

1 From evidence to practice: Developing best practice guidelines for the delivery  
2 of activities to people living with moderate to advanced dementia using a  
3 pragmatic observational study.

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# 1 Introduction

## 2 Background

3 UK currently has around 850 000 individuals living with dementia (Prince et al., 2014). This figure is estimated to rise to 2,000,000  
4 by 2050, with some predicting a threefold increase globally in this time (Livingston et al., 2017; Prince et al., 2014; World Health  
5 Organization & Alzheimer's Disease International, 2012). Management of dementia includes pharmacological and non-  
6 pharmacological treatments. A large meta-analysis identified pharmacological treatment resulted in minimal benefits in moderate  
7 to advanced dementia, yet patients suffered significant side effects including cardiovascular and neurological complications (Buckley  
8 & Salpeter, 2015). As a result, the focus of treatment is often on improving wellbeing and physiological function using non-  
9 pharmacological management such as physical activity (Cheyne, Abhyankar, & McCourt, 2013; Livingston et al., 2017; National  
10 Institute for Clinical Excellence, 2018; World Health Organization & Alzheimer's Disease International, 2012). Physical activity in  
11 moderate to advanced dementia may improve mood, pressure sores social relations, and balance and reduce restless behaviour  
12 (Alzheimer's Society, 2016; Edwards et al., 2008; Smit et al., 2016; Telenius, Engedal, & Bergland, 2015).

13 Whilst the benefits of physical activity is well documented, the best way to deliver them to those living with dementia is less well  
14 known. There is, however, evidence to suggest that delivering activities in a meaningful way can help address individuals  
15 psychological and social needs, and that this is related to the and the quality of their quality of the experience (Harmer & Orrell,  
16 2008). There is a need to research the context in which activities take place, along with training for those who lead such sessions,  
17 has also been emphasised (Heyn, Abreu, & Ottenbacher, 2004).

18  
19 Undertaking the evaluation of activity programmes amongst those living with advanced dementia can be challenging due to the  
20 more complex processes for consent and challenges in findings suitable methods for gathering data (Mansbach, Mace, Clark, & Firth,  
21 2016). Observational methods, such as Dementia Care Mapping (DCM), have the potential to assist in the evaluation of such groups  
22 (Angrosino, 2007). DCM is an observation tool developed by  
23 Bradford University (Brooker, 2005) and endorsed by UK National Institute for Health and Care Excellence (NICE). It has been used  
24 in the care setting to embed patient-centred care and to evaluate the quality and effectiveness of care (Khalid, Surr, Neagu, & Small,  
25 2019). DCM aims to gain, in so far as it is possible, the perspective of a person living with dementia when care, or an activity, is  
26 delivered to that individual (Kitwood & Bredin, 1992).

27 With an increasing incidence of dementia (Livingston et al., 2017; Pham et al., 2018; Prince et al., 2014; World Health Organization  
28 & Alzheimer's Disease International, 2012) it is important to ensure that interventions are developed that improve the quality of life  
29 for this group. Addressing this need forms the basis of this study which takes place within a wider evaluation of a physical activity  
30 programme called Mobile Me, for older adults living in group settings, including care homes.

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## 1 Mobile Me and the best practice case study

2 Mobile Me was a ten-week, physical activity intervention delivered by the regional sport partnership (Active Norfolk) in fifty  
3 sheltered housing and care home units in the English county of Norfolk between October 2015 and December 2017. Two coaches  
4 ran sporting activities such as indoor bowls in weekly sessions of between one and two hours in duration. Both were experienced in  
5 adapting physical activities for older adults and were trained 'Dementia Friends'.  
6 Evaluation of Mobile Me was carried out by the University of East Anglia (UEA), UK. Participation in the evaluation was initially  
7 limited to those that were able to give informed consent. However, as the intervention moved from sheltered housing to care  
8 settings, the delivery team observed anecdotal benefits to those living with advanced dementia; for example, increased engagement  
9 and attentiveness assessments progressed. Furthermore, the sports coaches developed some specific adaptations and approaches to  
10 delivery for those living with advanced dementia. For these reasons, an additional study was proposed to build on the growing bank  
11 of knowledge being developed and with the aim of producing best practice guidance. As the form of adapted bowling played  
12 normally involved only gentle movement, and because a number of broader social and emotional outcomes had been observed,  
13 best practice was conceptualised as practice that ensured that the sessions were as accessible and inclusive as possible (minimising  
14 physical and cognitive barriers), held participants' attention, encouraged positive social interaction and  
15 physical activity, and resulted in behaviours or signs consistent with positive wellbeing. The guidance was to be aimed at anyone  
16 that might wish to delivery physical activity sessions in group settings, including sports coaches, volunteers, and care staff.

17

## 18 Research methods

19 Study design was predicated on lessons learnt from the broader Mobile Me evaluation where even simplified questionnaires or basic  
20 functional tests had been found not suitable for those living with advanced dementia. These individuals normally had very limited  
21 recall, difficulties following instructions, and reduced ability to communicate. Many also had physical disabilities and sensory  
22 impairment. For this reason, observational methods were adopted.

23 A pilot observation was carried out of an activity session with individuals living with dementia with the capacity to consent (with  
24 approval from the local institution's ethics committee); this helped establish what aspects of delivery might be further explored and  
25 the number and type of observation sessions this might involve. Ethical approval to carry out the observation with those considered  
26 unable to give informed consent was obtained from the National Social Care Research Ethics Committee (reference: 17/IEC08/0011).  
27 Following this, observations were carried out with residents attending any of three activity sessions run within a large dementia care  
28 unit where a consultee (a relative or friend) had granted permission and where the resident did not express or exhibit any signs of  
29 not wishing to be observed. For this, two observers worked simultaneously; one carrying out DCM, and the second carrying out  
30 semi-structured observation. The DCM observer coded behaviour from a list of predefined categories and scored well/ill being every  
31 five minutes based on an individual's perceived mood and engagement; this was done for between four and five individuals at any

1 one session. While DCM produces quantitative results in the form of scores (Brooker, 2005) , on this occasion it was being used  
2 solely as a method of in-depth qualitative observation to tease out and capture what actions, or conditions, were associated with  
3 wellbeing and engagement of the participants. The second observer gathered broader contextual information about the sessions,  
4 such as reactions and interactions of the whole group using a framework developed for evaluating activities for people living with  
5 dementia (Sheard, 2008). The observers recruited were highly experienced in working within care settings and with people living  
6 with cognitive impairment; their expertise and judgement were considered by the research team to be an essential component of  
7 the research design. The observers were asked to consider a number of areas of interest that had arisen from the evaluation of  
8 Mobile Me thus far, including the pilot observation, for example how to encourage social interaction, the effect of room layout, to  
9 what degree staff participated and what affect this had.

10 The observations were carried out over three days in October 2017, including a morning and two afternoon sessions. Two sessions  
11 (1 and 3) were held in the residents' lounges, and one  
12 (session 2) in an unfamiliar environment (an activity room in another part of the facility). These variations were introduced to explore  
13 whether the time of day, or the type of space, influenced the experience. A total of 33 participants were observed; session 1-3 had  
14 14, 9 and 10 participants respectively. For each session 5 participants were observed in the context of DCM coding. All participants  
15 were observed by the second observer.

16 Two coaches delivered each session. The game played was a variant of Boccia called 'New Age Bowls' which involves throwing soft  
17 balls onto a target wedge. Participants sat in a semicircle with care staff interspersed or standing nearby. After each session the  
18 observers met with the Sports Coaches and a researcher to discuss their observations. After all three sessions the observers  
19 discussed their findings prior to writing their separate reports.

20 Following this, the research team synthesised the observers' findings, alongside findings from the broader Mobile Me evaluation  
21 (which had included interviews with the sports coaches and a member care staff responsible for dementia care) to produce the  
22 guidance material. A brief review of the literature was also carried out to identify any possible contradictions with this study, or  
23 omissions, and to help establish different approaches to layout, tone and content for the guidance. A set of overarching themes  
24 were developed inductively through reading and annotating the data, and through discussion with those involved in project  
25 evaluation and delivery. This secondary analysis was thus the interpretation of research findings which are themselves  
26 interpretations of participants' behaviours or understandings  
27 i.e. 'third order constructs' (Atkins et al., 2008).

28 The draft guidance was presented to a consultative group in a workshop in January 2018. Attendees included health professionals  
29 (an occupational therapist, a physiotherapist and a general practitioner), academics from the University of East Anglia, a  
30 representative from Norfolk County Council Public Health, and Active Norfolk Staff (including a Mobile Me sport coach), as well as  
31 the two researchers who conducted the observation study.

1 Following this, the final guidance materials were produced. During this stage, the original data were revisited not only to source  
 2 quotes and examples with which to illustrate findings, but as a check to ensure the message, and recommendations, remained  
 3 consistent with the data.

4 It is recognised that the production of the guide was influenced by the context in which it was developed and the interpretations of  
 5 those involved (Crossan, 2003). They may be considered however as ‘instances of a broader set of recognisable features’ (Williams,  
 6 2000, p.215) and thus transferable across different settings and for different circumstances. The steps in the development of the  
 7 guidance are shown in Table 1.

8 Table 1: Steps in the development of the best practice guidance

Activity	Informants	Information obtained	Interpretation and synthesis to produce guidance
Mobile Me evaluation	<u>Internal to the project:</u> Sports care coaches, setting	Information about best practice applicable to older people in group settings, including people living with moderate to advanced dementia.	Guidance synthesised by evaluation team in consultation along with activity deliverers.
Specialist observation	<u>External to the project:</u> Specialist observers using two observation methods	Further information about delivery to people living with moderate to advanced dementia that may not be obvious without specialist knowledge and without the focus of a structured observation	
Existing literature	<u>External to the project</u>	Information about best practice working with people living with dementia. Example best practice guidance.	

Consultative workshop	<u>Internal</u> and the <u>external</u> to from <u>project</u> : Stakeh social the health care, academia sports sectors	Feedback on the content of the draft guidance.  Multiple perspectives able to identify what's 'missing'. A reality check about dissemination.	
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### 3 Ethics

4 Ethical consent was obtained from the National Social Care Research Ethics Committee (reference: 17/IEC08/0011). This study has  
5 been checked against and meets the SRQR reporting standards for qualitative research (O'Brien et al., 2014).

## 6 Learnings and Results

### 7 Developing the key themes

8 Four themes were developed from the data to group the recommendations in the best practice guidance. They are described below  
9 using extracts from the observations reports to illustrate how the themes relate to the practice observed. All names have been  
10 replaced by pseudonyms.

#### 11 Theme 1: Environment

12 Observing the sessions in different spaces, and at different times, revealed how the environment could affect engagement and  
13 participation. For example, in one session walking frames and chairs cluttered the area, there were distractions from other activities  
14 taking place nearby, and from staff conversations in the corridors. Another session worked well because chairs were placed close  
15 together in a small circle allowing better opportunities for interaction. However, while there were fewer distractions which helped  
16 keep the focus on the game, the room was unfamiliar, and this appeared to cause anxiety to some individuals. The last session  
17 observed, which was considered the most successful, was in a familiar lounge which was free from clutter and distractions.

18 *Tables and frames had been moved out of the circle, and this created a clear view and sense of space for all to focus on the*  
19 *game. Everyone seemed to be gathered in the semi-circle for the same purpose – the game!*

20 This last session also had a clear structure, starting with an introduction from the coach. The refreshment breaks also had a defined  
21 start and end which meant that when play resumed all eyes were back on the game.

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## 2 Theme 2: Atmosphere

3 It was observed that key to delivering the sessions that raised participants' wellbeing was to create an atmosphere that was relaxed,  
4 welcoming and fun, and where each member of the group was felt included however they wished to participate (even if this was  
5 only  
6 watching). Residents often initially indicated they did not wish to play but eventually joined in after other people had played or  
7 after encouragement from sports coaches, care staff or relatives. This had been a learning from the broader Mobile Me evaluation  
8 and was also noted in the observation.

9 *People may have got into the habit of saying 'No' when asked if they want a turn as a way of avoiding embarrassment about  
10 finding themselves in a situation they don't understand or anticipate that they won't be able to manage.*

11 While the sport coaches accepted a firm 'no' where it was clear a participant did not want to play, they had learnt to gently persist  
12 to encourage participation.

13 *Jenny [sports coach] asks Connie 'Do you want to have a go?' Connie says 'No'. Jenny follows up with 'Are you sure? You're  
14 good at this.' Connie smiles and takes her turn, aiming deliberately as usual.*

15 Care staff and sports coaches found small achievements for praise and encouragement, meaning that the sessions were failure free  
16 and that individuals were valued.

17 *Jenny [sports coach] persists with Nora by saying 'You did very well last time' Nora says, 'I don't think so'. Jenny says, 'Have  
18 a go' in an encouraging way and Nora says,  
19 'I haven't had one, yet which is working'. Jenny ignores it, brushes over it by saying 'That's OK'. Jenny shows her how to  
20 release the ball down the ramp. 'When you're ready let go of that one; let go of that one; let go of that one. Brilliant, well  
21 done!'*

22 However, one observer reported that some players got less attention than others - those with less 'warm' personalities or those  
23 that appeared to be more able. An awareness of this could allow those delivering activities to consciously monitor their response to  
24 such individuals to avoid this.

25 In addition to ensuring that the players were positioned so that they could watch each other, one way of keeping the players engaged  
26 in the game was through competition. In this case through writing scores on a whiteboard, through calling out and commenting on  
27 each player's score, and through encouraging interaction within the group.

28 *People respond to encouragement – it works. 'Oohs' when they miss, 'Aahs' when they get the ball in.*

29 *Stan [sports coach] offers the scores for people to add up, 2 20's and 2 30's. Jack adds them up correctly*

1 Banter and encouragement from staff and participants helped build a sense of fun.

2 *'He was robbed!' A shout goes up from someone in the group .....full of humour and enjoyment.*

3 Care assistant says, *'Go on Jane!'* in encouragement.

4 Interaction between the players was encouraged. One player helped others with their play and was good humouredly referred to  
5 as 'coach'.

6 *Tim talks tactics with Faith who laughs and holds her hands up in mock resignation when the balls don't quite go in. Someone*  
7 *calls out 'Coach Tim'*

8 *'Can you pass them to Jean'* [the] sports coach [says] to the player as he is established as an expert at the game and he is  
9 encouraged to help his neighbour get started.

10 The contribution of care staff was particularly evident the last session observed, all of whom were evenly distributed around the  
11 group. Initially, this involvement took the form of encouraging and supporting residents verbally. Later in the session, the sport  
12 coaches asked care staff and others in the room (including the observers and UEA staff) to play, and this heightened the engagement  
13 and interaction of everyone, including residents.

#### 14 **Theme 3: Adaptations**

15 Physical adaptations used in the sessions included a practical aid; a bowling ramp. In addition to this, the way the game was played  
16 was adapted to improve accessibility. For example, the target wedge was moved from player to player for their turn; this was  
17 because moving players away from their seats had been found to be disorientating and to break the flow of play. This was an  
18 adaptation to the game that had been adopted by the sports coaches at an earlier point in the delivery of Mobile Me. The mat was  
19 also moved closer to players who were finding the game more difficult. Another example of adapting technique was to change from  
20 bowling under-arm to over-arm where this was more suited to a player with mobility issues, or where the player was impeded by a  
21 chair arm. Where adaptations were required, the sports coaches were observed to do this discretely and with little fuss.

22 Although many of the residents appeared to have mobility problems some might have been capable of bowling standing up rather  
23 than sitting down. One observer noted that was not really encouraged in the sessions where it might have been; however, standing  
24 up, where it is safe to do so, may be beneficial to players to develop mobility and balance.

25 **Theme 4: Communication** Some residents understood how to play the game, or took their cue from other players, other residents  
26 did not, or they forgot what to do between their turns. Communicating with these players could be challenging, and required  
27 persistence and adaptability from the sports coaches, for example, the use of repetition and the rephrasing of instructions.

28 *Jenny offers a great range of ways of saying the same thing, demonstrating gentle persistence in supporting residents to*  
29 *have a go [for example] 'When you're ready throw the red ball; throw that one; throw that to the floor; see if you can; pop*



- 1 *it in the ramp; let's do it together; pop it onto there then let go; take your hand away; little push little push; let's push it*  
2 *together.'*

The coaches also used their physical position and body language to help participants understand what to do. Often, they would position themselves behind the target wedge and encourage the player to throw the ball to the target using gestures. Where this did not work, a coach was observed encouraging the participant to 'throw the ball towards me', holding his hand out and motioning down to the mat. On other occasions, the coaches stood next to a player to demonstrate a throwing motion or guided the player's hand.

### Consultative group feedback on the draft guidance

The Consultative Group had only minor comments on the content and structure of the draft guidance, however they were able to identify additional recommendations from their own perspectives. One recommendation, for example, was to use the activity session to provide rehydration and a healthy snack. Another was to ensure that physical activities were integrated into the routine of a care setting. It was also recommended that the guide should include a section explaining the benefits of physical activity sessions in group setting in order to encourage buy-in from organisations such as care homes.

There was strong agreement that the main guide should be produced as a video, with written materials to supplement it. A video would allow the recommendations to be illustrated and could include a level of detail that may be off-putting in the written format. The group also recommended that the guidance materials should be available online.

## Producing the guidance

A video was developed alongside a poster; these are hosted on an active aging website being developed by Active Norfolk (see <https://www.activenorfolk.org/dementia1>). The structure of video and poster follow the four themes described above, each of which contains several sub-themes - these are shown in Table 2, column 2. The third column of the table 'Outcomes Framework' links the themes to the outcomes outlined in the initial conceptualisation of best practice for this project. Two additional outcomes for participants were identified, they are 'recognition' and 'encouragement' (for example, recognising individuals through the use their names, and encouraging individuals through recognising small achievements) and have been included in the outcome framework.

The video consists of footage of volunteers from a sheltered housing site (all of whom had the capacity to consent) participating in a bowling session with the Mobile Me instructor. The footage was taken to illustrate the themes and some of the outcomes identified, for example, the instructor assisting a participant to use a ramp, using individual's names, or praising participants and participants laughing and interacting. In addition, the DCM mapper, the Mobile Me instructor, and Dementia Care Lead for the care organisation that participated in Mobile Me were interviewed. Edits of the interviews, which are towards the end of the video, were selected not only to illustrate and reinforce points already raised, but also to provide real-life examples of positive outcomes that had arisen from the bowling sessions during the Mobile Me project. The poster, which acts as an 'aide-memoire' identifies the key points to be considered when delivering a session.

Table 2: Themes and outcomes framework for the best practice guidance

<b>Theme</b>	<b>Sub-themes</b>	<b>Outcomes framework</b>
Environment	Creating a suitable space Planning and organisation	Engagement
Atmosphere	Getting everyone involved Introducing challenge and competition Recognising small achievements	Inclusivity Engagement Social interaction Recognition Encouragement Wellbeing
Communication	Verbal communication Non-verbal communication Encouraging interaction	Inclusivity Social interaction Recognition
Adaptions	Physical aides Adapting techniques Avoiding disorientation	Inclusivity Physical activity

## Discussion

This research was undertaken with the aim of producing best practice guidance for the delivery of the physical activities for people living with moderate to advanced dementia residing in group settings. Our own observations indicate that the detail of delivery makes a difference to the quality of the experience for participants. This is supported by research with people living with dementia that indicates that the meaningfulness of activities for them is related to the quality of their experience (Harmer & Orrell, 2008). However, while there exists some general guidance on physical activity and dementia, for example, information about suitable types of activities (Alzheimer's Society, 2015), -more detailed guidance for facilitating such activities does appear to be available. These may be useful to those who are not used to working with this client group; for example, sports professionals who have experience working with older people or people living with physical conditions but not those living with more advanced dementia, or those with experience working with this group but who are unfamiliar with facilitating physical activity sessions. Recognising that delivery may be influenced by context, we have presented the guidance as 'what we found' rather than hard and fast rules, and therefore as transferable, to other settings (Lincoln & Guba, 1985).

While such guidance may be useful, they are not always easy to produce as ethical approval mechanisms for people without the capacity to consent are more complex and data collection methods must be suitable for people with reduced cognition (Mansbach et al., 2016). More generally, there is a lack of information on how to produce best practice guidance from evaluation findings, with the possible exception of guidance directed at clinical practice (National Institute for Health and Care Excellence, 2014; Shekelle, Woolf, Eccles, & Grimshaw, 1999). While DCM may be used to develop and improve practice within care settings, for example, quality monitoring (University of Bradford, 2018), it does not seem to be widely used for producing transferable best practice guidance across organisations and sectors. Yet, DCM is used in both evaluation and research to produce generalisable outputs (Brooker, 2005).

While the method adopted to produce the guidance involved a range of data collection techniques and stakeholders, the process has weaknesses and omissions. One was that first-hand data was not gathered from residents or care staff. This may have been important because the involvement of care staff in sessions was found to be a critical success factor during the observation study. One of the reasons for not interviewing care staff was the difficulties around planning the consent process, as it was not known ahead of time which staff may be present at sessions. Future work might provide an understanding of carer staff's perceptions about activities on site and about potential barriers to their participation in them, along with first-hand feedback from participants where possible. The guidance has not been tested for efficacy in terms of how it may improve well-being or other outcomes; this may also be a further area for research.

It was also noted that those observed did little actual physical activity as the sport was mostly played seated and the balls were retrieved by the sports coach; for these individuals the game involved only gentle movement. However, the results of the observation suggest there were other benefits including social interaction, communication, and increased wellbeing. This corroborates the findings of Friedman and colleagues, with communication and mood being the main measures of improvement in observational reports (Friedman & Tappen, 1991). The government's physical activity recommendations also state that some activity is better than none in older people and recognises the implications of ill health and disability in limiting physical activity in this group (Department for Health, 2011).

Consideration about how to relay the learnings from this study into best practice has resulted in the production of a video, along with a quick-access guide in poster format. Development of the best practice guidance has been multifaceted and has been undertaken in collaboration with a range of stakeholders, including researchers and clinicians working with individuals living with dementia. Nevertheless, the guidance produced is not intended to be definitive, rather an attempt to capture and build on learning made in the delivery of an activity in order that these may provide some support, and act as a starting point, to anyone that wishes to deliver a similar activity in the future. This is with the aim of identifying the best ways to engage with, and provide a service for, an otherwise seldom heard from group.

### Conclusions:

Previous research has highlighted some of the wider benefits (social and physical) of delivering a meaningful activity intervention to those living with moderate to advanced dementia; such activities are recommended by both World Health Organisation (World Health Organization & Alzheimer's Disease International, 2012) and NICE (2018). Our research indicates that the way such activities are delivered may make all the difference to how an individual experiences them. This may be due to small changes in delivery such as the positioning of seating, or communication methods. However, little detailed information exists on how to deliver such activities, or how to develop guidance for practitioners using evaluation evidence. The research described here aims not only to ensure that physical activities are delivered to optimise the suggested benefits, but also to provide an example of how best practice guidance may be developed across other areas for those living with moderate to advanced dementia.

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## List of Abbreviations:

Dementia care mapping (DCM), National Institute for Health and Care Excellence (NICE),

University of East Anglia (UEA), World Health Organisation (WHO)

Appendix 1: Best Practice Guidance Poster- Dementia Infographic



(see supplementary documents)