20) of the multiple-choice questions respectively. There were differences between what community members and organisational members believe the group is "doing well" in and where there is "room for improvement".

"Doing well" (ALL respondents answered YES / or ALWAYS / MOST OF THE TIME)

The results for "doing well" based on overall survey responses are in Table 5 below. Both community and organisational members agreed that the group is "doing well" in 45% of the questions (9 out of 20) of the multiple-choice questions. There were some differences between community and organisation member responses as indicated in the first two columns of the table.

Table 5: "Doing well" results for individual multiple-choice questions

Community members only	Organisational members only	Both community and organisational members
Questions 3, 4, 6	Questions 11, 13, 18, 20	Questions 5, 7, 8, 10, 12, 14, 19 21, 22 (9 of the 20 questions or 45%)
• **Members were given** enough information **about the group before they joined (7 yes)** • **Members** understand the purpose **of the group (7 yes)** • **Members** have enough support **to participate in the group and its activities (6 always, 1 most of the time)**	• Members are involved in **determining the next steps** of the work we are doing together (3 always, 4 most of the time) • It is **clear how decisions are made** in the group (6 always, 1 most of the time) • Member's **time and effort in the group is appreciated** by others group members (5 always, 2 most of the time) • Members **ideas and opinions are valued** and respected by other group members (6 always, 1 most of the time)	• People **understand what is expected** of them as part of the group (14 yes) • The group **agree on the way it works together** (8 always, 6 most of the time) • The **way we work is suitable** for our aim (7 always, 7 most of the time) • Members receive the **information** they need to participate fully in the group (13 always, 1 most of the time) • All group members are able to **contribute to the next steps** of the work we are doing together (10 always, 4 most of the time) • Members are **included in the decision makin**g of the group (11 always, 3 most of the time) • Members can be **honest with the group** and share ideas and opinions (11 always, 3 most of the time) • Members are an **equal member of the group** and have an equal say (12 always, 2 most of the time) • All members of the group are **valued and are able to contribute** to the aim of the group (14 always)

"Room for Improvement" (ONE or MORE respondents answered NO or UNSURE / SOMETIMES/ RARELY / NEVER)

The results for "room for improvement" based on overall survey responses are in Table 6 below. Both community and organisational members responded that the group has "room for improvement well" in 4 out of 20 (20%) of the multiple-choice questions. There were differences between community and organisation member responses as indicated in the first two columns of the table.

Table 6: "Room for improvement" results for individual multiple-choice questions

Community members only	Organisational members only	Both community and organisational members
Questions 11, 13, 18, 20	Questions 3, 4, 6	Questions 9, 15, 16, 17
Members are involved in determining the next steps **of the work we are doing together (1 rarely)** **It is** clear how decisions are made **in the group (1 sometimes)** **Member's** time and effort in the group is appreciated **by others group members (4 unsure)** **Members** ideas and opinions are valued **and respected by other group members (3 unsure)**	- Members were given **enough information** about the group before they joined (5 no, 1 unsure) - Members **understand the purpose** of the group (6 no, 1 unsure) - Members **have enough support** to participate in the group and its activities (1 sometimes)	- If there are **disagreements,** they are handled fairly (2 people unsure) - Members **skills, knowledge and experience contribute** to the group (2 sometimes, 1 unsure) - The **current membership** of the group is the right fit for our current activities (1 sometimes 2 unsure) **Tasks are shared** between group members (1 sometimes, 1 unsure)

Alignment with co-design principles

As discussed in the methodology section of this report, the two sets of co-design principles were mapped against the twenty multiple-choice questions to determine which principles were being measured by each question. Some questions measured more than one principle. None of the questions measured the TACSI principle Iterative. See Table 1 on page 7 for an overview of the mapping and Appendix C for the detail.

The group was considered successful in its implementation of a co-design principle if 60% or more of the multiple-choice questions that measured that principle were rated as "doing well" (note that: "doing well" is when ALL respondents answered YES or ALWAYS/MOST OF THE TIME).

The results of this analysis are in Table 7 over the page. These results show the number and percentage of questions rated as "doing well" by community members and organisation members. Results indicating the group was successful in its implementation of a co-design principle are highlighted in yellow.

Note: There is limited data available for Community West **principle 2** and **principle 4**. Only three questions measured **principle 2** and two questions measured **principle 4**. The limited data indicates potentially positive results for **principle 2** from organisations and neither a positive nor negative result for **principle 4**.
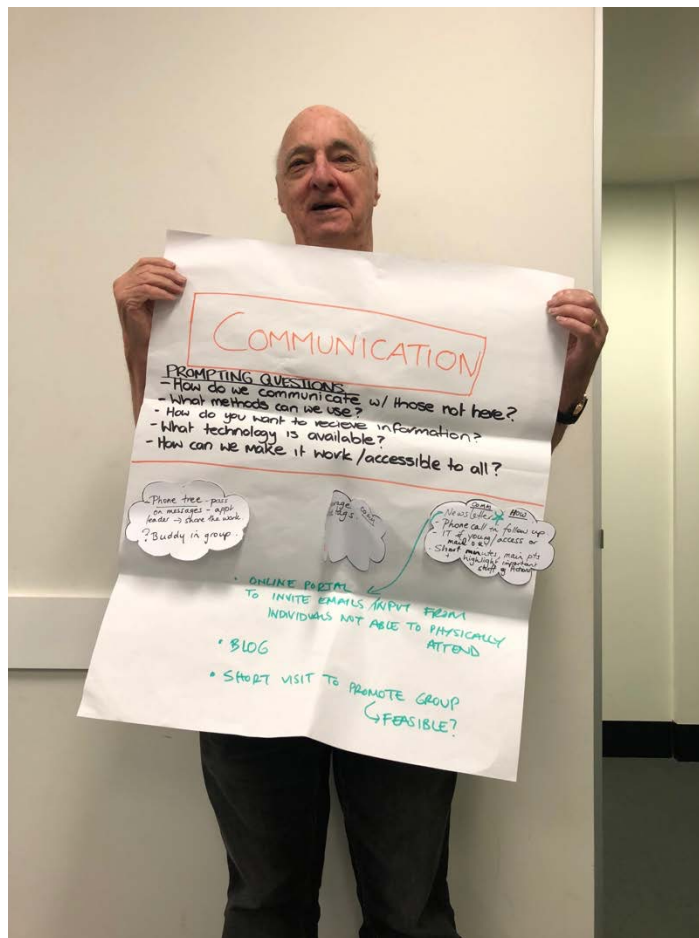
Table 7: Summary of multiple-choice question results for "doing well" based on co-design principles (ALL responses are YES or ALWAYS/MOST OF THE TIME) – successful implementation in <mark>yellow</mark>

Principles	Number of multiple-choice questions that measure this principle	Percentage of questions related to each co-design principle that were rated as "doing well" (60% or more = <u>successful</u> implementation of the co-design principle, highlighted in <mark>yellow</mark>)	
TACSI		**Community Members**	**Organisation Members**
Inclusive	9	56% (5 of 9 questions)	56% (5 questions)
Participative	9	67% (6 of 9 questions)	44% (4 questions)
Respectful	11	64% (7 of 11 questions)	82% (9 questions)
COMMUNITY WEST		**Community Members**	**Organisation Members**
1: People are assets: the skills and strengths they bring are used in the process of change	6	17% (1 question)	50% (3 questions)
2: People feel there is a safe space to speak up and be listened to	3	33% (1 question)	67% (2 questions)
3: People are equal partners in the process, ensuring accessibility for everyone	8	100% (8 questions)	62.5% (5 questions)
4: Everyone commits to contributing and benefits from being involved	2	50% (1 question)	50% (1 question)
5: Everyone is involved in decision making and it is clear how decisions are made	7	57% (4 questions)	86% (6 questions)

5.2 Quantitative Results Summary

Doing well:

Both Community and Organisation said the group is doing well with:

- Community and Organisation members understood what was expected of them as part of the group;
- Community and Organisation members were valued and able to contribute to the aim of the group;
- Community and Organisation members received the information they needed to participate fully;
- Community and Organisation members were included in decision making;
- Community and Organisation members could be honest with the group and share their ideas and opinions;
- Community and Organisation members were equal members of the group and had an equal say.

In addition, Community members were given enough information about the group before they joined and understood its purpose.

Room for improvement:

Community members:

- Community members were unsure whether the members time and effort was appreciated;
- Community members were unsure whether their ideas and opinions were valued.

Organisation members:

- Organisational members were unsure whether they had enough information before they joined the group;
- Organisational members were unsure about the purpose of the group.

Alignment with co-design principles

Table 8: Quantitative results – alignment with co-design principles

Principles	Successful implementation	
TACSI	**Community Members**	**Organisation Members**
Inclusive	NO	NO
Participative	YES	NO
Respectful	YES	YES
COMMUNITY WEST	**Community Members**	**Organisation Members**
1: People are assets: the skills and strengths they bring are used in the process of change	NO	NO
2: People feel there is a safe space to speak up and be listened to	NO	YES
3: People are equal partners in the process, ensuring accessibility for everyone	YES	YES
4: Everyone commits to contributing and benefits from being involved	INCONCLUSIVE	INCONCLUSIVE
5: Everyone is involved in decision making and it is clear how decisions are made	NO	YES

Note:

- Both Community and Organisation members indicated the group was less successful in implementing the TACSI co-design principle **inclusive**, but not significantly (in both groups 56% of the questions that measure this principle rated as "doing well" against a benchmark of 60% for "success").

- Both Community and Organisation members both indicated the group was less successful in implementing Community West **principle 1: People are assets: the skills and strengths they bring are used in the process of change.** This result was far more significant for Community members (only 1 question out of 6 was rated as "doing well" for this principle, or 17%) vs Organisation members (3 questions of 6 were rated as "doing well" for this principle or 50% of questions).

5.3 Qualitative Results

The full qualitative data results based on the **three key areas for exploration** (quality of the co-design process, benefits for participants, insights and recommendations for future work) are reported in Appendices D and E.

Strengths and weaknesses

Strengths:

Both community and organisation members mentioned the following strengths:
- The group gets along well with good rapport and respectful relationships;
- Group members are dedicated and enthusiastic about the purpose of the group;
- Group members have an equal say and listen to each other's views;
- The close to even split between organisation and community membership is a positive, especially as people with dementia and carers are involved;
- The co-design process was seen as a strength.

In addition:
- Community members mentioned leadership, venue and communication as strengths;
- Organisation members mentioned decision making by consensus and prioritising, shared responsibility for tasks, support provided, and information sharing and networking as strengths.

Weaknesses:

Both community and organisation members mentioned the following weaknesses:
- Time constraints and level of commitment required to be involved;
- The work moves too slowly.

In addition:
- Community members mentioned a lack of senior level buy-in from organisations;
- Organisation members mentioned that organisations should provide more assistance;
- Organisation members also mentioned membership, particularly, lack of people with dementia and retailers involved; and some misunderstandings between community members and services provided by organisation members.

Alignment with co-design principles

In addition to these strengths and weaknesses, the qualitative responses also indicated a high level of alignment with three of the TACSI co-design principles and four of the Community West co-design principles. See Appendix C for a detailed analysis of alignment with each of the co-design principles.

There were far more individual qualitative responses that related to the success of the co-design implementation (almost 40 responses) than there were related to the challenges (only 5 responses). Table 9 over the page provides a summary with successful implementation highlighted in yellow. There was **PARTIAL** success for some of the principles.

Table 9: Summary of the qualitative data results of alignment with the codesign principles (success in ==*yellow*==*)*

Principles	Evidence of successful implementation	
TACSI	**Community Members**	**Organisation Members**
Inclusive	PARTIAL	PARTIAL
Participative	YES	PARTIAL
Respectful	YES	YES
COMMUNITY WEST	**Community Members**	**Organisation Members**
1: People are assets: the skills and strengths they bring are used in the process of change	PARTIAL	PARTIAL
2: People feel there is a safe space to speak up and be listened to	YES	YES
3: People are equal partners in the process, ensuring accessibility for everyone	YES	YES
4: Everyone commits to contributing and benefits from being involved	YES	PARTIAL
5: Everyone is involved in decision making and it is clear how decisions are made	NO	PARTIAL

Benefits for participants

Both community and organisation members related the following benefits of their participation:
- They felt the positive and pleasant nature of the group, enabled the formation of friendships, that it had good rapport, was enjoyable and being involved was a positive experience;
- The group provided an opportunity to help others and the community and do something worthwhile;
- Involvement in the group led to increased knowledge and learning, new experiences and development of new skills;
- The group offered the opportunity to share members' skills and knowledge and make a personal contribution;
- Enabled group members to raise awareness about dementia in the community;

In addition:
- Community members commented that it provided an opportunity to interact with organisation members and link to their services, which they wouldn't have had otherwise;
- Organisation members said it helped to build the reputation of their organisation.

Just that it has been a positive experience and quite uplifting at times (organisational member)

5.4 Combined results – alignment with co-design principles

Table 10 below summarises the results for alignment with the co-design principles for both the quantitative and qualitative data. It shows that the qualitative data provides more evidence of successful implementation but that both sets of data have considerable similarities in their results. For example, both community and organisation members rated the group as not successful in implementing **inclusive** based on the quantitative data, while there was partial evidence for some success from the qualitative data. Similarly, both sets of data clearly indicate success in implementing **respectful** and **principle 3**.

Table 10: Summary of the quantitative and qualitative data results of alignment with the codesign principles (success in ==yellow==*)*

Principles	Quantitative		Qualitative	
TACSI	**Community**	**Organisation**	**Community**	**Organisation**
Inclusive	NO	NO	PARTIAL	PARTIAL
Participative	YES	NO	YES	PARTIAL
Respectful	YES	YES	YES	YES
COMMUNITY WEST				
1: People are assets: the skills and strengths they bring are used in the process of change	NO	NO	PARTIAL	PARTIAL
2: People feel there is a safe space to speak up and be listened to	NO	YES	YES	YES
3: People are equal partners in the process, ensuring accessibility for everyone	YES	YES	YES	YES
4: Everyone commits to contributing and benefits from being involved	INCONCLUSIVE	INCONCLUSIVE	YES	PARTIAL
5: Everyone is involved in decision making and it is clear how decisions are made	NO	YES	NO	PARTIAL

6 DISCUSSION

Overall, the survey results show general satisfaction of group members with the quality of the co-design process and a number of tangible benefits for all participants. There were some differences between community and organisational members' views that generally reflect the different contexts from which they participate. For community members, their lived experience of dementia and their passion to improve the quality of life of people in Forest Hill who are living with dementia and help others are a priority. For organisation members, their professional expertise and knowledge were primarily what they brought to the group. The results provide some useful insights and areas for improvement for this group and some general considerations for others who may be embarking on co-design.

This section will discuss the results of the evaluation as they relate to the three key areas for exploration:

1. Quality of the co-design process
2. Benefits for participants
3. Insights and recommendations for future work

In addition, other activities of the group and anecdotal reflections provide further insights into how well codesign was implemented by the group.

6.1 Quality of the co-design process

This section is organised by the TACSI co-design principles measured by the survey, reflecting on their alignment with the Community West principles and what this tells us about the quality of the co-design process in the Forest Hill DFC work.

Inclusive

The TACSI co-design principle **inclusive** is about the composition of the group and representation from key stakeholders, ensuring that there is the breadth of skills and strengths in the group so that the process of change to meet the objective of the group is successful. In the case of the Forest Hill DFC work, this would include people living with dementia who have the relevant lived experience, as well as others such as workers with professional experience, and carers of people living dementia. The **inclusive** principle aligns with Community West **principle 1: people are assets: the skills and strengths they bring are used in the process of change**. While the quantitative data indicated less success in implementing these principles, the qualitative data was quite positive.

Overall the data showed mixed results for this principle. In the qualitative data, both community and organisation members had positive comments about the existing diverse membership of the group, but there were also the greatest number of qualitative comments indicating "room for improvement" for these co-design principles. Organisation members particularly liked the voice of carers on the group and the equal number of community and organisation members. Organisation members said that more people living with dementia and more people with retail experience should be on the group. The quantitative data did not quite meet the benchmark for "success",

but it was quite close at 56% vs the benchmark of 60%. Both community and organisation members had concerns about whether their skills and knowledge contributed to the group and if the current membership of the group was appropriate.

In all co-design activities, it's important to ensure the people that are affected by the work are involved in the process. Involving people living with dementia can be challenging. Recently diagnosed people may still be coming to terms with their diagnosis. Some people living with dementia may not have had a formal diagnosis or acknowledge their dementia. Many people feel the stigma of living with dementia. Some people living with dementia have considerable cognitive decline, which can impact on their capacity to contribute meaningfully. Nevertheless, the concerns and needs of people living with dementia were included in other ways through discussions with dementia support groups and carers groups in the consultation phase of the project, and the inclusion of carers and one person living with dementia in the group. This was useful but not ideal as those accessing services are often more progressed in their dementia and less able to contribute meaningfully.

As the project targeted retail businesses, it would have also been good to have group members with retail experience. The group discussed this but was not successful in recruiting people with retail experience. Instead, the group sought advice from the WCC investment and economic development unit.

Participative

The **participative** principle is about ensuring that the process of co-design is open and responsive, benefiting from the knowledge of all participants to reach agreement about solutions. All participants are responsible for this occurring effectively.

This principle aligns with

- Community West **principle 4: everyone commits to contributing and benefits from being involved**
- There are also strong links with **principle 1: people are assets used in the process of change**
- and **principle 5: everyone is involved in decision making**.

There were mixed results from the data about the implementation of **participative** with variations between community and organisation members. The qualitative data indicated success for implementation of **participative** and **principle 1** from both community and organisation members. The quantitative data showed **participative** was successfully implemented according to community members only but was inconclusive for **principle 4** as limited questions measured this principle. Less success was indicated for **principle 1** by both community and organisation members. **Principle 5** was rated as successfully implemented by organisations only.

Group members indicated they were dedicated and enthusiastic about the shared purpose of the group and being able to raise awareness about dementia, using their skills and knowledge to make a personal contribution. In addition, co-design itself was mentioned as a strength, and involvement increased members' knowledge through new experiences and new skills.

Organisation members highlighted the strength of decision making by consensus and prioritising, and shared responsibility for tasks.

Community and organisation members did agree that they understood what was expected of them, the way the group worked together was suitable for its aim, and group members were able to share their ideas and opinions. While there was not enough data about Community West **principle 4** to draw any conclusions, organisation members believed that **principle 5** was successfully implemented. In particular, reaching agreement on the way the group worked together, being involved in determining and contributing to the next steps of the work, and being included in decision making. There was room for improvement to ensure group members skills, knowledge and experience contributed to the group, tasks were shared, and time and effort of group members, as well as ideas and opinions was valued and respected.

Meeting records show that community members had high attendance at the monthly meetings, were engaged and willing to contribute during meetings, responded to requests in between meetings, and supported events on behalf of the group when asked. This supports the evidence that they were highly engaged and willing to be involved and felt valued enough to be able to contribute and respond.

Organisation members mentioned that they were not given enough information prior to their involvement with the group and that they did not understand the purpose of the group. This suggests that more time could have been spent on recruiting and orientating organisation members. This may also be a reflection of the change in organisation membership from the inception of the work to the time of the survey. Only three original organisation members remained in the group.

Organisation members also indicated concerns about their own time constraints and the level of commitment required to participate and suggested the need for greater senior level buy-in from organisations. The level of commitment and time required to be involved and existing workloads was an issue for organisation members. This raises the question of resourcing for participation of organisation members. The qualitative comments about senior level buy-in may also be a reflection of this. Anecdotally, non-lead organisation members were less consistent in their attendance at meetings and not as readily able to contribute to actions between meetings compared to community members and lead organisations. Increasing senior level buy-in could provide greater recognition and legitimacy of the work and contribute to its potential success.

Respectful

Building on the inclusive principle, the **respectful** principle is about valuing everyone's input and ensuring that inequalities between group members are minimised. This also requires group members to put aside their own interests for the greater good of the work.

The **respectful** principle aligns most closely with:

- Community West **principle 3: people are equal partners in the process, ensuring accessibility for everyone,**
- but also has some alignment with **principle 2: people feel there is a safe space to speak up and be listened to**.

There was clear quantitative and qualitative evidence of success in implementing **respectful** and **principle 3**. There was some qualitative evidence of success in implementing **principle 2**. The quantitative questions that measured **principle 2** were limited and therefore inconclusive.

Community and organisation members felt they were equal members of the group, they had an equal say, could be honest with the group, share their opinions and listened to each other's views. Overall, they were positive about the support and information they had and felt valued and able to contribute to the aim of the group. Anecdotally, the group got along well, had good rapport and were respectful to each other. Participants reported in the qualitative data that it was enjoyable and pleasant.

The clear quantitative and qualitative evidence of success in implementing **respectful** and **principle 3** confirm the effectiveness of the following strategies by the lead organisations to balance the unequal power held by organisations:

- The importance of building rapport and trust was prioritised, with emphasis on getting to know each other such as having an informal morning tea as the first "meeting" and allowing time at all gatherings to share food and socialise;
- The group met in a local community venue rather than organisational offices;
- Time was spent developing shared group rules and ways of working together, including what would need to be in place to ensure respect between members and an environment where everyone gets a say.
- An external facilitator was engaged for the first few meetings to enable a more inclusive and less structured approach for all group members;
- Early meetings were in a workshop format to enable exploration of ideas and shared decision making;
- Organisational members were explicitly asked to leave their organisational "hats" at the door, including not wearing their ID lanyards or business wear;
- There were equal numbers of organisational and community members in the group;
- Community members were reimbursed for their time with shopping vouchers and provided with respite and transport if needed.

Iterative

The **iterative** principle is about trialling and testing possible solutions, making changes and testing again until the best outcome can be achieved. There is no equivalent Community West principle. This principle was not measured by the survey. Nevertheless, some observations can be made about how the group implemented this TACSI principle:

- The first meeting of the combined group of community and organisation members was a more "typical" meeting with a formal agenda, chair, note taker and set around tables. On reflection, this style of meeting lacked the rapport required to ensure genuine co-design of actions. As a result, IEPCP engaged an external facilitator and planned a series of "meetings" that were more like workshops with time spent on getting to know each other, involving all group members, determining ways of working together, and building group rapport and cohesion. This was critical in ensuring a positive working environment for the future. After a few months, the group was able to revert back to a more traditional

- meeting style and shared the chairing of meetings as group members became more familiar with each other.
- The group decided it needed a "brand" or logo to clearly identify its work. IEPCP engaged a graphic designer to develop some concepts. These were presented to and discussed by the group. As a result, feedback was incorporated, and the logo was further developed with the final open-door logo agreed to by group members a few months later. All group members were able to contribute to the logo development and could see it being shaped and changed based on their feedback. While not all group members loved the final concept, the process ensured group ownership was high.
- Similarly, considerable time was taken to develop a range of other resources to support delivery of the actions for the project, including an introductory flyer, brochure to promote the concept to retail businesses, and tips for businesses. Content was generated by the group, edited and changed over time to reflect the expertise of group members and external advisors such as the WCC economic and business development unit.
- The group agreed that it was important to train retail business staff in dementia awareness so they would be more dementia friendly. Training options were explored from providers such as Dementia Australia who presented one of its training sessions to the group to determine if it would be suitable for local businesses. It was agreed that a tailored session had to be developed instead. Over a period of 9 months the content was developed by all group members and delivery mode was explored. Interested businesses were consulted about what would work for them. The group did a run-through of the draft content and made further changes. As yet, this training has not been implemented due to the COVID-19 pandemic and restrictions on face to face gatherings.

Throughout the course of the work, the co-design process was applied to develop a way of working and agreed actions to make Forest Hill more dementia friendly. At each step, ideas and solutions were discussed, explored, drafted and amended based on input from group members as well as external contacts such as businesses and organisations.

6.2 Benefits of being involved for participants

It was clear from the qualitative data that there were many benefits of being involved in the Forest Hill DFC work, for both community and organisation members of the group. This is also supported by anecdotal evidence.

Friendship and inclusion

Community members developed friendships and enjoyed being part of the group. Over the 12 months of meetings prior to the survey, contact details were shared, computer help was provided; and support was given at times of stress, grief and bereavement.

> Group members said the "group was positive and cohesive", had "good rapport", "respectful relationships" and "provided an enjoyable experience" and "a chance to meet new people and make new friends"

Organisation members also enjoyed being part of the group and developed a sense of rapport. It was an enjoyable and positive experience for them.

Meetings were friendly and easy, food was shared, and socialising occurred before, during and after meetings.

> *Different opinions and information help in widening my knowledge and I feel friendships have resulted from our meetings (community member)*

Benevolence

For both community and organisation members, being able to share their own experiences and knowledge about dementia was very positive. It gave them a sense of doing important work, contributing to the community and helping others, especially on an issue they had a strong connection to and were passionate about.

> The group provided members an "opportunity to help others and the community" and "do something worthwhile"; The group offered the opportunity to share members' skills and knowledge and make a personal contribution. (survey results)

Capacity Building

All group members' skills and knowledge were enhanced by being involved in this work. In particular, new skills were developed in co-design, collaboration and partnership. Building the capacity of group members to understand what co-design is and how it can be implemented was an important element of the work and has a longer-term benefit to the individuals and organisations involved, and ultimately to the communities in which they live and work. Group members also experienced new and different ways of working, such as external facilitation of meetings, or use of technology to share information.

Mutual benefit

Group members benefited from each other's involvement. Organisation members provided individual support and links to services when there was a need. Some of the community members were linked to support services which they would not have accessed otherwise. Community members generously shared their lived experience of dementia with organisation members enabling them to learn first-hand about some of the day to day issues that carers and people with dementia face, particularly in a non-crisis and non-institutional environment.

The importance of creating good rapport, trust and group identity early on, and of equally valuing all members and respecting their contributions cannot be underestimated. Establishing good ways of working together provided positive benefits to all group members and contributed to the effectiveness of the work.

> *I have had assistance outside of our working group from two people who I only met through this (community member)*

6.3 Insights and recommendations for future work

This section outlines insights and recommendations for the Forest Hill DFC group and how they work together.

Ensure adequate representation on the group by all stakeholders targeted

At the start of any co-design process it is important to establish who should be involved to be more effective. In the case of the Forest Hill DFC work this would include more people living with dementia and people representing retail businesses. Other ways of involving people living with dementia in this work could be considered in the future. This could include attending dementia groups and taking ideas to them for discussion, recruiting individuals for consultation from time to time, and "walking with them" to better understand their experience of their local area.

In addition, given that the agreed action was to support businesses to become more dementia friendly, it would have been ideal to have people from retail businesses on the group when this became the focus. Options could be to approach the local business group.

Organisational support

A more strategic approach could be used to engage all organisations equally in the work. This could include gaining senior level buy-in, acknowledgement of involvement via memoranda of understanding, provision of appropriate resourcing and support from organisations involved, better orientation and information provision to organisation members, and clarity about the purpose of their involvement and the aim of the group.

Acknowledge time and commitment required to participate

Providing clear information to existing and new group members about the level of commitment and time required to be involved up front is important, as is regularly acknowledging the commitment made by all group members. It could be useful to ask participants how they can best participate and determine if that works for the group. For example, small groups may work on individual pieces of work. Some members may participate by email, telephone or online. Ensuring that members with caring roles are supported to participate as much as possible is also important. For community members, valuing their time and contribution through reimbursement is important.

Valuing contributions of group members

Similar to acknowledging the commitment and time of group members, it is extremely important to value and respect member's ideas and opinions and ensure that members' skills, knowledge and experience contribute to the work of the group. This requires skilful facilitation at group sessions and meetings.

Match the pace of the work with the group's needs

Some frustration was experienced by group members at what they felt was a slow pace of the work at times. This could be managed by being realistic about what can be achieved and

celebrating small achievements along the way. The group could build in small actions more often. Developing an action plan with timelines that the group can reflect on may be useful. It's also important to acknowledge the importance of taking time to build relationships and co-designing actions.

Equalise power

Implement strategies that ensure unequal power of group members is addressed and balanced as much as possible.

Other observations that may be useful for those embarking on co-design are:

- Invest time on building and maintaining rapport, trust and group cohesion to ensure a positive and productive working environment;
- Ensure all group members understand what co-design is and jointly decide the co-design principles that will be used to guide the way the group works;
- Regularly reflect on the way the group is working together and make adjustments as you go.

6.4 Limitations

There are several limitations of this evaluation methodology which highlight the need for some caution in analysing the results:

- As lead and support organisations, IEPCP and WCC developed the evaluation methodology and distributed the surveys, collected completed surveys and analysed the results. This may have impacted on participants responses in their surveys, given the positions of power both organisations hold in the group and also on confidentiality of the results. This is countered by the extensive work undertaken to balance the power, build rapport, and ensure group members are able to express their own views without judgement.
- IEPCP and WCC participated in the evaluation by completing the surveys. A recognised element of developmental evaluation, but also with potential to skew results given such a small number of participants (14). Both organisations acknowledged this at the start of the evaluation.
- Lack of co-design in the evaluation process-group members were not involved in designing and implementing the evaluation due to time constraints, raising a potential lack of ownership of the process and the results.
- In analysing the data, decisions were made by the IEPCP and WCC with regard to which co-design principle was being measured by each question and what type of or number of responses indicated "doing well" or "room for improvement". A more co-designed process would have included all group participants in this decision making but time did not allow it.
- Support was given to assist the only person with dementia in the group to complete the evaluation, by IEPCP. Whether this impacted on their responses is hard to know, but it could have. Alternately, an external person could have been engaged to do the "interview", but this also raises concerns about introducing a stranger to a person with

dementia and what other impact that may have had on their responses. As an alternative, another community member could have provided support;

- None of the questions in the survey the TACSI co-design principle of "Iterative" and few questions related to Community West principles 2 and 4.

7 CONCLUSION

This evaluation of the Forest Hill DFC group co-design process shows a high level of satisfaction with the quality of the co-design process, a number of benefits to participants, some insights into how the process could be improved, and considerations for future co-design evaluation.

While the survey showed there were some differences between community and organisational member's views, overall the process used did align with many of the codesign principles and the purpose of co-design. This data, along with other observations, indicate that the group developed a unified identity that emphasized collective contributions and decision making and valued members' skills and knowledge. Group members supported and encouraged each other, developing new friendships, connections, skills and knowledge. The strength of the co-design process meant that community members had strong engagement with the project and its actions.

This evaluation of the co-design process provides a useful guide for community service practitioners to replicate. Formally evaluating co-design processes using a participant survey can be useful to encourage reflection and improvement. Future evaluations of this type could be improved by clearly defining the co-design principles at the start of the process and ensuring a spread of questions to measure each principle. In addition, face to face interviews may provide richer data and opportunity to explore responses in more detail. Other techniques can also contribute to evaluation of co-design such as records and transcripts of activities, regular observation and reflection, outputs and outcomes.

Community and organisational members now have co-design skills that can be used to benefit the local community. While implementation was postponed due to COVID-19, the work can be resumed when interested businesses are ready to re-engage. This work has strengthened local partnerships between carers' organisations, Whitehorse City Council, community health, IEPCP and local businesses. The investment in social capital, together with the strong commitment derived through participation, will enable community to implement the project. The resources developed can be adapted to support other dementia friendly community work in other locations in the future.

The benefits of co-designing actions to build a more dementia friendly community have been demonstrated by this evaluation. Although the work was interrupted by COVID-19, the group is positive about what it has achieved and what it can implement in the future. Co-design can be a valuable and meaningful way to engage people with dementia and their carers to address issues of access and inclusion that people with dementia face every day in their local community.

8 LINKS & RESOURCES

Inner East Primary Care Partnership

Features resources developed by the Forest Hill Dementia Friendly Community to support businesses to become more dementia friendly

[Forest Hill Dementia Friendly Community](#)

Whitehorse City Council

Features a video of the Forest Hill Dementia Friendly Community group members talking about co-design

['Creating dementia-friendly communities'](#)

Dementia Australia

Resources and information for individuals, communities and organisations to assist all Australians to become dementia friendly

[Dementia Friendly Community hub](#)

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10 APPENDIX A: Evaluation design consideration

Evaluation methodologies considered for this research:

Developmental Evaluation

Developmental Evaluation (DE) is an evaluation approach which supports program development with a focus on innovation and adaptability within complex environments. It closely aligns with co-design principles: working with stakeholders to design and test ideas and solutions, adapting and changing as needed, and tailoring to fit specific complex contexts. (Patton 2008, 2011, 2012)

Evaluating co-design and participation

Man (et al) suggest that **evaluation of co-design** should focus on:

1. Assessing the benefits for participants

2. Assessing the quality of your co-design processes

3. Obtaining insights into how to achieve the intended outcomes

The Scottish Health Council provides a number of key questions to evaluate participation (2013, p.9):

- What was the planned activity?
- What happened?
- What were the gaps between the plan and the reality?
- What worked well?
- What were the problems?
- What was learned?
- What are recommendations for planning future participation activities?

Evaluating Dementia Friendly Communities

Blood and Associates (2016) developed a set of indicators and measures to specifically evaluate DFC based on a review of evidence and existing DFC evaluations and using a program logic approach (inputs, outputs, outcomes and impact).

Reviewing their work, co-design could be viewed as both an "input", i.e. structures and resources which enable DFC; and an "output" i.e. the activities undertaken to create a DFC. They suggest that a **process evaluation** is the most suitable measure for inputs and can also be a part measure for outputs, with the following indicators:

- Involvement of people with dementia
- Multiple stakeholder alliance
- Financial and human resources
- High level political commitment

Evaluating process (formative evaluation)

The Scottish Health Council (2013, p.10) note that a **formative evaluation** "would examine the progress of participation against the project objectives and identify unexpected barriers or outcomes as part of a continuous improvement cycle". By doing this the participation process could be improved with timely feedback from participants in the midst of the work. The downside is that a what is working well and what is not may not be entirely clear while the work is still in progress.

The WK Kellogg Foundation (2017, p.120), suggest a **process (formative) evaluation** should:

- Understand if a strategy, initiative or program is being implemented as planned and according to schedule

- Assess if the effort is producing the intended outputs

- Identify strengths and weaknesses of the effort

- Inform mid-course adjustments

11 APPENDIX B: The survey

Forest Hill Dementia Friendly Community Survey

<u>Information about this Survey</u>

Introduction

The Forest Hill Dementia Friendly Community working group is made up of community service organisation representatives and community members. The group is co-designing actions to make Forest Hill a place where people living with dementia, and their family and friends, feel supported to participate in their community. Co-design is about working together as equals, exchanging information, using the skills of group members, and involving all group members in the process.

This Survey

This survey is for members of the Forest Hill Dementia Friendly Community (DFC) Working Group. You are invited to answer the survey questions.

The aim of the survey is to help the group understand and reflect on how it is working together. It is your choice whether you participate in the survey. Please be honest and open with your answers.

The survey results will be shared with all members of the group and the organisations represented in the Group, including past and future members, and others, with the purpose of it being used to reflect on our work, report on our work, and help others to learn from our experiences. Information may be shared through a range of formats including written reports, presentations, meetings, forums and events.

If you have any questions or concerns please contact:

Sharon Porteous, Inner East Primary Care Partnership
Phone: (03) 8843 2254 or Email: <u>Sharon.porteous@iepcp.org.au</u>

**PLEASE BRING YOUR COMPLETED SURVEY TO OUR NEXT MEETING
ON 20 AUGUST 2019**

BEFORE YOU COMPLETE THIS SURVEY, PLEASE READ THE "INFORMATION ABOUT THIS SURVEY" PROVIDED

The survey is in two parts. In the first part, please CIRCLE the answer that best reflects your own opinion.
In the second part please write what you think in your own words. There are no right or wrong answers. Please be honest.

"the Group" – refers to the Forest Hill Dementia Friendly Community Working Group

1	Who do you represent in the Group?	Community Member	Organisation

PART1: PLEASE READ THE STATEMENTS AND CIRCLE THE ANSWER THAT BEST REFLECTS YOUR OWN OPINION

2	Before you joined this Group, were you involved in any other activities that were co-designed?	YES	NO	UNSURE
3	I was given enough information about the Group before I joined	YES	NO	UNSURE
4	I understand what the purpose of the Group is	YES	NO	UNSURE
5	I understand what is expected of me as part of the Group	YES	NO	UNSURE

6	I have enough support to participate in the Group and its activities	Never	Rarely	Sometimes	Most of the time	Always	Unsure
7	The Group agreed on the way the Group works together	Never	Rarely	Sometimes	Most of the time	Always	Unsure
8	The way we work together is suitable for our aim	Never	Rarely	Sometimes	Most of the time	Always	Unsure
9	If there are disagreements, they are handled fairly	Never	Rarely	Sometimes	Most of the time	Always	Unsure
10	I receive the information I need to participate fully in the Group	Never	Rarely	Sometimes	Most of the time	Always	Unsure
11	I am involved in determining the next steps of the work we are doing together	Never	Rarely	Sometimes	Most of the time	Always	Unsure
12	All Group members are able to contribute to the next steps of the work we are doing together	Never	Rarely	Sometimes	Most of the time	Always	Unsure
13	It is clear how decisions are made in the Group	Never	Rarely	Sometimes	Most of the time	Always	Unsure
14	I am included in the decision making of the Group	Never	Rarely	Sometimes	Most of the time	Always	Unsure

15	**My skills, knowledge and experience contribute to the Group**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
16	**The current membership of the Group is the right fit for our current activities**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
17	**Tasks are shared between Group members**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
18	**My time and effort in the Group is appreciated by other Group members**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
19	**I can be honest with the Group and share my ideas and opinions**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
20	**My ideas and opinions are valued and respected by other Group members**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
21	**I am an equal member of the Group and have an equal say**	Never	Rarely	Sometimes	Most of the time	Always	Unsure
22	**All members of the Group are valued and are able to contribute to the aim of the Group**	Never	Rarely	Sometimes	Most of the time	Always	Unsure

PART 2: WRITE YOUR ANSWER TO EACH QUESTION IN THE SPACE PROVIDED

23	**Why did you/your organisation want to be involved in this work?**	
24	**What benefits and rewards have you/your organisation experienced from being part of the Group and this work?**	
25	**Please tell us about any negative impacts being part of the Group and this work may have had on you/your organisation**	

26	**What is working well for the Group?**	
27	**What could be changed to improve the Group?**	
28	**Is there anything else you would like to tell us about how we work together and your experience in the Group?**	

12 APPENDIX C: Mapping of co-design principles measured by each multiple-choice question

Qn	Questions with rationale for allocation of co-design principles	Related to TACSI co-design principles:	Related to Community West co-design principles
3	I was given enough information about the group before I joined (P=process is open, empathetic and responsive)	Participative Inclusive	3 Equal partners/ accessible
4	I understand what the purpose of the group is (P=dialogue and engagement generate shared meaning)	Participative	3 Equal partners/ accessible
5	I understand what is expected of me as part of the group (P=dialogue and engagement generated shared meanings)	Participative	3 Equal partners/ accessible
6	I have enough support to participate in the group and its activities (P=open and empathetic process, R=Strategies used to remove inequality)	Participative Respectful	3 Equal partners / accessible
7	The group agreed on the way the group works together (I=involved in framing the issue)	Inclusive	5 Involved decision making 3 Equal partners / accessible
8	The way we work together is suitable for our aim (P= all responsible for effectiveness of process; R = negotiating differences for the common good)	Participative Respectful	4 All commit to contribute and benefit 5 Involved decision making
9	If there are disagreements, they are handled fairly (P=process is open, empathetic and responsive; R=input is valued and has equal standing)	Participative Respectful	5 Involved decision making 2 Safe space/listened to
10	I receive the information I need to participate fully in the group (R=strategies used to remove inequality, input is valued and has equal standing)	Respectful	3 Equal partners/ accessible
11	I am involved in determining the next steps of the work we are doing together (I=involved in the co-design project from framing to testing solutions, R= negotiate differences for the "common good"	Inclusive Respectful	5 Involved decision making
12	All group members are able to contribute to the next steps of the work we are doing together (I=involved in the co-design project from framing to testing solutions; using knowledge, skills, experience, R = negotiate differences for the "common good")	Inclusive Respectful	5 Involved decision making
13	It is clear how decisions are made in the group (P=process is open, empathetic and responsive)	Participative	5 Involved decision making
14	I am included in the decision making of the group (I=all involved in framing issue and developing and testing solutions; R=strategies used to remove inequality)	Inclusive	5 Involved decision making
15	My skills, knowledge and experience contribute to the group (I=uses experience, knowledge and skills of stakeholders)	Inclusive	1 People are assets used for change

Qn	Questions with rationale for allocation of co-design principles	Related to TACSI co-design principles:	Related to Community West co-design principles
16	The current membership of the group is the right fit for our current activities (I=includes reps from critical stakeholder groups)	Inclusive	1 People are assets, bringing skills
17	Tasks are shared between group members (I=stakeholders are involved in framing and testing solutions; P=all participants are responsible for the effectiveness of the process)	Inclusive Participative	4 All commit to contribute and benefit 1 People are assets
18	My time and effort in the group is appreciated by other Group members (R=input is valued)	Respectful	1 People are assets
19	I can be honest with the group and share my ideas and opinions (R=input is valued and has equal standing; strategies are used to remove inequality; P = process is open)	Respectful Participative	2 Safe space/ listened to
20	My ideas and opinions are valued and respected by other group members (R=input is valued and has equal standing)	Respectful	2 Safe space/ listened to 1 People are assets
21	I am an equal member of the group and have an equal say (R=input is valued and has equal standing)	Respectful	3 Equal partners/ accessible
22	All members of the group are valued and are able to contribute to the aim of the group (R=input is valued and has equal standing; I = stakeholders are involved)	Respectful Inclusive	3 Equal partners/ accessible 1 eople are assets used for change

Summary:

TACSI	Survey questions that measure this principle	Number of questions that measure this principle	Community West	Survey questions that measure this principle	Number of questions that measure this principle
Inclusive	3, 7, 11, 12, 14, 15, 16, 17, 22	9	1 People are assets	15, 16, 17, 18, 20, 22	6
Participative	3, 4, 5, 6, 8, 9, 13, 17, 19	9	2 Safe space/listened to	9, 19, 20	3
			3 Equal partners/accessible	3, 4, 5, 6, 7, 10, 21, 22	8
Respectful	6, 8, 9, 10, 11, 12, 18, 19, 20, 21, 22	11	4 All commit to contribute	8, 17	2
			5 Decision making	7, 8, 9, 11, 12, 13, 14	7

13 APPENDIX D: Qualitative Data Results based on 3 key areas for exploration

Note: Where responses from each group are similar, they are placed next to each other in the table. Numbers in brackets represent the number of individual responses.

1. Assessing the quality of your co-design processes	
Strengths (what's working well)	
Community members	**Organisation Members**
Get along well / cohesive / respectful (3)	Good rapport and relationships
Enthusiasm of members	Dedication of members to the purpose
Co-design	Co-design
Everyone has an equal say and is heard	Listening to others' views
Diverse membership	Voice of carers and people with dementia / Equal number of organisational and community members
	Able to find consensus and make decisions / Able to prioritise direction (2)
Leadership	
Time isn't wasted	
	Information sharing and networking
Venue (for meetings)	
	Support
Communication	
	Shared responsibility for tasks
	Regular meeting attendance
Weaknesses (what were the problems)	
Community members	**Organisation Members**
Time consuming	Existing workload / time constraints / level of commitment (3)
Moving too slow – other people are starting to do similar work	The work moves slowly
Lack of buy-in from senior management in organisations / need to increase organisational investment (2)	Greater assistance from organisational representatives
	Not many people with dementia involved; Lacks business/retail perspective on the group
Personal impact of calling dementia a "disease"	
	Misunderstandings between community and organisations about current services and what they can provide
No permanent chair	

2. Assessing the benefits for participants	
Community members	**Organisation Members**
Met new people / being part of the group / friendships/ pleasant group (4)	Rapport / enjoy doing group and community work / positive and uplifting to be involved (2)
Learning / education / increasing knowledge eg. about co-design (3)	Enhanced knowledge and experiences which are valued eg. co-design skills – can share with workplace (3)
Able to offer personal contribution / experience (3)	It's already part of /related to our work (3)
Able to help others / Sense of involvement / do something worthwhile / important work (5)	Helps the community / individuals with dementia and their carers (3)
Increases awareness (about dementia)	Raises awareness (about dementia)
Interactions between consumers and the sector / links to services (2)	
	Share similar values and goals
Hear different views	
	Consumer driven
	Builds reputation of organisation
3. Obtaining insights into how to achieve the intended outcomes	
Community members	**Organisation Members**
Increase the pace of the work	Quicker decision making/move the work faster
	• More people with dementia should be involved • People with business/retail experience should be involved
Increase senior management buy-in / investment	Organisational members should provide more assistance
Have a permanent chair	
	More anonymous suggestions

14 APPENDIX E: Qualitative data evidence of successful implementation of co-design principles

TACSI:	Type member	Positive evidence (successful implementation)	Negative evidence (change needed)
Inclusive	COMMUNITY	• Diverse membership • Able to offer person contribution/experience (3)	• Increase senior management buy-in/investment (2)
	ORGANISATION	• Voice of carers and people with dementia • Equal number of organisational and community members • It's already part of / related to our work (3) • Consumer driven	• Not many people with dementia involved – more should be involved • People with business / retail experience should be involved
Respectful	COMMUNITY	• Get along well / cohesive / respectful (3) • Everyone has an equal say and is heard • Met new people/being part of the group / friendships / pleasant group (4) • Hear different views	
	ORGANISATION	• Good rapport and relationships • Listening to others' views • Support • Rapport / enjoy doing group and community work / positive and uplifting to be involved (2)	
Participative	COMMUNITY	• Enthusiasm of members • Co-design • Communication • Able to help others/sense of involvement/doing something worthwhile/important work (5)	
	ORGANISATION	• Dedication of members to the purpose • Co-design • Able to find consensus and make decisions / able to prioritise direction (2) • Shared responsibility for tasks	• Organisational members should provide more assistance

		• Helps the community / individuals with dementia and their carers • Share similar values and goals	

COMMUNITY WEST	Type group member	Qualitative data evidence of "doing well"	Qualitative data evidence of "room for improvement"
1. People are assets: the skills and strengths they bring are used in the process of change	COMMUNITY	• Diverse membership • Able to offer personal contribution / experience (3)	• Increase senior management buy-in / investment (2)
	ORGANISATION	• Voice of carers and people with dementia • Equal number of organisational and community members • It's already part of / related to our work (3) • Consumer Driven	• Not many people with dementia involved – more should be involved • People with business / retail experience should be involved
2. People feel there is a safe space to speak up and be listened to	COMMUNITY	• Get along well / cohesive / respectful (3) • Met new people / being part of the group / friendships / pleasant group (4) • Everyone has an equal say and is heard • Hear different views	
	ORGANISATION	• Good rapport and relationships • Listening to others' views • Support • Rapport / enjoy doing group and community work / positive and uplifting to be involved (2)	
3. People are equal partners in the process, ensuring accessibility for everyone	COMMUNITY	• Get along well / cohesive / respectful (3) • Met new people / being part of the group / friendships / pleasant group (4) • Everyone has an equal say and is heard • Communication	
	ORGANISATION	• Good rapport and relationships • Listening to others' views	
4. Everyone commits to contributing and benefits from being involved	COMMUNITY	• Enthusiasm of members • Co-design • Able to help others / sense of involvement / do something worthwhile / important work (5)	

	ORGANISATION	• Dedication of members to the purpose • Co-design • Shared responsibility for tasks • Helps the community / individuals with dementia and their carers (3) • Share similar values and goals	• Organisational members should provide more assistance
5. Everyone is involved in decision making and it is clear how decisions are made	COMMUNITY		
	ORGANISATION	• Able to find consensus and make decisions / able to prioritise direction (2)	