

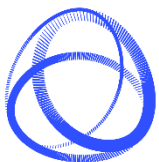
Sidney De Haan
Research Centre for Arts and Health (SDHRC)

Evaluation Report



Beyond the Stigma: The Royal Orthopaedic Hospital, Birmingham

Nina Worthington & Charlotte Grainger



Canterbury
Christ Church
University

OAK
FOUNDATION



Sidney De Haan
Research Centre for Arts and Health (SDHRC)

Sidney De Haan Research Centre for Arts and Health

Canterbury Christ Church University
North Holmes Road,
Canterbury,
Kent
CT1 1QU

Centre Director: Professor Angela Pickard
Centre Administrator: ellie.brown@canterbury.ac.uk

General Enquiries: sdhcentre@canterbury.ac.uk

Sidney De Haan Research Centre is committed to researching ways in which participation in creative and performing arts can contribute to and enhance health and wellbeing for individuals and communities: <https://www.canterbury.ac.uk/research/research-centres/sidney-de-haan-research-centre-for-arts-and-health>

Beyond the Stigma Research Team:

Dr Nina Worthington PhD, MA, BA (Hons.)

Charlotte Grainger MSc, BA (Hons.)

Beyond the Stigma Evaluation

Contents

| | |
|--|-----------|
| Introduction | 5 |
| Background | 5 |
| Disability Definitions | 5 |
| Disability in the Workplace | 6 |
| The Beyond the Stigma Exhibition | 8 |
| Exhibition Participants and their Stories | 10 |
| Video Data | 14 |
| The Evaluation | 15 |
| Methods: Interpretative Phenomenological Analysis | 15 |
| Research Governance and Ethics | 16 |
| Results: Experiencing Beyond the Stigma | 17 |
| A Process of Hesitancy and Comfort | 17 |
| Stepping Beyond Comfort | 18 |
| Anticipating Reactions | 19 |
| Approaches that Eased Discomfort | 21 |
| Perceptions of Impact and Contribution | 24 |
| Perceptions of Project Ownership | 24 |
| Expressions of Validation | 25 |
| Perceiving Long-term Impact | 28 |
| Journeying with Disability Understandings | 31 |
| Learning from Disability | 31 |
| Increased Openness to Sharing Disability Experiences | 33 |
| Proactivity and Community Connections | 34 |
| Headlines | 37 |
| Conclusion | 38 |
| References | 40 |

| | |
|---|-----------|
| Appendices | 41 |
| Appendix 1: Interview Schedule for Evaluation Participants | 42 |
| Appendix 2: Sample Transcript with Annotations | 43 |
| Appendix 3: Sample Table of Themes for an Individual Participant | 44 |
| Appendix 4: Master Table of Themes Across the Participant Group | 45 |

Introduction

This report provides the findings of an evaluation of Beyond the Stigma, 'an exhibition of stories about seen and hidden disability' (ROH, 2023a). The exhibition was about and created by NHS staff. It launched in July 2021 at the Royal Orthopaedic Hospital NHS Foundation Trust (ROH) in Birmingham, UK. Eight staff from the ROH took part in the project 'to share their experience of disability and to help others see beyond the stigma' (ROH, 2023a). The ROH is 'one of the largest orthopaedic units in Europe'; it is described as 'a values-based organisation with a commitment to inclusion and wellbeing and an employer of circa 1,500 people' with a priority to 'support people with visible and unseen disabilities' (ROH, 2023a). The Beyond the Stigma exhibition was funded by the NHS Workforce Disability Equality Standard Innovation Fund.



'it's a project that has enabled us as a Trust to really celebrate some of our staff [...] that previously erm had quieter voices.'

(Project Team Member)

The Sidney De Haan Research Centre for Arts and Health (SDHRC) at Canterbury Christ Church University partnered with the Royal Orthopaedic Hospital to research and evaluate the longer-term impact of this exhibition for individual participants. The broader aim of this evaluation was to consider how arts-based approaches to sharing lived experiences of disability may contribute to disability understandings and the wellbeing of disabled people in NHS workplaces and beyond. The ROH staff involved in creating Beyond the Stigma (BTS), including members of its ABLE Network, were keen

to pursue a detailed external evaluation of this initiative. This evaluation was funded by the ROH NHS Foundation Trust. The findings shared in this report offer evidence of how lived experience perspectives of disability are necessary for making sense of attitudes, structures, and environments experienced by disabled and non-disabled people in NHS workplaces and beyond.

Background

Disability Definitions

The Beyond the Stigma exhibition and this evaluation recognises the complexity surrounding disability definitions and identities, that impairment can 'be obvious or hidden, short-term or life-long' and that lived experiences of disability vary from person to person, shaping personal and professional identity (ROH, 2023a). You are 'disabled' under the Equality Act (2010) 'if you have a physical or mental impairment that has a "substantial" and "long-term" negative effect on your ability to do normal daily activities'. However, such policy-based definitions overlook phenomenological variance and how individuals may differ in whether they consider an impairment to have a negative affect or not. Disability scholars provide a wealth of literature detailing a range of disability models that it is not necessary to replicate here. However, the foremost distinction between the medical and social models of disability is helpful to highlight in introducing this report; behaviours and attitudes, approaches to

practice, workplace environments, and organisational structures are often based upon these theories. Oliver offers a simple description of this distinction, stating, ‘the idea underpinning the [medical] model was that of personal tragedy, while the idea underpinning the social model was that of externally imposed restriction’ (2004, p.19). The medical model identifies disability through medical diagnosis with this being the disadvantaging factor (Oliver and Barnes, 2012, p.11). Blame for lack of participation is attributed to ‘a problem population who possess conditions needing amelioration or cure’ (Sandahl and Auslander, 2005, p.7). This understanding is rejected by disabled-led organisations, but still pervades many attitudes and cultural representations of disabled people. It is, therefore, the opposing social model that underpins the aims of the Beyond the Stigma initiative and this evaluation.

The social model was born out of a reappraisal of the definition of disability by academics and disability rights campaigners in the 1970s (Shakespeare and Watson, 2002, p.3). The central aspect of the social model is the identification of disabled people as an oppressed social group, a definition with positive connotations associated with activism and shared identity (Goodley, 2011, p.9). Differentiation is made between the terms impairment and disability. Impairment is defined as, ‘the functional limitation within the individual caused by physical, mental, or sensory impairment’ (Barnes, 1991). Disability is defined as, ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (Barnes, 1991). In relation to disability in the workplace, the social model emphasises shared responsibility for change across disabled and non-disabled communities, and attitudinal, structural, and environmental adjustments as vital in substantiating the rights of disabled people. Lived experience of impairment and disability are intrinsically intertwined; as such, social model concepts frame terminology used in this report. It is, however, also appreciated that many people still find the terms disability, disabled, and impairment restricting, a factor that is discussed further in relation to participants’ interview responses.

Disability in the Workplace

In the UK around 16 million people report as disabled, that is around 24% of the population defining as having physical, cognitive, or mental health impairments (DWP, 2023a). Nearly 1 in 4 of the working-age population are classed as disabled, with 5.1 million disabled people in employment in the

‘A more inclusive environment for disabled people working and seeking employment in the NHS is better for our people, for teams and for patients’.

(NHS England, 2023)

UK (DWP, 2023b). The number of people reporting a long-term health condition and the number classed as disabled continue to rise. Data from 2022-2023 shows that 36% of the working-age population in the UK were reported as having a ‘long-term health condition’, 23% were classed as ‘disabled’ and 10% were classed as ‘disabled, limited a lot’ (DWP, 2023b). In addition, the number of disabled people with a mental health condition as their main condition has increased by 1.2 million (97%) between 2013/2014 and 2022/2023 (DWP, 2023b).

Historically, data records on disability in the NHS workforce have been minimal (NHS Digital). In 2019 the Workforce Disability Equality Standard (WDES) was launched as a way of improving practices across NHS trusts (Stephenson, 2018). The WDES is a survey of specific measures that allows NHS trusts to gather and compare report data on employment experiences of disabled and non-disabled

staff; the WDES 2023 metrics cover areas including ‘the Board, recruitment, bullying and harassment, engagement and the voices of disabled staff’ (NHS England). Latest figures show the total percentage of NHS staff declaring disability through electronic staff records (ESR) at 4.2% against a working age population of 23% (NHS England). NHS figures point to complexity and a high level of non-declaration of disability among its staff and new applicants, as the number of people declaring disability in the NHS Staff Survey was 23.3%, which is closely aligned with the working age population (NHS England).

Since the launch of WDES, report data from the Royal Orthopaedic Hospital shows an increase in the number of staff declaring disability. 2023 report data shows 6.2% of staff are disabled compared to 3.3% of staff in 2019; this shift in disclosure rates is acknowledged as ‘a steady increase [...] supported by the ABLE Network and the ESR team’ (ROH, 2023b); it suggests that disabled people employed in the Trust are increasingly open to sharing personal information and experiences. The ROH’s ABLE Network is a staff group that formed over a year before the launch of Beyond the Stigma; at that time, it was named the Disability Network. ROH data shows progress since 2021, with the percentage of ‘disabled staff saying their employer has made adequate adjustments to enable them to carry out their work’ reaching 77.5% in 2022, yet this reduced to 66.7% in 2023 (ROH, 2023b). Further areas for improvement are also reported by the ROH. These include a focus on inclusive recruitment of staff and board members, upskilling of managers, increasing disability awareness, and voicing and responding to requests for ‘reasonable adjustments’ (ROH, 2023b).

‘Stereotype assumptions about disabled people are based on superstition, myths and beliefs from earlier less enlightened times. They are inherent to our culture and persist partly because they are constantly reproduced.’

(Barnes, 1992)

Existing literature acknowledges fundamental barriers negotiated by disabled people in workplace settings that relate to stereotypes and misconceptions of their colleagues (Colella & Bruyere, 2011). One common stereotype is the view that disabled staff are unable to conduct equal levels of work performance compared to their non-disabled colleagues (Vornholt *et al.* 2018). The implications of such beliefs can create negative associations regarding disability in general, relying on negative views of disabled people as ‘pitiable and pathetic’, a ‘burden’, or ‘incapable of participating fully in community life’ (Barnes, 1992). Historically, these stereotypes have been reinforced by cultural representations of disability, primarily serving to further stigmatise the disabled

community. With a lack of disability awareness and understanding, disabled people continue to experience day-to-day implications of stigma.

Gewurtz and Kirsh discuss complexities of workplace barriers that require more than logistical adjustments to enable accessibility; individuals are affected by levels of acceptance, flexibility, and relationships in workplaces, additional barriers that are not immediately obvious (2009, pp.33-44). People with mental health conditions are recognised as most vulnerable to experiencing the ‘mistrust’ and ‘fear’ of others ‘because their disability is invisible and their skills and [impairments] not immediately ascertainable’ (Bos *et al.*, 2009, p.47). This is a reason why some individuals choose to conceal impairments or access requirements, with mental health conditions being some of the least disclosed (Vornholt *et al.* 2018); some disabled people fear that disclosure will incite discrimination, creating a disclosure dilemma (Kulkarni, 2022). Employers have a responsibility to provide reasonable

adjustments for disabled employees to perform their duties. However, past experiences and negative encounters with employers, reluctant to approve reasonable adjustments, influence individual's decisions to disclose; employers' lack of disability understanding is a key barrier for disabled people in requesting reasonable adjustments and fulfilling their employment goals (Olsen, 2022).

The Beyond the Stigma Exhibition

The Beyond the Stigma exhibition utilised photography and video as a creative way of sharing staff members' personal experiences of disability in their workplace setting. In contrast to most cultural representations of disabled people in the past, the intention of this arts-based initiative was to 'explore the impact of disability and promote a culture of openness, respect and compassion' (ROH, 2023a). Recent work by disability scholars Ann Fox and Carrie Sandahl resonates with the approach taken in creating the exhibition, recognising value in art forms that are 'inviting [...] spectators to stare and in doing so, rewrite old assumptions about the disabled body while discovering new aspects of disability aesthetics and disability gain' (2018, p.121). The initial aims of the exhibition also imply an appreciation amongst participants and the project team of how creative initiatives can offer potential to both draw attention to disability and disorientate and resettle disability understandings among disabled and non-disabled communities.



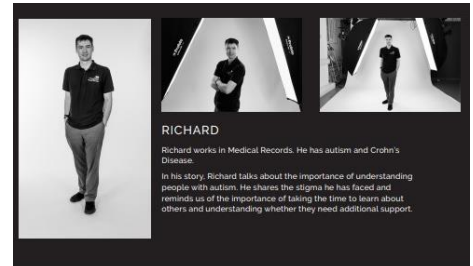
In meetings to plan this evaluation, the project team explained how the ABLÉ Network designed the project to include four elements; these comprised of a 'photography project portraying staff members who are passionate about highlighting and raising awareness of their disability or long term illness', 'talking head staff videos: short video clips of the staff members from the photography exhibition to enable staff to share their own individual story, in their own personal way', 'awareness sessions in addition to current work', and a 'buddy scheme available for all disabled staff to access when they join the Trust'. The project team included Clare Mair - Project Lead, Victoria Scott - Project Co-ordinator, and Amos Mallard and Pete Law - Visual and Media. The project team and members of the ABLÉ Network also participated in this evaluation.

Black and white photography portraits of the eight staff taking part in BTS were displayed on boards outside the ROH's main entrance to its outpatient's department and remained on display from July 2021 to the end of 2023. The project team used quotes from the staff videos to personalise participants' portraits. A small section of narrative was also included on the exhibition boards to introduce the individual and their role within the Trust. Exhibition spectators could scan a QR code on the boards that linked to a landing page on the Trust's website where they could watch each participant's unique video story. The videos were captioned and remain available to view on the ROH's website to date (ROH, 2023a). The boards were also designed to be accessible to wheelchair users and included text in braille.

The eight participants, the wider ROH staff team, and senior leaders were invited to attend a launch event. The boards were unveiled with short speeches made by Vickie, one of the exhibition participants, and the Trust's Chief Executive. Additional creative outputs of the project included a printed booklet that replicated images in the exhibition, and a framed print of each participant's exhibition board was presented to them. The project process has been shared in presentations as part of NHS national forums and with other trusts across the UK that expressed interest in the project.

'High production value really helps [...] you engage with it as... I wouldn't say necessarily a piece of art, but as a serious exhibition with a serious message.'

(Project Team Member)

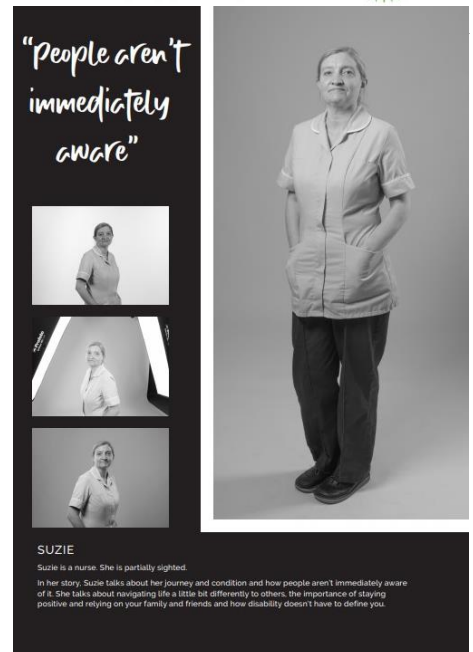


"Take the time to get to know people and understand"



Watch my story

Scan this code with your phone camera to visit the website and watch Richard's story
roh.nhs.uk/beyondstigma/richard



"people aren't immediately aware"



SUZIE

Suzie is a nurse. She is partially sighted.
In her story, Suzie talks about her journey and condition and how people aren't immediately aware of it. She talks about navigating life a little bit differently to others, the importance of staying positive and relying on your family and friends and how disability doesn't have to define you.



Watch my story

Scan this code with your phone camera to visit the website and watch Suzie's story
roh.nhs.uk/beyondstigma/suzie



ALEX AND MAUREEN

Alex works in Finance and Maureen works in Pharmacy. They both underwent chemotherapy and radiotherapy treatments.

Alex and Maureen became friends after having similar medical treatments. In their individual but connected stories they talk about the impact on their lives, the reality of being vulnerable and the importance of supporting people who are struggling.



Exhibition Participants and Their Stories

The eight staff involved in the exhibition came from diverse backgrounds not only in terms of disability experiences but across the nine protected characteristics. They represent a range of impairments, long-term health conditions, and diverse job roles across the ROH NHS Foundation Trust. Videos and exhibition content that is publicly available via the ROH website (2023a) has been reviewed and an outline of participants' personal information and stories they chose to share as part of the project is set out below. The ROH's Beyond the Stigma project team acknowledge, 'Every story is different but there is a common thread between them all; the need to be kind, the need to see the individual beyond the disability and the importance of taking the time to understand' (ROH, 2023a).



Monica

Monica is a nurse and has osteoarthritis. In her story she explains how the progression of her osteoarthritis meant that working on a ward was no longer sustainable due to prolonged periods of standing, so she transferred to another department that would better suit her needs. Monica describes how being labelled as disabled is difficult to accept; it wasn't until her osteoarthritis started impacting certain areas of her daily life that she began researching what adaptations could be put in place to support her in the workplace. Monica notes that she feels this was information she had to source herself, that there was no support within the Trust. She expresses a lack of understanding concerning her disability in the workplace and describes facing challenges to having 'reasonable adjustments' put in place. Finally, Monica reflects on the Disability Network becoming established within the Trust and the positive impact it has had on allowing staff to advocate for their own requirements to make the working environment accessible.

Stephen

Stephen works in Facilities as a Housekeeper Assistant and has a learning disability. In his video Stephen describes feeling supported at work, saying that he is treated fairly and that tasks are explained clearly for him to understand. He also shares stories about the impact of his learning disability outside of work. He describes experiencing some hurtful comments made by others in his local community that he felt were 'insulting'. Stephen suggests that disabled people should be treated with kindness and respect, and there is a need for more understanding.



Suzie

Suzie is a nurse and is registered as partially sighted due to the result of a brain aneurysm and stroke that has left her with no vision on her right side. Suzie describes this as a disability that is hidden, that people wouldn't be immediately aware of. In her video she describes experiences of facing stigma as being 'practicalities', such as not being able to drive. She perceives this as having the biggest impact on her everyday life. In the workplace, Suzie explains how colleagues are understanding, and how people should be more open-minded and aware that some people will have impairments that may not be obvious, to always have that in mind. Suzie suggests that her hidden disability doesn't impact her too much at work, but she does discuss taking more time to navigate new environments, in order not to bump or knock into things on her right side. She mentions the importance of having the support of family and friends and maintaining a positive mindset.

Alex and Maureen

Alex works in Finance and Maureen worked in Pharmacy (Maureen passed away in 2022). Alex and Maureen filmed their stories together as they both underwent chemotherapy and radiotherapy treatment. Maureen talks about the Disability Network and not realising that their conditions were considered as disability under the Equality Act. Alex mentions how people have stereotypical or traditional views of disability and Maureen suggests disability terms should be broadened to help support others to feel part of the disabled community and the Disability Network. Maureen describes the importance of everyone being treated equally across all departments in the ROH, and Alex notes that she wants people to feel safe and have safe spaces to share concerns. Maureen suggests colleagues must be aware that certain vulnerabilities continue after treatment is complete, but they do not want to be treated differently at work. She is open about finding time away from work difficult and how returning to work was a positive experience despite personal anxieties over work performance and self-acceptance because of her medication. Alex expresses value in being vulnerable in the workplace, accepting change, and not being hard on yourself or expecting perfection. Her advice to others with similar stories is to try and be open about their own experiences. Alex and Maureen acknowledge the Trust and the Disability Network at the ROH as being supportive and comforting in sharing their stories, making connections, and building friendships.



Richard

Richard works in Medical Records at the Royal Orthopaedic Hospital and has autism. In his video he explains how his autism means that he needs more time to understand things. Richard shares stories of facing stigma at work in the past, which left him feeling isolated. He suggests people need to take more time to understand and learn about impairments or hidden disabilities, to try to get to know a person and what their individual accessibility needs might be.



Vickie

Vickie works in Informatics and Digital and has mental health conditions. She describes this as a hidden disability. In her video Vickie describes experiencing stigma from friends and family who have perceived her struggles as attention seeking, which has impacted her self-esteem and confidence. At work, she explains how indirect stigma has meant that she has missed opportunities as it is assumed she would not be able to cope with the pressure. Vickie describes occasions she has felt bullied at work, that people have played on her vulnerabilities and treated her unfairly. Whilst acknowledging difficulties, she encourages those with a hidden disability not to hide it, suggesting the more open we can be about mental illness the more change will happen. The overriding message in her video was to be kind to each other.

Clair

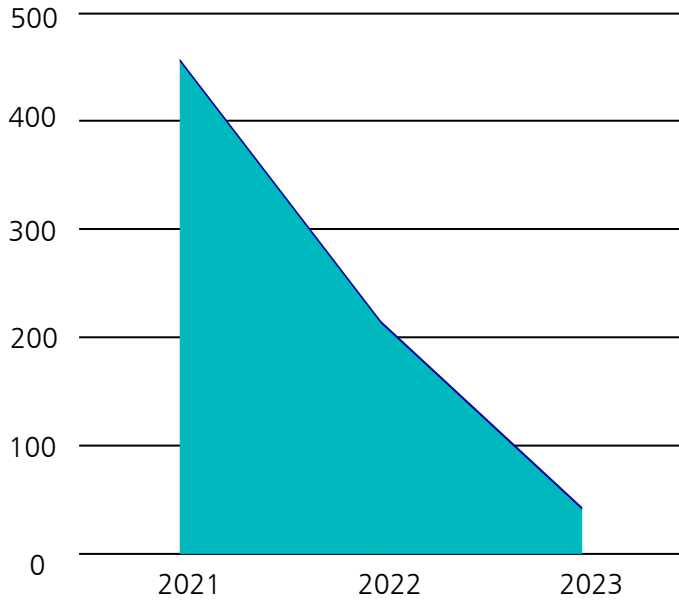
Clair works in administration and has diabetes. In her story, she suggests that her hidden condition has minimal effect on her day-to-day life as it is controlled by medication. Clair feels she has not faced much stigma but describes how some people want a warning when she is going to be ill despite this being very unpredictable. Clair explains how she feels a need to explain to others what could happen and discusses having a 'hypo'. She suggests people need to practice more kindness and not to assume something that isn't true, she notes how having a 'hypo' from diabetes often presents as appearing drunk and can be misunderstood. Clair finishes her video asking people to change their mindset, to question if someone is ill and needs help, to look after each other, and to ask if people are okay if you are unsure.



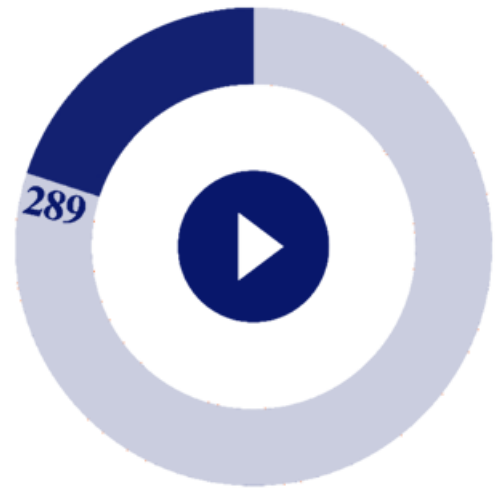
Video Data

The following charts show the number of times the BTS videos have been watched since the exhibition launched in July 2021 to May 2023.

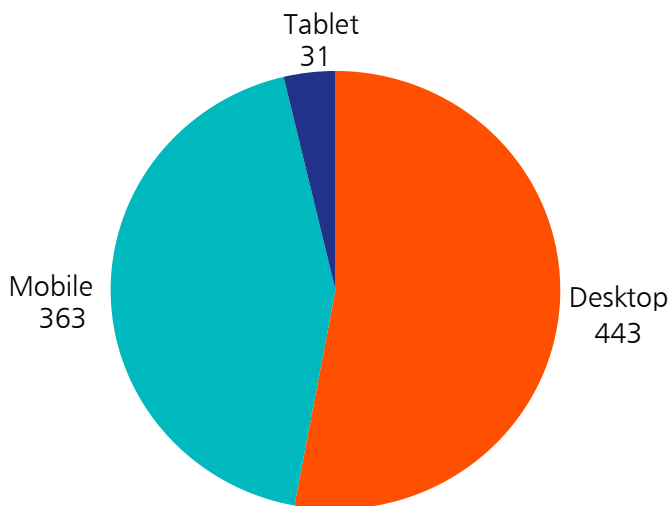
Total Views by Year



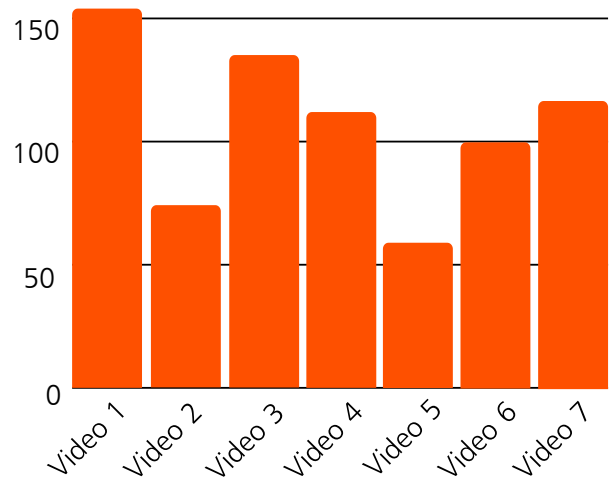
Total Views in First Month of Launch
15.07.2021 - 15.08.2021



Total Views by Device
15.07.2021 - 05.04.2023



Total Views by Individual Video
(in order listed on the ROH website)



The Evaluation

A series of meetings were held with staff at the ROH to discuss the most effective way to evaluate this photography and video exhibition project. In collaboration with the BTS project team and the ABLE Network, it was agreed that data collection would adopt a single-method design, aimed at gaining detailed understanding of participants' experiences of taking part in the project. Within the evaluation's scope, Interpretative Phenomenological Analysis (IPA) was considered an appropriate approach to uncovering how it felt for ROH staff to share their personal stories of disability, impairment, illness, and long-term health conditions publicly in their NHS workplace.

Methods: Interpretative Phenomenological Analysis

IPA continues to grow in popularity in the field of psychology and is increasingly adopted in interdisciplinary studies, it is 'committed to the examination of how people make sense of their lived experiences' (Smith, Flowers, and Larkin, 2009, p.1). IPA allowed for open questioning and created space for participants to reflect on their experience of taking part in the exhibition and to articulate 'the quality and texture of their experiences' (Willig, 2013, p.99). IPA is an inductive approach to identifying themes that gives attention to each participant's unique responses before making any generalisations across a group. IPA delves under the surface of how lived experiences are interpreted by the individual; in this case it uncovers how each Beyond the Stigma participant interpreted the long-term, personal, well-being, and professional implications of taking part in the exhibition. Design of a digital questionnaire to capture wider staff views on the exhibition was also supported by the researchers and created by ROH staff; responses to this did not yield sufficient data to capture within this report.





Almost two years after the exhibition’s launch, a series of one to one, in-person, semi-structured interviews were conducted with six of the eight participants who agreed to take part in the evaluation. The interview schedule was designed to allow participants to speak freely about their experiences of the exhibition in as much detail as possible (see Appendix 1). The interviews took place in the wellbeing room at the hospital, a familiar setting for participants. Brief interviews were also conducted with three members of the project team and with Sharon Malhi, the ROH’s Chief People Officer as a way of detailing the project’s background, aims, and wider impact.

Interview data has been analysed in line with the robust IPA process (Smith, Flowers and Larkin, 2009, pp.79-107). Audio recordings of each interview were transcribed before beginning the analysis. Each transcript was annotated line by line with exploratory reflections, comments, and observations for each participant. These were coded for descriptive, linguistic, and conceptional features. Emergent themes were identified and titled for each participant

and written alongside individual transcripts (see Appendix 2). Themes in each transcript were grouped with a descriptive heading and a table of superordinate themes was produced for each participant linking to the original transcripts (see Appendix 3). Finally, patterns were identified across participants and a master table of superordinate themes was created to show connections across the group (see Appendix 4). In line with the framework for IPA and in the discussion of results that follows, themes in the data are represented through verbatim quotes from interview transcripts. These enable the reader to evaluate connection between the raw data and interpretations and aim to retain the voice of participants including repeated words, pauses, and interjections such as ‘um’ or ‘ah’.

Research Governance and Ethics

This research was granted HRA and Health and Care Research Wales (HCRW) approval in December 2022. Formal approval for this evaluation was also granted by Canterbury Christ Church University’s Faculty of Medicine, Health, and Social Care Ethics Panel in January 2023, and by the ROH NHS Foundation Trust’s Research and Development Department in February 2023. Beyond the Stigma exhibition participants were notified of the evaluation both verbally at an ABLE Network meeting and via an information sheet with opportunity to ask questions about the research. Informed consent was obtained from all participants before beginning the interviews and the conditions of formal approvals were always adhered to. The real names of the exhibition participants were already in the public domain. All participants who were interviewed for this evaluation also consented to their real names being used in writing up this report. However, due to the sensitive nature of some of their responses, the researchers have removed participant names from the quotes shared in this report to offer a level of anonymity within the group. Reference to job role, impairment and/or health condition have been retained.



Results: Experiencing Beyond the Stigma

Three superordinate themes form the basis for discussing participants' individual lived experiences in the context of their involvement in the Beyond the Stigma initiative. The following list is taken from the Master Table of Themes Across the Participant Group (Appendix 4). It sets out how emergent themes are nested within three superordinate themes and the framework for discussing the findings that follow:

| |
|--|
| A. Process of Hesitancy and Comfort |
| i. Stepping Beyond Comfort |
| ii. Anticipating Reactions |
| iii. Approaches that Eased Discomfort |
| B. Perceptions of Impact and Contribution |
| i. Perceptions of Project Ownership |
| ii. Expressions of Validation |
| iii. Perceiving Long-term/Wider Impact |
| C. Journeying with Disability Understandings |
| i. Learning from Disability |
| ii. Increased Openness to Sharing Disability Experiences |
| iii. Proactivity and Community Connections |

The first superordinate theme, *Process of Hesitancy and Comfort*, concerns how the creative approach taken in Beyond the Stigma was interpreted by participants as risk, discomfort, and compromise. It exposes participants' purpose in choosing to take part and hopes for the exhibition's outcomes. It highlights how decisions made by the project team and perceptions of peer support increased a sense of ease and comfort for individuals through the project process. The second superordinate theme, *Perceptions of Impact and Contribution*, focuses on value given to participants' lived experiences of disability through the BTS project. It reveals individuals' sense of ownership surrounding the idea for the exhibition and initial positive interpersonal encounters and responses to the stories they shared following its launch. It also exposes participants' views and ongoing questioning around the organisational impact of BTS and its future potential. The final superordinate theme, *Journeying with Disability Understandings*, uncovers how participants associated BTS with intrapersonal reasoning around disability views, identities, conversations, and communities. It demonstrates how this initiative increased individuals' engagement with disability both inside and outside their workplace.

Process of Hesitancy and Comfort

'I kept one of my disabilities hidden [...] and I thought I'll just take part in this [...] now is the time just to tell them' (Participant A)

For most participants taking part in Beyond the Stigma meant stepping outside a personal comfort zone. Feeling nervous of being in front of a camera was perhaps expected, levels of comfort in this sense differed among participants. However, fear or caution about involvement in the project was not only a matter of self-confidence; for some participants, Beyond the Stigma presented a unique opportunity to disclose impairment or articulate personal disability experiences for the first time and in

their workplace. This theme points to a sense of workplace activism that demanded compromise from individuals', and, for some, risked perceived discrimination to promote change. Each participant's reasoning for taking part revealed a sense of personal responsibility felt in influencing workplace culture and the attitudes or beliefs of colleagues. This theme enables an examination of what taking part in BTS required from those who shared their stories, their hopes and expectations of the project's outcomes, and the skill, sensitivity, and collaborative approach required in appropriately navigating the exhibition process.

Stepping Beyond Comfort

Feeling at ease in front of a camera was a challenge for most participants. Participant B began the interview by describing discomfort experienced in this, saying 'the worst thing [...] was being filmed, that was the horrible bit. It was horrible [...] It was really, really hard [...] that feeling of just me' (p.1). Similar discomfort in feeling exposed by the camera was expressed by others, which heightened hesitancy in agreeing to take part, with comments like 'I'm not great at having my photograph taken [...] so I was really, really nervous' (Participant D, p.3). Reflecting on how it felt to share her story on camera Participant E describes:

that initial feel of whoa I can't breathe (*laughs*) [...] I'm not comfortable in front of a camera so the photography bit for me felt probably more challenging than the video [...] I don't want to have my photo taken [...] that bit was more difficult for me (p.3).

Other aspects of being in a studio setting required a step outside participants' personal comfort zones. Participant B, who finds new environments difficult due to their impairment, remarked on the experience of being in 'a different environment as well [...] the other side of Birmingham, and it was a place I didn't know [...] it's like not normal for me' (p.4). The project team made the decision to film and photograph participants in a professional studio setting in a different hospital. For some individuals, this increased personal unease and added to logistical requirements with travel and studio bookings needed. This decision also had positive implications in terms of the quality of the finished exhibition exceeding participants' expectations and value they felt was given to their stories, which will be discussed in later themes. Comments implying these benefits included, 'it was so professional how the videos were done' (Participant B, p.3), 'that was very nice [...] ooh we're going to a studio, which makes it all very glossy' (Participant E, p.3), and 'photos taken by the professional photographer at Heartlands were amazing [...] I don't think anyone else could have done it as good or a professional agency probably would have come up with the same kind of quality' (Participant C, p.5).

For BTS participants, it was not only the creative methods chosen to share their disability experiences or the studio location that impacted levels of personal comfort. The title of the project itself presented some unease for those who did not associate their lived experiences with notions of stigma. Participant F explained 'the word stigma [...] there's a bit of conflict in me about that' (p.2), Participant E commented 'I've never personally felt stigmatised' (p.1), and Participant D noted 'I never sort of suffered stigma before' (p.6). They repeatedly referred to disconnection with the title, yet there was also shared recognition among these participants that, whilst this term may not sit comfortably with them, it is fitting for the project. Participant F acknowledged:

there is stigma attached to having a disability [...] I don't mind that, but I can understand why maybe somebody else would be really strongly against the word stigma [...] I probably

personally wouldn't have called it stigma, but then I'd probably be a little bit unsure of exactly what I would say (p.2).

Participant E also explained, 'I know that there are people who experience stigma, um and discrimination, er but for me it probably doesn't... didn't fit for me. But I felt comfortable with the title generally' (p.1). Others perceived it as 'a really good sort of phrase [...] for the project' (Participant B, p.1).

Experiences of discomfort or hesitancy in taking part in the exhibition were also associated with uncertainty about how others in their workplace might respond when their story is made public. Participant A's quote opens this section of results and suggests a conscious decision to step beyond comfort and disclose impairment; it seems Beyond the Stigma was viewed as a unique, and perhaps, also safe opportunity to articulate lived experiences of disability in their NHS workplace. They explain the reason they 'kept one of my disabilities hidden' was 'I kind of felt [...] if I told people about it, it would make them maybe think a bit differently towards me' (p.1). Interpreting how they felt on the day of filming, they noted 'the nerves were probably more [about...] how people would more or less react when it when it's all been done' (p.2). This position was shared by Participant F who remarked 'I was probably very, very hesitant at first' (p.4), and later added 'I was very nervous because you're aware of actually where it might end up [...] it's going to be watched by potentially a lot of people' (p.6). They implied willingness to take what was perceived as a risk, to step beyond comfort when feeling uncertain of a positive response to the exhibition from colleagues. Participant A and D said their initial reactions to the invitation to take part were 'why not? [...] go for it' (A, p.2) and 'shall we go for this [...] let's have a go and see what we can come up with', adding 'it took us all out of our comfort zones' (D, p.1). Referring to recording their story in the studio, Participant C commented, 'I felt quite stoic about doing it' (p.4). Whether compromising personal comfort or preferences around the project's creative approach, chosen terminology, or risking a negative response from colleagues, all participants conveyed a sense of personal resilience and willingness to sit with the discomfort experienced in creating BTS as a route to promoting change.

Anticipating Reactions

Participants' reasons for agreeing to be filmed and photographed for the BTS exhibition pointed to outcomes they perceived as making the personal cost, nervousness, or uncertainty worthwhile; that is, the learning or actions they felt were needed by colleagues and leaders in the Trust. Hopes in sharing personal disability stories were to shift workplace structures, disability understandings, levels of personal acceptance, and to model openness to other disabled people. Participant F explained:

I was really passionate, really passionate about it [...] because it was a Trust initiative [...] I wanted to view it from both personal and manager [...] there is a little bit of lack of support really if you are actually managing somebody with a disability, erm but I'd also experienced that myself [...] when I first started to have issues [...] there was no support, it was like, where do I go with this (p.2).

This participant's past experiences of it being 'really, really difficult for me [...] in my role here [...] around identifying the needs that I required to be comfortable at work' (Participant F, p.1), and not feeling trained to respond to disability matters as a manager, were motivation for taking part in the exhibition. As is also acknowledged in the ROH's most recent WDES report (2023a), they perceive a need for further change in the Trust despite any positive progress made, and continued saying:

I wanted to get that message out there [...] we need to raise the awareness and we actually need to have the proper support mechanisms in place for both the [disabled] person and the managers that are expected to actually know all of this information when actually we've had no formal training (Participant F, p.2).

It appears this participant anticipated a proactive reaction to the Beyond the Stigma exhibition that might shift organisational structure and disability training. Participant F made clear, 'I definitely wanted the Trust to act' (p.3).

Participant E also anticipated organisational change as an outcome of the BTS initiative, yet their hopes for impact centred on shifting attitudes and understandings more than workplace structures. They described motivation for taking part as:

for people in the wider organisation to understand some of what we go through [...] to realise that some of us were disabled where perhaps we've had invisible disabilities [...] and just show we were proud to be who we were [...] who we are (Participant E, p.1).

There was an activist approach to sharing lived experiences of disability through the exhibition that was common across participants, with some having a dual purpose in seeking to promote change, as a disabled person and as a manager supporting disabled people in their teams. As someone with acquired impairments due to a long-term health condition, conveying disability pride in their workplace was also perhaps a bold step for Participant E, viewing the opportunity to share their personal story as trailblazing. It seems unlikely this was taken lightly or easy as they explained:

I feel a sense of responsibility in being somebody fairly senior in the organisation as well, to be open and proud of my own experiences in the hope that that will help others to feel comfortable [...] I don't really like broadcasting (*laughs*) things about myself [...] I'm quite introverted, but it just felt an important thing to be part of (pp.1-2).

A sense of positioning themselves as a role model for other disabled people in the Trust was also apparent in Participant C's ambition for their story to:

help people who have hidden disabilities that aren't brave enough to speak out and ask for the reasonable adjustments, to try and give somebody that kind of strength to say 'actually, that sounds like I get everyday' or 'that sounds like something I need help with', and I always said that if one person... if just one person was helped by the project, it was worth doing (p.1).

As someone who felt involved from the BTS project's inception, Participant C also explained 'I wanted to be the example that it's okay to take part' (p.3). This connects with their description of feeling 'stoic' (p.3) when being filmed, implying again that involvement in BTS was not viewed as easy but as a way to support other disabled people in their workplace.

Participant B noted how anticipated reactions to publicly sharing their story were not only that they might be a role model and raise awareness of their impairment, but that BTS might support their own journey with disability; a factor of their experience also discussed later. It appears they hoped the project would help them view impairment more positively and to embrace what disability scholars refer to as 'disability gains' (Bolt, 2017). They described:

I did think about it [...] about it being filmed [...] but then I was thinking it was sort of like a really negative thing that happened to me, so [...] trying to take a positive out of the negative [...] and sort of, you know, teach people about um people who are partially sighted [...] and that you can carry on and live your life to the full [...] you can still be a nurse [...] you can still fulfil your dreams [...] that was a real positive erm about doing it (p.1).

Anticipation that colleagues in the Trust might react to the exhibition in a way that would support individuals to feel accepted or better understood was also at the fore of Participant D's thinking about taking part. In the interview they detailed how others have made inaccurate assumptions about their long-term health condition and potential they perceived for BTS to change this. Participant D noted:

people make assumptions without really knowing [...] they don't actually think 'well, could they be ill?' [...] thinking past what you can actually see [...] particularly around mental health and hidden disability, so that... that's what it is for me, is to take those labels off (p.1).

Finally, Participant A, who suggests BTS was embraced as an opportunity to disclose impairment for the first time, described anticipated reactions to their personal story saying:

if [...] there's people who... who think [...] fair play, you know, well done for doing this and [...] still er thinking me is like the same person and understood my autism then... then that's great, erm just like more of an understanding really [...] that I have got autism [...] and that's [...] part of who I am (p.1).

It appears that all these participants had high expectations of Beyond the Stigma's potential to impact change in the Trust and in individuals, including themselves. From the onset, each had belief that their personal story might be powerful in shifting structures, disability understandings, and levels of acceptance or openness in their workplace. The perceived personal and professional benefits of their involvement in the exhibition, and a desire or need to drive change forwards, seemed to outweigh hesitancy and discomfort they felt in agreeing to take part and in speaking out publicly.

Approaches that Eased Discomfort

Participants in this evaluation expressed overwhelming satisfaction and relief in describing the professional quality of the photography and videos and praised the overall coordination and facilitation of the process by the project team in helping to alleviate discomfort. A sense of equal collaboration between participants and the project team also eased discomfort, which highlighted a sense of agency throughout the process.

It could be assumed that, as with those who shared their stories, this project demanded a step beyond comfort for the project team. Interviews with some of the team only informed the background to this evaluation rather than being part of the data analysis. Still, in considering approaches that eased discomfort for participants, it may be worth noting that two out of the three team members interviewed had some level of lived experience of disability in their families, two referred to friends with hidden disabilities, and one has a condition that they noted could be classed as disability. There was some familiarity and ease with disability matters, which is likely to have influenced the team's approach to leading the Beyond the Stigma initiative. The scale, design, and media adopted in creating the exhibition are expressed as unique for the ROH NHS Foundation Trust; this not only exceeded expectations of those who shared their stories but Clare Mair, the Project lead, also spoke repeatedly about the exhibition exceeding her expectations in terms of its physical scale and the interest it raised

both within the Trust and beyond. It may also be relevant to note that Clare referred to her role in leading this project as 'sitting in the background, supporting where it was needed' and 'sitting in the background and just making sure that things were moving on'. Leading on visuals and media, Amos Mallard's recognition of the importance of 'high production value' in terms of aesthetics was also a repeated theme in our conversations. As the person prompting individuals as they shared their stories on camera, one further thread in his and Victoria Scott's (project coordinator) background interviews was the recognition of participants' hesitancy and comfort; that is, an awareness that being in a 'professional studio' can be 'intimidating' and that 'it's a very vulnerable situation to be in [...] having your face outside the Trust and on websites'. Amos referred to needing to invite participation in a way that was 'non-threatening', 'disarming', 'easy', 'to make people feel comfortable'. Victoria referred to her role being 'to make sure they were all comfortable' and 'to make sure they were comfortable doing it and sharing their story'.

The project team described their aim for BTS was to elevate the voices of its participants; it seems that collaboration, professionalism, sensitivity, and clear and open communication were an integral part of easing discomfort in the process of doing so. Prior to recording their personal story, Participant E noted 'a conversation with us to make sure we felt comfortable with what was going to happen on the day', and that logistical details like 'you need to be here at this time, this day' were made clear (p.3). For Participant F, clear communication through the exhibition process seemed particularly important, they detailed conversations and support that felt beneficial to them, describing:

it was a really supportive process, as a small Trust sometimes there's initiatives that happen erm and there's nobody sort of set to lead it or [...] you don't quite know how you get from A to B, with this it was clear and concise from the ABLÉ group [...] the process was explained to us thoroughly we were all given the option [...] we could back out right at to the point where we're sitting in the room waiting to be filmed [...] there was no pressure put on us to do it [...] the support that we received both from Clare's team and the comms team was was... it was really good (p.5).

Participant F suggested a strong lead on BTS was beneficial and somehow unique in the Trust. As individuals on the project team were not part of the ABLÉ Network, it also seems significant that this lead was perceived as being from the 'ABLE group' (p.5). It seems the project team's view of their role as 'sitting in the background' also elevated the ABLÉ Network in driving communications, with the project team supporting; this is a valuable collaborative approach that also eased discomfort for the participants and, it seems, ensured they had agency throughout the process. Talking about the logistics of using an external studio, Participant F continued saying:

it was created with all of us in mind really, we were all given erm you know, options [...] supporting to get us to the appointments, erm how we were gonna get there, what was gonna happen while we were there, we were given full oversight of exactly how it was going to be done, how it was gonna be created, what was going to happen with that information (p.6).

Participants moved on to describe how discomfort or nerves were eased on their arrival at the studio and whilst filming, Participant F explained 'we did the filming first then the photography [...] it's a bit daunting waiting outside for somebody else to come out. It was all done privately' (p.6). Across the group there was a shared appreciation of the benefits in filming video stories before the photography, that this made the process more comfortable. Participant E commented:

of course, you feel a bit nervous [...] but I mean Amos was very good at putting you at ease. It was nice to have somebody we knew um to have those very intimate conversations with [...] somebody that you knew was supportive and... yeah was good at asking those kind of open questions and making you feel comfortable. (p.3).

Despite initial nerves and repeatedly making their discomfort in front of cameras clear in the interview, Participant B also remarked 'I almost forgot that the cameras were there' (p.3). Interpreting this shift in personal comfort levels, they noted 'skill at interviewing' and how 'Amos and Pete' (both supporting BTS's visual and media content) 'had taken real effort to make sure we did feel comfortable'. Participant C also commented on Amos' skill, describing him as 'a good person for getting people to open up and feel comfortable', and reflected 'I didn't feel awkward being interviewed' (p.4).

In a similar way, both Participant B and D suggested the act of recording their stories was made more comfortable by the project team and was less formal than anticipated. Despite repeatedly referring to being in front of a camera as 'horrible' and 'nerve racking' (p.1;4), Participant B reflected on filming saying, 'it was okay cause I think the team made you feel at ease [...] just chatting to you really, not really interviewing you, talking... chatting to you informally' (p.4). Informality was also important to Participant D, who was earlier quoted saying 'I was really, really nervous' (p,3). Their memory of the studio was:

it was really good [...] it was all set up [...] it was more relaxed and kind of informal process really [...] just Amos talking to us like... like you and I are talking [...] about who we were, and what we did, and what our disability was [...] it was just like having a general chat (Participant D, p.4).

In the studio, the skill, sensitivity, and attitude of the project team, particularly the person in the role of off-camera interviewer, seems crucial in supporting participants to tell their story in their own way. Benefits of this being someone familiar were acknowledged across the group, but it was also noted that this may inhibit participants' freedom to share workplace experiences. Despite this, and all referring to being nervous, all participants in the evaluation commented on feeling at ease, happy, or content with the stories they chose to share. Participant F clarified the freedom they experienced to share what felt comfortable, saying:

the information that we wanted to give about our own personal circumstances was very much up to us, we weren't told that we had to explain what our disability was erm, but to take part [...] I personally was aware that I'm gonna have to give some explanations of what my disability is, erm because that's the whole point [...] but there was no pressure for us to divulge any information that we didn't want to (p.7).

Clear communication and collaboration across the project team and participants appears to have continued and be important in easing discomfort up to the exhibition launch and in some ways beyond this. Although participants note that they did not see the exhibition boards complete before covers were taken off at the launch event, Participant D explained, 'they did show us all the photos and [...] we could look at the videos, we were consulted all the way through really if we were happy with them (p.4). Participant E suggested nervousness about the videos was eased by the opportunity to shape editing decisions, remarking that 'they took a lot of time afterwards [...] to edit it and erm make sure that we wouldn't be embarrassed with the outcomes. I think they'd kind of sensitively

edited [...] it felt nice, it felt good' (p.3). Finally, Participant F detailed positive communications after the launch, saying:

it was erm articulated really well from start to finish [...] we've always been fully aware of all of the feedback that's happened [...] the e-mail that we got from NHS England, that was shared with all of us erm so we've always had full oversight of what's happened with all of that [...] I've felt full... fully supported all the way through and fully informed and kept fully up to date with all of the progress (p.5).

Responses from interviews relating to this superordinate theme have pointed to important factors in the success of creating the BTS exhibition for participants. They have exposed key characteristics of the project team relating to skills, attitude, and sensitivity, which enabled individuals to experience increased ease in telling their story. They have also highlighted aspects of collaboration, clear and open communication, agency, and informality that appear to be crucial in promoting personal satisfaction and comfort in the process.

Perceptions of Impact and Contribution

'It's one of the things that I am proud of that I've been involved in and that probably surprised me a little bit' (Participant E)

This second superordinate theme focuses on participants' perceptions of the Beyond the Stigma initiative as validating their lived experiences of disability and its impact on others in the Trust. Although participants' experiences of creating the exhibition content have been considered, this section of results steps back further to expose claims to the initial project idea. It draws attention to how individuals interpret their personal contribution to BTS and how their story was valued by others in the workplace. This section of results also details contrasting perceptions and some uncertainty about its wider impact and future potential.

Perceptions of Project Ownership

Linking with previous themes, this subtheme highlights the importance of promoting agency and collaboration across the project team and participant group in creating the BTS exhibition. However, the following interview responses are less about participants' agreement to take part, feeling comfortable, or hopes for change; instead, they focus on value they perceived in their contribution of ideas. Participants spoke about BTS as an exhibition that belonged to them, not just about them.

This is Participant C's description of what and who sparked creative ideas for the project:

Beyond the Stigma came out of the Disability Network that I'm part of. We basically, Clare Mair she said that there's this money available [...] from WDES [...] for a project. So, we talked about it 'shall we put a bid in?' and I kind of suggested that it might be nice to have some sort of like storytelling project or something that you can kind of try and educate people and make people see different stuff and from out of that came Beyond the Stigma [...] we thought about videos would be the best way of doing it. So, I was kind of part of it from the start (p.4)

This participant recognised WDES funding was an important factor in sparking ideas for the BTS project. Yet, the decision to apply for funding is also expressed as shared across the project team and the ABLE Network. From its inception, it seems this participant felt their personal views and ideas shaped the project's methods and aims. Participant F's memory of what and who sparked initial project ideas offered a similar view, explaining:

[At] the ABLE Network several years ago, pre COVID, I happened to mention, you know, we need more awareness around the Trust [...] in our main corridor, as we walked through, we had a piece of work which was photographs and it was around staff members in uniform and what they like to do in their spare time [...] and there was [...] a little bit of synopsis about that person. So, I then said at the ABLE Network 'be really good if we could do something like that so that actually people are aware [...] just because you can't see something...' [...] and then it evolved from that and then before we knew it, Clare Mair was on board and had the funding' (p.1).

Participant F believed that ideas for BTS were sparked by their suggestions at the ABLE Network. That funding was not the motivation; instead, it enabled an existing desire to creatively share their lived experiences to be actioned. Like Participant C, they expressed a clear sense of ownership of the initial idea. Participant D's view of how ideas for BTS developed after hearing about the possibility of WDES funding, referred less to 'I' and more to 'we all', suggesting they felt able to contribute equally to what were perceived as group decisions. They described:

We all ended up having a meeting saying shall we go for this [...] and we put the application in, we all put our bits and thoughts about what we should do and how we should do it [...] we all decided that erm we'll talk about our disabilities, whether they were hidden or [...] not [...] we were all quite surprised and really pleased that the ideas we'd come up with, that they liked and that we got the funding [...] we ended up deciding that we'd take video [...] we did think about just telling our stories, but then um we put photography erm and ended up videoing what we were doing (Participant D, p.1).

Although the opportunity to apply for WDES funding was acknowledged as sparking conversations, BTS's initial purpose, methods, and output were acknowledged by these individuals as their preference. It is questionable whether this sense of ownership reflected the project team's openness to suggestions or whether this grew with the project. Either way, it seems significant that three out of six participants interviewed considered the original project idea to have developed from individuals in the ABLE Network. It was not perceived as manager-led or a Trust directive. As with approaches that eased discomfort, approaches to innovating BTS seemed to align with a common mantra of disability activists, 'Nothing About us Without Us' (Charlton, 2000). This phrase emphasises how disabled people must be valued as contributors in every sector. It parallels with the aims of BTS, reflecting a response to disability oppression and a move towards empowerment, which also resonates with participants' experiences shared in this evaluation.

Expressions of Validation

This subtheme makes it possible to link back to discussion around individuals' hesitancy and anticipated reactions to BTS. Interview responses shared here uncover how others' responses to the exhibition were experienced and interpreted by participants following the launch event. These were positive reactions to the stories shared and expressed as validating the effort individuals exerted to create the project and their lived experiences of disability. The decision to host a launch event at the

hospital, revealing the boards, inviting staff and leaders in the Trust, and including speeches, was interpreted as validating. Participant E, whose quote about pride in BTS opens this section of results, described her feelings at the launch event as:

It was it was really lovely to see, you know, taking aside my horror at my own photos (*laughs*), to see how it had been put together and the lovely booklets that they'd done [...] and they'd given us a small personal version of our own boards as well. [...] it's nice to have that [...] at home, that nice reflection of the day. Erm yeah, so very proud, very proud of what we'd achieved [...] and obviously Jo [CEO of the ROH] made a big erm sort of fuss of doing the exhibition as well, she did a big open event for it, erm and that was really really nice. [...] she did a big kind of reveal of it all er, yeah so that was great. She did a sort of speech and things as well [...] It was really good. I think it surprised me... yeah there was a sense of personal pride I think and how many people came to see it as well (p.4).

For this participant and others, endorsement from the senior leaders at the hospital mattered. The CEO did not just attend the event but also expressed support publicly. This, and the high profile of the event, seems interpreted as a significant gesture, with repeated use of the term 'big'. As someone who hoped the BTS exhibition would help 'people in the wider organisation to understand' (p.1), the support of leaders in the Trust was perhaps an indicator of its success. This participant's experience of initial 'horror' contrasts with the 'lovely' outcomes. The addition of being presented with a BTS booklet and a framed copy of their exhibition board, appeared to help this individual feel valued in their workplace; perhaps they also felt that their willingness to sit with discomfort of the cameras to promote disability pride was worth it. The presentation of a framed board is referred to by another participant as showing 'they recognised all the people on the project' (Participant C, p.6). Both the presence of colleagues and high production value are implied as important factors in feeling the Trust valued their personal contribution and story.

The launch event also offered relief to those who were nervous about having their portraits exhibited and how others' might react to their story. In contrast to those who described the process easing their nerves, it seems that for Participant A, relief was only experienced when the boards were revealed. Reflecting on this moment, they commented:

I thought wow, [...] this is gonna be [...] the first time we're... we're all gonna see our faces on on the board [...] I was a bit nervous about it [...] but it's just great, you know that, once it's revealed [...] it was just really good. Some managers, some people being being there [...] supporting us. It just felt like it was a good support [...] even my manager come with me as well [...] it was good to see some people there showing support. I think really seeing my face on on the board I thought wow, you know, my face is actually on the board [...] it's just there like, you know where where people wanna read it [...] and there's the the QR code to to er to go on to the link and see see my video. [...] it just like kind of felt surreal in a good way (p.3).

Like Participant E, experiences of the launch were unexpected. Participant A implied pleasant surprise at the level of interest in the exhibition and the support offered by leaders. Again, it appears that endorsement from managers, including his line manager, mattered. This participant also expressed a sense of ownership and pride in their comment 'my face is actually on the board' (p.3). Perhaps this was a first realisation that this exhibition was about them, that it raised their personal profile in the Trust as well as disability issues. As someone who had previously 'hidden' (p.1) one impairment, the launch appeared to affirm their decision to speak out. They repeatedly referred to being 'glad' (p.1) they took part and expressed relief in others' validating reactions, that 'people wanna read it' (p.3).

This experience of a raised personal profile is also reflected in repeated use of the term 'surreal' and 'strange' by Participant D. They recalled a new and seemingly validating experience, not at the launch event, but when a patient recognised them from the boards shortly after, saying:

you could see sort of people looking [...] but it was really strange [...] almost surreal cause it was kind of like... 'that's that lady over there', [...] and it was like, oh, oh, I've been recognised [...] it's really nice but [...] that was a bit strange that somebody actually recognising... recognising me from the board really around the Trust [...] 'all the staff would say, 'oh, saw your board' [...] 'you look really good' but I suppose it was a sort of a different side to it to have like a member of the public look at it and say 'oh that's that lady', a bit surreal really. (p.5).

It is possible Participant D and others felt self-conscious when the boards were first revealed. It seems that having a member of the public view their story felt different to colleagues. Yet, this new profile, visibility, or experience of feeling seen was also described as being 'really nice', a positive outcome.

Personal feedback on the exhibition from colleagues or friends also mattered to participants and is expressed as validating their contribution and lived experiences, with memories such as, 'people saying lovely comments around how proud they were and [...] how lovely the exhibition was' (Participant E, p.5). As detailed previously, Participant A considered people thinking 'fair play, you know, well done for doing this' (p.1) as being a positive anticipated reaction to their story. In reality, they explained:

I had a few well dones from people [...] one person er has said [...] well done [...] it's a great way to, you know, sell yourself on how your disability and and even the the others selling their disabilities and how it affects them day in and day out, and it's all being recognised and everything (Participant A, p.1).

The idea of selling yourself or disability may connect with raising awareness and notions of disability gain. It seems this feedback intended to express how lived experiences of disability were portrayed positively in the videos, which made the participant feel their story had been heard, and perhaps also that their capability in the workplace was recognised. Participant B also implied success that their contribution achieved what they had hoped, promoting their competency that 'you can still be a nurse [...] you can still fulfil your dreams' (p.1). They reflected on the launch and feedback from colleagues saying:

I thought you've really really caught what they wanted it to about the Beyond the Stigma and about hidden disabilities [...] it sold it so well [...] I thought, you know, it's quite good that I... that I'd been able to do that [...] a little bit of a pat on the back for, saying well done to, doing it. Yeah, I had like lots of messages on my Facebook and things like that saying [...] well done and everything, and amazing to still be a nurse and be able to tell the story [...] and lots of people just shocked cause they didn't know, cause obviously you wouldn't, would you? Um, so yeah, there was lots of praise and lots of positivity (p.5).

As with other participants, there was overall satisfaction with the exhibition product, and with the way that their story was received by others and with their personal achievement, 'a pat on the back' (p.5) for saying yes. Feedback seemed to affirm this participant's decision to take part and achieved the response they had hoped for, disclosing their impairment more widely and promoting a positive message about what disabled people can achieve. Participant B also suggests BTS was a validating

step forwards for them, adding ‘the safeguarding manager came and then she didn’t know [...] until she read my story, and she was [...] just really shocked um, not shocked, but, you know, surprised and was just sort of impressed’ (p.5). Similarly, Participant D noted ‘a couple of people have sort of said, oh, I saw you board and your video and didn’t know that [...] you were diabetic’ (p.5). For both, new awareness of their personal impairment or long-term health condition among colleagues is expressed as a positive outcome of the exhibition and achieved the desired response.

Admiration or recognition from colleagues is expressed as unexpected but welcome, suggesting further that a negative reaction from colleagues felt like a genuine risk and taking part in BTS was a bold step for some. Participant C also expressed pleasant surprise at others’ affirming reactions saying:

someone said to somebody else about me ‘I can’t believe you know somebody so brave and amazing’ and that’s like... that’s... I don’t consider myself brave and amazing, but it was nice that people had that reaction rather than ‘oh god what’s she doing’. So that surprised me that people like... admired me for doing it, didn’t judge me (p.6).

Bravery was a repeated theme in this participant’s interview; their hopes for the project were to ‘help people who have hidden disabilities that aren’t brave enough to speak out (p.1). It appears that feedback validated their personal aims to ‘be the example’ (p.3) of bravery. In this way, the exhibition was viewed by them as a success.

Finally, Participant F, who hoped their contribution to BTS would prompt action in the Trust around awareness and training, spoke about initial feedback being ‘very positive’ (p.9). It seems BTS not only raised new awareness of their condition, but it also validated their personal belief that awareness was lacking and change in the Trust is still needed. They reflected on the launch saying:

the reactions were very positive, erm certainly speaking to [...] friends, with quite a few other line managers as well [...] that was one of the really powerful things that came back from some really good friends and some family [...] it gave them a little bit more insight to actually when somebody is diagnosed with something [...] it’s going to be life changing [...] they hadn’t thought about it [...] the awareness side of it did take me by surprise and the lack of knowledge that people do actually have (p.9).

Overall, the launch event was expressed by all participants as a positive experience. Support from colleagues and leaders in the Trust affirmed personal decisions to speak out and, for most, specific feedback from colleagues confirmed a level of success in achieving the aims of the project. Participants’ responses have drawn attention to their pleasant surprise at the quality of the exhibition boards, the level of interest the launch raised, and how it elevated their personal profile and story. As was pointed to in Participant F’s comment above, however, there were also shared views across the group that the exhibition was a positive step towards change that is still needed.

Perceiving Long-term Impact

Long-term change was perhaps more difficult for some BTS participants to identify than others, yet this seems important in retaining the sense of validation individuals gained through the project. Participants were less clear and disparate in opinion on the long-term and wider impact of BTS, which may be attributed to differing levels of communication and employee position within the Trust. Uncertainty around outcomes or potential for BTS remains unsettling for some. Participant B repeated comments like ‘I don’t know how long those boards are staying up outside [...] we just thought it was

going to be temporary thing [...] then a couple of years down the line they are still there (p.4)'. They raised questions like 'how many people interact with the boards, how many visitors and staff go up to them and read them [...] there's something you can scan [...] I'd like to know how many people sort of do that' (Participant B, p.4). Participant F shared questions around whether their hopes for organisational change had been initiated, saying, 'I'm not sure if the message did really get through [...] I'm not 100% sure how much difference it made within sort of some of the structures of the Trust [...] that's a negative for me' (p.9). Participant C questioned how additional elements of the project were progressing, commenting 'I signed up for the buddy scheme [...] I don't really know how that's going (p.8). There were varied levels of awareness or knowledge among participants about the project's wider impact and a shared acknowledgement that initial levels of interest in the exhibition had declined. Participant B was aware of a shift from BTS being 'all over Facebook' and 'sharing it in their local communities' to, two years on, questioning if the stories were still being heard by 'new patients at the hospital' (p.4). Recognition of a decrease in interest was shared by Participant F who noted, 'it was around the Trust, there was a lot of feedback [...] it was out on social media [...] it probably did erm all die down significantly' (p.9). Participant C also remarked 'I feel like the output kind of stopped a little bit after the first output, but I don't know [...] I might be totally wrong' (p.8).

Although it could be expected that levels of interest in the exhibition might decrease, for some this was expressed as disappointment or frustration, with comments such as 'I'm not sure of the long-term impact [...] I've not seen any difference in the way people behave to me' (Participant C, p.6). BTS's potential to support disability, management, and staff training in the Trust seems the most significant factor in this; awareness sessions were noted as being one of four elements of the project design. Participant C later explained 'I don't think the training's really got that far from what I know, which is a shame cause part of the project output should have been manager training, trying to get managers to be more accommodating' (p.8). Participant F expressed a similar view saying:

I can't actually identify any specific training [...] that has been implemented since we've done the Beyond the Stigma [...] I think that's that's a very missed opportunity from the Trust [...] it's very frustrating when you've done that exhibition, you've been very vocal about the fact that you've got no support [...] we still remain in that place [...] I probably had naively thought that actually Beyond the Stigma would actually launch that [...] I just thought that would happen and then that that never did (p.13).

Both suggest a level of disappointment and frustration, which perhaps raises the need for clear and continued communication with participants about long-term plans for utilising BTS content. Participants also shared contrasting views that BTS is 'mentioned in the training' (Participant D, p.7) and 'the exhibition's been used a lot in general E and D training' (Participant E, p.6). Participant E, however, also added 'I don't think we've done enough specifically on disability' (p.6). Despite some frustration, there was also a shared view among participants that it is not too late for the videos to be shared further, with remarks like 'maybe the videos [...] could be used like for teaching and training' (Participant B, p.8), and 'I think people should watch the videos when they join the Trust, I think that um the managers need training' (Participant C, p.11).

The video and interview data included in this report will be shared with all participants and may assist them in understanding aspects of the project's impact. The evaluation itself was perceived as a positive long-term outcome of the project with Participant B closing their interview saying, 'I'm glad it's carrying on as well with your involvement [...] it's nice, it means it is still doing something [...]. It's not just in Birmingham obviously, the word's spread (*laughs*) (p.9). This positive response to how interest in BTS has extended beyond the Trust was also implied by Participant A, who remarked:

I know another Trust in the UK [...] they did actually a similar thing to Beyond the Stigma [...] they shared their experiences on on how disability affects them [...] and I thought [...] it is great [...] that gets noticed a bit more' (p.5).

There is a clear sense that using BTS content to its full potential mattered to individuals and there were also positive perceptions of change happening in the Trust and beyond. One significant change was in the title of the Disability Network, which is now known as the ABLE Network. Participants expressed this decision as reflecting a shift in thinking, with definitions of disability broadening and disability viewed as a positive identity by Network members. Participant D noted, 'that's sort of why we changed the name of the disability group to the ABLE group, because it's not what you can't do, it's what you can do' (p.6). Comments about how BTS had grown the ABLE Network were also common and included, 'the ABLE Network is definitely a positive' (Participant F, p.9), and:

the ABLE Network has been great [...]. We want to er expand it further, I think. We've been trying to use the exhibition as a way to sort of show the organisations commitment to the disabled workforce. I think that's been really helpful (Participant E, p.6).

Again, this participant implied there is scope and personal motivation to promote the exhibition content further, that potential, opportunity, and necessity for this remains. Participant C concluded their interview by noting a continued need to challenge discrimination in the workplace, explaining 'people think "I've done a great project but that's it now", but it's not. It's about building on that and giving people different routes into speaking out, so that the Trust understands that these problems haven't gone away" (p.12). They drew attention to the BTS exhibition as a springboard for continued and perhaps creative opportunities for disabled people within the Trust to speak out.

Finally, there was recognition of positive progress in disability disclosure rates that was conveyed as a long-term outcome of BTS. Participant D commented that:

people are more willing I think, since the exhibition, to sort of say that they have got a disability and they do need sort of help and you know, reasonable adjustments [...] I think there's been a lot more erm wellbeing and and looking at disability in terms of how we can help staff (p.8).

Participant E, who seems more informed about diversity discussions in the Trust than others, supported this view. They suggested openness among disabled people in the Trust was a lasting impact of BTS, stating:

I don't know how linked it is to the Beyond the Stigma, but I think it's partly erm that's affected people's willingness to disclose [...] that they are disabled. So, before the Beyond the Stigma, I think that was around 3% of our workforce was disabled. I think that's running somewhere around sort of high 6s to 7% now. [...] a big uplift from where we were [...] that's part of it (p.6).

It seems clear that after an initial buzz of activity and interest in the exhibition some participants felt expectations or potential for utilising their stories in the Trust were not yet met. There was also a sense of pleasure in discovering that other trusts or organisations had expressed interest in BTS and that signs of progress in the Trust are still emerging. Extending the BTS content to teaching and training settings seemed to be perceived as the most prominent area of missed opportunity. Still, even in this, there were mixed views on whether the videos have been used in staff training or not. There

was a shared view among participants that there does not need to be an end to the BTS initiative, that there is still opportunity to include the content in training and to extend BTS to other disabled people. Participant A suggested 'maybe they could do another Beyond the Stigma' (p.5), and Participant E stated 'I want to do sessions at team brief [...] the buddying thing [...] we need to do (p.6), referring to 'a snowball effect' (p.9).

Journeying with Disability Understandings

'I definitely use the words, 'I am disabled', a lot more than I ever did before. I would never have even admitted that' (Participant F)

Participants' responses relevant to this final superordinate theme were expressed as shifting views and tensions around personal journeying with disability understandings. These factors of their lived experience of Beyond the Stigma emerged as three subthemes connected with personal learning and perceptions of self, new openness to speak out, and actions. They demonstrate how the BTS project has been powerful in moving participants towards increased intrapersonal and interpersonal engagement with disability. They also present individuals' journeying with disability understandings as a live dynamic, an ongoing process that is navigated inside and outside their NHS workplace.

Learning from Disability

Participants made clear that involvement in BTS impacted their learning from disability. New learning was referred to as sparked by personal reflection, the process of articulating their story, and encountering other people's disability views and experiences. New learning from disability resulting from BTS was expressed as shifting intrapersonal views of disability definitions, language, and identity.

Participant B described their experience of watching a video recorded by someone else in the group saying:

I was really in tears watching it and you just don't know, because you see people at work [...] in the corridor but you don't know what's going on in their life [...] So, it really sort of like opened my mind big time erm to what other people are going through as well everyday [...] that was really eye opening (p.2).

They reiterated how new insight from the BTS videos had shifted their learning and perception of others, commenting, 'that made me really learn from that um the Beyond the Stigma [...] to be mindful of [...] what else people have got going on' (p.6).

Participant C implied a similar revelation or broadening of disability understanding, referring to another participant's video as 'simple but so powerful' adding 'I hope that somebody watched that and thought, "okay, it's not okay to be mean to somebody because they've got a learning disability" [...] I couldn't believe somebody could say so little but be so impactful' (p.3). Participant C continued to list what was learnt from others' stories and how this had shifted understanding and responses to others in the workplace for them, saying:

somebody in the group had got diabetes, talking about diabetes and um how that impacts them at work, and you're like, I don't think it realised that. [...] someone else talked about the effect of their cancer treatment [...] you don't realise that the treatment they've had is so brutal it makes them struggle with things probably for the rest of their lives. It just opened my eyes [...] So, that's made me a lot more aware of the wider range of long-term conditions and the impact it has on people and how you should be considerate... [...] I make a mental note now of 'okay' if I see them looking tired now, I go 'are you alright, you look a bit tired?' [...] it has changed my perceptions (p.8).

It seems significant that even staff in the ABLE Network had not had an opportunity to hear each other's stories before creating BTS. In this way, the project presented a new opportunity to build understanding among Network members and shifted personal disability definitions, as Participant E explained:

it was nice to hear, initially, some of the experiences that people are going through erm... and again to challenge your own conceptions about what what disability is, because it is very broad. [...] the more we talk about it, the more I understand what other people are going through [...] why it's classified as disability [...] and why does it give them significant challenge in their day to day lives (p.6).

In addition to shifting understanding and responses to others, learning from people's stories was also conveyed as influencing how participants identify or self-define. Participant D noted that part of their hesitancy to take part in the exhibition was 'I don't actually see me as having a disability' (p.1); yet, later in their interview they suggested that reflecting on their own and others' video stories prompted new intrapersonal reasoning with disability identities for them, describing:

it has kind of made me think about doing stuff for the film [...] looking at erm how it does affect day-to-day [...] I do declare it now, so I suppose that is another way that I've kind of moved forward [...] although I don't see it as a disability, I know it can come under that term disability [...] that is something that I see differently [...] it's changed me in that way [...] the video side of it and I think it's just made me think about it more (p.6)..

Participant F was also clear that involvement in BTS has shifted their perception of disability and self-identity. When first asked to take part, they described 'I was absolutely in denial about the fact that I had a disability' (p.3) and 'I just have struggled to accept it personally, for me, I always felt a bit labelled and didn't like that label' (p.11). However, they also detailed a shift in thinking, saying 'I'm not into denial anymore' (p.11). It is a line from their response below that opens this section of results:

it's opened me up and [...] I don't quite know what I was scared of, I don't know quite why I didn't want to be labelled with that... with the disability label [...] whereas now I'm probably... it doesn't me... it doesn't bother me at all. So, I think it was positive for that. I definitely use the words, 'I am disabled', a lot more than I ever did before. I would never have even admitted that. I would never use that word myself erm and probably that was a lot to do with the exhibition as well [...] I was more comfortable to use that (Participant F, p.11).

Participant F continued to interpret this shift in personal positioning with disability identity as:

probably a lot to do with watching the other videos as well and just seeing how [...] other people in within those films didn't seem to struggle with the fact that they were classed as

disabled. They talked quite openly. [...] there seemed to be a lot more acceptance with them personally about their own experiences [...] so yeah, there was an element of just seeing everybody else's experience that just made it much more accepting for me. But yeah, I do use the term disabled now, a lot (p.12).

For these individuals, exposure to other people's stories appears to have had long-term implications in terms of them seeing beyond their own situation or experiences. As people with a range of impairments and long-term health conditions, it is also possible that the videos exposed a shared 'battle' or struggle, and shared identity that some individuals had not acknowledged before (Participant C, p.7-8). For Participant F, others involved in BTS had demonstrated an ease with disability terms and identity that was expressed as shifting their thinking towards self-acceptance and new affinity with the disabled community.

Increased Openness to Sharing Disability Experiences

It was not just intrapersonal reasoning with disability terms or identity that was acknowledged as being influenced by involvement in Beyond the Stigma. All participants expressed a shift in their openness to sharing lived experiences of disability and increased confidence to speak out, which developed through the exhibition process. For some, new openness was pushed by their agreement to take part, like Participant A, whose comment 'now is the time just to tell them' (p.1) was mentioned previously. Participant D, who remarked on first joining the Trust and 'nobody really knew' about their long-term health condition, recognised 'I'm a little bit more open now and obviously it's up on the boards anyway, so anybody can see' (p.2); they implied surrendering to the fact that their story and photo are now public. Also, Participant C described how opportunities at and after the exhibition launch had enabled them to speak out or share about disability matters in new ways; they remarked that 'because I did that speech and I did that talk for NHS England [...] I've started to hold myself in a bit more high regard [...] I can see myself as being a survivor more than a victim' (p.8). It appears this opportunity to be open and to speak out was viewed by them as building their self-confidence and self-assurance. For all participants new openness to share their experiences was conveyed as a positive personal outcome of BTS with implications extending to and beyond their NHS workplace.

Participant D suggested new openness to share their experiences, sparked by BTS, has changed conversations about their condition in the workplace. They explained:

I've never been ashamed of it [...] I've just never been as open I suppose [...] I was less likely to talk about things before and how it affects me and all of that kind of stuff so I suppose it's made me more open about how things are and [...] how I can feel on a day-to-day basis sometimes [...] I do talk about it more (Participant D, p.6)

Whilst there is still resistance to self-defining as a disabled person, it appears that taking part in BTS made Participant D less opposed to talking about their condition; again, this seems a positive move towards self-acceptance and disability engagement in the workplace.

Participant E also recognised 'I'm definitely more comfortable sharing now than I probably was at the time of the exhibition' (p.2). They continued to describe how BTS created a new level of personal openness for them, remarking that:

my mum watched it as well (*laughs*) [...] it was interesting for her to watch as well because I don't talk very openly about how I feel. So, I've probably been more open in that than I have been with my friends and family (p.5).

They added:

I'm just generally more open about the fact that I'm disabled [...] I don't think I was necessarily ashamed before, but I think it's just something that you are more comfortable talking about particularly since how successful the exhibition was and how people seemed to really like it (Participant E, p.6).

This sense of the exhibition's success influencing individuals' ease in talking about disability matters was expressed as particularly important for Participant F; they also noted how their lived experiences of disability were first shared with family through the exhibition videos, saying 'it just highlighted to me that actually [...] it was worth doing' (p.9) and:

it was a definite positive [...] I've got two sons [...] I don't think I've ever really sort of really sat down and had to talk with them. [...] my husband as well really, and just made them aware of exactly how it was making me feel and how it was impacting me. [...] it did open up more awareness for them and certainly we had conversations off the back of the video (p.10).

It is a valuable outcome of the project that these individuals associate BTS with increased confidence and ease in discussing disability matters and lived experiences in the workplace. But what is perhaps more striking is how the BTS initiative presented an opportunity to share beyond what had even been communicated with family members. In some way, this emphasises the extent to which BTS participants felt a safe space was offered through this project and that their openness was a significant step forward. It also highlights the lack of opportunities for disabled people to voice their experiences, which is both beneficial and vital to relationships in and beyond workplace settings.

Proactivity and Community Connections

This final subtheme suggests how shifts in participants' beliefs around disability have influenced proactivity in the workplace and their sense of affinity with the disabled community. For some, confidence gained through BTS was conveyed as prompting new actions. Since the exhibition, one participant and one member of the project team have both become Chairs of networks in the Trust; both imply taking part in BTS was central in their decision to lead. Participant E reflected on how BTS prompted new 'confidence that you can do something that makes you feel uncomfortable, erm and it might have a good outcome' (p.5). Returning to notions of vulnerability raised in their video, they continued to describe how BTS has helped them realise that 'Being vulnerable isn't necessarily a bad thing [...] that you will be supported in this organisation' (p.5). They implied a realisation that sharing lived experiences of disability is not admitting weakness, it is brave, and feeling supported through the BTS project has made them braver. Furthermore, it seems they are willing to sit with discomfort again if their story has an impact, as they explained 'it's just given me a sense that I can be involved in some more outwardly facing things than perhaps I've previously been comfortable with' (p.5).

Proactivity to engage with disability and build connections with disabled people was also implied by Participant F as a result of BTS. They described:

I am much more erm active now within erm particularly around social media and disabilities, I'm much more passionate and follow lots of people that I know have got similar issues, very, very passionate about wheelchair access [...] I'm much more accepting of it and I am networking much more with disabled people than I ever was before [...] recognising if you need something that's different to everyone else, then ask for it [...] what's the problem about asking for it (Participant F, p.12).

This participant suggested positive outcomes of BTS for them include a new desire to connect with disabled people, new alertness and interest in accessibility issues, and new ease with asking for adjustments if required. It appears moving towards self-acceptance through BTS led to them seeking new community connections in and beyond the workplace and becoming 'very much on board with the ABLÉ Network' (p.15).

Increased connection with disabled people in the Trust was replicated in responses across the group. Participant C suggested that connections and support across the ABLÉ Network had been strengthened through BTS, noting:

I don't think the ABLÉ Network is as big as it should be, that's not our fault. It's difficult in a hospital, with people working shifts and working patterns. [...] The people that I do know through the ABLÉ Network I get on fine with, always get offers when I'm having struggles, I'm always getting offers, saying 'if you need to talk to me' that nice support network. [...] I think that's nice that, because that connection's there, we can all do that for each other (p.9).

They described effort to support others as well as feeling supported by the Network. Participant C also pointed to action since the exhibition to 'promote that material' (p.10) and commented 'I did a stall outside for disability week to try and encourage people to um think about disability [...] and raise the profile' (p.9). Describing their action to support the Network, Participant A noted, 'I took part in volunteering [...] which is something I've never done before [...] there was some people who took an interest and I'd explain to them [...] how the Disability Network came about' (p.4). They continued to explain how relationships have continued to develop with others who took part in the exhibition, saying:

we have all connected really just sharing our our stories [...] I do speak to er one of the people who's taken part [...] which is nice because I never knew him very well before [...] there is another person who, in fact, I used to work alongside [...] it's good that she's taken part in it as well [...] I speak to her a little bit (Participant A, p.4).

In this participant's video they described feeling isolated in the workplace. It seems that shared experiences with others and working together to create BTS made them feel more connected to, and able to engage with, colleagues in the Trust.

In a similar way, Participant D referred to building new connections with others with similar experiences, saying 'I've spoken to a couple of other colleagues and found out that they were diabetic as well, which I didn't know before' (p.3), and later remarked on 'people that I've found since were diabetic and said, 'oh, you know, I can relate to what you were saying in the video'' (p.5). This response points to the effectiveness of BTS in allowing for a community of shared experiences, seemingly making other staff and participants feel seen and heard. The initiative also had positive implications across the wider staff team that it is not possible to assess within the scope and scale of this evaluation. Still, this participant's continued story points to how a project like BTS can help build a

support network for those with the same impairment or health condition to build connections, new conversations, relationships, and a collective sense of identity.

Finally, a comment from Participant B highlights how personal journeying with disability understandings, moved forward by the BTS project, is a live dynamic for all involved. As someone who is not involved in the ABLÉ Network and suggests they did not build close connection with other people through the project, Participant B also stated: 'I probably should be in the ABLÉ Network, but I have really um taken part [...] I probably should do but I haven't as yet' (p.7). In closing their interview for this evaluation, they referred to joining the ABLÉ Network again and repeated, 'I probably need to, that's sort of teaching from here, yeah, I could do that' (p.9). For them, it seems BTS has made disconnection from other disabled people in the Trust uncomfortable. Involvement in BTS has perhaps also created a sense of shared responsibility for change in the workplace, which may increasingly become impossible for disabled or non-disabled staff to ignore.



Headlines

It is not possible to make generalisations across the participant group due to its small sample size and the nature of an IPA study. It is instead appreciated that all six individuals interviewed for the evaluation experienced BTS and its personal and professional outcomes in a unique way. As in the results section, it is also evident that there are some shared opinions, experiences, and themes across the group. As a more concise way of highlighting key experiences of the Beyond the Stigma project, the following list of headlines has been created. It is noted, however, that not all statements reflect the responses of all participants; this is intended to supplement and not replace the results section.

- Participants in the BTS exhibition felt able to contribute ideas and shape the project bid, aims, and methods from its inception. Innovative discussion between the project lead and the ABLE Network reflected the valued concept of 'Nothing about us Without Us'.
- Resilience and a willingness to sit with discomfort to promote change was required of individuals in creating the BTS exhibition.
- Chosen methods of video and photography, use of an external studio, and the title of the project increased participants' initial unease and discomfort, adding to perceived risk and compromise in taking part.
- BTS created a unique and supportive space for participants to disclose impairment, to articulate lived experiences of disability, and exhibit disability pride in their workplace.
- Participants had high expectations of BTS's outcomes with hopes for organisational and structural change, to demonstrate disability pride, promote disability gain, and increase openness in the Trust.
- Familiarity with disability, 'sitting in the background', and high-level creative, organisational, and interpersonal skills were important factors in the project team's ability to ease participants' nervousness or discomfort in the process of creating the exhibition.
- Keys to satisfaction with the project process and effective working across the project team and participants included collaboration, professionalism, sensitivity, clear and open communication, agency and freedom, and informality.
- Organisation of the launch event, active support from leaders and managers in the Trust, and exhibition feedback were experienced by participants as validating their contribution and pointing to successful outcomes.
- Participants expressed overall satisfaction with the quality of the finished exhibition, how it reflected the aims of the project, and how it appropriately and accurately elevated their personal story; high production value was key in this.

'I just think there's a lot of good that can be done in this organisation if people are proud of who they are and what makes them different'

(Participant E)

- Participants seemed unclear about the long-term impacts of BTS with some disappointed and frustrated with potential opportunities to utilise the videos in staff training, and expectations of the project, not yet feeling met.
- Continued potential to share, extend, and develop BTS was identified by participants as beneficial to managers and staff at the ROH, disabled people, and other trusts and organisations.
- The BTS initiative was perceived by participants as shifting their personal disability views, raising awareness of nuanced lived experiences, and creating new ease with disability definitions, language, identity, and self-acceptance.
- Participants in BTS expressed increased confidence and ease in sharing their experiences and engaging in disability matters in the workplace.
- BTS created a rare and vital opportunity for participants to experience a new level of personal openness with positive implications beyond the workplace.
- BTS allowed for a community of shared experiences, where all participants appeared to feel seen and heard, with some continuing to feel empowered to lead, build connections with others, and to press for change in their workplace.

Conclusion

Conclusions to this evaluation were not inevitable or predicted. Through the interview analysis we have conveyed participant-led stories about experiences of taking part in the ROH's Beyond the Stigma exhibition and drawn these together with our interpretations. The aim of this evaluation was to gain detailed understanding of participants' experiences of taking part and the longer-term impact of this exhibition for individuals. The broader aim was to consider how arts-based approaches to sharing lived experiences of disability may contribute to disability understandings and the wellbeing of disabled people in NHS workplaces and beyond. This was a limited evaluation in terms of its scope and numbers of ROH staff involved. However, there are clearly a variety of benefits and learning resulting from BTS that have been identified. These are not limited to the individuals who shared their stories, nor to the immediate temporal context of a one-off initiative. The observations made are supported largely by existing literature in the field, which serves to enhance the validity of the findings; BTS offers a valuable example of how arts-based methods can effectively support nuanced disability understandings in the workplace and the wellbeing of disabled people through the appropriate and accurate sharing of their lived experiences. BTS demonstrates how video and photography can be powerful in promoting what disability scholars might term as disability gain and disability pride in workplace settings. Acknowledging potential for the evaluation findings to contribute to the fields of arts, health, and disability studies may, therefore, be interpreted as lasting impacts of the BTS project.

This evaluation has pointed to how initiatives like BTS might contribute towards improving wellbeing outcomes for people who self-define as disabled, with impairments, and/or long-term health conditions in the ROH and beyond. Clear long-term and wellbeing benefits for some participants in BTS have been identified as increased self-confidence, openness, self-acceptance, and empowerment. Shifts in participants' personal disability views point to improved wellbeing through new awareness of diverse and shared experiences of disability, new ease with disability definitions, language, and identity, and new community connections. Personal resilience was also a common factor of participants' experiences, which points to benefits and learning; BTS enabled participants to step

outside their personal comfort zone, to take what was perceived by some as a risk. In this, long-term personal and wellbeing benefits may be identified as increased personal resilience, with BTS offering an opportunity to experience risk as having positive and satisfying outcomes. Observations from this evaluation also highlight how levels of risk, resilience, and compromise required in sharing personal experiences of disability in the workplace must not be underestimated and should be managed effectively. Approaches taken in BTS demonstrate effective routes to easing participants' discomfort that preserved wellbeing. Yet, there was also scope for expectations of the project's output and long-term plans for the exhibition content to be communicated to participants with more clarity. Likewise, beneficial opportunity for innovation, a sense of achievement, and ownership in seeing personal ideas come to fruition was offered through BTS. Yet, similar initiatives may benefit from approaches to innovation that give more consideration to the project title and its resonance with participants' lived experiences.

Many aspects of the BTS project offer an example of best practice in working creatively and effectively across disabled and non-disabled communities in a professional or healthcare context. The BTS exhibition offers a model that can be repeated, improved, and extended to support disabled people in the ROH and feed into recruitment and employment strategies. The concept of BTS could be adapted to other NHS Trusts, organisations, and professional settings in the UK and internationally. Important aspects of selecting a project team, achieving high production value, participant satisfaction, and support from leadership are evidenced in this report and demonstrated through the BTS project.

One thing that stood out in conducting interviews for this evaluation was the value all participants placed on BTS and its potential to promote change. No matter how near or far they felt the desired outcomes for were, or how difficult or easy these may seem to achieve, they valued BTS enough to step out of their comfort zone to tell their personal stories; additionally, they valued its potential enough to engage with researchers and reflect honestly and openly on their experiences of BTS both inside and outside the workplace. In the end, making sense of lived experiences of disability in the workplace matters. It is hoped that findings from this evaluation will prompt future projects that continue to 'explore the impact of disability and promote a culture of openness, respect and compassion' (ROH, 2023a), that shift disability understandings, and keep honest and open conversation going within the ROH and beyond.

Reference List

- Barnes, C. (1991) *Disabled people in Britain and discrimination*. London: Hurst and Co.
- Barnes, C. (1992) *Disabling imagery and the media*. Halifax: Ryburn.
- Bolt, D. (2017) 'Keynote', Disability gains for the academy: exploring pedagogies in disability studies. Liverpool Hope University, 15 September.
- Bos, A. E. R., Kanner, D., Muris, P., Janssen, B. and Mayer, B. (2009) 'Mental illness stigma and disclosure: consequences of coming out of the closet', *Issues in Mental Health Nursing*, 30, pp.509–513.
- Charlton, J. I. (2000) *Nothing about us without us: disability oppression and empowerment*. Los Angeles: University of California Press.
- Colella, A. J. and Bruyère, S. M. (2011). 'Disability and employment: New directions for industrial and organizational psychology' in S. Zedeck (ed.), *APA handbook of industrial and organizational psychology*, pp. 473–503. American Psychological Association.
- Department for Work and Pensions (2023a) *Family resources survey: financial year 2021 to 2022*. Available at: <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2021-to-2022>
- Department for Work and Pensions (2023b) *Employment of disabled people 2023*. Available at: <https://www.gov.uk/government/statistics/the-employment-of-disabled-people-2023/employment-of-disabled-people-2023>
- Fox, A. M. and Sandahl, C. (2018a) 'Beyond "cripping up": an introduction', *Journal of Literary and Cultural Disability Studies*, 12, (2), pp.121-127. Liverpool University Press.
- Gewurtz R, Kirsh B. (2009) 'Disruption, disbelief and resistance: A meta-synthesis of disability in the workplace' *Work*, 34 (1), pp.33-44.
- Goodley, D. (2011) *Disability studies*. London: Sage.
- GOV.UK (no date) *Definition of disability under the Equality Act 2010*. Available at: <https://www.gov.uk/definition-of-disability-under-equality-act-2010>
- Kulkarni, M. (2022) 'Hiding but hoping to be found: workplace disclosure dilemmas of individuals with hidden disabilities', *Equality, Diversity and Inclusion*, 41(3), pp.491-507.
- NHS Digital (no date) *Disability*. Available at: <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set/submit-data/data-quality-of-protected-characteristics-and-other-vulnerable-groups/disability>
- NHS England (2023) *Workforce disability equality standard 2022 data analysis report for NHS trusts and foundation trusts*. Available at: <https://www.england.nhs.uk/long-read/workforce-disability-equality-standard-2022-data-analysis-report-for-nhs-trusts-and-foundation-trusts/>

Oliver, M. (2004) 'The social model in action: if I had a hammer' in C. Barnes and G. Mercer (eds.) *Implementing the social model of disability theory and research*. Leeds: The Disability Press, pp.18-31.

Oliver, M. and Barnes, C. (2012) *The new politics of disablement*. Basingstoke: Palgrave Macmillan.

Olsen, J. (2022) 'Employers: influencing disabled people's employment through responses to reasonable adjustments', *Disability & Society*.

Sandahl, C. and Auslander, P. (eds.) (2005) *Bodies in commotion: disability and performance*. Ann Arbor: The University of Michigan Press.

Shakespeare, T. and Watson, N. (2002) 'The social model of disability: an outdated ideology', *Research in Social Science and Disability*, (2), pp.9-28.

Smith, J. A., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis: theory, method and research*. London: Sage.

Stephenson, J. (2018) 'Exclusive: nurses with disabilities face discrimination in workplace', *Nursing Times*. Available at: <https://www.nursingtimes.net/news/workforce/exclusive-nurses-with-disabilities-face-discrimination-in-workplace-06-03-2018/>

The Royal Orthopaedic Hospital (2023a) *Beyond the Stigma: an exhibition of stories about seen and hidden disability*. Available at: <https://roh.nhs.uk/beyond-the-stigma/beyondstigma>

The Royal Orthopaedic Hospital (2023b) *NHS workforce disability equality standard (WDES) report - October 23*. Available at: <https://roh.nhs.uk/doc-men-hidden/corporate-information/equality-and-diversity-report/wdes-workforce-disability-equality-standard-reports/298-wdes-report-2022-2023/file>

Vornholt, K., Villotti, P., Muschalla, B., Bauer, J., Colella, A., Zijlstra, F., Van Ruitenbeek, G., Uitdewilligen, S. and Corbière, M. (2018) 'Disability and employment – overview and highlights', *European Journal of Work and Organizational Psychology*, 27 (1), pp. 40-55.

Willig, C. (2013) *Introducing qualitative research in psychology*. 3rd ed. Maidenhead: Open University Press.

Appendices

Appendix 1: Interview Schedule for Evaluation Participants

Appendix 2: Sample Transcript with Annotations

Appendix 3: Sample Table of Themes for an Individual Participant

Appendix 4: Master Table of Themes Across Participant Group

Appendix 1: Interview Schedule for Evaluation Participants

| |
|---|
| <p><i>(Preamble)</i></p> <ol style="list-style-type: none"> 1. Can you start by describing the Beyond the Stigma project to me? 2. What does the project title (Seeing) Beyond the Stigma mean to you? 3. What was your main reason for agreeing to take part? <p><i>prompt: were there any other factors that impacted your decision? Why did you feel taking part was important? What did you first assume were benefits of taking part for you and others?</i></p> <ol style="list-style-type: none"> 4. Can you tell me one story about how disability affects you that you chose to share in the video? 5. Can you tell me one story about how disability affects you at work that you shared on the video? <p><i>prompt: are you happy with what you shared about your experiences? Is there anything you would change about the stories or opinions you chose to share?</i></p> |
| <ol style="list-style-type: none"> 6. What was the process of creating the exhibition like and how were you involved? 7. How did it feel to share your personal stories of disability using video and photography? <p><i>prompt: can you share any stories about your experience of filming?</i></p> <ol style="list-style-type: none"> 8. In what way do you feel that using video and photography to create the exhibition made it easier or more difficult to openly share your personal experiences of disability, impairment, or long-term health conditions in your workplace? |
| <ol style="list-style-type: none"> 9. What was your opinion of the finished exhibition content? 10. Can you describe how you felt when you first saw the exhibition displayed? <p><i>prompt: did your personal reaction to seeing the exhibition surprise you in any way?</i></p> <ol style="list-style-type: none"> 11. Can you share any stories about how you experienced other people’s reactions to the exhibition and to the personal stories you shared? <p><i>prompt: did other people’s reactions to the exhibition surprise you in any way?</i></p> |
| <ol style="list-style-type: none"> 12. Can you share any stories about any long-term impacts of the Beyond the Stigma project for you personally? <p><i>prompts: has the project impacted the quality of your health, work, or relationships? Has it impacted how happy, anxious, or satisfied you feel, or your confidence and sense of purpose?</i></p> <ol style="list-style-type: none"> 13. In the videos you were asked about how you experienced stigma in the past and in your work, can you describe your personal experience of stigma inside and outside of work now? <p><i>prompt: has that changed in any way since taking part in the project?</i></p> <ol style="list-style-type: none"> 14. Since taking part in the BTS project has your understanding of what it means to be ‘disabled’ changed in any way? <p><i>Prompt: has anything shifted in how you self-define or connect with others in the disabled community? Has anything changed about how you interpret the terms ‘disabled’ or ‘disability’? Did taking part in BTS play a part in this?</i></p> |
| <ol style="list-style-type: none"> 15. What has been your experience of other outputs from the BTS project, the buddy scheme, staff disability awareness sessions, and the ABLE/disability Network? <p><i>prompts: do you feel the experiences you shared in the exhibition impacted these outputs in any way?</i></p> <ol style="list-style-type: none"> 16. What long-term impact do you think the Beyond the Stigma project has had on attitudes, disability awareness, and understandings among the wider staff community? <p><i>prompt: can you share any stories about this?</i></p> |
| <ol style="list-style-type: none"> 17. Looking ahead, what are the benefits of continued and improved support for disabled people working at the ROH, and for you? <p><i>prompt: can you think of any practical factors that might help or limit this e.g., the environment, organisational structure, accessibility, other people?</i></p> <ol style="list-style-type: none"> 18. In what way do you think that increasing opportunities for disabled people to share their real-life experiences publicly in NHS settings might help move towards this? 19. What potential can you see for broadening creative projects like Beyond the Stigma in the future? <p><i>prompt: how could BTS be improved and extended within the ROH, to reach a wider group of NHS staff and visitors, and beyond the ROH? What do you perceive as potential benefits and challenges in this?</i></p> |
| <ol style="list-style-type: none"> 20. Is there anything else you would like to share about the benefits, challenges, or your personal experiences of taking part in the Beyond the Stigma project? |

Appendix 2: Sample Transcript with Annotations

| Themes | Line/ Page | Transcript | Comments |
|---|---|---|--|
| Disability pride/identity | 1 2 3 4 5 6 7 8 | (Q.1) um so for me it was really an opportunity to try and share some stories and er yeah for people in the wider organisation to understand some of what we go through. Um, perhaps for some people to realise that some of us were disabled where perhaps we've had invisible disabilities, erm, yeah and to just share those experiences really and just show we were proud to be who we were erm, who we were, who we are. Um, yeah just to... I think it's difficult particularly with disability, I've reflected on this a number of times that actually you may not realise that you're disabled under the law, so, I think it's good to share some of those circumstances where you might be. I think if you're perhaps part of the BAME group or or some of the other protected characteristics groups you kind of know you're part of that group. But actually, people don't... for disability, don't necessarily realise, and I've heard this quite a few times, that they don't realise that they are protected under the law. So, I think it's really important to share stories of people, who they are, what they're going through and, yeah, that actually you might be entitled to a whole range of things particularly around reasonable adjustments. I just wanted to be open really and about what I'd gone through and kind of how that felt um, yeah, it's really about just sharing those stories. | Reason for taking part. 'to try and share some stories' 'understand some of what we go through' <u>disability disclosure</u> 'to realise'. |
| Opportunity to share/to challenge understanding | 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 | (Q.2) erm, so I've... (sighs) for me, I guess I've never personally felt stigmatised, erm and that might be because er... I've probably not grown up... I've not grown up with disability and for me until [description of condition removed] or something like that for going through something and some of my other disabilities are around hearing and struggling to hear sometimes, so, it's obviously invisible, so, for me, I haven't really experience that. So, I know where the title came from, I'm sure that there are people, well I know that there are people who experience stigma, um and discrimination, er but for me it probably doesn't... didn't fit in that way for me. But I felt comfortable with the title generally, I think it came from discussions in our forum, but I can't remember if I'm honest, genuinely can't remember. (Q.3) I just think there's a lot of good that can be done in this organisation if people are proud of who they are and what makes them different and I think there's probably I feel a sense of responsibility in being somebody fairly senior in the organisation as well to be open and proud of my own experiences in the hope that that will help others to feel comfortable as well. So, there is | <p>Opportunity to share experiences and 'show we were proud' 'to express disability pride/identity' 'who we were'.</p> <p>Realising disability, a reoccurring reflection, 'a number of times' 'personal journey with disability understanding, identity, affinity with disabled community</p> <p>Others lack of understanding. Repeated 'realise' - 'don't [...] realise' (x2) Realisation of her own rights, being 'protected under the law' 'this is something new, a revelation?</p> <p>Shared stories bring change? 'really important' of disability and identity 'who they are' AND 'what they're going through'</p> <p>Raising awareness of legal entitlements – BTs exposing hidden awareness and experience of disability, and hidden rights too</p> <p>'what I'd gone through' 'willing to expose personal journey, she wants others to understand 'how that felt'</p> <p>Lack of connection with title/term 'Stigma' - 'never personally felt stigmatised', 'I haven't really experienced that', 'Title not a fit to her experiences, imposed, not chosen?' 'Didn't fit' - Has appreciation it 'fit' others? Affinity with others – shared experiences.</p> <p>Describes her impairments, acquired disability..</p> <p>'fit comfortable' 'with lack of fit with title – compromise rather than ownership?</p> <p>Purpose and feeling of involvement – Purpose 'Good [...] In this organisation' from exposed pride 'if people are proud of who they are' exposed identity, exposed difference.</p> <p>Responsibility for change 'being somebody fairly senior' Responsibility to expose personal story, to 'be open and proud' 'sees herself as a role model'?</p> |

Appendix 3: Sample Table of Themes for an Individual Participant

| Themes | P./Line | Key Words |
|--|--|--|
| <i>Recognition and support</i> Praised for involvement Recognised challenges Recognised expertise/need New dynamic to support | 5,34 5,1 7,35;8,1 8,14 | lots of messages [...] how well done and everything, and amazing to still be a nurse and be able to tell the story [...] people just shocked cause they didn't know [...] praise and lots of positivity [...] saying how good it was the Orthopaedic doing that the safeguarding manager [...] read my story [...] she was [...] surprised and [...] impressed [...] with what I've been through brought it to the forefront; interested to see if everything was in place [...] for patients [...] anything else that they could put in place for people in that situation. I think they are quite good at listening to their staff [...] beyond the stigma has brought to the forefront [...] to let people know, let your manager know [...] so they can put things in place [...] they are really good at assessing [...] staff and patients |
| <i>Learning from disability</i> Promoting disability gains Legacy of disability gain Moved by others' stories New awareness Questioning connections | 1,22; 40 6,9; 9,17 2,2; 6,34 6,36 7,17;9,1 | I was thinking... It was [...] a really negative thing that happened to me, so, [...] trying to take a positive [...] that you can go on and do [...] what you really want to do with your life despite these hurdles [...] that was a real positive em about doing it long term [...] It's always gonna be there [...] a good thing to think about that as a positive [...] to help other people; glad I did in the end [...] It was real positive. I just hope people have taken a positive about it as well. I was really in tears watching it [...] opened my mind big time erm to what other people are going through [...] fighting; people's videos that really opened my eyes to [...] colleagues. made me really learn [...] to be mindful [...] to understand [...] people's feelings and issues and things they've got going on I probably should be in the Able network, but I have really um taken part; that's the sort of teaching from here |
| <i>Experiences of discomfort</i> Stepping out of comfort Worthwhile discomfort Easing discomfort | 1,3; 4,1 2,14; 4,42 4,33 | being filmed, that was the horrible bit [...] really hard [...] lights on you and that feeling of just me that was the worst bit; it's a different environment as well [...] not normal for me real positive in the end. It was a bit scary being filmed, that was the main negative [...] that's only a little thing isn't it? [...] there were so many photos [...] they came out really good though. It was alright. it was quite nerve wrecking just me with those lights talking [...] the team made you feel at ease [...] not really interviewing you, talking... chatting to you informally. It's a new... it's a different environment as well, that was |
| <i>Exceeded expectations</i> A bigger commitment | 3,14 | bigger and bigger [...] just photos first [...] then little booklets [...] then films, I'm thinking okay, I'm I'll just have to put my big girl pants on |
| Surprised by scale/exposure Impressed with outcomes Expanding future impact | 3,28 3,45; 4,1; 5,26 8,34; 9,19 | I was surprised how big the boards were [...] there was like a big day when they opened all the boards outside. it was so professional how the videos were done. I was really impressed [...] black and white photos [...] really carried the story; it really sort of gets you [...] seeing those boards; I was so impressed [...] it sold it so well, it did it really well this was a really good idea [...] it's opened people's minds [...] maybe the videos [...] could be used like for teaching and training [...] a role model to other places; I'm glad it's carrying on as well with your involvement [...] the word's spread |
| <i>Feeling valued, contribution</i> Feeling valued in the process Sense of achievement Uncertain of impacts | 2,12; 3,33 4,4; 5,31 4,9;15; 6,15;7, | it was done so well [...] presented really really well [...] a little card and everything; really well organised [...] talked us through it [...] they told us exactly what was gonna be happening [...] done really smoothly and well organised we got a board to take home and a little booklet [...] was nice to share it with my family, it's quite good that [...] I'd been able to do that [...] a pat on the back for saying well done to doing it. how many people interact with the boards, how many visitors and staff [...] that would be quite interesting to know [...] how many people have scanned them; how long those boards are going to be out; I don't know what's happened |

Appendix 4: Master Table of Themes Across Participant Group

Process of Hesitancy and Comfort

i. Stepping Beyond Comfort

B: being filmed, that was the horrible bit [...] really hard [...] lights on you and that feeling of just me that was the worst bit; it's a different environment as well [...] not normal for me (1,3; 4,1).

C: There is stuff I wish I'd said; That's what I wanted to say [...] people with disability have voices as well; I felt quite stoic about doing it (3,29;45; 4,26).

D: Shall we go for this [...] let's have a go [...] it took us all out of our comfort zones; I'm not great having my my photograph taken [...] I was really, really nervous in terms of doing it (1,4; 3,28).

E: that initial feel of 'whoa I can't breathe'; not comfortable in front of a camera [...] don't want to have my photo taken [...] that bit was more difficult; absolutely hated it [...] horror; really had to push myself (3,38; 8,3)

A: I kept one of my disabilities hidden [...] if I told people about it, it would make them make me think a bit differently; the nerves were [...] how people would [...] react (1,12; 24; 2,35).

F: the word stigma [...] there's a bit of conflict in me about that; I was very hesitant; very nervous because you're aware of actually where it might end up [...] watched by potentially a lot of people (2,6; 4,46; 6,38).

ii. Anticipating Reactions

E: for [...] the wider organisation to understand [...] show we were proud; responsibility [...] to be open and proud [...] help others to feel comfortable; a celebration of of who we are; felt an important thing (1,1;36; 2,4; 3,44).

A: If [...] there's people who who think [...] fair play [...] well done [...] thinking me is like the same person and understood me autism [...] that's part of who I am really and [...] I just do a job day in and day out (1,26).

C: help people [...] that aren't brave enough [...] if just one person was helped by the project, it was worth doing; I wanted to be the example that It's okay to take part (1,20; 3,12).

B: a really negative thing that happened to me, so, [...] trying to take a positive [...] that you can go on and do [...] what you really want to do with your life [...] that was a real positive erm about doing it (1,22; 40).

D: sometimes people make assumptions [...] that's what it is for me, is to taking those labels off; it's bringing that understanding forward [...] not necessarily just what you see; think about it (1,23; 2,12; 29).

F: because it was a Trust initiative; I wanted to get that message out [...] raise the awareness; I definitely wanted the Trust to act (2,16;31; 3,12).

iii. Approaches that Eased Discomfort

A: I thought [...] there's some other people, people that were taking part, why not? [...] go for it and I did; we're all gonna see our faces [...] on the board [...] it's just great you know that once it's revealed (2,30; 3,18).

E: taken real effort to make sure we did feel comfortable [...] we wouldn't be embarrassed with the outcomes [...] sensitively edited [...] it felt nice, it felt good; putting you at ease [...] to have those very intimate conversations (3,28; 38).

C: a good person for getting people to open up and feel comfortable [...] I didn't feel awkward being interviewed (4,14).

B: it was quite nerve racking just me with those lights, talking [...] the team made you feel at ease [...] not really interviewing you, talking... chatting to you informally (4,33).

D: when we got over there [...] it was really good [...] more relaxed and kind of informal process really [...] a general chat; they did show us all the photos [...] videos, we were consulted all the way through (3,38; 4,35).

F: clear and concise [...] explained [...] given the option [...] aware of all of the feedback [...] fully supported all the way through and fully informed; given full oversight; no pressure for us to divulge any information (5,25; 6,8).

Perceptions of Impact and Contribution

i. Perceptions of Ownership

C: I was kind of part of it from the start; I was implementing the brand. I was kind of involved in that bit (1,5; 4,11).

D: we all put our bits and thoughts about what we should do and how [...] we all decided that erm we talk about our disabilities, whether they were hidden or [...] not (1,6).

F: I then said at the ABLE Network be really good if we could do something [...] so [...] people are aware [...] it evolved from that [...] before we knew it [...] had the funding [...] I was really passionate about it; we raised that (1,15; 36).

E: You are quite vulnerable [...] when you are going through [...] treatments [...] as a leader [...] I think that was important with this [...] I need to be really open about actually I do feel vulnerable but that's okay (2,14).

A: I'm [...] glad to have taken part and [...] how it was all done [...] that it was [...] filmed and on [...] websites and [...] explaining [...] for myself and [...] others [...] how our disability effects them day in and day out (3,5).

ii. Expressions of Validation

E: Chief Executive [...] did a big kind of reveal [...] It was really good; personal pride [...] how many people came [...] one of the things that I am proud of that I've been involved in [...] proud of what we'd achieved (4,27;34).

D: still people look at them [...] I've been recognised [...] the staff would say, oh, saw your board [...] it was a sort of a different side to it to have like a member of the public look at it and say oh that's that lady (5,7).

F: it was really impactful for both work [...] to me [...] worth doing just from the awareness [...] the lack of knowledge [...] was quite evident [...] the most powerful points from the feedback (9,17).

A: disability is being recognised; my face is actually on the board [...] where people wanna read it and [...] see my video; one person said, 'it's a great way to [...] sell yourself on how your disability [...] affects them' (3,10;28;34).

B: Lots of messages [...] well done and everything, and amazing to still be a nurse and be able to tell the story [...] people just shocked cause they didn't know [...] praise and lots of positivity [...] saying how good it was (5,34).

C: I don't consider myself brave and amazing, but it was nice that people had that reaction [...] that surprised me, that people like... admired me for doing it, didn't judge me for doing it (6,32).

iii. Perceiving Long-term/Wider Impact

B: how many people interact with the boards [...] would be quite interesting to know; opened people's minds [...] the videos [...] could be used like for teaching and training; it's carrying on [...] with your involvement (4,9; 8,34; 9,19).

E: ABLE [...] has been great [...] trying to use the exhibition [...] to [...] show the organisations commitment to the disabled workforce [...] used a lot in general E and D training; before 3% of our workforce was disabled [...] high 6s to 7% now (6,20).

D: people are more willing since the exhibition to sort of say that they have got a disability; it has made a difference across the Trust that people [...] coming forward a little bit more [...] asking for help (7,5; 8,6).

F: did erm all die down [...] I'm not sure if the message did really get through; around staff awareness, training [...] very frustrating when you've done that exhibition [...] I just thought that would happen (9,32; 12,4).

A: reactions um towards myself after the the project, it's been the same really; another Trust in the UK [...] did [...] a similar thing [...] shared their experiences [...] it was great [...] that gets noticed a bit more (3,47; 5,24).

C: the output kind of stopped a little bit; people should watch the videos when they join the Trust; building on that and giving people different routes into speaking out [...] these problems haven't gone (8,44;11,3; 12,33).

Personal Journeying with Disability Understandings

i. Learning from Disability

F: I was absolutely in denial about the fact that I had a disability; didn't like that label [...] I'm more accepting of it [...] that was a lot to do with the exhibition; I use the term disabled now (3,47; 11,28; 12,27).

D: I said yes and then I was kind of like [...] I don't actually see me as having a disability; I've kind of moved forward [...] I tend to declare it now [...] I class it as more of a long-term condition [...] it's changed me (1,40; 6,37).

E: it was nice to hear [...] challenge your own conceptions about [...] disability is [...] the more we talk about it, the more I understand [...] and why it's classified as disability; more open about the fact that I'm disabled (6,1;13).

B: people's videos that really opened my eyes to [...] colleagues [...] made me really learn [...] to be mindful [...] to understand [...] people's feelings and issues and things they've got going on (6,34).

C: I couldn't believe somebody could say so little but be so impactful; made me a lot more aware of the wider range of long-term conditions [...] I make a mental note now of 'okay' [...] now I go 'are you alright' (3,23; 8,18).

ii. New Openness to Sharing Disability Experiences

E: more comfortable sharing now than I probably was at the time of the exhibition; more open [...] with my friends and family; more comfortable talking [...] particularly since how successful the exhibition was (2,27; 6,13).

D: when I first came, nobody really knew [...] I'm a little bit more open now [...] it's up on the boards [...] anybody can see (2,32).

F: powerful things that came back from [...] friends and some family [...] life changing; my husband said [...] I'd never even realised how much in denial you were; I don't think I've ever [...] had a talk about that (8,41; 9,2; 10,12).

C: It was mad [...] they put me like first thing [...] people said I was really powerful doing the speech [...] I stepped out of my comfort zone a little bit; NHS England [...] asked me to talk to their team (5,40; 6,19).

A: I joined the ABLE er Network [...] I thought [...] now is the time just to tell [...] everybody [...] I've worked at the Trust for so long and I've never really spoke about my autism really (1,17).

iii. Proactivity and Community Connections

D: I've spoken to [...] colleagues and found out that they were diabetic as well; the people that I've found since were diabetic and said [...] I can relate to what you were saying in the video (3,1; 5,30).

E: the more you share about how you're feeling um the more supported I've [...] felt; confidence that you can do something [...] uncomfortable [...] more outwardly facing things (2,25; 5,14).

F: I am much more erm active now [...] around social media and disabilities [...] very passionate about [...] access [...] networking [...] with disabled people; very much on board with the ABLE Network (11,46;12,15; 43).

A: we have all connected really just sharing our our stories [...] we do speak sometimes when we see each other [...] I got to know him a little bit more (4,15).

C: when I'm having struggles, I'm always getting offers, saying 'if you need to talk to me' that nice support network. [...] I'm always getting offers, saying 'if you need to talk to me' [...] that connection's there (9,35)

B: I probably should be in the ABLE Network, but I have really um taken part; that's the sort of teaching from here, yeah, I could do that (7,17;9,14).



© **Sidney De Haan Research Centre for Arts and Health**

Canterbury Christ Church University
North Holmes Road, Canterbury, Kent, CT1 1QU
sdhcentre@canterbury.ac.uk

<https://www.canterbury.ac.uk/research/research-centres/sidney-de-haan-research-centre-for-arts-and-health>

Registered Company No: 04793659
A Company limited by guarantee
Registered Charity No: 1098136