Exploring the Impact of Digital Storytelling for Health

Summary Report for Swansea Bay University Health Board

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Abbreviations

DS	Digital story(ies)
DST	Digital storytelling
KESS	Knowledge Economy Skills Sponsorships
SBM	Swansea Bay Method
SBUHB	Swansea Bay University Health Board
USW	University of South Wales

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Introduction

This report is an outline and summary of the work undertaken for the Masters by Research funded by Knowledge Economy Skills Scholarships (KESS) and Swansea Bay University Health Board (SBUHB), through the University of South Wales (USW), published in the qualifying thesis. The research was undertaken with analysis of existing digital stories which had been captured within SBUHB, and the formation of new digital stories which were made with members of staff.

This report is broken down into subsections covering the background to the study, aim of the study, work undertaken, Swansea Bay Method, impacts identified within SBUHB, measurement of impacts, maximising impacts, conclusions and closing remarks.

Within this report I have used the terms existing stories to represent the original stories captured by SBUHB and reflective stories to represent stories made by staff about the original stories.

Background

SBUHB have been working with digital stories (DS) over the past 11 years, since they were introduced by the Arts in Health Co-ordinator, Prue Thimbleby. In developing the process, Prue formulated the Swansea Bay Method (SBM), from her experience of working with DS within communities, undertaking a masters, and linking in with the Capture Wales project being run by the BBC in Wales (Meadows, 2003).

The SBM is used within the masters level qualification, developed by Prue Thimbleby and Professor Emily Underwood-Lee, which is delivered by SBUHB in conjunction with USW. Training has been provided to many staff within the health board, with a current register of 39 staff (as of 10 February 2022) confident in capturing stories. Work has also been undertaken with Lesley Goodburn, Experience of Care Lead for Provider Improvement at NHS England NHS Improvement, to roll out the SBUHB accredited training throughout NHS England.

Since digital storytelling was introduced to SBUHB a library of stories has accumulated, with contributions from patients, relatives, and staff. The total number of stories held on the 1st of June 2022 (the date access to the data was granted) was 151, with many others underway, therefore the current total will now be much higher.

Stories are currently found through the following sources:

- Individual staff identifying patient stories which they feel are important to be shared.
- PALS teams who have spoken with patients or relatives about an aspect of care.
- Requests from SBUHB health board to find a story to provide context for current initiatives or discussions within the health board.
- Staff who feel it is important to share an experience they have had during the course of their work.

About the Author

As a mental health nurse, I have worked within ward and primary care environments; however, my health experience extends to running a primary care surgery, which I did before retraining. Whilst employed within the surgery and as a nurse, I have witnessed how stories are used every day to communicate about patients. I am genuinely intrigued as to how we use story, and how narratives shape people's lives.

I was selected as the research student for this project and commenced on the 1st of October 2021 officially; however, I was able to attend the SBUHB digital storytelling training during September 2021. My viva examination took place on the 11th of May 2023, and I was delighted to be awarded a pass without amendments.

This project was a privilege to undertake as it allowed me to examine stories and their ability to affect the way in which we consider, provide, and improve care.

Aim

The aim of the study was to consider the impact of DST within SBUHB, and how this translates to the people sharing their stories, the viewers, SBUHB as an organisation and the wider community. Part of the investigation included examining whether any identifiable impacts could be measured, and how this might be accomplished.

To provide context to the study, findings were compared with what is known about DST within the literature.

Work undertaken

To assess the available data, 146 digital stories, held on the SBUHB SharePoint database, were viewed. Five stories of the total 151 were labelled as Level 1 (see table 1) within the consent framework and could not be viewed by researchers.

Table 1: Consent levels utilised within SBUHB

Consent levels utilised within SBUHB	
Level 1:	Health and Social Services professionals and quoted in Health Board leaflets
Level 2:	Researchers for service evaluation and improvement beyond SBUHB
Level 3:	Meetings, Conferences - anyone may be present, but no online recording is made
Level 4:	Anyone including the Internet and social media

In order to capture any impacts, stories were to be collected with staff in relation to existing stories. Although it would have been more appropriate to consider making stories with the existing storytellers in addition to stories with staff, the time available for this project was prohibitive.

To enable staff to talk freely about their experiences with the existing stories, the stories chosen for analysis were all Level 4 which meant that they can be shown in the public domain, and therefore staff were able to talk freely about the content of the story without concern for breaching patient confidentiality. However, in line with current practice within healthcare, all original patient and relative stories were anonymised for the purposes of research and reporting.

Constraints on time and resources restricted the number of reflective stories collected, and the final analysis comprised of six stories made with staff members (reflective accounts), one semi-structured interview and seven existing stories.

Following a review of all eligible existing stories, the stories which were recorded as Level 4, and which would potentially yield the biggest impacts were selected. From these, with assistance from Prue Thimbleby, staff who were able to comment on the existing stories were identified and approached to participate in this study. A summary of the original stories and reflective stories is reproduced from the thesis in appendix A.

The literature was undertaken using a systematic approach, and 139 studies were included for review when writing the thesis.

Swansea Bay Method

The method introduced to SBUHB by Prue Thimbleby was found to be a useful method for capturing stories within health. Working on a one-to-one basis with participants is appropriate for a health board setting, especially when a complaint or criticism of the care received is being made. In addition, the nature of stories often involves sensitive and private information being discussed, and following the SBUHB method allows for confidentiality to be guaranteed until the storyteller is ready to share, and then, they are in control of how widely the story can be shared, through the two-step consent process.

Storytellers can remain anonymous if they so choose; however, much of the power of digital storytelling comes from hearing the voice of the teller which carries rich information through tone, volume, pace, pitch, and speed, revealing the emotion behind their words. In addition, sharing a story has been found, within the literature, to be empowering.

Impacts identified

The following table (Table 2) identifies the main reported impacts of DS, both from the research and the wider literature. A full discussion of the positive and negative impacts is contained within the thesis which this report has been derived from.

Outcomes/ impacts identified from the stories analysed, within SBUHB included:

Stories	Impacts
Stories 14 & 51 Two mothers discuss their experience of pregnancy, childbirth, and perinatal mental health care. The stories were made at different times, with the latter (51) reflecting an improvement on service from the initial story (14).	Opening of the perinatal mental health unit – the stories of patient experience were given equal weighting with other factors, and provided rich context, which enabled a fully informed decision to be made. Mothers are no longer sent to England for perinatal mental health care and have more opportunities to maintain their support network.

Story 19 A family reflect on the unnecessary death of their father, and the reluctance of services to investigate and learn from the tragedy.	Datix reporting and investigation procedures revised and amended, which included a review of how lessons are learned and shared from incidents investigated. The story was utilised in training to instil in staff the importance of reporting incidents. Changing the manner in which staff approach and regard incident reporting has contributed to a culture change promoting learning from mistakes. The policy for the use of infusion pumps was reviewed and updated. Further, staff have been made aware of the risk of infusion pumps operating at a faster rate than that prescribed.
Story 26 A patient talks about her experience with cannulisation and the issues she faced during a lengthy hospital admission.	Story used in training to raise awareness of available alternatives. Raising awareness through training has resulted in an increased number of referrals.
Story 150 A nurse talks about her experience of witnessing her first organ retrieval and the steps she took to change the experience for herself and others.	Story used to promote new ways of working which have been adopted across Wales, improving dignity and respect.
Story 2 A gentleman discusses the sudden illness and death of his wife.	The story encouraged reflection on when to ask families to attend resuscitation when children are present. A review of the practice of collecting stories was undertaken leading to improvements in documentation and communication, ensuring all parties associated with the story are aware it is being captured from the outset.

	The story was used in training to raise awareness of sepsis with General Practitioners.
Story 133 Paula talks about an early career experience and how this impacted upon her.	The change from Paula's story is generated through sharing the experience with others, helping them to feel understood and supported, and has been used in training and development to build an inclusive culture.

The stories examined and created within SBUHB, demonstrated that the impacts experienced from storytelling were not singular or isolated in nature. Each of the existing stories examined were told with the hope that improvements would be made for others, resulting in improvements for members of the community accessing services in future. The organisation benefits from awareness raising, having additional data for decision making, and the opportunity to make improvements. Staff can feel empowered to take action, increasing self-worth and job satisfaction (Hayes, Bonner, and Pryor, 2010).

Measurement of impacts

From the research conducted within SBUHB, it is apparent that digital storytelling has had a significant impact upon patients, relatives, staff, and the organisation; however, measurement cannot simply be recorded as a metric utilising a Likert scale. Whilst impacts were demonstrable, measurement requires the following to be considered:

1. What is the intent behind capturing a story, how will it be used? This process should be undertaken as a matter of course when requesting consent to capture a story – aligning purpose and consent. Being clear about intent will make it easier to identify potential areas for measurement.

2. Stakeholders involved need to identify and agree what should be measured given the number of potential impacts both anticipated and unanticipated. It may be necessary to revise the agreed measures, particularly when an unanticipated but important change or impact is identified.

3. Stakeholders need to be clear about what would be considered acceptable as evidence of impact. As noted above, and discussed within the thesis, questionnaires

will likely not be sufficient to capture the range of impacts a story can have, therefore, consideration needs to be given to using more qualitative or observational measures.

Table2: Impacts of digital storytelling

Positive Impacts	
Self-efficacy	Social sense of agency (groups)
Self-esteem/ self-worth	Emotional connection/ engagement
Confidence	Provides nuance and context
Mental health	Communication/ starts conversations
Emotional regulation	Relationships/ understanding
Mood	Empathy
Catharsis/ emotional acceptance	Viewer recall
Meaning-making	Social support
Emotional release/ 'letting go'	Decision making
Self-compassion/ understanding of self	Motivation
Sense of self/ self-identity/ agency	Changes and improvements
Being heard/ validation	Community
Empowerment	Attitudes and approaches
Acquiring new skills	Compassion fatigue
Self-mastery	Learning opportunities
Hope	Culture
Reduction in isolation	Reflection
Peer support (groups)	Encourages creativity
Reclaiming narrative/ gaining a sense of control	
Negative Impacts	
Stigmatisation	Differing versions of 'truth'
Re-traumatisation	Viewer distress
Emotionally demanding for teller	Staff morale (negative stories)
Stories being misused	Less favourable treatment following teller sharing experience
Third parties involved in the story may be subject to judgement/ criticism	Perception or opinion of storyteller may be altered

4. Measuring impact may not fit well with quantitative measures, as these often lack nuance and detail. Impacts from stories are often difficult to capture with check boxes and questionnaires, and therefore more creative solutions are required; however, it may be that an element of measurement can be quantitative, for example following the use of story 26, the demand for a service increased which was noted through the increase in referrals received. Studying the frequency of DATIX

complaints or issues, and applying a DST approach, may provide a health methodology for driving improvements, and begin to shape an approach to measurement which could be applied within healthcare.

5. How well do the stories being captured represent the views of the community which SBUHB serves? Perhaps more than one story is required, after all if stories are used to change services, it is important that services are fit for all.

6. Following up with storytellers, or actions, as a result of their stories, is essential to ensure that the impact or change is sustained over time. Measurement at the point of change is helpful but measurement over time can yield a more accurate picture.

Opening the perinatal mental health unit had a huge impact upon the immediate community and wider Welsh population. There are many opportunities to measure impact in this scenario, and although there is no line which can be drawn from stories to action, the fact that stories were used within the commissioning process, and as a measure of operating impact, demonstrates the power and benefit of utilising storytelling in decision making. The information contained within stories provides the human backdrop to the experiences of care, and truly listening to these experiences can provide evidence for change.

Maximising impacts

The research undertaken highlighted Sunderland and Matthews' (2019) meta-orator roles. Sunderland and Matthews (2019) have classified four roles involved in institutional listening: curator, host, caretaker, and broker. The four roles influence how stories are heard and actioned, with Sunderland and Matthews (2019) asserting that how a story is presented can significantly affect the response. Elements of these roles are already undertaken by staff within SBUHB, although they may not consider themselves in these terms. Ensuring staff are aware of their contribution, and the impact these roles can have, may help to maximise the impact of the stories they are working with, through providing the best conditions to ensure stories are heard.

The role of facilitator is extremely important in capturing stories. Stories are time consuming to produce and therefore ensuring that someone is properly trained, confident with the software requirements to record and edit stories and is afforded sufficient time to complete

the task is essential. Whilst some roles within SBUHB specifically encompass making stories, others, for example nurses, may find it difficult to undertake story projects when they are not allocated time to do so. Protecting time is important, otherwise the training investment is lost.

A further area where improvements could be maximised from stories is that of recruitment and retention. For example, utilising Story 150 (made by a member of SBUHB staff) showing commitment to listening to staff could be powerful, encouraging frontline staff, demonstrating that their ideas are welcomed, will be considered, and provoking them to think about how improvements in care can improve job satisfaction and promote a culture of inclusivity and involvement (Hayes, Bonner and Pryor, 2010). Recruitment and retention stories were not found within this study; however, it would be interesting to explore how they could be used, in an approach which differs from a Public Relations/ Communications style.

Conclusion

Digital storytelling within SBUHB has had significant impact upon the delivery of care and services to patients and the wider community. Staff have been provided with tools to improve care, through training and learning from patient experience, along with the opportunity to consider care from a patient's point of view. Understanding the patient experience has also been shown to improve communication and understanding with healthcare staff. SBUHB has been provided with rich data on which to base decisions and improve patient care.

As the Welsh Government moves towards an All-Wales policy for capturing patient stories, it may be prudent to consider how central storage of DS will affect the control of how and where stories are used. Stories need to be regularly reviewed to ensure that they are still appropriate for sharing, both to achieve their purpose, but also in consideration for the storyteller whose circumstances may have changed over time.

Within the research it was not possible to ascertain the make up of the storytelling population of SBUHB. In order to ensure that the digital stories made are representative of the local community, it is recommended that protected characteristics are captured and monitored.

Closing remarks

Since completing this research there have been a number of stories which have had a significant impact. One particular story was being made whilst the data for this study was being analysed and unfortunately it could not be included as part of the study; however, this story inspired a clinician to formulate a team to look after patients with cancer of unknown primary. Although only a small number of patients fall into this category, accessing cohesive care without an identified primary site previously resulted in patients being passed from one department within oncology to another, delaying care and treatment. The bravery of the relative who shared the story has helped others, and they have indicated that they have felt heard, gaining benefit from making the story.

Digital stories provide context and the opportunity for change. SBUHB has been leading the way within the United Kingdom in capturing and listening to stories. The impacts identified within the study are meaningful, the patients and staff of the SBUHB locality have been heard, and this practice has been shared with others throughout the United Kingdom. Work within SBUHB continues to support those making stories, with the launch of a Digital Storytelling Network, operated in conjunction with Cardiff and Vale University Health Board. The network meets quarterly and supports staff working with stories to share best practice.

References

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Appendix A

Story Number	Summary of Story	Reflective Story Maker	Summary of Reflective Story
2	A gentleman discusses the sudden illness and death of his wife.	**Andrea**	Andrea reflects upon the process involved in making this story, the impact it had the teller, her and her team, and the important lessons learned when working with personal narratives.
14 & 51	Two mothers discuss their experience of pregnancy, childbirth, and perinatal mental health care. The stories were made at different times, with the latter (51) reflecting an improvement on service from the initial story (14).	**Anita**	Anita reflects on the impact the stories gifted by patients and families have had on perinatal mental health services, and the changes made as a result of shared patient experience.
19	A family reflect on the unnecessary death of their father, and the reluctance of services to investigate and learn from the tragedy.	**Judith**	Judith reflects on the process of investigations at a time when the health board were receiving complaints and negative coverage in the press. Judith discusses how the families story shed a spotlight on the situation, leading to changes in process, along with the learning gained and how it was implemented.
26	A patient talks about her experience with cannulisation and the issues she faced during a lengthy hospital admission.	**Frankie**	Frankie discusses how she has used this story in training to raise awareness of her team and their services in a bid to improve patient experience.
133	Paula talks about an early career experience and how this impacted upon her.		Paula reflects on her experience of making a story, the effect it had, and how it has been used. This is the only reflective account made by the person who told and created their story.
150	A nurse talks about her experience of witnessing her first organ retrieval and the steps she took to change the experience for herself and others.	**Marcia**	Marcia reflects on making this story, challenges involved and pride in producing something which has been used to generate change, both to local and national policy.
		Prue	Prue completed a semi-structured interview regarding her history and experience with digital storytelling, and how she has incorporated it into SBUHB to gather patient experience.