An evaluation of Barbara’s Story:
Final report

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References

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Project team

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- Deborah Parker, Guy’s and St Thomas’ NHS Foundation Trust
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- Barbara Jayson, Guy’s and St Thomas’ NHS Foundation Trust
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Executive summary

Introduction

Dementia is a growing health issue within the UK population and all health and social care staff must develop awareness of the needs of people with dementia. In September 2012, Guy’s and St Thomas’ NHS Foundation Trust (GSTT) embarked on a new campaign using specially commissioned films ‘Barbara’s Story: her whole journey’. The films aim to raise awareness of dementia and the care of older people, for all GSTT staff working in Trust hospitals and in the community, and reinforce the Trust values. This report explains the evaluation of Barbara’s Story and includes the findings from: staff’s immediate responses to the initial Barbara’s Story film, focus groups conducted after all Trust staff had attended the initial Barbara’s Story film (Phase 1), and focus groups conducted after the presentation of the evolving Barbara’s Story films had been shown across the Trust (Phase 2).

Project overview

The initial Barbara’s Story film shows the experience of an older woman (Barbara) through her eyes, as she attends a hospital appointment and is admitted for investigations. The film was shown regularly from September 2012 to April 2013 and attendance was mandatory for all Trust staff: a total of 11,054 clinical and non-clinical staff attended. Barbara’s Story was also embedded into the corporate induction programme for new Trust staff. At each session, Barbara’s Story was shown, along with some group discussion and distribution of Alzheimer’s Society resources, Trust safeguarding and dementia and delirium information, and the Trust values and behaviours framework.

With funding from the Burdett Trust for Nursing, a second series of films was developed. These show Barbara’s health deteriorating and she receives care in hospital and community settings. From September 2013-March 2014, the films were shown, with one new episode available each month. Safeguarding team members facilitated a discussion after the film and highlighted key learning points. The second series was not mandatory for staff to attend. All the films are now accessible on the Trust intranet and an abridged version is available on YouTube. The films are also shown within the Trust’s dementia training days. A package with the DVDs, additional resources and facilitator guides is freely available for both Trust staff and externally and has been distributed widely: nationally and internationally.

Background and rationale

The number of people who are living with dementia is rising as the population is ageing. As dementia is primarily a condition that affects older people, many people with dementia have other conditions common to old age that precipitate hospital admission, and their concurrent dementia affects their treatment, care and recovery. Unfortunately many national studies and reports have revealed that the care of people with dementia in hospital is not of an acceptable quality. Many of these sources also highlighted that hospital staff have inadequate skills and knowledge to care for people with dementia and negative attitudes are revealed as a problem too. The Department of Health’s National Strategy for Dementia identified improved hospital care as one of the targets for improvement. The literature provides many examples of how staff can learn about dementia but these reports mainly focus on small scale projects, often with care home staff or students, rather than whole populations of hospital and community staff, as in GSTT’s Barbara’s Story project.

Evaluation aim

The evaluation aimed to investigate GSTT staff’s perspectives of the effect of Barbara’s Story on themselves, their colleagues and the organisation.
Method

The evaluation used a longitudinal design and gathered qualitative data from Trust staff at different stages through:
1) Open written comments (n=1246): Trust staff’s immediate responses to the initial Barbara’s Story film;
2) Phase 1: focus groups of staff, in discipline-specific groups (nurses, medical staff, allied health professionals and non-clinical staff) were held in September 2013. This was approximately one year after the launch of the project, but before the second series of Barbara’s Story commenced. In total, 68 staff took part, in 10 focus groups and one individual interview.
3) Phase 2: focus groups with staff, in discipline-specific groups (nurses, medical staff, allied health professionals and non-clinical staff) were held from April to September 2014, which was after the second series of films had been first shown within the Trust. In total 80 staff took part: in 16 focus groups and 3 individual interviews.

A content analysis was conducted of the written comments. The focus group and interview audio recordings were professionally transcribed and the data were analysed using the framework approach. The evaluation was registered with GSTT’s Clinical Governance department as a service evaluation. London South Bank University Research Ethics Committee approved the evaluation from an ethical perspective.

The Findings are presented in three sections: Immediate responses to Barbara’s Story, Phase 1 focus groups and Phase 2 focus groups.

Immediate responses to Barbara’s Story

Six themes emerged:
- Personal reflections on the film (n=17; 1%);
- What I will do in my personal life (n=22; 2%);
- What I will do in my professional life (n=927; 74%);
- What the organisation should do (general comments and training) (n=138; 11%);
- What others should do (n=26; 2%).
- Other comments (about the film and dementia) (n=116; 9%).

The majority of comments related to the theme: ‘What I will do in my professional life’, and of these, the largest sub-theme related to helping people who are confused, lost or anxious (n=223). The second largest sub-theme concerned communication improvements that staff intended to make (n=183). There were also large numbers of comments about treating people as individuals (n=130) and taking time (n=115). Other smaller sub-themes included: showing kindness, treating people with respect, introducing myself and other team members, and treating people as I would like to be treated.

Phase 1 focus groups

There are five themes presented.

Barbara’s Story as a project:
Staff perceived Barbara’s story as a very effective educational device and specifically commented on it being superior to a traditional teaching session. There was pride expressed that the Trust had launched such an initiative within the current NHS climate. Barbara’s Story enabled staff to see her healthcare experience from her perspective and the behaviour shown in the film prompted staff to reflect on their own behaviour and that of colleagues. The Chief Nurse leadership of the project was felt to give a powerful message to staff about the
importance of the topic. The whole Trust approach and the mandatory and interprofessional nature of sessions were viewed positively.

**Effect on individual staff:**
Barbara’s Story engaged staff emotionally and prompted empathetic responses. Staff related to her as an individual and her experience. Staff viewed Barbara as someone who could be their family member and for some staff, Barbara’s experience mirrored their own family experiences. Staff expressed increased awareness of dementia and how it could be recognised, both within the Trust and outside. They also recognised that people who have dementia could be anywhere within the Trust and staff became more aware of people outside their own clinical areas who might need help. Staff discussed how their own interactions with patients and behaviour had changed since watching Barbara’s Story, and they often referred to changes they had observed in other staff too. Changes included: giving more time to patients, improved communication, giving more information, and assisting patients who are looking lost or confused. Staff also discussed how Barbara’s Story had highlighted their professional responsibilities.

**Practice developments and improvements:**
Staff identified various dementia-related initiatives in the Trust and how these were reinforced by Barbara’s Story and becoming more embedded in the Trust. These initiatives included *This is me*, the use of the forget-me-not symbol, dementia champions and environmental improvements. Staff highlighted that improvements were supported by influencing others through guiding and teaching, leadership, and teamwork. Clinical staff identified that lack of time was a constraint to applying the learning from Barbara’s Story into practice.

**Trust values and culture:**
Staff discussed how they put the Trust values into action. The value ‘Patients first’ had a strong resonance and there were many examples of going ‘the extra mile’. Staff also discussed a perceived culture change within the Trust so that they felt able to spend longer with a patient or to challenge others about their practice. There was reference to standard setting and a new ‘norm’ having being established in the Trust.

**Sustaining the impact of Barbara’s story:**
Staff made a wide range of suggestions about ways of further improving care and experiences for people with dementia and other vulnerable people. Staff perceived there remained a need to develop more effective ways of recognising that people have dementia. The importance of sustaining the learning and developments achieved through Barbara’s Story was emphasised.

**Phase 2 focus groups**
There are five Themes presented; these mirror those from the Phase 1 evaluation but some sub-themes differed.

**Barbara’s story as a project:**
In comparison with the Phase 1 focus groups, there was more discussion about the context for Barbara’s Story in Phase 2, from both a national and a Trust perspective. Staff considered that Barbara’s Story had gained a high profile within the Trust; there seemed to be a gathering of momentum with Barbara being considered a ‘brand’ and a way that staff could communicate about dementia in the Trust. There were many positive comments about Barbara’s Story; the films were considered powerful and an effective learning tool. The way in which the films showed Barbara’s Story from her perspective was particularly insightful: being ‘in the shoes of Barbara’. Staff vividly recalled many of the images from the initial film as well as from the second series. Staff particularly liked how the series of films showed the
whole patient journey through hospital and community care. There were many examples of how the films prompted staff to reflect on their practice. As in Phase 1 focus groups, staff commented on the Chief Nurse’s leadership of the project positively. Barbara’s Story was referred to as being a shared experience in the Trust. Staff discussed the different modes of delivering Barbara’s Story that are now available and their merits: the large screen viewings, intranet availability, YouTube version, and the films being embedded in dementia training days. Many staff considered there are particular benefits to the interprofessional sessions with facilitated feedback to draw out learning points. However the flexibility and accessibility of the films being on the intranet were also appreciated. Many staff considered that the second series of the films should be mandatory.

Effect on individual staff:
Staff gave many examples of their own emotional responses to the films and of how they connected to the films personally and professionally. Barbara’s Story highlighted that some Trust staff are carers for relatives with dementia and some staff identified that a relative had dementia, from watching the films. Staff reported that they had developed an increased awareness and understanding of dementia and delirium. This had led on to actions such as referrals for dementia screening as well as staff feeling more confident to care, being more empathetic and viewing patients as individuals. Staff also identified their awareness of what detracts from good care for people with dementia, such as being task-orientated, inflexible and disease-focused. Staff reported improved interactions and behaviour, for example, giving more time, better explanations, listening, reassurance and attentiveness. As in Phase 1 focus groups, many staff offered examples of helping people who seemed lost or confused in hospital; Barbara’s Story had given staff confidence to be proactive and offer help. Staff also referred to recognising and attending to the ‘little things’ that matter to patients and of the value of building relationships.

Practice developments and improvements:
Whilst various initiatives were mentioned in the Phase 1 focus groups, the Phase 2 focus groups included much greater depth of discussion. Staff expressed how these developments were becoming embedded in the Trust with a perception that, whilst some of these were in development prior to Barbara’s Story, the project had reinforced and helped these developments to become more established. Dementia training was highly thought of and dementia screening was considered much more embedded. The initiatives discussed most in-depth were: This is me, improvements to food provision, specials (trained nursing assistants to provide one-to-one care), dementia champions and link nurses, and environmental changes. Staff who had used This is me were vocal about the benefits and the discussions highlighted that staff really appreciated the importance of knowing the patient. The issue most often raised as a challenge and a constraint to practice improvements was lack of time, due to staffing shortages and workload.

Trust values and culture:
Staff recognised that Barbara’s Story had been developed within the context of the Trust values and they discussed how they applied the values in action. There was recognition that each individual was representing the Trust and a sense of pride, which prompted certain behaviours. There was also discussion about a culture change having taken place following on from Barbara’s Story. Dementia was now seen as ‘everybody’s business’ with a Trust-wide awareness. Staff discussed that Barbara’s Story established standards expected within the Trust for patients generally and the expectation of improvement. It was also considered that Barbara’s Story had established the role that all staff were expected to play in improving patients’ experience, particularly for those who are most vulnerable. Barbara’s Story had also set out an expectation for staff to be proactive about challenging care.
Sustaining the impact of Barbara’s Story:
Suggestions for sustaining the impact of Barbara’s Story included updates, refreshers,
进一步培训，新闻通讯项目以及联系评估到Barbara’s Story。痴呆症
 champions were identified as having an important role in supporting sustainability of
Barbara’s Story. The learning points from Barbara’s Story could be reinforced through
preparing them for the care of other vulnerable people. It was suggested that more staff
should do the dementia training days. As regards suggested improvements, a more
personalised approach in outpatients and more involvement of volunteers were suggested.
Better communication across settings and more integrated care were other suggestions.

Discussion
Barbara’s Story was a timely project, being developed and implemented at a time when
dementia as a health issue has been recognised as being of high importance. The project
supported the National Dementia Strategy’s objectives, particularly in terms of hospital care
improvements. The project was highly ambitious with the goal of training all Trust staff using
the initial Barbara’s Story film. What was particularly unique was the recognition of the role of
non-clinical staff in patients’ healthcare experiences; policy documents, including the
recently published Health Education England curriculum (Richards et al. 2014), focus on
healthcare professionals alone. There were few differences between responses from staff of
different professional groups to the Barbara’s Story series of films and certainly all staff
considered the films to be relevant to their own practice. When comparing the findings from
the Phase 1 and Phase 2 focus groups, it can be identified that there were many similarities.
Whilst at the Phase 1 focus groups staff identified various dementia-related Trust initiatives,
these were discussed in much more depth at the Phase 2 focus groups.

The sustaining of the project from September 2012 to March 2014, and beyond through
embedding Barbara’s Story in induction, dementia training and on the intranet, has led to
Barbara’s Story gaining momentum, with an increasingly high profile and becoming a ‘brand’
that provides staff with a common language around care, not only for people with dementia,
but for others who are vulnerable too. There is always a risk that the impact of any project
can diminish over time but the concept of Barbara is now well embedded within GSTT, with
many related initiatives established too. When considering the transferability of the
evaluation findings, other settings would need to appreciate that for maximum effectiveness,
Barbara’s Story needs strong leadership and commitment to improving dementia care
through educating all staff within an organisation. A key factor in the project’s success was
that the initial Barbara’s Story was seen by all Trust staff (clinical and non-clinical) so there
was a shared experience and a common awareness and understanding gained. As
Barbara’s Story is now embedded in induction for new staff employed in the Trust, GSTT
have maintained the stance of having a whole staff population who have viewed Barbara’s
Story.

Conclusion
Barbara’s Story has developed an increasingly high profile within the Trust since the launch
in September 2012 and has raised awareness about dementia with the strong message that
dementia is relevant to all Trust staff, clinical and non-clinical, wherever they work. Staff
reported increased awareness and understanding and improved interactions in themselves
and others. The whole Trust approach to the project, with senior leadership, and the project
being contextualised within the Trust values, was beneficial and staff perceived there had
been a positive culture change within the Trust. The increased availability of flexible modes
delivery, the embedding of Barbara’s Story in induction for all new staff, the continued
availability of further dementia training in the Trust and a network of Dementia Champions
should all support sustainability of the project’s impact and support further improvements
and developments.
Section 1: Introduction

Dementia is a growing health issue and all health and social care staff must develop awareness of the needs of people with dementia. In September 2012, Guy’s and St Thomas’ NHS Foundation Trust (GSTT) embarked on a new campaign using specially commissioned films ‘Barbara’s Story: her whole journey’. The films aim to raise awareness of dementia and the care of older people, for all GSTT staff working in Trust hospitals and in the community, and reinforce the Trust’s values. The initial film shows the experience of an older woman (Barbara) through her eyes, as she attends a hospital appointment and is admitted for investigations. The second series of films continues to show Barbara’s healthcare experiences from her perspective as other health problems develop and her health deteriorates.

This report starts with an overview of how the Barbara’s Story project was implemented within GSTT. A review of relevant policies and previous research will follow, providing a background to this project. The method of evaluation for Barbara’s Story is then explained; a longitudinal and naturalistic design was used in different phases:
1) an analysis of staff’s immediate written responses to the initial Barbara’s Story film;
2) focus groups following the showing of the initial Barbara’s Story film to all Trust staff;
3) focus groups following the showing of the second series of Barbara’s Story films across the Trust.

The evaluation findings are then presented in the different phases, with themes and sub-themes that are illustrated with extracts from the data. The findings are discussed in relation to the evaluation objectives and finally, a conclusion from the evaluation is provided.

Section 2: Project overview

The initial Barbara’s Story film shows the experience of an older woman (Barbara) through her eyes, as she attends a hospital appointment and is admitted for investigations. The film aimed to raise awareness of dementia and the care of older people, for all GSTT staff working in Trust hospitals and in the community, and reinforce the Trust values: Putting patients first; Taking pride in what we do; Respecting others; Striving to be the best; Acting with integrity. It was mandatory for all Trust staff, clinical and non-clinical, to attend a session where Barbara’s Story was shown, along with some discussion and distribution of Alzheimer’s Society resources, Trust adult safeguarding and dementia and delirium information and the Trust’s values and behaviours framework. The film was shown on a regular basis from September 2012 to April 2013 and a total of 11,054 staff attended a session and watched the film. Barbara’s Story was also embedded into the corporate induction programme for new Trust staff.

With funding from the Burdett Trust for Nursing, a further five films were made and these reveal the evolving story of Barbara as her health deteriorates and she needs further hospital admissions and care in hospital and the community. After each film, a facilitated discussion took place to highlight learning points from the film. The films were shown within GSTT from September 2013-March 2014 with one new episode available each month. Unlike the initial film, it was not mandatory for staff to attend the second series. During September-March, there were 4190 attendances at the sessions (see Table 1); a wide range of staff attended, both clinical and non-clinical staff. Since the initial Trust-wide showing of the second series of the films, the films have been made available in a range of different formats. They are available for staff to watch on the Trust intranet and the films are used in the Trust’s dementia training days. An abridged version is available on YouTube. A package with the DVDs, additional resources and facilitator guides is freely available for both Trust
staff and externally and has been distributed widely nationally and internationally. The initial Barbara’s Story film continues to be shown at the induction for all new staff.

Table 1 Attendance at the second series of Barbara’s Story September 2013-March 2014

<table>
<thead>
<tr>
<th>Episode</th>
<th>Medical/Dental Registered nurses &amp; midwives</th>
<th>Allied Health Professionals</th>
<th>Administrative /Facilities</th>
<th>Other*</th>
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<td>4</td>
<td>178</td>
<td>27</td>
<td>44</td>
<td>51</td>
</tr>
</tbody>
</table>

*Other included: health scientists, additional clinical services, additional professional and technology services, students

Section 3: Background and rationale

This section provides a background to the initiative of Barbara’s Story and highlights the need for healthcare staff to be better educated about dementia. The review draws on reports, policy documents and previous research relating to the quality of care for people with dementia in hospital and the educational needs of healthcare staff.

3.1 Dementia as a growing health issue

Internationally, there are growing numbers of people with dementia and these figures are predicted to rise. Dementia is strongly associated with increasing age and as the world population ages, it is essential to ensure that the healthcare workforce is effectively prepared to meet the needs of people with dementia and their carers (Traynor et al. 2011). In the UK, in 2014, there were an estimated 835,000 people living with dementia, a figure expected to rise to 850,000 by 2015 (Alzheimer’s Society 2014a). In London the number of people who are living with dementia is estimated to be 72,000, a figure that is expected to rise by one third over the next ten years (London Health Commission 2014). In England and Wales in 2012, dementia was the second leading cause of death: the first leading cause for women, and the fifth leading cause for men (Office for National Statistics 2013). In the population over 80 years, dementia remains the leading cause of death in women and is the second leading cause of death in men (Office for National Statistics 2013). A third of all people who live over 65 years will end their lives with some form of dementia, even if another illness is the main cause of death (Brayne et al. 2006). Dementia is therefore a major challenge for governments in terms of promoting the health of their populations, and for health and social care provision. The human cost of dementia is also high with personal, social and emotional impacts on people with dementia, their families and friends. There are an estimated 670,000 people in the UK who act as primary carers for people with dementia (Alzheimer’s Society 2014a).

3.2 The strategic response to dementia

In recognition of the need for a strategic approach to dementia, in 2009, the Department of Health (DH) launched ‘Living Well with Dementia – A National Dementia Strategy’, followed by ‘Quality outcomes for people with dementia: building on the work of the National Dementia Strategy’ (DH 2010). The National Dementia Strategy for England completed in April 2014. In March 2012, the prime minister launched a ‘Challenge on dementia’, a programme to build on the national strategy and aimed at delivering major improvements in
dementia care and research by 2015 (DH 2012); the challenge completes in March 2015. The Department of Health's vision for the future of dementia policy in England, which will set a strategic direction for domestic dementia policy to 2020, will be published in 2015 (see http://dementiachallenge.dh.gov.uk/2014/12/19/department-of-health-dementia-policy-england-vision/). Alzheimer’s Society (2014b) emphasized the importance of national leadership on dementia and acknowledged that governments in England, Wales and Northern Ireland have made significant progress in improving the care of people with dementia. However, they asserted that more can be done to meet this challenge and recommended 14 actions that will ensure people affected by dementia can live well with the condition.

3.3 Hospital care of people with dementia

As dementia is primarily a condition that affects older people, many people with dementia have other conditions common to old age that precipitate hospital admission (Health Foundation 2011). Their concurrent dementia affects their treatment, care and recovery and people with dementia are at risk of developing delirium, due to infection, post-anaesthetic effects and side effects of some medications (Health Foundation 2011). Indeed, people who have dementia stay five days longer in hospital than those without dementia (Alzheimer’s Society 2009). In the UK, one in four of all adult hospital beds are occupied by people with dementia, the main reasons for admission being: falls (14%), fractures (12%), urinary tract infections (9%), chest infections (7%) or transient ischaemic attacks (7%) (Alzheimer’s Society 2009). Sampson et al. (2009) identified that 42 per cent of older people undergoing emergency medical admission had dementia but over half of these patients had not previously received a dementia diagnosis, highlighting the need for healthcare professionals to be able to recognise indicators of dementia. Many studies and reports have revealed that the quality of care for people with dementia who are admitted to general hospitals is unacceptable, leading to poor experiences and outcomes for patients (Alzheimer’s Society, 2009; Sampson et al. 2009; Cowdell 2010; Royal College of Psychiatrists [RCP] 2011). Areas of concern include person-centred care, eating and drinking, social interaction, and dignity and respect (Alzheimer’s Society 2009). The RCP’s (2011) audit illuminated continuing problems, including a non-dementia friendly and impersonal environment.

3.4 Education of healthcare staff about dementia

A recurring theme in the literature is that hospital staff lack knowledge and skills, related to caring for people with dementia, and that they therefore require improved education (Law 2008; Sampson et al. 2009; Cowdell 2010; RCP 2011; Calnan et al. 2013). The RCP (2011) found that only 32 per cent of staff said they had sufficient education and development in dementia care, including awareness training and skills based training. Most staff from all job roles agreed that further training would be beneficial and would improve the level of care received by people with dementia. Calnan et al. (2013) identified a skills gap amongst nurses and doctors for care of older people generally but particularly for those who are confused or have dementia. Staff attitudes have also been raised as an issue affecting care; Calnan et al. (2013) revealed that hospital staff had negative attitudes towards caring for older people generally, while Chan and Chan (2009) have asserted that ageism and stigmatisation of people with dementia is embedded in society and reflected in UK care systems. How professionals view people with dementia matters because their views influence the care that they provide (Jonas-Simpson et al. 2012). A number of reports therefore recommended that acute hospital staff are educated to be able to recognise dementia and care for people with dementia when they are admitted to hospital for other conditions (British Psychological Society and RCP 2007; Health Foundation 2011; RCP 2011). The National Dementia Strategy (DH 2009) set out that all health and social care staff involved in the care of people who may have dementia should have effective training so that
they can provide the best quality care. Recently, Alzheimer’s Society (2014b) argued for high quality mandatory training for all staff who provide formal care to people who have dementia.

In 2013, the DH produced a mandate to Health Education England (HEE) that included out a work programme to create and develop a tiered dementia training programme for all NHS staff. In response to this mandate, a Delphi study was conducted to access expert opinion and a set of standards for curricula content were produced for the commissioning of dementia education for health and social care staff (Richards et al. 2014). There are ten principles with standards identified, and there are three levels of education set out for each principle:

- Level 1: Awareness: Basic, essential competencies relevant to all healthcare professionals
- Level 2: Frequent contact: Competencies for healthcare professionals who are in regular contact with people with dementia
- Level 3: Extensive contact: Competencies for healthcare professionals working intensively with people with dementia and healthcare professionals who specialise in dementia care

The principles address content for dementia education but the methods of education to achieve these principles are not included.

3.4.1 Education methods

Various studies have focused on education about caring for people with dementia but few have focused on education of hospital staff. Innovative ways of educating care home staff have been reported (Hughes et al. 2008; Kontos et al. 2010). There are also examples of creative approaches to undergraduate education in the United States: medical students as creative story telling partners (George et al., 2011), audiology and speech and language pathology students being social partners to residents (Kaf et al. 2011) and carrying out activities with residents such as horticulture or scrap book making (Fruhauf 2007). Other educational approaches with undergraduate students have used actors to play people with dementia (Bradley et al., 2010) and action learning sets for students in practice (Dunphy et al. 2010).

From a study based in an acute hospital setting, Cowdell (2010) revealed that although staff worked hard and attempted to deliver ‘good care’, they showed little empathy for people who had dementia. She argued that rather than employing traditional, didactic forms of teaching, educational methods that engage staff on an emotional level are more likely to successfully prompt staff to ‘re-kindle’ empathy and become more person-centred. Reports of empathy education in healthcare have mainly focused on nurses (Brunero et al 2009, Williams and Stickley 2010) and medical staff (Pederson 2010) yet the whole of the healthcare team (clinical and non-clinical) affect patients’ care experiences. Studies of the teaching of empathy have mainly used experiential learning techniques but little is known about how best to teach empathy and many study designs have been methodologically weak (Reynolds et al 1999).

Barbara’s Story resembles the approach of ‘ethnodrama’, which is defined as the dramatization of information gained through sources such as qualitative research data, media reports and journal entries (Saldaña 2010). Barbara’s Story is firmly grounded within clinical practice and situated within GSTT; it is argued that the teaching of empathy should be clinically focused and related to the real situation (Reynolds 1999). Saldaña (2010) suggests that ethnodramatic representations of health and illness can highlight the vulnerability and fragility, and often resilience, of participants; he identifies the most common themes in ethnodrama as being: cancer, health care, HIV/AIDS, and substance abuse/addiction. It is argued that an ethnodrama provides a way for healthcare professionals to immerse themselves in the lives of people with dementia and their families (Kontos and
Naglie 2006). Jonas–Simpson et al. (2012) reported on the evaluation of a live-performed ethnodrama ‘I’m still here’, based on several research studies, which aimed to help healthcare professionals change their understanding and thinking about people living with dementia. A DVD has since been made of ‘I’m still here’, which will enable wider application. The evaluation used focus groups prior to seeing the drama and immediately afterwards. Jonas–Simpson et al. (2012) found that the ethnodrama transformed healthcare professionals’ understandings, images and intended behaviour towards people who live with dementia and their families. They planned to conduct further focus groups three and six months later but, as these are still unreported, sustainability of the educational approach is unknown. A review of studies of empathy education in nursing included none where ethnodrama was specified; most used experiential learning (Brunero et al. 2009).

Most of the studies referred to in this section were resource-intensive with a risk that they would reach only small numbers of staff and would be difficult to sustain. GSTT’s use of Barbara’s Story has several unique characteristics:
1) Its focus on the whole of the NHS Trust, both clinical and non-clinical staff, across hospitals and community healthcare;
2) The initiative can be used successfully with large groups of people; this ensures wide scale reach and makes long-term resourcing more feasible, thus promoting sustainability;
3) The project was developed in the context of the Trust values and has potential to impact on Trust culture and have wider application to care across the Trust.

Section 4: Aims / objectives

The evaluation aimed to investigate GSTT staff’s perspectives of the effect of Barbara’s Story on themselves, their colleagues and the organisation. The objectives were to:
1. Explore staff perspectives about the initial Barbara’s Story session and any effect on themselves, their colleagues and the organisation as a whole;
2. Explore staff perspectives on the evolving Barbara’s Story and any effect on themselves, their colleagues and the organisation as a whole;
3. Make comparisons between the responses of different professional groups to the initial Barbara’s Story, and the evolving Barbara’s Story (second series of films);
4. Make comparisons between the first set of focus group findings, and the second set of focus group findings, to evaluate responses over time;
5. Make recommendations for how awareness of dementia within GSTT can be sustained and further developed;
6. Draw conclusions as to how the project’s evaluation findings might transfer to other settings.

Section 5: Method

The evaluation used a longitudinal design and a naturalistic, qualitative approach to gather data from Trust staff through:
1) Analysing open written comments: Trust staff’s immediate responses to the initial Barbara’s Story film;
2) Phase 1: focus groups of staff, in discipline-specific groups (nurses, medical staff, allied health professionals and non-clinical staff) were held in August-September 2013. This was approximately one year after the launch of the project, but before the second series of Barbara’s Story commenced.
3) Phase 2: focus groups with staff, in discipline-specific groups (nurses, medical staff, allied health professionals and non-clinical staff) were held from April to September 2014, which was after the second series of Barbara’s Story films had been shown within the Trust.
Figure 1 displays the data collection methods linked to the phases of the project.

**Figure 1: Evaluation methods**

### Phase 1 Barbara’s Story commenced September 2012

1) Immediate written responses gathered on an ongoing basis while the film was shown throughout GSTT from September 2012-April 2013
2) Focus groups conducted August-September 2013

### Phase 2: Barbara’s Story second film series shown September 2013-March 2014

Focus groups held April-September 2014

### 5.1 Immediate written responses to Barbara’s Story

Barbara’s Story was shown on a regular basis from September 2012 to April 2013 and a total of 11,054 staff attended a session and saw the film. Of the attendees, 11,054 were GSTT staff and the other 670 were non-GSTT staff (e.g. students, university staff). Attendance was mandatory for all Trust staff: clinical and non-clinical, including staff who do not work directly with patients (e.g. human resources, IT services). Staff were provided with a pack, which included resources from Alzheimer’s Society, Trust safeguarding and dementia and delirium information and the Trust values and behaviours framework. A post-it note was attached to each pack. At the end of the session, staff were invited to write a comment on the post-it note with their immediate response to Barbara’s Story. The invitation to write a comment was posed very openly so that staff had the opportunity to comment on what they felt was important. Any staff willing to do so, left the post-it notes behind for collection by the session facilitators.

### 5.2 Phase 1 focus groups

Focus groups were used as they are an appropriate method for gathering in-depth accounts of people’s experiences (Plummer-D’Amato 2008). The interaction between the participants is part of the data gathering process and stimulates further ideas in the discussion (Kitzinger 1994). The focus group topic guide (appendix 1) was developed from the project aims, in discussion with the Trust project team. The aim was to run ten focus groups with staff in discipline-specific groups, and in different locations in the Trust. The project nurse advertised the focus groups through different forums, liaised with discipline leads and visited wards and departments distributing invitation letters and information sheets.

While the ideal number of participants would have been 8-10, in reality the focus group sizes were much more varied (2-14); in addition, one individual interview was carried out. Some disciplines were difficult to recruit to focus groups due to work commitments. The focus
groups were held on both of the two main hospital sites and one was held in a community setting. The nursing staff focus groups included ward-based nurses, specialist nurses, outpatients department nurses and Accident and Emergency (A&E) nurses. The therapy staff focus groups included occupational therapists, physiotherapists and dieticians. The nonclinical staff focus group included portering staff, receptionists and food services staff. The community focus group included midwives, district nurses, health visitors. Table 2 sets out the focus groups and their participants; a total of 68 staff participated. Each focus group lasted 40-60 minutes and was facilitated by a research team member with a second LSBU staff member taking notes. The focus groups were audio-recorded. Each focus group was assigned a unique identifier, so that data extracts used in the Findings sections are attributed to the specific focus group.

Table 2 Summary of focus group participants

<table>
<thead>
<tr>
<th>Identifier</th>
<th>Discipline</th>
<th>Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses 1</td>
<td>Nursing staff</td>
<td>2</td>
</tr>
<tr>
<td>Nurses 2</td>
<td>Nursing staff</td>
<td>6</td>
</tr>
<tr>
<td>Nurses 3</td>
<td>Nursing staff</td>
<td>6</td>
</tr>
<tr>
<td>Nurses 4</td>
<td>Nursing staff</td>
<td>3</td>
</tr>
<tr>
<td>Nurses 5</td>
<td>Nursing staff</td>
<td>6</td>
</tr>
<tr>
<td>Community</td>
<td>Community nursing staff</td>
<td>6</td>
</tr>
<tr>
<td>Therapists 1</td>
<td>Allied health professionals</td>
<td>14</td>
</tr>
<tr>
<td>Therapists 2</td>
<td>Allied health care professionals</td>
<td>8</td>
</tr>
<tr>
<td>Medical</td>
<td>Doctors and dentists</td>
<td>4</td>
</tr>
<tr>
<td>Non-clinical 1</td>
<td>Non clinical staff with patient contact</td>
<td>12</td>
</tr>
<tr>
<td>Non-clinical 2</td>
<td>Facilities manager (individual interview)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>68</td>
</tr>
</tbody>
</table>

5.3 Phase 2 focus groups

The focus group topic guide used in the Phase 2 focus groups (appendix 2) was similar to that used in Phase 1 focus groups and was developed from the project aims, in discussion with the Trust project team. As with the Phase 2 focus groups, the aim was to run approximately ten focus groups with staff in discipline-specific groups, and in different locations in the Trust. Initially staff who had been involved in the Phase 1 focus groups were contacted but this did not yield enough participants. The focus groups were then advertised through different forums and the Safeguarding Adults team supported recruitment through liaising with discipline leads and visiting wards and departments distributing invitation letters and information sheets. Medical staff were very difficult to recruit to focus groups and unfortunately only one focus group with two participants was held. Ward based nurses were also particularly hard to recruit to focus groups, due to difficulties in releasing them from the wards.

The focus groups were held in seminar rooms on both of the two main hospital sites and one was held in a community setting. As in Phase 1, focus group sizes were varied (2-13) and at one hospital site, three individual interviews were conducted with nurses in ward offices, in order to include more ward-based staff’s views in the evaluation. The nurses’ focus groups and interviews included ward-based nurses (registered and non-registered nurses), specialist nurses (including safeguarding), senior nurses (e.g. matrons), out-patients and A&E nurses. The non-clinical staff focus groups included portering, housekeeping, catering, administration and training staff. Table 3 sets out the focus groups/ interviews and their participants; a total of 80 staff participated. Each focus group lasted 40-60 minutes and was facilitated by a research team member with a second LSBU staff member taking notes,
where possible. As in Phase 1, each focus group was assigned a unique identifier, so that data extracts used in the Findings sections are attributed to the specific focus group (or interview).

**Table 3 Summary of focus group/interview participants**

<table>
<thead>
<tr>
<th>Identifier</th>
<th>Discipline</th>
<th>Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses 1</td>
<td>Nursing staff</td>
<td>3</td>
</tr>
<tr>
<td>Nurses 2</td>
<td>Senior nurses</td>
<td>3</td>
</tr>
<tr>
<td>Nurses 4</td>
<td>Nursing staff</td>
<td>5</td>
</tr>
<tr>
<td>Nurses 5</td>
<td>Nursing staff</td>
<td>10</td>
</tr>
<tr>
<td>Nurses 6</td>
<td>Nursing staff</td>
<td>13</td>
</tr>
<tr>
<td>Nurses 7</td>
<td>Nursing staff</td>
<td>8</td>
</tr>
<tr>
<td>Nurses 8</td>
<td>Nursing staff</td>
<td>2</td>
</tr>
<tr>
<td>Nurses 9</td>
<td>Nursing staff</td>
<td>2</td>
</tr>
<tr>
<td>Nurse 10</td>
<td>Registered nurse</td>
<td>1</td>
</tr>
<tr>
<td>Nurse 11</td>
<td>Senior nurse</td>
<td>1</td>
</tr>
<tr>
<td>Nurses 12</td>
<td>Nursing staff</td>
<td>2</td>
</tr>
<tr>
<td>Nurse 13</td>
<td>Registered nurse</td>
<td>1</td>
</tr>
<tr>
<td>Community</td>
<td>Allied health professionals and district nurse</td>
<td>6</td>
</tr>
<tr>
<td>Therapists 1</td>
<td>Allied health professionals</td>
<td>2</td>
</tr>
<tr>
<td>Therapists 2</td>
<td>Allied health professionals</td>
<td>5</td>
</tr>
<tr>
<td>Medical</td>
<td>Doctors</td>
<td>2</td>
</tr>
<tr>
<td>Non clinical 1</td>
<td>Non-clinical staff with patient contact</td>
<td>7</td>
</tr>
<tr>
<td>Non clinical 2</td>
<td>Non-clinical staff, mainly non-patient contact</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>80</strong></td>
</tr>
</tbody>
</table>

**5.4 Data analysis**

The post-it notes were typed up so that they were in electronic format. They were then analysed using content analysis: reviewing all the data, applying codes that emerged from the data and developing themes with sub-themes. The numbers of responses in different themes and sub-themes were calculated in order to identify areas that staff most frequently commented on.

The focus group audio recordings were professionally transcribed. The data were analysed using the framework approach (see Box 1), which is a 5 stage process (Ritchie and Spencer 1994). The Stage 2 thematic framework used in the analysis of the Phase 1 focus groups was used as the starting point for the analysis of the Phase 2 focus groups; a number of additional codes were added to ensure the coding framework was comprehensive. Finally, after completion of the Phase 2 analysis, the themes and sub-themes were critically reviewed across both sets of focus groups and a coherent set of themes and sub-themes were adopted as far as possible with the aim of enabling comparisons across the two data sets and therefore over the project’s timescale. However, there are some sub-themes unique to either the Phase 1 or 2 data analysis.
Box 1 Framework analysis process (Ritchie and Spencer 1994)

Stage 1: familiarisation with the data by reading through the transcripts and noting recurrent key issues and themes;

Stage 2: development of a thematic framework, by drawing together the issues and themes noted in Stage 1 with the concepts in the focus group topic guide;

Stage 3: systematic application (indexing) of the thematic framework to all the data;

Stage 4: charting of the coded data according to themes and sub-themes

Stage 5: reviewing the charts and searching for patterns in the data, leading to interpretation and explanations.

5.5 Ethical considerations

Ethical approval was obtained from London South Bank University’s Research Ethics Committee. The evaluation was registered with the GSTT’s Clinical Governance Department as a service evaluation. The participants were invited to take part in the focus groups on a voluntary basis. Invitation letters and information sheets were distributed. The focus groups took place in private Trust seminar rooms and participants were reminded that the discussion should remain confidential to the group. The participants were assured that they will only be identified by professional group and no individual will be identified in the report. The transcribed audio recordings were kept on password protected encrypted university computers. All participants signed written consent forms prior to the focus groups commencing; these are kept in a locked filing cabinet within a locked office at the university.

5.6 Presentation of findings

The findings are presented in three sections:

- Section 6: Immediate written responses to Barbara’s Story
- Section 7: Phase 1 focus groups
- Section 8: Phase 2 focus groups

Section 6: Immediate written responses to Barbara’s Story

Six themes emerged from the analysis of the immediate written responses (see Figure 2):

- What I will do in my professional life (n=927; 74%);
- What the organisation should do (general comments and training) (n=138; 11%);
- General comments (e.g. about the film, dementia) (n=116; 9%).
- What others should do (n=26; 2%);
- What I will do in my personal life (n=22; 2%);
- Personal reflections on the film (n=17; 1%).
Table 4 displays the themes and sub-themes (where applicable) and the total number of responses for each. Some individual responses covered more than one theme. Ten responses were discarded as they were illegible. In total 1246 comments were analysed.

Within the theme ‘What I will do in my professional life’, the most common sub-theme (223 responses) was ‘helping people who are confused/lost/anxious’. Despite the focus of the film being on an older person with dementia, many respondents wrote about how they would help anyone looking lost or confused, for example:

*Be aware of a person, young or old walking around looking confused and ask if they are ok.*

*If I see a lost person, I will definitely ask how is he/she and can I help them.*

The next most common sub-theme was ‘communication’ (183 comments). There were many general comments about communication, for example, ‘Try listening to the person’, but also more specific comments, especially with regards to giving information, for example:

*Explain what I’m going to do with the patient step by step, to relieve some anxiety. Keep a patient updated at all times.*

**Figure 2: Immediate responses to Barbara’s Story**

The next most common sub-theme within ‘What I will do in my professional life’ was: ‘Treating people as an individual’ (130 responses). Examples of comments were:

*I aim to treat each and every patient as an individual. An individual that is unique. To make time for every individual patient to ensure they feel reassured and like a person not a number/illness.*

Another common sub-theme was ‘taking time’ (115 responses). Some staff commented that they would now take more time to:

*Talk to patients about themselves to make them feel valued and respected. Not to get too busy and caught up with what I’m doing.*

However, a few staff members wrote about how difficult it was to give time:

*We want to give time - how are we to do this? Each patient on visit is based on a scoring system, therefore we only have an allocated amount of time per visit, at the moment community staff are inundated with visits per day therefore we are only focusing on the purpose of the visit.*
Smaller sub-themes included ‘treating people with respect’, ‘showing kindness’ and ‘introducing myself and other team members’, which had been highlighted in the film. Another issue that had specifically been highlighted in the film were comments about wheelchairs:

\[ \text{I will try to push the wheelchairs forwards instead of backwards (I'm guilty of that).} \]

Under the theme ‘What the organisation should do’, there was a variety of comments about how the Trust could improve dementia care, especially around the use of volunteers, for example:

\[ \text{Perhaps the trust could offer more helpful volunteers to improve patients’ ‘journeys’ through the hospital akin to ‘games makers’.} \]
\[ \text{Reception area at Guy’s is always bustling and busy. Some ‘meet and greet’ people to direct as well as reception staff would be good. For some people it is a long walk from one side of reception to another so ‘standing’ reception greets would be helpful.} \]

Other suggestions included larger name badges, training staff in sign language and limiting the amount of bed moves, especially at night. Comments about training were also included, for example that:

\[ \text{All healthcare personnel should be trained in dementia care from Drs, GPs, nurses and AHPs.} \]

There were also suggestions for increasing training on dementia care in other organisations, for example:

\[ \text{Share the films and training with local care providers and wider.} \]

There were comments about staffing too, for example:

\[ \text{SALT [Speech and Language Therapy] is key to dementia awareness. Please do not cut their jobs.} \]

Some staff suggested ways in which other members of staff could change; examples included:

\[ \text{Hospital transport. Staff need greater training to needs of elderly confused patients.} \]
\[ \text{Reception staff generally within the Trust need to smile more and be aware that they are the 1st contact point}^1 \]
\[ \text{Better customer care for all staff but particularly front line/ receptions/ porters etc.} \]
\[ \text{The management need to see this most of all – they do see all patients as a number or target and make staff feel the same – learn the hospital experience.} \]

A small number of staff wrote comments about what they would do in their personal lives, for example, contact older family members more. Some staff wrote personal reflections and emotions that had been triggered by the film, for example:

\[ \text{I've been reading Florence Nightingale Notes and lectures. It angers me that more than 100 years down the road, this kind of dehumanising ‘care’ still occurs in our institutions.} \]

Staff also referred to family members with dementia, for example:

\[ \text{Thank you, both my grandmothers had dementia and one of them was cared for in this hospital. So I was quite tearful. Glad this has been highlighted.} \]

Many staff also wrote to the Chief Nurse individually with their personal reflections, after seeing Barbara’s Story.

There were a variety of other comments which related to the film itself, to dementia and general observations. While there were many positive comments about the film there were a

\[^1\text{Reception staff have since requested specific training for all team members.}\]
few less positive views about the film too, that the film ‘does not reflect our multicultural staff’ and that the film was ‘patronising’.

Table 4 Initial responses to Barbara’s Story

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme (as applicable)</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>What I will do in my professional life</td>
<td>Helping people who are confused/lost/anxious</td>
<td>223</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>183</td>
</tr>
<tr>
<td></td>
<td>Treating people as an individual</td>
<td>130</td>
</tr>
<tr>
<td></td>
<td>Taking time</td>
<td>115</td>
</tr>
<tr>
<td></td>
<td>Introducing myself and other team members</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>Treating people with respect</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Showing kindness</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Treating people as I would like to be treated</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Creating a good environment</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>Giving my best</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>Needing/giving support</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Choice and shared decisions</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Showing empathy</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Being helpful</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Seeking consent</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Acting with integrity</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Having pride in my work</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Having concern for physiological needs</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Challenging poor practice</td>
<td>6</td>
</tr>
<tr>
<td>General comments</td>
<td>About dementia</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>About the film</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>General observations</td>
<td>13</td>
</tr>
<tr>
<td>What the organisation should do</td>
<td>General comments</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Training</td>
<td>19</td>
</tr>
<tr>
<td>What others should do</td>
<td></td>
<td>26</td>
</tr>
<tr>
<td>What I will do in my personal life</td>
<td></td>
<td>22</td>
</tr>
<tr>
<td>Personal reflections on the film</td>
<td></td>
<td>17</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>1246</td>
</tr>
</tbody>
</table>

Section 7: Phase 1 focus groups

While Section 6 captured responses immediately after viewing the film and engaging in the discussion, the focus groups explored participants’ views some months afterwards. Table 5 presents a summary of the themes and sub-themes and these will be explored next, with illustrative quotations, attributed to the focus group (identifiers as in Table 2, Section 5.2).
### Table 5 Focus group themes and sub-themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barbara’s story as a project</td>
<td>Barbara’s Story as an educational device</td>
</tr>
<tr>
<td></td>
<td>The delivery of Barbara’s Story</td>
</tr>
<tr>
<td>Effect on individual staff</td>
<td>Emotional engagement</td>
</tr>
<tr>
<td></td>
<td>Increased awareness and understanding</td>
</tr>
<tr>
<td></td>
<td>Interactions and behaviour</td>
</tr>
<tr>
<td></td>
<td>Professional behaviour and responsibilities</td>
</tr>
<tr>
<td>Practice developments and improvements</td>
<td>Initiatives in the Trust</td>
</tr>
<tr>
<td></td>
<td>Influencing others</td>
</tr>
<tr>
<td></td>
<td>Challenges and constraints</td>
</tr>
<tr>
<td>Trust values and culture</td>
<td>Trust values in action</td>
</tr>
<tr>
<td></td>
<td>Culture change</td>
</tr>
<tr>
<td>Sustaining the impact of Barbara’s story</td>
<td>Care improvement suggestions</td>
</tr>
<tr>
<td></td>
<td>Sustainability of Barbara’s story</td>
</tr>
</tbody>
</table>

#### 7.1 Barbara’s Story as a project: *She’s the most famous name in the Trust!*

Staff discussed their impressions of Barbara’s Story, their perspectives on Barbara’s Story as an initiative in the Trust and its delivery. There are two sub-themes: Barbara’s Story as an educational device, and the delivery of Barbara’s Story.

##### 7.1.1 Barbara’s Story as an educational device

There were a wide range of comments about Barbara’s Story as an initiative in the Trust. The high profile of Barbara’s Story drew comments for example:

*She’s the most famous name in the Trust!* (Therapists1)

In one focus group discussion, participants expressed a feeling of pride that the Trust had launched the initiative, particularly in the light of the high profile and negative reports about NHS care (Francis 2013):

- *With what was going on in the media in terms of things in Mid-Staffordshire and things where the NHS was just being slated from every angle and it was all quite negative. But then, at the same time, coming into something where it [Barbara’s Story] was an investment and a positive thing – ‘This is how it could be’ and ‘This is how we can do it’, rather than a ‘We don’t do anything right’. I think [I feel] quite proud as well – of the Trust and the way that people responded to it and the positivity around it.* (Therapists2)

One nurse admitted that some staff had initially been cynical about the initiative, but that once staff started to attend the sessions, attitudes changed because of how the film affected staff and as:

*The people who saw it in the first run, were actually quite positive, were really positive about it and were saying ‘Oh I was crying’ or ‘I was really sad’. […] it went from ‘Oh I’ve got to go and see Barbara’s Story’, rolling of eyes, to ‘It’s really good, it’s really good’, and it was quite positive between staff, you know, like telling other staff about it, and quite a few staff said ‘Oh I was crying’.* (Nurses1)

The film was described as: ‘*thought provoking*’ and there were many positive comments about its effectiveness as an educational device:

*It was kind of subtle in a way because it allowed you to watch and draw your own conclusions.* (Nurses5)
I think actually Barbara’s Story is a really good way of getting the message across, rather than sitting down and having a seminar with my staff, I don’t think that would be quite as interactive as actually watching a video or a DVD, actually seeing examples of things that happen, I think that’s the right way to go. (Non-clinical2) Sitting there watching the video actually probably had more of an impact than having someone just stand up there and say ‘This is what you should be doing’ because you see it, everyone cares about their patients, so to see it through a patient’s eyes was much more effective I think. (Nurses4)

There were a number of comments that the way Barbara’s Story was presented enabled staff to see her experience through her eyes:

I just remember coming away thinking it was just refreshing to see it through a patient’s eyes. (Nurses4)
It’s a story and people are getting to know who Barbara is and they are going to see her until the end. (Therapists1)
I liked the way it portrayed how she was feeling. (Community)

In several focus groups staff discussed the relevance of the film to their own practice and their related learning, for example:

It’s only from that story that we’ve started learning more and more about dementia patients and how to treat patients as they come into the hospital. (Non-clinical1)
After watching, after seeing that film about Barbara, it like enlightened me, or it made me feel, it’s like I have felt like I can be more accommodating. (Nurses2)

Another participant commented that while in their own speciality they see few patients with dementia, the film had wider application:

We don’t deal with a lot of dementia patients in [named specialism], but I think some of the messages that you will take are general to any patient. (Medical)

There was much discussion about the behaviour of the staff towards Barbara in the film and nearly all the comments were negative. The behaviours that seemed to leave the strongest impression on participants were: the receptionist’s communication with Barbara, which was perceived as brusque and unhelpful; the staff who walked by Barbara in the corridor when she was lost; and Barbara being ignored by staff and talked over. Examples of negative comments about staff behaviour were:

My mother has vascular dementia […] for my mother, if I have a conversation with my father and she’s not part of it she doesn’t like it. There were people talking about this lady [Barbara] without her really understanding. (Medical)
What I hated about seeing how she was treated was the way she was spoken to in such an impersonal way or in the third person often, with no sort of normal, natural kindness. (Nurses1)
The receptionist didn’t take any time, she was still just ticking everything off her list. (Non-clinical1)

Watching negative staff behaviour prompted reflective comments about how such behaviour affected Barbara’s experience:

Everybody was going past her [Barbara] and she was looking a bit bewildered and everybody pretty much ignoring her, and she was getting quite upset. (Therapists1)

In most focus groups, participants discussed how watching such behaviour prompted them to reflect on their own behaviour (see examples, Box 2). For other participants, the film prompted reflection on colleagues’ behaviour:

I think that it also raised some issues in terms of seeing how colleagues are dealing with those patients, which is quite striking. (Medical)

Most participants acknowledged that they had seen such behaviour in practice, for example:

I see that so often, kind of talking, ‘Now she’s compos mentis’ and talking about her, sort of the Queen’s ‘we’, I hate all of that really and I do see that going on. (Nurses1)
Box 2 Reflections on own behaviour, prompted by watching Barbara’s Story

It made me realise sometimes it’s easy to slip on that and just start talking about something else that is not related. So it made me aware of not doing that [talking over patients], when I’m on the ward with a patient, concentrate on the patient only, even if someone else asks me something personal. (Nurses2)

We tend to see all patients are the same but that makes you realise that some are different. Like in Barbara’s Story: she was a patient with dementia. You know a job for so long where you tend to think, ‘Okay, they’re all the same.’ But they’re not: each patient is different with different needs. So it makes you take a different approach really to patients. (Non-clinical1)

It was a negative situation but, without anybody actually doing anything … No one was going out of their way to be particularly nasty or mean or not do their job: it’s that they weren’t doing the ‘icing on the cake’ type of things to make that patient’s experience even better. So it highlighted very well that, if you just do your specific job, you’re still not helping that patient going through that pathway. (Therapists2)

Some participants considered that the busy hospital environment was an influencing factor:  
I think one of the key things I thought after Barbara’s Story was just how accurate it was. And even in terms of some of the maybe, the negative points were actually … It does happen; I have seen it happen. And so I thought it was quite accurate in terms of the busy hospital environment. (Therapists2)

However there were contrasting comments in one focus group that the behaviour of the doctors in the film was ‘not very typical’ (Medical) and that the receptionist was shown in a stereotyped way:  
The receptionist, she was pretty bad, but that I think is probably quite sort of stereotyping in that way. (Medical)

However, the focus group that included receptionists (Non-clinical1) did not refer to this scene as showing stereotypical behaviour.

Only in three of the focus groups was there any reference to positive behaviour shown in the film, which could indicate that the negative behaviour observed left the deepest impression. However, there was little positive behaviour in the film, with the exception of the character ‘Nurse Jane’ while a number of different staff (receptionist, nurses, porter, doctors) displayed behaviour perceived as negative. The participants who commented on Jane’s behaviour referred to her impact on Barbara’s experience:  
There was a nurse who clearly took the time to stop and talk to her, which she found reassuring. (Medical)
The lovely nurse who sits down with her is such a good breath of fresh air, is sort of gentle and looks her in the eye and she instantly feels much better. (Nurses1)

7.1.2 The delivery of Barbara’s Story

The leadership of the initiative by the Chief Nurse was felt to give a powerful message to Trust staff:  
Her presence and her passion for it, I think. And I think it added to the gravity of what we were talking about: that she felt compelled and that she would spearhead it: it was quite positive. (Therapists2)

In several focus groups staff discussed the Trust-wide approach to delivering Barbara’s Story and, related to this, the mandatory requirement to attend; these strategies were considered the right approach. One group referred to the importance of the whole Trust being involved in order to make the initiative successful (Nurses2). In another focus group...
participants talked about the challenge of engaging a whole workforce in the initiative but that:

* We all have to be singing from the same hymn sheets [...] I think it doesn't matter whether you're a consultant or a doctor or a receptionist, we all need to make sure that the experience in the hospital is a nice one. (Therapists1)

The Trust-wide approach of the initiative, with staff of all roles learning together, drew some positive comments:

* It did make you feel quite together and that we were all aiming at the same thing – which I don't think there's anything else that we're taught, where everybody is together quite in that same way, which was quite nice. (Therapists2)
* Obviously the Trust is taking it very seriously and being very proactive about it by setting up Barbara's Story [...] I think by making that mandatory for all staff as well was very positive. (Non-clinical2)

In relation to the mandatory nature of attendance at Barbara’s Story, a particularly interesting comment from a children’s nurse was that they and colleagues questioned why they had to attend but that afterwards they could see the film’s wider application:

* Afterwards: we were so happy we went because we thought that it is more about… not even about at the hospital really, it's more about everywhere, like even outside the hospital. (Nurses4)

However, in another focus group a participant reported some negative reactions from colleagues:

* I had some dialogue with some doctors who are like, 'We're going to get the sack unless we go to this'. And it almost feels like a little bit of that ‘tick box’ mentality: 'I have to do it because I have to do it' rather than actually, 'I’m going to something, see what I can learn and really try and engage with it and maybe change my practice for the better.' (Therapists2)

There were some participants who had seen Barbara’s Story as part of their induction and their comments were very positive:

* From my induction I’d say it was probably one of the things I remember the most, so I think that form of teaching is quite a good way of getting into people’s memories. (Therapists1)

Staff perceived Barbara’s story as a very effective educational device and specifically commented on it being superior to a traditional teaching session. There was pride expressed that the Trust had launched such an initiative within the current NHS climate. Barbara’s Story enabled staff to see her healthcare experience from her perspective and the behaviour shown in the film prompted staff to reflect on their own behaviour and that of colleagues. The Chief Nurse leadership of the project was felt to give a powerful message to staff about the importance of the topic. The whole Trust approach and the mandatory and interprofessional nature of the sessions were viewed positively.

### 7.2 Effect on individual staff: You put that bit of extra effort in because you think, ‘Yes, I can imagine if that was Barbara.’

Staff discussed the impact of Barbara’s Story on themselves as individuals. The sub-themes that emerged from these discussions were: emotional engagement, increased awareness; interactions and behaviour and professional behaviour and responsibilities. Each of these will be discussed next, with illustrative quotations from the focus groups.
7.2.1 Emotional engagement

In most focus groups there was discussion about emotions prompted by the film and these included staff feeling, upset, sad, annoyed or defensive. Other comments about personal impact included:

- It’s really stayed with me, how they treated her. (Community)
- Everybody crumbled a little bit. (Non-clinical1)
- That upset me quite a lot because she’s human, she’s one of us, she’s no different to any of us in the room yet she was so troubled and stressed and that’s what upset me about it. (Nurses3)
- To be honest when I was watching Barbara’s Story I felt like everything got to me, like at times it was really sad. (Therapists1)

In all focus groups, staff talked about Barbara as a person and of her experience visiting the hospital. The film seemed to touch staff emotionally and engage them with her as an individual, reminding them of the patient’s perspective:

- From her point of view or from any patient’s point of view hospitals are very scary, but it’s something we deal with every day and brush over our shoulder, and it sort of brought you back to what it’s like to be a patient. (Nurses5)
- There was the sequence where she was thinking about her youth and with children and the nostalgia […] that kind of enabled you, as an audience member, to relate to the individual. (Therapists2)
- Well I think for me it was definitely about having more respect for how isolating and lonely having Alzheimer’s can be and coming to an institution, and really to give more time. (Medical)

Staff remembered Barbara being ‘lost’, ‘confused’, ‘vulnerable’, ‘scared’ and ‘worried’. They engaged with her as a person who could be a family member:

- She resembles someone that we know, she’s a grandmother or an aunty or a mother, so that’s what brought it home to me. (Nurses3)
- I think you can see back into your family or some of your aunts or uncles, grandparents, it could be one of them. (Therapists1)

Some staff specifically related Barbara’s Story to a family member, which personalised the film’s story:

- It made me think of my nan, because I don’t see her that often because she lives far away, but I have noticed over the last five years she’s started to get more forgetful, whether it be with old age, whether she’s developing dementia, and it made me think about her and who goes with her to her hospital appointments. (Nurses2)

There was also acknowledgement that any of us could find ourselves in a similar situation:

- It also gives you awareness that it could be you. At one time in your life, you could go down that route. (Non-clinical1)

Barbara’s Story prompted many empathetic comments from the participants too, for example:

- What we take for granted every day, doing something – all the simple things – can, for some people be very, very difficult. (Community)
- It must be a very bleak experience to be ignored and not spoken to. (Nurses1)

7.2.2 Increased awareness and understanding

There were extensive discussions about increased awareness and understanding about people with dementia: in participants’ own practice area and more widely in the Trust, for example:

- It’s made me think more about to look for more signs that they might be somebody like that [with dementia]. (Community)
Some of my people [staff] would be on their own going in a room to fix something, so ‘excuse me can I just do this and that sort of thing’, so I think it’s important that they’re aware. (Non-clinical2)

We’re more aware when they [patients] come in. Just because they don’t look like they’ve got something [wrong], because they’ve not got a leg in plaster, it doesn’t mean that they’re thinking right. (Non-clinical1)

The need to remember that a person who has dementia may show no obvious outward signs, especially at an early stage, was also expressed in this comment:

You need to be reminded that there are all these people out there; on the surface of it, they’re walking around, looking, perhaps, absolutely fine but you don’t know what’s going on mentally for them. (Community)

Some staff discussed that in their particular speciality they see people with dementia regularly and so were already quite aware of dementia but there was also discussion about how awareness had increased much more widely across the Trust:

I think Trust-wise, throughout, there’s just generally a lot more awareness. Everyone’s aware of Barbara’s Story, everyone talks about it, so I think that it’s a really positive thing. (Medical)

I think everyone is much more aware of that [dementia], because you would say ‘On the type of ward we have, we don’t really have dementia patients, it doesn’t affect us’, but that’s not true, you know, because we get patients from all over the hospital. (Nurses1)

On the [named specialty ward], there’s a whole lot of older patients, so definitely be more aware of what they could be going through and just being there for support really. (Nurses4)

There were also many comments about staff needing to be aware of people with dementia outside their own specific practice area, particularly as the numbers of people with dementia increase. This learning seemed to arise from the image of Barbara lost in the hospital corridors:

You might be running to Marks & Spencer’s for your lunch but you’ve got a responsibility for people around you as well. (Nurses5)

It’s really put it into perspective about thinking about patients that aren’t necessarily your patients, like they’re not on your ward. (Nurses3)

A children’s nurse expressed how Barbara’s Story had increased her awareness about the whole family:

Like we see under 16s really and not many come with their grandparents, like they usually do come with their parents, but we do think about the other family members and what they could be going through at home. (Nurses4)

Some staff discussed the wider application of learning from Barbara’s Story to other patients in the Trust:

I think it’s made people aware about… it’s not just about helping people with dementia, people in the Trust helping patients, it’s a generalised thing. (Medical)

Staff in one focus group also highlighted that it was important to be aware that carers might have dementia too (Non-clinical1).

7.2.3 Interactions and behaviour

In most focus groups, staff discussed how their own interactions with patients and behaviour had changed since watching Barbara’s Story, and they often referred to changes they had observed in other staff too. Areas discussed included: giving more time to patients, improved communication, giving more information, and assisting patients who are looking lost. There were many examples relating to communication and giving more time; see examples in Box 3.
Box 3 Improving communication and giving time

We had a patient on the ward who had dementia and she was expressing it in just the way that Barbara was, sort of ‘Where am I?’ It was almost like she was on the video, never had a patient who was so classic, worried and vocalising the whole time, I’d never seen anyone quite like that before and I just knew that I really needed to sit with her and calm her. We actually needed a special, which we didn’t have, so we carried on taking it in turns to sit with her, because she was just questioning where she was the whole time. (Nurses1)

I just seem to remember thinking to give people time, to listen to what they say, to communicate clearly, well I hope I do that anyway, but maybe I was more aware of that in the early days or weeks after the film. (Medical)

Perhaps a bit more patient with people, I always talk really quickly but if it’s someone who has got dementia or is a bit older I’ll speak slower and I’ll make sure they understand what I’m saying rather than just saying my piece then leaving. (Therapists1)

I think one of the things that I try and do now, which maybe I didn’t do before, is ask a specific question around ‘Is there anything that you want to talk to me about?’ ‘Is there anything that you’re worried about?’ (Therapists2)

It just makes you think twice about how you deal with anybody. You put that bit of extra effort in because you think, ‘Yes, I can imagine if that was Barbara.’ (Community)

There were some specific comments about keeping patients informed, particularly when they are waiting for appointments, and about explaining what is happening in more detail:

Just popping out and saying to them ‘Don’t worry, I haven’t forgotten you’. I think I do think about that a little bit more as well. (Nurses4)

I think it’s making a point of explaining to patients where they are in the process and if you could help them and explain what’s going to happen to them as well, where they are going to go, what’s going to happen next. (Therapists1)

Some staff referred to having changed their approach to appointments now that they understood what an ordeal it is for some patients to have to attend hospital for an appointment (Therapists2)

The scene where Barbara was trying to find the toilet in the hospital corridors seemed to make a strong impression, and there were many comments about staff helping people in similar situations, for example:

Now, I do make more of an effort to chat to them, to make sure that they know where to go and when they need to be there and just try and make more of an effort to make sure they get to where they need to go, really. (Community)

I think the Barbara’s Story made me more aware of them so I go to help them where perhaps I may not necessarily have noticed them before. (Therapists1)

However in one focus group, participants had not detected a change in this aspect of behaviour; their perception was that staff had always been good in this respect:

I’m not sure I’ve noticed a change. I think, from what I’ve seen before, generally people are very good at helping patients. (Medical)

Participants also referred to their perceptions of how the interactions and behaviour of other staff had changed since the launch of Barbara’s Story. Most comments however were about behaviour of non-clinical staff, rather than clinical staff. There were a few comments relating to doctors:

The doctors are a lot more aware, […] before they would come and they would talk at the patients,[…] they are talking over them. Now I’ve seen that been reduced, it’s not completely gone but it has reduced a lot, they try to talk to the patient to make them
understand everything, so good facial contact and eye contact and ask the question ‘do you understand what I’ve just said, do you want me to repeat it again’. You know you don’t get it with every doctor but some of them have made changes. (Nurses3)

However in another focus group, there was a more varied view:

It’s a mix really. I think, some of the junior doctors, I’d like to say, I think have been exceptionally good. I don’t know if that’s a direct result of the induction process. But then, beyond junior, I don’t know if there’s been a massive amount of change really, to be honest. (Therapists2)

A manager in the non-clinical focus group, which comprised reception, portering and food services staff, said of their own staff;

What I learnt from our own staff, they were very dismissive people because of the time factor. And they’ve now been taught how to overcome that in a better way [instead] of just saying, ‘I haven’t got time. Sorry’ and just moving away from that patient. […] they do now give time. (Non-clinical1)

Staff in the clinical focus groups supported this view, as there were many comments about this staff group’s behaviour having changed towards patients; porters’ behaviour drew a particular mention. The participants referred to these staff members displaying gentleness and friendliness and giving better explanations; see Box 4 for examples of comments.

Box 4 Non-clinical staff: improved behaviour

I’ve noticed some of the porters are making a bit more effort with the patients they’re dealing with. Some of them have always been brilliant. […] just chatting to them a bit more and asking what their name is, and explaining where they’re taking them, […] just being a bit more gentle, like helping out with mobilising them back to the chair. Just now I had a really nice one upstairs who was sort of, I don’t know, just seemed a lot more friendly towards and more interactive with the patient than I’ve seen. (Nurses1)

- I think I’ve seen a big change in the porters. I really have – in terms of maintaining patient’s dignity when they’re being transferred. […] , them just taking the time to go really, really slowly and really, really gently over the bumps and the lifts. I’ve seen that so many times - I’ve seen a lot of them now, pushing them [patients in wheelchairs] forwards instead of dragging them, facing the other way.
- Some of the housekeeping staff have been more engaging with the patients, explaining if they’re moving stuff around. Making it more obvious what they’re doing, taking the time to have a bit of a joke with them and just interact. (Therapists2)

The porters just like go that extra little mile for them, just making sure they’re comfortable, or ‘Do you want a painkiller before you go?’ and things like that, and the porters spend time as well. (Nurses2)

In a striking example of staff behaviour, which was attributed to the whole of the Trust workforce having attended Barbara’s Story, one participant gave the example of the response of non-clinical staff when a patient needed to be found:

As soon as I said an older lady, possible dementia, confused, they were really quick to react to it, and they were like looking around, they were helping me, they were out the front, you know, searching all of the ground floor, and they were about to kind of escalate it up for a full hospital search to look for the lady, and I think that that reaction has probably come from everybody seeing Barbara’s Story and being made more aware of it. (Nurses2)
The importance of having staff who have the right attitude to work with patients was highlighted in the focus group with non-clinical staff: ‘You’ve got to be a people person’. The view expressed was that otherwise, staff should not work in a hospital, they should: ‘actually be working in an office on their own, for themselves’ (Non-clinical1). A focus group with therapists made a similar point:

If you want to get a job in a hospital you have to have some level of communication skills, you have to realise that you are going to be talking to patients, everybody should have these standards, so otherwise work in an office or somewhere else. (Therapists1)

In one of the nurses’ focus groups, participants expressed that they still encountered negative attitudes about people with dementia from some ward staff:

I still don’t think that they’re [patients with dementia] necessarily received with a particularly positive attitude on the ward. (Nurses5)

This comment indicated the need for on-going work to instil positive attitudes.

7.2.4 Professional behaviour and responsibilities

Many participants referred to the responsibilities of staff and expected professional behaviour, for example: to help patients, to show compassion, to advocate for patients and to display an appropriate attitude. As an example of advocating, one participant said:

Sometimes, I will speak to the department directly and say, ‘This really isn’t in the patient’s best interests to come to the hospital three times in one week. It’s too much. We need to find a way round that.’ So I’m doing that as well, which is probably something I wouldn’t have got involved with. (Therapists2)

There were a number of comments that referred to professional responsibilities for patients, with dementia:

It gave me a particular insight to what is expected of us to do when we are confronted with this type of issue with this dementia and our responsibilities as nurses. (Nurses5)

I think that actually I have more responsibility to take for these patients, to help them to get to the right place and make sure they know what’s happening. (Medical)

You need to get them [people with dementia] seen, get the porters up as quick as possible and get them home, into their own environment as quick as possible. (Non-clinical1)

Other staff discussed professional responsibilities from a broader perspective:

The way that we treat every patient or anyone in the community, I think the rules – that makes you think about how you deal with everybody that you come across as a professional. (Community)

It’s your role as a professional in this hospital to cater for everybody that comes in and out and not just your patient. (Therapists2)

7.2.5 Effect on individual staff: summary

Barbara’s Story engaged staff emotionally and prompted empathetic responses. They related to her as an individual and her experience. Staff related to Barbara as someone who could be their family member and for some staff, Barbara’s experience mirrored their own family experiences. Staff expressed increased awareness of dementia and how it could be recognised, both within the Trust and outside. They also took on board that people who have dementia could be anywhere within the Trust and staff became more aware of people outside their own clinical areas who might need help. Staff discussed how their own interactions with patients and behaviour had changed since watching Barbara’s Story, and they often referred to changes they had observed in other staff too. Changes included: giving more time to patients, improved communication, giving more information, and assisting patients who are looking lost. Staff also discussed how Barbara’s Story had highlighted their professional responsibilities.
7.3 Practice developments and improvements: *We work together as a team really well to put patients first*

Staff discussed dementia-related initiatives within the Trust, how staff influenced others to improve practice, and constraints and challenges in improving practice.

7.3.1 Initiatives in the Trust

Participants discussed various initiatives that were supporting improved care experiences for people with dementia in the Trust, and that enhanced care for other patients too. Examples included: *This is Me*², blue wrist bands for people with dementia, use of the forget-me-not symbol (to alert staff that the patient has dementia), making the environment more dementia-friendly, a patient assessment tool, screening for dementia, food charts, flash cards, use of music and pictorial menus:

*We've got a big menu, which is a pictorial menu where they [Food services staff] take that every time they see a patient so that they've got pictures, so that, if they [patients] don't understand, they can point. So there's a different way of actually making a service to your customer.* (Non-clinical1)

In several clinical staff focus groups, staff commented on the Trust's environmental changes, for example, use of colour in the older people’s wards. One participant explained about the Trust’s on-going work:

*I'm actually sitting on the [dementia] action group that’s meeting later this month, so I'm representing the non-clinical side […] quite a lot of that is in connection with signage, flooring, […] they’ve got a thicker vinyl going into some of the dementia related wards. It's very slightly more cushioned, so to try and reduce the number of fractures through falls. So there’s things like that and there’s quite a lot of signage requirements and perhaps changing signage in certain areas to be a bit more relevant to a person who might recognise symbols as opposed to lettering.* (Non-clinical2)

Some participants considered that Barbara's Story had raised the profile of initiatives and other work that was already in place for people with dementia, further reinforcing and helping developments to embed in the Trust, such as dementia study days and dementia champions (Nurses2) and use of the forget-me-not:

*It's [forget-me-not] being used more now than before Barbara’s Story, it was more on the shelf there, and you had to prompt people.* (Nurses3)

One group also referred to the Trust's Care Awards scheme, which reinforced good practice in the Trust and was considered to be a motivator for staff.

7.3.2 Influencing others

Comments about influencing others concerned guiding and teaching, leadership, and teamwork.

In relation to teaching, participants referred to guiding and teaching other staff to be more considerate and to do things differently:

*Empower others, as well, to take responsibility sometimes and say, ‘Actually, no, this is absolutely your job. And, regardless of how many tasks or the things you’ve got to do, this is really important. And just reminding people sometimes that, actually, we all have to care.* (Therapists2)

*If you see something that’s bad practice then you need to not let it continue because that could be your grandmother, that could be your mother, so you’ve got to nip it in the bud really.* (Nurses1)

² *This is me* is an initiative from Alzheimer's Society. Patients with dementia have a booklet (completed with them and/or their family) that sets out information about them e.g. likes and dislikes.
There was also reference to further training being organised, following on from Barbara’s Story:

*Instigated more training to have Food Services [trained in] assistance about individual needs, because that patient could be all right but the patient next to them could have dementia. So we put that into their training.* (Non-clinical1)

Staff also referred to leadership from other staff, for example matrons, in terms of care improvement. There were comments in the non-clinical groups about managing staff to ensure the messages from Barbara’s Story are embedded and sustained, for example, through recruitment strategies and monitoring staff:

*When I set out to employ people, they’ve got to have — it’s partly personality and partly communication. The other thing [job role] you can train them to do […] you can’t train people to want to serve people.* (Non-clinical1)

There were also some comments about the importance of team work in enabling staff to put into practice the learning from Barbara’s Story and the Trust values; for example:

*We work together as a team really well to put patients first.* (Nurses5)

*I think having a good team around you as well, it helps, you know, promote all of the Trust’s values, encouraging each other. […] if you’re down you can call the other wards in the directorate and ask for some extra hands, if they’ve got a spare healthcare assistant, so even within the wards everyone just works really well together.* (Nurses2)

### 7.3.3 Challenges and constraints in practice

There was discussion in all the clinical staff focus groups about constraints in practice that affected the ability of staff to apply the learning from Barbara’s Story and put the Trust values in practice. The recurring theme was about lack of time and the need for more staff; see Box 5 for examples.

**Box 5: Time constraints**

*It’s quite hard without the time, that’s what you need to sit and talk to the patient for a while to build up a rapport.* (Nurses5)

*At the end of the day you’ve got to get through a caseload of patients and you’ve only got however long a slot.* (Therapists2)

*The main issue that community nursing faces is the pressure of time.* (Community)

*Time, it’s always time, there’s just not enough hours in the day to look after eight patients, it’s a lot of work.* (Nurses3)

*When it comes down to it and you’ve got to prioritise your work and you’ve got your workload, sometimes you can only do what you can do, and much as you want to keep to those standards, you know, you’ve got to cut corners.* (Nurses1)

*I think, for the best part, people don’t behave in a negative way because they want to: it’s time; it’s all those other extra factors that impact on our abilities to do our job really well.* (Therapists2)

*We’ve got patients on a ward and we’ve got patients downstairs in other wards, we’ve got patients in the day room, they’re everywhere, and we have to be everywhere to look after all of them, that sometimes gets very, very difficult to manage.* (Nurses2)
In one group a participant identified the difference made by having additional nurses in post: 

_They’ve employed a lot more new nurses and so it’s going to reduce that workload a lot more so we have more time to give to the patients._ (Nurses3)

One focus group participant mentioned the impact of stress and the need to care for oneself: 

_If we’re not looking after ourselves so well we’re not able to then put our patients first, that’s sometimes difficult._ (Medical)

Also mentioned were the use of temporary staff, the challenges of caring for patients with varied needs, and the difficulties in achieving consistent good practice by all staff.

### 7.3.4 Practice developments and improvements: summary

Staff identified various dementia-related initiatives in the Trust and how these were reinforced by Barbara’s Story and becoming more embedded in the Trust. These initiatives included *This is me*, the use of the forget-me-not symbol, dementia champions and environmental improvements. Staff highlighted that improvements were supported by influencing others through guiding and teaching, leadership, and teamwork. Clinical staff identified that lack of time was a constraint to applying the learning from Barbara’s Story into practice.

### 7.4 Trust values and culture: It’s almost creating a new norm, isn’t it?

Staff discussed the Trust values in relation to practice and there were also discussions about a culture change as a result of Barbara’s Story.

#### 7.4.1 Trust values in action

Barbara’s Story was presented in the context of the Trust values: Put patients first, Take pride in what we do, Respect others, Strive to be the best, Act with integrity. Participants were therefore asked if they could give examples of how they applied these values in practice. Familiarity with the Trust values seemed particularly strong in the focus groups with therapists and the focus group and individual interview with non-clinical staff, for example, the following discussion took place in the non-clinical staff focus group that the values are realistic and achievable and should be able to be practised:

- They’re not values that you never are going to read.
- Correct.
- I mean, they’re basic, basic stuff. ‘Putting the patient first’: why wouldn’t you?
- Yes. Yes.
- And ‘respecting each other’: why wouldn’t you? So, it’s not that they’ve put things down that are way out of your remit.
- That’s right. It’s the same thing: to treat people like you’d want to be treated yourself.
- So they are achievable. (Non-clinical1)

There was reference to application of the Trust values being a whole approach and embedded in everyday practice:

- _It’s just that kind of customer service approach: that we are providing a service in addition to or on top of the medical facilities, it is that interface with the public and the image that we project of ourselves and the Trust._ (Therapists2)
- _I think I use them [Trust values] all the time, obviously, when I’m treating patients. Yes, every day, coming in to work, even outside, you know, in your personal life and what not, it’s how you treat people._ (Nurses4)

The Trust value of ‘Patients first’ seemed to resonate most strongly with participants and many staff gave examples of where they felt they had put this value into action:
We know the patients, they might not attend [outpatients] because they have other issues that they have to deal with, and we always try to help them and just rebook them as soon as (Nurses4)

For people on the ground reacting to the help desk calls, [...] ensuring that they're putting something right because that is all about the patient experience, whether it be a shower curtain that's not fixed properly, a door handle that's not working, all that's important. (Non-clinical2)

Participants sometimes used phrases like ‘going the extra mile’ or going ‘beyond the call of duty’; see Box 6 for examples.

**Box 6 Patients first: going the extra mile**

You go beyond the call of duty [...] a patient forgot her zimmer frame and she was transferring to another site, so I raced downstairs and eventually I found the ambulance and they were just departing and she got her zimmer frame back. (Nurses3)

In our area, we put patients first. Thinking about the patient all the time. You put them first. You go out the extra mile to make them happy. (Non-clinical1)

Asking that question at the end of your session with a patient – ‘Is there anything else you need?’ – I’m sure is a really basic measure to ensure a patient has that level of satisfaction and feels that they’ve been looked after and that you’ve gone that extra mile. (Therapists2)

Going the extra mile kind of thing, just doing that little bit extra than what you would normally do. (Nurses2)

Staff gave examples of the pride they felt in their work, accompanied by a sense of satisfaction:

> It makes you feel good about yourself as a person when you’ve been able to help. (Community)
> Just taking pride in what you do, you feel better yourself when you know that you’ve done a good job. (Nurses1)

Some staff referred to the wider team and indeed the Trust with pride:

> We have a very good team, very caring and before the Barbara’s Story our team was already there [...] We’ve got a brilliant manager, she is very caring and the whole team is very good. (Nurses3)
> I think our Trust is quite good in delivering care with compassion. (Nurses2)

In the non-clinical staff focus group, the following discussion took place, where staff expressed their pride in the Trust:

> -It’s [Barbara’s Story] opened your eyes up to why people want to come to this hospital.
> -And there are a lot of people that want to come here.
> -And lots of people want to come here because of how they’re treated.
> -Yes. We think we are very good, aren’t we?
> -No, we don’t think: we know we are. We know we are. (Non-clinical1)

There were also specific examples relating to other Trust values, though mainly from the non-clinical staff:

> Integrity: You need to stand up for, in spite of what others think, you just have to do the right thing. In spite of what other people think about you. (Non-clinical1)
> Respect: We always talk about respect to each other within departments and obviously to patients, to visitors, putting signage up so people are aware of what’s going on, what we’re doing. (Non-clinical2)
Striving to be the best: We’re striving to be the best, the patient satisfaction survey, patient experience questionnaire has recently come into play, so that’s a good way of gathering information from the patient, to see what we can be doing better. (Nurses2)

There were also some comments about how the values were embedded in the workforce, for example in appraisal.

### 7.4.2 Culture change

Some participants perceived that there had been a culture change that enabled staff to put patients first as they perceived senior staff would support then, for example:

*Like if we spend a bit longer with a patient, I don't know, if you go and you spend an hour with them on the ward talking things through with them, whereas before people might have had a bit of a pop at you for spending too much time, it may be a bit more acceptable.* (Nurses4)

*A lot of my colleagues have actually stopped people [to help them] through being actively encouraged to stop and it's okay to be late for a meeting rather than walk past somebody.* (Community)

One focus group explored this aspect in detail as a group (see Box 7).

#### Box 7 Focus group discussion: culture change resulting from Barbara’s Story

- I think that it empowers people to be able to challenge [behaviour] because it’s [Barbara’s Story] so high profile. It's relevant and in real time to be able to say, 'Okay, that isn't in line with what we as a Trust are moving forward for.' So I think that's quite beneficial: enables you to challenge negative behaviour as well.

- It's almost creating a new norm, isn't it? […] I think it's increased or raised the bar, as it were. I think that's why it's quite good, doing it in the induction programme, because it's creating a bit of an ethos as to how we're expected to behave.

- It also allows for people to feel it's okay to actually leave the admin side or the paperwork side for the direct patient contact on the ward.

- I kind of feel supported now that, if I don't see three patients, at the end of the day, because I've spent an extra half-an-hour with that person, that's absolutely fine. (Therapists2)

One group specifically mentioned the whole Trust approach to care, following on from Barbara’s Story:

*What I do think has changed is that it much more seems everybody's role now; not just the nurse's role to guide that patient through – or a doctor’s role. And I now very much feel like everybody does that. And I feel like that has changed.* (Therapists2)

### 7.4.3 Trust values and culture: summary

Staff discussed how they put the Trust values into action. The value ‘Patients first’ had a strong resonance and there were many examples of going ‘the extra mile’ to benefit patients. Staff also discussed a perceived culture change within the Trust so that they felt able to spend longer with a patient or to challenge others about their practice. There was reference to standard setting and a new ‘norm’ having been established in the Trust.

### 7.5 Sustaining the impact of Barbara’s Story: it mustn’t sit in a cupboard for ever and not be brought out again

Staff discussed ideas about what should happen next to continue to improve care of people with dementia in the Trust and to sustain and embed the learning from Barbara’s Story.
7.5.1 Care improvement suggestions

Participants made a wide range of suggestions about ways of further improving care and experiences for people with dementia and other vulnerable people; see Box 8.

**Box 8 Suggestions for improvements**

- Pathways/protocols for people with dementia who have other conditions too e.g. hearing impairment, dental problems
- Research to inform the care and treatment of people with dementia
- Network and interest group
- Improving patient feedback
- Involving families more
- Making the environment more dementia friendly
- Familiar items from home e.g. pictures, blanket
- Less confusing appointment systems, e.g. avoid multiple appointments
- Increased equipment e.g. more wheelchairs
- Staff who are skilled and confident to challenge others
- Improved communication for patients including written information
- Better inter-professional communication (e.g. when patients are referred/transferred)
- More specialist support for staff and further teaching and support for staff and students
- Flexible systems so that patients with dementia can be assessed at home
- More use of volunteers

There was some reference to the need to develop more effective ways of recognising that people have dementia:

> It’s tricky, you get these acute confusional states and some people, myself included frankly, it’s hard to differentiate between is this an acute confusional state, [or] is this a baseline, so it’s all very vague. (Nurses5)

> I still think the people don’t always want to admit that, actually, there’s problems. I don’t think there’s as much stigma as there was but I still think that there is a certain amount of reluctance to own up to things, apart from ‘Oh, I’ve forgot a phone number’ or something like that. (Community)

There were a few more general comments about the need for better services and support for people with dementia in the UK, and that there needs to be greater awareness of dementia within the general population.

7.5.2 Sustainability of Barbara’s Story

The need to sustain the impact of Barbara’s Story was highlighted in some focus group discussions:

> I found a big change of staff behaviour as soon as the film came out, I think everybody was very very aware of it but like anything it tailed off. (Nurses5)

> It would be surprising if a one-off session made a complete change, so reinforcing, repeating if you like, keeping it in your consciousness is probably important. (Medical)

> I think, just the fact that we’ve raised the awareness is great. And that needs to be an on-going thing: it mustn’t sit in a cupboard forever and not be brought out again. (Community)

There were some discussions about how the impact of Barbara’s Story can be sustained and built on further, for example, more training and promotion:

> I think that’s a really good initiative that’s been set up by the Trust, and I think that it should continue, obviously with the ageing population, we need to be prepared for it
There was a suggestion that the learning from Barbara’s Story could be sustained through regular reinforcement, and at appraisal, through asking for ‘one example of how you’ve adopted [Barbara’s Story] in your role’. (Non-clinical1). There were some concerns that the second series of Barbara’s Story would not be mandatory (Therapists1) and that this would affect attendance and indicate less importance attached to the films.

### 7.6 Phase 1 focus groups: summary of findings

Most of the staff’s written comments made immediately following the film (Section 6) inferred that they intended to apply learning from the film in their professional roles. The focus groups were conducted some months later and indicated that Barbara’s Story made a lasting impression on staff. The initiative prompted reflection on individual staff member’s own practice and that of others, leading to resolutions for improvements. There was strong evidence that Barbara’s Story raised awareness of dementia and, more generally, patients’ experience and their need for help. Barbara’s Story prompted staff to think more broadly about care provision in the Trust, rather than staff remaining focused only on their own specific practice area and patient group.

The focus group data analysis revealed many specific examples of where staff believed that they had made improvements in their own practice and/or had observed improvements in others’ practice, particularly in their interactions: communication and giving time. Most staff could relate to the Trust values as the context for Barbara’s Story. There was some indication of a culture change, particularly staff feeling able to give more time, and both leadership and teamwork were important factors that influenced application of learning from Barbara’s Story to practice. However, some clinical staff considered that time available posed constraints to being able to give the time needed to people with dementia. There were a number of suggestions about further improvements to care for people with dementia and there were also suggestions about how the learning from Barbara’s Story could be sustained.

### Section 8: Phase 2 focus groups

The findings are presented in themes that emerged from the focus group data analysis. Table 6 presents a summary of the themes and sub-themes and these will be explored next, with illustrative quotations, attributed to the professional group, as presented in Table 3.

**Table 6 Themes and sub-themes**

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8.1 Barbara’s Story as a project: there’s something around her face, the journey, the name ‘Barbara’

Staff discussed the context for Barbara’s Story, the films as an educational device, and the methods of delivery and their merits.

8.1.1 Context for Barbara’s Story

In comparison with the Phase 1 focus groups, there was much more discussion about the context for Barbara’s Story in Phase 2; perhaps staff had become more aware of national policy and Trust drivers. Some staff referred to the growing number of people who are living with dementia within the population:

- There is an initiative to recognise that dementia is a growing issue and with the population age getting older. (Nurses8)
- With the ageing population, I think it’s about time something is put into place. (Nurses1)

It was expressed in one group that dementia has become ‘a bit of a mantra in the NHS’ (Medical). From a Trust perspective, staff referred to: policies on dementia, a dementia campaign, a strategy, a dementia week celebration, a drive to increase dementia awareness with targets to meet, the Trust values as a context for the project, and the Commission for Quality and Innovation (CQUIN) target for dementia. It was discussed how dementia was now high on the Trust’s agenda and was being recognised as being relevant to all areas of the Trust: The word ‘dementia’, is on people’s lips and in the arena’ (Nurses3). As in the Phase 1 focus groups, staff expressed pride in working for a Trust that had initiated such a project:

- [The Trust] really grabbed dementia and did something really good about it […] actually did something very innovative that makes a difference. (Non-clinical1).
- This Trust is very good, and the way that they have pushed this whole dementia thing and Barbara’s Story. (Nurse11)

Thus overall, staff discussed Barbara’s Story within a broader context and the national and local drivers for the project.

8.1.2 Barbara’s Story as an educational device

Whilst the Phase 1 focus group participants considered that Barbara’s Story had gained a high profile within the Trust, there was considerably more discussion about this in the Phase 2 focus groups, indicating a gathering of momentum. Barbara’s Story was considered to be supporting dementia to become ‘high on the Trust’s agenda’ (Medical) and a ‘brand’ or a symbol for dementia care in the Trust:

- The impact it’s had on the hospital as a whole, and the fact that it’s really become… like everybody knows what Barbara’s Story is. (Therapists1)
- I think she’s become synonymous, I think she’s almost like a brand in herself, and I think there’s something around her face, the journey, the name Barbara. (Nurses3)

Barbara’s Story was referred to as a ‘shorthand’ for dementia so that ‘you talk about Barbara’s Story, everybody understands the reference’ (Nurses2); ‘You say Barbara’s Story, everybody knows exactly what you mean’ (Non-clinical1). ‘Barbara’ also became synonymous with someone who needed help in the hospital corridor:

- I’ve actually heard people come back to my office and say, ‘just met Barbara in the corridor, had to take her up to the eighth floor or the eye clinic’ or where ever else it is. (Non-clinical2).

Another staff member referred to consultants saying of patients with dementia who needed support as: ‘this is Barbara in the flesh here’ (Nurses1). It was expressed that the project had not only raised awareness of dementia but had demonstrated the complexity, and raised the profile, of older people’s nursing in general, engendering a pride in staff working within this field and redressing the sometimes negative perceptions about older people’s nursing
Barbara’s story was also considered to be one of the best projects the Trust had initiated (Nurses8).

Staff identified that the purpose of Barbara’s Story was:

*To be able to give people a journey with one person, a very emotional rollercoaster for this person to go through [...] this is about somebody living with a condition, it’s not about coming into hospital because you’ve got a dementia, it’s about living with a condition and dying, still with that condition over your head but not dying from that condition.* (Nurses3)

It was also identified that Barbara’s Story aimed to show staff that people who have dementia could be treated anywhere in the Trust: ‘everybody will have people with a dementia diagnosis in their wards’ (Nurses3). It was recognised that as well as telling the story and raising awareness, Barbara’s Story aimed to educate staff as there were ‘certain teaching points they wanted to get through as well’ (Non-clinical2) and staff identified that they had learned about supporting a person who has dementia or delirium and how to meet the person’s needs. Staff discussed specific learning from the films, for example learning about communication skills with people with dementia and the importance of nutrition. Some groups commented on the learning needs highlighted by Barbara’s Story: that staff needed to change their approach, and also the lack of understanding about the difference between dementia and delirium (Nurses4).

There were many positive comments about Barbara’s Story, for example: ‘very powerful’ (Therapists1; Nurses5), ‘outstanding’ (Nurses1), ‘high impact’ (Nurses3), ‘touching’ (Nurses3), ‘very cleverly written and acted’ (Nurses5), ‘very delicately portrayed, it’s very sensitive’ (Nurses6), ‘Really amazing [...] a very great success’ (Community) ‘the whole idea was fabulous’ (Non-clinical1). As in the Phase 1 focus groups, there were specific comments about the films being more effective than traditional teaching methods:

*It just made me realise how real it actually is, rather than just reading about it in a PowerPoint presentation.* (Nurses5)

There were many other positive comments about the effectiveness of Barbara’s Story as an educational tool.

As in the Phase 1 focus groups, some staff referred to initial scepticism about the project when the project started but this had been overturned as the project unfolded:

*We were being made to go to something, but basically the whole point of it was the patient getting the best patient experience and making sure the patient was in the best place, so probably I’ve been turned round and made more aware of dementia and the accompanying systems since Barbara’s Story.* (Therapists2)

*I think all of these things can almost come across a bit ‘Oh really? Are we going to watch a video?’ ‘I think I know what a patient with dementia looks like’, and actually it was more far reaching than that and I think that was very nice, it was a nice surprise.* (Nurses3)

It was expressed that some staff viewed the second series as being: ‘oh more film about dementia, more dementia, more dementia’ and that showing trailers to create interest in the next film might have helped attract more attendees (Nurses4). Another perception was that staff:

*Really don’t want to be told how to do all the soft, fluffy stuff because actually we haven’t got time for that and that’s all gold standard but actually in the real world, this is how nursing is.* (Nurses4)

Some negative attitudes were also encountered initially from staff working with children, who were reminded that:

*Children don’t exist in isolation, they’re part of multi-generational settings. You might have a child whose parents go out to work and it’s the grandparent who’s the carer. That person might be presenting with, you’re the health visitor going in, actually you’re trained across the life spectrum.* (Nurses4)
In the Phase 1 evaluation, a nurse working with children admitted to questioning the requirement to attend Barbara’s Story but then expressed that the session was really valuable (see 7.1.3).

A key feature of Barbara’s Story was that the films showed her experiences from her perspectives, which allowed staff to be more empathetic and there were many positive comments about this feature:

I think it’s seeing it from Barbara’s perspective the whole time, that’s what makes the difference [...] lots of other resources that are developed to help you think about dementia or dignity are actually about observing somebody, so looking at somebody and trying to identify what you might do, whereas this was from her perspective, what she was seeing so that it helped you to get a richer understanding of how people perceive an environment that we’re very familiar with. (Nurses2)

Staff were able to ‘see everything from the point of view of a person with dementia’ (Nurses5) and gain insight into ‘what it’s like from the other perspective’ (Nurse11). Barbara’s Story put staff: ‘In the shoes of Barbara [...] the point of view of a person with dementia, with disorientation’ (Medical). Staff expressed that seeing experiences from the patient’s point of view: ‘it really makes you stand back and think about what they’re experiencing’ (Nurse10).

There were many images from the second series that staff recalled. As in the Phase 1 evaluation, often it was negative staff behaviour in the films that seemed to leave the strongest impression and evoke an emotive response from staff, and the feeling of wanting to help:

The fact that people weren’t getting messages across and I did find that very emotive watching Barbara becoming more and more confused, like in A&E and thinking oh come on, she’s just there, just go and talk to her, go and hold her hand, and I noticed that amongst a lot of my colleagues as well that people did have quite an emotional response to that. (Therapists2)

For me some of the most powerful ones, I can’t remember which one they were, was the daughter not understanding, people not having time to give her the information. (Nurses3)

Barbara receiving a lack of explanations was another part of the storyline that many staff commented on. Staff particularly remembered the scenes in the first film: a lack of explanations from the receptionist and the doctor in outpatients, whilst also remembering the general manner of these individuals in the films and, in particular, a feeling that they did not treat Barbara as a human being: ‘see her as a person’ (Nurses6). These images evoked anger in some staff:

The way the reception was, I was getting really angry, [...] you can’t treat another human being like that, she clearly looked confused and lost. (Nurses5).

Other staff however commented that she was bombarded with information at other times:

The way that information is given to Barbara, there are lots of people talking to her and telling her all these things, come here, do this, you've got this appointment. (Community)

The way different staff behaved and whether they treated Barbara as an individual drew comment:

The difference between different people in the approach where someone tried to put her in a more comfortable position, others just acting by protocols without realising that she would need a special kind of help. (Medical)

Staff recalled many instances of what they considered to be a lack of care for example, Barbara’s meal tray being taken away when she had not eaten anything (Nurses9) and Barbara falling in A&E because: ‘she was in her stocking feet. She was just left lurking about on her own’ (Non-clinical2). Staff remembered Barbara being told that her husband was dead and her distress: ‘One of them said, “he’s dead”, which just seemed really harsh’
(Community). These examples illustrated the impact of such experiences across the whole patient journey:

What was good, it showed in detail the different parts but then how important each part is on the patient’s journey and like one negative will rule out 50 positives because it’ll be the one negative that will have the most negative impact on that person on the day. (Non-clinical1)

However, there were also examples of more positive behaviours that made an impression. The interactions of the healthcare assistant who was providing one-to-one care to Barbara made a strong impression with several staff commenting positively, for example, that she went:

Out of her way to speak with Barbara, to teach the daughter how to deal with eating, how to do the repetitive feeding etc. (Nurses2).

Other positive comments related to the communication of some staff who used touch and eye contact in their interactions, gave explanations in a way that Barbara could understand and related to Barbara as a person, which promoted her dignity: ‘when the nurse was talking to Barbara, [she said] “I saw that you used to be a teacher”’ (Nurses7). Staff remembered Barbara being brought tea in a china cup and this was an important teaching point about the value of using familiar objects in the care of people with dementia. However, one of the focus groups reported that they had never observed china cups in the Trust, and that their patient surveys indicated that patients prefer disposable cups as they believe them to be more hygienic (Non-clinical2).

Many staff commented on the storyline being realistic and lifelike and that they could identify with the characters and scenarios: ‘it’s almost like seeing a pattern of events that you can relate to patients that you see in hospital’ (Nurses8). Staff also commented that the second series of films helped viewers to ‘get more context to that patient’s journey […] I think it makes me think that there is more going on’ (Non-clinical1). The films highlighted for staff that all their older patients have a history and that:

Kind of opened my eyes to the fact that somebody has lived a full life […] there’s a lot that that person is carrying in terms of their memories and the experiences that they’ve had. (Nurses1).

Similarly other staff recalled that ‘Barbara’s job was really important to her’ (Nurses6).

There were particularly positive comments about the films showing Barbara’s whole experience across both hospital and community services – the whole patient journey (Nurses1):

I think from the community perspective it was lovely, it was fantastic to see community members of the trust represented as well. (Therapists2)

The community team’s focus group also recalled vividly the scenes shown in Barbara’s home, when she was struggling to cope, and staff commented ‘that was quite a good representation’. The community team however would have liked to see more of the series set in the community showing Barbara managing in her own home and how the carers worked with her as ‘quite often people are different in their own homes to hospital’. Some therapists commented that:

Perhaps in the community they could have actually drawn on the MDT a bit more to show the difficulties and a level of empathy that’s needed on an ongoing basis working with people in their homes. (Therapists2)

Therapists also expressed that the films were somewhat nurse and doctor focused and that the contributions of other staff could have been more prominent. Community staff made a similar comment that it would have been good to show more of the therapists’ contributions in the rehabilitation process. The community focus group also commented that while in an ideal world, care packages work out well, it might have been insightful to illustrate what happens when the care package is not working so well.
Some non-clinical staff made defensive comments about the films’ content, particularly in relation to interacting with patients and reporting back to clinical staff, for example, if a patient did not eat their meal. Some staff considered that the films portrayed little by way of behaviours that staff find challenging, for example, when a person with dementia ‘can suddenly turn up violent and start swearing all the time or screaming all the time’ (Nurses6). It was felt that this was because end stage dementia was not shown as Barbara died of another condition before her dementia deteriorated too much. It was also acknowledged that there needed to be a balance between reality and audience engagement and that in one set of films it ‘was difficult to encapsulate everything’ (Therapists2). A few staff commented that for the films to remain effective, there would need to be some updating as clothing worn and techniques used in care might change over time.

Many staff gave examples of how Barbara’s Story prompted them to reflect on their practice, enabling them to view healthcare and everyday practice through a different lens:

When Barbara was coming in and out of her ability to make some of those decisions and some of that state of flux of her capacity, which then sort of made you think, actually what do we do in those situations, do we hold decision making or do we become very paternalistic? Do we just say ‘Actually we have to do everything for people’, take over and almost sometimes make it worse. (Nurses3)

I think that’s had an impact, again for people to reflect a bit on actually it’s not just about the tasks we deliver, it’s about putting the chair back, it’s about asking, ‘are you lost, are you okay’ and that sort of aspect. (Nurses4)

The films prompted staff to reflect, ‘if I was there what would I do?’ For example:

It’s almost like seeing a pattern of events that you can relate that to patients that you see in hospital and you’re trying to think of a way you can intervene to stop that from happening, all these points where you think: oh someone should have said this, someone should have documented this or flagged it up, waved the red flag for her to be helped. (Nurses8)

You get sadness, you get, could we do more? Could she have been treated better? [...] you start to question yourself: what could I have done if I was there? (Non-clinical1)

Other staff specifically reflected on whether the behaviours shown in Barbara’s Story mirrored their own and their realisation of the need to improve. They particularly commented on communication and making time for patients (see Box 9).

**Box 9 Reflecting on own behaviour**

Our choice of words, our choice of phrases, we go along and say really daft things and actually we need to think more about the words that we use to have a better impact on somebody, including the care. (Nurses4)

It really does make me think about actually we’re saying ‘this is what good practice is’ and we need to just stop saying sometimes we’re too busy and we need to take stock of how people live. (Nurses4)

It’s remembering actually that might be the 50th person you’ve said hello to today but it’s actually their first time they’ve met you and I think Barbara’s Story is really a way of reminding us of that, that we should treat everybody how you treat the first person. (Non-clinical1)

You do have those patients that you just sort of feel need a bit of a check, just to make sure that they’re okay and you know that you can’t get that for those people on an ongoing basis, and it just hit home actually, there is a need for that and what can happen if that gets taken away. It was very sad. (Community)
There were specific comments about insights into family experiences too, in particular, the awareness of family situations and the need for support:

You've got to remember how it impacted on the family members as well, like when the daughter came in and she didn't understand what was happening to her mum and the mother couldn't remember her, you know how upsetting that would be to somebody if they hadn't seen this before. (Nurses6)

8.1.3 The delivery of Barbara's Story

As in the Phase 1 focus groups, the Chief Nurse's leadership of Barbara's Story was commented on positively: 'I think it carried a lot of weight' (Therapists1); the commitment shown by her continued delivery of the first film was acknowledged and her leadership was said to ‘create permission for other people to devote the time to the subject’ (Non-clinical2). Local leadership was also considered important; the Dementia and Delirium team liaised with locally based dementia champions and ward sisters, providing the training packs with the DVDs and reminding them that they could see Barbara's Story on the intranet too (Nurses1).

There was much discussion about how Barbara’s Story was delivered within the Trust and indeed how it might best be delivered in the future. Staff discussed the different modes available and their merits: the large screen viewings, intranet availability, YouTube version, and the films being embedded in dementia training days. Discussions relating to each of these are presented next.

Many staff believed there was much merit in the large screen viewing with facilitated discussion and the interprofessional format, with staff of different backgrounds, varied knowledge levels and views, was also well supported (Therapists1, Medical staff). The whole Trust approach used for the first film was particularly liked:

That’s the main thing that I’ve got from it, is seeing how much difference it’s made to everybody kind of having the same sort of teaching, because there’s nothing really that as a hospital as a whole, with different professions and doctors, nurses, porters, whoever, all getting the same teaching. (Therapists1)

In a number of the focus groups staff talked of Barbara's Story as being a shared experience of one patient ‘Barbara’, which was different from the individual experiences with patients that all staff experience:

Everyone has a shared experience of a patient and understands that patient as if it was their own person [...]. We all have experiences probably of patients that we've stopped to help or patients that have come in for some sort of treatment that have impacted on you, and that shapes your future care that you give or your learning or you share that with an immediate team. But this was an experience that everybody has shared at the same time, and it felt real. (Nurses3)

Other staff made similar comments with Barbara's Story being described as ‘unifying’ (Non-clinical1) and that Barbara's Story:

Kind of united us, it was we are watching this film and this is what we’re learning and this is how I feel, and I feel what they felt, we’re in this together and shared experience, it’s a shared experience across the trust. (Nurses2)

The mandatory nature of the first film created an imperative to attend, with staff being able to:

Justify taking that time out of your clinical work because actually this is something you have to go to and you need to go to and everyone wanted to go and see it. (Therapists1)

In the Phase 1 evaluation, there was some dismay expressed that the second series of films would not be mandatory (see section 7.5.2). In the Phase 2 focus groups too, a number of staff expressed that the second series should have been mandatory as staff found it more
difficult to prioritise seeing the second series of films over their clinical work. With the first Barbara’s Story film, staff with management responsibilities had a requirement to make sure everyone could attend: ‘because it was compulsory, I had a list of who had been and was trying to help them to free up time so they could go’ (Nurses2). The importance of managers supporting staff to attend the second series was especially emphasised; some managers, it was asserted, would always find a competing deadline to take priority and prevent their staff attending (Non-clinical2).

It was commented that there were more showings of the first film, which was shown over many months, several times weekly. Some staff commented on there being fewer showings of the second series and that it was rolled out rather quickly so staff found it difficult to catch each month’s viewing. For some staff, the films clashed with ward or unit activity, for example, lunchtime, and it was difficult to release staff on busy wards or departments:

Timings didn't work well with department workload and pattern […] more would have liked to have gone. (Nurses5). 

With the best will in the world, none of our wards, they wouldn't not want their staff to go but on the day, when it's ten to one and the film is being shown at one and lunches aren’t finished etc., then you’re not going to leave ‘Barbara’ to go and watch Barbara. (Nurses2) 

The difficulty for ward-based staff to leave the clinical area for an hour’s training was reinforced by the difficulty that the research team found in gaining their attendance at focus groups off the ward.

There were various other reasons discussed as to why attendance at the second series of films was lower. Some staff perceived that colleagues in some specialities possibly did not see the topic as being so relevant to them whilst ‘I suspect that people involved in general medicine have more interest and involvement in this project’ (Medical). There was also a point made by night workers that it was difficult for them to attend a session (Non-clinical1). However one staff member in this group expressed that a personal interest in the topic had prompted them to work late so they could attend:

There was no problem with me getting there. I'll work late, I don't mind, but colleagues, as soon as it's not mandatory, that's it. (Non-clinical1) 

Another comment was that for some staff, the topic was quite personal and thus, as it was not mandatory, they had chosen not to attend as they found it upsetting (Nurses5).

Since the initial showing of the second series of films (September 2013-March 2014), the films had been installed on the Trust intranet. There were many comments that this format provided additional flexibility for staff and a number of participants had watched some of the films using this format. There were some very positive comments: ‘It’s brilliant that you can watch it online as well’ (Nurse10). Some staff had used a ‘mix and match’ approach, seeing some in the large session and others on the intranet. Some staff had been directed to the intranet films from other training. There was reference to releasing a few staff to watch it together so that they could have some discussion. In one focus group, participants commented that they could have a more in-depth discussion in a small group watching Barbara’s Story on the intranet, rather than in a large lecture theatre (Nurses5). There were also examples of staff in managerial positions planning in time for staff to watch the films on the intranet.

Whilst overall the intranet format was seen as a positive additional resource, some staff nevertheless expressed that watching the films in a session with facilitated discussion was preferable. There was concern that without a facilitated discussion staff may not realise the areas where care was suboptimal, for example:

I think some of the episodes, I think particularly episode two, I remember sitting there thinking ‘This is alright care, this is alright’, and then at the end the speakers and [Chief nurse] said ‘Oh this could be done better’, and I’m sitting there thinking ‘Oh
gosh, if I’d watched that on my own I think I would have just said “Oh that’s alright”, because it’s like they weren’t unkind, they were trying really hard, they were offering her a cup of tea, telling her to sit down and do all of those things that you hear and you see all of the time, and actually the expectation from the Trust wasn’t that.

(Nurses3)

Non-clinical staff expressed that they had felt entirely comfortable to contribute to discussions in the large group screenings (Non-clinical2). There were comments that the ‘top tips that the dementia nurses gave’ were very valuable (Nurses3). In addition, Barbara’s Story was perceived by some as more powerful when shown on the large screen (Nurses4). Another view was that watching the films at a study day was more feasible than on the intranet as there would not be time to watch the films on the ward (Nurses8). There were some technical issues mentioned in relation to access on the intranet, for example, that the films could only be accessed at work and some staff expressed that accessing a computer was difficult as they were all in use for clinical purposes. Another issue raised was that some computers had no sound; there was discussion about the need for ‘sound cards’ and headphones but some staff were unaware of how to access these (Nurses2). Some staff groups did not consider it feasible to watch the films while at work, for example receptionists (Non-clinical1). There was a further issue in that community-based Trust staff could not necessarily access the Trust intranet (Nurses1). One focus group expressed the hope that large screen sessions would continue and that the film would not just be ‘stuck on the intranet’ (Therapists1). Perceptions of the intranet option varied widely; in one focus group a participant expressed that concentration was better with intranet delivery but another expressed that they could not concentrate at an intranet session (Nurses5).

As regards the YouTube version, some staff made positive comments, viewing this as a further option that increased flexibility. The fact that staff could access it so easily on their phones was considered a benefit (Nurses9). However some staff were concerned that this version did not include the learning points and could be misinterpreted by viewers. The particular example referred to was when a nurse tells Barbara that her husband is dead. Staff expressed concern that viewers seeing this without the facilitated discussion, might believe that this is the correct way of handling such situations. Other staff believed that in the condensed version, the presentation and lack of detail reduced the informative nature of Barbara’s Story (Therapists2; Community). One staff member said: ‘I dislike the way it’s put together, it’s timeframe, the bits it shows, the bits it leaves out’ (Non-clinical2). However in the same group a more positive view was that:

It will be interesting to see how many hits on YouTube wouldn’t it. Be amazing because then you’ll see how many people are actually taking note of it.

Staff also referred to other ways in which Barbara’s Story is delivered. Several staff had seen Barbara’s Story at Trust induction and there was strong support from participants that embedding Barbara’s Story in induction for all staff was important. In another focus group, it was considered that the whole series should be mandatory for new staff but with the series watched during the probationary period, discussed with a supervisor, which will ‘support all new starters, acknowledging the culture that we’re hoping to maintain’ (Therapists2). Some had seen the whole series as part of the dementia training day. Watching all the films together was considered an efficient way of seeing them all but it was perceived as intensive and: ‘it can be quite a lot to take on board when you see all six’ (Nurses7). Others considered that seeing all the films together would lose the impact and be ‘overwhelming’ (Therapists1). However, the Community staff focus group had seen all the films in their own setting in an arranged facilitated session and they did not comment negatively on the experience. Similarly in another focus group, staff expressed appreciation that the films had been brought to them, which reduced travel time between sites: ‘Barbara’s Story came to us’ (Non-clinical2).
Some staff expressed concern that agency staff in the Trust may not have seen Barbara’s Story. Also the high turnover of staff was mentioned with the related need to continue showing Barbara’s Story so that it did not become ‘something that happened in the past’ (Therapists1). There was also a view that Barbara’s Story should be rolled out across local boroughs (Nurses6) and there was a particular comment that junior doctors needed to see the film because, it was said, they had often never worked with older people before and ‘I think they’re scared sometimes when they come to us’ (Nurses7). Another view was that patients should be familiarised with the project as it was felt they would find it reassuring (Nurses9).

8.1.4 Barbara’s Story as a project: summary

In comparison with the Phase 1 focus groups, there was more discussion about the context for Barbara’s Story in Phase 2, from both a national and a Trust perspective. Staff considered that Barbara’s Story had gained a high profile within the Trust; there seemed to be a gathering of momentum with Barbara being considered a ‘brand’ and a way that staff could communicate about dementia in the Trust. There were many positive comments about Barbara’s Story; the films were considered powerful and an effective learning tool. The way in which the films showed Barbara’s Story from her perspective was considered particularly powerful: being ‘in the shoes of Barbara’. Staff vividly recalled many of the images from the first film as well as from the second series. Staff particularly liked how the series of films showed the whole patient journey through hospital and community care. There were many examples of how the films prompted staff to reflect on their practice.

As in Phase 1 focus groups, staff commented on the Chief Nurse’s leadership of the project positively. Staff expressed that Barbara’s Story was a shared experience in the Trust. Staff discussed the different modes of delivering Barbara’s Story that are now available and their merits: the large screen viewings, intranet availability, YouTube version, and the films being embedded in dementia training days. Many staff considered there are particular benefits to the interprofessional sessions with facilitated feedback to draw out learning points. However the flexibility and accessibility of the films being on the intranet were also appreciated. Many staff considered that the second series of the films should be mandatory.

8.2 Effect on individual staff: this film has changed my way of dealing with people

Staff discussed their emotional engagement with Barbara’s Story and the feelings provoked in themselves and other individuals. They discussed the increased awareness they believed they had developed in relation to dementia and delirium and the nature of good dementia care. They also discussed the impact of Barbara’s Story on their own interactions and behaviour.

8.2.1 Emotional engagement

Staff gave many examples of their own emotional responses to the films, for example, feeling sad, upset, distressed, frustrated, happy, guilty and at times angry about Barbara’s experiences. As in the Phase 1 focus groups, some staff recalled that the films had moved them to tears. The film was described as being evocative and:

*It’s not entirely always clear what’s personal and what’s professional, so there’s always a bit of an overlap, but yes I think that people have found it hard to watch some of it.* (Nurses2)

From a professional viewpoint:

*I think most of us were still quite affected by the power of the emotion, partly because they are the patients that I deal with primarily in my role.* (Nurses4)
It was also expressed that there had been some ‘very emotional responses from staff who felt guilty because they haven’t done the best for their patients’ (Nurses4).

Despite the emotions prompted, nevertheless: ‘it’s still very important to raise awareness of dementia’ (Nurses5). The project team were aware from the start that staff might be affected emotionally both personally and professionally and so Safeguarding team members were available to offer support and staff were told: ‘If you can’t stay then go, if you need support then someone will be there for you if that’s what you want’ (Nurses1). The widespread connection that staff felt with Barbara was expressed in this comment:

> What I’ve heard anecdotally, is that everybody because of the range of the films has had something that they can connect with on a personal and on a work level, so it’s hit people in both ways. (Nurses1)

Staff referred to feeling emotional in certain scenes, for example, when Barbara was remembering her husband Len:

> It was quite distressing at times to see this poor lady that was having this problem trying to struggle through everything and thinking that a doctor was her husband, you know, it was very hard from the patient’s perspective. (Nurse11)

Some examples provoked anger, for example, the way the receptionist spoke to Barbara in the first film (Nurses5). Other scenes that were found distressing in the first film were when Barbara was pulled backwards in a wheelchair (Therapists2). Staff recalled Barbara’s aloneness, feeling lost, and the effect of all the different voices around her (Nurses3). They perceived that Barbara was confused and disorientated and ‘needed somebody to sit with her and explain what was going on’ (Nurses7). The final film, where Barbara died, had a particular impact on some staff, triggering sadness, especially if staff had family members who were near the end of their lives.

Staff also related the film to their own experience: ‘everybody knows somebody that’s like Barbara and you visualise then being in that situation’ (Therapists2). Staff often related to the films from quite a personal perspective, for example, that they themselves could develop dementia in the future: ‘it just makes you realise it could be you’ (Nurses5). Another focus group expressed:

> It does trigger for a lot of us who are looking at retirement in the not too distant future, how many of our colleagues potentially have dementia waiting for them. (Medical)

Others linked the films to their personal experiences as a relative of someone living with dementia:

> One of the family is going through the stages and I can reflect through the films, you know, what is going on and how they see and how they view the world and the things around them (Nurses1)

> For me it was when she [Barbara] couldn’t recognise her daughter and that happened to my brother in law. (Nurses5)

A few staff mentioned that they knew of colleagues who chose not to attend the second series of the films as it was ‘too close to home’ because of their current personal situations, for example:

> One particular colleague of mine had to say this is too difficult for me, but was glad it was happening because it was raising awareness around what her family were going through […] because of her position at work she didn’t want to be seen to be out of control emotionally in front of colleagues. (Nurses2)

A staff member who had been a facilitator recalled that Barbara’s Story highlighted how many staff in the Trust were carers of relatives with dementia as after each session, staff would:

> Come up and talk about their own experience. Saying: well actually my mother, my grandmother, my great-grandmother, my neighbour, and it really flagged up issues in terms of what it meant to be if not a direct carer, just be a family member of someone
who has that sort of cognitive impairment or dementia illness. I suppose you tapped into an unknown issue there. (Nurses4)

It was discussed that the Trust initiative led to staff feeling able to disclose that they were a carer of a relative with dementia, rather than hiding this from colleagues (Non-clinical1). There were also instances of staff recognising, from attending a session, that their relative could have dementia, and then following this up:

After I watched it I went straight back to my mum and I said there are chunks of what she was doing that I've seen in my granddad and for me it made me a bit upset, I thought I'm going to get this sorted because it does make you more aware. (Nurses5).

I've known two or three people who've actually come out of seeing one of the films and realised that their parent has dementia. They've never seen it as a whole story, they've recognised something and they were supported by the safeguarding team. (Non-clinical2)

8.2.2 Increased awareness and understanding

There were many comments about staff having increased awareness of dementia: ‘this has actually enlightened so many people’ (Non-clinical1) and this was across all groups of staff, including transport staff (Nurses7). Others acknowledged however that the increased awareness of dementia could not definitely be linked to Barbara’s Story:

My feeling is that there is more awareness about dementia and more capability to pick up the early signs, any signs suggesting that the patient may have this problem, but whether or not this is related to Barbara’s Story I don’t know. (Medical)

Staff seemed to have taken on board that many people attending hospital for other health issues could have dementia as well and that they could be anywhere in the hospital:

[dementia] is seen as as important as the heart failure that might have brought them into hospital. (Nurses3)

Everybody will have people with a dementia diagnosis in their wards. There is no way that you won’t, because they are entitled to treatment. They're living with a condition but they will be susceptible to every other condition going. (Nurses4)

Staff perceived that Barbara’s Story had prompted them to look more closely:

Another additional thing is just how many assumptions we as healthcare professionals make about people, just because of how they may appear on the exterior, and that people may be okay without checking [...] I think that many more people need our help than we realise. (Medical)

Similarly, nurses expressed that their greater awareness led to them suggesting dementia screening for specific patients (Nurses9). Barbara’s Story had also increased staff awareness of people outside their own area of work who might need help and some described how they had applied their increased awareness away from the Trust and within their everyday lives. The increased awareness had prompted some staff to raise money for dementia during Dementia Awareness Week (Nurses5).

Staff referred to developing a better understanding of both dementia and delirium. There were specific examples of understanding that a person with dementia might express memories from when they were younger, for example:

‘Oh, my baby’s at home, I need to look after’, a memory that was years ago, but they think it’s just yesterday that I left my child at home. (Nurses7)

Understanding dementia better led to staff feeling more confident and better able to cope and support patients:

I guess a little bit calmer now in a sense, just a little bit more relaxed, that this is completely normal for that patient, so it helps us to understand that a little bit more. (Nurses12)

After seeing the video it makes those kinds of patients easier to speak with and it also reassures you, so for example in the video it talks about not taking them out of
their own reality, and I think that just reassures people that you can distract them and not ‘lie’ to them and that’s okay, and I think that’s reassuring to people that don’t know that much about dementia. (Therapists2)

It was further highlighted, that the greater understanding led to a more empathetic approach:

Once you have that insight [into dementia] it’s quite comforting to know what’s going on with a patient, it makes you a bit more empathetic as a nurse as well in terms of dealing with that patient. (Nurses7)

Staff identified that although they had encountered patients with the appearance of delirium, as shown in Barbara’s Story, they had never previously explored this condition (Nurses4).

Staff had also gained awareness of the tools available that could help them: ‘the This is Me document and the delirium bundle and the dementia pathway’ (Nurses3).

As section 8.1.2 discussed, many participants commented on how the films enabled them to appreciate the patient’s perspective. As a result of the techniques used, staff developed an increased awareness of patient experience. In particular many staff better appreciated that the hospital environment, so familiar to staff, could be alien and frightening to patients, particularly if they have dementia:

Although this is a completely normal environment for us, people coming into the hospital find this actually a very alien and strange environment. (Therapists1)

A hospital is very disorientating for people regardless of your cognitive state and I think then if you have a cognitive problem it’s very scary. (Medical)

Seeing the experience from a patient’s perspective prompted staff to realise that they made assumptions about what patients know:

I think the outpatient experience for me, outpatients, you kind of just think they know what to do and they know where to wait and where the toilets are, you take that for granted. (Nurse10)

The experience of when she’s having various tests and going to various different departments, I think again we make assumptions that for us as hospital staff it’s so familiar to us, but just the guiding somebody through what to expect next. (Medical)

Both clinical and non-clinical staff commented on how Barbara’s Story increased their awareness of patients’ sensitivity to staff behaviour and the impact of that:

They pick up on everything, you think they’re not paying attention to you but that little nod or smile that you’ve given them. […] or that little huff they pick up on, and it might not be directed at them but they’ve picked up on that instantly, and that’s it, that’s a bad experience. (Nurses5)

Obviously you walk in a hospital, maybe you waited for bad news or good news which could be a life changing situation for you and the last thing you need is a miserable receptionist or porter. (Non-clinical1)

This group also highlighted the role of individual staff in a patient’s experience:

It’s not the building who makes you welcome, it’s the people. If you found the right person at the right time, you will have a brilliant experience. If you get one wrong, it will go out of the window. (Non-clinical1)

The film reminded staff of the importance of approaching people as individuals, rather than numbers, and not to:

Forget our humanity then, and not get caught up in numbers, how many patients you’ve seen go through the clinic, time issues. (Therapists1).

Similarly, staff recognised the value of:

Just being human and empathetic, just forgetting okay I’ve got X amount to do, but looking at your patient, how are you, what do you need, simple things. (Therapists1)

Staff recognised that each older person had a history and that it was important to get to know the person as an individual and take a more holistic approach:

Doctors need to realise how important this background is, so behind any patient there is a person with family, with interests, with a past and memories and so on […] this is something that I think modern medicine is lacking and we should engage
people in understanding this, and this will certainly improve the relationship between doctors and patients. (Medical)

Staff discussed that knowing about the person and their history helped in building a rapport (Nurses7) and they identified the importance of understanding what is important to individuals, a point that was reinforced through Barbara’s Story (Nurses1).

Staff also discussed their awareness of what detracts from good care for people with dementia. A key issue was a lack of skills and knowledge, sometimes as a result of inexperience or fear (Therapists2). Staff discussed that inflexible hospital routines and the ‘very clear, unspoken rules in acute hospitals’ along with a lack of understanding about dementia can lead to responses like:

‘Oh my god he’s got his coat on and he wants to go’, rather than, actually he’s got a sense of purpose and it’s because something has caused that pain. (Nurses4)

It was further discussed that some staff were ‘obsessed with’ making patients sit down while ‘actually people can walk around for an hour, then they’ll sit down when they’re ready’ (Nurses4). Inflexible hospital routines would not allow for patients who wished to get up later or have breakfast at a different time (Nurses4). There were discussions about how task-focused approaches in hospitals detracted from good quality care for people with dementia (Nurses1) and there can be a lack of attention to psycho-social aspects of care (Nurses4).

It was discussed that as observed in Barbara’s Story films, people are often busy and:

Rushing around avoiding eye contact so they don’t have to be taken away from their job or task, and as a healthcare assistant I can see that a lot, that happens on the wards when people are busy. (Nurses8)

A further issue that was believed to detract from good care related to being disease-focused which led to a lack of focus on the whole person: and the concern that then:

Nowadays in medicine we don’t even see the whole patient, we see just the organ, so we are another step behind, so we treat kidney, heart, bowel, liver, without even realising that there is a whole person and behind the person a personality. (Medical)

In several focus groups staff discussed concerns that a diagnosis of dementia could mask other problems and the person’s voice could be lost, with the person being ‘defined by their disease’ and yet ‘sometimes they want something really simple or have a genuine upset that’s nothing to do with being confused’ (Nurse11).

5.2.3 Interactions with patients and behaviour

Staff discussed extensively, and gave many examples of, how they believed Barbara’s Story had influenced their own interactions with patients, for example, giving more time, better explanations, listening and reassurance. One focus group participant commented:

I think this film has changed my way of dealing with people and not even just dementia, but just any mild disorder of consciousness or awareness of personality, so I would recommend everyone to have this involvement and experience because I think this will make you a better doctor. (Medical)

As in the evaluation of Phase 1, there were many examples of staff assisting patients in the hospital’s reception area or corridors, when they appeared lost or confused. These changes in behaviour were believed to be a direct result of the powerful images of Barbara in the first film being lost in the corridor trying to find the toilet:

If you’re anywhere in the hospital and you see somebody that might be looking a bit confused or lost you can approach somebody and say ‘Can I help you?’ (Nurses7)

The scenarios described closely resembled examples given in the Phase 1 evaluation, indicating a sustained change in staff behaviour within the Trust that staff observed of colleagues as well:

I see that every day when I come to work now. Even just outside the main entrance, members of staff are stopping and taking people personally to where it is they
wanted to go. That's a legacy that's lasted. [...] I think that's one of the biggest things I've heard that's made a difference, is the corridors. (Nurses4)

This is probably one of the points that is more influential about this film, the ability to see people who may be just finding their way in the hospital with a different eye, so to understand that at that time they may really need someone to help. (Medical)

There were numerous similar examples given. Some staff expressed that Barbara's Story had given them permission and confidence to be more proactive as a Trust staff member in approaching people visiting the Trust and offering help. They felt able to do this regardless of whether they were in uniform or not and whether they were clinical or non-clinical staff. For example a non-clinical staff member, who had previously not felt that they could offer help to patients in corridors, now felt that they had a responsibility and the permission to help people visiting the Trust:

I'm not frightened to ask anybody anymore because I know everybody has seen it [Barbara’s Story] and everybody is going to do the same thing. (Non-clinical1)

Several staff gave examples of where they had been proactive in helping people outside of the Trust when they were not at work, for example while out shopping. They expressed that Barbara’s Story had given them confidence to offer help while previously they would not have felt able to do so.

Staff reflected on the need to understand patients’ wider situations and look for reasons for behaviour, for example, why a patient might not attend an appointment and therefore the need to understand what is happening to individuals. The result was that staff were more proactive in following up with patients:

We actually ring our patients for our outpatient service if they don’t turn up, we might give them a call, you know, 15 minutes in, ‘Oh is everything alright? Are you on your way or has something happened?’ (Therapists1)

Nurses also described being more inquiring about patients, reflecting, for example:

That there must be something else why this lady is here, so I try to bother and ask more questions [...] I think that improves my practice. (Nurses1)

Therapists discussed other changes they had made, which included having one staff member to deal with one individual specifically: ‘talking to them, explaining what’s going on, trying to keep them calm’ and, in relation to people with delirium: ‘giving them a little bit more time and making more time to speak to the family’ (Therapists2). Other staff members described improved communication, for example, better explanations and being more patient (Nurses6) and ensuring introductions and better eye contact (Nurses5). Staff talked of paying more attention to informing patients: “It’s okay, I’ll be with you in a minute” so they don’t feel they’re being left’ (Therapists2). Another staff member talked of being more attentive to patients waiting for transport following treatment:

When she finishes her treatment she stays with us on the ward, and it’s just occasionally you just go in and tell her what’s happening, it doesn’t matter how many times. (Nurses12)

In a community setting, a staff member described how, since Barbara’s Story, her interactions had changed as she was more aware of her non-verbal communication, of writing things down and being more patient: ‘treating everybody with that sort of respect’ (Community).

The issue of investing time with patients, despite the busy nature of the Trust and high workloads, was highlighted regularly:

I was always busy, didn’t give anybody any time, but since that [Barbara’s Story] I just make it my priority, sometimes you’ve just got to remember to take that extra time, and also remember you can engage them with things that might not necessarily matter to you right then but you’ll engage them and then you build a trust with them and it makes things easier. (Nurses7)
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You get a patient who is explaining something to you and then you might find that they explain it again to you, and even though you’re busy, it’s not about that for them, it’s about talking to someone when they don’t get the opportunity. (Nurses5)

Staff also described how rather than just reassuring patients, they would spend more time to uncover what issues there might be (Nurses1). Staff expressed that Barbara’s Story had given them permission to extend their conversations with patients to ask about their comfort and well-being (Nurses2) and had given staff the confidence to make time (Therapists2). Staff also expressed the value in interacting with patients while carrying our care:

*Engage them in a positive way about something that they can relate to, as opposed to carrying out a clinical task whilst the patient is sat quietly.* (Nurses1)

Staff discussed improved interactions that they had observed in other staff too, for example, being more patient and understanding (Nurses3), communicating with more sensitivity (Nurse11) and giving more explanations:

*I think I’ve definitely noticed a difference in that when people are being kind of moved around, the to and fro of the hospital, it being explained where they’re going to and being spoken to about what’s happening, and just checking that they’re okay.* (Therapists1)

It was believed that Barbara’s Story had given non-clinical staff the confidence to interact with patients more on the wards, for example, a therapist gave an example of non-clinical staff being more proactive and observant:

*She’d [catering assistant] noticed the lady had gone and she came to ask me is she alright, is she okay, because she’d saved her breakfast for her because she knew she might want it later even though she’d gone away, and it was a little thing but she was obviously very concerned about her.* (Therapists2)

In a similar example, nurses discussed how the cleaners will raise concerns about patients with nurses (Nurses9).

In the evaluation of Phase 1 of Barbara’s Story, there were many comments about staff ‘going the extra mile’ and actions that put the patients first, a principle embedded in the Trust values. In the Phase 2 evaluation, there were similar comments made and examples of staff personalising care within the hospital environment:

*People are looking for ways in which they can maybe adapt or make a minor adjustment to what they are doing, just to add a personal touch to the care that somebody is receiving.* (Nurses1)

A number of staff talked of recognising and attending to the ‘little things’ that matter to patients; Box 10 provides examples.

### Box 10 Little things that matter to patients

*There’s also something in that the small things matter, so sitting and reading a bit of a newspaper with somebody or making them a cup of tea or holding their hand […] it’s not the big heroic stuff all the time, it’s just guiding someone to where they need to be or responding to someone because they look lost.* (Nurses2)

*Finding someone to take a patient down to transport rather than them waiting an hour in the waiting room, it’s the little things that matter.* (Nurses5)

*I think it’s sometimes the simplest things, like putting on the radio or something, like especially for patients in the side rooms who are either end of life or even if they’re not responsive.* (Nuses7)
There was also discussion about the value of building a relationship and trying to ensure that there was some continuity for patients (Therapists2, Nurses8), for example, a staff member talked of one shift where she had been caring for a person with dementia and:

At the end of the shift I found that we’d kind of got to know each other and she [woman with dementia] was fine with me being there and she started to eat. (Nurses7)

Many other similar examples were given (see Box 11). Staff also discussed the importance of a high standard of documentation to give them insight into how the person had been previously (Nurses4) and of effective handovers between staff (Nurses6, Therapists2).

Box 11 Building a relationship

You are the person that they're going to remember, that they recognise as being the person that makes them feel safer, can comfort them at a certain point, looks after them. (Nurses8)

It’s having to build a trust, for a person to get to know your face, your voice, your kindness, they’ll always recognise that, first impression is very important. […] I find if they’ve got a good connection to you, if you come across them and they're upset later with someone else, you can come in and go ‘Oh what’s wrong? What’s happened?’ and they will talk to you and they will become calm. (Nurses7)

There was a patient who required several procedures off the ward and it was the same porter that came to see them every day and built up quite a good rapport with this person and even with the family, and when they left I think the family acknowledged that. (Therapists1)

Staff discussed the personal attributes needed to care for people with dementia and most of these were interpersonal skills, such as listening and questioning (Nurses8, Nurses4). Staff appreciated the need to understand the person with dementia’s reality, for example, if the person said: ‘Oh I have to pick kids from school’ (Nurses7). In one group staff talked about advocating for patients in their best interest, for example, to ensure that patients are not moved around unnecessarily or are admitted straight to a specialist ward where possible (Therapists2). This focus group asserted that with experience they were better able to stand their ground:

It’s quite difficult because you do feel pressured and it’s only when you get to a certain level of experience that you think I don’t care what you think, you can shout and scream at me, I don’t care, that could be my mum, my grandma, that’s the whole thing that I think people have to keep in their head. (Therapists2)

Staff related how they listened to patients with a history of dementia, taking their physical symptoms more seriously, rather than attributing them to their dementia: ‘we will now investigate it a little bit more […] any physical symptoms we will take seriously’ [rather than attributing it to their dementia or mental health condition (Nurse10). Similarly, in relation to behaviour, another nurse said:

I think it’s really important for staff to remember not to play a part in that stigma and not to make excuses if they’re upset or aggressive, not to put it down to their condition, sometimes they are just genuinely wanting something or upset. (Nurses8)

Staff talked of using music, singing and dancing with patients (Nurses7). Staff also discussed family support and involvement, including education and providing information with care and sensitivity (Nurses7), on an ongoing process in both hospital and community (Nurses9).
8.2.4 Effect on individual staff: summary

Staff gave many examples of their own emotional responses to the films and of how they connected to the films personally and professionally. Barbara’s Story highlighted that some Trust staff are carers for family members with dementia and some staff recognised that a relative had dementia from watching the films. Staff reported that they had developed an increased awareness and understanding of dementia and delirium. This had led on to actions such as referrals for dementia screening as well as staff feeling more confident to care, being more empathetic and viewing patients as individuals. Staff also identified their awareness of what detracts from good care for people with dementia, such as being task-orientated, inflexible and disease-focused. Staff discussed improved interactions and behaviour extensively, for example, giving more time, better explanations, listening, reassurance and attentiveness. As in Phase 1 focus groups, many staff offered examples of helping people who seemed lost or confused in hospital; Barbara’s Story had given staff confidence to be proactive and offer help. Staff also referred to recognising and attending to the ‘little things’ that matter to patients and of building relationships.

8.3 Practice developments and improvements: we filled out the whole
*This is me*

Whilst various initiatives were mentioned in the Phase 1 focus groups, the Phase 2 focus groups included much greater depth of discussion. Staff expressed how these developments were becoming embedded in the Trust with a perception that, whilst some of these were in development prior to Barbara’s Story, the project had reinforced and helped these developments to become more established. There were however some discussions about both constraints to practice developments and the challenges that staff experienced in practice.

8.3.1 Initiatives in the Trust

The initiatives that staff referred to are listed in Box 12.

<table>
<thead>
<tr>
<th>Box 12 Trust initiatives to support dementia care</th>
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<tr>
<td><em>This is me</em></td>
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<td>Improvements to food provision</td>
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<td>‘Specials’: dedicated and trained nursing assistants to provide one-to-one care</td>
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<td>Dementia pathway</td>
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Several groups mentioned the dementia pathway and/or the delirium bundle, indicating that these were becoming known across the Trust. Dementia training courses are well established in the Trust; participants were very positive about the training and thought it was essential for staff regularly caring for people who have dementia. Staff discussed in focus groups how they learned from each other within their team as well (Nurses7). There was a good awareness of the Dementia and Delirium team and several groups discussed developing closer links with the team. Dementia screening was referred to in a number of focus groups, and was considered well embedded across the Trust and the multi-disciplinary team (Therapists1). This is important as reports continue to express that screening and
earlier diagnosis should be prioritised and so health and care professionals need to recognise the importance of diagnosing people with dementia (Alzheimer’s Society 2014b). Some staff discussed their aspirations to make further changes, for example, giving longer appointments to older people in outpatients (Nurses2) and the need for dedicated psychology input within dementia services (Medical).

The initiatives discussed most in depth were: *This is me*, improvements to food provision, specials, dementia champions and link nurses, and environmental changes. These are discussed next in more detail.

**This is me**

It was noticeable that there was much more discussion in the focus groups about *This is me* than in the Phase 1 evaluation; nearly every focus group discussed *This is me* and commented on the increased use within the Trust. The discussions around the use of *This is me* highlighted that staff really appreciated the importance of knowing the patient. However there were a range of experiences with some focus group participants saying that they regularly used *This is me* whilst others had never seen it in practice, although they considered it was a good idea:

*I guess it’s quite useful if you’ve got someone who is perhaps a bit anxious or agitated, or something like that, if you had that information we could use it in a calming way or just almost a bit distraction so you could say ‘I hear that you used to do such and such, tell me about it’. (Community)*

Those who had used *This is me* were great advocates for the tool and the difference it made in practice:

*I saw it once in practice and I thought to myself, this is the best thing that anyone has ever done because it just made the care you gave so personalised and I remember the patient and it said in the notes, loves Coronation Street and EastEnders. So at 7.30pm I’d go and put on Coronation Street, just because I knew about it. (Nurses4)*

A medical issue you can get from the medical notes and you can piece something together, but there are some things that you won’t ever find out because they won’t tell you. […] It’s nice to know a bit more about them, what they like and don’t like, even if it’s just down to how they like their tea or they don’t like tea. (Nurses6)

In one focus group, an example of the benefits of *This is me* was explained:

*She [patient with dementia] was in for less than three days, got home, she wasn’t a delayed discharge but my point had been if This Is me hadn’t been filled in and she was distressed and constantly calling, they’d have given her [medication], shut her up, then she’d have been over-sedated, she wouldn’t have been eating and drinking, her delirium would have been worse. (Nurses4)*

It was considered important to start filling in *This is me* in at an early stage, rather than waiting until a person’s dementia had become severe (Nurses4). Staff had guided family members to accessing *This is me* on the internet so that they could complete it (Nurses1). One group pointed out that it might be difficult completing it for some people, often those who might most benefit, as they had no family:

*A lot of the patients that I see are actually our most vulnerable in society, so they don’t actually have the family support, they don’t have anyone to fill it out, so there is that element of yes, it was great in Barbara’s Story but actually perhaps that’s an area that we need to address. Maybe people have a next of kin or a neighbour […] someone who knows what TV programmes they like and what calms them down. (Therapists2)*

It was suggested that completing *This is me* could be a role for the ‘specials’ who provide one-to-one care for people with dementia. However, in another focus group a staff member
explained how the ward team had completed *This is me* over time for a patient cared for on the ward (see Box 13).

**Box 13 Completing *This is me*: a ward team’s experience**

A resident with dementia was admitted to a ward from a care home. He had a wife but she could rarely visit. A nurse described how the ward team completed *This is me* over time:

*He was with us for quite a while, and within possibly two weeks the staff themselves, we filled out the whole *This is me*, because over a period of time, it’s having to build a trust, for a person to get to know your face, your voice, your kindness, they’ll always recognise that, first impression is very important. So every nurse always found the time to have a little chat with him, then maybe go back a little bit, ‘What did you do when you were young and what’s your favourite things?’, and eventually over days and days they do start telling you all these important things, which then went into *This is me*, which became a great tool, obviously, for lots of people who came into his life who didn’t know him.*

*He also went to a nursing home from us so we sent *This is me* with him, and all of the important things to him were in there, all the things he liked and disliked, things that made him comfortable, made him upset, depressed, everything was in there by the end of two weeks. So a lot of the staff can do that as well, every little thing you learn about that particular patient you can just add it in and you’ll be surprised how, at the end of a time, if they’re there for a while especially, you’ll have lots of information in there because everybody will learn something about that person.*

(Nurses7)

Practical issues, such as where to keep *This is me*, so that it is accessible and easily found, were discussed at length in one focus group, who articulated that it was essential to ensure that *This is me* accompanied patients as they transferred between settings:

*It’s all very well us filling them out when they’re here and then when they go home how do we ensure that that then comes with them, because a lot of patients don’t have that family network, it could get lost or is it the paramedics’ responsibility for making sure they have it when they bring them here?* (Therapists2)

The group’s suggestions included that *This is me* could be scanned into the electronic patient record (EPR). They further discussed whether it could be completed and uploaded to the EPR while the patient is in the community, although it was also recognised that staff in different settings may not be able to access the EPR (Therapists2). Accessibility was a key issue discussed; therapists suggested that a patient’s *This is me* should accompany them to investigations in other hospital departments and another group identified that it would be valuable if all care home residents were accompanied by a completed *This is me*: ‘so the moment they come here at least we know the basics’ (Nurses6). Staff identified the importance of a completed *This is me* not being filed away in notes where it could not be accessed.

**Improvements to food provision**

Staff referred to many improvements in food provision for people who have dementia and they perceived that the improvements were reinforced by Barbara’s Story. The availability of a range of snacks, including finger foods, and hot drinks throughout the day, was identified as beneficial. It seemed that staff commitment to nutrition had changed too, for example:

*In the last year or two, we’re now much more proactive on the nutrition board, recognising the patients’ needs, that little bit of extra time, all these little extras after*
their meal, snacks. I've seen nursing staff go into the kitchen and say 'Okay, Mr So-and-so is still a bit hungry, I'm going to get him a sandwich'. (Nurses7)

Other improvements included the use of coloured trays to indicate different levels of help needed (Nurses7, Nurses8), coloured plates (Nurses6, Non-clinical2), cups and saucers (Nurses6) and a book with pictures of food to help patients choose their menus (Nurses8). The importance of the improvements in presenting food was discussed:

How meals are presented, so the cutlery and plates, have slightly increased the visibility of the food on the plate, so that has enabled people to eat the food. I think there’s quite a lot of work going on around that which I think is excellent. (Medical)

Staff discussed liaising with non-clinical staff serving food to ensure that the amount of food eaten is accurately recorded (Nurses7).

Specials

The second series of films featured a new initiative in the Trust where a senior nursing assistant, with additional training in dementia care, provided one-to-one care for Barbara, a role often termed 'specialling'. Previously, as at many other Trusts, one-to-one care could be delivered by staff without specific training in dementia, often agency staff, who took on a passive stance rather than engaging the person in activities, due to a lack of knowledge and confidence (Therapists2). Staff considered that dementia trained nursing assistants was a positive step, for example:

It's nice to know that you'll actually recruit people who would work with one particular person, a person with dementia, give them the attention. (Nurses6)

They've undergone specific training which I think is good because I know when I first started banking here I wasn't ready to special patients with delirium and dementia. (Nurses8)

This development was considered to be a way of patients getting the individual care they needed (Nurse11). Other staff described how they had observed the role working in practice, for example:

I have noticed that our long stay patients with end stage dementia, who are requiring one to one support or 24 hour close supervision, they generally try to keep similar people to encourage the continuation of care and also I've noticed that some of the specials are actually engaging with patients in terms of playing games, playing cards, doing crosswords, so there has been an element of improvement […] I think there has been a shift in culture about how those roles are fulfilled on the ward and the level of respect that they are given. (Therapists2)

Whilst acknowledging the benefits of having staff who could provide high quality one-to-one care, one group asserted that wards were sometimes too quick to ask for a 'special' when it might be that if the whole care team modified:

their interpersonal skills slightly or tried to think, what is underpinning this behavioural change, what's the antecedents, then you could look into this, what is it that they might want, can we distract them with something. (Nurses4)

Dementia champions and link nurses

In several focus groups staff referred to the role of dementia champions or link nurses who had an important role in leading teams and liaising between colleagues and the Dementia and Delirium (DAD) team to ensure staff have had training and are updated. The staff believed that the dementia champion role assisted in keeping other staff up to date with developments and also helped to keep the topic of dementia at the forefront of people’s minds. The dementia champion role was considered an important contribution to sustaining the impact of Barbara’s Story in the long-term:
By giving people ownership and having the dementia and delirium champions [...] I think if you have people in the trust whose remit it is to actually flag these things up and so it’s on the agenda. (Medical).

In some areas the role was clearly well developed with a team of champions of different disciplines, monthly meetings, promoting dementia training and keeping a noticeboard updated with information about dementia (Nurses5).

**Environmental changes**

Many staff referred to environmental changes that had been made within the Trust. It was noticed that the hospitals looked brighter and there was more natural light (Community) and some staff referred to refurbished, more homely day rooms (Nurses7). Several focus groups discussed improved signage within the hospital and individual wards and departments, which included the use of pictures on toilet and bathroom doors and better visibility of call buttons (Non-clinical2, Medical). Staff also referred to improvements in décor which made the hospital brighter as well as helping patients to find their way about:

*The whole ward, like the flooring and everything is softer, the rooms, so we have a female bay and that’s pink and we’ve the male bay and I think it’s green, and the door to the bathroom is the same colour as the room so the patient can see the door, and it’s a bright colour as well rather the old white, so they are pink and green now to help them recognise the doors.* (Nurses8)

Staff also explained how they could best use the environment for people with dementia, for example, to:

*Put somebody with dementia or delirium near a window so they can actually see day and night happening, rather than somewhere which is further back in a ward where you’ve no idea really what time of day it is.* (Nurses2).

**8.3.2 Challenges and constraints**

The issue most often raised as a challenge and a constraint to best care was lack of time, due to staffing shortages and workload.

**Time constraints**

Time was a key constraint identified, along with the perception that ‘people with dementia require a lot of your time’ (Nurses8). It was identified in one group that:

*Time management and stress are the only two barriers which I can see might stop an individual to change, even after seeing these movies.* (Nurses1).

Staff discussed the importance of having sufficient and high quality time for people with dementia (Nurses7, Nurses8) and the acknowledgement that time spent is of value:

*Recognising that if you’re spending one to one time with a person with dementia, whether it’s walking around talking about where the boat goes from, that is valid. That’s not, not doing work.* (Nurses2)

The pressure that staff are under in such a busy environment was referred to in most focus groups, for example:

*It can be really challenging for staff, everyone is so busy, people are rushing around, they don’t have time to explain.* (Therapists2)

*I think staff nurses have got a lot of pressure anyway […] you’ve always got time but it’s what you sacrifice of something else to do that.* (Nurses4).

*Sometimes we are so rushed off our feet we can’t afford to give anyone the time, although we would like to give them the time we just don’t have the time available to us because this is a very dynamic area.* (Nurses6)
In one of the non-clinical staff focus groups, a staff member described the conflicting priorities they had observed nurses encountered in practice. In one of the nurses’ focus groups it was discussed:

- We are busy, it’s a stressful job, we love it but it is stressful nonetheless and it embraces all the obstacles that come with that.
- Our ward is such a fast turnover.
- They don’t have that person to just sit there and talk or just play a game or something, like you can try and bring things up but it's hard. (Nurses7)

Several focus groups discussed current staff shortages that affected time available. It was acknowledged that staff may then rush patients unintentionally; however it was expressed:

You can certainly make that time with them better quality and make the most of their time, and to forget sometimes that list of things to do when you’re with that patient, because it affects the quality of time you have with them. (Nurses8)

It really does make me think about actually we’re saying this is what good practice is and we need to just stop saying sometimes we’re too busy. (Nurses4)

A further issue raised was increasing workload caused by targets:

‘people are really overloaded with the number of initiatives and boxes to tick and you’ve got to do these stats and those stats’ (Therapists2).

Other issues

A few other issues were highlighted in different focus groups. The importance of having information about people with dementia both within settings and across settings was emphasised but challenges were raised in several groups. People with dementia who are admitted as an emergency (particularly from care homes) were often not accompanied by information or a person who knew them and ‘so we are absolutely stumped’ (Nurses6). Accessing information across settings was difficult due to different IT systems (Therapists2). Within the hospital setting, the patient notes may not be detailed or personal enough to enable a nurse to discern: ‘actually they’re different today’ (Nurses4). A further issue raised in two focus groups was the hospital hierarchy, which could affect how information is communicated and received (Therapists2, Medical). However, in a non-clinical focus group staff perceived that ‘hierarchy is being broken down’ and that as non-clinical staff they were more able to challenge clinical staff:

Still a little bit of hostility is around. I’m not saying it’s perfect, it’s a perfect world up there, but it’s much better than it was. (Non-clinical1).

Finally it was highlighted that a further challenge was to ensure that all staff behave according to Trust values all the time. However, identifying staff who do not demonstrate the Trust values had become more evident since Barbara’s Story had reinforced the values across the Trust:

It’s pointing out the people that you think, if you still watch this and you still don’t understand, like you really don’t care, then you should not be in this job. (Nurses5)

8.3.3 Practice developments and improvements: summary

Whilst various initiatives were mentioned in the Phase 1 focus groups, the Phase 2 focus groups included much greater depth of discussion. Staff expressed how these developments were becoming embedded in the Trust with a perception that, whilst some of these were in development prior to Barbara’s Story, the project had reinforced and helped these developments to become more established. Dementia training was highly thought of and dementia screening was considered much more embedded. The initiatives discussed most in depth were: This is me, improvements to food provision, specials (trained nursing assistants to provide one-to-one care), dementia champions and link nurses, and environmental changes. Staff who had used This is me were vocal about the benefits and the discussions highlighted that staff really appreciated the importance of knowing the
patient. The issue most often raised as a challenge and a constraint to practice improvements was lack of time, due to staffing shortages and workload.

8.4 Trust values and culture: everybody is aware that they have a part to play

Staff recognised that Barbara’s Story had been developed within the context of the Trust values and they discussed how they applied the values in action. As in the Phase 1 evaluation, there was discussion about a culture change having taken place following on from Barbara’s Story.

8.4.1 Trust values in action

It was expressed that Barbara’s Story had reinforced the Trust values (Nurses1). There was recognition that each individual was representing the Trust and there was an accompanying sense of pride, which prompted certain behaviours:

[As] I’m associated with this hospital then I want to be seen as being helpful and approachable, and that’s pride in what we do. (Nurses2)

Non-clinical staff also expressed pride in working for the Trust and ensuring that the Trust values were embedded in their practice:

That [Barbara’s Story] came in and that was part of the Trust values and I think that moved our staff on big time, because it just showed them, it’s not about asking questions, it’s about you caring about somebody. (Non-clinical2)

Staff explained that the Trust values are embedded in appraisals which enabled behaviours to be addressed (Non-clinical2, Community, Nurses2):

We have values based [appraisals], and I think that allows us to reward people who behave as they should [...] I think it’s really nice to have a tool where people have to think about their behaviours and attitudes before they come and speak to you and to see what personal insight is. (Nurses2)

It was suggested that all new staff should watch Barbara’s Story prior to even starting in the Trust as this would:

Set the expectation in their head, ‘We expect you to watch this because this for us is important, you’re not going to get sent anything else but these are the values we expect you to bring with you.’ (Nurses3)

8.4.2 Culture change

It was expressed that the first episode of Barbara’s Story, because it had been seen by everyone in the Trust, had ‘a massive impact on the hospital, the feel of the hospital and the approach for all those patients as a whole’ (Therapists1). There was reference to dementia being considered ‘everybody’s business now, everybody’s job, which is good’ (Nurses12) and the Trust-wide impact was perceived to have reached:

All directorates and specialities, I think everyone has been affected by watching Barbara’s Story, it’s just raised the whole awareness and the way people do their job. (Nurses5)

In terms of dementia, it was considered that:

Barbara’s Story made an impact Trust-wide for awareness for dementia, comparing practice 10 years ago and now, you can see the massive difference of how they’ve increased awareness of dementia. (Nurses9)

Staff referred to the Trust-wide discussions prompted by Barbara’s Story:

It’s provoked discussions, not just here, but in the main department and in staff rooms, did you see that, what did you think about that, so any sort of discussion in
the department is always quite good because it keeps it at the front of people’s minds. (Therapists2)

Staff discussed that Barbara’s Story established standards expected within the Trust for patients generally and the expectation of improvement:

I do think that, as well as the story, teaching about dementia and Barbara’s experience, it tells you also how you should behave, as a member of the trust. (Community)

Regardless of whether they have Barbara’s issues or not, it’s just a social awareness of being more polite to the public. […] But there’s something about that permission to behave differently and that sort of shift, so it’s not only okay, it’s expected and we’re looking to see that now, so I think that’s good. (Nurses2)

There was some feeling that the learning from Barbara’s Story had wider application across the Trust, for example:

Younger patients, who may well be delirious but equally that fear of being in hospital, vulnerability, the way we communicate with anybody. (Nurses2)

So many things have got pointed out. I think when somebody comes back from some procedure, she gets moved and she misses dinner or breakfast. I think it just highlighted interpersonal skills, it doesn’t necessarily have to be just dementia patients, I think it was just a general reminder that things need to change. (Nurses4)

It was also considered that Barbara’s Story had established the role that all staff were expected to play in improving patients’ experience, particularly for those who are most vulnerable:

I think everybody is aware that they have a part to play, not matter how miniscule they might think it is, but they do have a part to play and they’ve made it everybody’s business to actually look out for people who are actually vulnerable, even not solely in your own departments but wherever you might be within the Trust. (Nurses1)

The value of the non-clinical staff group in the care of people with dementia was highlighted through Barbara’s Story and acknowledged in clinical staff focus groups:

A lot of the time patients are being moved around a lot for whatever tests they’re having done and whatever is going on, so you might have a doctor there but the porters are the glue. (Therapists2)

[non clinical staff] They play a big part in the patient care as well, they’re the people who are in the bay and they’re cleaning the bay so they do strike up conversation with them most of the time […] I thought that was quite a nice input that they put into the story to say that they’re not invisible people, they’re people too and they do talk to the patients. (Nurses8)

Staff talked of Barbara’s Story prompting staff to be proactive in challenging care (Nurses4, Nurses5, Nurses7, Non-clinical1). A few staff were however unsure whether the initiative had made a significant difference to staff behaviour in the Trust; it was sometimes hard to be certain that changes were a result of Barbara’s Story, for example: I can’t say it’s made a difference from then to now, but then it maybe has (Nurses3).

Staff referred to a ‘cultural shift’ that now enabled staff to be able to talk about emotions (Non-clinical2) and being able to put patients first in accordance with Trust values (see Box 14).
Box 14 A culture change

I think it’s just reinforced for me that it’s actually okay to not always tick off things from my to
do list, that if I see someone walking up to the toilet who is looking a bit confused or
wandering around, it’s okay for me to take them or see if they want a cup of tea, that’s now
okay, whereas I think before it was, not frowned upon, but are you really working [...] I think
for me that’s been a huge change in the culture [...] there is time to care, we’re permitted to
do that. (Therapists2)

It’s a culture change so you’re less nervous now of approaching people and saying, do you
want help, can I help you. [...] I think they’re bringing out the human part of us a little bit
more rather than the paperwork bits. (Non-clinical1)

Some of the care that you saw was sort of acceptable, but it wasn’t the best. [...] The
expectation was that you took it to another level and that you actually gave time and you sat
down and you said ‘Actually, out of all the things in my diary today, Barbara, you are the
most important and we’re going to sit down and we’re going to do this’. (Nurses3)

8.4.3 Trust values and culture: summary

Staff recognised that Barbara’s Story had been developed within the context of the Trust
values and they discussed how they applied the values in action. There was recognition that
each individual was representing the Trust and a sense of pride which prompted certain
behaviours. There was also discussion about a culture change having taken place following
on from Barbara’s Story. Dementia was now seen as ‘everybody’s business’ with a Trust-
wide awareness. Staff discussed that Barbara’s Story established standards expected within
the Trust for patients generally and the expectation of improvement. It was also considered
that Barbara’s Story had established the role that all staff were expected to play in improving
patients’ experience, particularly for those who are most vulnerable. Barbara’s Story had
also set out an expectation for staff to be proactive about challenging care.

8.5 Sustaining the impact of Barbara’s Story: you’ve got to follow it up
and keep on having those conversations

Staff made a number of diverse suggestions about both sustaining the impact of Barbara’s
Story and other developments that could build on the project.

8.5.1 Sustaining the impact of Barbara’s Story

Suggestions for sustaining the impact of Barbara’s Story included updates, refreshers,
further training and newsletter items. It was also identified that dementia champions had an
important role in supporting sustainability of Barbara’s Story (Nurses5, Medical).

It was believed that staff would need a ‘refresher to actually say, don’t forget this is what
we’re all about’ and that staff could be ‘reminded that it’s there to be watched and
encouraged to watch it again every so often’ (Non-clinical2). Another group similarly
commented:

I just think it’s ongoing, this is a great tool that has sparked conversation, but actually
you’ve got to follow it up and keep on having those conversations or else something
else will knock it off the top spot. (Nurses3)

Other suggestions were that screenings should continue and be publicised and that there
should be annual reviews to discuss progress made and what further improvements could
be taken up (Therapists2, Nurses13). As one nurse pointed out, with Barbara’s Story being
on the intranet, it was openly accessible to all (Nurse13). A further suggestion was that the dementia pathway could be reviewed at audit meetings (Therapists2). Staff discussed updates and what these might comprise, for example:

*It could be something else, if there’s an update to say ‘This is what we expect from our staff’ […] to make sure that everybody is still aware.* (Nurses3)

One focus group asserted the need to prioritise time for Barbara’s Story to promote sustainability:

*It won’t have a lasting impact unless time is devoted to it, unless people know that it’s okay to spend time watching it and discussing it, […] it needs to still be prioritised as part of your working in whatever shape and form.* (Therapists2).

It was suggested in both non-clinical groups that appraisals could be linked to Barbara’s Story with seeing and discussing it made an individual objective.

The learning points from Barbara’s Story could be reinforced through preparing them for the care of other vulnerable people (such as those with learning disabilities, physical disabilities, sensory impairment) and highlight ‘how to approach and how we can make that person safe and support carers as well’ (Nurses1). It was further discussed that there could be branding using the word ‘Barbara’, or ‘Barbara’s Story’ (in the same way as other Trust campaigns (such as ‘Safe in our hands’ or ‘Showing we care’) and a picture of Barbara with a reminder like ‘Do you remember when she…?’ (Nurses3). Several focus groups suggested that a newsletter or bulletin, or articles within the Trust newsletter, could help keep up the profile of the project and support the developments (Nurses3, Non-clinical2, Nurses5). Suggestions for content included reminders like: ‘Don’t forget the delirium and dementia bundle’ as it was thought that these would mean that ‘it’s always in people’s psyche, so it doesn’t go away’ (Nurses3) or patient stories related to dementia (Nurses5). Other suggestions were that a newsletter could prompt people about seeing Barbara’s Story, including dates for showings, whilst also giving feedback and information about supporting people with dementia in the Trust (Non-clinical2). A further suggestion was to set up an email account: ‘so you could say, “Dear Barbara, how would you like this to happen” or whatever’ (Non-clinical2).

There were a number of training related suggestions made, in particular, for more staff to access the dementia training days (Nurses8, Nurse11, Medical, Community). It was suggested that staff providing hospital transport should also have dementia awareness (Nurses12). Additional suggestions were for more training in relation to safeguarding vulnerable adults, with reference to mental capacity:

*We come across those challenges, and I think if we had a little bit more information or a little bit more confidence in that process then I think that would make us feel more confident […] Barbara is a very good starting point for that because people identify with someone.* (Therapists2)

Staff in one group suggested that learning in the simulation centre would be particularly effective (Therapists1). A further suggestion was that training should include a patient’s experience, as this was considered particularly powerful (Medical).

### 8.5.2 Suggestions for further improvements

Staff made varied suggestions for further improvements. These included providing more support for people attending outpatients:

*I think the one thing that we’re still not really doing is supporting our patients as they access the hospital from the community to attend outpatients appointments or to attend procedures as an outpatient. […] I still don’t think there’s much support for those patients in terms of having - I don’t know whether it’s an escort to come to those appointments or somebody that meets them once they get off transport, to then kind of guide them through that process, whereas at the moment they just seem to kind of arrive.* (Therapists1)
It was also suggested that there could be a more personalised approach to outpatients, with longer appointments for people who need more time, and following up of people with dementia who do not attend (Nurses3). Several staff suggested that there could be more involvement of volunteers, for example, to sit with people waiting for transport and ‘Keep them company’ (Non-clinical1) and also to provide some social interaction with patients in inpatient areas (Nurses7).

The importance of effective communication across settings and between services, including transport, was also considered essential. Staff questioned how to improve communication, for example:

- **How do we let people know that these people may need additional time or there’s something around this individual which means you need to look out for them, you know, maybe phone the GP and say ‘We sent an appointment, they’ve not turned up, is this because they haven’t read the letter or is there a problem?’**, rather than just saying ‘Oh two DNAs now’ and cancelling the referral. (Nurses3)

Staff discussed effective discharge planning for people with dementia (Nurses9, Nurse13) and ensuring good links with the transport department so that:

- **They [people with dementia] wait with us on the ward and the transport department will bring them right back, straight up as well, they don’t wait.** (Nurse10)

Staff were aware of the need to integrate across hospital and community (Nurses12) and recognised the importance of social services and family involvement (Nurse13).

Some staff expressed that there still needed to be better ways of identifying people with dementia as the forget-me-not and wristbands could not easily be seen (Non-clinical1). It was discussed that there could be better communication and liaison from care homes and community to hospital and that perhaps there could be a community-based liaison nurse who would appreciate the stress of transferring from community to hospital (Nurses6, Therapists1).

A few staff identified that one way of building on Barbara’s Story would be to highlight other vulnerable groups, for which many of the principles learned could be applied, such as, people with learning disabilities, visual or hearing impairment (Nurses1) or Parkinson’s Disease (Community). Staff also raised the importance of learning from situations that they had found challenging: ‘I think it’s important for wards to do reflections on that and say how can they do it better’ (Nurses8).

One group discussed that the Trust should be involved in educating the community about dementia and the services available and that information should be available in non-Trust settings, such as supermarkets (Community).

### 8.6 Phase 2 focus groups: summary

Suggestions for sustaining the impact of Barbara’s Story included updates, refreshers, further training, newsletter items and linking appraisals to Barbara’s Story. Dementia champions were identified as having an important role in supporting sustainability of Barbara’s Story. It was suggested that more staff should do the dementia training days. The learning points from Barbara’s Story could be reinforced through preparing them for the care of other vulnerable people. As regards suggested improvements, a more personalised approach in outpatients and more involvement of volunteers were identified. Better communication across settings and more integrated care were other suggestions.
Section 9: Discussion

Barbara’s Story was a timely project, being developed and implemented at a time when dementia as a health issue has been recognised as being of high importance. The project supported the National Dementia Strategy’s objectives, particularly in terms of hospital care improvements. The project was highly ambitious with the goal of training all Trust staff using the initial Barbara’s Story film. What was particularly unique was the recognition of the role of non-clinical staff in patients’ healthcare experiences; policy documents, including the recently published Health Education England curriculum (Richards et al. 2014), focus on healthcare professionals alone. The decision to develop a film with a drama told from a person with dementia’s perspective was a step away from traditional training materials and was unanimously well supported by GSTT staff. The sustaining of the project from September 2012 to March 2014, and beyond through embedding Barbara’s Story in induction, dementia training and on the intranet, has led to Barbara’s Story gaining momentum, with an increasingly high profile and becoming a ‘brand’ that provides staff with a common language around care, not only for people with dementia, but for others who are vulnerable too. There is always a risk that the impact of any project can diminish over time but the concept of Barbara is now well embedded within GSTT, with many related initiatives established too.

The evaluation aimed to investigate GSTT staff’s perspectives of the effect of Barbara’s Story on themselves, their colleagues and the organisation. A longitudinal design was used in order to capture staff perspectives at different stages of the Barbara’s Story project’s implementation. Each of the specific objectives will now be discussed.

Objective 1: Explore staff perspectives about the initial Barbara’s Story session and any effect on themselves, their colleagues and the organisation as a whole

The staff’s written responses to Barbara’s Story captured their immediate views about the project and indicated staff intentions to make changes in their professional lives, most of which related to their interactions with patients or other visitors to the Trust. It was evident from the comments that one particular image made a strong impact: that of Barbara making her way along hospital corridors lost, confused and ignored by passing staff. At both the Phase 1 and Phase 2 focus groups, staff continued to refer to this image with many staff relating how they go out of their way to assist people looking lost or confused, how they have frequently observed colleagues assisting too, and how the Trust culture was perceived to be supportive to all staff, clinical or non-clinical, giving assistance, even if this led to them being late for a meeting. The branding of such a scenario led staff to refer to having met ‘Barbara’ in a hospital corridor. Other frequently given responses from staff immediately after the films included treating people as individuals and giving time. Again both the Phase 1 and Phase 2 focus group participants gave examples of how they endeavoured to give patients more time but that also, the Trust culture would support staff giving patients more time, following on from Barbara’s Story. However, staff did also discuss the realities and constraints of workload and staffing issues and these remained challenges.

The focus group discussions highlighted the importance of knowing individuals and attending to ‘little things that matter’ to patients. As regards the impact on the organisation, staff perceived a much wider awareness of dementia, a recognition that dementia was everyone’s business and that people who have dementia could be anywhere across the Trust as a patient or carer. There were particular comments about the positive effect of Barbara’s Story on non-clinical staff’s interactions and behaviour.
Objective 2 Explore staff perspectives on the evolving Barbara’s Story and any effect on themselves, their colleagues and the organisation as a whole

Staff perspectives of the evolving Barbara’s Story, revealed within the second series of films, were gained through the Phase 2 focus groups. Staff continued to discuss the initial Barbara’s Story but also discussed the films as a whole. Staff perceived that the second series had further increased their own and colleagues’ awareness of dementia and delirium. The series illustrated the whole patient’s journey across hospital and community services and as most staff are based in one setting, understanding the whole patient’s experience gave valuable insights. As with the initial Barbara’s Story, gaining the patient’s perspective was particularly insightful helping staff to appreciate that the familiar hospital environment can be frightening and confusing for patients. The evolving Barbara’s Story alerted staff to dementia-related Trust initiatives, such as This is me and trained nursing assistants to give one-to-one care; the films reinforced and supported the embedding of these initiatives within the Trust.

Objective 3: Make comparisons between the responses of different professional groups to the initial Barbara’s Story, and the evolving Barbara’s Story

There were few differences between responses from staff of different professional groups to the Barbara’s Story series of films. All of the themes and sub-themes were broadly supported across the different focus groups. There was widespread support for the Barbara’s Story project and the various dementia-related initiatives in the Trust. The effect of Barbara’s Story on individuals, including the emotional engagement, increased awareness and understanding about dementia, and improved interactions and behaviours, were described across all the focus groups. There were however some subtle differences within the responses. In the Phase 1 focus groups, non-clinical staff and therapy staff discussed the Trust values in relation to Barbara’s Story much more extensively than other professional groups. Clinical staff were much more likely to discuss the constraints and challenges in practice than non-clinical staff. Non-clinical staff discussed how Barbara’s Story had given them the confidence to interact more with patients and to assist people looking lost in the hospital corridors. In particular, non-clinical staff seemed to have really taken on board the impact that they could have on a patient’s experience; this was highlighted within the films and was commented on by clinical staff too. Certain Trust initiatives were discussed much more by clinical staff (e.g. This is me) but others, such as improving food provision and environmental changes, were discussed across all groups. Therapy staff would have liked to see their roles more being more prominent within the films. Overall however, the responses to Barbara’s Story were similar across all focus groups and certainly all staff considered the films to be relevant to their own practice.

Objective 4: Make comparisons between the first set of focus group findings, and the second set of focus group findings, to evaluate responses over time

When comparing the findings from the Phase 1 and Phase 2 focus groups, it can be identified that there were many similarities. Barbara’s Story as an educational device and the large group interprofessional delivery was well received. In the Phase 2 focus groups, there were now, however, different modes of delivery available and their merits were discussed. Staff at both the Phase 1 and Phase 2 focus groups strongly supported the mandatory
nature of the initial Barbara's Story and all agreed with the film being embedded in the corporate induction. There were concerns expressed in the Phase 1 focus groups that the second series would not be mandatory. At the second series of films, the difficulties with prioritising attendance when the films were not mandatory were highlighted. However, it was apparent that staff were accessing the films via the other modes now available. At the Phase 2 focus groups, there was greater awareness of the context (national and Trust) for Barbara's Story. At both the Phase 1 and Phase 2 focus groups, staff identified that the continued senior Trust leadership of the project was powerful. At the Phase 1 focus groups, staff considered that there had been a culture change and this was discussed more extensively at the Phase 2 focus groups. The increased awareness and improved interactions and behaviour were similarly described at both Phase 1 and 2 focus groups.

Whilst at the Phase 1 focus groups staff identified various dementia-related Trust initiatives, these were discussed in much more depth at the Phase 2 focus groups. In particular, This is me was spoken of very positively and was being well used in some areas, though still needed further embedding. The role of Dementia Champions also seemed well established. Overall, the Phase 2 focus groups indicated a gathering of momentum about dementia care and an understanding that dementia is ‘everybody's business’.

Objective 5: Make recommendations for how awareness of dementia within GSTT can be sustained and further developed

At both the Phase 1 and Phase 2 focus groups, sustainability was explored with staff. Some key aspects have already been instilled and these should be continued, namely:

- Barbara’s Story embedded in the Trust induction for all staff;
- Dementia champions with a remit to update colleagues about dementia and resources available and to liaise with the Dementia and Delirium team;
- Dementia training (with the Barbara’s Story films) for staff working regularly with people with dementia;
- Barbara’s Story accessible on the intranet, with staff encouraged and supported to access this.

Other suggestions that staff made and could be considered by GSTT are:

- A regular update on dementia initiatives, with stories from staff or patients/carers, within the Trust newsletter or bulletin and reminders about resources (e.g. the delirium bundle);
- A regular programme of large group viewings with facilitated discussion of the films;
- Review of individual’s learning from Barbara’s Story at staff appraisals;
- A project with a focus on other patient groups who are vulnerable (e.g. learning disabilities or physical disability) so that care principles highlighted in Barbara’s Story could be revisited and reinforced with another patient group.

Objective 6: Draw conclusions as to how the project’s evaluation findings might transfer to other settings.

A few participants suggested that Barbara’s Story should be shown within other settings so they clearly perceived that it would be relevant to staff outside of GSTT. The findings strongly support Barbara’s Story as an educational device and delivered interprofessionally with facilitated discussion. It is important however to recognise the set of conditions that were in place that are likely to have influenced the success of Barbara’s Story within GSTT. These conditions are:

- Senior Trust leadership of the project and commitment to improving dementia care across the Trust;
A team of staff with expertise (the Adult Safeguarding Team and Dementia and Delirium team) to facilitate sessions, support staff and act as an ongoing resource;

- Resources to assist staff in applying learning from Barbara’s Story in practice: dementia pathway, delirium care bundle, This is me, flexible food provision, dementia-friendly care environment, screening protocols.

A key factor in the success was that the initial Barbara’s Story was seen by all Trust staff (clinical and non-clinical) so there was a shared experience and a common awareness and understanding gained. As Barbara’s Story is now embedded in induction for new staff employed in the Trust, GSTT have maintained the stance of having a whole staff population who have viewed Barbara’s Story (with the exception of agency staff).

When considering the transferability of the evaluation findings, other settings would need to appreciate that for maximum effectiveness, Barbara’s Story needs strong leadership and commitment to improving dementia care through educating all staff within an organisation.

**Section 10: Conclusion**

This report has presented the evaluation of the project Barbara’s Story. The findings are based on data collected at different points in the project’s trajectory: immediate staff responses to the initial Barbara’s Story film, one year after the project was launched after all Trust staff had seen Barbara’s Story, and following the second series of films showing Barbara’s evolving story, with the final focus groups conducted two years after the project launch. Barbara’s Story has developed an increasingly high profile within the Trust and has raised awareness about dementia with the strong message that dementia is relevant to all Trust staff. Staff articulated increased awareness and understanding and improved interactions and behaviour in themselves and others. The whole Trust approach to the project, with senior leadership, and the project being contextualised within the Trust values, was considered beneficial and staff perceived that there had been a positive culture change within the Trust. The increased availability of flexible modes of delivery, the commitment to embed Barbara’s Story in induction for all new staff, the continued availability of further dementia training in the Trust and a network of Dementia Champions should all support the learning from Barbara’s Story in the future.
References


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Appendix 1 Focus group topic guide: Phase 1 focus groups

The facilitators will ask open questions on the following topics, with probes used for examples and more depth of responses.

1) Participants’ recall about watching Barbara’s Story:
   - The key points they remember about the film
   - Their feelings when they watched it at the time
   - Any thoughts about they had about changes they would make to their own practice
   - Any thoughts they had about improvements that should be made for people with dementia within the Trust

2) Move on to participants’ experiences since watching Barbara’s Story:
   - Any changes they have made to their day to day practice, having watched Barbara’s Story – how they have made these changes
   - Any specific examples of situations where their feelings or behaviour were different, as a result of having watched Barbara’s Story
   - Any examples they have seen in the Trust of other staff behaving differently with people with dementia or other vulnerable people, that might be related to ‘Barbara’s Story’
   - Any views about the Trust’s values and approach to people with dementia and those who are more vulnerable: whether there have been any changes in the organisation as a whole since the Trust launched Barbara’s Story

3) The Trust’s values: Put patients first, Take pride in what we do, Respect others, Strive to be the best, Act with integrity
   - Any examples of where they have used these in practice
   - What helps them to put these values into action
   - What hinders them from putting these values into action – any suggestions about what the Trust needs to do

4) The future:
   Anything else that participants feel they need, so that they can support people with dementia, or other vulnerable people, who are visiting GSTT, or are inpatients

5) Any other comments that participants would like to make about Barbara’s Story
Appendix 2 Focus group topic guide: Phase 2 focus groups

The facilitators will ask open questions on the following topics, with probes used for examples and more depth of responses.

1) Barbara’s evolving story:
   - Which films did the participants see – general views and feelings about the series
     o Any particular film that stands out?
     o Were there any barriers to attendance – for you or colleagues? If yes, explore
   - Impact of the Barbara’s Story series
     o What they have learnt from watching the films: impact on their feelings and behaviour
     o Any changes they have made in practice, during the Barbara’s Story series: specific examples of how they have made these changes, any other changes they would like to make, any barriers to making changes for them or colleagues
     o Any examples they have seen in the Trust of other staff behaving differently with people with dementia or other vulnerable people, that might be related to the evolving series of ‘Barbara’s Story’
     o Any views about the Trust’s values and approach to people with dementia and those who are more vulnerable: whether there have been any changes in the organisation as a whole since the Trust launched Barbara’s Story

2) The future:
   o Suggestions about how any impact of Barbara’s Story can be sustained over time: what would affect sustainability? What could help impact be sustained?
   o Anything else that participants feel they need, so that they can support people with dementia, or other vulnerable people, who are visiting GSTT, or are inpatients
   o Anything else that participants feel that the Trust needs to do, to be a ‘dementia-friendly’ care environment?

3) Any other comments that participants would like to make about the Barbara’s Story series