

# CATALYSTS FOR CHANGE FINAL REPORT

## **Project Title: Our Visit**

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(Photo credit: Kirstin James)

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## 1. Summary

## **Background**

The QNIS study explored hospital visiting time for people with dementia from the perspective of professional care givers. This was important because older people with dementia experience significant health inequalities compared to those without a dementia diagnosis. This includes poorer outcomes from a hospital stay. Research has shown that participating in meaningful activity creates improved conditions for health. Alongside this, family members are becoming more involved in the day-to-day care of people with dementia when they are in hospital. As a marginalised group, family care givers might also experience health inequalities.

#### **Study Aims**

The intention of the QNIS catalyst study was to explore, discover, and start to co-create, an intervention by beginning to understand visiting time. The overarching aims of 'Our Visit' are ongoing and include:

- 1. To collaboratively develop an intervention and 'resource kit' as appropriate-currently named 'Our Visit'- to stimulate meaningful activity participation together
- 2. To co-create a method to embed 'Our Visit' into visiting times
- 3. To provide strategic recommendations as to the future development of services in line with Commitment 11

This QNIS study had the additional aim:

4. To develop the 'research readiness' of community nurses

## Method

Qualitative methodology framed the research, with specific methods applied from Appreciative Inquiry. Family and professional care givers were invited to participate in the study by displaying posters and information leaflets around one community hospital. A total of four professional care givers took part in two focus groups, which were facilitated by two researchers. No family care givers took part: a significant limitation of the study. Written informed consent was obtained from participants, and participation was voluntary. Focus

groups were audio-recorded, with consent, and the audio transcribed verbatim by a transcriber. Transcript data were analysed using thematic analysis methods, and potentially important findings were discussed and considered with participants to discover what might be important about visiting time.

#### **Ethical Approval**

NHS Ethical Approval was granted from West Midlands - Edgbaston Research Ethics Committee (reference 211544) and The University of the West of Scotland Research Ethics Committee. Permission was also granted from the local NHS Research and Development Board.

#### **Findings**

Two over-arching findings emerged from the data. First, 'A Good Visit', showed how visiting time might be used by visitors and their family member and may provide an important bridge between the community and the hospital. Work is still needed to understand how best to support families during visit time. Second, 'Meaningful Objects' illustrated how physical objects might provide a source of attachment and security for the person with dementia; could be used to facilitate activity and are a source of potential comfort. Therapeutic dolls appeared to offer the strongest means of attachment and might have the potential to complement how people with dementia are supported when they are in hospital.

#### Conclusion

Developing an understanding and a way of enhancing visiting time has the potential to improve the conditions for health both for people with dementia and their care givers. Outcomes from this project will catalyse larger studies of visiting, not necessarily limited to hospital environments.

## **Key Messages for Community Nurses**

Participatory engagement in meaningful activity, as 'Our Visit', has the potential to benefit people with dementia, their families and the professionals who work with them. Visiting

time may be an opportune moment for this, and meaningful objects, especially therapeutic dolls, may provide a valuable focus and stimulus for activity participation.

#### 2. Background

According to Alzheimer Scotland, over 90,000 people are living with dementia in Scotland (Alzheimer Scotland 2016) of whom approximately 97% are aged over 65 years. Thorpe (2011) predicted that by 2031 this number will rise to at least 127,000 people. Older people with dementia are important users of hospital systems (Phelan et al 2015). However, when compared to older adults without a dementia diagnosis, they experience extended admission periods (Alzheimer's Society 2009), poorer outcomes (Holmes and House 2010) and greater mortality (Sampson et al 2012) because of their hospital stay. This situation demonstrates an important health inequality and it is vital to understand a mechanism by which this situation can be improved. Furthermore, family care givers have long been recognised as a marginalised group by means of gender and age, and the adverse impact care giving has on their economic status (Innes et al 2004). The community nurses involved in this project worked collaboratively to drive and influence a development to address these situations.

There is a significant body of work to demonstrate that participation in meaningful activity by older people with dementia creates the conditions for health (Nyman and Szymczynska 2016; Waller and Masterson 2015; British Association of Occupational Therapists 2013). Research has been carried out to help to understand how increased participation might be achieved in some environments, for example care homes (British Association of Occupational Therapists 2013). Yet, little is currently known regarding the facilitation of meaningful activity in community hospitals.

At the same time, anecdotal evidence is emerging regarding the positive effect increasing the involvement of family care givers has for people with dementia, when they are in hospital. This has led to a campaign to promote the right for family care givers to stay with people with dementia when they are in hospital (John's Campaign 2016). Little robust research has been undertaken to show why and how the presence of family improves

overall experience. Demonstrating the central role families have in care giving has the potential to validate and explain the importance of this role (Innes et al 2004).

In addition, Commitment 11 of the Dementia Strategy (Scottish Government 2013) extended previous 'Strategy' improvement work to other settings, including community hospitals. Commitment 11 has an important focus on managing stressed and distressed 'behaviours', sometimes observed when people with dementia are in hospital, by developing individualised, non-pharmacological interventions. These interventions could include increasing activity participation. However, further work is required to understand what those activities might be, and how they might be facilitated.

Finally, QNIS is committed to building the research capability of community nurses to address health inequalities through its 'Catalysts for Change' grant programme (Queen's Nursing Institute Scotland 2017) of which this study was a recipient. The project therefore aimed to facilitate 'real life' engagement by community nurses with a health research project to build their research readiness. A community nurse worked actively as a research assistant throughout this project.

## 3. The Project

To address the lack of knowledge regarding hospital visiting times, project objectives were:

- 1. To collaboratively develop an intervention and 'resource kit' as appropriate-currently named 'Our Visit'- to stimulate meaningful activity participation together
- 2. To co-create a method to embed 'Our Visit' into visiting times
- 3. To provide strategic recommendations as to the future development of services in line with Commitment 11
- 4. To develop the 'research readiness' of community nurses

The findings from this project aim to catalyse larger-scale research, not necessarily limited to hospital environments.

#### 3.1 Method

Qualitative methodology as it applies to a health care environment framed the research (Mason 2002), with an Appreciative Inquiry approach used for some of the methods (Cooperrider and Whitney 2005; Dewar and Sharp 2013).

## **Recruitment**

Convenience sampling was the method for recruitment (Mason 2002). Family and professional care givers with direct experience of visiting time were sought. Contact details for the research assistant were given on the poster/leaflet and potential participants were invited to make further contact with him by telephone, e-mail, and letter or to express their interest in person. Further information was then provided by letter, e-mail, telephone or in person, based on the individual inquiry. If the potential participants then decided they wished to be included in the study, information regarding the date, time, and location of the focus group was sent to them by mail or given to them in person. In line with focus group methodology, a maximum of 10 participants was aimed for, to take part in either or both focus groups (Stewart et al 2007). Four professional and no family care giver participants were recruited. The absence of family care giver participants is a significant limitation to the study.

## **Data Collection and Transcription**

Focus groups were used as the method of data collection (Cooperrider, Whitney and Stavros 2015) and facilitated by both researchers. Focus groups were audio-recorded (with permission) and audio files were later transcribed verbatim by a transcription service. Pseudonyms were applied at the point of transcription, and are shown in Table 1 below. All data was anonymised at first read and any identifying information, such as names or locations, removed.

After training offered by QNIS, and in consultation with experts from UWS, two specific methods arising from the Appreciative Inquiry framework were applied to elicit personal stories, or 'story telling', from the participants in the focus groups (Bushe 2013). First, photo-elicitation, using 'envision cards' (My Home Life 2017) shown in Figure 1 below, was applied as a tool to start a 'conversation' amongst focus group members (Dewar 2012). (Please note those shown in Figure 1 were not study participants.) Second, the topic guide

for the focus group was more a series of 'prompt' topics that hoped to facilitate creative and positive story telling by the participants about their experiences (Dewar 2012).



Figure 1 Photo Elicitation (Photo Credit: Kirstin James)



Figure 2 Therapy Doll (Photo Credit: Kirstin James)



Figure 3 Therapy Doll (Photo Credit: Kirstin James)

Items such as packs of cards, games, pens and papers, and a therapy doll (shown in Figures 2 and 3) were taken into the first focus group to stimulate dialogue about and around how these or similar objects might add to, or take away from, activity participation.

## **Data Analysis**

Thematic analysis of transcript data was under-taken (Trajkovski et al 2013). As study time was limited, a first level analysis was possible (Alhojailan 2012). Preliminary themes and findings were discussed between the two researchers then presented to the second focus group as points for dialogue and for co-creation and confirmation of what might become the final themes.

## 3.2 Ethical Approval

NHS Ethical Approval was granted from West Midlands - Edgbaston Research Ethics Committee (reference 211544) and The University of the West of Scotland Research Ethics Committee. Permission was also granted from the local NHS Research and Development Board.

## **Ethical Considerations**

Signed consent was taken by the lead researcher prior to participation in the focus groups. Participants were made aware that participation was voluntary and they may withdraw from the study at any time. Further consent will be sought, should the participant wish to withdraw, to continue to use their anonymised data. Should consent be withdrawn, any data relating to their participation will be removed and destroyed. As any family participants were anticipated to be older adults themselves, great care would be taken to ensure comfort measures were available. Reimbursement for taxis was offered; to ensure focus groups were as accessible as possible though was not applied as families did not take part.

There was the intention to form a 'Study Steering Group' to inform the progress of the study, with potential members from service user, care giver, professional and academic groups with an interest in the care of people with dementia. In practice, it proved difficult to attract members to a formal group. Instead, families, service managers, consultants and UWS academics were kept up to date with the progress of the study informally, and invited to comment as they wished.

## 3.3 Findings and Discussion

In qualitative projects, such as this, there are different ways of setting out findings and then discussing them in the context of extant literature (Mason 2002). For the purposes of this study, findings are set out and discussed in tandem. Illustrative extracts are taken from the data to enhance reporting of the findings, and are woven through the text below.

Details of the participants in the study are shown in Table 1, with pseudonyms.

Participant	Pseudonym	Role
1	F1	Professional-Nurse
2	F2	Professional-Nurse
3	F3	Professional-Nurse
4	F4	Professional-Nurse
Undetermined	F	Participant
Interviewer	I	Researcher
Interviewer	M1	Research assistant/nurse

Table 1 Participants

As can be seen from the table, the four participants were all professional care givers from a nursing background.

Two over-arching findings emerged from the data, and these were then considered between the researchers and participants until some consensus regarding what appeared to be important about visiting time was arrived at. 'A Good Visit' showed how visiting time might be used by visitors and their family members and how it may provide an important 'bridge' between the community and the hospital. Work is still needed to understand how to support families during visit time. 'Meaningful Objects' illustrated how physical objects might provide a source of attachment and security for the person with dementia; could be used to facilitate activity and are a source of potential comfort. Therapeutic dolls appeared to offer the strongest means of attachment. From the stories of the participants, engaging with them provided a way of soothing and calming for people with dementia when in a distressing situation, potentially offering an opportunity to reconsider how best to support people with dementia when they are in hospital.

#### A Good Visit

There was consensus amongst the focus group participants that there could be a 'good' visit. But this also meant that sometimes visiting time did not go so well. When a visit was good, or not so good, they described how it could affect the atmosphere in the hospital for the rest of the day. It also had the potential to soothe or distress the person with dementia. The participants explored and discussed what might make for a 'good' visit.

One of the most important circumstances that meant a good visit was possible was that family care givers needed to be approached early on in their visits to the hospital, usually by the nursing staff, to invite them to 'be' with their family member however and wherever they wished. What was important was that the ward staff had to recognise that this was vital to 'good' visiting, and they had to take the initiative to approach the family member themselves.

Age UK recently collaborated with 'John's Campaign' to write a booklet to advise health care staff how best to support family visitors to hospitals (Age UK 2017). Although the main aim of 'John's Campaign' is to encourage hospitals to have extended (or open) visiting times, and to work with family members as partners in the care of someone with a dementia diagnosis,

many of their recommendations fit well with the findings of this study. Recognising families as experts on their family member, valuing their role as a team member and initiating a dialogue from the nursing staff were all considered important (Age UK 2017).

Similarly, 'Carers UK' have introduced a 'Carers' Passport' scheme (Carers UK 2016) which identifies carers as such by means of wearing a badge, and recognises that carers need support in their caring role from hospitals. In addition, they recognise that forming a relationship very early between the hospital and carer is essential. However, the participants described that although they recognised forming such a relationship with families was vital, it could be challenging for several reasons.

- I think in some areas I've experienced it where nursing staff are reluctant to go and approach relatives and it's something that, when I do ... visits I always look to see the interaction between the nursing staff and the relatives and if don't see much interaction I'll ask why that is but there some time is a reluctance from nursing staff. I don't know if it's a, a time thing and they think well we're going to be caught up sort of thing but something that I do expect to see frequently is nursing staff intervening with relatives.
- I Yeah and what do you think, so if there's a little bit of reluctance there, because I kinda understand what you're saying there and I think we touched on it last time, like this might open up a can of worms
- F1 Uhuh, uhuh

The participants suggested that there may be some reluctance to open a conversation with family care givers because the nurses might be concerned they do not have enough time for what might 'come up'. This suggests that a lack of initial engagement could present a challenge to the concept of a 'good' visit and further work is needed to meet the recommendations set out by John's Campaign (Age UK 2017) and Carers UK (Carers UK 2016).

#### Time, People, Places, and What Happens

The participants described what happens at visiting time in some detail. Although the hospital where they worked had 'open visiting', that is there were no set visit times; most people would come to visit around two o'clock in the afternoon. But it also meant that there was a 'flow' of people coming and going throughout the day. They told that although it

could be anyone who came to visit, from friends to any family member, it tended to be the closest relatives, especially spouses, who came most frequently to the hospital and spent the most amount of time there.

Certainly in [place name] the, the Relatives' Support Groups I think was something that ran quite well 'cause people would come in to visit and then have that time together and then actually I think what happened was the, the visitors actually got more out of the time when the staff left that group, the staff that were facilitating
and just left people to just spend time together

Many hospitals in Scotland now have a policy of open, or 'flexible', visiting (Scottish Government 2017). This means that hospital visiting should be at a time that suits the family, rather than set times allocated by the hospital. Other studies have found this approach to visiting useful too, as flexible visiting better suits the rhythm of family life and means anxiety can be lessened for families as they can visit when and for as long as they want (Berwick and Kotagal 2004). There were benefits to the participants too as they found that because the wards were less 'crowded', and there was a 'flow' of people visiting (rather than all at once), they were better able to spend time with visitors.

- F3 Yeah, I do personally because I see, I've got quite a lot of relatives that come in at half past 11 but equally so you've got them coming in the afternoon and it's much more spread over the time
- 1 Yeah
- F3 sort of thing so it gives you more time, gives the nursing staff more time rather than it being concentrated, say visiting two till four where you get a big influx whereas it's a steady flow throughout the day.

In the experience of the participants, most families stayed around the bed side of the person they were visiting. Again, the families needed encouragement to go to other parts of the hospital; to cafés or to social spaces. The participants recognised that some areas of the hospital had made attempts at making parts more 'homely' with crockery and table cloths, but there was still much work to be done to understand how to enable families to feel part of the 'life' of the ward.

I think there would be the kinda expectation about just explaining what areas are available, where, what can happen where cause I know certainly like if you've got access to a garden area, so we need to be making relatives aware at the very start that actually they might not have free and easy access, which is something we'll maybe aim for in the future but at the moment they would have to be approaching a member of staff to say it's a nice day can I actually go out, come to visit in the garden so you would expect that kinda conversation to happen

The participants described what happened at visiting time in terms of activity. Most of the time appeared to be spent in dialogue between family members. Food was a very important focus for being together and was often brought in by families and shared. This could be anything from small sweet treats, to sandwiches, to pieces of cake from celebrations. Some small 'grooming' activities took place too, such as polishing nails and doing hair.

- F3 but I think it's really good to encourage we've like for example, one lady that her husband comes in every day and spends all afternoon with her and it's even nice for to see them sitting down having a meal together
- I Yeah, uhuh
- F3 so I would like to encourage that just to make it as normal as possible

In this way, family rituals, especially sharing food, appeared to be kept alive through the visit time. This could be a challenge to the participants however as they were very aware of a potential risk to health from contaminated food or choking hazards. They describe how they had to frequently consider this potential consequence and had information leaflets to give to families about food.

- F2 just got to be careful in that, that sense but there is, we have got a leaflet, bringing food into hospital, so
- I Oh right
- F2 we tend to give that out if we need to. Some people do have swallowing difficulties. In [place] the patients are more around the relatives whereas in [place] it's like a separate area so the people with swallowing difficulties, their relatives would look after them, that type of thing, but if they were in a communal area in [place] the relatives might say are they okay to get a bit of this cake or something like that so they would always, they tend to always check. Folk are aware of people being diabetic, they type of things, so got to watch for their sugar intake so most folk tend to check, in my experience anyway.

## A Bridge

The participants suggested that visiting time could become an important 'bridge' between the hospital and the community for all involved, be it the family, person with dementia, or themselves as professionals. For the participants, it offered an opportune time to meet with families and discuss practical arrangements, such as discharge plans or changes to medications. They suggested that for the person with dementia it was an important time to keep meaningful contact with their significant others and to keep in touch with their life outside of the hospital. For the family, they too could form relationships with staff (which were often enduring) and gain practical information.

M1 Certainly in [place name] the, the Relatives' Support Groups I think was something that ran quite well 'cause people would come in to visit and then have that time together and then actually I think what happened was the, the visitors actually got more out of the time when the staff left that group, the staff that were facilitating

M1 and just left people to just spend time together

Other studies have recognised the importance of the relationship between families and those working in hospital. This relationship is considered vital in reducing the detrimental impact an older person can experience from a hospital stay (Clissett et al 2013). In addition, as here, Clissett et al (2013) asserted that families benefit too from visiting hospital as they can gather information and be supported in making plans for what happens next.

However, work is still needed to understand how best to support families during visit time. This is especially important with regards to how to support and facilitate purposeful activity together. Dialogue, sharing food and engaging in some personal care, such as polishing nails, were recognised as activities families engaged in together. Theoretically engaging in purposeful activity creates the conditions for health (Nyman and Szymczynska 2016; Waller and Masterson 2015; British Association of Occupational Therapists 2013), but it was largely absent from what the participants told took place at visiting time. More work is needed to understand whether more, or different, engagement with activity would be beneficial. The absence of family care givers from the study was particularly noticed regarding how they might understand and engage with 'activity' when they visit hospital.

## **Meaningful Objects**

The discussion moved on in the focus group from how people spend time together to what they might do together. The participants described how they had seen people with dementia engaging with items and objects alone or together with other people. As described above items including books, cards, puzzles, and a therapeutic doll were taken into the focus group to elicit dialogue about what they might mean in the context of visiting time. All items except for the therapeutic doll were not thought to be of any real value.

The participants then told many lively stories together about when and how they had seen people interacting with therapeutic dolls. They themselves had introduced therapeutic dolls into their wards for people to engage, interact and participate with, and had bought 'toy' dolls to do this with.

Uhuh and I guess there's alternatives that could be explored in terms of, you know,

the cost of just a doll

F Uhuh, uhuh

I bought from 'Toys'R'Us'

M1 Yeah

I versus something that is very, very lifelike and how, you know, if you're thinking about something like one to one, which is a huge expense

F1 Uhuh, yeah, yeah

M1 Yeah

I what's the cost benefit of that

F1 Absolutely

They told many colourful stories about how people with dementia in their work areas had come together around a therapeutic doll to look at it, pass it around, and talk about it. In this way, interacting together around the therapeutic doll became a spontaneous social and group activity. However, this type of interaction could take place at any time people were together, and was not necessarily limited to visiting time.

M1 I think as well F1 spoke about the, in a scenario she was describing about a male patient as well, so it's not even like

I Yes, yeah

M1 it's, you know, it's not restricted

I No, uhuh, uhuh

M1 the lady was sitting holding the patient and one of the, the guys were over

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I Yeah, really interested.M1 UhuhI Yeah
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#### Attachment

The participants had all seen people they worked with become very engaged with the therapeutic dolls when they were alone. They pondered whether they were witnessing people re-engaging with times from their past when they had had babies in their arms.

M1 It's this what you wonder if that's, I mean for some people it is just about that triggering memories or how, how they've always felt about babies and, and cause in the same way as the music, certain pieces of music trigger memories for, for different people, so you wonder if it's rather than either playing or believing it's a baby, is it just that
I Yeah, is it
M1 memory
I uhuh, memory, uhuh

They told also of how they saw interactions that were very like what they would expect from somebody cradling a baby.

- It's hard to tell, but they do, they treat it like a baby, they definitely treat it like a baby. I don't know if they know that's a doll, it's just they see it, they cradle it, they shoo it and they're like with their cheeks and make sure their clothes are all okay but if it was a, if they didn't have dementia I don't know if they would do that, you know, they would know it was a doll, there's that distinction there but if they've got the dementia it's hard to tell.
- I Uhuh. So do you think people treat it as if it's their own baby?
- F2 Like a baby, yeah they definitely treat it like a baby. They're very delicate with it and
- 1 Yeah
- F2 yeah, just that, it seems natural, like a natural reaction

The literature in support of the benefits of engaging with therapeutic dolls for people living with dementia is limited. A recent critical review of the literature pertaining to this found few empirical studies, and were very limited in relation to their use within hospitals

(Mitchell, McCormack and McCance 2016). One thread that is emerging from the existing literature is how engagement with therapeutic dolls for people with dementia may link to the attachment theory of the psycho-analyst John Bowlby (Bowlby 2008).

However, Mitchell, McCormack and McCance (2016) advise caution when associating engagement by people with dementia with therapeutic dolls as akin to the parental attachment to a child as postulated in attachment theory (Bowlby 2008); the theoretical under pinning for this association is scant. Much more rigorous theoretical analysis is needed to understand what might be 'happening' when a person with dementia is relating to a therapeutic doll.

Moreover, although attachments to therapeutic dolls appeared strongest, the participants had also seen powerful scenes when people with dementia interacted with other 'toys', including a toy dog, and when listening to music via the "Playlist for Life" programme (Play List for Life 2017). What is also of note for this study is that, although the participants told of how people with dementia interacted together and alone in a playful way with such meaningful objects, they did not tell any stories of how people with dementia had interacted together with their families. This is an important absence of activity. As interacting with objects gives many opportunities for purposeful, meaningful activity, more work is needed to understand how or if families might do this together.

#### **Comfort Measures**

With the nature of such seemingly strong attachments to therapeutic dolls, the participants told of times when they had seen immense comfort being brought by them. This was noticeable when the person with dementia was faced with a potentially uncomfortable situation, such as having podiatry, or a similar procedure, when they may become distressed. They told of how they had only seen such a similar effect from prescribed medications.

- I It potentially could because what, what was described last time actually I think it was compared to, the therapy doll was as powerful as having a medication
- F1 Uhuh
- I is how you described it and it was almost as important as other kinds of quite physical interventions
- F1 Uhuh, uhuh

The participants also described how they observed people with dementia being quietly soothed by interacting with therapeutic dolls.

M1 and you do, you wonder if somebody who may well have a, quite a high level of confusion but an awareness that actually they're quite unsteady on their feet, sitting with the doll

F1 Yeah, I'm just wonder, I can totally see this person that I'm thinking about

M1 put people off

I Sitting quiet and what you described it sounded like the person was, what I would call soothed

F1 Uhuh, uhuh

F2 Yeah

In summary, this theme has shown how people with dementia can form what appear to be strong attachments to objects that have meaning to them, especially (but not limited to) therapeutic dolls. Although the nature of this attachment is currently not well understood, these moments of purposeful, meaningful engagement, have the potential to bring comfort, potentially ease discomfort, and provide an opportunity for social interaction and playfulness. The perceptions of the participants were that more work is needed to understand how this phenomenon can be built on for people with dementia to engage in together with their families.

#### 3.4 Conclusions

Perceptions of the participants have highlighted that visiting times can provide an important bridge between hospital and the community. Visits tend to take place most frequently in the afternoon and those closest to the family member tend to come most often and stay the longest. There is an important function of visiting time in that it can also support the visitors, but professionals on the wards must acknowledge the visitors by approaching them, and invite them to be part of the ward. Food is an important element of visiting, but social spaces still need thought as to their creation.

There is some emerging evidence that attachments can be made to meaningful objects, including dolls, by people with dementia (Gibson 2005). A recent critical review of the literature determined that therapeutic dolls can "increase levels of engagement,"

communication and reduction in episodes of distress" (Mitchell, McCormack and McCance 2016, p.976). Such an attachment might therefore provide a focus and mechanism for activity participation. This study therefore also set out to explore what objects, including but not limited to 'therapeutic' dolls, might be used to facilitate participation in meaningful activities. However, participants perceived that what seemed most important was being together, rather than doing things together and more work is needed to understand the nature and importance of this way and its relationship-if any-with activity.

The absence of family care givers was a significant limitation to this study. Only the stories of nursing participants were gathered as to what they knew of visiting times and how the people they worked with interacted with various items which may or may not be useful methods and means of engaging families together at visiting time. This study was conceived as a 'catalyst' for future research and some potentially important phenomena have been uncovered which merit further future investigation. It is essential in future studies to learn from the methods applied in this project and consider how best to include families. A relationship centred approach to research, such as Appreciative Inquiry, may provide a framework to do this in the future.

## 4. Impact

## Challenges, Successes, and Lessons Learned

Recruitment of family care givers was the biggest challenge to this study. Although professional care givers were successfully recruited, and two focus groups were run effectively, the voice of the family was absent. Alternative recruitment methods, such as visiting family support groups (with permission) to invite family care givers directly to take part in research will be considered for any future studies. Applying an Appreciative Inquiry framework to future studies may help to better achieve this. That said, this study offered some important insights into what visiting times mean, and these findings will be used to catalyse future research.

Another challenge was the continued participation of community nurses. Originally three community nurses were involved in the development of the project. Barry Sneddon, Community Nurse and Clinical Co-ordinator was involved in each stage of the process and

acted as a research assistant. A second community nurse, and a Nurse Consultant, left the study as it progressed due to competing work and other commitments.

#### **Professional Development**

One of the key aims of the project was to develop the research readiness of community nurses. Barry Sneddon, community nurse and Clinical Co-ordinator was involved as a research assistant on the project; his first experience of participating in research. He has written a reflective account of his experience, offered below:

"In 2015 I took the opportunity of a secondment to the role of Project Lead for the delivery of Commitment 11 within NHS Forth Valley. As part of this role I was keen to explore ways in which we could reduce the use of antipsychotic and sedative medications within our specialist dementia wards at times where patients were experiencing stress and distress. Having previously spoken to Professor Debbie Tolsen about the impacts of doll therapy in dementia care, I made contact with her to discuss this further. We arranged a meeting at the University of the West of Scotland and it was there that I was introduced to Dr Kirstin James and Dr Margaret Brown. We agreed that whilst doll therapy has the potential to alleviate symptoms of stress and distress, it would not be appropriate for all patients within these areas. This led onto the idea of exploring other ways of engaging patients with dementia in a meaningful way which could benefit not only the patient themselves, but visitors and care givers as well. The basis for the project was then formed and given the title of 'Our Visit'.

In the weeks after this initial discussion, I met with Dr James on a number of occasions to finalise our plans for the project. We also kept in regular electronic contact. This included the completion of the ethics application which required a lot more detail than I had anticipated given that this was my first experience of research. Dr James spent a lot of time explaining this process to me and liaised with my colleagues within the NHS Forth Valley Research and Development department. Posters and letters were devised in order to advertise the project and recruit participants. These were placed around the ward in areas frequently used by relatives and carers.

I did find this process slightly frustrating as I was keen to draw the attention of visitors to the project in an effort to share my enthusiasm and hopefully encourage participation. However, having had discussions with Dr James around the recruitment process, I was aware that this was a caution because we were concerned peoples' families may feel "pressurised" to take part. However, for future studies this way of recruiting will need a re-think. Once we had dates for the focus groups arranged, I did feel a little disappointed that we had been unable to recruit any relatives or carers. However, I would still say that the focus groups themselves still provided fantastic learning and it was encouraging that the attendees shared our enthusiasm for the project.

Participating in this project has given me a valuable insight into research. I have enjoyed working with Dr James and the team from the University of the West of Scotland. I am also thankful to the QNIS for this fantastic opportunity to learn more about research and improve the care we offer our patients. Having been a registered nurse for the past 16 years, I do feel that being part of the 'Our Visit' project did allow me to think of other possible career options." Barry Sneddon, Community Nurse and Clinical Co-ordinator, August 2017

By participating in the research project, there was exposure to many research skills including research design, literature review, data gathering by means of focus groups, data analysis, the dissemination of findings and considering the development of an intervention. Relationships developed through the research process meant that a strong working partnership was built which hopefully can be built on in the future.

#### Summary of the Impact of the Project as a Whole

Returning to the intended aims of the study, impacts are summarised as follows.

- 1. To collaboratively develop a resource kit-currently named 'Our Visit'- to stimulate meaningful activity participation
- 2. To co-create a method to embed the 'Our Visit' resource kit into visiting times
- 3. To provide strategic recommendations as to the future development of services in line with Commitment 11
- 4. To develop the 'research readiness' of community nurse

Each aim is addressed below.

- Steps towards collaborating and co-creating methods, mechanisms and resources to stimulate meaningful activity together were made in this catalyst study. The participants recognised that this could not be meaningfully taken further without the presence of families. Future research studies must consider other recruitment strategies to increase the chance of family carers taking part.
- 2. Similarly, the conversation was started about how to embed meaningful activity into visiting times, but again the absence of families was notable.
- 3. Since the commencement of this project, Scotland's National Dementia Strategy has been extended from 2013-2016 (Scottish Government 2013) to 2017-2020 (Scottish Government 2017a). A focus of this project was to explore how activity-facilitated at visiting time-might address Commitment 11 of the 2013-16 strategy. Commitment 11 aims to advance non-pharmacological interventions. While there are many questions that still need to be addressed, engagement with meaningful objects appeared to offer some comfort and soothing which may help when caring for people with dementia. Much more work is needed to understand this phenomenon and how people might engage with objects together.
- 4. The full involvement of a community nurse as a research assistant in this project meant that they were exposed to the research skills of literature review, data gathering by means of focus groups, data analysis, the dissemination of findings, and participation in a conference, and the beginnings of the development of an intervention. This was captured by gathering the story of the nurse involved by way of a written reflection.

#### **5. Sharing Your Work**

An abstract was accepted by the British Gerontology Society with the title "Our Visit. Exploring Visiting Times as a Way to Enhance Meaningful Activity Participation: a Collaborative Research Project" (James and Sneddon 2017). The findings from the study

were presented at their conference at Swansea University, in July 2017. See Figures 4 and 5 which were taken during the conference at Swansea University.



Figure 4 Swansea University British Gerontology Society Conference (Photo Credit: Louise Ritchie. Used with Permission)

Details of the conference can be found here: http://www.swansea.ac.uk/bsg17/

## 6. Next steps

The next steps to share the findings and to build on the research are as follows:

- 1. To use this study to catalyse future research. This must involve families.
- 2. To publish findings from the study in appropriate peer reviewed journal(s)
- 3. To seek to disseminate the findings further, by submitting an abstract to an international conference
- 4. To share the report with the local Research and Development Department
- 5. To discuss with NHS partners and the team from University of the West of Scotland how the findings from this study can contribute to further research
- 6. To write a summary pamphlet (or briefing paper) for participating members and the Health and Social Care Board which can also be shared publicly, for example by posting on relevant websites, in collaboration with QNIS.



Figure 5 'Our Visit' Presentation (Photo Credit: Louise Ritchie. Used with Permission)

## 7. Final Remarks

Developing an understanding and a way of enhancing visiting time has the potential to improve the conditions for health both for people with dementia, family, friends and their care givers. Outcomes from this project will catalyse larger studies of visiting, not necessarily limited to hospital environments. This study has also provided an opportunity for a busy community nurse to experience and take part in 'real world' research. They have begun to prepare for future research activity by doing so.

## 8. Thanks and Acknowledgements

With many thanks to the participants for giving up their valuable time to take part in the focus groups. Thanks to the QNIS Catalysts Team for their ongoing interest and support.

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## 10. Financial report

A summary of how the money was allocated is shown in Table 2 below. Please note, there is an under spend for this project.

Item	Detail	Budget	Actual	Remaining
Staff Costs (detail number of staff and number of hours allocated to project)		Zero	Zero	Zero
<b>Travel Costs</b> (detail travel for staff and for participants, including travel to two QNIS	Travel to Swansea Bay University x 2	1,500.00	632.51	867.49
workshops)	Travel and refreshments for participants to attend the focus groups	1,500.00	147.10	1,352.90
Venue Costs (include hire costs for rooms)		Zero	Zero	Zero
Other (materials, postage, evaluation etc)	Transcription costs	540.00	226.50	313.50
	Training: conference attendance	1,200.00	1,004.86	195.14
	Resource Materials	260.00	15.97	244.03
Total		5,000.00	2,026.94	2,973.06

Table 2 Financial Summary

Transcription costs were for transcribing two focus group audio files by FM Transcription Services. Travel and subsistence was requested for project participants. It was anticipated that many family care givers who visit community hospitals may be older, and have health needs, too. Therefore, the comfort and well-being of research participants was of the utmost importance. Round-trip taxi-fare reimbursement was offered in order that they might be able to participate in comfort. This was not requested. Refreshments and a light meal were offered during the focus group. Community nurses participating in the focus groups will also be offered reimbursement for their travel. Again, this was not requested.

Travel and subsistence was requested for the research assistants (and potentially the project lead dependent on actual costs). This represented part of the research training of the research assistants. Findings will be presented at a national research conference applicable to the project aims. Funds sought include registration fees, standard class air or train travel and overnight accommodation. Kirstin James and Barry Sneddon attended the British Gerontology Conference at Swansea University and presented the project. Other costs include buying materials for the research and for the *Our Visit* resource kits. NHS Forth Valley has agreed to contribute £1,000 towards this cost but this was not required.