



Minerva Access is the Institutional Repository of The University of Melbourne

**Author/s:**

Thompson, Z; Tamplin, J; Clark, I; Baker, F

**Title:**

Therapeutic Choirs for Families Living with Dementia: A Phenomenological Study

**Date:**

2023-01-01

**Citation:**

Thompson, Z., Tamplin, J., Clark, I. & Baker, F. (2023). Therapeutic Choirs for Families Living with Dementia: A Phenomenological Study. *Activities Adaptation and Aging*, 47 (1), pp.40-74. <https://doi.org/10.1080/01924788.2022.2056682>.

**Persistent Link:**

<https://hdl.handle.net/11343/326697>



35 **Abstract**

36 This paper seeks to represent the perspectives of community-dwelling people who are living  
37 with dementia and their family care-partners, who participated community-based, therapeutic  
38 choirs that were formed as part of the Remini-Sing project. Interpretative Phenomenological  
39 Analysis (IPA) was used to analyse data from interviews with fourteen participants (7 people  
40 living with dementia [4 women, mean age = 82] and 7 care-partners [5 women, mean age =  
41 68]). Eight themes identified the perceived benefits of choir singing and elements of the  
42 choirs and research project more broadly that influenced participation. Findings support past  
43 research that suggests choir singing is an accessible and enjoyable activity that can support  
44 the health and wellbeing of people living with dementia and their family care-partners.  
45 Challenges with recruitment and sustainability of programs post-research are highlighted.

46

47 Key words: dementia, family care-partners, choir, singing, music therapy

48

49 Dementia is an umbrella term for a range of degenerative neurological conditions that can  
50 impact various components of cognition; these may include memory, executive function,  
51 social cognition, language and communication, and motor planning (World Health  
52 Organisation, 2004). As the prevalence of dementia continues to grow, action plans to  
53 support people living with dementia are becoming prioritised globally (World Health  
54 Organisation, 2012). Recently, the discourse in dementia care has shifted towards greater  
55 recognition of the need to support people to live well with dementia (Dementia Alliance  
56 International, 2017; Rowe, Brown, & Holland, 2014), and to maximise independence and  
57 living at home (Australian Government Department of Health, 2015). There is a strong call to  
58 develop and implement non-pharmacological supports for people living with dementia to  
59 address a range of symptoms and support needs that medication cannot treat (Sikkes et al.,  
60 2021). However, despite this shift towards non-pharmacological supports, people with  
61 dementia continue to report that upon receiving their prognosis, the focus continues to be on  
62 preparing for the worst, rather than focusing on how people can live well as their dementia  
63 progresses (Swaffer, 2018). Social relationships, connectedness, positive environments and a  
64 sense of agency and autonomy are described by people with dementia as key factors that  
65 influence their quality of life (Holopainen, Siltanen, Pohjanvuori, Makisalo-Ropponen, &  
66 Okkonen, 2019; O'Rourke, Duggleby, Fraser, & Jerke, 2015). However, people with  
67 dementia also describe a lack of opportunities to participate in society (Biggs, Carr, &  
68 Haapala, 2019; Clarke & Bailey, 2016).

69 People with dementia who live at home may rely on informal support from family or  
70 close friends (henceforth referred to as care-partners) (Brodaty & Donkin, 2009; Brooks,  
71 Ross, & Beattie, 2015). Literature focusing on maintaining the wellbeing of care-partners is  
72 prominent (Brooks et al., 2015), however, negative depictions of ‘caregiver burden’ often  
73 results, further contributing to the stigma that impacts people with dementia (Dementia  
74 Australia, 2018). The discourse is beginning to shift to focus towards understanding how  
75 challenging and positive aspects of supporting a loved one can influence the wellbeing of  
76 care-partners in dementia (Grover, Nehra, Malhotra, & Kate, 2017), however there remains a  
77 need to develop and evaluate interventions or activities that support their mutual relationship  
78 (Yu, Cheng, & Wang, 2018).

79 Singing has been described as a fun and accessible activity for older adults that can  
80 promote social connections and better health and wellbeing (Clements-Cortés & Yip, 2020;  
81 Clements-Cortes, 2013) and increasingly recognised as an accessible and therapeutic activity  
82 for people living with dementia (McDermott, Crellin, Ridder, & Orrell, 2013) due to the  
83 capacity for music to stimulate music-evoked autobiographical memories (El Haj, Fasotti, &  
84 Allain, 2012), and emotional wellbeing (Huber et al., 2021; Matthews, Chang, May,  
85 Engstrom, & Miller, 2009).

86  
87 Community-based singing groups for people with dementia and their informal care-  
88 partners are becoming more common around the world (Clark, Tamplin, & Baker, 2018;  
89 Harris & Caporella, 2018; Osman, Schneider, & Tischler, 2016). There have been several  
90 qualitative studies published regarding the experience of people with dementia and care-  
91 partners participating in such community-based groups, which reveal that community-based  
92 choirs provide an enjoyable space for participants to connect socially and experience personal  
93 benefits such as improved mood, connection to identity, and mutuality in relationships  
94 between care-partners and participants living with dementia (Clark et al., 2018; Lee, O'Neill,  
95 & Moss, 2020; McCabe, Greasley-Adams, & Goodson, 2015; Osman et al., 2016; Unadkat,  
96 Camic, & Vella-Burrows, 2016). Research suggests that there may be aspects of community-  
97 based choir singing that influence the accessibility of choir participation for people with  
98 dementia, which may impact the enjoyment and benefits they experience (McCabe et al.,  
99 2015; Unadkat et al., 2016). Studies with older adults and staff living or working in an  
100 independent living community and community choir singing found that effective leadership  
101 and program features (such as location, timing, preferred repertoire) were important  
102 considerations for designing an accessible choir program (Thompson, Baker, Tamplin, &

103 Clark, 2021). As credentialed music therapists are trained to assess and respond to the needs  
104 of people living with dementia and their care-partners, the skills and training of music  
105 therapists may be useful in designing and facilitating community-based choirs for these  
106 people with varied and complex access needs (Clements-Cortés, 2019). However, the  
107 majority of research relates to choirs led by community-musicians, rather than designed and  
108 led by credentialed music therapists (Clark et al., 2018; Lee et al., 2020). Further  
109 understanding of the impact of therapeutic design and facilitation of choirs for people living  
110 with dementia and care-partners is therefore needed. The ReminiSing project, from which the  
111 current study stems, aimed to investigate the potential benefits of therapeutic choir singing  
112 for people living with dementia and care-partners, and the role of music therapists in this  
113 context. The results of this project are currently under review for publication. As the  
114 perspectives of people living with dementia are often underrepresented (Novek & Wilkinson,  
115 2019), the present study aimed to ensure that the lived experiences and perspectives of  
116 participants in the ReminiSing project are represented in the literature, and to provide further  
117 insights into the findings of the larger study. The following section provides further context  
118 to the study and the resulting aims of the current paper.

119

## 120 **Background to Present Study**

121 The Remini-Sing project was a Randomised Controlled Trial (RCT) led by researchers at  
122 The University of Melbourne in partnership with Uniting Agewell, that involved establishing  
123 community-based therapeutic choirs for community-dwelling people living with dementia  
124 and family care-partners in Victoria, Australia. The choirs were established during 2018 and  
125 were intended to continue on beyond the completion of the 20-week research project.  
126 However, due to low recruitment numbers and lack of suitable funding options, the choirs  
127 were unable to be sustained long-term. Consequently, only two of the three choirs formed as  
128 part of the RCT chose to continue beyond the end of the 20-week trial period, with additional  
129 funding sourced by participants, the research team, and Uniting Agewell that lasted until mid-  
130 2019. Although our initial hopes were for the choirs to be sustained beyond this additional  
131 funding period, further recruitment and funding challenges precluded this from eventuating.  
132 One choir continued on in a self-sustaining manner for an additional year (2020), while the  
133 other chose to disband, and 2/3 of the participants chose to join an existing choir (the choir  
134 established during the pilot study, which continues on). In the present study, we interviewed  
135 participants from the two choirs that continued following the end of the RCT, towards the  
136 end of the additional funding period in 2019. As part of our commitment to representing the

137 perspectives of participants, we adopted a qualitative, phenomenological approach, and as  
138 such, our aims were emergent and evolved throughout the project. (Smith, Larkin, &  
139 Flowers, 2009). While we initially aimed to interview participants in order to gain insights  
140 into their experience of participating in ongoing therapeutic, community-based choirs, the  
141 focus of our study shifted to understanding their experience of being involved in the project  
142 more broadly. Firstly, as we felt it important to acknowledge the challenges involved in the  
143 study and honour their experiences of this, and secondly, to provide insight into the  
144 experience of being involved in a program designed for research purposes, and how this may  
145 impact participants experience of wellbeing in such programs. With this in mind, research  
146 question was broad: how did participants who are living with dementia and family care-  
147 partners experience participating in the Remini-Sing choirs?  
148

## 149 **Method**

### 150 **Study Design**

151 **Interpretative Phenomenological Analysis.** Phenomenology in research relates to  
152 qualitative approaches in which researchers aim to understand the lived experience of  
153 participants of a particular phenomenon (e.g. a specific experience or event) (Finlay, 2011;  
154 Smith et al., 2009). Phenomenology is not generalisable; rather, it aims to produce a nuanced  
155 understanding of participants' lived experience that can illuminate findings from other  
156 research and clinical practice (Finlay, 2011). Interpretative phenomenological analysis (IPA)  
157 is a phenomenological approach to analysis that is underpinned by three tenets: a) reflexive  
158 analysis of participants' subjective experience; b) a focus on the unique (ideographic)  
159 experiences of participants in a particular context; and c) an understanding that interpretation  
160 (both on the part of the participant and the researcher) is an unavoidable aspect of analysis  
161 that cannot be disregarded (Finlay, 2011; Smith et al., 2009). In this approach, participants  
162 make sense of their experiences of a phenomenon, while researchers interpret the sense-  
163 making of the participants, rather than searching for answers that are pre-defined (Smith et  
164 al., 2009). IPA was selected for the present study, firstly, as we recognise that perspectives  
165 of people living with dementia remain underrepresented in the literature, and aimed to  
166 understand their perspectives on their lived experiences of being involved in the Remini-Sing  
167 study and choirs. Secondly, we felt it important to honour the ideographic experiences  
168 participants in relation to both the research and choir contexts.  
169

170           **Researcher Reflexivity.** In traditional and descriptive phenomenology, researchers  
171 attempt to set aside their pre-conceived ideas that may influence their interpretation of data  
172 (Smith et al., 2009). However, IPA acknowledges the impossibility of disregarding the  
173 researcher’s own interpretations, and instead advocates for researchers to acknowledge their  
174 potential biases through reflexive processes throughout the analyses (Finlay, 2009). In the  
175 present study, we exercised reflexivity during analysis through maintaining a reflexive  
176 journal (author 1), and supervision (between authors 1 and 4). Here, we share some of the  
177 authors’ pre-conceptions for transparency.

178           Author 1 (ZT), who conducted the interviews and primary analysis, had been  
179 facilitating the choir that resulted from the Remini-Sing pilot study, and consequently had  
180 developed preconceptions about facilitation. ZT also attended one of the choirs involved in  
181 the present study for two months, and the other for one session prior to engaging participants  
182 in the interviews, to build familiarity and rapport (Thompson, Baker, Clark, & Tamplin,  
183 2021). Preconceptions therefore, may have formed about choir members based on their  
184 existing relationship with Author 1. Authors 2, 3 and 4 (IC, JT, and FB) have extensive  
185 experience working clinically and researching the effects of music and singing for people  
186 with dementia, which may have also influenced their a priori assumptions. Throughout the  
187 research process, all authors practiced reflexivity through meetings and discussions, and ZT  
188 kept a reflexive research journal.

189

## 190 **Recruitment and Participants**

191           Ethics approval for this project was granted by The University of Melbourne (Ethics  
192 ID: 1749728) and written consent obtained prior to participation in interviews. Participants  
193 were able to withdraw at any time, and the researcher frequently checked for ongoing consent  
194 during the interviews. Inclusion criteria were for participants who were: a) able to speak  
195 English; b) over the age of 65; c) living with a clinical diagnosis of dementia (any type), or d)  
196 a family care-partner of someone who has dementia; e) living at home in the community; and  
197 f) attending a Remini-Sing choir for more than six months. In this study, we did not collect  
198 specific diagnoses of participants, other than that they had a confirmed diagnosis of dementia.  
199 This was due to a commitment to ensuring that the study was open to people of any type of  
200 dementia, and acknowledging that the music therapists who facilitated the choir were trained  
201 to assess and tailor activities to meet the specific needs of individual participants, regardless  
202 of diagnoses.

203

204 **Format of the Choirs**

205 The structure of each choir session was designed based on the Therapeutic Group  
206 Singing (TGS) model that emerged from the Remini-Sing pilot study (Tamplin, Clark, Lee,  
207 & Baker, 2018). This model was informed by person-centred care, Kitwood's theory of  
208 Validation (Kitwood, 1997), and Community Music Therapy (Stige & Aarø, 2011). Sessions,  
209 facilitated by one or two registered music therapists, were approx. 90 minutes in duration,  
210 and included warm-ups, singing participant-selected repertoire, and more challenging singing  
211 activities when appropriate, followed by afternoon tea. Participation was aided by having  
212 lyrics presented on a projector or television screen.

213

214 **Data Collection**

215 Participants engaged in semi-structured interviews as either: a) individuals; b) dyads;  
216 c) focus groups; or d) a combination of the three options, according to their preference  
217 (Thompson, Baker, Clark, et al., 2021). Participants could choose the location and time of the  
218 interviews, which were audio-only recorded on a mobile device. Interview questions were  
219 initially broad, so as to not lead the interview in a particular direction and to allow for any  
220 topics that might arise to be explored (Smith et al., 2009). However, broad, explorative  
221 questions typical of phenomenological interviews are not always accessible for people living  
222 with dementia (Novek & Wilkinson, 2019). Based on past research on making qualitative  
223 interviews accessible for participants with dementia (Cridland, Phillipson, Brennan-Horley,  
224 & Swaffer, 2016; Novek & Wilkinson, 2019; Thompson, Baker, Clark, et al., 2021), an  
225 interview schedule with semi-structured questions and adaptive prompts for participants who  
226 may have had difficulty with communication, or difficulty recalling the program was created  
227 and used as needed (Appendix 1).

228

229 **Data Analysis**

230 Data was analysed following the six-step IPA procedure described by Smith et al.  
231 (2009) (Figure 1). Interviews were transcribed and read several times by ZT to enable  
232 immersion in the data. Initial noting and exploratory comments were made, which were  
233 categorised as descriptive (represented by plain text), linguistic (italicised) and conceptual  
234 (underlined) comments. The exploratory comments were used to inform the construction of  
235 emergent themes, through transforming the comments into succinct conceptual ideas (Smith  
236 et al., 2009). ZT then identified commonalities between themes, grouping similar themes and  
237 creating a descriptive label (superordinate themes), while discarding themes that did not align

238 with the emerging concepts. These steps were repeated for each interview, before a final  
 239 cross-case analysis was conducted to identify ‘recurrent themes’ across all participants’  
 240 experiences. For focus-group analyses, we used an adapted form of IPA (Palmer, Larkin, de  
 241 Visser, & Fadden, 2010; Rabiee, 2004), to navigate the complexity of having multiple voices  
 242 contributing to the discussion. This included an additional four steps (Figure 2) that  
 243 functioned to re-address the data, considering each factor that may have potentially  
 244 influenced participants’ responses, and examining the function of these responses. These  
 245 detailed steps ensured that contextual group factors were taken into consideration. For each  
 246 interview and after each stage of analysis, the notes and themes were reviewed by FB. A  
 247 meeting was held between the ZT and FB after each step to discuss and reflect on each  
 248 other’s interpretations.  
 249

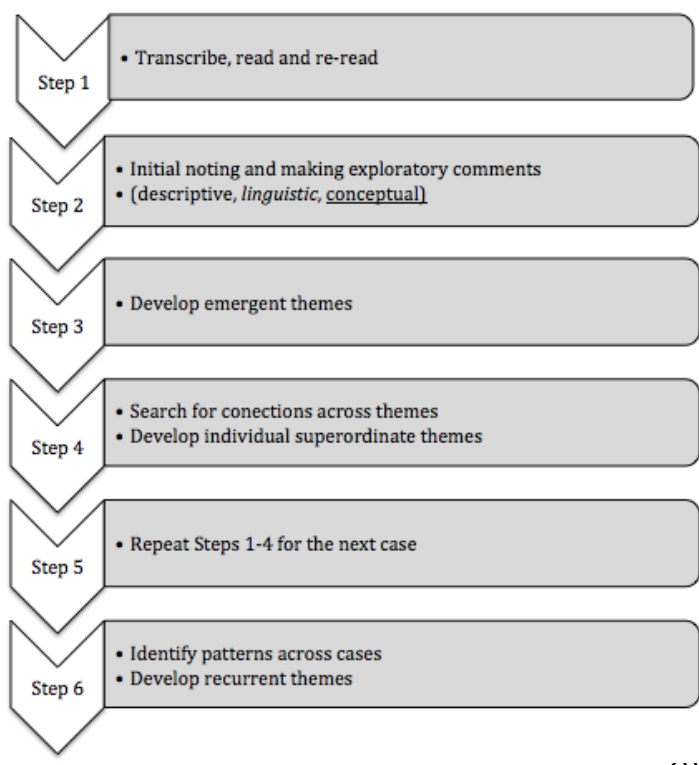
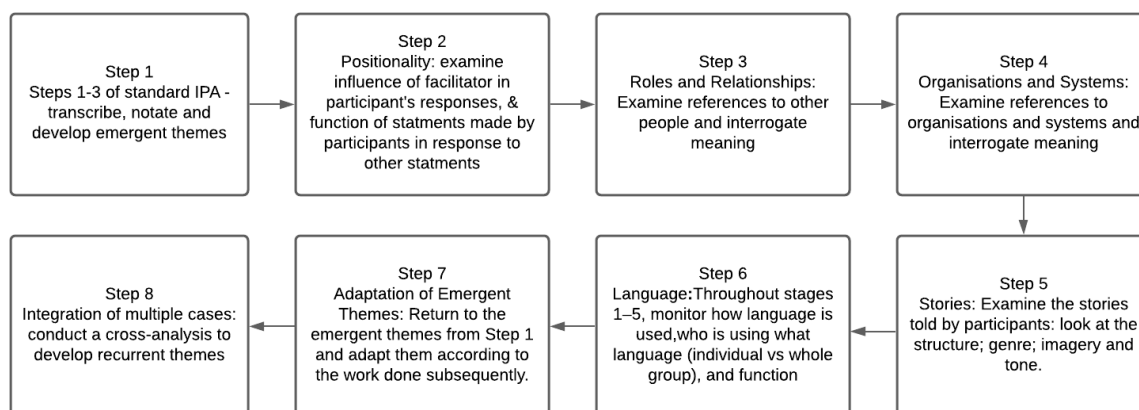


Figure 1. Steps for Interpretative Phenomenological Analysis, adapted from Smith et al., 2009



267  
 268 *Figure 2. Additional steps for analysing focus group data using IPA adapted from Palmer et*  
 269 *al., 2010*

270  
 271  
 272

### Findings

273 Fourteen participants (seven dyads) from the two Remini-Sing choirs agreed to  
 274 participate in interviews. Participants' educational background ranged from having  
 275 commenced high school but not completed (2), completing high school (3), trade  
 276 school/vocational training (2), undergraduate degree (4) and post-graduate degree (3).  
 277 Participants with dementia had a range of mild-moderate cognitive challenges based on their  
 278 MMSE scores, which ranged from 13-26, with a mean score of 20. Ten participants opted for  
 279 dyad interviews with the person they attend choir with, four of whom also participated in the  
 280 focus group interview. A further four participants joined the focus group interview only.  
 281 Interviews typically lasted between 45 to 60 minutes, and transcripts were, on average,  
 282 approximately 20 pages long. Participant characteristics and interview type are listed in Table  
 283 1. Participants had been attending the choir for at least six months at the time of interviews,  
 284 which took place approximately 1.5 months prior to the proposed end of project funding. At  
 285 the time of interviews, choir members and researchers were in negotiations to find ways to  
 286 continue funding the choirs.

287  
 288

Table 1. Participants

Name (relationship)	Age Range	Type of Interview
Colin (husband, diagnosis of dementia)	70-79	Dyad
Nancy (wife, care-partner)	60-69	

Malcolm (husband, diagnosis of dementia)	90-99	Dyad
Eileen (wife, care-partner)	80-89	
Bridget (mother, diagnosis of dementia)	80-89	Dyad
Kate (daughter, care-partner)	50-59	
Joan (mother, diagnosis of dementia)	80-89	Dyad and Focus
Mark (son, care-partner)	50-59	Group
Roxanne (wife, diagnosis of dementia)	70-79	Dyad and Focus
Patrick (husband, care-partner)	70-79	Group
Valerie (mother, diagnosis of dementia)	80-89	Focus Group
Christine (daughter, care-partner)	50-59	
George (husband, diagnosis of dementia)	70-79	Focus Group
Amanda (wife, care-partner)	70-79	

289

290 Eight recurrent themes were developed through the analysis process, representing the  
 291 perspectives of the Remini-Sing participants (Table 2). These themes are grouped into two  
 292 overarching themes 1) Participating in the Remini-Sing choirs afforded experiences of  
 293 personal and social benefits; and 2) Pragmatic aspects of the choirs and research design  
 294 impacted the experience for participants. Identifiers will follow each person's name to clarify  
 295 if they have a diagnosis (D) or are attending as a care-partner (C) throughout the findings.

296

297 Table 2. Recurrent Themes and Sub-themes

Recurrent Themes	Sub-themes
<b>Overarching Theme 1: Participating in the Remini-Sing choirs afforded experiences of personal and social benefits</b>	
Theme 1: Therapeutic Choir Participation	1.1 Transient Experiences of Joy While Participating
Fosters Positive Feelings	1.2 Choir Participation Affords a Subtle Improvement to Mood
Theme 2: Singing in the Choir Promotes Cognitive Stimulation, Connection to Identity, for People with Dementia	2.1 Choir provides opportunities for cognitive stimulation, fostering confidence in ability
	2.2 Singing Stimulates Reminiscence
	2.3 Learning and Maintaining Skills

Theme 3: Opportunities to Engage Musical Identity	3.1 Developing a Musical Identity
	3.2 Connection to Existing Identity
Theme 4: Choir Participation Enables Much Needed Social Connections	4.1 The Need for Social Connection
	4.2 Choirs Fostered A Deep Sense of Belonging
	4.3 Sense of Safety Within Choirs
	4.4 Social Support
Theme 5: Participating as Dyads for Pragmatic and Personal Reasons	5.1 Attending Together for Convenience/Practicality
	5.2 Reflecting Existing Relationship Dynamic
	5.3 Participating Together Supports Dyadic Relationship
<b>Overarching Theme 2: Pragmatic Aspects of the choirs and research design impacted the experience for participants</b>	
Theme 6: Getting Started Can Be Challenging - A Welcoming Environment is Needed	6.1 Hesitance to Try Something New
	6.2 Reluctance Due to Singing Anxiety
	6.3 Pressure to Continue Due to Small Membership.
Theme 7: Accessibility of Therapeutic Design	7.1. Logistical Aspects of Choirs Enable Successful Participation
	7.2 Accessible Program Design Enables Participation
Theme 8: Sustainability of Choirs is Desired	8.1 Concerns Around Group Ending
	8.2 Group Size and Recruitment Challenges Impact Sustainability of the Group.
	8.3 Strategizing for Sustainability

298

299 **Overarching Theme 1: Participating in the Remini-Sing choirs afforded experiences of**  
300 **personal and social benefits**

301 Participants generally described the Remini-Sing choirs as enjoyable, fun and positive  
 302 experiences. They felt they experienced benefits that were intra-personal (within themselves)  
 303 and inter-personal (between members of the dyad and members of the choir groups). The first  
 304 three themes capture the intra-personal benefits that participants perceived, while themes four  
 305 and five relate to inter-personal benefits. Figure three depicts the relationship between these  
 306 themes.

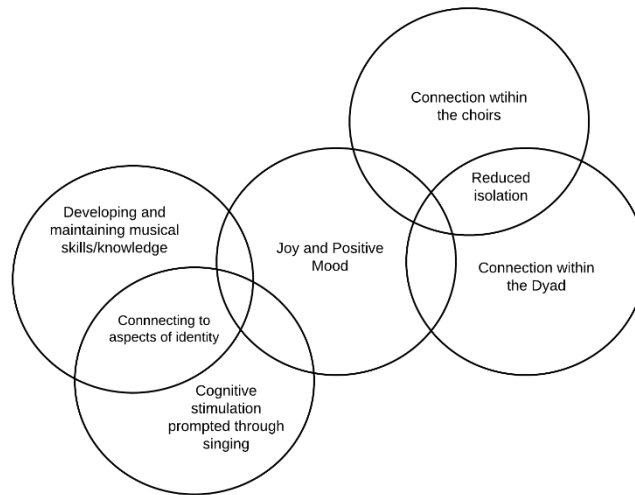


Figure 3. Relationship between personal and social benefits of choir participation

307

308 **Theme 1: Therapeutic Choir Participation Fosters Positive Feelings**

309 **Sub-theme 1.1: Transient Experiences of Joy While Participating.** Participants  
 310 described feeling a positive boost while participating in the Remini-Sing choirs. They often  
 311 used language such as ‘fun’, ‘enjoy’ or ‘joy’ to describe how they felt during the act of  
 312 singing together with others, as well as participation in the groups more broadly. Roxanne  
 313 (D) stated: “*it just makes me, I feel happy, I’m happy doing it*”, while Eileen (C) described  
 314 the joy experienced while participating as beneficial to her and her husband: “*I think it’s good*  
 315 *for Malcolm; I think he enjoys it, enjoys the company, the singing, he certainly joins in and*  
 316 *sings... it’s really good...I feel it’s doing us good, I really enjoy it*”. Participants often  
 317 seemed reluctant to elaborate on the impact that participation had on their mood more  
 318 broadly. Joan (D) felt that singing was “*...broadly speaking overall...enjoyable and*  
 319 *cheerful*”, although felt that she couldn’t say whether the group had a longer-term impact on  
 320 her mood: “*I don’t want to be dismissive...because I really enjoyed it very much...I wouldn’t*  
 321 *say it’s having a big impact on my life, but it’s been enjoyable and encouraging from that*  
 322 *point of view*”. Although Joan experienced memory challenges, she was able to describe how

323 she felt within the groups; therefore, she seemed to be reluctant to ascribe a stronger impact  
324 on her mood.

### 325 **Sub-theme 1.2: Choir Participation Affords a Subtle Improvement to Mood.**

326 While Joan felt that she could not confirm whether participation in the choirs had a sustained  
327 impact on her mood, her son (Mark) challenged her opinion, and highlighted how subtle  
328 changes may be difficult for one to notice within themselves, as captured in the following  
329 exchange:

330 *Mark (C): "... I don't think you're being fair enough...I think it's...the kind of benefit*  
331 *that it's easy to not notice; that you're coming away in a good mood"*

332 *Joan (D): "yeah, well that's true"*

333 *Mark (C): "and that spills out onto the rest of your day and even on the rest of your*  
334 *week"*

335 *Joan (D): "mm hmm, there you go"*

336 *Mark (C): "And I think for me it reinforces how much you're a social creature, that*  
337 *you enjoy company not just being in it but engaging it talking and doing and being*  
338 *actively engaged in company"*

339 *Joan (D): "well I think that is true"*

340

341 A more distinctive impact on mood was described by other participants. Kate (C) reported  
342 feeling calm following the groups: *"peacefulness... more calmness...it does make you feel*  
343 *more calmer"*. Roxanne (D) felt the participating in the choirs had a larger impact on her and  
344 her husband, declaring that *"it colours our lives"*.

345 Some participants were also unsure of what it was that impacted their mood  
346 specifically. Colin (D) felt that the combination of *"bringing people together...sharing*  
347 *music...[and other participants' giving] themselves freely"* influenced the positive feelings  
348 that were fostered with in the choir. The collective experience of the program, rather than one  
349 particular aspect, was responsible for the positive feelings that participants associated with  
350 the choirs.

351

### 352 **Theme 2: Singing in the Choir Promotes Cognitive Stimulation, Connection to Identity, for** 353 **People with Dementia**

354 Participants described the impact they felt the Remini-Sing groups had on various  
355 aspects of cognition and memory, which was valued by participants with dementia as it  
356 helped them to connect to aspects of their identity.

357           **Sub-theme 2.1: Choir provides opportunities for cognitive stimulation, fostering**  
358 **confidence in ability.** Participants felt that the groups provided opportunities to exercise their  
359 minds and stimulate cognition. Colin (D) reported enjoying “*getting exercise in learning*  
360 *something*”, while Bridget (D) described the feeling that singing had on her brain: “*...For*  
361 *starters, your brains are working...well your brains are going, and I reckon that’s great*”.  
362 For these participants, the benefit of cognitive stimulation appeared related to feeling  
363 invigorated through participating and learning; it appears this induced a sense of confidence  
364 and excitement as they were able to exercise their cognitive abilities that were otherwise  
365 challenging.

366           Some care-partners felt that the group provided opportunities for their loved ones to  
367 practice cognitive tasks. Mark felt that the singing warm-ups afforded opportunities to  
368 practice memory skills “*...without feeling stupid about not knowing someone’s name*”. Eileen  
369 (C) felt that the format of encouraging participant choice helped to encourage her husband to  
370 participate: “*...I think it’s good for Malcolm...because he’ll join in, and I’ve got to try and*  
371 *not speak for him...he’s got to choose one of the songs, which he would normally get me to*  
372 *choose...*”

373  
374 For care-partners, the choirs provided an accessible way for their partner to exercise their  
375 cognitive skills, which again seemed to relate to opportunities for their partners to experience  
376 confidence or competence in their abilities.

377           **Sub-theme 2.2: Singing Stimulates Reminiscence.** Participants described how the  
378 repertoire sung in the choir triggered reminiscence for participants with dementia. Joan (D)  
379 described enjoying the way that singing familiar songs brought back memories of making  
380 music with her family: “*...I really do enjoy that [reminiscence] aspect...a lot of the music is,*  
381 *you know, reminiscent to me of times when...I played the piano for [my father] to sing to...I*  
382 *enjoy that aspect of it all*”. Mark (C) observed a similar effect when a song triggered  
383 memories for participants with dementia:

384  
385           Mark (C): “*...I can see the lights go on in the participants eyes, as distinct from what*  
386 *I’m feeling, what I’m seeing...some people just [relate] to [a] song at a whole other*  
387 *level and you can see them switch on...[and] you see people engaging...with the*  
388 *songs, all the conversation that comes up immediately afterwards.*”

389

390 The familiar nature of the songs in the choirs' repertoire helped participants to recall  
391 memories from times in their lives that may otherwise not have been able to access. This, in-  
392 turn, prompted conversations between choir members, allowing participants to express  
393 aspects of their autobiographical identities, and develop connections with other members.

394 **Sub-theme 2.3: Learning and Maintaining Skills.** Participants described how the  
395 group afforded them opportunities to learn new skills or practice existing ones. Colin (D)  
396 reported that learning new musical skills motivated him to participate: "...*that was one of the*  
397 *reasons I was doing [it]... learning the music, learning to sing in unison with the others*".  
398 For Colin, who had limited musical experience prior to joining the choir, was able to explore  
399 a new musical identity through learning musical skills within the choir.

400

401 Patrick (C) observed his wife Roxanne (D) was able to maintain her memory of lyrics  
402 outside of the session, despite having difficulty with her short-term memory. In the following  
403 exchange during the focus group interview, Patrick's observation that Roxanne was able to  
404 recall lyrics following choir practice prompted another member, Valerie (D) to reflect on this  
405 retained ability:

406

407 *Patrick (C): "... I've observed that when I... go from here, or tomorrow, I can sing a*  
408 *song and Roxanne finishes it off..."*

409 *Valerie (D) [to Roxanne]: "can you remember it though? Get the words right?"*

410 *Patrick (C): "she is remembering you know, the last bit of the song sort of thing...it's*  
411 *the regular commitment, it's the revisiting songs that we knew and we know, and you*  
412 *know, refreshing the memory of things. It's amazing really I think how much we*  
413 *remember isn't it?"*

414 *Valerie (D): "marvellous what comes up, isn't it?"*

415 *Roxanne (D) [emphatically]: "absolutely, yeah"*

416

417 Roxanne and Valerie appeared heartened by the way that lyrics could be recalled despite  
418 other memory challenges. Patrick felt that the regular refreshing of familiar music helped  
419 Roxanne to recall lyrics outside of sessions. As Patrick and Roxanne were experienced  
420 musicians, this provided a space for them to enact their musicality together, both within the  
421 choir and at home.

422

423 ***Theme 3: Opportunities to Engage Musical Identity***

424 While the cognitive stimulation promoted by singing helped participants with  
425 dementia to express parts of their identity that may have been difficult to access due to their  
426 cognitive challenges, for some participants, a key benefit of the choirs was the chance to  
427 express their musical identity more broadly. An interest or history in music was frequently  
428 noted as one reason for participating in the study and continued participation in the choirs.

429 **Sub-theme 3.1: Developing a Musical Identity.** Some participants described  
430 enjoying the fact that they were able to learn about different aspects of music, be it songs,  
431 musical skills, or facts about the songs themselves:

432

433 *Mark (C): "I'm astounded at what I learned...there's a bunch of... 1930s kind of stuff*  
434 *that belongs with that age group, then there's a bunch of...1960s...and Patrick's got*  
435 *his Irish and Scottish stuff, which is just outside of my reference...so it's a wonderful*  
436 *education for me."*

437

438 For Mark, it seems that the choir afforded the opportunity to nurture and grow his musical  
439 identity through developing knowledge of musical styles and history. Colin (D) felt that this  
440 was an intrinsic benefit of being in the group, stating it is 'worthwhile' to be learning about  
441 music: "...we're learning something about...the history of [the music] ...and that little bit of  
442 history makes it worthwhile". This indicates a benefit removed from the experience of living  
443 with cognitive challenges, or caring for someone with dementia; the chance to explore other  
444 aspects of identity through learning was valued.

445 **Sub-theme 3.2: Connection to Existing Identity.** For some care-partners, the choirs  
446 provided a chance to connect to different parts of their identity. Mark and Patrick (Cs)  
447 enjoyed the opportunity to share their instrumental skills with the group. Mark commented:  
448 "*personally, thought it [indulging in playing instruments] was selfish. I enjoyed the hell out*  
449 *of it, and I saw different stuff in Patrick's playing*". Roxanne (D) acknowledged the need for  
450 others to witness her husbands' musical identity, outside his role as care-partner: "...I thought  
451 *they all needed to hear him on his instrument...because he's so good on his instrument...and*  
452 *I thought it would make them open...their eyes a bit wider when looking at and listening to*  
453 *him*". For Roxanne, she felt it was important for her husband to be able to express this aspect  
454 of his identity. Eileen (C) similarly described valuing the way that the group witnessed her  
455 cultural identity through sharing her favourite music: "...they really take an interest in your  
456 *own background...so it's good...I think the group makes you feel worthwhile*".

457

458 **Theme 4: Choir Participation Enables Much Needed Social Connections**

459 Participants described how the choirs provided opportunities for members to  
460 experience strong and meaningful connections that they felt they had been excluded from  
461 since diagnosis.

462 **Sub-theme 4.1: The Need for Social Connection.** Social connection was described  
463 as an important need of participants with dementia and care-partners, and a reason they  
464 joined the choir. Valerie (D) felt that due to the stage of her life, opportunities for social  
465 connection were becoming scarce: *“it’s a good idea to belong into a group though probably,  
466 because we’re all getting sort of older and people are dying and disappearing”*. Eileen (C)  
467 stressed the importance of maintaining social connections for personal wellbeing:

468  
469 *“but I think it’s really important that we keep being social, rather than just going out  
470 ourselves, we’re meeting with groups. And I find it very helpful...it’s really good to  
471 have the company... I think it’s good for both of us, I think I need the company too, so  
472 I enjoyed joining in.”*

473  
474 Although Eileen did not articulate precisely why she needed companionship from others, this  
475 was echoed by other participants who felt that they had become socially isolated due to  
476 friends becoming distant following the diagnosis of dementia. Amanda (C) commented that  
477 she was unsure *“whether they (friends) are embarrassed, or they’re not quite sure how to  
478 join you in”*, and that forming friendships with people who understood their situation was a  
479 motivator for her and her husband to participate: *“...we thought it would be nice if there were  
480 people in the same situation, we would get a group that was in...the same...area, and...things  
481 might swing from that as well, you might [meet for] coffee...”*. Forming friendships with  
482 people who have similar experiences appeared to be a priority for participants.

483  
484 **Sub-theme 4.2: Choirs Fostered A Deep Sense of Belonging.** Participants described  
485 experiencing a sense of deep sense belonging in the Remini-Sing choirs. Several participants  
486 compared the group to a community or club, or feeling as if they were ‘at home’ (Roxanne,  
487 D). Mark (C) emphasised that beyond his enjoyment of the musical aspect of the choirs, he  
488 felt rewarded by this sense of belonging: *“...I like the singing and...the music very much, but  
489 even more than that, I feel like I’ve joined a club, and that’s rewarding”*. George and  
490 Roxanne discussed together the way that they felt the group connected:

491

492 *George (D): "they're all very... good people...and so, they come together nicely"*

493 *Roxanne (D): "and we like to do that"*

494 *George (D): "yeah"*

495 *Roxanne (D): "and I think that's kind of very obvious to everybody, really...when*

496 *they join the group, they just feel immediately at home"*

497

498 Eileen (C) speculated that the participatory nature of the group created a more mutual sense

499 of belonging than other social groups: "...mainly the participation...there's more than just

500 *being entertained...there's just a feeling of mutual, [more] than say [support group]...*

501 *so...you feel more belonging, I suppose?". Nancy similarly felt that "...listening to the other*

502 *voices around and blending..." helped to create a "connectedness" between choir members.*

503 This suggests that the act of singing together with others helped to foster the sense of

504 belonging that participants experienced.

505 **Sub-theme 4.3: Sense of Safety Within Choirs.** Some participants described feeling

506 a sense of safety or security within in the group that was enabled by their connections with

507 one another. Patrick (C) and Roxanne (D) observed that as group members became more

508 familiar with one another, they were more comfortable to engage:

509 *Patrick (C) "...I couldn't put my finger on it, but I think I can...observe*

510 *that...everybody's sort of...contributing better now than they did at the start, you*

511 *know?"*

512 *Roxanne (D): "Yeah...well we all know each other now, don't we?"*

513 *Patrick (C): "Yeah, and...some people are basically coming out of their shells a bit*

514 *more"*

515

516 Colin (D) and Nancy (C) felt safe within the group due to the relaxed nature of the music;

517 that they had permission to make mistakes, because "*everyone just laughs it off*". Kate (C)

518 and Bridget (D) similarly felt accepted by members of the group, irrespective of their

519 abilities:

520

521 *Kate (C): "Acceptance"*

522 *Bridget (D): "nobody has said anything to me, anyway 'what are you here for?'"*

523 *Kate (C): "and no questions asked whether you can sing or not sing, no, or look at*

524 *you 'you're not singing in key today' – everyone just sings and does what they can*

525 *do."*

526 For Kate, this sense of acceptance seemed to relate to her perceived singing abilities that the  
527 group allowed for a relaxed approach to musical participation. For Bridget, however, this  
528 appeared to relate more to her experience of living with dementia and disclosing her  
529 diagnosis; her comment that no one had ‘*said anything*’ about why she was attending  
530 indicates a sense of comfort at being accepted regardless of her cognitive challenges.

531 **Sub-theme 4.4: Social Support.** Participants also reported feeling supported by  
532 people who had similar experiences:

533

534 *Christine (C): “I thought the support, the social support type stuff was really good, it*  
535 *was lovely to be with a group of people”*

536 *Valerie (D): “with different things going on”*

537

538 Amanda (C) elaborated on the importance of this shared experience, as she described feeling  
539 supported without needing to explain to others what was going on: “...*a wonderful*  
540 *underlying thing that everybody knows what we’re all, what the baseline is underneath, and*  
541 *so you don’t have to explain it if you’re having a crap day, at all”*. For participants in this  
542 study, the ‘social support’ seemed to relate to an unspoken understanding, and a ‘*kindness*’  
543 (Kate, C) that members could afford each other due to their shared understanding of what it’s  
544 like navigating a dementia diagnosis.

545

#### 546 ***Theme 5: Participating as Dyads for Pragmatic and Personal Reasons***

547 Dyads described practical and relational benefits of choir participation.

548 **Sub-theme 5.1: Attending Together for Convenience/Practicality.** Participating  
549 together was beneficial for practical reasons. Amanda (C) reported that it was more  
550 convenient for her to stay for the sessions than to drop off/pick up her husband. Christine (C)  
551 came to support her mother, who she felt would not be able to attend independently:

552 *“[someone] offered to pick mum up, and I just thought that would be too hard”*. Valerie (D),

553 Christine’s mother, expressed a sense of guilt at this arrangement, feeling that her daughter

554 *“...had to put up...”* with attending to support her: *“I felt guilty that my daughter gets*

555 *involved in doing something”*. Colin (D) also acknowledged that he relied on his wife’s

556 support to attend: *“...I think that there’s an advantage in [attending together] ...accepting*

557 *now...I’ve got a disability...”*. Although Valerie expressed concern regarding her daughters’

558 involvement, Colin on the other hand felt it advantageous that his wife was able to support

559 him to participate.

560           **Sub-theme 5.2: Reflecting Existing Relationship Dynamic.** Nancy (C) and Colin  
561 (D) reported that they enjoyed attending together because it reflected their approach to co-  
562 participation throughout their lives. Nancy stated: “*There’s just been a huge amount of*  
563 *togetherness right from the word go...so it probably is more reflective [of how we’ve lived]”*.  
564 Eileen (C) felt that participating together with her husband was something they prioritised,  
565 and that the choir provided an enjoyable platform for the two of them to do so:

566

567           *Eileen (C): “...it’s something that we both can equally be involved in. And even*  
568 *though Malcolm can’t remember much afterwards... he enjoyed it when he was there.*  
569 *So, we’re really living for the moment...and that’s something that you’re doing at*  
570 *[Remini-Sing], you’re enjoying the moment.”*

571

572 For Eileen, participating together was valued, as it enabled her and her husband to experience  
573 positive moments together, even if Malcolm (D) could not recall them.

574           **Sub-theme 5.3: Participating Together Supports Dyadic Relationship.** Some  
575 participants described the different ways the group impacted their relationship with their  
576 care-partner. Roxanne (D) felt the regularity of the group helped her and her husband to  
577 maintain their relationship by giving them something positive to do together:

578

579           *Roxanne (D): “... I think it’s helped us...come to terms...with each other in some*  
580 *positive ways, and that’s because I think that it’s every week...so we haven’t really*  
581 *got time to fall out with our, with each other or the material.”*

582

583 Several participants reported feeling that attending with their family member(s) gave them  
584 something to bond over at home. Roxanne (D) reported that she and her husband “*enjoyed*  
585 *practicing [choir] pieces at home*”. Bridget enjoyed the fact that “*...when you come home, if*  
586 *you want to, you can talk about [the group]”* – a sentiment echoed by Colin and Nancy:

587

588           *Colin (D): “...I think it meant that you’re sharing, and you can talk about it later....*  
589 *you reflect on it... And you can say ‘gee, did I make a mess of that piece’ or, you*  
590 *know...”*

591           *Nancy (C): “...just talking about some of the different people...who had done the*  
592 *songs or what the songs meant.”*

593

594 For these participants, the choirs provided a mutually enjoyable experience that afforded  
595 additional ways for them to connect with each other.

596

597 **Overarching Theme 2: Pragmatic aspects of the choirs and research design impacted**  
598 **the experience for participants**

599 Throughout the interviews, participants were at times critical of the researchers and  
600 execution of the study, likely due to the fact that the interviews were conducted during a  
601 period when the future of the choirs was uncertain. Despite these critiques, participants also  
602 highlighted aspects of the group that they felt were helpful and/or beneficial. The following  
603 three themes depict the critique and aspects of the experience that participants felt were  
604 important to create a welcoming and accessible environment that allowed participants to  
605 experience the benefits they described in the previous section. Figure 4 depicts the  
606 relationship between these various elements.

607

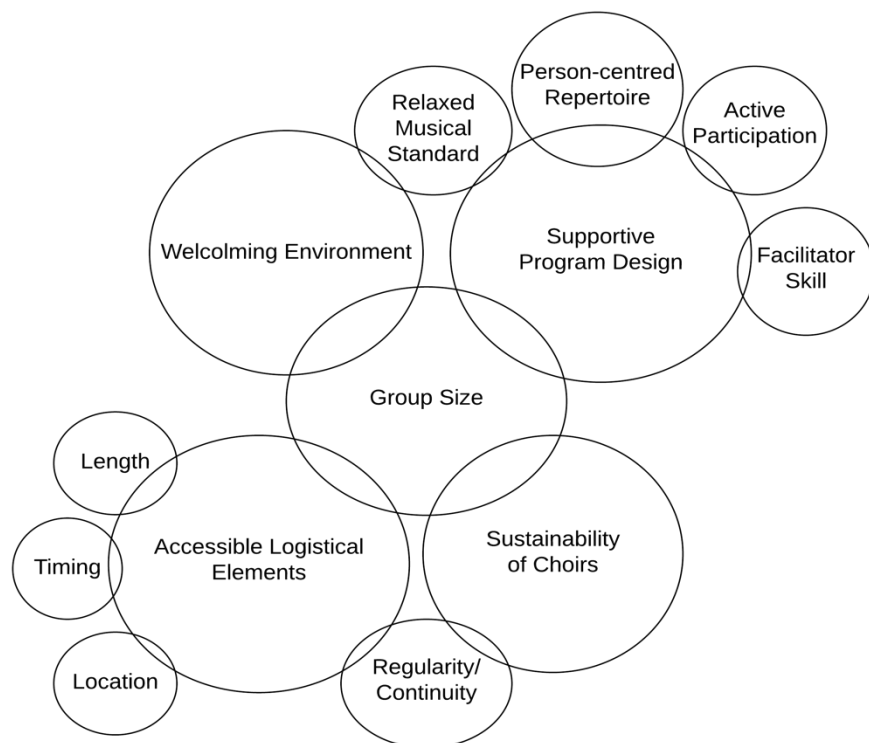


Figure 4. Relationship Between Elements That Influence Accessibility of Choirs

608

609 **Theme 6: Getting Started Can Be Challenging - A Welcoming Environment is Needed**

610 Participants described aspects of the choir (and research) design that contributed to  
611 feelings of hesitance or reluctance to join, and a subsequent need for a welcoming  
612 environment to overcome these feelings.

613 **Sub-theme 6.1: Hesitance to Try Something New.** Some participants described a  
614 sense of nervousness at starting something new. Christine (C) noted that starting a new  
615 routine could be stressful for some participants: “[starting] actually caused a bit of strain as  
616 well because then mum got anxious about leaving dad at home”. Amanda (C) described some  
617 nervousness about joining an already established group: “oh we were a bit like that [nervous]  
618 coming here, I thought ‘well, they’re a group that know each other, and we don’t live in the  
619 area’, and I thought ‘we don’t want to push in’.”

620

621 Mark and Amanda agreed that a fear of starting can be a deterrent for some people:

622

623 Mark (C): “it’s a real risk that people sort of self-select, opt out before you even give  
624 yourselves a start. I’m built that way; I’ll do that 90% of the time.”

625 Amanda (C): “yeah, I think we all do a bit.”

626

627 **Sub-theme 6.2: Reluctance due to Singing Anxiety.** Concern about singing ability  
628 led some participants to feel reluctant to join the choir initially. Although some participants  
629 felt reluctant to sing in front of others, their interest in music appeared to help them overcome  
630 this hesitancy. Joan (D) felt surprised that she had overcome this hesitancy to participate:  
631 “I was a reluctant starter and said... ‘well you know I really can’t sing and I certainly can’t  
632 stand up and sing in front of other people’ ...low and behold, here we are”. Joan’s enjoyment  
633 of reminiscence prompted by singing familiar songs (described in sub-theme 3.2),  
634 demonstrates how connecting to her past experiences of music helped to alleviate anxieties  
635 around singing in front of others.

636

637 **Sub-theme 6.3: Pressure to Continue Due to Small Membership.** Participants  
638 described feeling compelled to participate due to the low recruitment numbers in the early  
639 stages of the choirs. Kate (C) expressed concern that if she had not continued attending, then  
640 “that would be the end of [the choir]”, and that people on the waitlist would miss out on the  
641 opportunity all together. Christine reported a similar sense of duty to attend, and noted that  
642 this increased the stress of attending, as she felt pressure to come along even when her  
643 mother was feeling hesitant:

644

645 *Christine (C): “ ...[low numbers] made it a bit stressful at the beginning,*  
646 *because...mum being a bit hot and cold about the whole thing, if mum said she didn't*  
647 *want to go, you'd think 'oh no, we're letting down the only other people who are*  
648 *going to be turning up', that's just a major... drawback.”*

649

650 Although ultimately this sense of duty to attend was advantageous to the choirs, as it helped  
651 to grow participant numbers, the discomfort or distress that it caused to participants was  
652 evident. This adds to the importance being able to blend within a larger group, not just to  
653 mitigate nervousness relating to singing, but to allow for flexible participation, where  
654 participants do not feel pressure to attend.

655

### 656 ***Theme 7: Accessibility of Therapeutic Design***

657 Participants described various aspects of the therapeutically designed choirs that were  
658 important to the success of the group. As Colin suggested, there were multiple elements that  
659 when combined, enabled successful participation.

660

661 *Colin (D): “...I think a combination of things has got to be added: the distance to*  
662 *where we are going...logistics is an important issue...the sort of people you meet is*  
663 *an important issue...so if you balance out all these little pieces, they are small pieces*  
664 *because it's part of the makeup of what our group is.”*

665

666 Participants identified a range of elements, each of which influenced their experience of  
667 accessibility of the choirs for participants with dementia and care-partners. These elements  
668 are discussed under two key Sub-themes below: a) logistical factors; and b) program design.

669

#### 670 **Sub-theme 7.1: Logistical Aspects of Choirs Enable Successful Participation.**

671 Several logistical aspects of the choir design were felt to be accessible; these included  
672 location and accessibility of the venue (particularly proximity to home), timing, and group  
673 size. Timing of sessions was the most prevalent logistical factor described by participants.  
674 Sessions were held from 1pm-3pm, and this was felt to be a suitable time, as it was accessible  
675 for getting to the venue: “...it's early afternoon...we're out by three, so you're not running  
676 into traffic, you know there's after schools and things...I prefer the afternoon” (Eileen, C).

677 Mark (C) felt that in addition avoiding traffic and the need to rush, there was a benefit to  
678 being active around the lunch-period in relation to stimulating cognition throughout the day:

679

680 Mark (C): “...whether you fall asleep sort of post meal straight away, or whether you  
681 do exercise and you fall asleep an hour later will be up for what activity you do. So some  
682 people will fall asleep after lunch. But if you do some exercise, they'll stay awake and fall  
683 asleep at three o'clock.”

684

685 Mark felt that remaining active in the afternoon may have a protective or “postponing”  
686 function against distress that some people with dementia may experience later in the evening,  
687 as participants would “spend their petrol tickets” while engaging in the choir, and therefore  
688 be more prepared to relax later on.

689 Participants felt that the 90-minute length of the sessions was acceptable: “...it's the  
690 right amount of time that they're spending - anything longer and you get, not bored, but you  
691 get worn out” (Colin, D). Mark (C) similarly felt that the 90-minute length was a “sweet  
692 spot”, balancing the desire for longer periods spent together with the energy and effort that  
693 participation requires.

694 The regularity of sessions was highlighted as an important aspect of the choir; the  
695 group discussed that weekly sessions were useful in creating a habit of attending:

696

697 Valerie (D): “making it a regular habit is useful too, to do it every Tuesday...you  
698 know, on a regular day?”

699 Joan (D): “yes, yes it does.”

700 Mark (C): “I'm certain.”

701

702 Patrick highlighted that regular participation in the choirs was important, as experiencing “a  
703 few little high points in the week, it's sort of...a bit dull, isn't it...we need a little few...  
704 highlights in the week”. In addition to the comfort that a regular routine can provide,  
705 consistent attendance provided regular opportunities for positive moments, which were  
706 important in the context of challenges that participants were facing in their lives.

707 As discussed in the previous theme, the size of the groups was highlighted as an  
708 element of the choirs that impacted participation. However, despite the pressure caused by  
709 low numbers, participants generally appreciated the intimacy and tailored support that small  
710 groups afford:

711 Colin (D): “...I don't know whether or not if it's bigger, you lose sight of the other  
712 people...everyone gets a choice, whereas if you had a bigger group...it would be  
713 limiting the amount of time that you could give to each one...”

714

715 Participants additionally acknowledged, however, that larger groups would support  
716 sustainability of the choir:

717 Patrick (C): “...we're a bit vulnerable to people going on holiday, or people not  
718 being well, or people being too tired, you know...we're sort of almost below a critical  
719 weight really.”

720

721 Smaller choirs were seen to be advantageous in regards to the person-centred, therapeutic  
722 design, however, they also left the group in a precarious position, which at times added  
723 pressure to participants.

724

725 **Sub-theme 7.2: Accessible Program Design Enables Participation.** Participants  
726 described various elements of the design of the Remini-Sing choirs that impacted  
727 accessibility. These are presented in the context of two minor themes: the role of the  
728 facilitator, and the structure of the sessions.

729

730 **Facilitator Skill Influences Participation.** Participants felt the facilitator played a  
731 role in helping participants feel comfortable and actively engage in sessions. While  
732 facilitators were generally described positively, Kate (C) highlighted some experiences where  
733 facilitation was lacking, which resulted in her and others feeling confused and stressed:

734

735 Kate (C): “...on that first day, it was late to start...and [Facilitator] just  
736 started...there was no explanation of 'I want you to do what I'm doing', and she just  
737 started making these 'ahh'... 'mumumumum' [sounds]...and you're just sort of sitting  
738 there, and you just sort of start imitating her...we soon got into [it], but that very first  
739 week was quite confusing.”

740

741 Unclear instruction and leadership from the facilitator created a sense of confusion for new  
742 participants.

743 Colin (D) emphasised the importance of facilitator training, noting that he felt  
744 facilitators should have specific knowledge about the people they are working with: “...they

745 *had an interest in the people that were participating like ourselves...if you don't have that*  
746 *sort of person running it, it loses... it...goes out of existence very quickly".* Mark (C) and  
747 Joan (D) felt that at times, the role of the facilitator appeared subtle, and that the true  
748 importance of the facilitator was only revealed when there were issues in the group (where  
749 participants needed particular support):

750

751 *Mark (C): "But maybe, maybe things don't happen by accident. They happened by*  
752 *good endeavour."*

753 *Joan (D): "Hmm. Maybe it's...partly the leadership of the group."*

754

755 Mark went on to describe a moment where this became evident for him:

756

757 *"... I remember [the facilitator]...said, 'sometimes you know, the music or the*  
758 *conversation or something can be...emotional and triggering of negative as well as*  
759 *positive'...we had a moment [in the session that made it] suddenly [make]*  
760 *sense...when I saw that play out. I [had previously] thought 'what could possibly go*  
761 *wrong?' And then I looked at that and thought...that could have gone very wrong."*

762

763 In challenges instances within sessions, the role of the facilitator demanded more than  
764 musical direction, and therapeutic facilitation skills were important in supporting individual  
765 needs as well as managing group dynamics.

766

767 ***Session Format/Structure Enhances Accessibility of Singing.*** Although singing was  
768 described as something that participants with dementia could engage in, regardless of their  
769 cognitive challenges, participants felt that the relaxed musical expectations helped to create  
770 an environment where all abilities were welcomed. Colin (D) spoke of how important it was  
771 that everyone could participate, even if they *"might all be out of tune, in and out of...the*  
772 *words or the way we sing..."*. Others spoke of appreciating how they could choose the way  
773 that they engaged. Eileen (C) felt that her husband was *"...fairly relaxed [in the group]*  
774 *because...he's...not one for joining in a lot, although he's happy in a group'*. Malcolm (D)  
775 liked that he *"...didn't have to play the music"* if he did not want to. Patrick (C) described the  
776 importance of everyone being afforded an opportunity to select repertoire: *"...everybody can*  
777 *contribute, people get a chance to choose music, we get a chance to listen to other people's*

778 *music*". Mark echoed this sentiment, and felt that the way that activities (such as warm ups  
779 and song choice) were designed to encourage active participation was important:

780

781 Mark (C): "...there was a level of ownership about it, you felt included, as distinct  
782 from sitting back and watching. You can sort of opt out...[but] you almost have to  
783 opt-in."

784

785 The relaxed musical standard, compared to other choirs or musical groups, was also seen as a  
786 factor that made the groups accessible. Joan (D) explained: "...I think this one's more  
787 relaxed" compared to another choir she had been involved in, which "...was led by a fellow  
788 who was a pretty high standard musician...". Although relaxed musical standards were  
789 appreciated, Nancy (C) described enjoying a good balance between repertoire that was  
790 familiar and easy, and that which was more challenging:

791

792 Nancy (C): "...[we] had the three-part rounds... that was really a good feel...it  
793 wasn't challenging for me, but it was challenging for some of the people  
794 there...but...I think it was a good challenge and I think was good for them."

795

796 The inclusion of afternoon tea (and in particular, cake) was frequently cited as a crucial  
797 aspect that provided opportunity for relaxation and social time: "Yes, and the cakes...that  
798 helps a little too" (Colin, D).

799

## 800 ***Theme 8: Sustainability of Choirs is Desired***

801 All participants expressed concern about the future of the groups, either during their  
802 interview or privately to ZT. This is likely due to the interviews being conducted close to the  
803 end of the funding for the groups, during a time when the future of the groups was uncertain.  
804 Although this was positive in the sense that it indicated that participants valued the group  
805 enough to want it to continue, there were instances throughout the interviews where distress  
806 at the prospect of the group ending was evident.

807 **Sub-theme 8.1: Concerns around group ending.** Uncertainty about the groups  
808 ending was frustrating to participants. Amanda (C) reported that she was frustrated that there  
809 was no clarity so close to the finishing date: "...we're still, there's nothing happening for the  
810 next round; when you say 'we'll see you in 6 weeks' – too bad in 6 weeks."

811           **Sub-theme 8.2: Group size and recruitment challenges impact sustainability of**  
812 **the group.** Membership and recruitment were discussed as a key factor impacting the long-  
813 term security of the group. Participants expressed concern that the low membership numbers  
814 of their respective groups made them vulnerable to collapse, both due to lack of attendance,  
815 and the cost-effectiveness of running small groups. Kate (C) reflected:

816

817           *“...I know they’re trying to ...keep on the program, and I’m sort of thinking... we get*  
818 *afternoon tea, I don’t know how much [the facilitator costs]...and I’m thinking are*  
819 *they going to be thinking about the cost of the afternoon tea, the cost of [facilitator],*  
820 *for what, 7 people?”*

821

822 The lack of success recruiting new members, both during the initial study period, and the  
823 extended post-study time was cited as a point of frustration. Amanda (C) and Mark (C)  
824 described how the initial recruitment and ongoing effort was inadequate:

825

826           *Amanda (C): “... when you’re talking about ‘is the group going to change, are we*  
827 *going to get more people when it stops being under [the research] umbrella?’, and*  
828 *nobody’s done anything about advertising, and we’re now only 4 weeks away or 6*  
829 *weeks away and that drives me nuts I think!”*

830           *Mark (C): “That’s entirely true, and I think that was even reflected on the original*  
831 *sign, sort of the identity of what we’re coming to, I think it was a bit [disorganised]. It*  
832 *was a formal study and so, that kind of doesn’t have an identity, if it’s an ongoing*  
833 *entity, no one really knows what it is.”*

834           *Amanda (C): “No.”*

835

836           **Sub-theme 8.3: Strategizing for Sustainability.** On several occasions, participants  
837 strategized about how they could support the groups to continue themselves. Several  
838 discussed new recruitment strategies, while Amanda (C) suggested that the choir could be  
839 held “*at our house...if we really got stuck...*”. This was indicative of the value they saw in  
840 the groups, and that participants had taken some ownership of the program. While this is  
841 encouraging in regards to highlighting the value of the groups, the distress that this caused  
842 participants was evident in their responses during the interviews, and may have impacted  
843 their ability to experience the benefits they had previously described.

844

## Discussion

845

846 This study sought to understand the perspectives of people with dementia, and their  
847 family members who support them as care-partners, about the experience of singing in  
848 therapeutically designed, community-based choirs that were formed as part of the Remini-  
849 Sing RCT. The findings revealed that participants found the choirs to be enjoyable and  
850 valuable, to the point that they were strategizing for how the choirs could continue once the  
851 research funding ceased. The themes that indicated the perceived benefits of choral/group  
852 singing for people with dementia and familial care-partners reflect results of previous  
853 qualitative inquiries (Thompson, Baker, Tamplin, et al., 2021) . These themes relating to  
854 social connections, positive feelings, identity, and cognition also align with factors identified  
855 as influential on quality of life for people living with dementia (Holopainen et al., 2019;  
856 O'Rourke et al., 2015).

857

858 Several studies have similarly reported that social benefits of group singing are of key  
859 importance to participants (Clark et al., 2018; Harris & Caporella, 2018; Lee et al., 2020;  
860 Osman et al., 2016), which is unsurprising, given that increased social isolation due to  
861 changing needs, inaccessibility and associated stigma is well documented (Biggs et al., 2019;  
862 Burgener, Buckwalter, Perkhounkova, & Liu, 2015). Participants in the present study  
863 highlighted the need for accessible opportunities for social connection, and the strength of  
864 connections they found within the Remini-Sing groups. One participant theorised that music  
865 was the ‘vehicle’ that enabled the deep connection between group members to occur (Mark,  
866 C), which echoes similar findings in past research (Lee et al., 2020; Unadkat et al., 2016).  
867 Theme Four (Choir Participation Enables Much Needed Social Connections) highlighted  
868 three ways that the choirs fulfilled the need for social connection (Figure 4). These social  
869 benefits reflect factors that influence of quality of life (QoL) generally (World Health  
870 Organization, 1998), and factors that people with dementia recognise as central to their  
perception of good QoL (Holopainen et al., 2019; O'Rourke et al., 2015).

871  
872  
873  
874  
875  
876  
877  
878  
879  
880  
881  
882  
883  
884  
885  
886  
887  
888  
889  
890  
891  
892  
893  
894  
895  
896  
897  
898  
899  
900  
901  
902  
903  
904

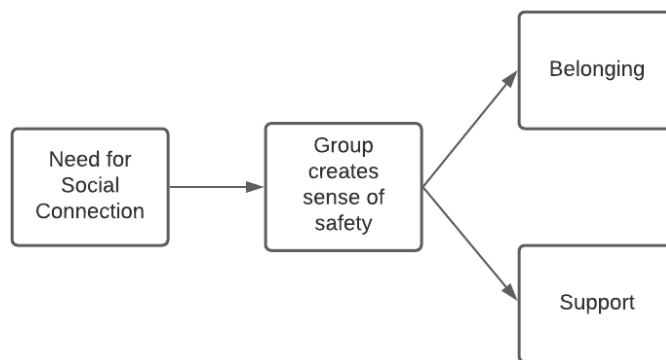


Figure 4. Dimensions of Social Benefits of Group Singing

A sense of joy and positive impact on mood was also highlighted as a benefit of the choirs. Across the interviews, all participants used simple descriptors such as ‘enjoy’, ‘fun’ and ‘very good’ when describing how the choir made them feel, while only a few participants went further to describe a specific change in mood following choir. Unadkat et al. (2016) reported similar descriptions, and theorised that feelings of ‘enjoyment’ described by participants related to ‘in-the-moment’ benefits to mood, distinct from effects that carried on post-session. In the present study, some participants acknowledged that they found it difficult to describe the exact impact that group singing had on their mood, either due to being unable to find the words (due to aphasia) or being unable to recall the impact post-session. Some participants theorised that changes may be subtle, and therefore difficult to describe, which may explain why some participants did not describe their experiences of mood in more depth. However, research also indicates that people with dementia may use happiness as a measure for their quality of life (O'Rourke et al., 2015), and may be drawn to activities that promote positive feelings in-the-moment, as they may be more accessible than other activities (Bohn, Kwong See, & Fung, 2019). Research also indicates that for some people with dementia, the memory of emotions triggered by an event may remain even when they can no longer recall the actual event (Guzmán-Vélez, Feinstein, & Tranel, 2014; Reschke-Hernandez, Belfi, Guzman-Velez, & Tranel, 2020). Therefore, these descriptions of joy and fun may hold a deeper meaning than participants were able to describe, and further work is needed to better understand the importance of joy and fun in this context.

Previous research has reported how group singing can support identity for people living with dementia, through increased confidence (Camic et al., 2011; McCabe et al, 2015; Unadkat et al., 2016), acceptance of diagnosis (Osman et al, 2016), and a sense of purpose and accomplishment (Clark et al, 2018; Lee et al., 2020; McCabe et al, 2015). In the present

905 study, however, participants appeared to reflect on the way that the choirs influenced their  
906 identity in relation to music specifically. Participants described how learning about music  
907 (both learning musical skills and learning about genres or music history) was a benefit in and  
908 of itself. This reflects previous research that report how participants with dementia can  
909 experience increased confidence through being able to participate and achieve new things  
910 through group singing programs (Camic et al, 2011; McCabe et al, 2015; Unadkat et al,  
911 2016). Notably, in the present study, care-partners also described the opportunity to re-  
912 connect and share their own musical identity with others. Songwriting has been reported as a  
913 way for care-partners to explore and support their identity (Baker, Stretton-Smith, Clark,  
914 Tamplin, & Lee, 2018). However, to our knowledge, the affordances of group singing with  
915 care-partner-dyads to support identity for familial care-partners have not been investigated.

916 The second overarching theme (Pragmatic aspects of the choirs and research design  
917 impacted the experience for participants) reflect findings from previous research that has  
918 highlighted aspects that make group singing accessible and motivating for people with  
919 dementia and care-partners (Thompson, Baker, Tamplin, et al., 2021) . Interestingly, although  
920 most participants described having some pre-existing relationship with music (either through  
921 learning or just enjoying music), several still reported feeling apprehensive about joining the  
922 choir due to concerns about not being able to sing well enough. This reflects concerns  
923 expressed by older adults regarding the design of community singing groups (Fu, Lin, Belza,  
924 & Unite, 2015). During recruitment for the Remini-Sing RCT, we altered the wording in  
925 advertising from ‘choir’ to ‘singing group’ due to concerns that the term ‘choir’ may be off-  
926 putting for people who have no experience as singers. However, this did not seem to impact  
927 recruitment rates. Participants reported that being able to blend into the group helped to  
928 alleviate some of their concerns around singing, which may have contributed to the sense of  
929 safety that helped participants to overcome their initial hesitance. This has important  
930 implications regarding the importance of in-person singing for providing a sense of group  
931 safety. A study on the perspectives of choir facilitators leading dementia inclusive online  
932 groups during the COVID19 pandemic found that although online singing was acceptable  
933 during physical-distancing restrictions, the physicality of in-person group singing was  
934 preferable (Lee, O’Neill, & Moss, 2021). As online platforms preclude the ability to sing in  
935 unison (Dowson & Schneider, 2021), it is possible that reduced sense of safety when singing  
936 alone via an online platform may contribute to this preference for in-person group singing  
937 experiences.

938           The skill and training of facilitators was referenced by participants as an important  
939 determinate of the success of the choirs. Although feedback about facilitators was generally  
940 positive, some participants observed differences between different facilitators, which  
941 impacted their enjoyment and comfort within the group. This echoes past findings, which  
942 report that training and ability of facilitators impacts comfort of participants and success of  
943 the groups (Clark et al., 2018; McCabe et al., 2015; Unadkat et al., 2016). Although the  
944 facilitators in the Remini-Sing study were credentialed music therapists who received specific  
945 training for the study, the findings suggest that individual differences between facilitators still  
946 impacted the experience for participants. It is possible that a transition from two facilitators to  
947 one when the initial study period ended may have impacted the experience for participants.  
948 Similarly, initial training for the therapists involved in this study focused on larger groups; it  
949 is possible that further training to support the therapists to adapt to the smaller group sizes  
950 was needed.

951           The sustainability of the groups was of central importance to the participants at the  
952 time of the interviews, as they were nearing the end of the allocated funding period and  
953 therefore facing the prospect that the groups would end unless further resources were  
954 provided. Participants reported feeling stressed and frustrated at the lack of clarity around the  
955 future of the choirs, and the perceived lack of action from the research team. Although choirs  
956 established within the Remini-Sing study were initially designed to be sustainable, this did  
957 not eventuate. These findings raise some important considerations for future research. Firstly,  
958 despite multiple and varied efforts to recruit more participants, the group sizes remained  
959 small. A brief analysis of the reasons for withdrawal and difficulty recruiting revealed that  
960 the time commitment required of the RCT component, strict eligibility criteria, progression of  
961 dementia or other illnesses preventing participation, and lack of means to directly invite  
962 potentially eligible participants were the main reasons. However, regardless of the reasons for  
963 the challenges in recruitment and sustainability, researchers should ultimately hold  
964 responsibility for the sustainability of groups established for research purposes, and for clear  
965 communication regarding the situation to minimise distress to participants.

966           **Limitations.** Although the findings of this study reflect similar findings to other  
967 qualitative research in this area, the results are rooted in the lived experience of the  
968 participants of the Remini-Sing study and should therefore be interpreted as such; they are  
969 not generalisable. Our aim was to represent the perspectives of participants in the Remini-  
970 Sing choirs, both those living with dementia and care-partners. Although participants were  
971 offered several formats of interview, including individual interviews, all opted for dyad

972 and/or focus-group interviews. Therefore, it is possible that participants may not have  
973 described some aspects of their experience due to not wanting to offend or upset their partner  
974 or other group members. This was evident in some interviews, where participants  
975 (particularly care-partners) spoke in euphemisms, or self-censored when talking about their  
976 partner's needs.

977         **Practical Recommendations for Professionals.** The benefits described by  
978 participants in this study generally relate to benefits that are experienced either during or  
979 shortly after each session, or as a consequence of regular sessions. Additionally, as dementia  
980 is a progressive condition, and circumstances change over time, the need for regular sessions  
981 is increased, as benefits may be forgotten or outweighed by other events happening in an  
982 individuals' life (Bruer, Spitznagel, & Cloninger, 2007; Osman et al., 2016; Särkämö et al.,  
983 2014). Our recent systematic review of the literature relating to singing and dementia  
984 revealed that regular group singing may act as a prophylactic against psychological distress  
985 and reduced wellbeing (Thompson, Baker, Tamplin, et al., 2021). Therefore, the findings  
986 from the present study add further support to the importance of regular sessions for  
987 maintenance of wellbeing, rather than short-term supports or interventions.

988         This study once again highlights the accessibility of music and singing for people  
989 living with dementia and supports the notion that community-based singing can be an  
990 accessible and beneficial support for both people living with dementia and their family  
991 members who support them. As Clark et al. (2018) note, group-singing is a low-cost activity  
992 that can support a large number of participants at a time. The themes captured in the second  
993 overarching theme of this study indicate aspects of session design and sustainability that can  
994 be used to maximise the experience, which have also been acknowledged in previous  
995 literature relating to group singing and dementia (Thompson, Baker, Tamplin, et al., 2021).  
996 Notably, participants in this study described enjoying the length of the choir sessions (90  
997 minutes of singing followed by afternoon tea), and the time of day (early afternoon). This  
998 may challenge assumptions or stereotypes about the types and timing of activities that older  
999 adults may be interested in, and supports previous findings that longer sessions are suitable  
1000 for people living with mild-moderate cognitive challenges (Shoesmith, Charura, & Surr,  
1001 2020).

1002         The present study also found that personality, skill, and training of facilitators was an  
1003 important factor in successful and accessible choir facilitation, and that the therapeutic  
1004 background of facilitators alone was not enough to provide effective leadership. Therefore,  
1005 training in the specific needs and contexts of choir participants is needed, as well as an



- Participants experienced personal benefits (positive feelings, connection to identity) and social benefits (connection with others, acceptance, and social support)
- Participants described elements of the choir that positively impacted their experience (creating an accessible environment through therapeutic design, leadership, logistical elements such as timing and location, and sense of safety when singing in a group)
- Participants highlighted elements of the research project that made their experience challenging (confusion regarding recruitment, sustainability of the choirs beyond the research project, differences in facilitator styles)
- Ongoing, accessible opportunities for people living with dementia and care-partners are desired

### **Key Recommendations**

- Facilitator training, effective advertising, and accessible design are important considerations for establishing future choirs
- Further research is required to determine if social benefits are experienced in asynchronous online formats

1036

1037

1038

### **1039 Acknowledgements**

1040 We acknowledge that this research project took place on the traditional lands of the  
1041 Wurundjeri and Boonwuring people of the Kulin Nation. We acknowledge their sovereignty  
1042 and pay our respects their Elders, past and present.

1043

1044 We thank the participants in this study who offered their time and perspectives for this  
1045 research project – your contribution is greatly appreciated. We acknowledge our research  
1046 partner, Uniting Agewell for their assistance with recruitment and venue provision for the  
1047 choirs. We also extend our thanks to MIND team member Kate Teggelove, who was the  
1048 Remini-Sing clinical trial manager.

1049

### **1050 Declaration of Interest Statement**

1051 We the authors declare that we have no competing interests to disclose.

1052

### **1053 Funding**

1054 The first author (Ms Thompson) was supported by an Australian Government Research  
1055 Training Program (RTP) Stipend and RTP Fee-Offset Scholarship through The University of  
1056 Melbourne. The second author (Dr Tamplin) is funded by a National Health and Medical  
1057 Research Council - Australian Research Council Grant (1106603).

1058

1059

1060

1061

## References

1062

1063 Australian Government Department of Health. (2015). *National framework for action on*  
1064 *dementia 2015-2019*. Canberra: Commonwealth of Australia Retrieved from  
1065 [https://agedcare.health.gov.au/ageing-and-aged-care-older-people-their-families-](https://agedcare.health.gov.au/ageing-and-aged-care-older-people-their-families-and-carers-dementia/national-framework-for-action-on-dementia-2015-2019)  
1066 [and-carers-dementia/national-framework-for-action-on-dementia-2015-2019](https://agedcare.health.gov.au/ageing-and-aged-care-older-people-their-families-and-carers-dementia/national-framework-for-action-on-dementia-2015-2019)

1067 Baker, F. A., Stretton-Smith, P., Clark, I., N. , Tamplin, J., & Lee, Y.-E. C. (2018). A group  
1068 therapeutic songwriting intervention for family caregivers of people living with  
1069 dementia: A feasibility study with thematic analysis. *Frontiers in Medicine, Vol 5*  
1070 (2018). doi:<https://doi.org/10.3389/fmed.2018.00151>

1071 Biggs, S., Carr, A., & Haapala, I. (2019). Dementia as a source of social disadvantage and  
1072 exclusion. *Australasian Journal on Ageing, 38*(2), 26-33.  
1073 doi:<https://doi.org/10.1111/ajag.12654>

1074 Bohn, L., Kwong See, S. T., & Fung, H. H. (2019). Preference for emotionally meaningful  
1075 activity in Alzheimer's disease. *Aging and Mental Health, 23*(11), 1578-1585.  
1076 doi:<https://doi.org/10.1080/13607863.2018.1506750>

1077 Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues In*  
1078 *Clinical Neuroscience, 11*(2), 217-228.  
1079 doi:<https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty>

1080 Brooks, D., Ross, C., & Beattie, E. (2015). *Caring for someone with dementia: The economic,*  
1081 *social and health impacts of caring and evidence based supports for carers - Paper*  
1082 *42*. Queensland, Australia: Alzheimer's Australia Retrieved from  
1083 [https://www.fightdementia.org.au/files/NATIONAL/documents/Alzheimers-](https://www.fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-42.pdf)  
1084 [Australia-Numbered-Publication-42.pdf](https://www.fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-42.pdf)

1085 Bruer, R. A., Spitznagel, E., & Cloninger, C. R. (2007). The temporal limits of cognitive change  
1086 from music therapy in elderly persons with dementia or dementia-like cognitive  
1087 impairment: A randomized controlled trial. *Journal of music therapy, 44*(4), 308-328.  
1088 doi:<https://doi.org/10.1093/jmt/44.4.308>

1089 Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of  
1090 perceived stigma on quality of life outcomes in persons with early-stage dementia:  
1091 Longitudinal findings: Part 2. *Dementia, 14*(5), 609-632.  
1092 doi:<https://doi.org/10.1177/1471301213504202>

1093 Clark, I. N., Tamplin, J., & Baker, F. A. (2018). Community-dwelling people living with  
1094 dementia and their family caregivers experience enhanced relationships and feelings  
1095 of well-being following therapeutic group singing: A qualitative thematic analysis.  
1096 *Frontiers in Psychology, 9*. doi:<https://doi.org/10.3389/fpsyg.2018.01332/full>

- 1097
- 1098 Clarke, C. L., & Bailey, C. (2016). Narrative citizenship, resilience and inclusion with  
 1099 dementia: On the inside or on the outside of physical and social places. *Dementia*,  
 1100 15(3), 434-452. doi:<https://doi.org/10.1177/1471301216639736>
- 1101 Clements-Cortés, A. (2019). Understanding the continuum of musical experiences for people  
 1102 with dementia. In A. Baird, S. Garrido, & J. Tamplin (Eds.), *Music and dementia: From*  
 1103 *cognition to therapy*. New York: Oxford University Press.
- 1104 Clements-Cortés, A., & Yip, J. (2020). Social prescribing for an aging population. *Activities*,  
 1105 *Adaptation & Aging*, 44(4), 327-340.  
 1106 doi:<https://doi.org/10.1080/01924788.2019.1692467>
- 1107 Clements-Cortés, A. A. (2013). Buddy's Glee Club: Singing for life. *Activities, Adaptation &*  
 1108 *Aging*, 37(4), 273-290. doi:<https://doi.org/10.1080/01924788.2013.845716>
- 1109 Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and  
 1110 recommendations for conducting in-depth interviews with people with dementia.  
 1111 *Qualitative Health Research*, 26(13), 1774.  
 1112 doi:<https://doi.org/10.1177/1049732316637065>
- 1113 Dementia Alliance International. (2017). Dementia Alliance International Retrieved from  
 1114 <https://www.dementiaallianceinternational.org/>
- 1115 Dementia Australia. (2018). Dementia language guidelines. Retrieved from  
 1116 <https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf>
- 1117 Dowson, B., & Schneider, J. (2021). Online singing groups for people with dementia: Scoping  
 1118 review. *Public Health*, 194, 196-201. doi:<https://doi.org/10.1016/j.puhe.2021.03.002>
- 1119 El Haj, M., Fasotti, L., & Allain, P. (2012). The involuntary nature of music-evoked  
 1120 autobiographical memories in Alzheimer's disease. *Consciousness and Cognition*,  
 1121 21(1), 238-246. doi:<https://doi.org/10.1016/j.concog.2011.12.005>
- 1122 Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world*: Wiley.
- 1123 Fu, M. C.-C., Lin, S.-Y., Belza, B., & Unite, M. (2015). Insights of senior living residents and  
 1124 staff on group-singing. *Activities, Adaptation & Aging*, 39(3), 243-261.  
 1125 doi:<https://doi.org/10.1080/01924788.2015.1063332>
- 1126 Grover, S., Nehra, R., Malhotra, R., & Kate, N. (2017). Positive aspects of caregiving  
 1127 experience among caregivers of patients with dementia. *East Asian Archives of*  
 1128 *Psychiatry*(2), 71. Retrieved from <https://pubmed.ncbi.nlm.nih.gov/28652500/>
- 1129 Guzmán-Vélez, E., Feinstein, J. S., & Tranel, D. (2014). Feelings without memory in Alzheimer  
 1130 disease. *Cognitive and Behavioral Neurology: Official Journal of the Society for*  
 1131 *Behavioral and Cognitive Neurology*, 27(3), 117-129.  
 1132 doi:<https://doi.org/10.1097/WNN.0000000000000020>
- 1133 Harris, P. B., & Caporella, C. A. (2018). Making a university community more dementia  
 1134 friendly through participation in an intergenerational choir. *Dementia (London,*  
 1135 *England)*, 18(7-8), 2556-2575. doi:<https://doi.org/10.1177/1471301217752209>
- 1136 Holopainen, A., Siltanen, H., Pohjanvuori, A., Makisalo-Ropponen, M., & Okkonen, E. (2019).  
 1137 Factors associated with the quality of life of people with dementia and with quality  
 1138 of life-improving interventions: Scoping review. *Dementia - International Journal of*  
 1139 *Social Research and Practice* 18(4), 1507-1537.  
 1140 doi:<https://doi.org/10.1177/1471301217716725>
- 1141 Huber, A., Oppikofer, S., Meister, L., Langensteiner, F., Meier, N., & Seifert, A. (2021). Music  
 1142 & memory: The impact of individualized music listening on depression, agitation, and

1143 positive emotions in persons with dementia. *Activities, Adaptation & Aging*, 45(1),  
1144 70-84. doi:<https://doi.org/10.1080/01924788.2020.1722348>

1145 Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Milton Keynes: Open  
1146 University Press.

1147 Lee, S., O'Neill, D., & Moss, H. (2020). Promoting well-being among people with early-stage  
1148 dementia and their family carers through community-based group singing: A  
1149 phenomenological study. *Arts & Health* Oct 29(1-17).  
1150 doi:<https://doi.org/10.1080/17533015.2020.1839776>

1151 Lee, S., O'Neill, D., & Moss, H. (2021). Dementia-inclusive group-singing online during  
1152 COVID-19: A qualitative exploration. *Nordic Journal of Music Therapy*, 1-19.  
1153 doi:<https://doi.org/10.1080/08098131.2021.1963315>

1154 Matthews, B. R., Chang, C.-C., May, M. d., Engstrom, J., & Miller, B. L. (2009). Pleasurable  
1155 emotional response to music: A case of neurodegenerative generalized auditory  
1156 agnosia. *Neurocase*, 15(3), 248-259.  
1157 doi:<https://doi.org/10.1080/13554790802632934>

1158 McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). 'What I want to do is get half a dozen  
1159 of them and go and see Simon Cowell': Reflecting on participation and outcomes for  
1160 people with dementia taking part in a creative musical project. *Dementia*(6), 734.  
1161 doi:<https://doi.org/10.1177/1471301213508128>

1162 McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: A  
1163 narrative synthesis systematic review. *International Journal of Geriatric  
1164 Psychiatry*(8), 781. doi:<https://doi.org/10.1002/gps.3895>

1165 Novek, S., & Wilkinson, H. (2019). Safe and inclusive research practices for qualitative  
1166 research involving people with dementia: A review of key issues and strategies.  
1167 *Dementia* 18(3), 1042. doi:<https://doi.org/10.1177/1471301217701274>

1168 O'Rourke, H. M., Duggleby, W., Fraser, K. D., & Jerke, L. (2015). Factors that affect quality of  
1169 life from the perspective of people with dementia: A metasynthesis. *Journal of the  
1170 American Geriatrics Society*(1), 24. doi:<https://doi.org/10.1111/jgs.13178>

1171 Osman, S. E., Schneider, J., & Tischler, V. (2016). 'Singing for the Brain': A qualitative study  
1172 exploring the health and well-being benefits of singing for people with dementia and  
1173 their carers. *Dementia - International Journal of Social Research and Practice*, 15(6),  
1174 1326-1339. doi:<https://doi.org/10.1177/1471301214556291>

1175 Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative  
1176 phenomenological approach to focus group data. *Qualitative Research in Psychology*,  
1177 7(2), 99-121. doi:<https://doi.org/10.1080/14780880802513194>

1178 Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition  
1179 Society*(4). doi:<https://doi.org/10.1079/pns2004399>

1180 Reschke-Hernandez, A. E., Belfi, A. M., Guzman-Velez, E., & Tranel, D. (2020). Hooked on a  
1181 feeling: Influence of brief exposure to familiar music on feelings of emotion in  
1182 individuals with Alzheimer's disease. *Journal of Alzheimer's Disease*, 78(3), 1019-  
1183 1031. doi:<https://doi.org/10.3233/JAD-200889>

1184 Rowe, B., Brown, T., & Holland, J. (2014). *A Good Life With Dementia*. Retrieved from  
1185 London, UK: <https://www.revealingreality.co.uk/work/a-good-life-with-dementia/>

1186 Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., &  
1187 Rantanen, P. (2014). Cognitive, emotional, and social benefits of regular musical  
1188 activities in early dementia: Randomized controlled study. *The Gerontologist*, 54(4),  
1189 634-650. doi:<https://doi.org/10.1093/geront/gnt100>

- 1190 Shoesmith, E., Charura, D., & Surr, C. (2020). What are the required elements needed to  
 1191 create an effective visual art intervention for people living with dementia? A  
 1192 systematic review. *Activities, Adaptation & Aging*, 1-28.  
 1193 doi:<https://doi.org/10.1080/01924788.2020.1796475>
- 1194 Sikkes, S. A. M., Tang, Y., Jutten, R. J., Wesselman, L. M. P., Turkstra, L. S., Brodaty, H., . . .  
 1195 Bahar-Fuchs, A. (2021). Toward a theory-based specification of non-pharmacological  
 1196 treatments in aging and dementia: Focused reviews and methodological  
 1197 recommendations. *Alzheimer's & Dementia: The Journal of the Alzheimer's*  
 1198 *Association*, 17(2), 255-270. doi:<https://doi.org/10.1002/alz.12188>
- 1199 Smith, J. A., Larkin, M., & Flowers, P. (2009). *Interpretative phenomenological analysis:*  
 1200 *theory, method and research*. Los Angeles; London: SAGE.
- 1201 Stige, B., & Aarø, L. E. (2011). *Invitation to Community Music Therapy. [electronic resource]:*  
 1202 Hoboken : Taylor and Francis, 2011.
- 1203 Swaffer, K. (2018). Human rights, disability and dementia. *Australian Journal of Dementia*  
 1204 *Care*, 7(1), 25-28. Retrieved from [https://journalofdementiacare.com/human-rights-](https://journalofdementiacare.com/human-rights-disability-and-dementia/)  
 1205 [disability-and-dementia/](https://journalofdementiacare.com/human-rights-disability-and-dementia/)
- 1206 Tamplin, J., Clark, I. N., Lee, Y.-E., C. , & Baker, F. A. (2018). Remini-Sing: A feasibility study of  
 1207 therapeutic group singing to support relationship quality and wellbeing for  
 1208 community-dwelling people living with dementia and their family caregivers.  
 1209 *Frontiers in Medicine*, 5. doi:<https://doi.org/10.3389/fmed.2018.00245>
- 1210 Thompson, Z., Baker, F. A., Clark, I. N., & Tamplin, J. (2021). Making qualitative interviews in  
 1211 music therapy research more accessible for participants living with dementia –  
 1212 Reflections on development and implementation of interview guidelines.  
 1213 *International Journal of Qualitative Methods*, 20, 16094069211047066.  
 1214 doi:<https://doi.org/10.1177/16094069211047066>
- 1215 Thompson, Z., Baker, F. A., Tamplin, J., & Clark, I. N. (2021). How singing can help people  
 1216 with dementia and their family care-partners: A mixed studies systematic review  
 1217 with narrative synthesis, thematic synthesis, and meta-integration. *Frontiers in*  
 1218 *Psychology*, 12(4446). doi:<https://doi.org/10.3389/fpsyg.2021.764372>
- 1219 Unadkat, S., Camic, P. M., & Vella-Burrows, T. (2016). Understanding the experience of  
 1220 group singing for couples where one partner has a diagnosis of dementia. *The*  
 1221 *Gerontologist*(3), 469. doi:<https://doi.org/10.1093/geront/gnv698>
- 1222 World Health Organisation. (2004). *ICD-10 classifications of mental and behavioural*  
 1223 *disorder: clinical descriptions and disgnostic guidelines* [10]. In W. H. Organisation  
 1224 (Ed.), (10 ed., Vol. 2). Retrieved from  
 1225 <http://apps.who.int/classifications/icd10/browse/2016/en>
- 1226 World Health Organisation. (2012). *Dementia: A public health priority*. Retrieved from  
 1227 [http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](http://www.who.int/mental_health/publications/dementia_report_2012/en/)
- 1228 World Health Organization. (1998). *Programme on mental health : WHOQOL user manual,*  
 1229 *2012 revision*. Retrieved from <https://apps.who.int/iris/handle/10665/77932>
- 1230 Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in  
 1231 dementia: An integrative review of research literature. *International Journal of*  
 1232 *Nursing Studies*, 79, 1-26. doi:<https://doi.org/10.1016/j.ijnurstu.2017.10.008>

## 1234 Appendix 1

### 1235 Interview Questions and Prompts for Choir/Singing Group Participants

1236

1237 As interviews were conducted using an open, semi-structured format, the following questions  
1238 were used as a guide, however other topics were able to be explored if they arose during the  
1239 course of the interview.

1240

1241 Questions to prompt discussion are on the left, with some probing/prompting options on the  
1242 right – prompts in italics are general, prompts in bold are simplified options for people who  
1243 may be having challenges in responding due to memory, language or verbal processing  
1244 challenges. Other tools, such as recordings of songs that participants associated with the  
1245 groups and photos of the group space, were also prepared to help prompt memory for  
1246 participants.

1247

---

Question	Additional Prompts
1. Why did you decide to join the [name of group] singing group?	What were you expecting/hoping to get from joining the singing group?
2. Why do you keep coming to the [name of group] singing group?	
3. How would you describe the experience of singing with this group?	[use name of group] <ul style="list-style-type: none"><li>- <i>What do you like about singing in this group?</i></li><li>- <i>Is there something you don't like about singing in this group?</i></li><li>- <i>How do you feel when you come to this group?</i></li></ul>
4. Has participating in this group impacted your life outside of the group?	<b>[simple prompts:]</b> <ul style="list-style-type: none"><li>- <b>Has coming to the group changed your life at home?</b></li><li>- <b>Has coming to the group changed your mood/made life easier?</b></li><li>- <b>Does the group/singing make you feel better or worse?</b></li><li>- <b>Has the group made your life better/worse?</b></li></ul>

---

<p>5. How could the group be improved to better suit your needs?</p>	<ul style="list-style-type: none"> <li>- <i>What could be better about the group?</i></li> <li>- <i>What would you change about the group?</i></li> </ul> <p><b>[simple prompts]</b></p> <ul style="list-style-type: none"> <li>- <b>Is the group good or bad?</b></li> <li>- <b>What is good about the group?</b></li> <li>- <b>What is bad about the group?</b></li> <li>- <b>How can we make it better?</b></li> </ul>
<p>6. What would you say to others who might be going through similar challenges about joining a group like this</p>	<ul style="list-style-type: none"> <li>- <i>Would you recommend the group to others? Why/why not?</i></li> </ul>
<p>7. <b>** particularly if verbal discussion is challenging:</b> Did you have any favourite musical things to do? Can you show me? (maybe listen to or sing a song with the couple)</p>	<p><b>[Use the music itself as a prompt]:</b></p> <ul style="list-style-type: none"> <li>- <b>Do you like this song?</b></li> <li>- <b>What do you like about it?</b></li> <li>- <b>How does this song make you feel?</b></li> </ul> <p><i>*If participants are unsure, suggest a known-preferred song from the group sessions</i></p>

1248

1249

1250

1251

1252