Event Evaluation: Coma, consciousness and decision-making: reflecting on care for vegetative and minimally conscious patients and their families

Julie Latchem (2016)

1. Introduction

This two-day event held at Badby Park Care Centre, Daventry showcased art works and theatre inspired by research conducted with families by the Coma and Disorders of Consciousness Research Centre (CDoC), Universities of Cardiff and York.

The event (5th-6th November 2015) included a range of art, installations, performances and talks about prolonged disorders of consciousness (based on research by Professor Jenny Kitzinger and Professor Celia Kitzinger (academics with personal family experience of severe brain injury). It also included the presentation of PhD research from their colleague Julie Latchem (a sociologist and physiotherapist) on the care and rehabilitation of people with severe brain injuries in long-term care; and contributions from the charity ADA (Advance Decisions Assistance).

A full description of each element of the event are given in the relevant sections below, but, in brief:

1) The Arts engagement exhibitions/activities included:

   a. A shadow puppet performance of ‘Where are you now’ by Karin Andrews-Jashapara, Play of Light Theatre exploring family experiences of long-term ‘coma’ (and a separate performance of a fairy tale performance as well for the entertainment of residents).

   b. A set of three ink on canvas installations by Seth Oliver inspired by research into family experiences

   c. A selection of ‘messages on postcards’ from families with experience of catastrophic brain injury – recording key messages they wanted to convey.
d. A set of ‘digital stories’ (developed with Digital story teller Lisa Heledd-Jones) about one individual severely brain injured (illustrated with the woman’s own cartoons and drawings)
e. An installation by Julie Latchem charting initial findings of her doctoral research using sketches, quotes and observational material.

The formal talks given included:

f. Introducing people to the healthtalkonline.org resource about VS/MCS family experience.
g. Exploring families’ experiences and perceptions of physiotherapy given to their relatives
h. Explaining the Mental Capacity Act and best interest decision-making.
i. Outlining Advance Decisions
j. Discussing life-sustaining treatments

1.1. Event target audience

The two-day event was advertised both internally and externally. Internally individual letters of invitation were sent to families with relatives in disorders of consciousness in the centre, staff were informed of the event and plans made for the release of as many staff as possible from ‘the floor’ so they could attend. Externally, the event was advertised in the local press and direct invitations were sent to organisations and individual professionals through established professional networks held by Badby Park professionals. The first day was focussed on Badby Park staff and family members and the second day external health care professionals.

1.2. Event objectives

CDoC had three key objectives for the event:

1) To raise awareness of the healthtalkonline.org resource about VS/MCS family experience.
2) To improve understanding of the Mental Capacity Act and best interest decision-making.
3) To raise awareness of Advance Decisions.

Julie Latchem, from her PhD research had four key objectives for the event:

1) Improve family-staff relations through awareness of one another’s experiences (and to recognise mutual understanding as well as potential for conflict).
2) Raise awareness of the contribution that ‘hotel service’ staff make to rehabilitation.
3) Bring together all layers of the organisation to engage in key issues within the care of people with severe brain injury.
4) Build capacity within Badby Park staff body by providing opportunities for innovative continuing professional development.

2. Methods of evaluation

Feedback was collected from attendees across the two days via:

- 18 formal feedback questionnaires (see Appendix 2)
- 15 audio vox pops
- 23 written comments on cards (‘flower card’ messages and Postcard messages)
- Notes taken of audience responses and questions during events, including observations and the noting of conversations as people went round the exhibition
- Post event email, twitter feeds and reflective conversations

3. Overview of the evaluation

3.1. Audience and Attendance

Both days of the exhibition were well attended. The first day opened with around 40 people in attendance including members of Badby Park senior management, therapists, therapy assistants, nursing and care assistant staff and seven residents’ family members. Some housekeeping staff also viewed the exhibition, attended some of the talks and the shadow puppet performance. Attendance was so high that the afternoon events had to be run twice, simultaneously to allow the audience to be divided but able to attend all events. All family members in attendance and many staff stayed for all the events that day (from 2-6pm).

The second day was also well attended by approximately 25 people. This included 15 external professionals, a Badby Park Director and a selection of Badby Park nursing and care staff, some of whom had chosen to attend on their day off. External attendees included Physiotherapists, Nurse Managers, Consultants and CHC assessors. As on day one, hotel service staff and further Badby Park care staff attended part of the day, to view the exhibition, attend a talk and/or view the shadow puppet performance. One family member returned in the afternoon of the second day to spend more time viewing the exhibition and another had wanted to return but could not get the time off work to do so.

Badby Park staff who chose to come to the exhibition on their day off reported that they had chosen to attend the event because they wanting to gain knowledge to empower them to do their jobs better and provide the best care for residents and families that they could. They spoke about being interested in and intrigued by the exhibition and wanting to attend to see what they could learn.
3.2. General observations and overall comments

The event was unanimously experienced and talked about as hugely successful by those who attended. There was an atmosphere of warmth, mutual support and pride surrounding the exhibition.

All of the above objectives were achieved – and more. The numbers (and type) of attendees, the length of attendance (i.e. family and staff members, and external visitors attending all day), the amount of discussion generated, the level of engagement with the exhibition and presentations and the formal feedback provided is testament to this.

Family members verbalised their thoughts and experiences following talks and performances, talked to staff and to one another in response to the exhibition. Staff too spoke of their experiences, what they had learned, what they felt they needed to better support residents, families and one another. For example, one Badby Park health care professional commented:

*The whole exhibition has given a lot of food for thought in a professional sense. Knowing some of the messages and feelings shared by relatives will stay with me and influence how I perceive some of the residents I work with.*

Responses to and comments about the exhibition as a whole recorded on feedback forms from staff, external professionals and families included:

*Thought provoking, painful but so honest & necessary* (Health care professional)

*Absolutely incredible* (Health care professional)

*Very reassuring* (Family member)

*Fabulous event, sensitively done* (Family member)

*This whole day has been illuminating, it’s amazing* (Family member)

One senior health care assistant who assisted with the evaluation recorded her own sense of the impact the event was making in the moment:

*It seems to be sparking a lot of emotion amongst staff, relatives particularly and even some of the professionals today. It seems to be giving them ideas in which to use to improve the standards of care being delivered.*

The importance of the use of art and a broad multidisciplinary approach to tackling the issues surrounding the care of people in prolonged disorders of consciousness was also noted. As one therapist explained:
This particular challenge of working through, as clinicians with relatives, how to address the challenges that patient in PDoC present, can’t be addressed through the clinical. Where we try and address these issues as isolated clinical challenges it doesn’t work. What we need is to interrogate this in an interdisciplinary approach with sociologists, with philosophers and with the families to get it right, and that requires the arts and the humanities as well as the sciences. This exhibition has drawn all of that together.

3.3. What they learned

Family member attendees reported that they had learned that they could access the stories of other family members and that through attending the exhibition they had come to realise that they shared experiences with others. Furthermore, the exhibition highlighted to them that staff members recognised and sought to understand what they ‘are going through’. Family members highlighted that they had not previously been aware of the existence of advance decisions and one remarked on their learning about the differing perspectives people can hold regarding physiotherapy.

Staff and external health care professional attendees reported feeling they had a better understanding of family experiences, feelings and perceptions. They remarked that the exhibition, through tackling issues such as death and the withdrawal of life-sustaining treatments highlighted to them that these previously ‘taboo’ issues could be discussed in an open forum. Some non-qualified staff members reported an improved understanding of best interest decision-making and the Mental Capacity Act.

One therapist, new to the clinical area of neurology reflected on her learning and the impact the event would have on her own practice:

I found today absolutely fascinating and quite emotive. I definitely feel that I’ve learned a lot and I will be going away to read some more, and definitely use the website resource. I can’t believe actually how emotional it’s been and quite shocking some of things that I’ve read from families. I definitely feel as a professional it has given me a completely different and advanced perspective on those patients that I will be coming across in my future practice. I’d like to think that this is going to actually inform my practice and make me a better practitioner and much more empathetic to not just the person who I am treating but also to the family around them and what they have been going through and experiencing. I definitely feel I need to be explaining all the interventions I’ll be doing and what I’m hoping to get from them and what the person I’m treating is going to get from them.
3.4. Change in Knowledge

The event improved attendees’ knowledge (as self-assessed). Attendees rated their level of knowledge about issues surrounding care of people in prolonged disorders of consciousness, on average, 2.76 on a five point scale prior to attending the exhibition and 4.71 afterwards (i.e. an improvement of 1.95 points).

This breaks down in the following ways: Of the 17 people who completed the feedback form, 15 people indicated that they felt better informed about the topic after attending the event and 2 attendees rated their knowledge to have stayed the same.

3.5. Planned future actions and suggestions for change

Staff members and health care professional attendees reported plans to use the healthtalkonline.org resource to improve service delivery, to work closer with families and look within their own services to see how families could be better supported. One health care professional reported the need to “normalize interactions with relatives, rather than have professional vs family”. The majority of attendees reported that having attended the exhibition, they now planned to write their own advance decision.

From what attendees had learned or the debates and discussions that had been stimulated through the event, attendees began to suggest actions and idea to help tackle issues or create change. One manager reflecting on a section of Julie Latchem’s talk about family’s perceptions and experiences of physiotherapy commented:

“I think Julie mentioned about when [therapy] care is withdrawn, kind of resonated, there was a mention of commissioner’s decisions, basically bureaucrats not knowing the impact of their decisions down the line. I mentioned to Julie that actually it’s in the gift of the therapists and the clinical team along with the families to actually challenge that, and I know they do, but quite often because they feel alone they don’t take it all the way. I thought there’s an ideal opportunity on that website to start challenging that as a group. I understand that the website is a very supportive website but I also think it could be very constructive in it’s challenge to the people who hold the purse strings.”

3.6. Key discussions and reflections generated

The exhibition and talks presented stimulated a broad range of debates and discussion, raising multiple key issues for those present. What was generated by each individual element of the event is detailed below, but where attendees were asked to comment on the event as a whole or offer an ‘in the moment’ response, a broader range of reflections and issues were evident.
Attendees remarked on how the exhibition had for them raised broader issues and themes which cut across other areas of practice and societal concerns such as what is quality of life and death? What is it to be a person, to be human? - and the tensions and contradictions around the way in which one might perceive and feel about these questions. As one health care professional questioned:

*How much of the human body can you lose before you’re actually no longer really human, and it’s quite a difficult question to answer that because you would never wish your relative to not be classed as human*

Several attendees highlighted that they felt the whole event opened up a space within which death could be talked about, thought about, being presented as something that can be planned for just like other aspects of our lives.

Attendees discussed the tension between on one hand being proud of services they provided, the sanctity of life and believing in the rehabilitation process and what it can achieve, while on the other hand recognising that a life of severe disability would not be wanted in all cases. As one therapist remarked:

*I’m immensely proud that a place like [Level 1 Specialist Unit] nurtures… the slightest little bit of life in a person, and in many other countries that wouldn’t happen, but I am very aware that some people wouldn’t chose to live like that.*

*We do as a society have to ponder what we are trying to do – physically we can keep people going but mentally we haven’t got the capacity to influence that as much and perhaps we are consigning an awful lot of people to what for them, and possibly some of their relatives is a living hell and that’s an awful thought because you don’t come in to [health care] to think you might be doing that.*

Attendees also raised service issues, how much rehabilitation and input was needed for this patient group and staff’s wish that they were more adequately resourced to meet needs of both patients and families.

Many attendees reported being emotionally moved by the exhibition and this was also visible in both families and staff reactions as they engaged with the art. For staff members, many reflected and drew not only on their professional experiences but their own personal experience of death and grief, of family members with disabilities, long-term care needs or coping with impairments following injury and illness. They remarked on the impact of these experiences on both themselves and their memories of their loved ones, and were often able to use these experiences to relate to the experiences of families as presented in the exhibition in some way.
Staff also spontaneously spoke about what they would want for themselves. Some had a clear idea while others spoke about not knowing what they would want, being and feeling conflicted and unsure, and discussed the complexities around making decisions in advance.

4. Individual events/installations and key responses

4.1. Talks/lectures

Four different talks/lectures were given by CDoC members across the two days based on research findings from interviews with families of people in a prolonged disorder of consciousness. 1) Professor Jenny Kitzinger and Professor Celia Kitzinger gave a talk on a healthtalkonline.org resource – which summarises research findings about family experiences of having a relative in a prolonged disorder of consciousness and includes around 250 clips from filmed interviews, 2) Julie Latchem presented research findings discussing families’ experiences and perceptions of physiotherapy (and other allied health professions and their treatments) given to their relative, 3) Professor Celia Kitzinger and Professor Sue Wilkinson talked about the law on decision making, advance decisions (formerly known as ‘Living Wills’) and lasting power of attorneys and 4) Professor Jenny Kitzinger presented research on best interests decision-making and life-sustaining treatments.

Approximately 40 people attended the talks on the first day and between 20 and 30 attended each talk on the second day. Audiences engaged well with each talk asking questions and beginning discussion and debating issues both with the speakers and one another. Both families and health care professional in attendance commented on new knowledge they had gained – be it factual in terms of the existence of advance decisions or experiential, such as the multiple perceptions held by families of physiotherapy interventions.
Attendees reflected on what the talks had raised with one another, the CDoC team and artist collaborators throughout the event and afterwards. Talks sparked staff led conversations about their frustrations surrounding decision making insufficiencies, prognostic capabilities and the impact of this upon families. As one non-clinical manager said:

*Decisions are quite often out of the hands of people, or they’re not informed enough, early enough or you have just got to wait, and I’m trying to get my head around when do you stop waiting?, or when do you learn enough to know actually, time to free your loved one in whatever way.*

The opportunity for staff to hear and be presented with family’s perceptions and experiences provoked deep reflection in some staff attendees. One senior health care assistant fed back:

*It’s seeing it from the family’s point of view, the physio bit got me […] I think you just presume that the families want you to do anything you can for them, regardless […] but you tend to see it from the residents’ point of view not the family, so it’s given me a whole new insight on all that.*

### 4.2. “Don’t say I didn’t tell you”: Digital stories by Jenny Kitzinger & Lisa Heledd Jones (StoryWorksUK), with cartoons, collage and art by Polly Kitzinger, and Polly’s door and poem

This installation consisted of a series of short 'digital stories' explore one woman's reflections on the heroic medical interventions that ‘saved’ the life of her sister, Polly, after she was catastrophically brain injured in a car crash. Each short film takes a different approach to exploring who Polly was - and what she might have wanted if she could have made her own choices.

The stories are illustrated with Polly’s own art as well as cartoons she used to draw. The final 'story' is a reading from a poem written by Polly before the accident expressing her wish to live life on her own terms, and fear of losing her independence. The ‘stories’ were on ipads, attached by clips to Polly’s actual bedroom door (taken from the family home) – onto which Polly had built up a collage of magazine clippings, badges and statements expressing her approach to life over 20 years and presented on a series of laptops and separate ipads to maximise viewing potential.
Both Polly’s door and the digital stories were visited by most attendees across the two days. Those who sat down to listen to the digital stories listened to all three of them and if they were disrupted from listening returned later to finish them.

Digital story teller Lisa Heledd-Jones was present throughout the exhibition and set-up of the ipads and made sure those wanting to view the stories were enabled to do so. This meant that a constant flow of people wanting to view were enabled and any technical issues immediately resolved.

Polly’s door and the connected digital stories made both a significant impact on many attendees that looked and listened and were successful in delivering it’s key messages – evident by attendees’ abilities to re-tell the issues within the stories, make comment and reflect upon them. As a manager and a therapist recounted:

The poem, where basically she’s talking about not being restrained, needing to be free, not wanting to be bogged down. She was a free spirit and the mere fact that she then finds herself in a vegetative state, or a prolonged [disordered] state of consciousness, it’s quite ironic, but the message is there ‘don’t let me be like this’. [Manager]

I look at the door there and I would be completely with her in her view that actually I would rather live fast and loose, you know really go for the life that I had and when it was at an end I’m not sure I’d want to linger. [Therapist]
The materiality of Polly’s door generated a connectivity with attendees to ideas of personhood, of individuality and the importance of self-expression and creativity. Attendees easily identified with the door as an artefact and instantly told their own stories about teenage life.

*It allows you into Polly’s thoughts and mind. I love her, amazing.* [Manager]

*I was drawn to the door because I wanted to understand it.* [Manager]

Attendees also noted how the door – and the collage was a powerful means of communication.

*Words don’t do much for me but pictures and images really trigger my imagination* [Senior Health care assistant]

*‘It’s a bit like an ‘all about me’ book. Not so much in terms of ‘how am I positioned’ and ‘what splints I need’ and ‘what my PEG feed is’ and all those sorts of things but in, ‘this is me’ really or ‘this used to be me’, and you get a real sense of who she was and who she is’. Perhaps we could make an equivalent available, relatives could make a collage of what they either felt their loved ones would have wanted on that door.* [Therapist]

*The door itself is amazing, I can remember being a teenager and kicking my door in, the last thing I would have thought about was trying to cover it up with stories and feelings and episodes of my thoughts, but that is just a wonderful way to get down on something your thoughts at that moment, it’s a beautiful way to capture it, and I thought the narration of it and how certain highlights of it have depicted, it’s just wonderful.* [Manager]
4.3. After/Becoming/Before: Ink on Canvas: Seth Oliver, 2015

Ears/Hope/Eyes – Audio: collaboration with @CDoCuk and sound artists: Rowan Talbot

The drawings and sounds works are parts of a series of meditations identifying moments in time. There is a constant flux between any certain shape of life & death. Between the traumas & the glimpses of hope we are after becoming before.

The canvases were installed by Badby staff, who took care to tilt the canvases and replicate their position and order as the artist himself had done at previous exhibitions. The canvases were exhibited in the corner of the room in which the talks were also held – to provide both a strong point of interest for those waiting for talks to begin and as a backdrop to the discussions to be had. One Badby Park staff member commented:

The artwork is amazing, the emotion drawing out of all three pictures tells a story.

A sound track accompanying the canvasses is available but due to the shared space (along with concerns that the content of the soundtrack may cause distress in this context) was omitted from this exhibition.
4.4. The postcard exhibition: messages from ‘coma’ families

The postcard exhibition consists of a set of 100+ ‘messages on a postcard’ from individuals with a father or mother, son or daughter, sister, brother or partner in a long-term coma, vegetative or minimally conscious state. The messages are addressed to doctors, care staff, and other family members and give a vivid insight into the challenges faced by families and the questions raised by their experiences. The exhibition includes images chosen by family members - ranging from Munch's 'The Scream' to the image of a chocolate teapot (representing support services that have failed). The postcards are also accompanied by illustrations by artist Tim Saunders.

The postcard exhibition was read by many attendees, who tended to spend many minutes reading most, if not all of the messages, pointing certain messages out to one another.

4.5. Shadow Puppetry

The shadow puppet pieces were performed on both days, the first ‘Where are you now?’, a collaboratively developed piece of theatre performed by Karin Andrews-Jashapara, Play of Light theatre explores findings from research with families of people in disorders of consciousness conducted by Professor Jenny Kitzinger and Professor Celia Kitzinger – co-directors of the Coma and Disorders of Consciousness Research Centre [CDoC]. The second, ‘The Lemon Princess’, a shadow puppet performance of a fairy-tale was performed for residents.
Where are you now?

‘Where are you now?’ was performed twice on each day. Due to the number of attendees who wanted to see the performance and the space available, performances were given back to back, with attendees being divided into two groups, with half attending the performance and half attending Professor Celia Kitzinger and Professor Sue Wilkinsons talk on advance decisions and then swopping over.

The shadow puppetry performance was watched by approximately 70 people (across the two days). The show attracted a wide range of attendees throughout the organisation, including housekeeping staff, health care assistants, therapists, managers and nursing staff. One of the company directors, although initially reluctant was persuaded to attend the performance. Afterwards he reflected on the communicative and emotive power on the piece and the reinforcement of duty to care well, with personalisation and dignity for people in a disorder of consciousness.

Attendees watched the performance attentively and the show generated multiple emotional responses, a period of quiet and reflection afterwards and lengthy discussions/reflective conversations. Attendees asked questions following the performance, made comment and in some instances reflected on their own clinical practice and person-as-practitioner experiences. One professional reflected upon how the performance brought to the fore the reality that brain injury ‘could happen to any of us, the show actually brings it to yourself, as something that could happen’. She then noted how that raised a conflict for her, between feeling the emotion of the situation as a person for both herself and others and needing to be a ‘rational’ professional.

It’s a big conflict between emotion and rationale, almost between yourself as a person and yourself as a professional. Because although you need to make sure that you don’t let your emotions interfere with your work, you’re bound to, if you’re human, you are bound to develop emotions towards your clients.
This dyad, divided identity of health care professionals as person and as professional was a struggle verbalised by multiple professionals during the course of the event. Professionals repeatedly highlighted the need for the suppression of emotion either for ‘professional’ requirements and to maintain professional status or to sustain working within the field, airing concerns of emotional burnout if they allowed themselves to become emotionally engaged.

The idea that one could both be professional and emotional, or engage emotionally was not frequently aired or explored and remained largely unspoken despite the evident deep emotional engagement of all in attendance. However there was recognition that emotional engagement and understanding and being able to show this is critical to positive relations in health care.

Staff members reflected deeply on the experiences of families and how they must feel and highlighted how what they saw in the performance resonated strongly with what they saw in families they worked with. As one therapists commented:

*I think that summarises something that took me years to learn, very quickly, so I think it’s brilliant.*

In feedback forms multiple comments were made about the shadow puppetry, including the power and effectiveness of the medium to communicate. As two therapists remarked:

*Disembodied voices with the puppet show - really focuses you on the words & feeling behind the words.*

*Unusual medium – words they don’t cover that much. A medium which really lets you hear the words – it was the words I heard. Simply visual presentation allowed you to hear.*

This was added to by requests that the exhibition be taken to other health care settings as a whole and also that there should be “generous funding for the puppet show to go out and about. That was a very powerful medium for conveying the experiences of the families.”

The lasting impact of ‘Where Are You Now?’ was captured by a reflection of one of the Badby team who saw the show several months earlier (at a previous event in Cardiff) who spoke about how it had affected her and the impact she hoped it would have on her own colleagues and others who saw it. She said:

*It’s still quite haunting the message of it all, I still remember it clearly. Hopefully those who have seen it over the last two days will remember it just as clearly as I do and can put some of the things they’ve learned and understood into practice and we hope that the care for people in disorders of consciousness will continue to improve.*
The Lemon Princess

The exhibition at Badby Park was the first time in which the collaborative artworks and the exhibition as a whole had been brought into a care space. With the focus of the exhibition and event fundamentally about the care of people with severe brain injuries the team felt that it was important to provide something for residents, while recognising that the content of the exhibition in the main would not be appropriate nor entirely accessible for residents. Karin Andrews-Jashapara therefore gave two performances of a fairy-tale, told through narration and shadow-puppetry.

Five to six residents attended each of the two performances. Residents appeared transfixed by the performance in the main, watching intently and smiling. Several residents in attendance who would normally struggle to focus or concentrate or can be agitated remained calm, attended and watched the whole performance. Staff noted responses of smiles and active watching from these residents.

Following each performance Karin Andrews-Jashapara took the music instruments used in the performance to the residents to play. Some were assisted by staff or CDoC members. Those who had dexterity took instruments and played with them, while those without enjoyed the proximity of the sound, smiled, sang of made vocalisations to the musical sounds. One resident engaged in a duet with Karin. Karin played the clarinet and the resident took the percussion instruments and accompanied. This resident had only recently been admitted and her musical flair was identified through this encounter. One resident enjoyed the performance so much she returned to watch it for a second time on the second day.
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The work of hotel service staff

One key element of PhD corner was the display of the work of ‘hotel service staff’ – and the role they play in the rehabilitation of people with severe brain injuries. The thesis considers how the futures of people with severe brain injuries are shaped – the display about hotel service staff highlights the role hotel service staff play discussing how the work they do maps to and acts as informal rehabilitative work, and that this work and the way in which these staff interact with residents is significant in their rehabilitation.

4.6. PHD CORNER:

Doctoral student Julie Latchem (Cardiff University) displayed some initial findings from her PhD research ‘Shaping, sharing and negotiating futures in brain injury rehabilitation’ – a study which explores care and rehabilitation of people with severe brain injuries in the independent sector.

Following a five-month ethnography in two neurological care settings, Julie’s exhibit included the exploration of the work of ‘hotel service’ staff and their contribution to care and rehabilitation and the display of sketches, interview excerpts and postcard messages depicting both the conflicts and care in family-staff relations in these settings.
Through the use of a number of statements printed in bold Julie linked how the work of these people contributes to the lives in the now and the futures of people with severe brain injuries.

One key futures related statement that was displayed can be seen below:

They enable the opening up of residents’ futures and are quiet but critical future makers.

Concerned about whether or not the theoretical frame of temporality would resonate with attendees, the presentation of the theoretical statements were heavily considered before the exhibition. This concern however was put aside when during the exhibition, a member of clinical management took Julie’s hand and let her across to PhD corner. Stopping by the hotel service staff board she pointed directly to the statement shown above and said: ‘That is it, and nobody sees it’
Following the event, a discussion held with a therapy assistant further highlighted the impact of this section of PhD corner, when she was able to verbalise that ‘everyone is a part of everything’ and told me how what housekeepers and maintenance personnel do a lot for residents.

**Thematising PhD corner with flowers**

Key themes and messages from the data collected during the PhD was mapped onto and displayed using five key flowers and their meanings – the forget-me-not, the bluebell, Iris, daffodil and snowdrop.

Data was displayed using the **forget-me-not** chosen because of its meaning of ‘love and memories’ and to indicate a key message from her findings. Julie illuminated how the rehabilitative stories of very particular patient types prevail in the narratives of staff when asked to think about residents’ futures and how the dominance of these stories masks, stunts and highlights how the futures of others go unimagined.
Using the **bluebell**, with its meaning of humility and gratitude Julie highlighted how staff members and residents, families and staff talked about what they were grateful for (often the care and support of one another), and how staff in particular spoke with humility about their work despite the huge challenges they face day-to-day, which often included physical threat and injury to themselves.

The **daffodil**, with its meaning of forthrightness provided the opportunity for postcard messages collected from staff following interviews with them to be displayed. These postcards highlighted key areas of concern that staff raised and key messages they wanted to send to commissioners and managers to create positive change in these environments.

Data was displayed using the **iris**. Through its meaning of hope and faith, Julie explored the faith that staff and families have in the rehabilitation process, how assured they were about what was ‘good’ for residents, what they needed and what they hoped for in the development of their work and care of people with severe brain injuries.

Using the **snowdrop**, through it’s meaning of newness and change, Julie charted what changes staff foresaw in their area of work, in their place of work, what changes they wanted and future they foresaw.

Alongside the meaning of each flower and the data presented to match, five key questions were asked of attendees.

1) Pick up a forget-me-not and tell me - What should be remembered about care and rehabilitation of people with severe brain injuries?

2) Pick up a bluebell and tell me – What are you grateful for in your work or the care of your relative?

3) Pick up an iris and tell me what you hope for in the future for your work, your place of work or the people cared for within it.

4) Pick up a daffodil and tell me what issues need to be tackled in the care and rehabilitation of people with severe brain injuries? What do we need to be forthright about?

5) Pick up a snowdrop and tell me what needs to be overcome to make positive change?
Attendees were invited to take a flower card, answer or comment on the corresponding question and then ‘plant’ their card in pots places around the exhibition space.

Having written their flower card and ‘planting’ their ideas/thoughts, attendees were invited to take a small parcel of bulbs and plan those for real, in the hope that when the bulbs flowered in the spring they would be reminded of the exhibition, the thoughts and ideas they had from it.
Fourteen flower cards (five bluebells, four forget-me-nots, four iris and one daffodil) were written and ‘planted’ and over 30 parcels of bulbs were taken to be planted.

A selection of the messages written of these cards are presented below.

I hope the future for my place of work continues to pull together the unity of all impacted by tragedy. I love where I work xxx

I am grateful to work in this environment because I have learnt what it is like to truly ‘care’ for somebody and not in just the sort of friendship – ‘care’ for somebody kind of care. I am grateful because it’s made me realise how precious life is and how we should not ever take anything for granted!

Remember that patients are people. Just because they can’t talk doesn’t mean they can’t understand. When professionals talk in front of patients as if they aren’t there, how “professional” are they being?
I’m grateful to be able to care for the residents and watch their progress while the therapies are used. You notice different progresses in different strategies.

I am grateful for being part of the residents lives and being able to care for them.

I am grateful in my work that I can just be myself and able to make some of the residents laugh, it gives me a feeling that I’ve achieved something positive.

I wish people would remember that the residents are still human beings. A resident once said to me “Don’t define me by my illness”

There should be more charities helping people and families through this, especially children.

**Family-staff relationships**

Alongside the key PhD themes, the display included a series of other elements to the display to highlight further ‘findings’ of the research. This included messages from families to staff, from families to other families, from staff to families and from staff to other staff that had been written by participants at the end of interviews.

These ‘messages’ demonstrated a ‘mirroring’ of understanding and the existing and surprising appreciation of one another and the recognition of each groups’ experiences.
A selection of data also charting the perilous work of care assistants - how they are frequently injured and recover, with humility and bravery having being attacked by residents with challenging behaviours was displayed. Despite these less obvious and more hidden elements of the PhD corner display, these were all looked at.

**Engagement and interaction with PhD corner**

Across the two days attendees viewed the exhibits in PhD corner and the related display boards around the yellow room. Staff and families stood and read the boards intently. Some people took pictures of the boards, or elements of it. Content filled the full lengths of the board and many attendees went to the effort of crouching to view the bottom sections. Attendees photographed elements of each section of PhD corner, especially those who were visiting from other organisations.
As highlighted above, the sections of data displayed which were linked to the meanings of flowers were dressed with baskets of bulbs. The board displaying the work of hotel service staff was dressed with objects to represent each of the key occupations – a mop and bucket and a washing line to indicate housekeeping, tools and wellington boots to represent maintenance work and a washing up bowl filled with crockery to highlight catering.

Housekeeping staff who viewed the exhibit touched the mop and joked that the one in the exhibit was better than theirs. The washing line was decked with underwear – some of which was purposely scant to draw attention to and generate engagement with the exhibit. While the underwear drew some of the hoped for engagement through jokes, one clinician remarked that she was pleased to see the use of younger style and more sexy underwear in connection with an event about people with neurological conditions. She remarked that people could forget or not see people with disabilities as being and wanting to wear that sort of underwear.

Within PhD corner sketches taken directly from ethnographic notes which portrayed moments of ‘care’ or problematic care scenes were both displayed within each section and a selection printed onto postcards. Attendees were invited to write their own messages on these postcards and ‘post’ them into a post box.
Nine postcards were filled out and ‘posted’, the majority choosing to use the card with the below image printed on it, selecting it because of the ‘heart’ radio image on the television, not because of the link to music but merely to the emotional meaning of ‘heart’ and it’s connection to care.

A selection of post card messages can be seen below:

“Never feel guilty for feeling sad, angry, annoyed, frustrated, tired, a little less caring today, we know love is always there, and while you are remembering this for yourself, remember this for others too.”

“I think it is worth knowing that what we do is always at the heart of residents’ best interest and what we think is positive, however I now, after the conference understand that the communication between us and families’ needs to be a lot stronger in order to understand what families would want or how they feel.”
5. Post event discussions with staff

Approximately one month after the event Julie Latchem returned to Badby Park to speak with staff and family members about the exhibition and to ask them for any further thoughts and feedback. Several therapists highlighted how the presence of families at the exhibition on the first day enabled and supported the voice of families but at times made it difficult for them to feel able to express their own views, thoughts or ask questions. This silencing of staff voice however wasn’t across the board as some staff did feel able to contribute to open discussion throughout the days and many staff members expressed their thoughts feelings and concerns in discussions, reflective conversations over coffee with one another or during ‘vox pop’ recordings.

For those staff who attended the sessions on advance decisions, they reported finding it difficult to both experience and to be part of some challenging end of life debates, especially those where families were present.

However staff also reflected that they felt the event had opened up and generated an interesting dialogue highlighting that “Therapists are people too, you brought out therapists as people.” Similarly housekeeping staff who had attended the exhibition reflected with Julie that the exhibition had raised awareness of their contribution, that they felt noticed by the work and that the exhibition had led them to reflect themselves more about the contribution they were making and what more they could do for residents.

6. Feedback from the CDoC team

All of the CDoC team (and the artists who produced the collaborative pieces), all of whom had delivered this exhibition previously at other locations were overwhelmed by the level of engagement and feel of the exhibition. Karin Andrews-Jasapara described the event as ‘a game-changer’. She was pleased by attendees’ responses to her ‘Where are you now?’ performance and the discussion it generated. She was deeply moved by the impact of her ‘Lemon Princess’ performance on residents and appreciated the opportunity to work with residents.
Digital story teller Lisa Heledd-Jones said she felt ‘deeply privileged’ to be involved in the event and was impressed by the helpfulness and capabilities of staff who she enjoyed working with.

All three Professors Jenny and Celia Kitzinger, and Sue Wilkinson called the event ‘superb and very special’, and were all moved by the level of engagement from all in attendance. They were very impressed with the event organisation, the team working from all departments and particularly enjoyed the food! They appreciated the reflectiveness and care of staff.

Julie Latchem CDoC member and organiser was thrilled by the engagement of Badby staff during the event and the lead up. She was moved by the depth and breadth of staff responses to each component of the exhibition and is proud to have been part of providing something that stimulated such deep and well-articulated expression of the key issues surrounding the care of people in prolonged disorders of consciousness from staff.

She was touched by the attendance of all the families and overwhelmed by the atmosphere of real care and support across the board that was generated and shown by those attending the event. She was pleased to see staff from each department attend individual parts of the programme and view the exhibition.
7. Development opportunities for Badby staff

A core team of Badby Park staff were central in the organisation of the event and all of Badby Park support services (housekeeping, administration, maintenance and catering) were involved. The event ran very smoothly with ‘the venue’ of Badby appearing clean, tidy and smart and the food provided well received and considered of very high quality to the members of CDoC present – so much so that a number of tweets were tweeted praising the high quality of the food by the academics presenting talks at the event.

The Badby Park staff who were core members of the organising team – Cashana Bull, Kirsty Page, Sarah Timms, Michelle Ord, Fiona Whyment and Liz Maund attended meetings and were heavily involved in both the publicising, organisation, curating and/or evaluation of the event.

With our thanks to Badby Park, it’s staff, residents, residents’ families and all who attended and contributed to this very special event.