Evaluation of Acute Care Development Programme

Detailed Report
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CONTENTS OF REPORT

LIST OF TABLES .................................................................................................................. 4
ACKNOWLEDGEMENTS ....................................................................................................... 5
EXECUTIVE SUMMARY: KEY MESSAGES ........................................................................ 6
1. BACKGROUND .................................................................................................................. 12
2. WHAT WE DID ................................................................................................................ 14
   2.1 What we did ................................................................................................................ 14
   2.2 Hospital Context ......................................................................................................... 16
   2.4 Who were included in the research ........................................................................... 21
   2.5 How we interpreted the data ................................................................................... 22
   2.4 Ethical considerations .............................................................................................. 22
3. FINDINGS: BENEFITS AND CHALLENGES ................................................................ 25
   3.1 Participant characteristics ....................................................................................... 25
   3.2 Benefits of implementing interventions .................................................................... 27
      3.2.1 Benefits to family carers .................................................................................. 27
      3.2.2 Benefits to patients with dementia ..................................................................... 28
      3.2.3 Benefits to staff ............................................................................................... 30
      3.2.4 Benefits to volunteers ...................................................................................... 32
   3.3 Challenges of implementing interventions ............................................................... 34
      3.3.1 Hospital focused challenges ............................................................................ 34
      3.3.2 Patient and carer focused issues ..................................................................... 39
      3.3.3 Staff focused challenges .................................................................................. 41
4. DISCUSSION .................................................................................................................... 45
   4.1 Staff who are skilled and have time to care ............................................................. 45
   4.2 Partnership working with carers .............................................................................. 48
Acute Care Development Programme

4.3 Assessment and early identification .......................................................... 48
4.4 Care that is individualised ......................................................................... 49
4.5 Environments that are dementia friendly .................................................. 50
4.6 Further research and limitations ............................................................... 51

5. CONCLUSIONS ......................................................................................... 52

6. RECOMMENDATIONS ............................................................................... 56

REFERENCES ................................................................................................. 58

APPENDICES .................................................................................................. 60

Appendix 1: Patient Information Sheet ........................................................... 60
Appendix 2: Patient Consent Form ................................................................. 65
Appendix 3: Family Carer Information Sheet ................................................... 66
Appendix 4: Family Carer Consent Form ......................................................... 71
Appendix 5: Interview Guide ........................................................................... 72
Appendix 6: Staff and Volunteers Information Sheet ....................................... 73
Appendix 7: Staff and Volunteers Consent Form ............................................ 78
Appendix 8: Focus Group Topic Guide ............................................................ 79
Appendix 9: Staff and Volunteers Diary .......................................................... 80
Appendix 10: Patient and Family Carer Diary ............................................... 81
Appendix 11: Poster displayed on hospital wards .......................................... 82
LIST OF TABLES

Table 1: Description of interventions .......................................................... 18
Table 2: Description of additional interventions ......................................... 20
Table 3: Participant inclusion and exclusion criteria .................................... 21
Table 4: Type and number of participants in interviews and focus groups .... 26
Table 5: Participant codes ........................................................................... 26
Table 6: Examples of activities and staff that enable individualised care ....... 50
We would like to thank everyone who participated in this project. Thank you to the people with dementia and their carers and the hospital staff and volunteers for taking part in the interviews, observations, and focus groups; and to the staff in each hospital who facilitated our visits and helped us to locate participants. We would also like to thank anyone else who engaged with this project, we appreciate your time and honesty when sharing your experiences with us.

Thanks to Katherine Barbour from Wessex Academic Health Sciences Network (AHSN) for her support and input into this project, and to the Wessex AHSN for funding this research.
Background

We know that people with dementia over the age of 65 use up to one quarter of UK hospital beds at any one time, and are staying in hospital for longer than other people who go in for the same procedure; putting a resource strain on an already struggling health system. We also know that there are still areas that require improvement, including assessment for delirium, communication of relevant information at discharge, recording of information pertinent to patients’ care and dementia awareness training at staff inductions.

In a move to improve outcomes for people with dementia while in hospital in Wessex, the Academic Health Sciences Network (AHSN) has been working with eight acute hospitals on an Acute Care Development Programme, which set out to identify, spread and share good practice of dementia care in hospitals, determine what practices or interventions were making the greatest impact and assess their impact via quantitative and qualitative research.

Each Trust was engaged in a range of improvement activities and the work of Bournemouth University Dementia Institute (BUDI) was to evaluate whether and how the programme made a difference to patients with dementia and their family members in the participating hospitals. We also wanted to find out staff views and experiences of setting up and working with the interventions, with the aim of sharing successes and challenges across the region and beyond.

The questions we set out to answer were:

- What are the experiences of receiving and delivering the intervention?
- What impact does the intervention have on recipients, in terms of their well-being?
What we did

This complex evaluation examined the benefits and challenges of delivering a variety of interventions in 8 acute hospitals across Wessex; intended to improve the experiences of people with dementia who spend time there and improve the experience of family carers. The research was carried out over two days in each of the hospitals and used different methods to explore from patients with dementia, family carers, and staff and volunteers their experience of delivering or receiving the interventions.

We carried out 6 focus groups in 5 of the hospitals and, in these, spoke with 22 staff and 3 volunteers. We carried out 11 interviews with patients with dementia (8 single interviews and 3 dyads with carers). We observed and made notes of different interventions taking place in different wards of each hospital and we asked participants (patients, family carers, staff and volunteers) to keep a five day diary of their experiences of delivering or receiving particular interventions.

We had the audio files from focus groups and interviews transcribed by a University approved transcription company. All transcripts and observation notes were scrutinised and categorised into themes to illustrate the benefits and challenges of either delivering or receiving particular interventions. We only received one diary from a member of staff.

What we found

Our findings reveal that family carers experienced peace of mind that their family member in hospital had someone (often a volunteer) to keep them company or engage with them. They also appreciated the flexibility with visiting, car parking and access to meals that John’s Campaign allowed, and they experienced pleasure at seeing their relative with dementia enjoying creative activities. Findings from interviews and focus groups indicated that many interventions had the potential to uphold the personhood of patients with dementia, for example: activity boxes promoted conversation and interesting activity, memory boxes promoted conversation and reminiscence, familiar music facilitated a more familiar space and a
dementia-friendly day room facilitated companionship between patients with dementia. Although not specifically mentioned by family carers, there was concern among staff that an intervention such as John’s Campaign that facilitates open visiting, might serve to reduce the amount of rest or respite a family carer, particularly one who is older, might get whilst their family member is in hospital.

We also identified benefits to staff and volunteers of some interventions. A key benefit to staff was having a member of staff whose sole role is a focus on patients with dementia and family carers. This role is broad and includes screening patients to diagnose dementia, signposting of information to carers, staff awareness raising and training, and co-ordinating care. Staff valued the signifiers that alerted them to the fact that a patient has dementia. Staff also felt that some of the interventions, particularly John’s Campaign served to formalise practices they were already undertaking, and this had a validating effect on them. However, they also noted that there was inconsistency within a hospital in how an intervention was understood and delivered; potentially causing confusion to patients and family carers. Our comparative findings also indicate there is inconsistency across hospitals in how the same intervention is delivered. Staff also raised concern that some interventions, particularly Twiddlemints, might be used indiscriminately. This is linked with some staff reflections of insufficient knowledge of the purpose of an intervention and also linked with a recognised need for more staff awareness of interventions within and across hospitals; the consequences of which can impact on patients’ and family carers’ experiences while in hospital. Across the hospitals that had volunteer ward companions, there was acknowledgement that more volunteers would be helpful and that they might be able to offer more support with more targeted training and support. Our findings also highlight the fragility of relying on a group that is potentially transient and thereby, at times, not as committed to their work as they might be.

Staff spoke of many challenges, from organisational to individual level of implementing interventions. We identified two key factors that impacted on whether an intervention was developed and delivered successfully or not: management
support and the presence of a member of staff or staff team to champion and drive the intervention forward. While sufficient funding was raised as a potential barrier to successful delivery of an intervention, in some cases the commitment and resourcefulness of staff in securing their own funding meant that an intervention was delivered successfully. Along with the fragility of relying on volunteers to fill workforce gaps, we suggest there is also fragility in using ad hoc fundraising to deliver or sustain innovative practices.

We also provided a comparative description of the work being undertaken to improve the well-being of patients with dementia in the eight hospitals that participated in this study. We highlighted how the work to improve the well-being of patients with dementia and in these eight hospitals is meeting some of the principles of the RCN SPACE model (RCN, 2011), which in turn is meeting the objectives of the National Dementia Challenge. Using the RCN SPACE model (RCN, 2011) alongside these examples of practice, may be useful for hospitals generally to compare and contrast their provision for patients with dementia.

Recommendations

Our recommendations are developed from our findings and we suggest that individual hospitals consider how to take them forward within the context of their own organisation.

- Scope the provision of interventions across each hospital to ensure consistency of access to patients and families and quality of practice.

- Develop a Dementia Strategy with clear actions and targets to underpin the direction of work and ensure that all staff (from Senior Management to Ward level) are aware of the commitment to dementia.

- Share good practice across each hospital and between hospitals so that staff and managers can learn from and be supported by others who are successfully engaging in particular interventions.
• Develop a bank of volunteers assigned to each ward and introduced to all staff. Provide clear roles and responsibilities supported by appropriate training and support.

• Develop a toolbox of interventions that can be used to meet patients’ preferences, including options by the bedside for those who are bed bound.

• Encourage more family members to contribute to the care of the patient with dementia, without over-burdening them.

• Expand training and support to volunteers to enable them to carry out more activities to meet patients’ needs. For example to go for a walk with a patient if they are restless.

• Ensure that ward refurbishments take into account the needs of patients with dementia by adhering to dementia-friendly environment principles.

• Where applicable, repurpose rooms on wards that are not used to their full potential such as day rooms or staff rooms to create activity/reminiscence rooms for patients to use.

• Consultation with staff, patients and visitors on what improvements might be made to improve patients’ time in hospital. For example, staff had useful ideas about possible initiatives that might improve patients’ experience. These are listed below:
  
  - Consider developing existing under-used spaces into step-down wards that are more homely and supportive of patients’ abilities – this could be a centralised space where patients with dementia from different wards could go.
  
  - Use objects that look more familiar – a record player, tape recorder rather than digital or modern equipment.
  
  - Purchase a Paro seal http://www.parorobots.com/ - particularly for patients nearing the end of life or who are socially isolated.
  
  - Create a workshop for male patients with dementia.
  
  - Increase staffing numbers to support purposeful activities with people with dementia.
  
  - Move wards for people with dementia onto the ground floor.
  
  - Interesting pictures on walls.
- More appropriately sized jigsaws (1000 pieces are too many for people with dementia).
- More meaningful training for staff – role play, putting oneself into the patient’s shoes.

Family carers and patients with dementia also had suggestions on how to improve their stay in hospital, as listed below:
- Invite someone to give an interesting talk on different topics, using the talent already in the hospital.
- Provide a room for visitors who have a long distance to travel, particularly if they need to stay overnight.
- Provide an orientation screen or board with the day, season, weather etc.
- Provide free TV for people with dementia as many would not be able to operate the system.
The Alzheimer’s Society (2009) estimated that people with dementia over the age of 65 use up to one quarter of UK hospital beds at any one time, and are staying in hospital for longer than other people who go in for the same procedure; putting a resource strain on an already struggling health system. The latest audit of dementia care in hospitals in England and Wales (Royal College of Psychiatrists, 2013) indicates that, despite improvements from 2010/2011, there are still areas that require improvement, including assessment for delirium, communication of relevant information at discharge, recording of information pertinent to patients’ care and dementia awareness training at staff inductions. The Care Quality Commission (2014) has also identified instances of poor care and inconsistent assessment, information sharing, planning and delivery of personalised care in hospitals. Similar concerns have been reported by carers, families and friends of people with dementia too. In a survey on Facebook in 2015 (see, Alzheimer’s Society, 2016), out of 570 respondents:

- only 2 per cent said that, in their experience, all hospital staff understood the specific needs of people with dementia;
- 57 per cent said they felt the person they care for was not treated with understanding and dignity in hospital;
- 90 per cent said they felt the person with dementia became more confused while in hospital;
- 92 per cent thought hospital environments were frightening for the person with dementia.

The survey also revealed instances of people with dementia being treated with excessive force, of poor catheterisation leading to a urinary tract infection, of visits from family members and carers being denied, and of people not being changed or cleaned up after being incontinent (Alzheimer’s Society, 2016).
In a move to improve outcomes for people with dementia while in hospital in Wessex, the Academic Health Sciences Network (AHSN) has been working with eight acute hospitals on an acute care development programme, running until March 2016. This programme set out to identify, spread and share good practice in dementia care in hospitals, determine what practices or interventions were making the greatest impact and assess their impact via quantitative and qualitative research.

Each Trust was engaged in a range of improvement activities and the work of Bournemouth University Dementia Institute (BUDI) was to evaluate whether and how the programme made a difference to patients with dementia and their family members in the participating hospitals. We also wanted to find out staff views and experiences of setting up and working with the interventions, with the aim of sharing successes and challenges across the region and beyond.

The questions we set out to answer were:

- What are the experiences of receiving and delivering the intervention?
- What impact does the intervention have on recipients, in terms of their well-being?

The remainder of this report is divided into a further five chapters outlining: what we did; the benefits and challenges of implementing these interventions; discussion of the findings; conclusions; and suggested recommendations to support hospitals, regionally and nationally, to take forward their work to improve the well-being of patients with dementia in acute hospital.
2. WHAT WE DID

This section describes what we did to answer the research questions and how we interpreted the data. We also include a discussion of the ethical issues considered prior to and during the research.

2.1 What we did

We used a variety of methods (observations, interviews, focus groups and participant diaries) to gain feedback from patients, family carers and staff of the interventions that each hospital was undertaking. Using various methods allowed different types of information to be gathered about the hospital wards and interventions and allowed for a deeper understanding of each.

Over a five-month data collection period (between May and September 2016), researchers gathered data from each of the eight hospitals. One researcher spent two days in each hospital visiting between two and five different wards (dependent on the direction from the Dementia Lead at each hospital). We used different methods to gather information to address our research questions, as described below:

- Unstructured observations of the delivery of the intervention in each hospital. This involved the researcher writing down what she observed, including a description of the setting, the context for interactions and delivery of an intervention and descriptions of patients’ responses.

- Semi-structured interviews with patients in each hospital to explore their experience of the intervention and the impact it had on them. Patients were invited to participate in single interviews or in dyads with their family carers. Interviews were carried out in the ward area and were focused on the experience of receiving the intervention and more generally on their stay in hospital. Patients were also asked to make suggestions for improving their hospital. We aimed to speak to up to 40 patients (5 per hospital); however in reality we spoke to between 0 and 3 patients in each hospital. There were
many patients with dementia staying on the wards during our visits to each hospital, however a large number of those patients were either unable to provide informed consent due to the severity of their dementia, or unable to take part because of how unwell they were at the time of our visit. Potential participants for interviews were initially approached by a member of hospital staff who explained the research to them. If they expressed an interest in knowing more about the study then our researcher was then introduced to the patient and described the study both verbally and in writing using an information sheet (Appendix 1). Patients were then given time to decide whether or not they wished to participate in the interview, those who decided to participate were then asked to sign a consent form (Appendix 2). There were different versions of the information sheet (Appendix 3) and consent form (Appendix 4) for family carers. An interview guide was used in all interviews to guide the discussion (Appendix 5). Eight interviews were audio-recorded with participants’ consent and later transcribed, the researcher made notes during the remaining three interviews which she typed up afterwards.

- Semi-structured focus groups with staff involved in delivering or overseeing delivery of the interventions. Each focus group comprised a range of staff from each setting, including Nurses and Health Care Assistants. We hoped to recruit 8-10 staff and undertake 1 focus group in each hospital. In reality we held 6 focus groups in 5 of the hospitals (in 1 hospital we held 2 focus groups), with between 3 and 6 members of staff in each. Staff suggested that it was difficult to get a group of relevant staff released from the ward to take part in the focus groups as this would leave the ward short staffed. To overcome this, as part of the ward observations, the researcher spent time talking to relevant members of staff and volunteers and made notes on these conversations which they included in their field notes. Following introductions and an explanation of the research, all focus group participants were provided with an information sheet (Appendix 6) which they were invited to read and had summarised where necessary. Once everyone had read and understood the information sheet and had had any questions answered, they were asked to sign a consent form (Appendix 7). A topic guide was used at all focus groups to guide the discussion (Appendix 8), all focus groups were audio-recorded with participants’ consent and later transcribed. Staff and volunteers
were also asked to make suggestions for improving the well-being of patients with dementia in their hospital.

- We also asked participants to keep a diary over five days (Appendix 9 – staff and volunteer version; Appendix 10 – patient version). We asked them to record their experiences and thoughts of the intervention(s), its utility, benefit, challenges or areas for improvement. However, we had a really low response to this, receiving only one completed diary back from a member of staff at one hospital. Feedback received from staff and volunteers was that they are too busy to complete the diaries. Patients stated that they were being discharged home the day we interviewed them, or felt they were only able to take part in the interview as they were too ill to complete the diary.

2.2 Hospital Context

This study took place in the Wessex Region of the United Kingdom, which is made up of the counties of Dorset, Hampshire, Wiltshire and the Isle of Wight. It is estimated that there are currently 38,540 people aged 65 and over living with dementia in the Wessex region (NHS England, 2016). However, it is important to note that only 24,899, or 64.6% of people aged 65 and over who are anticipated to be living with dementia in the Wessex Region, have received a diagnosis (NHS England, 2016). This means that many people with dementia who are admitted to hospital may not already have a diagnosis of dementia, and they may or may not be aware of having had symptoms either. The CQUIN screening process (NHS England, 2015) may therefore be the first time that a patient receives a diagnosis of dementia. We should also note the wider issue of delayed discharge from hospitals amongst the over 65 population (Kings Fund, 2016), which staff from all of the eight hospitals mentioned has had a huge impact on the all of the patients on their wards, as staff are left to care for people with dementia who are medically fit and able to leave the ward, yet waiting for their placement in a the community. Some patients have been left to wait for months before being discharged from the wards and staff commented that most often it is patients with dementia who are left waiting, and that this can lead to worse health outcomes and increased long-term care needs.
(National Audit Office, 2016). Despite this, throughout our data collection visits we found that each hospital is engaging in substantially more innovative and potentially therapeutic initiatives than previously documented, as discussed in the next subsection.

2.3 What interventions we observed or heard about

We were given details of the interventions that were being delivered at each hospital by the Wessex AHSN prior to our visits, so that we knew what to evaluate in each hospital. Each hospital was delivering between one and five interventions according to this list. These interventions were: Carer's Café, John’s Campaign, Dementia Champions, Dementia Case Workers, Twiddlemitts, Volunteer Ward Champions, Activity/Reminiscence rooms, Memory Boxes, Identifier Stickers/Magnets, Coloured Plate Scheme, and Arts in Health. See Table 1 for a full description of each intervention.

In all eight cases the hospitals were providing other interventions, over and above those on our original list, meaning that in reality each hospital was delivering (or at least in the process of planning and/or seeking approval) five to eight interventions. Some of these interventions were specified on our original list, although those that were not are outlined in Table 2. In the main, we focused on the interventions in the original list, however where appropriate we have discussed some of the interventions from the amended list too. We planned to evaluate the interventions as they were happening on the wards during our two day visit. However, this was not always possible, for two reasons: either the interventions were not running on the days we were able to visit, or the interventions were not yet running as ward staff were waiting for approval from hospital managers or Boards of Directors. This did significantly limit the amount of time we were able to spend observing interventions happening.

1 This does not form part of our research as it is being evaluated by another University.
Table 1: Description of interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Description</th>
<th>Hospitals currently implementing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer’s Café,</td>
<td>A weekly opportunity for carers to meet with staff, have a cup of tea, talk to staff and obtain any information or support they may need. Supported by local charities in the health and social care sector who attended with information and wider knowledge of rights of carers.</td>
<td>2</td>
</tr>
<tr>
<td>John’s Campaign</td>
<td>Campaign for the right of people with dementia to be supported by their carers in hospital, to include open visiting hours for carers and overnight stays where appropriate. For further details see: John’s Campaign (2016).</td>
<td>7</td>
</tr>
<tr>
<td>Dementia Champions</td>
<td>Members of staff with an interest in dementia usually one or two on each ward. Raise awareness of dementia and challenge poor practice and negative language (for example staff using terms such as ‘dementia sufferer’).</td>
<td>3</td>
</tr>
<tr>
<td>Dementia case workers</td>
<td>Support patients with dementia and their carers/family throughout their journey in hospital. Level of support varies from one patient to the next but can include signposting to external agencies, help completing the This Is Me document, accompanying patients to x-rays or operations, and being a familiar face as patients move from emergency to a ward.</td>
<td>1</td>
</tr>
<tr>
<td>Twiddlemitts</td>
<td>Tube shaped brightly knitted muffs with tactile items stitched onto them. Given to patients who are agitated or to distract from taking out hospital equipment such as cannulas on hands etc.</td>
<td>8</td>
</tr>
<tr>
<td>Volunteer Ward Companions</td>
<td>Volunteers who were supporting staff on the wards by chatting to patients. In some hospitals they have access to an activity trolley of board games, cards, arts and crafts etc.</td>
<td>4</td>
</tr>
<tr>
<td>Topic</td>
<td>Description</td>
<td>Score</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Activity/Reminiscence room</td>
<td>Room containing objects (books, DVDs, arts and crafts etc.) for patients to use - located on or near to the ward. Some also provided a structured activity programme throughout the week (including knitting club and afternoon tea).</td>
<td>3</td>
</tr>
<tr>
<td>Memory Boxes</td>
<td>Themed boxes filled with objects to help facilitate conversation or reminiscence amongst staff, volunteers, families and patients. Examples of externally funded projects coming in to deliver memory box sessions with patients (Wessex Heritage, 2016), boxes borrowed on a monthly cycle form a local charity (Dorset Memory Box, 2016), and boxes created by ward staff and kept on the wards or in the Activity Room. In one hospital a member of staff had actually purchased the box and objects themselves, out of their own pocket.</td>
<td>4</td>
</tr>
<tr>
<td>Identifier Stickers/Magnets</td>
<td>Discreet way of identify patients with dementia forget-me-nots, sunflowers and butterflies.</td>
<td>4</td>
</tr>
<tr>
<td>Coloured plate scheme</td>
<td>White plates being replaced with other colours of plates to help patients see their food more easily and encourage them to eat more. Examples of blue, red and orange plates being used. Also changing the colour of other crockery such as water glasses and jugs to encourage patients to drink more.</td>
<td>3</td>
</tr>
<tr>
<td>Arts in Health (music at the bedside)¹</td>
<td>Musicians playing and singing to patients on the wards (this does not form part of our evaluation as a pilot took place in 2015 which is being evaluated by another University).</td>
<td>3</td>
</tr>
</tbody>
</table>

¹ This does not form part of our research as it is being evaluated by another University.
Table 2: Description of additional interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Description</th>
<th>Hospitals currently implementing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time4you</td>
<td>Volunteer lead initiative where volunteers spend time with patients one to one.</td>
<td>1</td>
</tr>
<tr>
<td>Finger food/picture menu</td>
<td>Menus with pictures of meals to help the patients decide what to order. Finger food menus are for patients with a smaller appetite.</td>
<td>2</td>
</tr>
<tr>
<td>Ice Lollies</td>
<td>Freezers and ice lollies have been purchased and are stored close to the wards for older people. During the data collection period the weather was hot and so patients were eating less. Staff would sit with the patients and chat eating ice lollies together – good for keeping patients and staff hydrated in hot weather.</td>
<td>1</td>
</tr>
<tr>
<td>Reminiscence therapy music player</td>
<td>An electronic system that allows staff and volunteers to pick music or film/tv clips to play to patients. Costs £5,000 per system.</td>
<td>2</td>
</tr>
<tr>
<td>Pat Cat and Dog Therapy</td>
<td>Animals such as cats and dogs being brought into the wards to visit patients. Some hospitals let families bring in pets to see loved ones, whilst others were brought in by volunteers to visit the patients on the ward who stated they wanted to see them.</td>
<td>2</td>
</tr>
<tr>
<td>Therapy Garden</td>
<td>A garden within the grounds of the hospital that patients with dementia were offered opportunities to be taken to by staff and/or volunteers.</td>
<td>1</td>
</tr>
<tr>
<td>Enhanced Care Support Team</td>
<td>Team of staff providing one to one support, including sitting and chatting to patients, playing games or reading and walking with patients.</td>
<td>1</td>
</tr>
<tr>
<td>Activity Coordinators</td>
<td>Staff providing one to one support, including sitting and chatting to patients, playing games or reading and walking with patients.</td>
<td>1</td>
</tr>
<tr>
<td>Carers Advisor</td>
<td>One person who provides information and support to carers.</td>
<td>1</td>
</tr>
</tbody>
</table>
2.4 Who were included in the research

Our criteria for who was included in the research (see, Table 3) were outlined in our application for ethical approval (see section 2.4) prior to collecting data. At this point we had also included ‘in receipt of one of the therapeutic interventions’ under the inclusion criteria for people with dementia, however as discussed in the previous paragraph we found that not all of the hospitals were running the interventions during our visits so this was not always possible. We therefore took this out of our inclusion criteria.

Table 3: Participant inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>INCLUSION CRITERIA</th>
<th>EXCLUSION CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People with dementia</strong></td>
<td><strong>People with dementia</strong></td>
</tr>
<tr>
<td>A diagnosis of dementia</td>
<td>Unable to give informed consent</td>
</tr>
<tr>
<td>Visitors to the ward</td>
<td>Not visitor to the ward</td>
</tr>
<tr>
<td>Able to give informed consent</td>
<td>No diagnosis of dementia</td>
</tr>
<tr>
<td>A patient on the relevant ward</td>
<td>Not a patient on the relevant ward</td>
</tr>
<tr>
<td>Not very ill or frail</td>
<td>Very ill or frail</td>
</tr>
</tbody>
</table>
2.5 How we interpreted the data

Each data set was interpreted separately before undertaking a comparative analysis and triangulation of the data (Denzin, 1978). Triangulation of the data allowed for a deeper, more comprehensive understanding of the hospital context and the impact of delivering or receiving the intervention. Data from unstructured observations were examined for contextual information relevant to the intervention. This formed the basis of a detailed description of the hospital setting where the intervention was taking place.

Interview and focus group voice files were fully transcribed. Transcripts were thoroughly read and re-read for emerging themes and concepts relating to delivery of the intervention and its reported impact on those delivering and receiving it. The data were managed in NVivo10: a qualitative data management tool. NVivo10 also allowed for comparative analysis of different data sets to identify areas of similarity, difference or contradictions between them.

2.4 Ethical considerations

Ethical approval to undertake the research was obtained from the National Health Service Research Ethics Committee (NHS REC) and permission obtained from the Research and Development department of each participating hospital Trust. Principles of informed consent, right to withdraw, prevention of harm, confidentiality, anonymity and data security were adhered to. Of importance when researching with people with dementia is ensuring informed consent. We ensured this by writing information sheets and consent forms in Plain English. However, as this had to be balanced with the wording requirements of the REC, they were not as easily understood as we would have liked. We also allowed sufficient time for potential participants to digest the information and to ask questions before signing the consent form. We only recruited people with dementia deemed by the medical team, family carers or themselves as able to give informed consent, therefore all participants
were able to provide informed consent. While we obtained written consent, the researcher adhered to the principle of ‘ongoing consent’ (Dewing 2002); that is, observing the participant for signs of withdrawal of consent, for example becoming disengaged or restless, and respecting their withdrawal.

We adhered to the following ethical principles throughout the data collection:

- One week prior to our visit to the hospital we asked staff to display a poster with information about our study on the relevant wards. On the first day of our visit we changed the posters to ‘we are here today’ posters (Appendix 11). Information sheets (Appendix 1 – patients; Appendix 3 – family carers; and Appendix 6 - staff and volunteers) explained why the research was being undertaken, what participation would involve for individuals and a description of issues of consent, voluntary participation, confidentiality and anonymity. Photographs of the researcher that would be undertaking the data collection along with their contact details were also included in case people needed further clarification. Prior to the start of each interview or focus group the researcher distributed the information sheets to the participants and talked through the content with them. Those who wished to participate were asked to complete and sign a consent form (Appendix 2 – patients; Appendix 4 – family carers; and Appendix 7 - staff and volunteers).

- Participants were assured that participation was entirely voluntary and that they could stop, or leave, at any time.

- Participants were asked for permission to audio-record the interview and focus group conversations and were reassured that the data would only be used for this project, that any quotes used in the report to the funders or any publications would be anonymised and that no-one would be identifiable in any reports or publications.

- The audio recordings were transcribed by a university approved transcription service.
• Interview transcripts were anonymised prior to analysis and participants were assigned a code number in line with confidentiality and anonymity arrangements.

• To comply with the University’s records management policy, all project files are stored on password protected network drives and data are not available to third parties.

• A lay summary of the findings will be sent to all the gatekeepers to circulate to the participants involved.
3. FINDINGS: BENEFITS AND CHALLENGES

This section outlines the participant characteristics and the key themes that arose following from our interpretation of the data. The key themes presented here cut across the data and are taken from comparing all the information from interviews, focus groups, diaries and observations. We present the themes in two sections: benefits of implementing the interventions; and challenges of implementing the interventions. Firstly though, we provide an overview of the participant characteristics.

3.1 Participant characteristics

A total of 39 people took part in 11 interviews and 6 focus groups. This equates to 22 members of staff, 3 volunteers, and 11 patients with dementia (8 single interviews and 3 dyad with carers present, 1 signing proxy consent on behalf of the patient with dementia who expressed a wish to participate but was unable to sign the form), as shown in Table 4. All interviews and focus groups were lively and many participants were eager to contribute their experiences and views. Interviews ranged in their duration from 6 to 28 minutes, whilst focus groups lasted between 35 and 55 minutes. The participant codes used in the findings section of this report are explained in Table 5.
Table 4: Type and number of participants that took part in interviews and focus group

Type and number of participants

<table>
<thead>
<tr>
<th>Hospital code</th>
<th>Patients with dementia</th>
<th>Carers</th>
<th>Staff or volunteers</th>
<th>Total participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
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<td>6</td>
<td>7</td>
</tr>
<tr>
<td>B</td>
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<td><strong>Total</strong></td>
<td><strong>11</strong></td>
<td><strong>3</strong></td>
<td><strong>25</strong></td>
<td><strong>39</strong></td>
</tr>
</tbody>
</table>

Table 5: Participant codes

Participant codes

<table>
<thead>
<tr>
<th>Hospital code</th>
<th>Participant Type</th>
<th>Gender</th>
<th>Participant number</th>
</tr>
</thead>
<tbody>
<tr>
<td>A-H</td>
<td>C = Carer; P = patient with dementia; S = Member of staff; V = Volunteer.</td>
<td>M= Male; F= Female</td>
<td>Order spoke in the focus group</td>
</tr>
</tbody>
</table>

Examples:

ASF1 = Hospital A first female member of staff to speak in focus group.

CPM1= Hospital C male patient living with dementia.
3.2 Benefits of implementing interventions

In this section, we describe the benefits of the interventions as experienced by family carers and people with dementia and also by staff and volunteers.

3.2.1 Benefits to family carers

Family carers appreciated having extended visiting time, such as that promoted by John’s campaign. For this family carer, it meant peace of mind that her mother was comfortable:

Yeah. It is important to me, ‘cause I like to be with her and she likes me to be here. Although sometimes she’s asleep a long time, but I’m here for her and I’m...you know, rather than sit at home and worrying, you know, what’s happening, how is she, I’m here and, you know...and I’m on hand. (GCM1)

John’s Campaign not only facilitates carers remaining in the wards for as long as they want, but it aims to make this easier by providing subsided parking and meals. However, this does not appear to operate consistently across Trusts, for example one hospital provided carers with badges to signify to the canteen that they are entitled to subsided meals, while another did not provide subsidized meals. Another hospital only authorized subsided or free parking to the main carer at the ward sister’s discretion, depending on the length of time the patient is in hospital, while another hospital operated a pass system where carers can apply for a reduction in parking fees.

Hospital staff at all eight hospitals reported that they encouraged family members to help with their relative’s care, for example helping them at meal times or providing stimulation during visiting time through the use of activity boxes.

There were some very moving stories recounted by hospital staff of their observations of benefits to family carers of particular interventions. For example one staff member spoke of a family member’s joy at seeing her mother smiling and
enjoying live music played for her by a musician. Family carers were also reported to value volunteer befrienders spending time talking to patients with dementia, as this participant stated:

*The wonderful thing about it is...and especially with the dementia people is that the relatives appreciates it so much.... They really like to think that there is somebody with their loved one when they're not there and it does make a big difference.* (GVM1)

This carer spoke of her experience with a volunteer befriender:

*Yes, I saw one, who was male, down in A&E, and he offered us...we had several cups of coffee, and he came and chatted to mum, yes, he was very nice.* (DCF2)

### 3.2.2. Benefits to patients with dementia

There were two key benefits to patients identified: interventions had the potential to *uphold personhood*, and *facilitate reminiscence*. These will be discussed in turn.

**Upholding personhood**

Ward staff spoke about initiatives that are actually happening and initiatives they would like to see happen. Both types of initiative have the potential to promote a person-centred (Kitwood, 1997) approach to practice; in which the individual is recognized and respected and their abilities and preferences are supported. The memory boxes are a good example of an initiative that prompts conversation, allows for a variety of activities and abilities and can be used flexibly at the bedside or in a dayroom. They can be used by staff and family carers alike. Familiar music being played in ward bays, instead of a potentially unfamiliar radio station is another example of an attempt to create a more personalized space for patients with dementia. In one hospital, a musician played instrument to small groups of patients
or individually. This volunteer recounted the impact on a family member of a musician playing for her mother:

... and she said, well dad passed away in May, we know mum’s not coming home and that smile on my mum’s face... is what she is going to remember for rest of her life. (GVM2)

This patient with dementia described his thoughts on spending time in the day room, how he finds going there relaxing and how he experiences a reciprocal bond with the other patients with dementia who go there:

Oh, I like it in there, it’s relaxing… Nice cup of tea. The folks in there are much in the same boat as yourself… so there’s a bond there immediately because you know...you understand each other. You don’t have to talk about it but you know it. (FPM1)

This is a powerful example of the positive impact an alternative, comfortable space within the hospital can have on patients with dementia.

In one hospital, John’s campaign had been extended to include anyone with a cognitive impairment or learning difficulty, in the recognition that open visiting would also be beneficial to these groups of people too. This is a good example of an intervention, having been used successfully in one area, being widened out across the hospital to benefit a wider patient population.

**Facilitating reminiscence**

Staff in one ward spoke of the value of activity boxes, memory boxes and scrap books for stimulating conversations and facilitating reminiscence:

*They (patients) absolutely love them (scrap books), especially all the food bits, because it’s got a picture of all the different types of food in the ‘50s. Yes, that’s really good. (GSF3)*

Other staff spoke of the power of music to stimulate interaction and singing:
.. and the music activity again is quite similar because you’re getting all kinds of levels of interaction from the bedbound, who suddenly start singing. (FSF3)

One participant with dementia reminisced about his own time as a musician following an enjoyable session with the hospital musician:

*I played the clarinet extensively and I had the opportunity to play in two…the 1914 war.* (APM1)

### 3.2.3 Benefits to staff

There were three key benefits of the interventions reported by hospital staff: some helped to identify the patient as having dementia and some helped to manage complexities of caring and some formalised care practices. These will be discussed in turn.

**Identifying the patient as having dementia**

Different hospitals used different methods to signal to staff that a patient has dementia. One hospital used the butterfly scheme: a picture of a butterfly placed on the board next to the patient’s bed and another on the whiteboard at the ward nursing station to signify to staff a diagnosis of dementia. This was seen as a discrete way of alerting staff to the fact that a patient had dementia:

... *it reiterates the importance of, actually, when you’re looking after somebody with dementia. And, it’s quite discrete, that’s what I like about the Butterfly Scheme, it’s not in your face, you know, it’s not, like, an I’m allergic band, it’s something that’s quite discrete and quite subtle.* (DSF1)

Other hospitals used an image of forget-me-not or sunflower in the same way. Some wards used coloured plates at meal times:

*Any kind of visual key, or prompt, just to remind the staff.* (DSF2)
Another hospital used the red tray scheme:

… we do sometimes have patients on a red tray which flags up to the nurses that they need support or supervision. (GSF1)

Only one participant with dementia commented on the use of a coloured plate when asked if it made a difference to him:

No, I don’t personally, but you always notice it's on a blue plate, you notice that. (APM1)

This suggests that, while acting as an alert to staff, it didn’t impact negatively on his well-being. However, it also suggests that there is a fine line between the utility of these methods for staff and the risk that they might be seen as labelling or patronising by patients or family members.

**Formalising care practices**

Introduction of interventions were seen by some staff as a formalization of good or innovative practice already carried out. For example, in relation to John’s Campaign, this participant expressed their realization that what they had been doing to support family visitors to the ward was essentially the practices promoted by the campaign:

...anything that we would ever have said before John’s Campaign anyway. So I think we were halfway there but we didn’t really realise it, well probably 90 per cent there but didn’t really realise it. So we’ve just made it a bit more official. (ASF2)

John’s campaign was reported by staff to have the potential to promote consistency of practice and therefore patient and family experience across the hospital. This seemed particularly relevant for those patients who experience multiple bed moves during their stay in hospital:

a lot of our patients have been on every single ward in the trust haven’t they so actually if you do different things on each ward it makes it quite...(ASF2)
Helping with complexities of caring

Staff spoke of some of the complexities of caring for people with dementia in different hospital settings: Radiology, Accident and Emergency or acute care. For example, this staff member reported a benefit of the Twiddlemitts (brightly knitted muffs with tactile items stitched onto them):

*Patients when they’re going for diagnostic imaging, it’s quite comforting and settling for them.* (DSF1)

Staff also spoke of the value of having volunteer befrienders on the wards to talk with patients, keep them company, and use the memory boxes to reminisce with them. However, it was acknowledged that this role could be extended to enable volunteers to go for walks with patients if they were restless:

*I’d like to see the role really beefed up a bit more because I think it’s great that they (volunteers) sit and chat with patients but it’s something around, and I’m happy to put the training in or source the training in, that they’ll have some training around reminiscence therapy, they’re using the memory boxes. So activities and engagement because half the issue of someone with dementia or cognitive impairment wanting to walk is because they want something to do and I feel that role would be much more expanded, that actually take somebody for a walk along the corridors if they want to.* (ASF1)

Staff who valued the role of volunteers in the wards also felt there could be more of them to better support their work:

*Exactly, yeah. But we need lots of you.* (HSF4)

### 3.2.4 Benefits to volunteers

Volunteers spoke of the benefits to them of the work they do to support patients with dementia in the wards, and of the impact of their work on family members. For
example, this volunteer, speaking of a patient’s positive response to their presence with a musician said:

I think volunteers get a lot out of it as well to be honest with you. (GVM2)

Another volunteer expressed their satisfaction with engaging with someone who may not have spoken for a long time:

I find it very rewarding because I get people who probably haven’t spoken to anybody for a very long time. (HVF1)

There were many accounts of volunteers’ experiences of working in creative ways with people with dementia, from engaging in craft work, to reminiscing with scrap books or memory boxes, to spending time sitting or talking with patients.

But we play cards, we do colouring, we do all sorts. It's lovely. (HVF1)

Summary of benefits of interventions

- Family carers appreciated having extended visiting time, such as that promoted by John’s campaign.
- Family carers were reported to value volunteer befrienders spending time talking to patients with dementia.
- Interventions can uphold personhood of patients with dementia.
- Activity boxes, memory boxes and scrap books are useful for stimulating conversations and facilitating reminiscence.
- Staff find methods for signifying that a patient has dementia useful.
- Some interventions have formalised existing innovative care practices.
- Some interventions can help with the complexities of caring for patients with dementia.
- Volunteer befrienders on the wards to talk with patients and keep them company are highly valued.
- Staff and volunteer ward companion’s value being able to participate in and benefit from innovative initiatives.
- Staff, volunteers and family carers value seeing the positive impact on patients with dementia of innovative initiatives.
- There is the potential for successful interventions to been extended beyond the population of people with dementia.
3.3 Challenges of implementing interventions

Participants reported many challenges with implementing interventions. We will report them under three headings: hospital focused challenges; patient and carer focused challenges and staff focused challenges.

3.3.1 Hospital focused challenges

Securing funding

Issues of cost or lack of funding was reported widely across the hospitals as being a challenge or barrier to implementing initiatives, such as John’s campaign, the Butterfly scheme, coloured plates or trays or other initiatives staff thought would be useful. The constraints of funding meant that some interventions were only partially implemented:

>The only thing we’re missing is the beakers they’re white still, they’re clear so it will be beakers that need to change next. (ASF3)

Not continued:

>No, the coloured plate scheme was going ahead but, actually, due to costings again, and coming out of ward budgets, it wasn’t unfortunately taken forward. So, again, it’s about how do we get that money to have the coloured plates, we’re talking about the red plates. We have red trays, where patients need help for eating, feeding, and that, but actually we didn’t get any further ahead with it, and it fizzled out in February. (DSF1)

Or delayed:

>The butterflies, we’re just going to start… (DSF3)

There was a pause, wasn’t there, but it’s started up again, because we’ve got the funding for another year. (DSF1)
However, many staff reported their commitment to ensuring initiatives went ahead and this extended to them using their own money to buy items:

*We have multi-coloured cups but I have to buy those from IKEA.* (ASF2)

Other staff spoke of their fundraising efforts:

*Well, I was going to say, we bought the equipment to make the cakes and make the forget-me-nots, we gave up our lunch hours to sell it.* (FSF4)

Others spoke of seeking support from charitable organisations, as well as asking local organisations to donate their time and resources. For example, in one hospital a dementia garden is being funded, designed and created by sources external to the hospital and the landscaping company are delivering workshops to support the sustainability of the garden. Seeking funding through fundraising or resources from external sources relies on the generosity of the general public or the commitment of the staff to benefit their patients; indicating the potential fragility of these ways of securing funds for initiatives to benefit patients and families, as alluded to by this participant:

*You wouldn’t believe how generous people are. That was only four days’ work in the main hospital. But I think we’re all so passionate about it here that if we want something we’ll work for it and get it ourselves. So, yeah, we all just work really hard together don’t we?* (HSF1)

**Lack of equity in access to initiatives**

As noted previously, participants stated that, even within their own hospitals, there seemed to be a difference between wards in their implementation or knowledge of particular interventions. For example, in relation to colour coding certain features to make them more recognizable for patients with dementia, this participant noted that some wards had yellow toilet doors while others did not. She stated:

*It would be nice if every ward had the same.* (GSF5)
There was also recognition that some wards in a hospital implemented the John’s campaign while others stuck to advertised visiting times. Some wards advertised the campaign through the use of banners and carer leaflets, while others did not advertise it at all.

There was also concern that the variety in visiting times across hospital Trusts could be distressing for patients and visitors who experience moves from hospital to hospital. Consistent implementation of John’s campaign across hospital Trusts might alleviate this distress.

**Lack of awareness of interventions**

This challenge is closely related to the previous one, as often an inequity in access to a service or intervention stemmed from lack of awareness that it exists, or its purpose. Lack of awareness of an intervention within a hospital can lead to incorrect information given to family members, as noted by this participant:

> I had somebody rang me because she went to the Alzheimer’s Society to say that her husband was admitted to (Name of ward), he’s got dementia and she wanted to stay but she was told, this was only two weeks ago, visiting hours is da, de, da you can come in those hours and she was quite concerned. And they then gave her my number she did ring and leave a lot of messages on my phone so then I toddled along to (Name of ward), had a long chat with her and said we do do John’s Campaign and she explained it all, so I went and spoke to the staff and they said oh yeah, yeah we do. So I think it’s something about everybody knowing what we’re doing, what’s being done rather than mixed messages... (ASF1)

This is reiterated by this family carer:

> I didn’t realise it was open visiting, I was told it was two until three and seven until eight. So, is it open visiting? (DCF2)
Lack of awareness of an intervention also meant that family members might not even receive the relevant information, again relating to open visiting:

*I think people still presume there are limited visiting hours, it needs to be emphasised.* (FSF3)

**Insufficient training and understanding**

Some staff had concerns over the level of training and support volunteers received and this appeared to have implications for their reactions to certain patients, for example those with alcohol related brain disease, as this participant states:

*we’ve had a complaint from one of them (volunteer) because they didn’t want to sit with alcoholic patients as they didn’t think that was part of their job. We’ve said to them they might not have dementia they’ve got massive cognitive impairment… but they didn’t like our kind of patients.* (ASF5)

Another concern related to the perceived skill level of volunteers and their ability to helpfully support staff on the wards, as this participant noted:

*But also with the volunteers, where we need them, because they’re not allowed to feed the patients that have swallowing problems, and so if anybody’s on a…they can…and they are the patients that need feeding, aren’t they? And so unfortunately that’s where I think that service falls down a little bit. But they sort of come and say, oh, is there anybody…and we say, oh, brilliant, yes… Oh, actually you can’t do that one.* (GSF2)

Whether this is a role for volunteers would need to be clarified.

A final concern of staff was the potential indiscriminate use of an intervention, without considering its utility, appropriateness or value for the patient. For example, one participant noted that occasionally every patient in a bay would be given a Twiddlemitt, regardless of whether they are appropriate or not for each patient.
Levels of support to effect change

A further challenge noted by staff was the degree to which the different levels of support impacted on their experience of implementing an intervention. One participant spoke of a request put to the hospital management previously to have sitting companions for patients with dementia. This had not happened until the Chief Executive of the hospital committed the hospital’s support to developing this. On a ward level, another participant noted that initial variation in support for an intervention might be resolved by giving ownership and responsibility for it to ward staff. The value of having Dementia Champions to help take initiatives forward was also raised as an important facilitator for change:

I will certainly be able to feed through the idea then, so all the Champions; there should be somebody on each ward who can then take it forwards.

(FSF2)

When and where to run interventions

The final hospital focused challenge was when and where to run interventions. For example, in one hospital where staff signpost carers to a carers’ café, they noted that due to short visiting times, the carers preferred to stay with their relative in the ward. A solution put forward was to have the café go to the wards. This comment also demonstrates the lack of awareness of John’s Campaign amongst staff in this hospital, as this hospital had already implemented open visiting for carers as part of this intervention.

Another challenge was where to accommodate family members who want to stay overnight, particularly if the patient with dementia is very ill or agitated, as this participant noted:

If somebody is poorly enough, or if somebody is agitated, and they want to stay with their loved one, we will try and accommodate them overnight. But,
the problem is that, obviously, we’ve got no relative’s rooms, the wards are very limited, so it is a case of put me up on a chair. (DSF1)

However, there were also proposals for a solution in the development of a room for people with dementia that would be accessible to carers. In one hospital, ward staff suggested that carers could use the activity room overnight to sleep if the hospital purchased some fold away beds, they were however waiting for approval to do so as there was a concern about fire risk:

….the idea was to have so they could stay over, have a bed to sleep in here, that hasn’t materialised though, because that was one of the main...to try and get a camp bed or Z bed. There were some concerns about.... the fire issues, somebody actually sleeping in here, so that’s gone back to the fire officer, which would be nice, because at least if they wanted to stay, they could stay. (FSF1)

3.3.2 Patient and carer focused issues

Two themes related to considering the needs or wishes of carers emerged: concern not to over-burden and managing expectations. One theme relating to people with dementia was the importance of using different interventions to meet different people’s preferences and abilities: flexibility of intervention use. These will be discussed in turn.

Concern not to over-burden and managing expectations

Hospital staff recognized that relatives of people with dementia may themselves be older and frail, or have other caring commitments. As such, John’s Campaign may have the unintended consequence of removing the opportunity for rest or respite if relatives spend much of their time in the ward with the person with dementia.

the carers of people with dementia tend to be their spouse who in my case can be quite old and to be quite honest I think they need a break. (ASF2)
However, in reality those hospitals that had implemented John’s Campaign had not seen an increase in the number of carers wanting to stay overnight, or for the whole day:

*Occasionally [relatives stay overnight], but not …not in the dementia bay… There’s one of our patients, her husband’s in all day, but then he goes home, because he comes in at ten in the morning, doesn’t he, and goes home about half seven in the evening. (GSF3)*

Instead it meant that carers were able to come onto the wards earlier in the daytime so that they could support staff with activities such as helping to feed patients at lunch time.

*I think, from our point of view, really, the John’s Campaign is really, really good. I mean, we’ve always been quite proactive with allowing relatives to come, we try and promote it, especially for patients living with dementia, because actually they’re familiar to them, so we do encourage that. So, we have, sort of, been doing a little bit of that anyway, and I think it’s a good thing, to get the relatives to come in. (DSF3)*

On the other hand, the same member of staff was aware that some relatives of people without a cognitive impairment might use the principles of John’s Campaign to enable them to stay with their relative all day:

*I just find that some people, or some relatives, are trying to use that as a way of stopping all day. Whereas, we need to make sure we’re targeting the right people. (DSF3)*

These issues reflect the need for widespread information and understanding throughout each hospital of the existence and purpose of different interventions, so that those who they are intended for benefit appropriately.

**Flexibility of intervention use**

This theme reflects the recognition by staff that interventions should not be used generically for all patients: that some patients will benefit from and value one
intervention, while not benefitting from or valuing another. Some staff in the hospitals using the Twiddlemitts had strong views about the appropriateness of their use. For example, as noted previously, staff reported their observation that, at times, everyone in a bay would be given one regardless of their need or wish for one. However, flexibility of use relies on trial and error, as this participant noted:

*I think, some people do like them [the Twiddlemitts], other people just throw them straight on the floor.* (DSF3)

Flexibility of use also relies on knowing the patient’s condition and abilities and tailoring an intervention to match these, as this participant noted about the use of Twiddlemitts:

No, I we, sort of, watch and wait really. Because, I think, some people living with dementia tend to be quite proactive themselves, and they will be able to walk around, and do things. I think we tend to use them more when they become more bed bound, and not able to do a lot for themselves, and it just gives them a little bit of something to be able to do, or we give magazine and things. But, not so much with ones that are quite mobile, I think it’s good to try and promote their activities of daily living as much as we can. Because, actually, it’s good for them to still be able to be in a routine of what they were doing, but I think end stage dementia we use them more, rather than at the beginning really. (DSF4)

The challenge of using interventions appropriately with patients and family carers reflects a more person-centred approach with benefits for patients as noted above.

### 3.3.3 Staff focused challenges

A key staff focused challenge was insufficient staff and volunteers to meet the needs of patients or satisfy the wish of staff to be more person-centred. Other staff-focused challenges were a reliance on volunteers and insufficient management support.
Insufficient personnel

Those staff in hospitals with volunteers stated that, while the volunteer presence was generally very useful, there just were not enough of them to do more specific one to one work with patients with dementia, as this participant stated:

I have two but they just come to...tend to come and do tea rounds they don't...I want some dementia sitting volunteers which I've asked for and I still haven't got them. (ASF2)

Of note here is that this participant has requested more volunteers without success. This is further illustration of the fragility of relying on one source to meet the more holistic psycho-social needs of patients with dementia. Another issue was volunteers not being introduced to ward staff, therefore ward staff not knowing who their volunteers were. This suggests a resource that is under-recognised, under-used and therefore potentially under-maximised.

Having insufficient personnel to safely manage an intervention (in this case an activity room for people with dementia) is risky and stressful as this participant stated:

The problem I've got with my day room is as soon as I go out to the toilet with someone, someone else can fall, and we had two falls when I first started, and we haven't had any more since, touch wood, but it's always the fear that as soon as I turn my back or I need to go and get a wheelchair to get someone else to come in, the people here are unsupervised. So that's been, I think, it's a difficulty, it's a drawback to having a separate room. (FSF3)

In another hospital, the ad hoc, opportunistic nature of delivering an intervention was a consequence of staff striving to be therapeutic despite being understaffed on the ward, as noted below:

It tends to just be whoever is on and has some free time. So nurses (name of Support Worker), absolutely anybody. We love doing that side of it. (HSF1)
These challenges to delivering interventions has, at times, been overcome by the commitment of staff to deliver care other than task driven care despite the added stress this might entail. However this is a fragile solution.

**Fragility of relying on volunteers**

A related issue in two of the hospitals that had volunteers going to the wards to support staff was the fragility of relying on them solely to deliver or manage therapeutic interventions. Participants spoke of volunteers not turning up when they were scheduled to, leaving just as everything (paperwork, safety checks) were in place, being unsuited to the work or not being fully committed because they were students and had exams. This participant encapsulated both the fragility of relying on a few volunteers and a potential solution:

> I’d like to have a bank of three or four, rather than one or two, so it’s the gaps in between, you can’t plan a consistent delivery of service without the second volunteer. (FSF3)

**Insufficient management support**

This theme only arose from one hospital and therefore cannot be generalised. However, staff felt that there was a lack of support from management to enable them to take forward interventions and activities for patients with dementia. They described the key challenges as: needing to obtain approval from the Board of Directors for any new intervention or activity, lack of funding and staff to take forward initiatives, and resistance from other staff towards any new interventions or activities. This illustrates the importance of staff feeling supported in their attempts to introduce innovative practices to improve the experience of their patients.
Summary of challenges of implementing interventions

- Interventions do not appear to operate consistently across Trusts.
- Even within hospitals, there seemed to be a difference between wards in their implementation or knowledge of particular interventions.
- Issues of cost or lack of funding was reported widely across the hospitals as being a challenge or barrier to implementing initiatives.
- The constraints of funding meant that some interventions were only partially implemented, not continued or delayed. However, staff are very committed to fundraising and seek local support for meeting costs of valued initiatives.
- An inequity in access to a service or intervention stemmed from lack of awareness that it exists, or its purpose.
- Lack of awareness of an intervention within a hospital can lead to incorrect information being given to family members.
- The value of having Dementia Champions to help take initiatives forward was raised as an important facilitator for change.
- Some staff had concerns over the level of training and support volunteers received.
- Some staff were concerned about the potential indiscriminate use of an intervention, without considering its utility, appropriateness or value for the patient.
- Different levels of support throughout the hospital are necessary to effect change – implementing interventions without management support is difficult.
- Finding appropriate space to deliver interventions can be a challenge.
- Hospital staff recognized that relatives of people with dementia may themselves be older and frail, or have other caring commitments; therefore they are concerned not to over-burden them.
- Some staff were concerned that interventions should not be used generically for all patients: that some patients will benefit from and value one intervention, while not benefitting from or valuing another.
- Insufficient personnel to deliver interventions is a widespread concern.
- Staff recognise the fragility of relying on volunteers to deliver an intervention.
This section provides a comparative description of the work being undertaken to improve the well-being of patients with dementia in the eight hospitals that participated in this study. We present this using the SPACE model, to demonstrate the potential impact of the interventions we have evaluated in helping these hospitals to meet the key objectives of the National Dementia Strategy. The Royal College of Nursing (RCN) published the SPACE model which outlines five principles for improving dementia care in hospital settings covering: staff who are skilled and have time to care; partnership working with carers; assessment and early identification; care that is individualised; environments that are Dementia-friendly (RCN, 2011). The principles were designed to enable hospitals to take forward a key objective of the national dementia strategy, to improve hospital care for people with dementia (RCN, 2011). We hope that this example is useful for both the hospitals in this study, and others regionally and nationally, to demonstrate how they can structure their work to improve the well-being of patients with dementia and show how it is meeting the objectives of the National Dementia Challenge. The descriptions below are developed from the field notes taken by the researcher during her time in each hospital ward, with some references to the focus group findings where appropriate.

4.1 Staff who are skilled and have time to care

The SPACE model suggests that staff need support in delivering improvements in practice that can be facilitated by Clinical Leads and dementia-specific roles including Dementia Specialist Nurses and Ward Champions (principle 1, number 2) (RCN, 2011). There was a variety of staff that each hospital identified as taking forward their dementia related work. Four hospitals had identified a team of staff; in some of the hospitals this was a team of Dementia Specialist Nurses, whilst in others this including Dementia Specialist Nurses, Support Workers, a Consultant and Administrative Support. Two of those Dementia Teams were supported directly by volunteers who provide one to one support to patients that are identified by the Dementia Specialist Nurses as benefitting from further support. The main remit of the
Dementia Team in these four hospitals is to screen all patients aged 75 and over who come into the hospital as emergency admissions, which falls under the national Commissioning for Quality and Innovation (CQUIN) plan set out by the government to improve areas of dementia care in hospitals in the UK (NHS England, 2015). In one of these hospitals four Dementia Specialist Nurses screen an average of 700-800 patients per month. In one of the hospitals they also routinely call the carer of the patient with dementia to check they are ok and, if they need support, they offer them a listening ear or signpost them on to other agencies. In one hospital the Dementia Lead is currently being supported, for a temporary period, by a Nurse on secondment. Their remit is to raise awareness of dementia across the hospital, train staff in dementia and to run the weekly carers café. In three of the hospitals the person assigned the Dementia Lead role also held another full time role, and they all expressed how difficult it was to take forward the dementia related work.

We found three hospitals that had identified one or two Dementia Champions on each ward. In each hospital these were members of staff with an interest in dementia who were then asked if they would like to become a Dementia Champion. In each of the hospitals the role of the Dementia Champion was the same; to raise awareness of dementia, challenge poor practice and negative language (for example staff using terms such as ‘dementia sufferer’). Dementia Champions in each hospital meet bi-monthly to update on policies, processes and share experiences and good practice. However, staff also noted that it often proved difficult for all the Dementia Champions to be able to meet together as they were not able to be released from their wards due to needing to provide cover (Focus Group Findings). One hospital tried to find a solution to this in that they expected Dementia Champions to attend two of the six meetings held in any year. Some other interesting roles have been developed in three of the hospitals to support patients on the wards for older people. The Enhanced Care Support Team provide one to one support, including siting and chatting to patients, playing games or reading and walking with patients. This is similar to the role of Activity Coordinators in another hospital, however there is a set programme of activities each week (such as Circle Dance exercise, Meditation) usually hosted in a room away from the ward, alongside the more specific one to one support within the bays. In another hospital two Dementia Case Workers support
patients with dementia and their carers/family throughout their journey in the hospital. The level of support varies from one patient to the next but can include signposting to external agencies, help completing the This Is Me document, accompanying patients to x-rays or operations, and being a familiar face as the patient moves from emergency admission to a ward. These roles are primarily Monday-Friday during office hours, and in some cases there are no evening and weekend options. Many staff agreed that these additional support roles were a positive step to support the well-being of patients with dementia, as these staff have time to sit with patients and provide one to one support to those who require it (Focus Group Findings). However, on the other side a couple of members of staff felt that it could lead to deskilling nurses and other ward staff if they focused solely on task based activities and not on listening and supporting patients.

The SPACE model suggests that attention is given to staff training about dementia, including listening to the way that people with dementia want to be cared for and hearing the views of family carers (principle 1, number 1) (RCN, 2011). There was variety in terms of the dementia training for staff and volunteers across the hospitals. This included bespoke training that focuses on what it is like to have dementia (which several members of staff commented was the best training they have ever had), a DVD with scenarios to work through, ward based training with simulation suits, and Alzheimer’s Society Dementia Friends sessions. In one hospital a Dementia Trainer has been appointed to deliver Tier 1 and 2 dementia training to all staff and volunteers. Volunteers support the hospital staff in all eight of the hospitals. In some hospitals this support is at meal times helping to feed patients who are less able to feed themselves, whilst in others they provide one to one support as Ward Companions or have developed their own interventions to support patients with dementia (Time4you). Given appropriate training, volunteers can support patients who require one to one support, and play a crucial role in aiding ward staff to improve the well-being of patients with dementia. One of the hospitals mentioned that they have a Dementia Strategy in place which helps to ensure the dementia related work is taken forward in all areas of the hospital, not just in the wards for older people. In one of the hospitals staff commented that the Board of Directors is ‘forward thinking’ and happy to invest in dementia related initiatives. This means they
are given some autonomy to make decisions at ward level; for example, they are able to trial and roll out interventions for patients with dementia quickly, without the need to seek Board level approval beforehand.

4.2 Partnership working with carers

The SPACE model suggests that effective care acknowledges the needs of families and carers who have been supporting the person with dementia through flexible visiting and approaches to routines (principle 2, number 3) (RCN, 2011). John’s Campaign has been implemented, or at least is in the planning stages of being implemented, in seven of the hospitals. However, there were differences in the application of John’s Campaign across these seven hospitals, with some not wanting or able to provide carers opportunities to stay overnight with their loved ones. In some instances carers were provided with a badge to help ward staff identify them as carers of patients and not challenge them for being on the wards outside of visiting hours. Some hospitals were supporting carers with subsidised or free parking and reduced meal costs in the hospital restaurant, but this was not the case in all of the hospitals. One hospital will not be implementing John’s Campaign as the hospital Board do not want to change their visiting hours (currently 2-8pm). The SPACE model suggests that the hospital admission of a person with dementia may be an ideal opportunity to identify the carer and recognise their needs (principle 2, number 1) (RCN, 2011). Two hospitals were running a Carers’ Café once per week, and another hospital has recently appointed a person to be the Carers’ Advisor. Both the Carers’ Café and the Carers Advisor provide carers with an opportunity to talk, seek information, and be signposted to other agencies for support.

4.3 Assessment and early identification

The SPACE model states that carrying out a dementia screening is fundamental to good care and to enable people with dementia to access the services that they will need in hospital and when they are discharged from hospital (principle 3, number 1) (RCN, 2011). Four hospitals stated that they screen all patients aged 75 years and
over admitted in an emergency through the CQUIN plan process (NHS England, 2015). In some of these hospitals this is undertaken by Dementia Specialist Nurses in the Dementia Team and in others Consultants are responsible for this screening. However, some hospitals struggle to screen all patients aged 75 and over through this process, as there may only be one person doing these screenings. The remaining four hospitals did not mention any process for screening patients for dementia, so we are unable to report whether these processes are taking place or not. Further to the screening for dementia, four of the hospitals were also using stickers and magnetic images (forget-me-nots, sunflowers, or butterflies) above the patient’s bed and on the main whiteboard at the nursing station, to help staff and volunteers easily identify the patients with dementia once they were on the ward. In one hospital an image of a butterfly is used to identify patients with a dementia diagnosis, whilst the same image is used in a transparent form to identify patients with Mild Cognitive Impairment. In another hospital, staff from the Dementia Team use the Sunflower Scheme (a sunflower sticker on the board above their bed, help completing the This Is Me document, and an Abbey Pain Scale) with all patients with a dementia diagnosis.

4.4 Care that is individualised

The SPACE model states that ensuring that care is based on the individual, their biography, preferences and an understanding of their abilities is particularly important for people with dementia in achieving person-centred care, and advocates provision of appropriate activity to encourage social engagement, maintenance of function and recovery (principle 5, number 4) (RCN, 2011). There were many examples in the hospitals of activities that enable individualised care, as well as staff who have been employed for this role specifically (see Table 6 for some examples). These interventions are person-centred, in that they can be tailored to suit each individual patient’s needs. Staff also highlighted the importance of sitting and talking to patients (which was facilitated by many of these activities), and the vital role of family members’ knowledge of the person’s likes and dislikes as well as the importance of completing the ‘This Is Me’ document with details about their life.
Table 6: Examples of activities and staff that enable individualised care

<table>
<thead>
<tr>
<th>Examples of activities and staff that enable individualised care</th>
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<tbody>
<tr>
<td>Finger food/picture menu</td>
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<tr>
<td>Ice Lollies</td>
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<tr>
<td>Reminiscence therapy player</td>
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<tr>
<td>Twiddlemints</td>
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<tr>
<td>Pat Cat and Dog Therapy</td>
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<tr>
<td>Memory Boxes</td>
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<tr>
<td>Therapy Garden</td>
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<tr>
<td>Coloured plate scheme</td>
</tr>
<tr>
<td>Activity/Reminiscence rooms</td>
</tr>
<tr>
<td>Volunteer Ward Companions</td>
</tr>
<tr>
<td>Arts in Health (music at the bedside)¹</td>
</tr>
<tr>
<td>Enhanced Care Support Team</td>
</tr>
<tr>
<td>Activity Coordinators</td>
</tr>
<tr>
<td>Carers’ Advisor</td>
</tr>
<tr>
<td>Time4you</td>
</tr>
</tbody>
</table>

4.5 Environments that are dementia friendly

The SPACE model states that the hospital environment can be difficult for patients with dementia to navigate, or too noisy and confusing; something that can be minimised by design and person-centred care (principle 5) (RCN, 2011). Five of the hospitals had had one or two wards refurbished using dementia friendly design principles. However, staff from all of the eight hospitals commented that the refurbishment was expensive and so they either did not replicate it on other wards, or replicated as much as they had funding to. In one hospital one of the Dementia Specialist Nurses had become the ‘go to person’ who other wards consulted with to ensure their refurbishments meet the needs of patients with dementia. In another hospital staff commented that they did not feel they had been adequately consulted in the refurbishment process and that this has resulted in the space not being optimal in terms of being dementia-friendly. A general observation was that some of

¹ This does not form part of our research as it is being evaluated by another University.
the hospitals had a slightly different interpretation of the dementia friendly design principles, for example in one hospital the toilet door was yellow with red signage and in another it was blue with white signage.

The SPACE model (RCN, 2011) provides a useful framework to explore the work being undertaken by acute hospitals to improve the well-being of patients with dementia. Hospitals using this model in a similar vein could also read the examples of good practice outlined in Alzheimer’s Society (2016).

4.6 Further research and limitations

This research was undertaken over an 11 month period (November 2015-September 2016), with 5 months for data collection. The researchers experienced a number of time constraints during throughout the project which had an impact on the timeline, including the complexity of obtaining NHS REC approval and accessing the relevant staff in each hospital to arrange visits.

The short period of two days per hospital for data collection also limited the amount of interventions we were able to observe taking place and the number of patients we were able to talk to. We therefore suggest that further research, in the form of a longer term ethnographic study, would allow for a richer data on the experiences of patients in receipt of these interventions.

In the next section we summarise our overall conclusions of this research.
5. CONCLUSIONS

This was a complex evaluation of the benefits and challenges of delivering a variety of interventions in eight hospital Trusts in Wessex. The research was carried out over two days in each of the hospitals and used different methods to explore from patients with dementia, family carers, staff and volunteer perspectives and experience of delivering and receiving the interventions. Our intention was to evaluate the interventions identified by the Wessex AHSN as occurring, or in development, in the hospitals. These were:

- Carers’ café
- John’s Campaign
- Dementia Champions
- Dementia Case Workers
- Twiddlemitts
- Volunteer Ward Companions
- Activity/reminiscence rooms
- Memory boxes
- Identifier stickers/magnets
- Coloured plate scheme
- Arts in Health

However, we also found other examples of innovative practice taking place in all the hospitals, indicating the breadth of work to improve the experiences of people with dementia in acute hospital. These were:

- Time4you
- Finger food/picture menus
- Ice Lollies
- Reminiscence Therapy Music Player
- Pat Cat and Dog Therapy
- Therapy Garden
- Enhanced Care Support Team
- Activity Coordinators
- Carers Advisor

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1 This does not form part of our research as it is being evaluated by another University.
A thematic analysis of 6 focus groups with hospital staff and 3 volunteers and 11 interviews with patients with dementia (8 single interviews and 3 dyads with carers) revealed the benefits and challenges of delivering the interventions and the benefits or challenges of receiving interventions.

Findings revealed that family carers experienced peace of mind that their family member in hospital had someone (often a volunteer) to keep them company or engage with them. They also appreciated the flexibility with visiting, car parking and access to meals that John’s Campaign allowed, and they experienced pleasure at seeing their relative with dementia enjoying creative activities. Although we spoke with fewer patients with dementia than anticipated, we were able to develop an idea of the impact of interventions on them from their accounts, family carer accounts and observations from staff and volunteers. Findings from interviews and focus groups indicated that many interventions had the potential to uphold the personhood of patients with dementia, for example: activity boxes promoted conversation and interesting activity, memory boxes promoted conversation and reminiscence, familiar music facilitated a more familiar space and a dementia-friendly day room facilitated companionship between patients with dementia. Although not specifically mentioned by family carers, there was concern among staff that an intervention such as John’s Campaign that facilitates open visiting, might serve to reduce the amount of rest or respite a family carer, particularly one who is older, might get whilst their family member is in hospital.

We also identified benefits to staff and volunteers of some interventions. Staff valued the signifiers, whether a butterfly, forget-me-not or sunflower, that alerted them to the fact that a patient has dementia. Other signifiers to promote more targeted support were coloured plates and trays and these were used as triggers to offer more support at mealtimes. While one patient with dementia noticed his blue plate, he did not feel it made a difference to his experience of mealtimes; possibly an indicator that the plate did not feel stigmatising. Staff also felt that some of the interventions, particularly John’s Campaign served to formalise practices they were already undertaking, and this had a validating effect on them. However, they also noted that there was inconsistency within a hospital in how an intervention was understood and
delivered; potentially causing confusion to patients and family carers. Staff also raised concern that some interventions, particularly Twiddlemitts, might be used indiscriminately. This is linked with some staff reflections of insufficient knowledge of the purpose of an intervention and also linked with a recognised need for more staff awareness of interventions within and across hospitals; the consequences of which can impact on patients’ and family carers’ experiences while in hospital. Our comparative findings also indicate there is inconsistency across hospitals in how the same intervention is delivered. Volunteer ward companions were generally hugely valued for their work in supporting staff with the complexities of caring and they reported feeling very satisfied with their work. Across the hospitals that had volunteer ward companions, there was acknowledgement that more volunteers would be helpful and that they might be able to offer more support with more targeted training and support. Our findings also highlight the fragility of relying on a group that is potentially transient and thereby, at times, not as committed to their work as they might be. A key benefit to staff was having a member of staff whose sole role is a focus on patients with dementia and family carers. This role is broad and includes screening patients to diagnose dementia, signposting of information to carers, staff awareness raising and training, and co-ordinating care.

Staff spoke of many challenges, from organisational to individual level of implementing interventions. We identified two key factors that impacted on whether an intervention was developed and delivered successfully or not: management support and the presence of a member of staff or staff team to champion and drive the intervention forward. While sufficient funding was raised as a potential barrier to successful delivery of an intervention, in some cases the commitment and resourcefulness of staff in securing their own funding meant that an intervention was delivered successfully. Along with the fragility of relying on volunteers to fill workforce gaps, we suggest there is also fragility in using ad hoc fundraising to deliver or sustain innovative practices.

We also provided a comparative description of the work being undertaken to improve the well-being of patients with dementia in the eight hospitals that participated in this
study. We highlighted how the work to improve the well-being of patients with dementia in these eight hospitals is meeting some of the principles of the RCN SPACE model (RCN, 2011), which in turn is meeting the objectives of the National Dementia Strategy. Using the RCN SPACE model (RCN, 2011) alongside these examples of practice, may be useful for hospitals generally to compare and contrast their provision for patients with dementia.

In summary, this was a relatively small study allowing a snapshot of different types of non-pharmacological interventions to improve the experiences of people with dementia while in acute hospital, and also the experiences of family carers. All hospitals used a variety of interventions to meet different needs (for example nutrition, socialisation, comfort and additional support) in ways that had the potential to uphold the personhood of those with dementia. Using a ‘toolkit’ approach has the potential to meet the preferences and needs of the heterogeneous population of people with dementia in hospital. Such a toolkit could also be rolled out more widely, as indicated previously. We have identified key benefits to patients, family carers, staff and volunteers and identified two key facilitators of successful implementation of interventions: management support and a dedicated Dementia Champion or Dementia Team. In the next section we set out some recommendations to support sustained delivery of interventions and facilitate easier introduction of interventions shown to be beneficial.
These are the recommendations developed from our findings. Individual hospitals will need to consider them within the context of their own organisation, and then decide how they can operationalise them to suit the particular needs of their organisation.

- Scope the provision of interventions across each hospital to ensure consistency of access to patients and families and quality of practice.

- Develop a Dementia Strategy with clear actions and targets to underpin the direction of work and ensure that all staff (from Senior Management to Ward level) are aware of the commitment to dementia.

- Share good practice across each hospital and between hospitals so that staff and managers can learn from and be supported by others who are successfully engaging in particular interventions.

- Develop a bank of volunteers assigned to each ward and introduced to all staff. Provide clear roles and responsibilities supported by appropriate training and support.

- Develop a toolbox of interventions that can be used to meet patients’ preferences, including options by the bedside for those who are unable to get out of bed.

- Encourage more family members to contribute to the care of the patient with dementia, without over-burdening them.

- Expand training and support to volunteers to enable them to carry out more activities to meet patients’ needs. For example to go for a walk with a patient if they are restless.

- Ensure that ward refurbishments take into account the needs of patients with dementia by adhering to dementia-friendly environment principles.
• Where applicable, repurpose rooms on wards that are not used to their full potential such as day rooms or staff rooms to create activity/reminiscence rooms for patients to use.

• Consultation with staff, patients and visitors on what improvements might be made to improve patients’ time in hospital. For example, staff had useful ideas about possible initiatives that might improve patients’ experience. These are listed below:

  - Consider developing existing under-used spaces into step-down wards that are more homely and supportive of patients’ abilities – this could be a centralised space where patients with dementia from different wards could go.
  - Use objects that look more familiar – a record player, tape recorder rather than digital or modern equipment.
  - Purchase a Paro seal http://www.parorobots.com/ - particularly for patients nearing the end of life or who are socially isolated.
  - Create a workshop for male patients with dementia.
  - Increase staffing numbers to support purposeful activities with people with dementia.
  - Move wards for people with dementia onto the ground floor.
  - Interesting pictures on walls.
  - More appropriately sized jigsaws (1000 pieces are too many for people with dementia).
  - More meaningful training for staff – role play, putting oneself into the patient’s shoes.

Family carers and patients with dementia also had suggestions on how to improve their stay in hospital, as listed below:

  - Invite someone to give an interesting talk on different topics, using the talent already in the hospital.
  - Provide a room for visitors who have a long distance to travel, particularly if they need to stay overnight.
  - Provide an orientation screen or board with the day, season, weather etc.
  - Provide free TV for people with dementia as many would not be able to operate the system.
REFERENCES


Appendix 1: Patient Information Sheet

INFORMATION ABOUT THE RESEARCH FOR PATIENTS

Title of Research: Evaluation of Acute Care Development Programme

Name of Researchers: Dr Fiona Kelly and Dr Michelle Heward

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the study is being done and what it would involve for you.

One of the researchers will go through this information sheet with you and answer any questions you have. This should take about 10 minutes.

- Part 1 tells you about this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about how the study will be carried out.

Talk to others about the study if you wish, and ask us if there is anything that is not clear.

If you decide that you would like to take part in this study you will be given a copy of this information sheet and a signed consent form to keep.

PART 1 - PURPOSE OF THE STUDY

1.1 What is the purpose of the study?
The Acute Care Development Programme is being rolled out in eight hospitals across Wessex (Dorset, Hampshire and Isle of Wight) to improve the experiences of people with dementia and their families when they are in hospital. Each hospital is taking part in a variety of development projects under the programme and [name of Trust] is one of them. We are seeking your views on your experiences of the project(s) happening in [name of Trust]. Your views will help us work out
whether and how the project is making a difference, so that Wessex NHS can spread these across Wessex and nationally.

1.2 Why have I been invited?
You have been invited to take part because you are a patient at one of the eight hospitals that are delivering the Acute Care Development Programme. To find out your experiences, we would like to spend some time in the ward looking at what is happening and to talk with you about what it is like being in hospital as a patient. We would also like you to complete a five day diary. If you would prefer, a family member or carer can join the conversation with you.

1.3 Do I have to take part?
It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

1.4 What will happen to me if I take part?
If you decide to take part, we will ask you to talk with us about your experiences of being a patient. The conversation will last as long as you want it to, but we expect it to take between 15 and 30 minutes. We would like to tape-record the conversation. If you are not comfortable with this, but would still like to talk with us, let us know and we can write your comments down.

We would also like to observe what is happening in the ward you are in and we will take notes of what we see.

Finally, we will ask you if you would like to keep a diary over five days to record your experiences and thoughts of the project that is happening in your ward. We will provide a note book and pens for this and guidance on what to include in the diary.

All the information we collect during our observations, conversations and through diaries will be treated in confidence, and only the research team will look at them.

We will write a report and other publications on our findings and may like to quote you to illustrate the points we make. If we do use your words we will not include your name – this ensures that you cannot be identified in any publications.
1.5 Expenses and payments
Participation in this study is voluntary; therefore no payments are available to those who chose to participate.

1.6 What are the possible disadvantages and risks of taking part?
We do not think there will be any disadvantages or risks if you choose to participate in this study.

1.7 What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get will help improve the experience of other people with dementia staying in hospitals.

1.8 What happens when the research study stops?
After the research stops we will write a report and other publications on our findings. If you would like us to send you a summary of our findings after we have written these reports please tell the person going through this information sheet with you.

1.9 What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this information sheet.

1.10 Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2. This completes Part 1.

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*
PART 2 - CONDUCT OF THE STUDY

2.1 What if relevant new information becomes available?
If the study is stopped for any reason we will tell you. This will not impact on your continuing care.

2.2 What will happen if I don’t want to carry on with the study?
If you decide to withdraw from the study before we remove your name from the information you have given us, then we will be able to withdraw your data from the study completely. If you withdraw after we have removed your name from the information you have given us, then it will not be possible to withdraw your data from the study.

2.3 What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You can speak to Dr Michelle Heward on 01202 962538. If you remain unhappy and wish to complain formally, you can do this by contacting Dr Jan Weiner on 01202 961822 or email jwiener@bournemouth.ac.uk.

2.4 Will my taking part in this study be kept confidential?
Yes, the information gathered through our observations, conversations and through diaries will all be kept confidential and stored securely, following Bournemouth University and Data Protection requirements.

Audio recordings will be kept until they have been transcribed, and then deleted. The transcription of audio recordings will be done by a trusted external company based in the UK. Transcripts will be kept for five years and then securely deleted. Participants will be anonymised on the transcripts before the transcripts are examined.

The information collected will only be used for this study and only members of the study team at Bournemouth University will look at it.

2.3 Involvement of the General Practitioner/Family doctor (GP)
We will write to your GP to tell them that you participated in this study.

2.5 What will happen to the results of the research study?
After we have analysed the information you have given us, we will write a report and other publications on our findings. We will also write up a summary of our findings to give to you if you would like a copy.
2.6 Who is organising and funding the research?
The Wessex Academic Health Science Network (AHSN) is funding this research. This research is being conducted by researchers who are employed by Bournemouth University. None of the Hospitals or any Doctors/Nurses are being paid to take part in this study.

2.7 Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central – Hampshire A Research Ethics Committee.

2.8 Further information and contact details

For specific information about this research project, please contact:

Dr Michelle Heward
Bournemouth University Dementia Institute
Telephone: 01202 962582
Email: mheward@bournemouth.ac.uk
Appendix 2: Patient Consent Form

CONSENT FORM - PATIENT

Title of Project: Evaluation of Acute Care Development Programme

Name of Researchers: Dr Fiona Kelly and Dr Michelle Heward

Please initial box

1. I confirm that I have read and understand the information sheet dated 25/02/2016 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that all of the data collected during this study will be kept confidential and stored securely by Bournemouth University Dementia Institute.

4. I agree that all of the data collected during this study can be used on condition that it is anonymised.

5. I give my permission for the researcher to observe what is happening in the ward and to take notes, on condition that notes will not contain identifiable information.

6. I give my permission for interviews to be audio-recorded.

7. I understand that all of the data collected during this study will only be seen by members of the study team, and anonymised transcripts of audio recordings will be kept for five years (this is in line with University and data protection requirements).

8. I agree to my GP being informed of my participation in the study.

9. I agree to take part in the above study.

Name of participant: Date: Signature:

Name of researcher: Date: Signature:

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

IRAS number 192712  Version 3  Page 1 of 1  25/02/2016
Appendix 3: Family Carer Information Sheet

INFORMATION ABOUT THE RESEARCH FOR FAMILY VISITORS

Title of Research: Evaluation of Acute Care Development Programme

Name of Researchers: Dr Fiona Kelly and Dr Michelle Heward

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the study is being done and what it would involve for you.

One of the researchers will go through this information sheet with you and answer any questions you have. This should take about 10 minutes.

- Part 1 tells you about this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about how the study will be carried out.

Talk to others about the study if you wish, and ask us if there is anything that is not clear.

If you decide that you would like to take part in this study you will be given a copy of this information sheet and a signed consent form to keep.

PART 1 - PURPOSE OF THE STUDY

1.1 What is the purpose of the study?
The Acute Care Development Programme is being rolled out in eight hospitals across Wessex (Dorset, Hampshire and Isle of Wight) to improve the experiences of people with dementia and their families when they are in hospital. Each hospital is taking part in a variety of development projects under the programme and [name of Trust] is one of them. We are seeking your views on your experiences of the project(s) happening in [name of Trust]. Your views will help us work out
whether and how the project is making a difference, so that Wessex NHS can spread these across Wessex and nationally.

1.2 Why have I been invited?
You have been invited to take part because you are a visitor of a patient with dementia at one of the eight hospitals that are delivering the Acute Care Development Programme. To find out your experiences, we would like to spend some time in the ward looking at what is happening and to talk with you about what it is like being in the hospital as a visitor. We would also like you to complete a five day diary.

1.3 Do I have to take part?
It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

1.4 What will happen to me if I take part?
If you decide to take part, we will ask you to talk with us about your experiences of being the visitor of a patient. The conversation will last as long as you want it to, but we expect it to take between 15 and 30 minutes. We would like to tape-record the conversation. If you are not comfortable with this, but would still like to talk with us, let us know and we can write your comments down.

We would also like to observe what is happening in the ward you are in and we will take notes of what we see.

Finally, we will ask you if you would like to keep a diary over five days to record your experiences and thoughts of the project that is happening in the ward. We will provide a note book and pens for this and guidance on what to include in the diary.

All the information we collect during our observations, conversations and through diaries will be treated in confidence, and only the research team will look at them.

We will write a report and other publications on our findings and may like to quote you to illustrate the points we make. If we do use your words we will not include your name – this ensures that you cannot be identified in any publications.
1.5 Expenses and payments
Participation in this study is voluntary; therefore no payments are available to those who chose to participate.

1.6 What are the possible disadvantages and risks of taking part?
We do not think there will be any disadvantages or risks if you choose to participate in this study.

1.7 What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get will help improve the experience of other people with dementia staying in hospitals.

1.8 What happens when the research study stops?
After the research stops we will write a report and other publications on our findings. If you would like us to send you a summary of our findings after we have written these reports please tell the person going through this information sheet with you.

1.9 What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this information sheet.

1.10 Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2. This completes Part 1.

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*
PART 2 - CONDUCT OF THE STUDY

2.1 What if relevant new information becomes available?
If the study is stopped for any reason we will tell you. This will not impact on the continuing care of the person you are visiting.

2.2 What will happen if I don’t want to carry on with the study?
If you decide to withdraw from the study before we remove your name from the information you have given us, then we will be able to withdraw your data from the study completely. If you withdraw after we have removed your name from the information you have given us, then it will not be possible to withdraw your data from the study.

2.3 What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You can speak to Dr Michelle Heward on 01202 962538. If you remain unhappy and wish to complain formally, you can do this by contacting Dr Jan Weiner on 01202 961822 or email jwiener@bournemouth.ac.uk.

2.4 Will my taking part in this study be kept confidential?
Yes, the information gathered through our observations, conversations and through diaries will all be kept confidential and stored securely, following Bournemouth University and Data Protection requirements.

Audio recordings will be kept until they have been transcribed, and then deleted. The transcription of audio recordings will be done by a trusted external company based in the UK. Transcripts will be kept for five years and then securely deleted. Participants will be anonymised on the transcripts before the transcripts are examined.

The information collected will only be used for this study and only members of the study team at Bournemouth University will look at it.

2.5 What will happen to the results of the research study?
After we have analysed the information you have given us, we will write a report and other publications on our findings. We will also write up a summary of our findings to give to you if you would like a copy.
2.6 Who is organising and funding the research?
The Wessex Academic Health Science Network (AHSN) is funding this research. This research is being conducted by researchers who are employed by Bournemouth University. None of the Hospitals or any Doctors/Nurses are being paid to take part in this study.

2.7 Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central – Hampshire A Research Ethics Committee.

2.8 Further information and contact details
For specific information about this research project, please contact:

Dr Michelle Heward
Bournemouth University Dementia Institute
Telephone: 01202 962582
Email: mheward@bournemouth.ac.uk
Appendix 4: Family Carer Consent Form

| 1. | I confirm that I have read and understand the information sheet dated 25/02/2016 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. |
| 3. | I understand that all of the data collected during this study will be kept confidential and stored securely by Bournemouth University Dementia Institute. |
| 4. | I agree that all of the data collected during this study can be used on condition that it is anonymised. |
| 5. | I give my permission for the researcher to observe what is happening in the ward and to take notes, on condition that notes will not contain identifiable information. |
| 6. | I give my permission for interviews to be audio-recorded. |
| 7. | I understand that all of the data collected during this study will only be seen by members of the study team, and anonymised transcripts of audio recordings will be kept for five years (this is in line with University and data protection requirements). |
| 8. | I agree to take part in the above study |

Name of participant: ______________________________ Date: __________ Signature: ______________________________

Name of researcher: ______________________________ Date: __________ Signature: ______________________________

When completed: 1 for participant; 1 for researcher site file.

IRAS number 192712 Version 1 Page 1 of 1 25/02/2016
Appendix 5: Interview Guide

Topic guide to discuss the experiences of being in hospital

Introductions
Information sheet and consent forms
Demographic information

Can you describe what your experiences of being in hospital have been?

I would like to speak with you about xx (description of the intervention) – can you tell me what it is?
  • What does it feel like?
  • Do you like it? If yes, explain, if no, explain.
  • How does it help you to feel better?
  • Is there anything that could be improved with it?

What would you like to be able to do in hospital?

Does this intervention help you achieve this?

Is there anything else the hospital staff could do to help you have a better time in hospital?

Is there anything else you would like to tell us?

Finish up and thank you.
Appendix 6: Staff and Volunteers Information Sheet

INFORMATION ABOUT THE RESEARCH FOR STAFF AND VOLUNTEERS

Title of Project: Evaluation of Acute Care Development Programme

Name of Researchers: Dr Fiona Kelly and Dr Michelle Heward

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the study is being done and what it would involve for you.

One of the researchers will go through this information sheet with you and answer any questions you have. This should take about 10 minutes.

- Part 1 tells you about this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about how the study will be carried out.

Talk to others about the study if you wish, and ask us if there is anything that is not clear.

If you decide that you would like to take part in this study you will be given a copy of this information sheet and a signed consent form to keep.

1.1 What is the purpose of the study?
The Acute Care Development Programme is being rolled out in eight hospitals across Wessex (Dorset, Hampshire and Isle of Wight) to improve the experiences of people with dementia and their families when they are in hospital. Each hospital is taking part in a variety of development projects under the programme and [name of Trust] is one of them. We are seeking your views on your experiences of the project(s) happening in [name of Trust]. Your views will help us work out whether and how the project is making a difference, so that Wessex NHS can spread these across Wessex and nationally.

IRAS number 192712   Version 3   Page 1 of 5   25/02/2016
1.2 Why have I been invited?
You have been invited to take part because you are a member of staff or volunteer at one of the eight hospitals that are delivering the Acute Care Development Programme. To find out your experiences, we would like to spend some time in the ward looking at what is happening and to talk with you about what it is like being in hospital as a member of staff or volunteer. We would like to talk with you in a small group with other staff or volunteers at this hospital. We would also like you to complete a five day diary.

1.3 Do I have to take part?
It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect your role as a member of staff or volunteer.

1.4 What will happen to me if I take part?
If you decide to take part, we will ask you to talk with us about your experiences of being a member of staff or volunteer in a small group with other staff or volunteers from this hospital. The group discussion will last as long as you want it to, but we expect it to take around 40 minutes. We would like to tape-record the conversation. If you are not comfortable with this, but would still like to talk with us, let us know and we can write your comments down.

We would also like to observe what is happening in the ward you are in and we will take notes of what we see.

Finally, we will ask you if you would like to keep a diary over five days to record your experiences and thoughts of the project that is happening in your ward. We will provide a note book and pens for this and guidance on what to include in the diary.

All the information we collect during our observations, conversations and through diaries will be treated in confidence, and only the research team will look at them.

We will write a report and other publications on our findings and may like to quote you to illustrate the points we make. If we do use your words we will not include your name – this ensures that you cannot be identified in any publications.
1.5 Expenses and payments
Participation in this study is voluntary; therefore no payments are available to those who chose to participate.

1.6 What are the possible disadvantages and risks of taking part?
We do not think there will be any disadvantages or risks if you choose to participate in this study.

1.7 What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get will help improve the experience for people with dementia staying in hospitals.

1.8 What happens when the research study stops?
After the research stops we will write a report and other publications on our findings. If you would like us to send you a summary of our findings after we have written these reports please tell the person going through this information sheet with you.

1.9 What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this information sheet.

1.10 Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2. This completes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.
PART 2 - CONDUCT OF THE STUDY

2.1 What if relevant new information becomes available?
If the study is stopped for any reason we will tell you. This will not impact on your role within the hospital.

2.2 What will happen if I don’t want to carry on with the study?
If you decide to withdraw from the study before we remove your name from the information you have given us, then we will be able to withdraw your data from the study completely. If you withdraw after we have removed your name from the information you have given us, then it will not be possible to withdraw your data from the study.

2.3 What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. You can speak to Dr Michelle Heward on 01202 962538. If you remain unhappy and wish to complain formally, you can do this by contacting Dr Jan Weiner on 01202 961822 or email jwiener@bournemouth.ac.uk.

2.4 Will my taking part in this study be kept confidential?
Yes, the information gathered through our observations, conversations and through diaries will all be kept confidential and stored securely, following Bournemouth University and Data Protection requirements.

Audio recordings will be kept until they have been transcribed, and then deleted. The transcription of audio recordings will be done by a trusted external company based in the UK. Transcripts will be kept for five years and then securely deleted. Participants will be anonymised on the transcripts before the transcripts are examined.

The information collected will only be used for this study and only members of the study team at Bournemouth University will look at it.

2.5 What will happen to the results of the research study?
After we have analysed the information you have given us, we will write a report and other publications on our findings. We will also write up a summary of our findings to give to you if you would like a copy.

2.6 Who is organising and funding the research?
The Wessex Academic Health Science Network (AHSN) is funding this research. This research is being conducted by researchers who are
employed by Bournemouth University. None of the Hospitals or any Doctors/Nurses are being paid to take part in this study.

2.7 Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central – Hampshire A Research Ethics Committee.

2.8 Further information and contact details

Dr Michelle Heward

Bournemouth University Dementia Institute

Telephone: 01202 962582

Email: mheward@bournemouth.ac.uk
Appendix 7: Staff and Volunteers Consent Form

CONSENT FORM – STAFF AND VOLUNTEERS

Title of Project: Evaluation of Acute Care Development Programme

Name of Researchers: Dr Fiona Kelly and Dr Michelle Heward

1. I confirm that I have read and understand the information sheet dated 25/02/2016 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that all of the data collected during this study will be kept confidential and stored securely by Bournemouth University Dementia Institute.

4. I agree not to discuss the information shared in the focus group outside of the group meeting.

5. I agree that all of the data collected during this study can be used on condition that it is anonymised.

6. I give my permission for the researcher to observe what is happening in the ward and to take notes, on condition that notes will not contain identifiable information.

7. I give my permission for group discussions to be audio-recorded.

8. I understand that all of the data collected during this study will only be seen by members of the study team, and anonymised transcripts of audio recordings will be kept for five years (this is in line with University and data protection requirements).

9. I agree to take part in the above study.

Name of participant: ___________________________ Date: __________ Signature: ___________________________

Name of researcher: ___________________________ Date: __________ Signature: ___________________________

When completed: 1 for participant; 1 for researcher site file.

IRAS number 192712  Version 3  Page 1 of 1  25/02/2016
Appendix 8: Focus Group Topic Guide

**Topic guide for staff and volunteers to discuss experiences of delivering the intervention(s)**

**Introductions**
- Information sheet and consent forms
- Demographic information

- Can you describe what intervention you are delivering in this ward?

- What was the process of getting it off the ground?
  - Who was involved in setting it up
  - What were the challenges?
  - What was easy about setting it up
  - What advice would you give to anyone else wanting to do something similar?

- Can you describe your experiences with delivering the intervention?
  - Hard, challenging aspects?
  - Rewarding, easy aspects?
  - Patients’ responses?

- What do you think are the consequences for 1) patients, 2) family visitors 3) you of this intervention?

- Is there anything you would change to make the intervention more effective?

- Anything else to tell us?

- Finish up and thanks.
Appendix 9: Staff and Volunteers Diary

Evaluation Acute Care Programme

STAFF AND VOLUNTEER DIARY

Please write in your diary for the next five days. You can write in your diary as many times you would like to. You can write about your experiences on the ward, including the delivery of interventions, or anything else that you would like to share with us that you think is relevant for this study.

Some suggested questions that you might like to think about when you write in your diary.
1. Tell us what happened/what intervention was delivered…
2. What did it feel like?
3. What were the good points?
4. What were the not so good points?
5. How could your experience be improved in the future?
6. Any other comments you would like to share with us?

At the end of the five days please give your diary to NAME OF STAFF MEMBER, they will pass it on to us securely.

Many thanks for taking the time to complete your diary and sharing your experiences with us.
Appendix 10: Patient and Family Carer Diary

Evaluation Acute Care Programme

PATIENT AND FAMILY VISITOR DIARY

Please write in your diary for the next five days. You can write in your diary as many times you would like to. You can write about things that have happened whilst you have been staying on the ward, including any activities you have taken part in, or anything else that you would like to share with us that you think is relevant to this study.

Some suggested questions that you might like to think about when you write in your diary.

1. Tell us what happened....
2. What did it feel like?
3. What were the good points?
4. What were the not so good points?
5. How could your experience be improved in the future?
6. Any other comments you would like to share with us?

At the end of the five days please give your diary to ?, they will pass it on to us securely.

Many thanks for taking the time to complete your diary and sharing your experiences with us.

Version 1 27/11/15
Appendix 11: Poster displayed on hospital wards

Researchers from Bournemouth University Dementia Institute (BUDI) are on this ward today to find out what it is like to be in hospital when living with dementia or memory problems.

Michelle is here today and would like to chat with you about your time in hospital.

Dr Michelle Heward
mheward@bournemouth.ac.uk
Telephone: 01202 962538 or 07809 225207

Participation is voluntary, you can choose whether or not to take part. You are also free to withdraw from the study at any time.