



An evaluation of Barbara's Story Phase 1 report

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Executive summary

Introduction

Dementia is a growing health issue and all NHS Trust staff must develop awareness of the needs of people with dementia. In September 2012, Guys' and St Thomas' NHS Foundation Trust (GSTT) embarked on a new campaign using a specially commissioned film 'Barbara's Story'. The 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 aims 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.

Barbara's story was shown on a regular basis from September 2012 to April 2013 and about 12,500 GSTT staff saw the film. 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. Attendance was mandatory for all Trust staff: clinical and non-clinical. Barbara's Story was also embedded into the corporate induction programme for new Trust staff.

Background and rationale

The numbers of people who have 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 staff, as in the Barbara's Story initiative with GSTT.

Aim and objectives

The evaluation aims to investigate GSTT staff's perspectives of the effect of Barbara's Story on themselves, their colleagues and the organisation. This report addresses the first objective, which is to: Explore staff perspectives about the initial Barbara's Story session and any effect on themselves, their colleagues and the organisation as a whole. The report also draws out differences and similarities between responses from different staff groups. Other objectives of the evaluation will be addressed during phase two of the evaluation.

Method

The evaluation used a naturalistic approach to gather data from Trust staff through:

- 1) Open written comments (n=1246): Trust staff's initial responses to Barbara's Story;
- 2) Focus groups with groups of staff, in discipline-specific groups (nurses, medical staff, allied health professionals and non-clinical staff). These were held approximately one year after the launch of the project, but before the new series of Barbara's Story commenced. 67 staff took part in 10 focus groups and one individual interview was conducted.

The written comments were analysed using a thematic approach. The focus group 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.

Findings

Six themes emerged from the written comments:

- 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.

The themes and sub-themes from the focus groups were:

- *Impressions of Barbara's Story and its effectiveness*: Relating to Barbara; Reflections on staff behaviour; Barbara's Story as an initiative;
- *Since Barbara's Story*: Awareness; Interactions and behaviour; Influencing others; Professional behaviour and responsibilities; Trust initiatives; Constraints in practice;
- *The Trust values in action*;
- *The future*: Care improvement suggestions; Sustainability of Barbara's Story

Conclusion and next steps

The evaluation to date indicated that Barbara's Story made a lasting impression on staff and the initiative prompted reflection on their 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 staffing and 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 also suggestions about how the learning from Barbara's Story could be sustained.

With funding from the Burdett Trust, a further five films have been made and these reveal the evolving story of Barbara as her health deteriorates and she needs further hospital admissions and care. These are being shown to staff from September 2013-March 2014. A further phase of focus groups will then be conducted, to complete the evaluation of the initiative.

1. Introduction

Dementia is a growing health issue and all NHS Trust staff must develop awareness of the needs of people with dementia. In September 2012, Guys' and St Thomas' NHS Foundation Trust (GSTT) embarked on a new campaign using a specially commissioned film 'Barbara's story'. The 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 and 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. Barbara's story was also embedded into the induction programme for new Trust staff. With funding from the Burdett Trust, a further five films have been made and these reveal the evolving story of Barbara as her health deteriorates and she needs further hospital admissions and care. These are being shown to staff from September 2013-February 2014.

This report presents the findings from the evaluation of the initial Barbara's Story film (Phase 1), which was conducted through 1) an analysis of comments written by staff immediately after they attended the sessions, and 2) the analysis of focus groups that were conducted with a range of staff approximately one year after Barbara's story was launched, just before the launch of the second series of films. The report includes a background and rationale for educating healthcare staff about dementia, the method of carrying out the evaluation, the evaluation findings and conclusions. Further focus groups will be conducted after the second series of films has been shown, and then a further report will be presented.

2. Background and rationale

2.1 Dementia as a growing health issue and strategic response

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, there are an estimated 800,000 people with dementia (Alzheimer's Society 2012) and dementia is the third leading underlying cause of death in women, and seventh in men (Office for National Statistics 2011). 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.

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' in 2010. 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). Thus, the UK government seems to have a well-established strategic commitment to dementia care.

2.2 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). 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 (The Alzheimer's Society 2009). The RCP's (2011) audit illuminated continuing problems, including a non-dementia friendly and impersonal environment.

2.3 Education of hospital 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).

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; Skog *et al.* 2000; Kontos *et al.* 2010). There are also examples of creative approaches to undergraduate education in the US: 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).

Barbara's story uses the approach of 'ethnodrama', which 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 as yet unreported, sustainability of the educational approach is unknown.

While the projects reviewed used innovative and creative methods, most of these 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;
- 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 links into the Trust values and has potential to impact on Trust culture and have wider application than approaches to people with dementia.

3. Aims / objectives

The evaluation aims to investigate GSTT staff's perspectives of the effect of Barbara's story on themselves, their colleagues and the organisation. The objectives are 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;
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.

This report presents findings from objective 1 and contributes to objective 3.

4. Method

The evaluation used a naturalistic approach to gather data from Trust staff through:

- 1) open written comments to capture staff's initial responses to Barbara's Story, and
- 2) focus groups with small groups of staff, in discipline-specific groups, held approximately one year after the launch of the project, but before the new series of Barbara's Story commenced.

4.1 Initial written responses to Barbara's Story

Barbara's story was shown on a regular basis from September 2012 to April 2013 and about 12,500 GSTT staff saw the film. 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.

4.2 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 nurses' focus groups included ward-based nurses, specialist nurses, out-patients department nurses and Accident and Emergency nurses. Table 1 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.

Table 1 Summary of focus group participants

Identifier	Discipline	Number
Nurses 1	Nurses	2
Nurses 2	Nurses	6
Nurses 3	Nurses	6
Nurses 4	Nurses	3
Nurses 5	Nurses	6
Community	Community staff (midwives, district nurses, health visitors)	6
Therapists 1	Therapists (occupational therapists, physiotherapists, dieticians)	14
Therapists 2	Therapists (occupational therapists, physiotherapists, dietician)	8
Medical	Doctors and dentists	4
Non-clinical, patient contact	Porters, receptionists, food services staff	12
Non-clinical, non-patient contact	Facilities manager (individual interview)	1
Total		68

4.3 Data analysis

The post-it notes were typed up so that they were in electronic format. They were then analysed thematically by reviewing all the data, applying codes that emerged from the data and developing themes with sub-themes (Patton 2002). 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).

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 interview 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.

4.4 Ethical considerations

Ethical approval was obtained from London South Bank University's Research Ethics Committee. The evaluation was registered with the Trust'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 are 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.

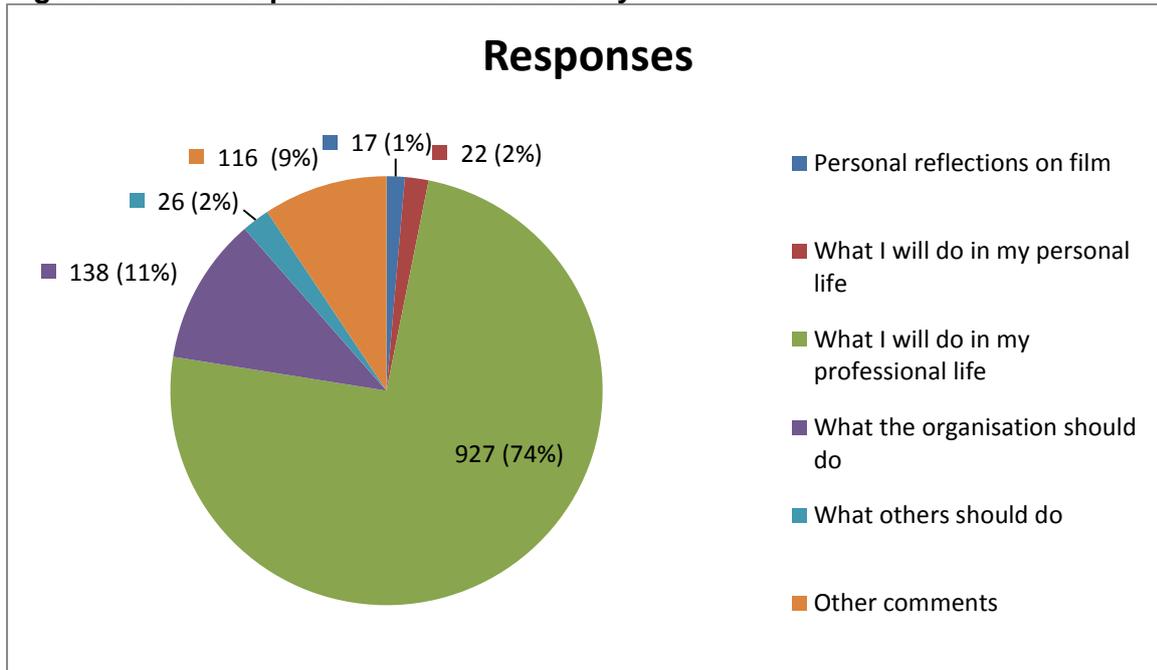
5. Findings

The findings are presented for the initial and immediate responses to seeing Barbara's story, which was captured on the *Post-it* notes, and the themes that emerged from the focus group data analysis: reflections on Barbara's story, one year after the initiative's launch.

5.1 Initial responses to Barbara's story

The themes that emerged from the written comments fell into six themes (see Figure 1): 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 findings of the thematic analysis of the *Post-it* notes are displayed in Table 2, which shows the themes and sub-themes 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.

Figure 1: Initial responses to Barbara's story



An overview of the common sub-themes with sample quotes is presented next. A summary sheet with further examples of comments under different themes/sub-themes is shown in Appendix 2.

Common sub-themes

The most common 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

and

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'. 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.

'Treating people as an individual' was the next most common theme with 130 responses. Examples of comments are:

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

Table 2 Initial responses to Barbara's story

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

Some staff felt saddened that care of patients at the Trust could be like that reflected in the film, for example

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.

Another common 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 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

I will try to push the wheelchairs forwards instead of backwards (I'm guilty of that).

There was a variety of comments about how the Trust could improve dementia care, especially around the use of volunteers, for example:

Perhaps the trust could offer more helpful volunteers to improve patients' 'journeys' through the hospital akin to 'games makers'.

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. There were many suggestions for increasing training on dementia care to other organisations, for example:

Share the films and training with local care providers and wider.

A number of staff suggested ways in which other members of staff could change, for example:

Hospital transport. Staff need greater training to needs of elderly confused patients.

Reception staff generally within the Trust need to smile more and be aware that they are the 1st contact point¹.

Better customer care for all staff but particularly front line/ receptions/ porters etc.

The management need to see this most of all – they do see all patients as a number on target and make staff feel the same – learn the hospital experience.

There were also many suggestions for how dementia care in particular could be improved

Discuss in team meetings. Ensure patient information is 'dementia friendly'!

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

All healthcare personnel should be trained in dementia care from Drs, GPs, nurses and AHPs.

¹ Reception staff have since requested specific training for all team members.

However, there were a few less positive views about the film

Barbara says, "...that doesn't mean I'm mad". Unfortunately, I found that also disrespectful. Universal values apply to all.

Negative aspect- The film does not reflect our multicultural staff

Increase staff: patient ratio - increase amount of time we can spend with patients. Don't waste our time patronising us with films like this

Finally a small number of staff wrote comments with personal reflections and emotions that had been triggered by the film. In particular, they referred to family members with dementia, for example:

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.

5.2 Reflections on Barbara's story

While Section 5.1 captured initial responses immediately after viewing the film and engaging in the discussion, the focus groups explored participants' views some months afterwards. Table 3 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 1.

Table 3 Focus group themes and sub-themes

Theme	Sub-theme
Impressions of Barbara's story and its effectiveness	Relating to Barbara Reflections on staff behaviour Barbara's story as an initiative
Since Barbara's story	Awareness Interactions and behaviour Influencing others Professional behaviour and responsibilities Trust initiatives Constraints in practice
Trust values in action	
The future	Care improvement suggestions Sustainability of Barbara's story

5.2.1 Impressions of Barbara's story and its effectiveness

The participants were asked open questions about their recollections of Barbara's story, their thoughts and feelings at the time. The discussions centred around the staff's impressions of Barbara's story: how they related to Barbara and her experience, their reflections about the staff behaviour observed in the film, and their perspectives on Barbara's story as an initiative in the Trust.

Relating to Barbara

In all focus groups, staff talked about Barbara as a person and 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)

Staff remembered her 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-clinical, patient contact group)

Barbara's story prompted many empathetic comments from the participants, for example:

What we take for every day, doing something – all the simple things – can, for some people be very, very difficult. (Community)

It did help kind of remind us and reiterate how lonely it is for the patient. (Medical)

It must be a very bleak experience to be ignored and not spoken to. (Nurses1)

Reflections on staff behaviour

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 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-clinical, patient contact)

The nurse was talking to the porter and wasn't even talking to her, and generally like talking to other members of staff right in front of her about her in the third person. (Nurses2)

Watching staff behave in this way 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 reflection and an increased awareness of their own behaviour:

The thing that they [colleagues] took away from it was talking over patients and it made them aware of talking over patients. (Nurses1)

It made me realise sometimes it's easier 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 clinical, patient contact)

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)

I was able to realise and do a little bit of reflection on my day-to-day activities, especially when I'm at work. So it's like a matter of 'What if I'm in Barbara's shoes, being confused, don't know what to do'. I've been more conscious of what's happening in the environment, especially here at work. (Nurses2)

For other participants, the film prompted reflection on colleagues' behaviour:

I think that it also raised some issues in terms of to see how the 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)

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 isolated comments, that the behaviour of the doctors in the film was 'not very typical' (Medical focus group) 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-clinical, patient contact) 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)

Barbara's story as an initiative

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, 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)

Areas that staff discussed included: the emotional impact of the film; the relevance of the film to their own practice and/or the Trust; and the effectiveness of the film and its delivery method.

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-clinical, patient contact)

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)

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 its impact:

I know that the film, when it first came out, people were a bit cynical about it and they were saying 'Oh God, got to go and see Barbara's Story', but 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'. You know, there was nothing negative about it, it went from 'Oh I've got to go and see Barbara's Story', rolling of eyes, to 'No, no, no, 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)

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 clinical, patient contact)

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)

The film was described as: '*thought provoking*' and there were many positive comments about its effectiveness and about the way the initiative was delivered, for example:

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-clinical, non-patient contact)

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 was also a comment about Barbara's story setting a standard in the Trust:

Once you saw the video, it was like, 'Okay. Well, that's what's expected of us when we're dealing with patients with dementia or cognitive impairment.' Yes, as you said, it just felt like it set the bar. (Therapists2)

In several focus groups staff discussed the Trust-wide approach 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 and obviously following it up with other ones as well. (non-clinical, non-patient)

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.' It was kind of 'Yes, we're being chased round the hospital. If we don't go, we're going to get the sack.' (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)

I saw it at my induction, seven months ago. It was the best part of my induction, without a shadow of a doubt. [It] actually meant something to everyone there: if you were a doctor or a porter. (Non-clinical, patient contact)

There were comments in one of the focus groups about Part 2 of the film not being realistic, as Barbara (now in her own home) seemed too articulate (Therapists1); however as a result of early feedback the second part is no longer being used.

5.2.2 Since Barbara's story

Staff were asked open questions about what had happened since the launch of Barbara's story and, specifically, any changes in their own practice or that of colleagues, and any changes observed in the Trust in general. The key sub-themes that emerged from these discussions were: awareness; interactions; influencing others; professional behaviour and responsibilities; Trust initiatives; and constraints in practice. Each of these will be discussed next, with illustrative quotations from the focus groups.

Awareness

Many participants discussed how Barbara's story had increased their awareness of patients' experience, which impacted on their approach:

It's very good for making people recognise how other people feel and a lot of people are a lot more clued up to that. (Nurses5)

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)

On the prosthetic or dental, 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)

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)

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-clinical, non-patient contact)

There were extensive discussions about increased awareness about people with dementia: in participants' own practice area and more widely in the Trust. Some participants referred specifically to their awareness having increased:

It's made me think more about to look for more signs that they might be somebody like that [with dementia]. (Community)

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-clinical, patient contact)

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 participants discussed that there was now generally a heightened awareness of dementia in 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 it's made everyone more aware of dementia and the care of the dementia patient. I think everyone is much more aware of that, 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)

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)

There's a likelihood that we'll be coming into a lot more contact with people perhaps in corridors and things. (Non-clinical, non-patient)

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)

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-clinical, patient contact).

Some staff commented that they considered that they were already aware of dementia anyway:

Within our department, we're quite aware of Alzheimer's because we get a lot of referrals for patients with Alzheimer's and dementia, so we've always been fairly aware. (Medical)

Interactions and behaviour

In most focus groups, staff talked about 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:

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 have a patient who I am looking after today who needs total care from top to bottom and you have to feed him. I give that time from Barbara's story. I have learnt, because I would like that to be done to me and so I give it back. (Nurses3)

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)

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 participants referred to having changed their approach now they understood what an ordeal it is for some patients to have to attend hospital for an appointment, for example:

I've definitely changed my approach to getting patients back in as outpatients or arranging the follow-up appointments, having seen [Barbara's story] having more of an understanding of the kind of stress that it might put on somebody until they actually get into that room. (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:

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 don't think I've ever stopped and asked someone if they're lost and if they know where they're going quite so much as I do now. (Nurses4)

You need to take more time with people now. [...] Whereas, maybe you would have sort of - 'point them in the right direction'. Now you direct them [...] You take them. (Non clinical, patient contact).

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 was one comment 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 [...] I want to say thanks to Barbara's story. (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, patient contact' 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-clinical, patient contact)

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:

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 now.

-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 following comment implies a culture change, which allowed staff to help:

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)

The importance of having staff in post 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'. 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.

Influencing others

Comments about influencing others concerned guiding and teaching, leadership, and teamwork, and there were also some comments about a culture change that enabled staff to behaviour in a different way.

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 sometimes. (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)

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-clinical, patient contact)

There were several aspects of leadership referred to in relation to Barbara's story. These included the leadership of the initiative by the Chief nurse, which 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)

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 clinical, patient contact)

There were a few 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)

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)

Some participants also perceived that there had been a culture change that enabled staff to put patients first as they perceived senior staff would support them, 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)

One focus group explored this aspect in detail as a group:

-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)

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-clinical, patient contact)

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)

Trust initiatives

Participants discussed various other 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-clinical, patient contact)

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:

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.

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-clinical, non-patient contact)

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:

Obviously before Barbara's Story [dementia nurse lead] was fairly proactive with promoting interventions, because there used to be yearly study days held, which I've attended previously, and then obviously Barbara's Story came and the safeguarding team have been doing some one day study days as well recently. And also I know there's a big thing with dementia champions and they're trying to get those in every area, to obviously keep promoting it and raising awareness, and just to make sure that we are doing all the extra things that we can be doing and just make them part of our everyday life rather than having to be that extra thing all the time. (Nurses2)

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.

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, for example:

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.

5.2.3 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. There was a discussion in the focus group with non-clinical, patient contact staff, 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-clinical, patient contact)*

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-clinical, non-patient contact)

Participants sometimes used phrases like 'going the extra mile' or going 'beyond the call of duty':

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-clinical, patient contact)

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, and sometimes with reference to the whole team or Trust:

I guess 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 and you walk away thinking 'Oh everything's done'. (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 was there 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 when it comes to dementia patients. I think with dementia but care of the elderly as well. (Nurses2)

In the non-clinical, patient contact 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.

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-clinical, patient contact)

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-clinical, non-patient contact)

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.

5.2.4 The future

Participants discussed ideas about what should happen next to continue to improve care of people with dementia in the Trust and also, how the learning from Barbara's story could be further embedded and sustained.

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 2.

Box 2 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
- Further teaching and support available to staff and training students
- Flexible systems so that patients with dementia can be assessed at home in their own surroundings
- More use of volunteers e.g. to sit with people with dementia

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.

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. It's rare that single events lead to a change in behaviour. (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 as nurses and as a Trust, to keep promoting it and make sure that our training and awareness, you know, keeps getting reiterated. (Nurses2)

There was a suggestion that the learning from Barbara's Story could be sustained through regular reinforcement, and at appraisal:

- *Perhaps, dates could be put in through the year to revisit with the whole department*
- *We could ask them for ideas as to how they have adopted Barbara's Story in their life.*
- *In the appraisal, e.g. 'one example of how you've adopted in your role'. (Non-clinical, patient contact)*

There were also some concerns that the second series of Barbara's Story would not be mandatory:

I'm surprised to hear that Barbara's Story is not going to be now mandated and the next bit is not going to be mandated and I think they've created something and it's raising awareness and we're not going to see that so people learn more, and that everybody else can learn more and we can get good practice. (Therapists1)

6. Conclusions from Phase 1: Barbara's Story

The evaluation to date indicated that Barbara's Story made a lasting impression on staff and the initiative prompted reflection on their 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 staffing and 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 also suggestions about how the learning from Barbara's Story could be sustained.

7. Next steps for Barbara's story and the evaluation

The evolving Barbara's story set of films are being shown to Trust staff, from September 2013; these are due to be completed in February/March 2014. After the series is completed, further focus groups will take place. These will be analysed using the framework approach and comparisons will be made between the Phase 1 and Phase 2 focus groups, as well as between disciplines. A final report will then be compiled for the Trust. Work to embed the learning from Barbara's Story is on-going within GSTT, for example, each directorate has developed an action plan focused on the changes that they plan to make.

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Appendix 1 Focus group topic guide

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 Initial responses to Barbara's story

Theme	Sub-theme	Total number of responses	Examples of quotes
Personal reflections on the film		17	Reminding of personal experiences of a family member with dementia. I 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. My grandfather had dementia. I know 5 years before I was told. I could see it in his tears. Perhaps he missed me, or perhaps he couldn't remember much. I'll never forget those days we shared. I thought about my grand parents and I would hate them to feel as Barbara did- I will try to accompany them to hospital more and consider all patients in GSTT as potential Barbara's
What I will do in my personal life		22	Look out for and respect anyone who seems to have dementia – out of work, colleagues, porters, taxi drivers. Don't make them more agitated I'll kiss and hug my elderly parents Call my mum more, she lives abroad
What I will do in my professional life	Giving my best	24	Observe signs of confusion and make sure I give my best to help them feel wanted and welcomed Go extra miles to assist patient Really pay attention
	Showing kindness	35	Help with kindness Kindness and communication is a fundamental requirement when dealing with the elderly
	Needing/giving support	17	They need more family/friends/social support
	Treating people as an individual	130	Improve awareness of identifying needs of individual patients Preserving dignity, being patient, friendly, asking questions See the person not the condition and take the time to appreciate the person is an individual and has needs. They are going to be anxious about their health, we are there to care for them as an individual not condition Make time to treat patients like people, not tasks I am to treat each and every patient as an individual. An individual that is unique. In turn I intend to provide him/her with the respect and attention that they deserve and require Think about how your patient is feeling and to remember that each patient may not feel the same way. Always make it a point to ask my patients their preferred name and how they would like to be addressed. To make time for every individual patient to ensure they feel reassured and like a person not a Make each patient special and valued. Treat them as an individual Find out about patient's life and take an interest to make them feel more comfortable Treat every patient as an individual. I will endeavour to treat everyone as an individual and not their circumstance/ Remember that every single person is an individual and treat them that way. Always treat patients as an individual Make people/patients aware of why and what they are in hospital for – explaining properly, be friendly, kind I will remember that patients in hospital all have their own lives and experiences and should be treated like I always make sure I put my patients at the centre of my care even after a long busy day I treat people as human as individual. To be more sensitive to patient giving careful attention to them and be more aware of what they are feeling at the moment we see them Recognise the patient as a person. Think about things from a patient's point of view I've been reading Florence Nightingale note and lectures. It angers me that more than 100 years down the road, this kind of dehumanising 'care' still occurs in our institutions.
	Showing empathy	14	As someone who is in their 70s it made me realise even more how much empathy we need to have with I will be like nurse Jane...show empathy
	Being helpful	14	The importance of helpful and attentive attitude with every patient (in and out patient) Receptionist could be more helpful
	Communication	182	To communicate more with people and be nice to them. Try listening to the person Greet patients, introduce yourself, communicate the reason for interacting, ask for consent, explain results, allow patient to ask questions, do not discuss personal issues in presence of patients To seek to communicate with people and not to overlook them. Effective communication To see patients in a more holistic way, to make sure I listen to them more carefully and give them all my Ensure good and effective communication Listen to them Take time to communicate with patients Patience, empathy, understanding, Effective listening and communication skills Always be patient and greet everyone with a smile and friendly face Listen more Smile – ask questions. Explain what I'm going to do with the patient step by step, to relieve some anxiety. Keep a patient updated
	Seeking consent	13	To always seek consent before commencing my assessment. Gain informed consent from the patient
	Treating people with respect	69	To treat people with courtesy and respect. Show respect – be patient and be encouraging Respect them and help them to make their stay as comfortable as possible Respect each and every human being, acknowledge each person