

# **DIGITAL STORYTELLING IN HEALTH AND SOCIAL CARE**

A photograph of footprints in sand, with the largest footprint in the foreground and smaller ones receding into the distance. The sand is a light, warm yellow color, and the footprints are dark, suggesting a person has walked on it.

## **Interim Report**

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**DIGITAL STORYTELLING IN HEALTH AND SOCIAL CARE:  
Interim Report**

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# DIGITAL STORYTELLING IN HEALTH AND SOCIAL CARE: Interim Report

## Executive Summary

The **Digital Storytelling in Health and Social Care project** has resulted in the creation of several story collections comprising more than 70 digital stories and has supported the introduction of the digital storytelling methodology in four pilot locations. The stories have been screened and discussed in a variety of fora, from local awareness raising workshops to national stakeholder events. To encourage more widespread use, a searchable online digital story library is currently being developed.

At the time of its inception, the project mapped the envisaged contribution of digital storytelling to five thematic areas where more traditional stories, such as those gathered through *Discovery Interviews*, have previously been found to have an impact:

- Service improvement;
- Service user and carer involvement;
- Service user and carer experience;
- Education;
- National debate.



Over the last year, the digital stories have been found to contribute to each of these thematic areas to varying degrees. More specifically, digital storytelling has served less as a means of collecting data to reveal specific service level improvements, and more as a means of gaining a deeper understanding of the real-lived care experiences of service users and carers, contributing to changes at individual practitioner level and the shift towards a more person-centred culture in health and social care.

To date the digital stories have made a moderate contribution within formal educational contexts, in supporting the shift to seamless services and in informing national debate, but have demonstrated strong potential in these areas. Making best use of the existing stories in these contexts, together with evidencing the learning from staff digital stories are activities that should receive increased attention in the immediate future.

While it was prerequisite that the making of digital stories should support active and meaningful participation, the contribution of the methodology to service user and carer experience has, when followed closely, proved to be an area of particular strength. It is therefore encouraging that the potential of the digital storytelling methodology itself, rather than simply its outputs, is now being recognised and further explored in a therapeutic context.

An unforeseen but nevertheless strong contribution of digital storytelling has been in supporting the implementation of a specific change initiative, namely piloting the User Defined Service Evaluation Toolkit (UDSET) and the shift to an outcomes focus in community care. It may seem reasonable to assume that digital stories could play a similar role in supporting other change implementations in future. However, it should be noted that its success here was the result of close and sustained working not only between the two initiatives, but also between the UDSET project and the partnership pilots, thereby enabling storytellers to be identified in a timely manner. The digital storytelling project and the UDSET also shared common aims and core principles, which were conducive to joint working. Moreover, it should be noted that whenever digital stories are being created with a view to linking with a particular service or agenda, the risk of exploitation must be very carefully managed. The observed contribution of the digital storytelling project is summarised in *Appendix 2*.

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## Document Purpose

This Interim Report provides an account of the progress that the **Digital Storytelling in Health and Social Care project** has made to date. It revisits the project rationale, including the *theoretical* or anticipated contribution of digital storytelling, before summarising activity within each of three parallel workstreams. The report then considers the advantages and disadvantages of the digital story format and methodology, relating them to the *observed* contribution of digital storytelling within each of five thematic areas.

There is now some interest from the Long-Term Conditions Collaborative in making use of digital storytelling, and local application of the approach, in the pilot areas and elsewhere, is beginning to take hold. This report serves to take stock, reflect and evaluate in order to inform the future direction of digital story work, as led by the Joint Improvement Team, and to maximise these emerging opportunities.

## Revisiting the Project Rationale

### The Role of Story in Health and Social Care

There is currently much emphasis on the importance of placing the person at the centre of health and social care services. Person-centred care requires understanding of the person in the context of their life, moving beyond their basic physical and mental requirements to consider their emotional and spiritual needs, together with their aspirations and concerns. This in turn emphasises the importance of health and social care professionals hearing the individual's story.

Further, while stories have until recently been devalued as the basis of evidence used to shape and develop services, there is now growing recognition that our understanding of what works in complex health systems requires the inclusion of narratives as part of the evidence base.

The advent of modern multimedia simply broadens the narrative approaches available.

### The Theoretical Contribution of 'Digital' Stories

We live in an age shaped by new media and technology. Increasingly people want messages to be appealing, simple and presented quickly, and in a format that is easy to digest. Combining still images, music and voice into short multi-media presentations, digital stories have the potential to fulfil these criteria, enabling ordinary people to present their experiences in their own words in an engaging and accessible medium.

*Appendix 1* outlines the *theoretical* contribution of digital stories to:

- Service improvement
- Service user and carer involvement
- Service user and carer experience
- Education
- National debate

The ***Digital Storytelling in Health and Social Care Project*** set out to determine the *actual* contribution of digital stories to each of these thematic areas, together with any limitations.

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## Project Activity Summary

This section summarises the progress that has been made within each of three parallel work streams:

- Creating Thematic Story Collections
- Sharing Digital Stories
- Developing Local Capacity

### 1. Creating Thematic Story Collections

The project has created several digital story collections, comprising more than 70 stories:

- **Whose Care, Whose Lives?** Perceptions of care in various environments
- **Who Cares?** Carer assessment stories
- **What's It All About?** Intermediate Care experiences
- **Living at Home with Dementia** – The Richmond Fellowship collection
- **Differently the Same** - Stories of life before and after dementia
- **Something in Common** – Sinclair Integrated Day Care stories
- **Back to the Future?** The UDSET Collection

Story collections currently in development include:

- **Safety First?** Telecare stories
- **Getting it Right for Carers** – Sharing best practice (Carers Coalition)<sup>1</sup>
- **Single Shared Assessment Stories** (at planning stage)

Several stories have also been created under the Long-Term Conditions (LTC) banner, primarily for use at key events, notably the joint launch event of the Long-Term Conditions and Mental Health Collaboratives in April and the LTC Alliance Scotland Self-Management launch event in September.

Supporting documentation has been produced as required including checklists and questionnaires for 'sponsors', 'taking part' information leaflets, 'thinking about my story' preparation sheets and 'storyboards' for storytellers, together with consent and story release forms.

### 2. Sharing Digital Stories

From the outset, the project recognised the potential pitfall of focusing too heavily on digital story creation at the expense of distribution and use, and undertook to:

- Identify opportunities to share stories at relevant national and local events
- Publish and distribute stories via DVD / web as appropriate
- Identify and create other opportunities to share the stories more widely
- Actively solicit feedback on story usage
- Develop a 'sharing stories' pack

It was further recognised that initiatives that rely solely on capturing stories and placing them in static archives are usually ineffective and early efforts therefore concentrated on identifying and creating opportunities to share the stories at national and local events. This has worked extremely well, generating considerable interest in and demand for the stories, while at the same time informing the nature and content of the proposed 'sharing stories' pack.

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<sup>1</sup> There may need to be a spin-off collection – 'Getting it Wrong for Carers' as a number of identified storytellers have also identified specific difficulties or issues that they wish to voice

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To date, the stories have been used at local, national and international<sup>2</sup> conferences and key stakeholder events. More recently, a story entitled '*Beyond the Magic Wand*', told by Lorraine, a mental health service user, won an award at the 2008 Mental Health Arts and Film Festival, meriting screening at the Edinburgh Filmhouse.

The digital stories are increasingly finding applications in local training and other educational contexts with a possible extension sitting alongside the new *Intermediate Care Capability Framework*, where existing digital stories could serve to reinforce the importance of the majority of the identified capabilities. The most extensively used stories are those featured in the UDSET collection. The role that digital stories have played in supporting the UDSET in implementing a focus on outcomes in community care is described in full in the (draft) paper: *Evidence about stories and story-based evidence: towards better outcomes for service users and their carers in Scotland* (authors: Emma Miller & Karen Barrie)

In order to meet the demand for digital stories, several DVD collections have been professionally produced en masse, with other stories being made available on DVD individually or in combination upon request. Although the uptake has been heartening, this distribution method is known to be inefficient and also fails to showcase the full range of stories that now exist. It is also likely to become increasingly resource-intensive as the bank of stories continues to grow.

An alternative distribution channel is the web. Indeed, low resolution versions of a small selection of stories have already been made available on through the JIT website. This online collection was put together in a matter of hours and takes the form of a single web page. Despite its obvious limitations, it has been the source of a number of enquiries from organisations in Scotland, England and Wales and recently featured as 'website of the month' in the online journal '*Care Appointments*'.

It was originally anticipated that the public website would expand over time. However, a number of storytellers, although delighted for their stories to be used within health and social care contexts, were reluctant to make their stories available in a public domain. Further, for other stories, notably those featuring vulnerable individuals and/ or created for specific learning events or debates, the arguments against making the stories publicly available far outweigh those in support. Together these observations have pointed to the need for a secure web-based resource that supports ready discovery and download of all digital stories created to date, and allows for continued expansion over time. The online *digital story library* specification, including a catalogue data model, has been signed off and is currently being developed by the SHOW team.

Efforts to identify and create further opportunities for sharing and discussing the stories are continuing in parallel.

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<sup>2</sup> A The Living at Home with Dementia stories were created in conjunction with the Richmond Fellowship and were screened at an International Dementia Conference in Ireland earlier this year, while a selection of stories was screened at the Western European Nurse Researchers Chronic Illness Management Conference in Vienna earlier this month as part of the NHS Lanarkshire symposium 'From the myth of cure, to the reality of care'.

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### **3. Developing Local Capacity**

There will most likely continue to be one-off national events and other occasions where the facilitation of digital story creation is best conducted by external personnel. However, the project also recognised from the outset that if the making of digital stories is to become a routine part of local consultation practices / service delivery, individuals working in the locality / providing the services will be better placed to undertake the work. To this end, a third work stream has been supporting the implementation and evaluation of digital storytelling in four quite different local care contexts: NHS Fife and NHS Tayside, and Moray and North Lanarkshire Councils.

An initial workshop bringing together the staff from the four pilot sites was held in November 2007 and this has been followed by several local workshops / follow-up training sessions, and / or hands-on support during initial story creation efforts, as required. A range of reusable training materials and 'getting started' packs have also been produced.

The digital storytelling approach has been implemented to some degree in all four areas, but most extensively in Moray, where digital storytelling is perceived as having applications within consultation / evaluation activities, education and training and as a means of further enhancing service user skills and self-esteem. Two digital story project officer posts have now been created and filled, initially for a period of six months (one funded by Moray Council, the other by NHS Grampian). Both came into post on 1<sup>st</sup> September, are based at the Employment Support Centre in Elgin, and have received three days fairly intensive training in the use of the associated technologies and in facilitating digital storytelling workshops.

Local capacity development is also now taking place with the PFPI lead for NHS Greater Glasgow and Clyde in the form of 'learning while doing' training, initially in the context of evaluation of the stroke service.

Additional interest in using the digital storytelling approach has recently been expressed from various quarters including carer organisations and academic researchers. To date the project has provided advice and support in response, but may look to run further facilitation workshops. Finally, following a workshop in August, held jointly with visiting psychiatrists /photo therapists from Russia at the Moray Arts Centre, considerable interest has also been expressed by art therapists and speech and language therapists in exploring its application in a therapeutic context, possibly in conjunction with the Moray team.

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### Advantages and Disadvantages of Digital Storytelling

The preceding summary answers the question: “*What has the project done?*”? However, the more pertinent question is “*To what end?*”

Before assessing the actual contribution of the digital story to the five thematic areas envisaged, consideration is given to the advantages and disadvantages of the digital story format and to the strengths and weaknesses of the digital storytelling methodology.

#### Advantages and Disadvantages of the Digital Story Format

##### Advantages

One of the main advantages of the digital story format is that it can be easily shared and used in multiple fora.

In addition, the context and impact of each individual story is not only preserved, as is the case with written and audio-recorded stories, but additional layers of meaning are also introduced in the form of images, music and audio-visual effects, impacting on the participants and the audience in different ways. Digital stories can provide more detailed context than conventional verbal stories and may therefore be more emotionally stimulating and memorable. With regard to stimulation, photographs have the ability to convey emotion, mood, timeframe, ideas and messages - all of which are important elements of storytelling and bring the person’s biography alive for all concerned. This has proved particularly poignant in the case of older people’s stories, where photographs of the storyteller in the current care context have been interspersed with photographs capturing key moments in their lives.

Another advantage of storytelling with images is that it affords economy of language, making it possible for the viewer to get a real sense of ‘who the storyteller is’ without having to rely on words. This economy is important, allowing strong messages to be conveyed in moments. The typical duration of a digital story is only three minutes, greatly extending the opportunities for inclusion in meetings and events.

Stories captured in digital format can also be viewed with greater objectivity and dissociation. The digital story offers a buffer between the storyteller and the audience, and this distance in time and space allows potentially difficult, challenging or even painful subjects to be explored in a more comfortable context than one where the storyteller and audience are co-located.

From the storyteller’s perspective, the main advantage of the digital format over formats such as interview or questionnaire is that he / she can physically see the result and understand exactly how the contribution will be used. Also, the story can be told once and used many times, offsetting demands on time.

##### Disadvantages

The main disadvantage of the digital story format is that it is not universally accessible, for instance to audience members who have visual or hearing impairments (although subtitles can be added to offset the latter concern). Many government organisations have also blocked the transmission of video files, restricting distribution channels and the stories can present technical difficulties when screening at venues that are not equipped with integrated audiovisual systems.

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A further disadvantage is that the short duration of the story means that the level of detail contained is low compared to traditional written or audio case studies.

### Strengths and Weaknesses of the Digital Storytelling Methodology

#### Strengths

The process of making a digital story also has much to commend it. Consistent with traditional narrative approaches, emphasis is placed on personal 'voice'<sup>3</sup> and exploring ideas important to the storyteller, who ultimately decides which story to tell. In addition, it is a creative process and can be extremely empowering.

Importantly, the method can be customised according to the individual life circumstances of the teller, taking cognisance of factors such as physical and mental health status, the environment of care, competing demands on the teller's time and the level interest in the more technical aspects of the process. This means that the opportunity to make a digital story can be offered to people whose voices would not otherwise be heard, such as frail elderly service users and care home residents. Health and social care professionals are asked to identify potential participants based on their willingness and physical / mental ability to take part, rather than on account of their communication skills or because they have a particularly remarkable story to tell. On the contrary, emphasis is usually placed on the ordinary rather than the extraordinary.

By opening up the approach in this way, considerable care and attention has to be taken to ensure that individuals fully understand the processes involved in recording a digital story prior to commencing. To this end, the methodology stipulates that information leaflets are supplied in advance to local care staff to help them explain to potential participants what taking part in a digital story would involve. The leaflets are modelled upon those used by the UK charity DIPEX and cover all categories of information demanded by the 'informed consent' principle. Upon visiting the storyteller, care is again taken to ensure that the purpose of the stories and the processes involved are understood, and perhaps most importantly, to repeat the assurance that the participant retains editorial control over the final product.

Although the approach can be individualised, a number of core principles should always be observed. At a minimum, storytellers are audio recorded talking about their life circumstances and the aspects of care that matter most to them as people. The storyteller may be helped to shape the story, but must ultimately decide what to say and what to omit and occasional prompting with open-ended questions or deeper probes aims to encourage free exploration and expression of ideas. Storytellers are also invited to provide personal photographs to stimulate dialogue and to illustrate their stories (although the option of retaining anonymity is also made). Although this expression of interest in the person rather than just a specific care experience is not unique to digital storytelling, many storytellers enjoy the opportunity of sharing memories in this informal way.

In some cases storytellers are encouraged to take the additional step of telling the story spontaneously or creating and recording their own story script. Others go on to develop a 'storyboard', choosing a selection of personal photographs and identifying other suitable images or even taking new photographs to illustrate specific aspects of the story, and identifying an appropriate music genre. In some cases the storytellers are assisted in assembling the various components using computer software and physically making their own digital story, which can be very rewarding.

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<sup>3</sup> Not to be interpreted too literally - although all stories created to date have included an audio component, one is currently being developed with a young telecare service user who is unable to communicate verbally, but a whiz with technology.

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While this latter approach gives the storyteller total ownership of the story throughout its development, all storytellers retain final editorial control and are the first to see the completed story, ideally during a return visit. At this time, the storyteller is encouraged to identify any required modifications and is offered the opportunity to withdraw. Only when wholly satisfied with the digital story is the storyteller asked to give consent to its release and to stipulate any usage restrictions. At this stage, particular care is taken to ensure that individuals understand the potential range of applications of the stories. The general conditions of use stipulate that each story is shown in its entirety, affording assurances that remarks will not be taken out of context or manipulated in any way. Each storyteller also receives a personalised copy of the story on DVD, with additional copies for family members or use within local support groups made available on request. Together, these features contribute to the storytellers knowing that they are in control, adding to their senses of achievement and empowerment.

### **Weaknesses and Concerns**

One weakness of the approach is that it can be quite time-consuming (averaging 2 days per story). This has proved a significant barrier to implementing the approach in some localities. Although all staff members who have attended the facilitation workshops have identified potential applications within their own work, many have found it difficult to 'take time out' to do this in practice.

A related concern is that in some situations it may not always be cost-effective to create digital stories. While most stories have been used extensively, a few have been created for one-off events enjoying a limited audience and have found little subsequent use. Others still were created more as a contingency and have never been screened. Although this concern may be offset by the creation of the online story library, there is also a need to be more discerning when agreeing to create stories and perhaps to implement qualifying criteria and conditions.

Another related weakness of the methodology is that the opportunity of making a digital story can only be offered to a limited number of people. Further, as identification of potential participants typically requires an assessment of mental / physical capacity by local care staff, this runs the obvious risk of cherry picking. This is not problematic where stories are 'billed' as highlighting good practice. However, while digital stories are never portrayed as representative, the potential for abuse and for promoting specific agendas cannot be ignored and requires careful management, often requiring the facilitator to invest time in becoming familiar with the policy context and competing perspectives.

A further concern is that the revisit and personal screening of the completed story is an important aspect of the methodology, but logistics renders this impossible in some cases. Although this is being countered in part by the development of capacity in some localities, it is likely to remain an issue for the foreseeable future and local arrangements for supporting story review may need to put in place.

Finally, assisting people to share personal stories, often of highly emotive care experiences, can be quite draining. Moreover, the facilitator is often immersed in the audio recording of the experience for many hours and is literally unable to switch off. As the approach is introduced into different localities, it is important that this aspect of the methodology is not overlooked and that appropriate support is made available.

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### Observed Contribution of Digital Storytelling

When the project was initiated in late October 2007, the rationale for making use of digital storytelling detailed its *theoretical* contribution to:

- Service improvement
  - Individual level change
  - Service level change
  - Development of seamless services
- Service user and carer involvement
  - Organisational level changes in culture
  - Service improvement
- Service user and carer experience
- Education
- National debate

Detailed in *Appendix 1*, this theoretical contribution was based on the *theories of change* model developed for more traditional 'patient' stories captured through Discovery Interviews. (CHD Collaborative, 2005). While there has been no formal evaluation of the *actual* contribution of the digital stories created through the project to each of these thematic areas, it is nevertheless possible to document a number of observations at this time.

#### Theme 1: Service Improvement

##### Individual Level Change

"Stories act as stimuli for staff to reflect and re-evaluate their relationships with service users and carers and gain a deeper understanding of how they experience care"

A recurrent theme within many of the digital stories is the impact that good and bad communication has on the overall care experience. The importance of being listened to and being given time also features strongly, as does the converse.

By setting the care experience within the context of the storyteller's life, the stories also make plain the importance of understanding unique life circumstances and priorities, reaffirming that it is the level of success in identifying and focusing on the things that matter to the individual that determines the quality of the care experience.

Watching the stories at training sessions, workshops and events was witnessed to have a stilling effect on frontline staff and managers. Afterwards, many people also remarked upon their capacity to make you think and their emotive power.

Given the advantages of the digital story format over more traditional story forms, it would appear that digital stories can serve as stronger stimuli for reflection and enhance deeper understanding of the experience of care, thereby making a strong contribution to individual level change.

***Contribution Rating: Strong***

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### Service Level Change

“Stories can reveal specific improvements that can be made at service level – immediately, following review or upon deeper investigation”

Consistent with the JIT’s overarching focus, the main focus of the digital storytelling project has been improving outcomes for service users and carers. The first digital story collection, *Whose Care, Whose Lives*, illustrated the reality of the care experience in various environments, coincidentally reinforcing the outcomes that matter to people in so doing. Subsequently, the *Living at Home with Dementia* and *UDSET* collections have shared this focus, while the *Intermediate Care* collection focused on models of service and the extent to which these models respected individual life circumstances, rather than aspects of services themselves. Similarly the *Sinclair Integrated Day Care Service* stories focused on the very different life circumstances of the people using the service and their carers.

Nevertheless, a number of digital stories do reveal aspects of service that could be improved, such as poor orientation towards the service, communication breakdowns between staff or gaps in the continuity of care. Other shortcomings to emerge, such as delays in access, are often attributable to a failure to listen to the service user or carer.

Digital stories can be very effective in *illustrating* specific improvements that can be made at service level. However, considering the first three identified weaknesses of the methodology, namely that digital stories are time-consuming to make, may not be cost-effective and can only involve a small number of people, it is not the best means of revealing specific service improvements. Other more traditional methods such as questionnaires, instruments based on semi-structured interviews and focus groups are better suited to this task.

**Contribution Rating: Weak**

### Development of Seamless Services

“Bringing together organisations / departments to consider stories can facilitate shared empathy, a more person-centred service and an enhanced sense of team work”

Digital stories are beginning to find applications in local contexts involving multi-disciplinary teams. However, this application has primarily served to raise awareness of the outcomes agenda, rather than to generate a sense of shared empathy.

Given the powerful impact that the stories have had on individuals, it does not seem too great a leap to hypothesise that the empathy invoked could be shared across professions. The digital story’s ability to provide a buffer between the teller and viewer also affords discussion of sensitive issues in a relatively comfortable setting.

In addition, the digital stories have been witnessed to contribute to an enhanced sense of teamwork in a way that was not initially envisaged; namely through the creation of staff stories. The stories, created by physiotherapists, occupational therapists, district nurses, social workers and managers, have served to acknowledge the different understandings that exist across professional groups, together with the different values instilled in the respective professions. The staff storytellers shared their initial misgivings and also acknowledged the things that they have learned from other disciplines. Although a fairly

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recent development, the potential contribution of staff stories toward the development of seamless services is apparent, resulting in the inclusion of a new theory of change:

*“Staff stories can serve to acknowledge and share different understandings and values across professional groups”*

***Contribution Rating: Moderate (with Strong potential)***

### **Theme 2: Service User and Carer Involvement**

#### **Organisational Level Changes in Culture**

*“Stories act as stimuli for and are integral to a shift to a more person-centred culture / strategy within the context of an overall drive towards working in partnership with service users and carers”*

The digital story's brevity and ability to be easily shared has resulted in screenings at a variety of events comprising quite different audiences, from frontline staff to senior management and government ministers. All have been struck by the power of the stories and provided with a gentle reminder of who 'the service' is for.

Moreover, although each story makes a different point and delivers a different take home message, all reveal how people who use services or who provide informal care 'make sense' of their experience of doing so. For instance, for one storyteller, living in a continuing care hospital was dominated by the sense of loss of independence and a desire to return home, while for others the familiarity of the surroundings, or the enjoyment of company or the enhanced sense of security were much more prominent. Collectively the stories illustrate that if efforts to care for people or to consult them about their views are to occur in an individualised and sensitive way, then they must be based on some understanding of the person's own sense of meaning in being a service user. This sense of meaning can only be gained through a more person-centred approach.

Digital stories alone of course will not bring about an organisational level change in culture, but they can act as one of many stimuli, reasserting the value of 'stories' in interactions between the people who use services and those who provide them and within health and social care contexts generally.

***Contribution Rating: Moderate***

#### **Service Improvement**

*“Service users and carers can become involved in groups in the development of changes that have emerged from the stories”*

Giving people an opportunity to become involved in improving specific service shortcomings that they have helped to identify is a feature of methodologies such as *Discovery Interviews*. For instance, a former stroke unit inpatient who highlighted that nobody offered to clean his dentures during his stay, despite clearly being unable to do this himself due to impaired movement, now plays an active role in the stroke network's oral hygiene action group.

However, this phenomenon has not been observed in the current project and given that the digital story format's contribution to revealing specific service level improvements is weak, this form of contribution is likely to be negligible.

***Contribution Rating: N/A***

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### Theme 3: Service User and Carer Experience

#### Listening and Healing

“Storytelling is a creative, empowering and even cathartic experience, which can contribute to service user or carer’s sense of being listened to and understood”

The strengths of the digital methodology include its ease of customisation, genuine interest in the teller as a person, rather than merely as a recipient of a particular form of care and giving the teller the opportunity for free expression and to retain control. These features are entirely consistent with the assertion that the experience of making a digital story is creative, empowering and even cathartic and this has been substantiated through feedback from participants, their families and care staff. Consistent with the findings about outcomes-based approaches to assessment and review, service users and carers who created digital stories often reported benefiting from the simple act of being listened to and having their thoughts accurately recorded in tangible form. Many storytellers reported enjoying the experience and the attention. Staff in one hospital setting noted “a buzz about the place” after four long-term inpatients had recorded their stories, while relatives enjoyed having “something new to talk about” during visits.

There have also been some unanticipated benefits for user and carers from participating in the digital stories work, such as the sense of pride in the product. Many have reported that they enjoyed sharing their stories with their families. One of the most dramatic impacts was for an older service user who, having recorded and then subsequently viewed her story, made the transition from asking why she couldn’t go home to channelling her energy into making the progress required to leave the care environment. A carer called Christeen felt very empowered when the PRTC requested copies of her story for use in training by all of their centres and a mental health service user called Lorraine, who has waged a long battle with depression, received a major boost when her digital story won an award at the 2008 Mental Health Arts and Film Festival.

With regard to the second aspect of this contribution, ‘**healing**’, the founder of the approach, the Digital Storytelling Center, takes great care to avoid making claims as to the therapeutic value of the methodology and this caution has also been exercised by the project.

However, an opportunity has now arisen to explore the application of digital storytelling within a therapeutic context, due to interest from arts therapists and speech therapists who attended the project’s *Observer Effect* Workshop in Findhorn. The results of their endeavours will be monitored with great interest.

Although the number of people that the digital storytelling approach has been made available to is currently small, the experience of those who have taken part has been very much in accordance with expectations, where the methodology has been adhered to.

However, it should be noted that a preoccupation with the outputs of digital storytelling has, on occasion, resulted in pressures to depart from the core principles of the methodology. In situations where the questions that people hope to get answers to are fixed, digital stories can amount to little more than illustrated questionnaires. Where the ‘right’ answers to these questions are assumed to be known in advance, digital stories have the potential to amount to little more than exploitative promotional plugs.

**Contribution Rating: Strong**

# DIGITAL STORYTELLING IN HEALTH AND SOCIAL CARE: Interim Report

## Theme 4: Education

### Workforce Development

**Digital stories are used in the ongoing education of health & social care professionals**

The stories are increasingly finding applications within various local training contexts. While some of the applications may be time-limited others, notably those highlighting aspects of communication and interpersonal relationships, would appear to have ongoing value. The project originated from an initiative in Lanarkshire where former stroke patient stories were embedded in a training course aimed at promoting a more holistic approach to care and were found to play a key part in the development of active listening skills and a more empathic approach to care.

There was some initial interest in incorporating some of the *Whose Care, Whose Lives* stories in pre-registration courses for allied health professionals and it would be worth revisiting this interest once the online library development is completed. Similarly, there has been some interest in using a number of the dementia stories from Dementia Centre in Stirling and the Carers Coalition are also keen to embed the stories being created for the *Getting it Right* conference within online training modules.

One more widespread use of the stories is in conjunction with the new *Intermediate Care Capability Framework*, where existing digital stories could serve to reinforce the importance of the majority of the identified capabilities. Discussions about creating a web-based version of the framework are currently underway and preliminary discussions have been held regarding possible tie-ins with the online digital story library.

In addition, although unanticipated at the time of the project's inception, the creation of staff stories has made a very positive educational contribution. This has taken the form of additional learning for the audience, together with self-development and reflective practice for the storyteller.

For the audience, staff stories have conveyed important messages around the development of seamless services. The possibility of embedding staff stories within a broader educational context to deliver messages around listening to service users and carers and taking a more person-centred approach, could be complemented by messages around partnership working, learning from other professions and overcoming key challenges to specific initiatives.

For the storytellers, in every case, staff viewed their own story positively. In particular, staff identified satisfaction in contributing to efforts to improve professional practice. Additionally, and on a more personal level, the stories were viewed as validating their professional efforts. Staff storytellers also reported enjoying the experience of making a digital story, with many benefiting from the opportunity to reflect on a past experience and make sense of it. Some staff members instinctively shared their version of events, including their own realisations, shaped by background, expertise, frames of reference and prejudices. Others however, accustomed to sharing more traditional service user case studies, required time and encouragement before framing the story in the first-person and giving a personalised account.

Interestingly, some staff members were happy to have their stories recorded digitally, despite expressing reluctance to present their experiences on a public stage. In particular, these individuals drew comfort from not having to stand up in front of an unknown audience, and in the knowledge that any mistakes or hesitations could be edited out during the production process.

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Prior to the recording of staff stories, a number of partnerships had found the sharing of frontline staff experiences within local training sessions most helpful. However, managers were concerned that requests for staff participation in this way would place undue demands on their time. Making digital stories offset this by supporting maximum story reuse.

Together these observations have resulted in the inclusion of an additional contribution within the framework:

Digital storytelling contributes to the development of self-esteem and reflective practice in health and social care professionals

**Contribution Rating: Moderate (but Strong potential)**

### Theme 5: National Debate

#### Rethinking

“Stories provide a new perspective on service user and carer experience, placing it in a broader context leading to re-thinking at national level”

The JIT's role in taking the digital storytelling project forward has been crucial, enabling thematic story collections to be purposely created for and screened at key stakeholder events. The *Whose Care Whose Lives* stories were shown at the Continuing Care Review and the Shifting the Balance of Care Joint Commissioning event, ensuring that the experiences of service users and carers were brought firmly into focus before the deliberations commenced.

Other collections such as *Intermediate Care* and *Living at Home with Dementia* have illustrated possibilities, while the forthcoming conference *Getting it Right for Carers* aims to highlight current best practice in the hope that the audience will strive to emulate or even build upon this.

Many of the digital stories have however been created for more localised uses and their potential contribution to national debates to date remains largely untapped.

**Contribution Rating: Weak (with Moderate potential)**

### Theme 6: Implementing an Outcomes Focus and Supporting the UDSET

#### Organisational Level Changes in Culture

“Stories reaffirm the importance of outcomes in the lives of individual service users and carers and illustrate the advantages of taking an outcomes based approach to assessment and review, within the context of an overall drive towards a focus on outcomes in community care”

Although not featured in the theoretical contribution framework devised for stories of the type gathered through *Discovery Interviews*, the area where digital stories created by the project have made their strongest contribution to date has been in supporting the implementation of a specific change initiative; the piloting of the User Defined Service Evaluation Toolkit (UDSET) and the shift towards an outcomes focus in community care.

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The role that digital stories have played in supporting the UDSET in implementing a focus on outcomes in community care is described in full in the (draft) paper: *Evidence about stories and story-based evidence: towards better outcomes for service users and their carers in Scotland* (authors: Emma Miller & Karen Barrie)

In short, the digital stories were first used to highlight how service users and carers valued key outcomes as part of their everyday lives. Staff stories also introduced the voices of peers into training settings, situating the various issues and challenges that the implementation encountered within the context of everyday practice. Perhaps most importantly, the stories played a key part in retaining a focus on service users and carers against the constant danger that the implementation process would be sidetracked by ever more complicated policy processes.

**Contribution Rating: Strong**

### Conclusions

The digital storytelling project has been *observed* to contribute to the thematic areas identified in *Appendix 2*. More specifically, the digital stories have served less as a means of collecting data to reveal and inform specific service improvements, and more as a means of enabling various stakeholders to listen to and gain a deeper understanding of the real-lived care experiences of service users and carers, causing reflection and contributing to individual level change and the shift towards a more person-centred culture in health and social care.

To date the digital stories have made a moderate contribution within formal educational contexts, in supporting the shift to seamless services and in informing national debate, but have demonstrated strong potential in these areas. Making best use of the existing stories in these contexts, together with evidencing the learning from staff digital stories are activities that should receive increased attention in the immediate future.

While it was prerequisite that the method of making digital stories should support active and meaningful participation, the contribution of the method to the service user and carer experience has proved to be an area of particular strength. It is therefore encouraging that the potential of the approach itself, rather than simply its outputs, is now being recognised and further explored in a therapeutic context. This development will be monitored with interest.

The most significant contribution of the digital stories however has been in supporting the UDSET in implementing an outcomes focus to community care in Scotland. Here the stories were created alongside implementation efforts, initially reinforcing the importance of outcomes in the lives of individuals before going on to illustrate what could be achieved through this focus and to address emergent issues.

It may seem logical to assume that digital stories could play a similar role in supporting other specific change initiatives in future. However, it should be noted that its success here did not happen by chance. Rather, it was the result of close and sustained working not only between the two initiatives, but also between the UDSET and the partnership pilots, thereby enabling appropriate storytellers to be identified in a timely manner. The digital storytelling project and the UDSET also shared common aims and core principles, which were conducive to joint working.

Finally, whenever digital stories are being created with a view to linking with a particular service or agenda, the risk of exploitation must be very carefully managed.

## Appendix 1 – Theoretical Contribution of Digital Stories

Theme	<i>Service Improvement</i>			<i>Service User and Carer Involvement</i>		<i>Individual Service User and Carer Experience</i>	<i>Education</i>	<i>National Debate</i>
<i>Theory of Change</i>	<i>Individual Level Change</i>	<i>Service Level Change</i>	<i>Development of Seamless Services</i>	<i>Organisational Level Changes in Culture<sup>4</sup></i>	<i>Service Improvement</i>	<i>Treatment and healing</i>	<i>Workforce Development</i>	<i>Rethinking</i>
<b>Summary</b>	Stories enable staff to gain a deeper understanding of how people experience care, based on the circumstances of individual lives	Stories can reveal specific improvements that can be made at service level – immediately, following review or upon deeper investigation	Bringing together organisations / departments to consider stories can facilitate shared empathy, a more person-centred service and an enhanced sense of team work	Stories act as stimuli for and are integral to a shift to a more person-centred culture / strategy within the context of an overall drive towards involving service users and carers	Service users and carers can become involved in groups in the development of changes that have emerged from the stories	Storytelling is a creative, empowering and even cathartic experience, which can contribute to service user or carer's sense of being listened to and understood	Outputs are used in the ongoing education of health & social care professionals	Stories provide a new perspective on service user and carer experience, placing it in a broader context leading to re-thinking at national level

*Adapted from CHD Collaborative – Evaluation of Discovery Interviews April 2005*

<sup>4</sup> Stories can also support other organisational level cultural changes by helping to retain focus against a backdrop of complex processes and language e.g. retaining an outcomes focus in community care

## Appendix 2 – Observed Contribution of Digital Stories

Theme	<i>Service Improvement</i>			<i>Service User and Carer Involvement</i>	<i>Community Care Outcomes Focus</i>	<i>Individual Service User and Carer Experience</i>	<i>Education</i>	<i>National Debate</i>
<i>Observed Change</i>	<i>Individual Level Change</i>	<i>Service Level Change</i>	<i>Development of Seamless Services</i>	<i>Organisational Level Changes in Culture</i>		<i>Treatment and healing</i>	<i>Workforce Development</i>	<i>Rethinking</i>
<b>Summary</b>	<p>Stories enable staff to gain a deeper understanding of how people experience care, based on the circumstances of individual lives</p> <p><i>Stories act as stimuli for staff to reflect upon and re-evaluate their interactions and relationships with service users and carers.</i></p>	<p>Stories can reveal specific improvements that can be made at service level – immediately, following review or upon deeper investigation</p>	<p>Bringing together organisations / departments to consider stories can facilitate shared empathy, a more person-centred service and an enhanced sense of team work</p> <p><i>Staff stories can also serve to acknowledge and share different understandings and values across professional groups, and to address specific issues &amp; challenges as they emerge</i></p>	<p>Stories act as stimuli for and are integral to a shift to a more person-centred culture / strategy within the context of an overall drive towards working in partnership with service users and carers</p>	<p><i>Stories reaffirm the importance of outcomes in the lives of individual service users and carers and illustrate the advantages of taking an outcomes based approach to assessment and review, within the context of an overall drive towards a focus on outcomes in community care</i></p>	<p>Storytelling is a creative, empowering and even cathartic experience, which can contribute to service user or carer's sense of being listened to and understood and even to their sense of self-esteem and wellbeing</p>	<p>Outputs are used in the ongoing education of health and social care professionals.</p> <p><i>Digital storytelling contributes to the development of self-esteem and reflective practice in health / social care professionals</i></p>	<p>Stories provide a new perspective on service user and carer experience, placing it in a broader context leading to rethinking at national level</p>



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Strength