



### Improving the Involvement of People with Dementia in Developing Technology-Based Interventions: a Narrative Synthesis Review and Best Practice Guidelines

Harleen Kaur Rai, Aline Cavalcanti Barroso, Lauren Yates, Justine Schneider, Martin Orrell

#### Submitted to: Journal of Medical Internet Research on: December 18, 2019

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## Improving the Involvement of People with Dementia in Developing Technology–Based Interventions: a Narrative Synthesis Review and Best Practice Guidelines

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### Abstract

**Background:** Technology can be helpful in supporting people with dementia in their daily lives. However, people with dementia are often not fully involved in the development process of new technology. This lack of involvement of people with dementia in developing technology–based interventions can lead to the implementation of faulty and less suitable technology.

**Objective:** This systematic review aims to evaluate current approaches, and create best practice guidelines for involving people with dementia in developing technology–based interventions.

**Methods:** A systematic search was undertaken in January 2019 in the following databases: EMBASE, PsycINFO, MEDLINE, CINAHL and Web of Science. The search strategy included search terms in three categories: "dementia", "technology", and "involvement in development". Narrative synthesis wove the evidence together in a structured approach.

**Results:** Twenty-one studies met the inclusion criteria. Most studies involved people with dementia in a single phase such as development (n = 10), feasibility and piloting (n = 7), or evaluation (n = 1). Only 3 studies described involvement in multiple phases. Frequent methods for involvement included focus groups, interviews, observations, and user tests.

**Conclusions:** Most studies concluded it was both necessary and feasible to involve people with dementia, which can be optimised by having the right prerequisites in place, ensuring technology meets standards of reliability and stability, and by providing a positive research experience for participants. Best practice guidelines for the involvement of people with dementia in developing technology–based interventions are described.

(JMIR Preprints 18/12/2019:17531) DOI: https://doi.org/10.2196/preprints.17531

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## **Original Manuscript**

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## Title: Improving the Involvement of People with Dementia in Developing Technology–Based Interventions: a Narrative Synthesis Review and Best Practice Guidelines

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#### **Keywords**

Dementia, technology, co-production, participation, development.

#### Introduction

Technology may be used to address some of the challenges of dementia care and enable people with dementia to maintain their independence for as long as possible [1]. Despite the wide variety of available technology (eg, reminder devices, touchscreen devices and apps, and computerised cognitive/physical interventions) [2], there is a lack of evidence on efficacy and many interventions are either in the development or in a prototype phase [3]. Moreover, there has been little involvement of people with dementia in the development of technology–based interventions [4]. Possible reasons for this lack of involvement include stigma, concerns about the frailty of older people, and the anticipated distress among participants caused by trying out less developed information technology applications [5]. Underdeveloped technology–based interventions with inadequate involvement could have residual faults, and could potentially make early prototypes harder for people with dementia to operate and lead to a reluctance to use them [5]. Consequently, technologies are being developed which are not user-friendly, nor fit for purpose for people with dementia [3, 4]. Technology that is faulty or poorly designed may not be helpful in supporting people with dementia.

A previous systematic review showed that people with dementia are able to provide useful feedback such as comments on screen size, language difficulties and the importance of personalization on private spaces of websites, which help to improve the quality of the intervention [4]. This approach improves the usability and acceptability of the technology–based intervention [4] and can generate enjoyment and enthusiasm in the participants with dementia [6, 7]. However, Span, Hettinga [4] reviewed papers up to 2010, and many innovations in technology have taken place subsequently. Furthermore, Astell, Alm [8] and Span, Hettinga [4] assert that in order to optimize technology by ensuring the needs and preferences of people with dementia are addressed, it is crucial to implement a participatory process in which people with dementia are involved throughout the development process [4, 8].

Information on how to optimise the involvement of people with dementia is dispersed and

there is a clear need to bring the evidence together in a systematic matter through an appraisal of the involvement of people with dementia in technology–based interventions, and guidelines on how to best facilitate and optimise this involvement.

#### Aims

This narrative synthesis systematic review sets out to appraise the methods used by applying existing frameworks such as the Medical Research Council (MRC) Framework for the Evaluation of Complex Interventions and Centre for eHealth Research (CeHRes) roadmap [9, 10], and to create best practice guidelines on how to better involve people with dementia in developing technology–based interventions accompanied by a logic model.

#### Methods

#### Narrative

#### Synthesis

Narrative synthesis is "an approach to the systematic review and synthesis of findings from multiple studies that relies primarily on the use of words and text to summarise and explain the findings" [11]. Narrative synthesis can be used to address a multitude of questions regarding the effectiveness of interventions including what works but also why and how. Narrative synthesis is preferred for this review as it can be used to convert the evidence into clear, structured best practice guidelines on how to facilitate the participation of people with dementia in the development of technology–based interventions. The approach consists of four elements:

Element 1: Theory Development

Theory development underpins the systematic review, informing the review question and the types of studies to include. Our starting point is the desirability of end-user involvement in technology development. Several studies suggest that feedback from people with dementia can lead to improvements in the overall quality of the technology [4, 8]. This would result in more useful and

suitable pieces of technology, and would also increase the willingness to use the technology. Furthermore, the involvement of end users in developing technology could also support implementation of a technology in the future leading to a better range of technology to improve the quality of life of people with dementia. We therefore only include studies which clearly illustrate how feedback was gathered from people with dementia during development. This would exclude studies with a sole focus of including participants as objects of studies where no meaningful involvement has taken place. The narrative synthesis undertaken here will contribute to a refinement of our theoretical starting point and support the application of the review's findings [11].

Element 2: Developing a Preliminary Synthesis

The preliminary synthesis develops an initial description of the results of the included studies organised in such a way that a pattern can be described in terms of effects or impact [11]. This can be done through the use of textual descriptions, grouping and clusters, and tabulation. This preliminary synthesis is necessary in order to inform the next steps of the narrative synthesis.

**Relationships** Exploring Within **Studies** Element 3: and Between The patterns that emerge from the preliminary synthesis are subjected to a more detailed analysis in which the reviewers move towards exploring the relationships within and across the included studies [11]. Relationships between the characteristics and reported findings of different studies are reviewed. This element of narrative synthesis will help identify the factors which may have influenced the results, and will seek to provide an explanation of how and why a particular intervention works [11]. Methods used here include qualitative case descriptions and the development of a conceptual model based on the grouping of study findings. This will help to structure the inferences drawn from our results.

The final element of narrative synthesis sets out to review the trustworthiness of the results [11]. Trustworthiness of the synthesis is affected by the quality and quantity of the evidence base on which the synthesis is built and by the methods used. Therefore, an appraisal is undertaken to judge strength of the evidence for the findings, and for generalising them to different populations and contexts [11].

#### **Searches** Electronic Screening and

This review was registered in the international prospective register of systematic reviews (PROSPERO) under protocol number: CRD42017068933. After conducting two pilot searches, we systematically searched the following databases: EMBASE, PsycINFO, MEDLINE, CINAHL and Web of Science in January 2019. Studies published between 2000 and 2019 were considered. The search strategy consisted of combinations and variations of search terms in the following three key categories: "dementia", "technology", and "involvement in development". Involvement terms also included "co-design'. "participatory research", and "user participatory development".

After removal of the duplicates, a three stage screening process was independently conducted by two review team members (HR and ACB): (1) titles were screened for relevance to the review question, irrelevant studies were archived, (2) abstracts were assessed (referring to the full text whenever necessary to clarify relevance of the study), and (3) quality assessment of the remaining studies (see section on quality assessment). Reasons for exclusion were recorded by archiving the excluded studies in relevant folders in Endnote. In case of a disagreement between the two reviewers, a third review team member was consulted (LY). The additional studies from the review by Span, Hettinga [4] were distributed separately among four review members (ACB, JS, HR, and LY) for data extraction and quality assessment. The reference lists of studies that passed the quality assessment were reviewed in order to ensure the inclusion of other relevant papers.

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#### **Criteria for Inclusion and Exclusion of Studies**

Types of participants: People with a diagnosis of dementia, irrespective of age, type of dementia orstageofthedisease.Types of intervention: Involvement of people with dementia in the development process of atechnology-basedintervention.Types of studies: Quantitative, qualitative, and mixed methods studies published from the year 2000onwards as English language journal paper with sufficient study quality (a minimum of 5 criteria metas assessed with CASP guidelines or 50% of the criteria met as assessed with the Downs and Blackchecklist).

Description of Development Pha	t <b>Phases</b>	Deve	of	Description
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The development process of a technology–based intervention consists of several stages. In order to identify the key stages of technology development for this review, we have employed the MRC Framework, together with the CeHRes roadmap [9, 10]. Both frameworks have a focus on developing interventions however, where the MRC Framework is more widely used for developing complex interventions, the CeHRes roadmap has a focus on digital health interventions (Table 1). **Table 1.** Description of the MRC Framework [9] and CeHRes roadmap [10]

	MRC Framework	CeHRes roadmap
Development	Single phase	<ul> <li>Multiple phases such as</li> </ul>
	<ul> <li>Identifying evidence base</li> </ul>	contextual inquiry, value
	(eg, systematic review)	specification and design
	<ul> <li>Identifying/developing</li> </ul>	<ul> <li>Identifying problems and</li> </ul>
	theory (eg, scope existing	needs of intended users (eg,
	theories and interviewing	literature review, field
	stakeholders)	observations, interviews,
	• Modelling process and	workshops)
	outcomes (eg,	Determining most
	undertaking a pre-trial	favourable solutions based
	economic evaluation,	on stakeholders' values
	focus groups, surveys,	• Building prototypes to fit
	case-studies)	values and user

		requirements (eg, focus		
		groups and field-testing)		
Feasibility/	Specific phase for •	Feasibility/piloting and		
piloting	feasibility/piloting	evaluation taken together:		
•	Activities consist of:	operationalisation		
	testing procedures for •	Activities to introduce and		
	acceptability,	implement technology in		
	determining appropriate	healthcare (eg. piloting,		
	sample size, estimating	effect study, creating a		
	rates of recruitment	business model)		
Evaluation •	Assessing clinical and •	N/A (part of		
	cost effectiveness (eg,	operationalisation)		
	RCT)			
•	Understanding processes			
	(process evaluation)			
Implementation •	Getting evidence into	Assessment of impact of		
	practice	eHealth technologies in		
•	Surveillance, monitoring,	clinical, organizational, and		
	and long term outcomes	behavioural terms		

#### **Data Extraction and Study Quality Assessment**

A standardised data extraction form was developed by the primary researcher (HR) in which the review team members recorded the extracted data from the final studies including the study quality rating (Multimedia Appendix 1).

Quality was assessed using the Critical Appraisal Skills Programme (CASP) guidelines. These guidelines consist of 8 checklists for various types of studies and include items which assess multiple aspects of research (eg, recruitment, risk of bias, confounders, data collection, data analysis, results, and implications) [12]. The studies were rated as high quality if 8 or more criteria were met, medium quality if 5-7 criteria were met and low quality if they met 4 criteria or less [13]. Studies not meeting the criteria for assessment with the CASP guidelines were assessed with the Downs and Black checklist [14]. This checklist is appropriate for both randomised and non-randomised studies and consists of 27 items over 5 domains (reporting, external validity, internal validity: bias and confounding, and power). The maximum score was dependent on the study design but each study was rated as high quality if it met over 81% of the criteria, medium quality for 66% to 80% of the criteria, fair quality for 51% to 65% of the criteria and low quality if it met 50% of the criteria or less [15]. Studies considered to have low quality were excluded. The review team members independently assessed the studies for sufficient study quality. Any differences in judgement between two reviewers were resolved by a third review team member.

#### Consultation with the Patient and Public Involvement group

One reviewer (HR) presented the findings at a Patient and Public Involvement (PPI) consultation meeting on two different occasions. This PPI group is run on a monthly basis at the Institute of Mental Health in Nottingham. The aim of both meetings was to gain insights in people's own views on optimal involvement in developing technology–based interventions, their feedback and comments on the findings, and more specifically their feedback on the guidelines drafted by the authors. This feedback would then be integrated within the findings from this review and used to strengthen the best practice guidelines.

The first meeting was attended by 2 people with dementia, 1 carer, 1 volunteer, and 1 researcher and lasted for 45 minutes. The second meeting was attended by 2 people with dementia, 2 carers, 1 volunteer, and 4 researchers and lasted for 25 minutes. After a brief introduction on the review and its findings, the best practice guidelines were presented one at a time on a projector. In the first meeting, printed hand outs were distributed to each participant. A short discussion in terms of relevance and accuracy encompassed each guideline and notes were taken throughout the meeting.

# Results (Narrative Synthesis Element 2: Developing a Preliminary Synthesis) Search Results

A total of 2156 potentially relevant titles were identified across the 5 databases (Figure 1). Removal

of duplicates, screening of titles, abstracts, and full texts resulted in 20 studies that met the inclusion criteria. Most frequent reasons for exclusion were the lack of a technology–based intervention and absence of a development process. Additional hand searching led to the inclusion of one other study making up a total of 21 studies. This study came from the review by Span, Hettinga [4] which was not captured by the current search strategy. Other studies from the same review not captured by the search strategy (n = 7) were excluded due to not meeting the inclusion criteria (eg, not a journal paper, low study quality). The reference lists of studies passing the quality assessment were reviewed to ensure any other relevant studies would be included.

CINAHL	=	438
PsycINFO	=	335
EMBASE	= 6	593
Web of Sci	ence :	= 225
MEDLINE	= 465	

Excluded papers (N = 1652):	<b>2156</b> results
Duplicates = 916	
Intervention for/with carer = 159	←────
Intervention for/with professionals = 72	
No abstract + unlikely to be related = 14	
No technology–based intervention = 340	<b>504</b> results remaining
	after title sift
Excluded papers (N = 445):	
No development process = 181	↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓ ↓
No involvement of person with dementia =	
50	<b>59</b> results remaining
Nohutechaplogymbasedeprinterstantion = 90	after abstract (line)blokesd, non-peer-reviewed preprin
Not for dementia = 23	18 papers from Span et
Other: 101 (or no results available abstract	al's review)



The main study characteristics of all 21 studies include study sample and design, description of the technology–based intervention, and rating of study quality (Multimedia Appendix 1 and 2). Using the CASP Qualitative checklist, 11 studies were assessed as high quality and 8 studies were of medium quality. Only one study was assessed with the CASP Randomised Controlled Trial (RCT) checklist and this met 7 out of 11 criteria [16]. One other study was assessed with the Downs and Black checklist. It was rated as fair quality, meeting 65% of the criteria for a before and after follow up study [17]. Most studies were conducted in Europe (n = 17), 3 studies took place in Australia [17-19], and one other in Canada [20].

A majority of the studies adopted purely a qualitative methodology (n = 14). A total of 6 studies employed a mixed methods approach, of which 1 combined qualitative methods with a controlled trial [16]. Only one study adopted a purely quantitative methodology [17]. The studies described a variety of technology–based interventions including communication aids, music tools, devices to support activities of daily living, reminder systems, and tracking devices. In the majority of the studies people with dementia were involved along with carers or other professionals who either supported the person with dementia in their involvement or provided separate input themselves (n = 17). Only 4 studies solely included people with dementia [17, 21-23].

#### Methods of Involvement and Key Findings

The methods used to involve people with dementia along with the phases of the MRC Framework and CeHRes roadmap are summarised in Table 2 allowing for an initial synthesis of the findings. **Table 2.** Methods used to involve people with dementia in the studies (N = 21) according to the MRC Framework phases

MRC Framework phase		Mathada af '
		Methods of involvement
Development (contextual inquiry,	value	Behavioural observations [21, 24],
specification, design)		Focus groups [6, 7, 22, 25-28]
		Interviews [6, 22, 23, 26, 28-31],
		Workshops [7, 29],
		Questionnaires [21],
		User tests [6, 7, 22-24, 26]
Feasibility/piloting		Behavioural observations [17-20, 32, 33],
		Interviews [18-20, 29, 31, 33, 34],
		Questionnaires [17, 20, 33, 34],
		Field-testing [22, 29, 33],
		Technical system usage [31]
Evaluation (operationalisation)		RCT [16], focus groups [16], interviews
		[16], questionnaires [16]
Implementation		N/A
Development Phase		(n =

A total of 10 studies involved people with dementia solely in the development phase which coincides with the contextual inquiry, value specification, and design phase of the CeHRes roadmap. The majority of these studies primarily employed qualitative methods such as focus groups and semistructured interviews. These were at times accompanied by user tests, observations, and questionnaires. Table 2 gives an overview of all methods used in the development phase. The aims of the studies ranged from identifying people's needs, wishes, and thoughts regarding certain areas for development (eg, independence or cognitive reinforcement) to gaining feedback on the design of

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future or existing technologies (Figure 2).

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Needs Design of Technology Assessment and Future Two studies included needs assessments followed by discussions about the design of future technology using qualitative methods. Boman, Nygard [25] used focus groups to capture experiences, expectations, and thoughts concerning a videophone and its design concepts. The design should be flexible in order to meet the needs of people with dementia, be easy to use and not look like assistive technology. Another example is the study by Robinson, Brittain [7] who also used focus groups to elicit their views and concerns about independence from people with dementia and carers. A list of priorities was derived from the findings. Areas for functional improvement included two-way communication, flexibility of functionality, and something to "guide" them home when outside. Workshops were then used to identify the preferred design and functionality aspects of future technologies. Finally, user tests were performed with paper prototypes until two fully functional devices were developed.

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Needs Assessment and User Tests
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In three other studies, needs assessments were followed by user tests with functional technologies. Orpwood, Chadd [23] used interviews with users (user surveys) to compile a wish list of issues that were of importance in maintaining quality of life of people with dementia. A large list of potential technologies that could address these issues was generated. Four of these were selected for initial development: a music player, a device to reduce social isolation, a conversation prompter, and a device to support sequences of tasks. Useful design guidelines were derived from the user tests particularly for intuitive control interfaces (eg, controls need to stand out, be big, and simple).

Touch screens appear to be very intuitive and prompts seems to be more effective than verbal or visual instructions. Hanson, Magnusson [6] used focus groups to identify user needs

and preferences, and to structure the material within a multimedia programme. A prototype was taken forward in user tests followed by in-depth interviews. These led to the identification of problems such as logging into and out of the programme, and accessing the exercises. Participants enjoyed the computer training sessions and gained considerable satisfaction from learning a new skill that they previously thought was not feasible. Lopes, Pino [26] used interviews to analyse user needs and identify commonly misplaced items such as keys, glasses, cell phones and identity papers. Focus groups and user tests were then used to try out existing item locators and define the following system requirements of a new item locator prototype: ease of use, capacity for customization, low price, non-stigmatizing design, and being "fun" to use. The next step included user tests with the first prototype in which participants commented they would prefer to be guided by a customised sound of a voice system to find an item.

Design of Existing or Future Technology

In two studies, feedback was solely gathered on the design of future technologies using qualitative methods only. In Meiland, Hattink [28], non functional mock ups were reviewed after discussing potential functionalities of an integrated, assistive system in focus groups and interviews. Participants valued help in case of emergencies, navigation support, and the calendar function the most. The least preferred functionalities were activity support and picture phone dialling. McCabe and Innes [27] found that people with dementia and carers gave specific feedback on the form and features of a potential global positioning system (GPS) design during focus groups (eg, waterproof watch style design with a range of colors) however, participants would have preferred to comment on an actual and active device rather than talking hypothetically as it did not provide them with enough context.

In three studies, participants gave feedback on the design of an existing and functional technology. Freeman, Clare [21] analysed observational data of people with dementia using two websites. This data helped to uncover three major problems: scrolling, non recognition of more information on a page, and becoming stuck. There was a high degree of overall satisfaction with both

sites measured through questionnaires. Kerkhof, Rabiee [30] interviewed residents after bench-testing a memory aid (planning board). The majority appreciated the use and function of the aid but successful implementation was difficult due to installation errors, limited user friendliness and lack of knowledge regarding the function and use of the aid. Areas of focus for improvement include: software program adaptation, additional technological applications, internet connectivity, accessibility, and addition of media. Lastly, Klein, Uhlig [24] also observed participating while testing two prototype devices. Based on the findings from these tests, a third prototype device was developed. Special attention was given to more personally relevant and engaging content, contextual factors, higher levels of immersions, and more control for the user.

#### Feasibility and Piloting Phase (n = 7)

Seven studies included only the feasibility and piloting phase which comprises the operationalisation phase of CeHRes roadmap [17-20, 32-34]. In this phase, people with dementia were given the opportunity to try out a piece of technology in a pilot study or through field-testing. Often the aim was to gain insights in the usefulness of a device along with its acceptability and usability (see Figure 2). In the majority of the studies (n = 5), a mixed methods approach was adopted where participants were observed while using the device and feedback was obtained through semistructured interviews and questionnaires. Table 2 gives an overview of all the methods used in the feasibility and piloting phase.

Begum, Wang [20] used observations to investigate adherence to prompts from a robot, engagement with the robot and how often a task was completed. Interviews and questionnaires gave information on the acceptance, ease of use, usefulness, and physical attributes of the assistive robot. Meiland, Bouman [33] field-tested an integrated digital prosthetic with multiple functionalities. Data on usability was collected through behavioural observations, interviews, and questionnaires and it was deemed to be user-friendly and useful but there was a wish for more personalization and configuration of reminders.

Moyle, Jones [19] explored the acceptability of a telepresence robot using observations through video recordings and follow up interviews. Participants indicated a positive social presence, which was also observed through the display of positive emotions. A similar methodology was adopted in another study by Moyle, Jones [18]. Observations through video recordings were used to describe the effectiveness of a Virtual Reality Forest (VRF) on engagement, apathy, and mood states. Overall, the VRF was perceived to have a positive effect but there were higher levels of fear/anxiety. Follow up interviews were used to explore the experiences of using the VRF. Most participants reported positive perceptions and suggested to make the experience more active.

Topo, Mäki [34] used questionnaires to collect information on functional ability of people with dementia. Through interviews, data was collected on the usage and usefulness of an existing music tool two weeks after installation in a care home. Most participants benefitted from its use and had positive experiences. Some problems were reported with the sensitivity of the touch screen and the font size being limited due to the screen size.

Jamin, Luyten [32] used a qualitative approach where participants were involved in usability testing and were observed while interacting with "VENSTER". The content of VENSTER, which needs to provide enough context in order to be meaningful, was interesting and suitable for the participants. Khosla, Nguyen [17] was the only study using a quantitative methodology where participants were observed while interacting with a social robot to gain insights in emotional, visual and behavioural engagement. In addition, user surveys were used to assess the acceptability. The participants generally had a positive attitude towards social robots. Most of the participants gave high ratings in terms of the perceived usefulness and enjoyment of their experience with the robot.

#### **Development + Feasibility and Piloting Phase (n = 3)**

Three studies elaborated on both the development, and feasibility and piloting phase [22, 29,

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31]. These studies systematically described the involvement of people with dementia over the course of each phase: the identification of user needs and wishes, determination of the design, and testing a prototype version through a pilot- or field test. For each of these activities, a wide array of methods was applied such as focus groups and interviews but also workshops and usability tests.

In the study by Span, Hettinga [22], the development phase consisted of interviews to identify needs and preferences for an interactive web tool and focus groups to discuss the results of the interviews and to make any additions to the problems and experiences shared. Several user requirements were identified such as social contacts, daily activities, care, and autonomy, involvement, communication specifically for the decision making process. Paper mock ups were discussed in focus groups in order to design the interactive prototype. Hereafter, individual user tests were organised to gather feedback on an interactive prototype regarding design, content, and user friendliness. Some participants found it difficult to comment on paper mock ups but overall mentioned that information per screen and the amount of screens should be decreased, and the accuracy of language was of importance. For the feasibility and piloting phase, an interactive prototype was field-tested to gain feedback on the user friendliness of the tool, participants' contentment, and how they valued the tool for decision making.

Martin, Augusto [31] used interviews in the development phase to establish the main issues and risks, and care needs arising during night time. Main themes included: promoting independence, maintaining dignity, maximising social inclusion, managing risk, and providing stimulation. In the feasibility and piloting phase, participants were involved in any of the three phases of iterative validation and evaluation of a prototype through technical system usage and interviews. The phases included testing for stability, usability and integration within a full telecare system, and implementation of music and light. Participants

liked the mobile component of the night time system and the easy navigation.

Davies, Nugent [29] used both interviews and workshops to identify user needs in specific areas of cognitive reinforcement in the development phase. The following areas were identified by the participants: remembering, maintaining social contact, performing daily life activities, and enhanced feelings of safety. Interviews accompanied field-testing in the feasibility and piloting phase. After trying out four prototypes, participants highlighted the need for personalization, less complex functionality, and an extended use within the home environment.

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Evaluation Phase (n = 1)
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One study involved people through evaluation in a controlled trial [16]. Participants used an assistive system and filled in posttest questionnaires to assess impact. Despite no significant effects on impact, posttrial interviews and focus groups were used to assess qualitative impact and participants found the system to be very useful but not user-friendly due to the technical difficulties including unresponsiveness of touch screens, issues with gaining access etc. For people who had not used touch screen before, the system was deemed unintuitive.

Involving		People	with	Dementia
Impact	on	the	Developed	Technology

In all but five studies [17, 19, 23, 24, 29] researchers directly reflected on the involvement of people with dementia in the development of the technology–based intervention. Researchers concluded that it was both necessary and feasible to involve people with dementia throughout the development process. In addition, Kerkhof, Rabiee [30] argued that it is not sufficient to respond to the needs of people with dementia by solely involving carers or staff members. This is further supported by Meiland, Hattink [28] and Lopes, Pino [26] who found that exploring the user perspectives from various stakeholders including people with dementia is

in order to understand the problem and come up with possible solutions. Jamin, Luyten [32] also emphasized that co-design with all stakeholders can make the overall experience more pleasurable but also more meaningful as it allows for the users to be kept at the centre of the decision making process and adaptations can be made to new insights as they emerge. In several studies it was recognised that people with dementia continue to be one of the most excluded groups from research and the design of new services [6, 25]. Possible reasons for this could be difficulties in recruitment or the cognitive impairment of people with dementia [20, 33]. However, despite these challenges, all studies recommended to involve people with dementia in future studies as this could lead to obtaining views on new concepts or ideas for technology, to more concrete feedback on the usability and user friendliness of a device. For instance, one study determined how to maximise website suitability for people with dementia after receiving feedback [21]. Another study adapted the appearance of a robot and made it more socially interactive [20]. Lastly, people with dementia suggested the interaction between end users and a virtual reality system could be improved by incorporating reminiscence within the tool [18].

Impact on the Person with Dementia Positive effects of involvement for people with dementia themselves included the empowering effects of involvement which were evident in increased feelings of well-being, being able to voice opinions, learning a new skill through the use of technology, and an enhanced sense of control experienced by the majority of the participants [6]. Participants were also motivated to make a contribution to research and a better quality of life for future people with dementia [22, 30]. No distress or adverse events from involving people with dementia were reported in any of the studies.

**Outcomes of the Patient and Public Involvement Consultations** PPI group members reflected both on how to optimise involvement in research and in developing technology–based interventions, and endorsed the guidelines (Multimedia Appendix 3). Additions were made to some guidelines. For example, there was consensus among members that researchers need to focus on individual research participants, which includes awareness of their type of dementia, any other relevant conditions, and any specialised knowledge of participants which could further support the development of technology. Awareness among participants in terms of the relevance and positive effects of involvement for them was also important.

A friendly research environment was helpful to make people feel comfortable to ask questions in case they did not understand something. This is especially helpful when developing new technology, which can include some unknown aspects and so researchers should also aim to avoid abbreviations and acronyms on top of avoiding technology–related jargon. In addition, PPI group members suggested that researchers should present their materials at a PPI meeting before an actual research activity takes place to ensure the use of jargon is limited.

Involving people with dementia as early as possible in the development process and in multiple phases of development, should lead to increased familiarity and a better understanding of the technology. Members were also positive about encouraging technology developers to interact directly with people with dementia, but did highlight that a mediator (eg, a researcher) would be necessary to ensure a good level of understanding among both people with dementia and the developers. A person with dementia also mentioned taking a technology into the community (eg, a memory café) to gather feedback as this would allow for technology be life the to used in а real setting. Lastly, a "Wizard of Oz" method was suggested by a researcher where participants interact with a working prototype, but under guidance from an unseen researcher. The two PPI group members with dementia mentioned they would not have an issue with this in terms of ethics and it was regarded as a good idea. This method could serve as a way to limit the amount of errors.

# Discussion (Narrative Synthesis Element 3: Exploring Relationships Within and Between Studies)

People with dementia can contribute effectively to the development of technology but are often excluded from research in this area. With the rise of innovative technology, there is a need for an overview of the current evidence regarding the involvement of people with dementia and recommendations on how to optimise this involvement in the development process. This is to ensure the developed technologies are suitable and tailored towards the needs of the end users. This is the first narrative synthesis review to synthesize the findings from high quality studies of involvement of people with dementia in developing technology–based interventions, and has created best practice guidelines based on the evidence summarized below.

A strength of this review is the strict inclusion criteria leading to the synthesis of high quality papers. This has further supported the robustness of the findings and the developed guidelines. Furthermore, the application of narrative synthesis in this systematic review allowed for a highly systematic approach to searching for and making sense of the evidence. The underpinning theory as part of the first element of narrative synthesis helped define the research questions and the studies to be included in the review. In addition, the preliminary synthesis supported the tabulation of the findings, which is highlighted in the text, tables and figures. This approach also proved helpful in converting the evidence into best practice guidelines by looking for relationships within and between the studies. Good examples of

involvement were extracted and incorporated into the guidelines, which were modified by the input of the PPI group. This enabled the invaluable perspective of people with lived experience on the findings, and helped strengthen the robustness of the synthesis and relevance of the guidelines.

#### Summary and Interpretation of Findings

The findings suggest that the involvement of people with dementia varies depending on the development stage and methods used which is in line with previous research [4]. A big part of involving people with dementia revolves around identifying user needs and preferences. The majority of the studies included this aspect in their research and primarily used qualitative methods such as focus groups and interviews. The identification of needs often helped to prioritise the most pressing issues for people with dementia.

Another component is gathering feedback on either the prospective or existing design of a device. These activities mostly include qualitative methods to gather using observations and questionnaires. People with dementia take on an active role in voicing their opinions and trying out the available prototypes. Once a piece of technology has been developed into a more refined version, the involvement of people with dementia shifts more towards the participants becoming the objects of study. In several studies, people with dementia were asked to use a piece of technology more rigorously during a field-testing phase accompanied by observations, and to give feedback after the test phase. Interestingly, no studies involved participation of people with dementia in the implementation phase.

These findings are congruent with findings from Span, Hettinga [4]. However, in this review we found studies, which described more elaborately the involvement of people with dementia and demonstrated that it is feasible to include them throughout the entire development process rather than in a single phase. The involvement of people with dementia started with exploring their needs and gaining understanding of a current problem, which led

to the development, and testing of various prototypes together with people with dementia in order to tailor it to their needs. These studies set a good example for future studies by also applying various methods and obtaining in-depth data from people with dementia. The impact of the involvement is also evident as studies gave examples of concrete pieces of feedback from people with dementia, which improved the developed technology. However, there is also impact of involvement on the person him/herself as some studies showed that involvement of people with dementia can be empowering and lead to increased feelings of well-being [6]. Participants expressed the importance of being able to make a contribution to the research through voicing their own opinions [4, 6, 30]. None of the studies noted any distress caused through the involvement of people with dementia. This is helpful for future studies as anticipated distress from trying out underdeveloped technology was seen as reason not to include people with dementia in development [23].

Some challenges were described in the involvement of people with dementia such as the risk of obtaining socially desirable answers [25, 33]. However, this risk is not specific to this population and in general, is not uncommon in research. Another challenge was obtaining in-depth feedback from participants as the use of unfamiliar terms related to technology made it difficult for participants to comprehend the questions [34]. Jamin, Luyten [32] emphasized the need for the involvement of multiple stakeholder but acknowledged that this adds a level of complexity to the design process as researchers or developers would have to navigate various differing opinions. Despite these challenges, all studies recommended that people with dementia should be involved in developing technology and also to keep including relevant stakeholders such as (in)formal carers and technology developers where possible.

# Best Practice Guidelines (Narrative Synthesis Element 4: Assessing the Robustness of the Synthesis)

Based on the findings from the studies included in this review and the contributions from the PPI consultation meetings, best practice guidelines for the involvement of people with dementia in developing technology–based interventions were developed (Multimedia Appendix 3). A previous best practice model included in a systematic review by Di Lorito, Birt [35], served as an example to better organise the findings according to goals of involvement, preparations and, the contributions from the PPI consultation meetings. A score can be allocated to each guideline depending on whether it has been fully met (2), partly met (1), or not met (0). The availability of twelve guidelines means that a total score of 24 can be achieved, indicating that each guideline has been met in full when developing a technology–based intervention for people with dementia.

Having the right prerequisites in place prior to involvement can help overcome the challenges and to optimise the involvement of people with dementia. When it comes to the participants, prioritising their well-being and ensuring they are aware of the purpose and relevance of their involvement can help contribute to an enjoyable research experience [6, 25]. Both findings from this review and suggestions from the PPI group members emphasized the need for skilled researchers, and the need for a comfortable research environment. Researchers need to take time to get to know participants and PPI group members added that researchers should be aware of any specialised knowledge of people with dementia prior to their involvement. This could strengthen their contributions and furthermore, it would easily enable them to become co-researchers. Furthermore, determining the goal of involvement and where it is best suited in the development process will help avoid wasting time of people with dementia

Keeping in line with this, multiple methods for involvement need to be considered to

obtain the most optimal feedback and where possible multiple phases of development should be included. This was confirmed by the PPI group members and in addition to this, early involvement of people with dementia was considered to be helpful as it would also help to identify their own needs and ideas for technology. The latter is crucial in some of the studies included in this review in which people with dementia are involved in needs assessments and prioritising areas for functional improvement before moving on to prototype development. It is also recommended to involve all relevant stakeholders and allow interaction between them to obtain a well rounded view from several user perspectives but also to enable people with dementia to become part of the research and development team [30, 32]

During the involvement of people with dementia, the research experience can be further enhanced if participants are able to learn a new skill involving technology [6, 22]. This can lead to increased motivation and feelings of empowerment. In addition, the use of appropriate terminology can be helpful in obtaining meaningful and more in-depth answers [34]. Technology must meet an acceptable standard of stability and reliability when evaluating its impact [16]. This can help to avoid frustration among participants and to avoid missing out on essential feedback. PPI group members agreed it would be more useful to use functional devices during testing, and added that the technology should be compatible with different platforms if applicable (eg, a computer or a mobile phone). However, members also reflected on the "Wizard of Oz" method and the idea of an unseen researcher operating the device from a distance while people with dementia would interact with it. This method could potentially function as a good alternative where paper-based prototypes are not suitable but fully functional prototypes are not available either. After involvement has taken place, it is advisable to keep participants up to date regarding further development or implementation of the technology. new

Figure 3 includes a logic model based on the findings from this review and the best

practice guidelines. It describes the current problem of a lack of involvement of people with dementia in developing technology and how this can be remedied through key intervention change technique such as setting goals of involvement and using appropriate methods. This will lead to key- and long term outcomes including more useful pieces of technology and decreased costs of dementia care.



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#### the Synthesis)

This review included very few studies, which involved people with dementia in multiple stages of technology development. Furthermore, although this review did not focus on the passive involvement of people with dementia (eg, in large-scale RCTs), few studies allowed for impact evaluation and subsequent sharing of feedback such as in the study by Hattink, Meiland [16]. Lastly, no studies were found which included the involvement of people with dementia in the implementation phase of development.

The definition of involvement in a development process was partly based on previous research and therefore only included studies in which people with dementia played an active part in development or were able to give feedback. This might have caused the exclusion of other potential relevant studies, which involved people with dementia through other methods, which is a limitation of this review. Another limitation is the focus on English language peer reviewed journal papers only which may have led to the exclusion of other, potentially relevant content.

#### Future

#### Research

In order to develop more tailored technology and explore the possible roles for people with dementia in other phases, future studies should expand on the level of involvement of people with dementia. People with dementia should be co-researchers or advisors, and be made an integral part of the research team and the study. This would enable the same group of people with dementia to consistently provide feedback from the early stages of development (eg, formulating the problem) towards the mid- and end stages (eg, design and implementation). Especially considering the lack of studies focussing on the implementation phase, future research should explore the role of people with dementia in both implementation and

dissemination of a new technology. In addition, in some current studies the researcher often acts as a mediator between the person with dementia and the technology developer. However, future studies could aim to facilitate direct knowledge transfer between the two in order for the technology developers to receive raw feedback.

#### Conclusion

Over time, studies have involved people with dementia more rigorously in developing technology however, technologies still need to be more tailored to the needs and preferences of people with dementia. In order to do this, people with dementia need to be given an active role in the development of technology so they can have the opportunity to voice their thoughts and opinions. This narrative synthesis review has shown that it is feasible for people with dementia to assume a more active role throughout the development process from discussing and commenting, to try outs and testing. Involvement of people with dementia is associated with several benefits namely the development of better and more useful technology, an improved uptake of the technology and an increased willingness to use the technology. In addition, the evidence–based, best practice guidelines were deemed to be relevant by PPI group members and will help support future researchers, technology developers, and people with dementia to optimise involvement when developing technology. This will not only ensure that future technology–based interventions are suitable but will also allow people with dementia to feel empowered by making an effective contribution to technology development and research in general.

Textbox 1. Summary guidance for involving people with dementia in developing technology

Prepa	re for	involvement:
•	Make this a positive experience for participants by creating a friendly	/ environment,
	where people can ask questions and feel supported.	

• Involve a variety of stakeholders and users in order to collect a range of feedback

and perspectives.

- Ensure all practicalities for involvement are in place to meet the needs of participants.
- Participants should be made aware of the purpose and relevance of their involvement to meet their expectations and encourage honest feedback.
- Explore the available methods for collecting feedback and select the ones best suited for the goal of involvement.

#### Practice

involvement:

- Use appropriate terminology/words when asking questions to promote understanding and generate more in-depth feedback.
- Offer participants the opportunity to learn a new skill through their involvement in order to enhance well-being and empowerment.
- Involve participants throughout the development process to create a more suitable piece of technology for wider uptake.
- Keep participants informed after their involvement so they can stay up to date on further development and implementation of the technology.

#### Authors'

#### Contributions

HR and MO developed the research question for the review. MO provided supervision and guidance throughout the review process. HR conducted the searches, screening for eligibility, data extraction, PPI consultations and drafted the paper. ACB, LY, and JS supported screening for eligibility, and data extraction. All authors read and approved the final paper.

#### Acknowledgements

We would like to thank the PPI group members at the Institute of Mental Health in Nottingham who gave their time to review our findings and give essential feedback. We would also like to thank Emma Young (information specialist, Duncan Macmillan & Rampton Staff Libraries and Institute of Mental Health) for her support in defining the search strategy and in running the first pilot searches for this review. The research presented in this

paper was carried out as part of the Marie Curie Innovative Training Network (ITN) action,

H2020-MSCA-ITN-2015, under grant agreement number 676265.

#### **Conflict of Interest**

None.

#### Abbreviations

CASP: Critical Appraisal Skills Programme CeHRes: Centre for eHealth Research GPS: Global positioning system ICT: Information communications technology MRC: Medical Research Council PPI: Patient and public involvement RCT: Randomized controlled trial VRF: Virtual Reality Forest

Multimedia Appendix 1: [Main characteristics of included studies]Multimedia Appendix 2: [Methodological quality of included qualitative studies]Multimedia Appendix 3: [Best practice guidelines for the involvement of people with

dementia in developing technology-based interventions]

#### References

1. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. World Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost and Trends. London: Alzheimer's Disease International, 2015.

2. Gibson G, Newton L, Pritchard G, Finch T, Brittain K, Robinson L. The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia. 2016 Jul;15(4):681-701. PMID: 24803646. doi: 10.1177/1471301214532643.

3. Tak SH, Benefield LE, Mahoney DF. Technology for long-term care. Res Gerontol Nurs. 2010 Jan;3(1):61-72. PMID: 20128544. doi: 10.3928/19404921-20091103-01.

4. Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C. Involving people with dementia in the development of supportive IT applications: a systematic review. Ageing Res Rev. 2013 Mar;12(2):535-51. PMID: 23318684. doi: 10.1016/j.arr.2013.01.002.

5. Orpwood R, Sixsmith A, Torrington J, Chadda J, Gibson G, Chalfont G. Designing technology to support quality of life of people with dementia. Technol Disabil. 2007;19:103-12. doi: 10.1007/s10209-009-0172-1.

6. Hanson E, Magnusson L, Arvidsson H, Claesson A, Keady J, Nolan M. Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. Dementia. 2007;6(3):411-34. doi: 10.1177/1471301207081572.

7. Robinson L, Brittain K, Lindsay S, Jackson D, Olivier P. Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. Int Psychogeriatr. 2009 Jun;21(3):494-502. PMID: 19193255. doi: 10.1017/S1041610209008448.

8. Astell A, Alm N, Gowans G, Ellis M, Dye R, Vaughan P. Involving older people with dementia and their carers in designing computer based support systems. Univers Access Inf Soc. 2008;8:49-58. doi: 10.1007/s10209-008-0129-9.

9. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ. 2008;337. doi: 10.1136/bmj.a1655.

10. van Gemert-Pijnen JE, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G, et al. A holistic framework to improve the uptake and impact of eHealth technologies. J Med Internet Res. 2011 Dec 5;13(4). PMID: 22155738. doi: 10.2196/jmir.1672.

11. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC Methods Programme: Lancaster University; 2006.

12. Critical Appraisal Skills Programme. CASP Checklists 2017 [cited 2019 15 March]; Available from: http://www.casp-uk.net/checklists.

13. Bayliss A, Currie L, McIntosh T, Bazian L, Gallagher R, Watson M, et al. Infusion Therapy Standards – Rapid evidence review. London: Royal College of Nursing 2016.

14. Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. J Epidemiol Community Health. 1998;52:377-84. PMID: 9764259. doi: 10.1136/jech.52.6.377.

15. McDermott O, Charlesworth G, Hogervorst E, Stoner C, Moniz-Cook E, Spector A, et al. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. Aging Ment Health. 2018 Jan 17:1-11. PMID: 29338323. doi: 10.1080/13607863.2017.1423031.

16. Hattink BJ, Meiland FJ, Overmars-Marx T, de Boer M, Ebben PW, van Blanken M, et al. The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact. Disabil rehabilitation Assist Technol. 2016;11(1):61-71. PMID: 24989993. doi: 10.3109/17483107.2014.932022.

17. Khosla R, Nguyen K, Chu M. Human Robot Engagement and Acceptability in Residential Aged Care. International Journal of Human–Computer Interaction. 2017;33(6):510-22. doi: 10.1080/10447318.2016.1275435.

18. Moyle W, Jones C, Dwan T, Petrovich T. Effectiveness of a Virtual Reality Forest on People With Dementia: A Mixed Methods Pilot Study. Gerontologist. 2017 Jun;58(3):478-87. PMID: WOS:000432280300012. doi: 10.1093/geront/gnw270.

19. Moyle W, Jones C, Dwan T, Ownsworth T, Sung B. Using telepresence for social connection: views of older people with dementia, families, and health professionals from a mixed methods pilot study. Aging Ment Health. 2018 Dec;23(12):1643-50. PMID: 30450924. doi: 10.1080/13607863.2018.1509297.

20. Begum M, Wang R, Huq R, Mihailidis A. Performance of daily activities by older adults with dementia the role of an assistive robot. IEEE International Conference on Rehabilitation Robotics. 2013. PMID: 24187224. doi: 10.1109/ICORR.2013.6650405.

21. Freeman ED, Clare L, Savitch N, Royan L, Litherland R, Lindsay M. Improving website accessibility for people with early-stage dementia: a preliminary investigation. Aging Ment Health. 2005 Sep;9(5):442-8. PMID: 16024403. doi: 10.1080/13607860500142838.

22. Span M, Hettinga M, Groen-van de Ven L, Jukema J, Janssen R, Vernooij-Dassen M, et al. Involving people with dementia in developing an interactive web tool for shared decision-making: experiences with a participatory design approach. Disabil Rehabil. 2017 Jun;40(12):1410-20. PMID: 28286969. doi: 10.1080/09638288.2017.1298162.

23. Orpwood R, Chadd J, Howcroft D, Sixsmith A, Torrington J, Gibson G, et al. Designing technology to improve quality of life for people with dementia: user-led approaches. Univers Access Inf Soc. 2009;9(3):249-59. doi: 10.1007/s10209-009-0172-1.

24. Klein P, Uhlig M, Will H. The Touch and Feel of the Past-Using Haptic and VR Artefacts to Enrich Reminiscence Therapy for People with Dementia. Technologies. 2018 Dec;6(4). PMID: WOS:000454335200016. doi: 10.3390/technologies6040104.

25. Boman IL, Nygard L, Rosenberg L. Users' and professionals' contributions in the process of designing an easy-to-use videophone for people with dementia. Disabil rehabilitation Assist Technol. 2014 Mar;9(2):164-72. PMID: 24512219. doi: 10.3109/17483107.2013.769124.

26. Lopes P, Pino M, Carletti G, Hamidi S, Legué S, Kerhervé H, et al. Co-Conception Process of an Innovative Assistive Device to Track and Find Misplaced Everyday Objects for Older Adults with Cognitive Impairment: The TROUVE Project. IRBM. 2016;37(2):52-7. doi: 10.1016/j.irbm.2016.02.004.

27. McCabe L, Innes A. Supporting safe walking for people with dementia: User participation in the development of new technology. User Participation. 2013;12(1):4-15. doi: 10.4017/gt.2013.12.1.006.00.

28. Meiland FJ, Hattink BJ, Overmars-Marx T, de Boer ME, Jedlitschka A, Ebben PW, et al. Participation of end users in the design of assistive technology for people with mild to severe cognitive problems; the European Rosetta project. Int Psychogeriatr. 2014 May;26(5):769-79. PMID: 24507571. doi: 10.1017/S1041610214000088.

29. Davies RJ, Nugent CD, Donnelly MP, Hettinga M, Meiland FJ, Moelaert F, et al. A user driven approach to develop a cognitive prosthetic to address the unmet needs of people with mild dementia. Pervasive Mob Comput. 2009;5(3):253-67. doi: 10.1016/j.pmcj.2008.07.002.

30. Kerkhof YJ, Rabiee F, Willems CG. Experiences of using a memory aid to structure

and support daily activities in a small-scale group accommodation for people with dementia. Dementia. 2015;14(5):633-49. PMID: 24339118. doi: 10.1177/1471301213504210.

31. Martin S, Augusto JC, McCullagh P, Carswell W, Zheng H, Wang H, et al. Participatory research to design a novel telehealth system to support the night-time needs of people with dementia: NOCTURNAL. Int J Environ Res Public Health. 2013;10(12):6764-82. PMID: 24304507. doi: 10.3390/ijerph10126764.

32. Jamin G, Luyten T, Delsing R, Braun S. The process of co-creating the interface for VENSTER, an interactive artwork for nursing home residents with dementia. Disabil rehabilitation Assist Technol. 2018;13(8):809-18. PMID: 29037109. doi: 10.1080/17483107.2017.1385102.

33. Meiland FJ, Bouman AI, Savenstedt S, Bentvelzen S, Davies RJ, Mulvenna MD, et al. Usability of a new electronic assistive device for community-dwelling persons with mild dementia. Aging Ment Health. 2012;16(5):584-91. PMID: 22360649. doi: 10.1080/13607863.2011.651433.

34. Topo P, Mäki O, Saarikalle K, Clarke N, Begley E, Cahill S, et al. Assessment of a Music-Based Multimedia Program for People with Dementia. Dementia. 2004;3(3):331-50. doi: 10.1177/1471301204045164.

35. Di Lorito C, Birt L, Poland F, Csipke E, Gove D, Diaz-Ponce A, et al. A synthesis of the evidence on peer research with potentially vulnerable adults: how this relates to dementia. Int J Geriatr Psychiatry. 2017;32(1):58-67. PMID: 27633160. doi: 10.1002/gps.4577.

# **Supplementary Files**

Figures

## **Multimedia Appendixes**

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Main characteristics of included studies (N = 21). URL: https://asset.jmir.pub/assets/1169378d5c8995d52aca7fe6637d8379.docx