Including the Marginalised: Engaging People with Dementia and the Elderly in Technology-Based Participatory Citizen Storytelling

Tony Sumner

Abstract

In a prescriptive, top-down approach to healthcare development and configuration the narrative of the system can dominate the stories of the marginalised that could inform and enable improvement. Digital storytelling is a methodology used in health and social care, education and quality improvement in which the creation and ownership of stories moves from the system to the marginalised (by age, dementia, etc.) service users. The digital storytelling process has inherent benefits to the storyteller beyond the creation of the storied product, as the verbs of engagement change from harvesting or capturing the stories of the excluded to facilitating and empowering them.

Keywords

Dementia · Digital · Story · Facilitation · Inclusion · Facilitation · Autoethnography · Identity · Elderly

'An important challenge to humanity is to recognise that lives are the pasts we tell ourselves.' [1]. Narrative and storytelling are increasingly important factors and forces in the development and delivery of health and social care services. Digital storytelling and digital stories are an empowering and effective process and product through which marginalised groups can reframe their own experience and expertise, with the aim of influencing provision of services to them. What then if the group of citizen storytellers is marginalised through age and/or Dementia? How do we facilitate their full participation as citizens in a digital age?

This chapter will first use a longitudinal view, charting the sequence of stories made by an 82-year-old nun over the span of 4 years to explore how appropriately adapted digital storytelling processes can create a space for reflection on ageing and end-of-life issues.

Secondly, an orthogonal view of the challenges and benefits of digital storytelling with citizen groups who would otherwise be excluded from sharing their experiences by technological barriers will look at several reflective digital storytelling workshops with elderly nuns, and people with dementia and their partners and carers.

Finally, the chapter will then explain the adaptations to processes and technologies that can minimise exclusion of the elderly and people with dementia from participation in (paradoxically) inclusive technologies.

T. Sumner (✉)
Patient Voices Programme, Pilgrim Projects Limited, Durham University, Durham, UK
e-mail: tony@pilgrimprojects.co.uk

S. Dobson et al. (eds.), *Learning Inclusion in a Digital Age*, Sustainable Development Goals Series,
https://doi.org/10.1007/978-981-99-7196-1_11

1 Digital Storytelling

There has been a realisation over the last few decades of the power and importance of narrative and story. This has been acknowledged as both a benefit for those who create the stories [2] and those who incorporate narrative and story into medical education [3], acknowledging the patient's own areas of expertise, i.e. his or her own life and unique experience of illness [4].

The terms "Digital Stories", "Digital Storyteller" and "Digital Storytelling" have acquired a wide range of meanings over the last three decades. A digital story is perhaps easier to clarify although it has been used to describe creations ranging from a PDF file of a document on a website to the narrative created by a player with a computer game. Here it is used to refer to a multimedia object, created in the tradition of StoryCenter (www.storycenter.org) that consists of a voiceover, images (photographic or drawn/painted), and perhaps video footage, music or sound effects which are assembled together by the digital storyteller and presented as a short video file of around 3 min in duration.

The usage here of digital storyteller is centred on the teller of a first-person narrative or story, and who has as much agency, creativity and control as is possible within the process of Digital Storytelling.

The form of the Digital storytelling process referred to here is, again, one in the tradition of StoryCenter [5], but with adaptations to make it as accessible to the particular groups of storytellers discussed—the elderly and people with dementia. In this tradition, trained facilitators take the storyteller through the structure and nature of stories. Whilst the eurocentric definition of a story from Aristotle [6] in *On the Art of Poetry*, proposes that a narrative structure requires a beginning, middle and end organised in a causal direction with events that are joined together to reveal a plot, in the digital storytelling process storytellers are encouraged to explore other structures that may help them better express their meaning. This involves the work of Kurt Vonnegut[1] on the shapes of stories and the thoughts of film directors such as Jean-Luc Godard who said that "A story should have a beginning, a middle and an end, but not necessarily in that order" [7]. Their escape from the linear structure of Aristotle's model is further empowered by the multimodal nature of the digital storytelling process (Fig. 1) that allows them to construct and tell their story in dimensions beyond a linear text, through the use of images, sound and their vocal delivery. The storyteller then writes their own first-person script. This script is then performed by the storyteller to a group of other storytellers and the facilitators within a story circle and amended or updated by the storyteller in the light of feedback from the group, and with support from the facilitators. The storyteller voices and records their script as an audio file.

Facilitators then help storytellers explore the use of visual imagery, music and sound effects with digital stories, and support them in their curation or creation of visual and aural resources for use within their digital story. In the final turn to the process, the facilitators support storytellers through the process of assembling (Fig. 1) the vocal, visual and aural elements they have created, collected or curated into a digital story using video editing software such as WeVideo, iMovie or Premiere Pro.

While digital storytelling may take place as a part of a formal learning programme, in the cases described here, there is no assessment of the work of the storytellers and so it may be regarded as a process of non-formal learning. The completed stories are then shared within the group of storytellers in a premiere showing [8].

If the storyteller gives permission, then completed stories made in Patient Voices workshops are then released via the Patient Voices website (www.patientvoices.org.uk) from where they are freely viewable. Thus, the creative and reflective process provides three opportunities for what Christopher Johns [8] described as "the performative turn"—first the reading and re-reading of

[1] Vonnegut, K. The shapes of stories https://www.youtube.com/watch?v=oP3c1h8v2ZQ

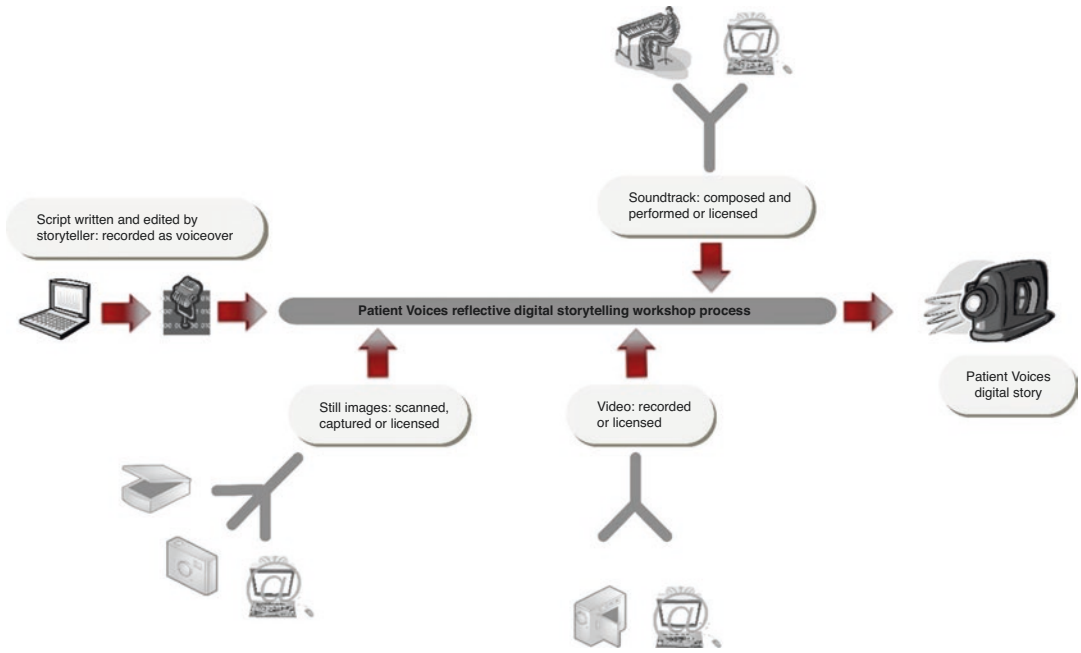

Fig. 1 The flow of components into a digital story ([8], p. 25)

their script to a group of other storytellers, secondly the premiere screening of their digital story at the end of the workshop, and finally the ongoing performative turn of their stories being viewed from the Patient Voices website.

> *Stories are products of reflection, but we do not usually hold onto them long enough to make them objects of reflection in their own right…. When we get into the habit of recording our stories, we can look at them again, attending to the meanings we have built into them and attending, as well, to our strategies of narrative description.* [10]

1.1 Purposive Digital Storytelling

Digital Storytelling originally grew from community theatre and oral history traditions [5] and flourished in supported projects such as the BBC Capture Wales project [9]. However, as the educator Donald Schön [10] argued:

… storytelling is the mode of description best suited to transformation in new situations of action….

Digital storytelling provides the storyteller with the ability to frame their stories in an accessible and distributable manner. Through this digital storytelling process they can, returning to Schon again, address the problem of the impermanence of stories:

The distributable nature of digital stories in a world of multimedia and social media means that they and their storytellers can move from a marginalised state to one where their performative turn can be heard in lecture theatres and boardrooms across the world [11]. The powerful nature and ease of dissemination of the digital stories of the marginalised allows them voice in story-based service transformation programmes such as that set out in the Patient Voices journey model [11] shown in Fig. 2.

1.1.1 The Expertise of Experience

As the Patient Voices stories are created and then released to the Patient Voices website, their availability on this site has created a growing fund of

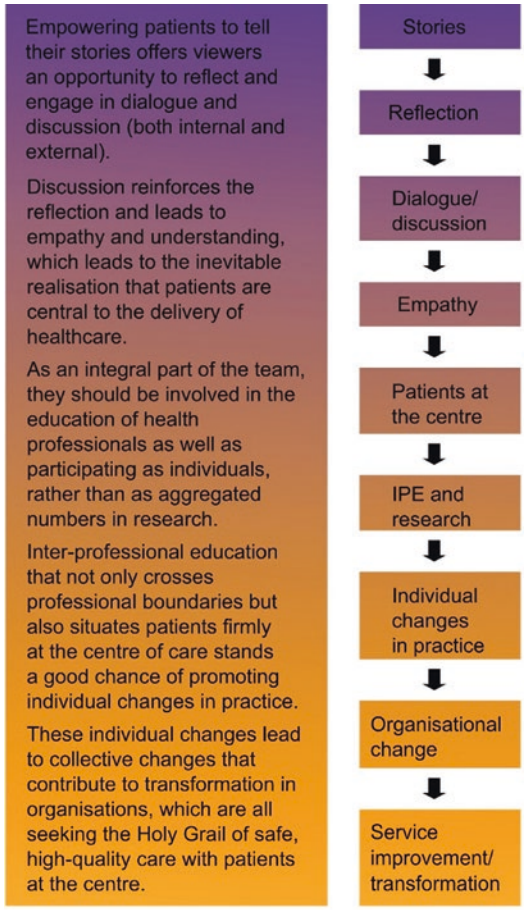

Fig. 2 A story-driven journey to service transformation [11]

knowledge, derived by the storytellers from their own expertise in their experiences and conditions, that can be shared across political and cultural borders and contexts, whether policy, professional, family or community-based ([12], p. 113). Within each workshop group, and across storytellers and story viewers with similar or related experiences and/or conditions, the shared stories can sit at the centre of a fund of identity [13] created by storytellers and story viewers around shared stories (see Fig. 3).

The initial conception of digital storytelling in the Patient Voices programme was as a process that could yield a product (the digital stories) that

Fig. 3 A fund of identity, created by storytellers and story viewers around shared stories

could then be used as "atomic learning objects" within elearning materials [14]. The availability of the stories via the Patient Voices website under a Creative Commons Attribution, non-commercial, no derivatives licence [15] allows the work of the storytellers to become a piece of social capital, invested by them in promoting inclusion via the sharing of their own experiences, stories and expertise with others as Open Educational Resources [16].

1.1.2 Marginalisation

One of the first effects of the marginalisation of a group is that they become less important to policymakers, less visible to the rest of the population, and in so doing become less of a priority, whether for care, housing or social support. They matter, and belong, less to society. This applies to both people with dementia, and the elderly.

> *The most important lesson is that even with our differences, we are connected by the need to matter and the need to belong.* [17]

Lack of understanding, stigma, the use of discriminatory practices and language can result is the marginalisation of people with dementia. This is not limited to the elderly, but also affects younger people with early onset dementia [18].

Marginalisation of the elderly is a global issue, recognised by the WHO. Indeed, in 2020, Maria Branyas, a 113-year old survivor of the 1918 Spanish Flu epidemic, stated that: '*the elderly are the forgotten ones of society*' [19].[2]

1.1.3 A Life Told in Her Own Stories: Eva

Not all Patient Voices reflective digital storytelling workshops start as expected. All storytellers are different, all stories are personal and all need the right approach.

After the first session of a workshop Eva, an 82 year old Nun—tiny and frail but with the formidable nature of someone who had spent decades working with drug users and trafficked and abused women, said "well, I rather think I've been sent here on false pretences". We chatted in the garden, and she agreed to join the rest of the morning's sessions on the promise of a latte during the mid-morning break—but she negotiated to get chocolate sprinkles on the top.

By the end of the workshop, she had made her first story, "Standing on my own two feet" [20]. This story encapsulated her independence and determination—and was an insight into the background and life experiences that had nurtured and honed the negotiating skills she displayed over her coffee preferences. After making her first story, Eva came to three more workshops over a period of nearly 4 years. Her stories told of her past and her future, her fears and hopes.

Her second story "From darkness into light: new worlds" [21], explored the fear she felt about changes she could feel in her mind and the possibility of a diagnosis of dementia framed, for her, in the fear that one word can raise.

Having acknowledged that word, in her third story, "A chocolate watch", [22], made later that year, she sought to preserve one of the stories and memories that she did not wish to lose, the story of her escape from Nazi Germany on the Kindertransport after the Kristallnacht in the 1930s.

A remarkable woman, she came to one more workshop in 2011—travelling as ever, by herself on the train. But this time she made the journey twice, because she came once on the wrong day. Typically of her independent nature, she simply waited for the next train back to London, and told us of her adventure when she came to the workshop on the correct day, a week later. It is fitting that, in that final workshop, she made "The Sun also rises" [23] which tells of how she had come to terms with her diagnosis and her future.

These four digital stories, as a collection created by one elderly Nun facing old age and dementia, form a powerful insight into the journey she made, as she described in her final story "From darkness into light" [22].

1.1.4 Everyone Is Different: Workshop Experiences with the Elderly and People with Dementia

Over the two decades that we have been practising digital storytelling facilitation, we have had the honour to work with other storytellers with dementia, their carers and partners. These groups have all been different. Some have been solely people with dementia, some have been a mix of people with dementia and their partners/carers, and some have been groups of elderly storytellers amongst whom there were people with dementia.

1.2 Society of the Holy Child Jesus (SHCJ) Workshop

Later in the year after Eva came to make her first story, we worked with more Nuns from her community at their retirement home in Yorkshire; a group of storytellers ranging in age from their 60s to just over 102. The aim was to give elderly members of the order the opportunity to reflect on their vocation and calling so that their order could better understand the personal nature of their faith.

Near the beginning of the workshop, the group formed a story circle. As they gathered, another

[2] https://www.theguardian.com/world/2020/may/16/worlds-oldest-coronavirus-survivor-the-elderly-are-the-forgotten-ones-of-society

Nun was added, Sister Josephine. Hunched over and unmoving in her chair, the other Nuns said that she never spoke, or responded, but they always included her in the activities of the community.

Because many of the Nuns had hearing impairments, we had brought with us a radio microphone and a speaker. The microphone was passed around the circle as the Nuns told, in turn, their stories of vocation and calling.

Suddenly, as the Nun to her left passed the microphone across her to the Nun on her right, Sister Josephine sat bolt upright and said, 'I want to tell a story.' She told the story of a young child who, during the first world war, meets a man she does not recognise [24]. Then she passed the microphone on and slumped back into silence.

A selection of the digital stories created by Nuns from the order was used at their annual convocation, allowing the experiences and expertise of a group that would otherwise have not been heard to play a part is a discussion and debate on the Order's key tenets.

1.3 Lancashire County Council

These stories were created at a Patient Voices workshop for people with dementia, their carers and partners in Lancashire in March 2015. Statistics tell us much about populations, but cannot tell us how it feels to be an individual with dementia or caring for someone with dementia. We need to hear the stories told by people affected by dementia if changes in policy and practice are to be effective, meaningful and appropriate.

> Statistics tell us the system's experience of the individual, whereas stories tell us the individual's experience of the system. [25]

To gain insights into the experience of people affected by dementia by giving individuals the opportunity to create their own digital stories about their experiences. When shown to practitioners and policy makers, their stories would illuminate what really matters to them about dementia.

Eight patients/carers affected by dementia came to a reflective digital storytelling workshop. Over 2 days, each person identified and distilled their personal story, drafted a script, recorded a voiceover, selected photos for, and edited a short audio-visual piece about their life with dementia.

The stories revealed some unexpected themes, and provided valuable evidence about what needs to improve, particularly in relation to suitable environments for People With Dementia (PWD) [26].

The process illuminated issues in supporting PWD and their carers through creative processes, the interactions between PWD and their partners/carers and some of the social/family pressures and attitudes to PWD.

The stories offer viewers a chance to see things differently and think about things differently and, when shown to a range of professionals from housing associations, the police and allied health professions, enabled these groups to see more clearly what is needed in order to create healthy environments.

Stories and storytelling fulfil a deep need to understand ourselves and each other as fellow human beings. The opportunity for people with dementia to think about and articulate their story and then to create their own audio-visual piece which can be heard anywhere in the world in itself contributes to their sense of agency, purpose and well-being.

The stories themselves speak to hearts as well as minds, shifting perceptions and refocusing efforts where they will have maximum impact. Based on the stories that came from the workshop, a need for standards for housing and commissioning—and a related self-assessment tool within which:

> The main principle being applied in this tool is that all available assets and resources need to be combined, both to create the conditions that reduce the risk of developing dementia, and to develop a framework of support to help those with dementia, their families and carers, to have as good a quality of life as possible.

Working with couples where one partner has a diagnosis and the other does not proved particularly rewarding for us as facilitators and for the couples who were each able to create and share their own stories of this stage of their lives. For

these couples one, or sometimes both partners were excluded from understanding the entirety of the other's experiences. In the final premiere of their stories, they were able to see, both sides of their joint stories.

1.4 Dangling Conversations

Digital stories provide a creative way for people to tell their stories using an amalgamation of voice, image and music, and can be used to engage nurses with others' experiences in the classroom setting. Seven people with early-stage dementia and one carer participated in making their own stories during a Patient Voices Reflective digital storytelling workshop in April, 2011. These participants experienced particular and varied challenges relating to telling a story and engaging with the technical process of digital storytelling. They were supported in overcoming these challenges through person-centred relationships with facilitators, allowing them to negotiate the help required. During the workshop a number of positive changes were observed in the participants: increased confidence, improved speech, a sense of purpose and increased connection [27].

The responses of the storytellers bore out some of the writings on story that we have used to underpin the Patient Voices approach. Jean Vanier [28] wrote that:

> *People reach greater maturity as they find the freedom to be themselves and to claim, accept and love their own personal story, with all its brokenness and its beauty.*

This was reflected back to us by a storyteller who said in their evaluation of the process that:

> *I feel like me again.*

In "*The five people you meet in heaven*" Mitch Albom [29] writes about stories that:

> *Each affects the other and the other affects the next, and the world is full of stories, but the stories are all one.*

This, again, was reflected in the feedback from storytellers who said that:

> *Everybody's story meant so much.*
>
> *We've been learning from each other, and supporting one another.*

2 Digital Autoethnography: Fighting Marginalisation Through Empowering Citizen Researchers

When using first-person reflective digital storytelling with the elderly and/or those with dementia, it is a process through which individuals can reflect upon, create, preserve and share their life experiences.

So, can Digital Storytelling be an autoethnographic process? Can it provide a process through which the individuals that we refer to as storytellers may document their own lives and, through their stories illuminate the strengths and weaknesses of policy and practice, demarginalize themselves through reasserting control and ownership of their stories and influence and change the practice and policies of others though the dissemination of their stories?

Richardson [30] describes five criteria with which to hold all ethnography to high standards (Table 1) which Denzin [31] goes on to include in his sets of criteria for performative autoethnography.

The evaluation or assessment of digital stories is a complex issue, given the multi-modal nature of a digital story, and the reflective and creative nature of the process, but these criteria are very appropriate for the assessment of an individual digital story [32], a series of stories by a single storyteller [20–23] or a set of stories created by a group of individuals with related experiences [33–38] Dementia Insights https://www.patient-voices.org.uk/di.htm

We see these characteristics in the digital stories created by older people and by people with dementia and detailed above. Furthermore, Denzin [31] reminds us that:

> Autoethnography cannot be judged by traditional positivist criteria. The goal is not to produce a standard social science article. The goal is to write performance texts in a way that moves others to ethical action.

Table 1 Richardson's five assessment criteria for ethnography

1	Substantive contribution: Does this piece contribute to our understanding of social life? Does the writer demonstrate a deeply grounded (if embedded) human-world understanding and perspective? How has this perspective informed the construction of the text?
2	Aesthetic merit: Does this piece succeed aesthetically? Does the use of creative analytical practices open up the text, invite interpretive responses? Is the text artistically shaped, satisfying, complex, and not boring?
3	Reflexivity: How did the author come to write this text? How was the information gathered? Ethical issues? How has the author's subjectivity been both a producer and a product of this text? Is there adequate self-awareness and self-exposure for the reader to make judgments about the point of view? Do authors hold themselves accountable to the standards of knowing and telling of the people they have studied?
4	Impact: Does this affect me? emotionally? intellectually? generate new questions? move me to write? move me to try new research practices? move me to action?
5	Expresses a reality: Does this text embody a fleshed out, embodied sense of lived experience? Does it seem "true"—a credible account of a cultural, social, individual, or communal sense of the "real"?

This connects with the purposive nature of digital storytelling as practiced by the Patient Voices Programme where the goal of the storytelling facilitation process is to support the storyteller in creating a digital story that is "Affective, Effective and Reflective" [39]. It has become apparent over the years that one key change that has affected the status which is afforded to patient stories by professional, educators and policy makers has been to treat a patient story as a creative work—just as we would an article, paper or conference presentation—and to reference it appropriately and respectfully as their contribution to the canon of knowledge about the experiences and conditions. Their stories are, after all "auto-analysed data" in that they are the raw data of the storytellers' lives and experiences, analysed by the storytellers themselves through an auto-ethnographic process in this way they are the antidote to anecdote, in that and anecdote or a narrative is unprocessed data describing experience, whereas a reflective story is auto-analysed information—the information of experience [40]. They are, as John Grierson defined documentary film to be "A creative treatment of actuality" [41] made possible and more powerful by the fact that they are, in Wordsworth's phrase "Emotions reflected in Tranquillity" [42].

3 Agility and Adaptability: Lowering Barriers, Empowering Storytellers

We have learnt to innovate and adapt our processes to the particular needs of each storyteller, modifying workshop times and schedules, providing more facilitators, and 'chauffeurs' as one storyteller called them, to drive the computers for them.

This 'adaptive facilitation' has, in our experience been never more important than when working with people with dementia. For the "Dangling Conversations" project [36] that adaptive facilitation applied both to the scheduling of the stages of the workshop, and the approaches adopted to facilitate storytellers in creating their own stories. It became apparent during per-workshop discussions, that the energy and concentration levels of storytellers would vary.

3.1 Workshop Processes

We were very used to this with storytellers with long-term conditions such as rheumatoid arthritis, and so adaptations to the workshop schedule were discussed and agreed with the storytellers and their support workers, and the schedule changed accordingly (Table 2).

(a) Facilitation approaches

Within the workshop itself, we decided to move to a different approach to facilitating storytellers. We would use 1 to 1 facilitation ratios, chauffeur rather than coach, and take individual approaches to storytelling prompts, script work, photo and image selection and creation, and audio (voiceover) recording.

Table 2 Adaptations to workshop schedule for people with dementia

Typical face-to-face Patient Voices workshop	Schedule adapted for people with dementia
7–10 storytellers	8 storytellers
2–3 facilitators	4 facilitators
2–3 days	4 days (8 half-days)
7–10 stories	8 stories

(b) Adapting the workshop process

In order that we did not create a culture of ableist exclusion, we decided to eschew our standard approach to the workshop process and embrace the capabilities and creativity of the storytellers (Table 3).

(c) Changes to facilitator goals

As facilitators, our role clarified after the first couple of hours of working with the storyteller. We realised that our success would be measure by helping this group of storytellers in:

- Finding (and holding!) a story
- Looking through photos
- Finding memories
- Harnessing memories
- Scripting
- Recording
- Working together
- Reviewing their story.

(d) Individual and group adaptations.

Some adaptations, beyond adjusted schedules and facilitation styles, were common to all storytellers. For example, all scripts were printed out in a large sans-serif font. But then, each individual person with dementia would most benefit from adaptations that recognised the disparate and individual natures of their abilities—maximising inclusion across the group.

So for example, for Storyteller A who had cognitive issues that affected their ability to scan a sentence across the wrap at the edge of a page, their script was printed out and then cut into strips of paper, each with a single line of text (Fig. 4).

Table 3 Comparison between typical and adapted workshop processes

Typical process	Adapted process
Day 1 Introductions Seven elements of digital storytelling Story circle Script development Day 2 Image editing tutorial Recording the voiceover Storyboarding Day 3 Video editing tutorial Assembling the video Premier of stories Debrief and reflection	Day 1 • Introductions and showing exemplar Patient Voices digital stories • Discussion of process of workshop • Work individually to find and develop stories • Write script • T.S. scan all images into computers Day 2 • Read scripts to the group in story circle • Practice reading scripts • Record voiceovers • Decide what images would want to go with script • Collecting additional images—photographs or videos—the participants idenfitied as necessary for their stories Day 3 • Listen to voiceovers and drop images in to make digital story using video editing software • Chose music and decide whether it plays in background under voiceover • Facilitators tidy up transitions between slides in digital stories Day 4 • Participants, staff and facilitators gather mid morning for premiere showing of all stories • Cake and celebratory lunch

Other storytellers needed individualised adaptations to maximise their participation in the process, and so, for Storyteller B, audio recording was done one paragraph or sentence at a time, with opportunities to review and re-record each sentence. For Storyteller C, the script was printed out in a very large font, and for Storyteller D, the facilitator and storyteller co-created a created a sequence of textual ‘prompts’ from which the storyteller could recount the story.

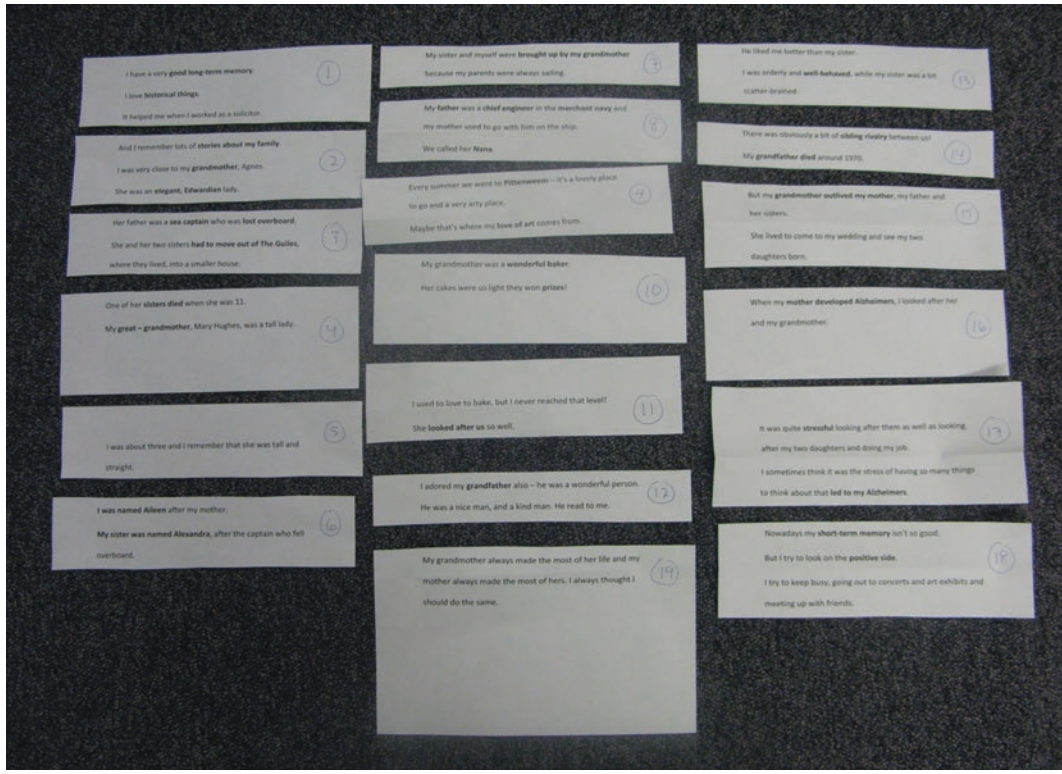

Fig. 4 Adapting printed scripts for reading by Storyteller A

4 Conclusion

In *Being Mortal: Illness, Medicine and What Matters in the End*, Atul Gawande [43] writes that:

> *We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive.*

If doctors and nurses, teachers, bureaucrats, politicians and care workers are to enable wellbeing, they must understand those reasons—they must hear the first-person stories that convey those wishes. The wishes and motivations of the marginalised person may not be what are expected. In one elderly woman's story, she is apparently liberated from the constraints of lung disease and geographical isolation from care systems by telehealth technology, but the core of her story is that she will now be able to look after her granddaughter again [44].

Digital storytelling can provide a process through which citizens marginalised by age and/dementia can take back control over the telling of the narratives of their lives. It can provide opportunities to reflect on life experiences; to make sense of those experiences; to shape how those experiences are described when they are shared with others; to support others going through similar experiences by allowing them to walk in their shoes for a while; and to inform and educate clinicians, carers and commissioners of services through the sharing of a first-person story told in their own words.

Digital storytelling can be described as a movement that is:

> *Explicitly designed to amplify the ordinary voice. It aims not only to remediate vernacular creativity but also to legitimate it as a relatively autonomous and worthwhile contribution to public culture. This marks it as an important departure from even the most empathetic 'social documentary' traditions.* [45]

To achieve this, however, best practices in facilitation are essential, and the digital storytelling process must be adapted to the abilities and needs of the storytellers. There are potential barriers to engagement that are common to many cohorts of digital storytellers (technological resources, skills…) but there are barriers that are relatively higher for the elderly and people with dementia. These include memory and cognitive impairment; vision and hearing issues; physical stamina and emotional energy levels. All these can be addressed with careful programme design and appropriate facilitation skills and resources.

The stories told and shared have also been of immense value to others working in or using the care services, and those managing end of life care, and they continue to inform and educate. The three most viewed stories on the Patient Voices website[3] "Stripped of dignity" [46], "My journey with David" [47] and "The book of Stephan" [48] are about Dementia and care of the elderly and their story pages have, together, now been visited over 350,000 times (as of 31st December 2022).

When the digital storytelling process is successfully adapted to a marginalised group, whether as in this case the elderly and people with dementia or other groups such as asylum seekers and refugees from the war in Kosovo [35] the process can be a powerful experience, and the and the product, the digital stories, can be active and influential advocates for those that may not otherwise be heard, in places they could not reach.

[3] http://www.patientvoices.org.uk/

References

1. Ochs E, Caps L (1996) Narrating the self. Annu Rev Anthropol 25:19–43
2. Pennebaker JW, Seagal JD (1999) Forming a story: the health benefits of narrative [Research]. J Clin Psychol 55(10):1243–1254. https://doi.org/10.1002/(SICI)1097-4679(199910)55:10<1243::AID-JCLP6>3.0.CO;2-N
3. Charon R, Montello M (2002) Stories matter: The role of narrative in medical ethics. London, Routledge
4. Greenhalgh T, Hurwitz B (1999) Why study narrative? Br Med J 318:48–50
5. Lambert J (2002) Digital storytelling: capturing lives, creating community, 1st edn. Digital Diner Press
6. Aristotle (1965) On the art of poetry. Penguin, London
7. Godard J (2011) Quoted in The Guardian
8. Sumner, T. (2009) Stories and statistics https://www.patientvoices.org.uk/flv/0851pv384.htm
9. Johns C (2000) Becoming a reflective practitioner. Wiley
10. Meadows D (2004) Digital storytelling: research-based practice in new media. Vis Commun 2(2):189–193
11. Schön DA (1988) Coaching reflective teaching. In: Grimmett P, Erickson G (eds) Reflection in teacher education. Teachers College Press, New York, pp 19–29
12. Hardy P (2007) An investigation into the application of the Patient Voices digital stories in healthcare education: quality of learning, policy impact and practice-based value. https://www.pilgrimprojects.co.uk/papers/pvreview.pdf
13. Moll L, Amanti C, Neff D, González N (1992) Funds of knowledge for teaching: using a qualitative approach to connect homes and classrooms. Theory Pract 31(2):132–141
14. Hogg L, Volman M (2020) A synthesis of funds of identity research: purposes, tools, pedagogical approaches, and outcomes. Rev Educ Res 90(6):862–895
15. Hardy P, Sumner T (2018) Cultivating compassion: how digital storytelling is transforming healthcare. Palgrave Macmillan
16. Creative Commons (2023). https://creativecommons.org/

17. UNESCO (2019) Recommendation on open educational resources (OER). UNESCO. https://unesdoc.unesco.org/ark:/48223/pf0000373755/PDF/373755eng.pdf.multi#page=3
18. Schlossberg NK (1989) Marginality and mattering: key issues in building community. New Dir Stud Serv 48:5–15
19. Nwadiugwu M (2021) Early-onset dementia: key issues using a relationship-centred care approach. BMJ Postgrad Med J 97:598–604
20. Guardian (2020) https://www.theguardian.com/world/2020/may/16/worlds-oldest-coronavirus-survivor-the-elderly-are-theforgotten-ones-of-society
21. Heymann E (2008) Standing on my own two feet. www.patientvoices.org.uk/flv/0249pv384.htm
22. Heymann E (2009a) A chocolate watch. www.patientvoices.org.uk/flv/0412pv384.htm
23. Heymann E (2009b) From darkness into light: new worlds. www.patientvoices.org.uk/flv/0345pv384.htm
24. Heymann E (2011) The sun also rises. www.patientvoices.org.uk/flv/0517pv384.htm
25. Turnbull J (2008) The feet on the sofa. https://patientvoices.org.uk/flv/0286pv384.htm
26. Sumner T (2009) Stories and statistics. https://www.patientvoices.org.uk/flv/0851pv384.htm
27. Housing Learning and Improvement Network (2016) Dementia and housing: an assessment tool for local commissioning. https://www.housinglin.org.uk/Topics/type/Dementia-and-housing-An-assessment-tool-for-local-commissioning/
28. Stenhouse R, Tait J, Hardy P, Sumner T (2013) Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early-stage dementia. J Psychiatr Ment Health Nurs 20(2):134–141. https://doi.org/10.1111/j.1365-2850.2012.01900.x
29. Vanier J (2004) Drawn into the mystery of Jesus through the Gospel of John. Paulist Press
30. Albom M (2003) The five people you meet in heaven. Hyperion
31. Richardson L (2000) Evaluating ethnography. Qual Inq 6(2):253–255. https://doi.org/10.1177/107780040000600207
32. Denzin NK (2014) Interpretive autoethnography. SAGE
33. Wood S (2011) The day the singing stopped. https://www.patientvoices.org.uk/flv/0545pv384.htm
34. Patient Voices (2008a) Communities of heath. http://www.patientvoices.org.uk/newham-htm
35. Patient Voices (2008b) Stories from the Society of the Holy Child Jesus. https://www.patientvoices.org.uk/shcj.htm
36. Patient Voices (2009) End of life stories. https://www.patientvoices.org.uk/naoeol.htm
37. Patient Voices (2011) Dangling conversations. https://www.patientvoices.org.uk/dc.htm
38. Patient Voices (2015a) Dementia insights. https://www.patientvoices.org.uk/di.htm
39. Patient Voices (2015b) Living with dementia. https://www.patientvoices.org.uk/lwd.htm
40. Sumner T (2008) The power of e-flection. https://www.patientvoices.org.uk/pdf/presentations/Tony%20Sumner%20eFlection%20slides.pdf
41. Sumner T (2014) From data to insight: obtaining the patient/service user voice. Presentation to the Independent Information Governance Oversight Panel. https://www.patientvoices.org.uk/pdf/presentations.htm
42. Grierson J (1933) Cinema Q
43. Wordsworth W (1800) Preface to Lyrical ballads in lyrical ballads with other poems. Longman and Rees
44. Gawande A (2014) Being mortal: illness, medicine and what matters in the end. Macmillan
45. Cameron M (2010) My pod. https://www.patientvoices.org.uk/flv/0451pv384.htm
46. Burgess J (2006) Hearing ordinary voices: cultural studies, vernacular creativity and digital storytelling. Continuum 20(2):201–214
47. Wesolovski K (2015) Stripped of dignity. https://www.patientvoices.org.uk/flv/0858pv384.htm
48. Farrell M (2009) My journey with David. http://www.patientvoices.org.uk/flv/0392pv384.htm
49. Scarsbrook S (2015) The book of Stephan. https://www.patientvoices.org.uk/flv/0845pv384.htm