CREATING LEGACY PROJECTS FOR HOSPITAL HOSPICE AND COMMUNITY

REPORT BY

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I would like to thank my hardworking colleagues from the palliative care team at Central North West London NHS Healthcare Trust for their support and encouragement during the application process for the Fellowship. I would also like to thank them for their understanding and generosity of spirit during the six weeks I spent travelling in the USA and Canada and for all of the extra work they undertook in my absence.

I would like to thank all of my hosts in the USA and Canada for making time to introduce me to their inspiring projects and answer all of my questions. I encountered such kindness as well as professionalism and was made to feel welcome everywhere I visited.

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My thanks to the Winston Churchill Memorial Trust for offering me this incredible opportunity and for providing ongoing guidance and support. I am hugely honoured to be a Churchill Fellow.
I qualified as a nurse in 2009 and currently work as a community palliative care clinical nurse specialist within Central North West London NHS Healthcare Trust. My role is to provide specialist support and advice to patients and their loved ones who are living with serious illnesses, and who may be nearing end of life.

Prior to training as a nurse, I worked as a freelance illustrator for over a decade and have had my work published in magazines, newspapers and books internationally. I have held several exhibitions of artwork in London and Australia both collaboratively and as a solo artist. In April 2015 I launched an online magazine www.prnmagazine.com which aims to explore the connections between medicine, science, design, culture and technology. Founding PRN Magazine has given me the opportunity to bring my two worlds of art and nursing together on a personal level, and on a larger scale has opened my eyes to the wealth of possibilities that exist between health and creativity.
The idea that ‘everybody has a story to tell’ was the starting point for my exploration into legacy projects for hospital, hospice and community. Legacy activities are described as projects that may: ‘assist individuals and families in initiating the process of life review’ and ‘result in a product that can be enjoyed by family and friends prior to and after the individual's death’. These projects can take on many forms and can be carried out by a variety of facilitators in different settings. Legacy projects have shown to aid with psychosocial, spiritual and physical symptoms at end of life and can help with the bereavement process for loved ones, yet are not routinely offered within palliative and end of life settings within the UK.

In April 2016 I spent six weeks in the USA and Canada on a Winston Churchill Travelling Fellowship investigating existing legacy projects in the USA and Canada. My aim was to learn about the impact on patients and and their loved ones who engage in these projects with a view to adapting models of good practice for hospice, hospital and community in the UK.

My main findings are:

- The largest legacy project currently underway in the USA is the StoryCorps Legacy Initiative. This has proven beneficial for all participants, including clinicians who have acted as facilitators. There is potential for a similar model to work within healthcare settings in the UK.

- Narrative is present in many interactions within everyday clinical practice. Understanding more about the field of Narrative Medicine can potentially enhance these interactions and teach clinicians to better understand the ‘stories of illness’.

- Many facilitators of legacy work place a higher value on the process and meaning of legacy work rather than the final product.

- Art therapists and music therapists can be facilitators of legacy projects, however their work is often part of an individually tailored therapeutic process.

- Involving artists and musicians in projects offers the opportunity for unique and creative approaches to legacy work.

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• Bringing different communities together in legacy projects can result in multiple benefits for all parties involved.

• Digital legacy is becoming more relevant as an increasing number of people have social media accounts and online lives. Healthcare professionals may be required to help guide patients through safeguarding their digital assets and creating a digital legacy.

• A number of legacy projects, digital and otherwise, can be completed by people without the need for a facilitator. People may require signposting to these projects.

• Legacy projects do not stand alone within an end of life care context and are reflections of the society in which they are taking place, and of the individual’s understanding of their illness and mortality.

• Innovative thinking around death and dying may help break taboos and encourage discussion around advance care planning as part of ‘everyday’ conversations. Considering your legacy may become part of these conversations.

Recommendations following my findings:

• Legacy Projects can aid with psychosocial, spiritual and physical symptoms for those near end of life, and may help the bereavement process for loved ones. There should be greater awareness around legacy projects amongst those working in palliative and end of life care and greater opportunity to partake in legacy projects as part of advance care planning for patients and those important to the patient. The development of a ‘Legacy Toolkit’ may help guide facilitators and clinicians around the identification, facilitation and evaluation of legacy projects.

• Each community offers a wealth of opportunity with regard to legacy activities. An effort should be made to identify possible collaborations between palliative patients, their loved ones and relevant members of the community such as artists and art students. These types of projects can prove beneficial for all parties involved and can allow legacy to be explored from a creative perspective. Collaborations between medical students and patients have shown to develop greater communication skills and feelings of empathy amongst the students who took part. This can help to develop compassionate clinicians of the future.

• Digital Legacy and digital assets should be considered when discussing advance care planning with patients and their loved ones. Many people now have an online presence and patients or their loved ones may require assistance to access or preserve digital assets. There is a growing trend for digital platforms to curate legacy and clinicians may need a knowledge of these platforms when considering legacy activities for patients and their loved ones.
I am extremely privileged in my role as a community palliative care clinical nurse specialist to be invited into people’s lives at arguably some of their most stressful, vulnerable and uncertain times. I often meet people at a critical point where what is ‘normal’ takes on a very different shape, and they and their loved ones are coming to terms with changing identities, routines and futures. Our team have a unique insight into how people live with life-limiting illnesses, and therefore, in my opinion, have it within our power to help shape how this looks for the better.

It was with this thought that I applied for, and was fortunate to be awarded, a Winston Churchill Travelling Fellowship to research legacy projects for hospital, hospice and community. This report documents my findings, recommendations and dissemination plan following my six week trip to the USA and Canada throughout April-May 2016.

**Background**

I first became interested in legacy projects after reading about StoryCorps Legacy Initiative in the USA and listening to some of the powerful and moving interviews on NPR (National Public Radio) and the StoryCorps website. The concept behind StoryCorps is beautifully simple: to record conversations and interviews between everyday people living in America which are then stored in the Library of Congress. The mission of StoryCorps is to create a tapestry of voices talking about their lives and experiences in order to build connections and to preserve and share people’s stories. StoryCorps Legacy Initiative records the voices of people who are living with serious illnesses and has formed partnerships with hospitals, communities and hospices all over the USA.

I was struck by the simple power of creating the time and space for people to reflect on their lives when they may be facing death through gently guided interviews either with friends and family members, or clinicians. Discovering the StoryCorps Legacy Initiative prompted me to further explore legacy projects and specifically their role within palliative care.

Legacy projects can take on many different forms including audio and video recording, scrapbooks, song writing, artwork, writing and photography and have been defined as projects that may: ‘assist individuals and families in initiating the process of life review’ and ‘result in a product that can be enjoyed by family and friends prior to and after the individual’s death.’

Legacy projects can be carried out by a variety of people including nurses, doctors, allied health professionals, art therapists, music therapists, students, volunteers, artists and musicians.

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3 https://storycorps.org/legacy/
Literature suggests that legacy projects have shown several significant patient benefits including decreased breathing difficulties, distraction from pain and negative thoughts, increased religious meaning, greater social interaction, preparation for end of life, greater appreciation for self\(^5\) as well as improved family communication and decreased caregiver stress.\(^6\)

The potential benefits of legacy projects align with the World Health Organisation’s definition of palliative care as being ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual\(^7\)’. The national framework \textit{Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020}\(^8\) places an emphasis on the individualisation of care plans for patients and their loved ones, and highlights the importance of having honest conversations around death and dying. The \textit{Ambitions} document states that ‘caring for the individual includes understanding the need to support their unique set of relationships with family, including preparing for loss, grief and bereavement.’ This is further echoed by the July 2016 paper ‘\textit{Our Commitment to you in end of life care: The Government response to the Review of Choice in End of Life Care}’\(^9\) where the plan for providing ‘Better, personalised care for people approaching end of life’ is laid out. This includes developing and documenting a personalised care plan and having honest conversations around needs and preferences for physical, mental and spiritual wellbeing in order to live well until death.

One key study into legacy projects at end of life concludes that ‘legacy interventions show promise and are relatively simple to implement.’\(^10\) If this is the case, and if legacy projects have the potential to enhance existing palliative care practice whilst aligning with current policy and guidance, I asked myself why we were not offering them to our patients and their loved ones. It was with this thought and the mantra of StoryCorps; ‘every voice matters’ that I embarked on a six week trip to the USA and Canada to learn from existing practice around legacy projects for end of life.

\(^7\) http://www.who.int/cancer/palliative/definition/en/
\(^8\) http://endoflifecareambitions.org.uk/
After discovering the potential of legacy projects for people approaching end of life and those important to them, I looked into other examples of projects and found that there were several places in the USA and Canada where legacy work was being carried out. Through the generous grant awarded by the Winston Churchill Memorial Trust, I was able contact and plan to visit organisations and people involved in the innovation and implementation of many of these projects.

My objectives were:

- To research and document existing legacy projects in the USA and Canada in order to learn about the impact on patients and their loved ones who engage in these projects with a view to developing models of best practice for hospice, hospital and community in the UK.

- To collaborate with patients and their families/friends, clinicians, NHS policy makers and stakeholders and other interested parties in the UK to effectively disseminate my findings with a view to shaping culturally appropriate legacy models for hospice, hospital and community in the UK.

- To contribute to research in the UK around the impact of legacy projects through audit and evaluation of chosen models.

- To develop and maintain strong international relations with colleagues in the USA and Canada and to continue sharing ideas around best practice to enhance choice at end of life.

**Methods**

I learned that the National Hospice and Palliative Care Organisation’s (NHPCO) annual conference was taking place in mid-April near Washington DC and planned the beginning of my trip around this date. I wanted the opportunity to get a feel for the current issues and areas of innovation within palliative care in the USA and felt this conference would be a good place to start. I also wanted to attend an annual Dignity Therapy workshop in Manitoba, Canada at the end of May facilitated by Dr Harvey Chochinov who has contributed to a wealth of research around legacy and life review in palliative care.
The rest of my trip was structured around these two events at the beginning and end of my trip. I organised visits to significant organisations across the USA which I found through research and recommendation by other professionals. My main method of contact was via email and I found that most of the organisations and individuals I contacted were very responsive and helpful when working out possible dates to meet. My trip was based primarily around the East and West Coasts of America as this was where the highest concentration of organisations and people undertaking legacy work appeared to take place. My visits mainly took the form of shadowing and interviewing professionals involved in legacy projects. I also wanted to visit places and meet people involved in the ‘death positive’ movement and find out more about public engagement projects designed to encourage people to consider their own mortality.

When planning visits specific to legacy work I considered several questions:

1: Which model/models of legacy project are being used and why?

2: Is the project local, national or international?

3: Who carries out the projects?

4: Is there a tool that helps people identify those who may be eligible for legacy projects?

5: How is the project evaluated?

6: Could this be adapted for practice in the UK and in which setting?

I kept written notes following each visit and meeting as well as documenting my trip photographically. I also wrote several articles for my online magazine under a section named ‘The Legacy Project’. These can be found here: https://prnmagazine.squarespace.com/about-the-project-1/
Key Themes and Findings

StoryCorps Legacy Programme

Storytelling is integral to the human experience and transcends age, race and socioeconomic barriers. One of the largest organisations dedicated to capturing people’s stories is StoryCorps which was founded in 2003 by Dave Isay. It has since gone on to win an Institutional Peabody Award, the MacArthur Award for Creative and Effective Institutions and the 2015 TED prize. StoryCorps mission is to ‘preserve and share humanity’s stories in order to build connections between people and create a more just and compassionate world’ and is based on Dave Isay’s idea that ‘listening is an act of love.’ Most StoryCorps interviews take place in a recording booth where participants, who may be friends or family members, interview each other about their lives. These stories are then preserved in the Library of Congress as part of America's largest oral history project to date.

After being inspired to apply for the Fellowship following my discovery of StoryCorps Legacy Initiative, one of the main focuses of my trip was to find out more about this project. The Legacy Initiative offers the opportunity for people living with serious illnesses to record and share their stories and has partnered with hospitals, hospices and community organisations across America.

I visited the StoryCorps Legacy Team and their headquarters in Brooklyn, New York, on the day a ‘Listening Lunch’ was being held. The Listening Lunch was an opportunity for many of the interns who had been working with StoryCorps Legacy, and who had been pivotal in the organisation and production of many interviews, to take time to remember some of the people who had taken part in recordings.
It was clear that working with the Legacy Initiative meant a great deal to the interns as we sat and listened to a selection of interviews, each introduced with the backstory of how they came about, who was involved and a little about the impact of the project on the people who took part. After the Listening Lunch I sat with several members of the Legacy team and talked about the work that goes into creating, training and maintaining partnerships with healthcare providers, as well as the recent evaluation of the project.

The StoryCorps Legacy Initiative differs from most of the other StoryCorps programmes in the sense that the recording comes to the people, rather than people travelling to attend a recording booth - as many would be physically unable to do this. Through creating partnerships with hospitals, hospices and community organisations, StoryCorps have devised a ‘train the trainer’ model which enables partners to then offer StoryCorps Legacy interviews and recordings as part of their practice. The training usually lasts three days and over this time partners are shown how to use recording equipment, how to facilitate interviews and how to obtain consent to carry out recordings. The StoryCorps Legacy team told me that the involvement of clinicians in the recording of interviews has resulted in many clinicians reporting hugely positive benefits for themselves. This was not initially considered as being a target of the project, but has rather grown organically as more and more people gave feedback around how participating had positively affected them. A quote from Johns Hopkins Bayview Department of Medicine Chair David Hellmann speaks volumes to this; “we are better doctors because of your work.”
In February 2016 the first evaluation of the legacy initiative was published. Entitled ‘StoryCorps Legacy: An Unexpected Gift at a Sacred Time. Findings from Participant Interviews’ the evaluation, which was carried out by an independent consultancy,\(^1\) details the effects of the initiative through seven key findings:

1. Legacy is a highly positive and emotionally rewarding experience; all participants would encourage others to participate.
2. Altruistic reasons drive the decision to participate in Legacy.
3. Preserving the story for family and future generations is of great value to Legacy participants.
4. More than half of the interviewers and storytellers found Legacy to be different from, and more special than, sharing or listening to a personal story in other circumstances.
5. For some participants, the full impact of the StoryCorps Legacy interview/recording may take time to evolve.
6. The Legacy experience was slightly different for paediatric storytellers and their interviewers - they reported discussing topics that were more current or future focused rather than reminiscent.
7. Many Legacy participants didn’t cover everything they wanted to cover in their interview/recording.

When discussing the evaluation with the Legacy team at their headquarters, they told me that they were extremely encouraged by the positive findings, and that they now have a much clearer idea of how to make changes and shape future partnerships using the feedback.

In the UK the StoryCorps model has been adopted by BBC Radio 4 and is named ‘The Listening Project\(^2\). Interviews are recorded in booths and then stored in the British Library archives as part of an oral history project which mirrors the StoryCorps mission. At the time of writing ‘The Listening Project’ has not as yet extended into the StoryCorps Legacy Initiative model, however I believe there is real potential for this to be piloted. There is also a StoryCorp app available which is free to download and offers the opportunity to record and upload interviews on a smartphone. This may offer the opportunity for people to record interviews guided by the StoryCorps model relatively easily and with no cost.

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1. Carried out by Touchstone Consulting. Published in February 2016.
2. [http://www.bbc.co.uk/programmes/b01cq3b](http://www.bbc.co.uk/programmes/b01cq3b)
I met Lauren Brooks, a third year internal medicine resident from Johns Hopkins Bayview Medical Centre in Baltimore, MD, who was pivotal in bringing the StoryCorps Legacy Initiative to her medical programme alongside fellow resident Kadee Winters. Lauren describes this as happening very much by chance following an ad hoc conversation between Lauren and Kadee about their mutual interest in narrative medicine. Lauren then contacted StoryCorps and was put in touch with the Legacy team who worked closely with Lauren and Kadee to bring their initiative to Johns Hopkins. Lauren cites a very supportive course leader and a specific focus on patient centered medicine as being integral to the success of the project. Residents can typically work 80 hour weeks and to bring an added element into their already packed schedules requires passion and dedication. Lauren says that prior to this project she wasn’t aware of any specific work around legacy for patients at Johns Hopkins. Lauren describes working with StoryCorps as a very positive experience. They visited Johns Hopkins and ran a four day ‘train the trainer’ course where participants (all volunteer resident MDs from Lauren and Kadee’s course) learned how to recruit people, use the recording equipment, make the most out of interviews and about the legal aspects of the initiative. They then involved the patients and their loved ones who had shown an interest in participating. In total they completed 31 recordings, some of which were between patients and doctors, some between patients and their loved ones, and others were doctor to doctor. Lauren felt that the StoryCorps project helped residents remember why they were dedicating so much time and energy to training, and also helped them to reconnect with patients as people.

Lauren cited several examples of the StoryCorps project having a ‘ripple effect’ of positivity; from the granddaughter who received a CD of her grandfather talking about her grandmother which was then played at his funeral, to the inspiring and moving Listening Party which was held after the project wrapped up and which, Lauren believes, reaffirmed the commitment of the department to their patient centered focus.

The project ran for four months at no cost, and on reflection Lauren believes it could have run for much longer if it was not for the rotation of residents involved in the project, and the amount of time needed to run the project alongside the many other responsibilities of a third year resident. The project may also have been able to run for longer if there was a dedicated volunteer or permanent staff member in a specific department who could take the lead for the running of the initiative.
The project is one of Lauren's proudest achievements of her residency, and she believes it was a transformative experience for many of the people involved. The recordings are now available as a testament to the department's belief in patient centered care, and can serve as training materials for future residents and other clinicians.

Other places visited:

**Mount Sinai Hertzberg Palliative Care Unit, New York.**

I spent the day with Art Therapist Sarah Yazdian who uses StoryCorps Legacy as part of her 'toolkit'. Although Sarah uses StoryCorps Legacy in her work, she says she takes her 'therapist hat' off when interviewing and recording participants. StoryCorps does not require the skills of a trained therapist to produce interviews, and in this respect has the potential to be utilised by a greater number of people, both interviewers and participants.

**Zen Hospice Project, San Francisco, California.**

The power and potential of storytelling is very highly valued at the world renowned Zen Hospice Project. StoryCorps Legacy Initiative is incorporated into their model of care and they have a dedicated member of staff responsible for coordinating recordings and training staff.

*Narrative Medicine*

Every patient has their own unique story of their illness, and clinicians are told these stories every day. How a clinician extracts, hears, interprets and acts on these stories in order to better understand and treat the storyteller has been developed into a practice known as narrative medicine. The pioneer of narrative medicine is Rita Charon, Professor of Clinical Medicine and Director of the Program in Narrative Medicine at Columbia University in New York. I had the honour of spending time with Dr Charon in her office in Presbyterian Hospital in upper Manhattan, and was quite awed by someone who so skilfully and delicately weaves connections between literature, storytelling and medicine. Dr Charon is a Primary Care physician who undertook a PhD in English Literature when she realised how central narrative was to her work as a doctor. She and her colleagues in the Narrative Medicine Department - aside from teaching a full programme - now guide clinicians at Presbyterian Hospital in drawing out narratives from their own practice, as well as educating them on how to be skilled readers and listeners.
Dr Charon writes about the practice of narrative medicine; ‘As my colleagues and I in the Program in Narrative Medicine are discovering, not only is diagnosis encoded in the narratives patients tell of symptoms, but deep and therapeutically consequential understandings of the persons who bear symptoms are made possible in the course of hearing the narratives told of illness.’

Dr Charon suggests that asking the simple question; ‘can you tell me what you think I need to know about your situation?’ followed by close listening and observation as the patient tells the narrative of their illness, can transform the relationship between clinician and patient, and offer the opportunity for greater diagnostics and treatment as a result.

Speaking to Dr Charon I found myself reassessing my own interactions with patients and their loved ones, and considering how I could begin to integrate the principles of narrative medicine into practice. Whilst StoryCorps Legacy Initiative certainly has potential to be successful in an English setting, perhaps the stories captured should be along the same continuum of a narrative approach to practice. Instead of listening to our patients’ stories for the express purpose of recording them for a specific occasion, perhaps we should also be connecting the dots between how someone speaks of themselves and their illness and using these connections to respond in a more humane and effective manner every time we interact with our patients.

Legacy is often explored through storytelling and oral history.

The largest legacy project currently underway in the USA is the StoryCorps Legacy Initiative. This has proven beneficial for all participants, including clinicians who have acted as facilitators. There is potential for a similar model to work within healthcare settings in the UK.

Narrative is present in many interactions within everyday clinical practice. Understanding more about the field of narrative medicine can potentially enhance these interactions and teach clinicians to better understand the ‘stories of illness’.

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The idea of undertaking a legacy project suggests that something tangible will be produced to pass onto loved ones after someone has died. This final product may hold great value for bereaved friends and family, but the creation process for the dying person is seen by many facilitators as a valuable opportunity to address existential, physical and psychosocial issues. I visited several organisations and met with people facilitating legacy work who specifically focused on the therapeutic aspects of creating a legacy.

Sarah Yazdian - Art Therapist at Mount Sinai Palliative Care Unit, New York.

I shadowed art therapist Sarah Yazdian who uses many different techniques in her approach to legacy work. Sarah has many tools to hand as an art therapist and views legacy work as a therapeutic process rather than a means to creating a ‘product’ to pass onto loved ones, though this may ultimately be the outcome. Sarah is the editor-in-chief of ‘The Loom’, a magazine which showcases the work that art therapists carry out with people on the palliative unit. Each picture, poem, photograph or object is the result of skilled therapeutic work between Sarah and her client. Through the use of various different mediums patients can make meaning from their experiences and communicate what may be difficult to speak of through creative means. In Sarah’s experience the process of working with different materials can often have effects on symptoms, both physical and psychological. One patient in particular found handling clay reduced her need to use pain relief dramatically, and she ultimately produced a series of clay Christmas decorations for her family to remember her by - including one for herself. Sarah describes this process as being a journey that she travelled with her patient as she came to terms with the reality of dying and not being with her family for Christmas, as she always had been. What may ultimately appear to be a simple project - producing clay decorations - was the result of in depth, sometimes painful, work between therapist and client.
Music Therapy at Seasons Hospice, Baltimore, Maryland.

I spent the day with Anne Hansen, Director of Supportive Care for Seasons Hospice, Maryland. Seasons Hospice is a nationwide organisation and one of the largest in the United States. Anne is a social worker by background and is a great advocate of legacy projects. Seasons produce a specific leaflet for patients and their loved ones about their ‘Leaving a Legacy Program’ which is described as being ‘a way to capture life stories, lessons, sentiments, memories, and traditions.’ Legacy projects they offer include creating milestone notes, life interviews, photo projects, slide shows, cook books and audio recordings. Seasons are also one of the only organisations to have music therapists as part of the MDT and they place a great emphasis on the possibilities of using music therapy at end of life.
I met with a music therapist at one of the inpatient units near Baltimore who described some of the work that she carries out including writing original songs with patients, turning poems and letters into songs, creating playlists for people, and simply singing and playing music for patients at their request. I attended an MDT whilst at Seasons and observed how the music therapist was given equal time and opportunity to discuss current projects and the perceived impact on their client and friends and family. A quote from a patient called Calvin Harris who turned a poem he wrote into a song with the help of a music therapist is testament to the potential of music therapy; “First, I was serving in the Air Force during the Vietnam War; then I was a fireman; then, I got cancer. And now...now I have a song. You just don’t know what that means to me.”

A ‘Legacy Project Brag Board’ at Seasons Hospice in Baltimore, Maryland.

The work that art and music therapists carry out is undeniably valuable, however neither art therapists nor music therapists are part of every MDT within palliative care in the UK, as is also the case in the USA. Both music and art therapy are specific interventions which are underpinned by evidenced based practice. It is not the case that the work of art or music therapists can be replicated by an untrained volunteer, and projects that are carried out by people other than trained therapists should not be advertised as ‘therapy’. Whilst these projects can have some therapeutic effects, the knowledge and training of an art or music therapist allows them to approach music or art-based interventions in a truly therapeutic manner.
Dignity Therapy

Dignity Therapy was pioneered by Canadian physician Dr Harvey Max Chochinov, and is described as a ‘brief psychotherapy that can enhance a sense of legacy while addressing the emotional and existential needs of patients receiving hospice or palliative care’. People who partake in Dignity Therapy work with a trained Dignity Therapist who interviews them about their memories, achievements and lessons they wish to pass on to their loved ones. This interview is then transcribed and edited - alongside the patient - and then presented as a final document to be passed onto chosen friends and family. Dignity Therapy is internationally renowned, and is the subject of a relatively large body of research, mainly overseen by Dr Chochinov and his team at the Manitoba Palliative Care Research Unit. Typically Dignity Therapy is carried out over four one hour sessions and is guided by questions detailed below.

**Dignity Therapy Questions:**

- Tell me a little about your life history; particularly the parts that you either remember most or think are the most important?
- When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others?
- What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other[s])?
- Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- In creating this permanent record, are there other things that you would like included?

I was very keen to see Dignity Therapy in practice, and also undertake training myself in order to see how transferable and feasible this would be for my own team in the UK.

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Dignity Therapy in Practice

Whilst in San Diego, California, I spent time with Psychology Professor Lori Montross who is involved in Dignity Therapy research at the University of California through her affiliation with Dr Chochinov. Professor Montross very kindly organised for me to observe Dignity Therapy being carried out in practice at a long term care facility several miles outside of San Diego. I was fortunate to bear witness to the ‘editing’ process of Dignity Therapy which took place between Tom, a chaplain who worked at a local hospice, and Rita, a resident from the long term care facility. Rita was a vibrant 87 year old with multiple myeloma who was still mobile, self-caring and with no cognitive impairments. Tom had previously spent one session with Rita in order to complete her initial interview, and had subsequently transcribed the recording to make a first draft of the document. The editing session was an opportunity for Tom to read the transcription out loud to Rita, who could then suggest any changes or edits before publishing the final document. I sat in Rita’s beautifully decorated room, adorned with pictures of her nine children and multiple grandchildren and great grandchildren, and listened as Tom read back Rita’s words to her - essentially speaking her life story out loud. To observe this in action was a very moving experience as I saw Rita’s face change as she went through different emotions ranging from humour, pain, defiance and joy. Rita considered herself to have had a very good life, and that her nine children were her greatest achievement. She had also known difficult times through a failed marriage and ill health, but ultimately felt she had been very lucky with her lot. After the reading Rita said she felt very proud listening to her story, and that it had given her extra energy and a sense of wellbeing. She told me she had undertaken Dignity Therapy as a way to pass her legacy onto her children, and said that when she finally held document in her hands she would feel a sense of completion and contentment.

Dignity Therapy Training

I attended the annual Dignity Therapy Workshop held in Winnipeg, Canada which is home to the Manitoba Palliative Care Research Unit. The training is facilitated by Dr Harvey Max Chochinov and his team of researchers, and was attended by people from all over the world including China, Mexico, Australia and Taiwan. This took place over two and a half intensive days, and comprised of seminars as well as group activities where we learned how to practice being both interviewer and interviewee. In essence the concept of Dignity Therapy is quite a simple one, however I (and the majority of my fellow trainees at the workshop) soon realised that navigating and facilitating an hour long interview with someone which aims to be a record of their life requires a great deal of skill and emotional intelligence. The questions serve as a guide and in no way are meant to be worked through chronologically and robotically, and instead Dr Chochinov encouraged us to use questions almost as ‘pins on a map’ and have an idea of where we were going to place the next few ‘pins’ as the person spoke, in order to navigate them to the richest waters.
It certainly felt that when so much of the potential outcome of the final document was down to the skill of the interviewer, a certain level of confidence and competence to carry out such in depth and personal questioning was required. As many of us were partaking in the workshop from overseas and would be returning as the sole trained Dignity Therapists, I was unsure if this skill and confidence could actually be acquired over such a short period of time, and without continuing mentorship after the completion of the workshop.

On the second day of the workshop we had the opportunity to observe Dr Chochinov carry out a Dignity Therapy interview with a 53 year old woman with metastatic breast cancer and who had a prognosis of less than a year. She had fully consented to being interviewed in front of an audience, and her health at the time was good enough for her to be able to travel to the venue. Observing the pioneer of Dignity Therapy carry out an intense, often bittersweet and emotional interview with a woman who didn’t have children, but who had lived a fulfilling, intellectually rewarding life and who wanted her interview to be used for educational purposes was a unique experience. Prior to this interview I had been concerned that much of Dignity Therapy appeared to focus on creating a legacy for people with children, so was reassured to witness someone who had no children consider part of her legacy as being a continuation of the thread of education that had run through her life.

By the end of the workshop I ultimately concluded that Dignity Therapy was undeniably an effective legacy tool for a small cohort of people. The time and skill that is involved in interviewing, transcribing, editing and publishing a Dignity Therapy interview is unfortunately not readily available in most busy NHS settings.
Furthermore, the timing of introducing the concept of Dignity Therapy in a person’s illness trajectory requires their sufficient understanding of prognosis and eventual end of life coupled with enough lucidity and energy over a period of approximately a month in order to complete the full Dignity Therapy document. As Dignity Therapy cannot be adapted or shortened in any way and can only be carried out by someone who has undergone training, this further limits how many people could benefit from this as a legacy tool.

Many organisations offer ‘life review’ in terms of recording or writing life stories, which bears a resemblance to Dignity Therapy though is not the same structured intervention, however may ultimately be a more realistic model in practice.

Key Findings

Many facilitators of legacy work place a higher value on the process and meaning of legacy work rather than the final product.

Art therapists and music therapists can be facilitators of legacy projects, however their work is often part of an individually tailored therapeutic process.

Dignity Therapy is one of the most recognised life review interventions and was pioneered by Dr Harvey Max Chochinov. Dignity Therapy is designed to address psychosocial and existential distress at end of life by offering an opportunity to record meaningful aspects of a person’s life which can then be passed onto their loved ones. This may work for a small cohort of people, however may not be easy to translate into practice due to factors including time and skill required to carry out Dignity Therapy.
Legacy Projects, creativity and the wider community

Artistic engagement has been shown to have positive effects on health\textsuperscript{16} and being an illustrator as well as a nurse I am always interested the creative arts being incorporated into healthcare. During my travels I came across several organisations where art and music were being used to explore ideas of identity, healing, memory and legacy. I also discovered examples of ‘cross-pollination’ where different communities joined together to work on projects that ultimately had positive benefits for everybody involved. In any community there are untapped resources and opportunities to bring people together through different projects. I was keen to discover the types of projects already in existence with a view to setting up similar projects within my own community in the UK.

Zen Hospice Project

The Zen Hospice Project in San Francisco is renowned as a place of innovation around approaches to end of life. I spent a morning with Director of Marketing Geoff Dunlop who gave me a tour of the beautiful Victorian building which is filled with artwork created by both patients and artists. Geoff told me that the hospice places a large emphasis on creativity and has an artist-in-residence programme, with each artist bringing their own unique take on their interactions with people in the hospice and themes that arise from spending time considering the nature of life, death and everything in between.

Their artist-in-residence programme began in 2014 with performer and filmmaker Josh Kornblunth\(^\text{17}\) who is currently working on a film about his transformative experience and who now volunteers weekly at the hospice. The most recent artist-in-residence was illustrator and graphic journalist Wendy MacNaughton\(^\text{18}\) who has worked for The New York Times and The Wall Street Journal amongst many other clients.

The Zen Hospice Project was also involved in an internationally acclaimed project by artist Claudia Bicen entitled ‘Thoughts in Passing’\(^\text{19}\) which drew worldwide press and has been exhibited in both the USA and the UK. ‘Thoughts in Passing’ is the result of a two year exploration into a question Claudia has been transfixed by since being a small child: how should we live? In order to find answers to this, Claudia contacted local hospices in the Bay Area of San Francisco and interviewed, recorded and drew nine people who were close to the end of their lives. The resulting project is a tender portrayal of nine individuals who talk about their joys, regrets, life lessons and worries as they approach death. Their words are transcribed onto their clothing as well as heard over their portraits in three minute recordings.

‘Jenny’ by Claudia Bicen - shown at the Smithsonian Portrait Museum in Washington DC.

\(^{17}\) http://joshkornbluth.com/

\(^{18}\) http://wendymacnaughton.com/

\(^{19}\) http://www.thoughtsinpassing.com/
I interviewed Claudia Bicen for PRN Magazine about ‘Thoughts in Passing’ and asked, among other questions, about the impact of her work on her subjects and the importance of leaving a legacy:

**Did the people you drew and recorded find the process cathartic? What were their reactions to the finished project?**

CB: Yes, I believe they did. The feedback I received from all of my subjects was very positive. I think that in our culture we shut away people who are dying because they are considered no longer able to contribute to society. This project turned that idea on its head because my subjects were creating this project with me right up until they died. During a period typically defined by loss, the act of creation was certainly cathartic. I recently held an exhibition at the Chapel of the Chimes in Oakland, California, and one of my subjects, Judith, was able to visit with her friends and family. They sat in front of her portrait and listened to the audio for a long time. Every time I saw her after that she was beaming with joy.

**Do you think it’s important to leave a legacy - whatever form that may take, and regardless of the ‘success’ of your life?**

CB: Absolutely. I often think about how incredible it would be to have a collection of letters and audio recordings from all the generations in my family going back in time. What challenges would we share as human beings and what would our differences be? What could they teach me about life that I am still struggling to learn? It seems so simple to do this, but it requires great foresight and an acceptance that you are but one piece in a long string of people through time. I’m currently 16 years into a project whereby I write to my future self once a year about what I have learned. I hope to be able to pass this work down to my children one day.


**The California State University Institute for Palliative Care**

The California State University Institute for Palliative Care is based outside of San Diego, California, and provides training and education programmes for students and healthcare professionals whilst also educating the local community about the benefits of palliative care. I spent a day with Faculty Director and Professor of Psychology, Dr Sharon Hamill, who introduced me to the varied and fascinating array of projects and programmes the Institute offers. I was particularly interested in the community outreach programmes which used the arts to address issues such as bereavement and post-traumatic stress disorder.
Healing Through Art

*Healing Through Art*[^20] is an 8-week “train the facilitator” program offered by CSU Institute of Palliative Care. Facilitators are trained for four weeks in art techniques, how to run discussions, and how to recognise and refer those who need more assistance. The faculty also hosts art workshops for widows and widowers, run by a widower, where they are encouraged to use creativity as an outlet for bereavement.

Peace Paper Project

Due to the proximity of Camp Pendleton, the West Coast base of the United States Marine Corps, CSU offers workshops specifically for veterans and families of veterans. I was particularly inspired by a project called ‘The Peace Paper Project’[^21] which “uses the ancient tradition of hand papermaking as a vehicle for personal expression and cultural change.” Veterans are asked to bring their old military uniforms and are then shown how to turn these garments into pulp in order to make paper, which they can then decorate however they choose. The workshops offer the opportunity to share stories, connect to other veterans, and transform suffering into healing through the literal transformation of uniform into blank paper, on which are then often written messages of hope and survivorship. I was very fortunate to be given one of these handmade papers, on which is written ‘I am rare + precious. All life around me is equally so.’ The idea of creating a legacy through such a powerful process demonstrated to me how the arts can offer an opportunity to explore personal experiences from a unique angle which would not have been possible without the skills and ideas of the artists involved.

Compassionate Allies

Whilst at Seasons Hospice in Baltimore, Maryland, I was introduced to the Compassionate Allies project which brings together pre-medical students at Wayne State University School of Medicine and people living with serious illnesses who may be nearing end of life. Compassionate Allies was a research project which took place between 2012-2015 and which aimed to assess the feasibility of pre-med students volunteering with hospice patients and assisting in the completion of a legacy project.

[^20]: https://csupalliativecare.org/campuspartners/csusm/
[^21]: http://peacepaperproject.org/
In the USA the term ‘hospice’ is used to describe people who may be at home and at end of life, as well as those who may be an inpatient in a hospice organisation. This distinction is important as Compassionate Allies partnered students with people living in their own homes, so therefore demonstrates that this project is possible within a community setting.

The idea behind piloting Compassionate Allies was to introduce pre-medical students to people at end of life and to encourage them to develop skills in communication and empathy, and also gain experience in talking about death and dying. Through working with them on a legacy project, they then had an opportunity to address the psychosocial, emotional, spiritual and physical needs of patients and families when faced with end of life. In return patients and their loved ones who involved in the Compassionate Allies project had an opportunity to complete a legacy project and hopefully feel supported by the student working with them.

*The table below shows the results of the primary and secondary project goals and is taken from the final report of the Compassionate Allies Project by Principal Investigator Robert J. Zalenski, MD, MA.*

<table>
<thead>
<tr>
<th>Summary Table of Project Goals</th>
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</thead>
<tbody>
<tr>
<td><strong>Primary Goals:</strong></td>
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<tr>
<td>● Provide Seasons Hospice Foundation with a program that could be replicated at other universities and Seasons Hospice sites.</td>
</tr>
<tr>
<td>● Demonstrate a hospice and university partnership to provide pre-medical undergraduates with training and experience in end-of-life issues.</td>
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<tr>
<td><strong>Secondary Goals:</strong></td>
</tr>
<tr>
<td>1. Train and empower pre-med students to assist patients and families to better cope with and manage the challenges brought about by incurable illness.</td>
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<tr>
<td>2. Educate pre-med students on the best utilization of hospice and palliative care</td>
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<tr>
<td>3. Provide pre-med students with a service-learning opportunity by matching students with needy hospice patients and families, creating Compassionate Allies</td>
</tr>
<tr>
<td>4. Obtain qualitative and quantitative feedback from Compassionate Allies, patients and their families on the program.</td>
</tr>
</tbody>
</table>

This is an example of a mutually beneficial project which has the potential to be replicated in other Medical Schools. Compassionate Allies is now part of the formal preclinical co-curricular Program of the Wayne State University School of Medicine which is the largest single campus medical school in the U.S.
Other student-lead projects

During my time with Lori Montross, Professor of Psychology at the University of California in San Diego, I learned about a research project which involved psychology students and nursing home residents who have dementia. The students used an iPod with a selection of the resident’s favourite music to trigger memories and encourage joyful sing-a-longs as well as building relationships between the students and residents. The research aims to measure cortisol levels of residents involved in the project to find out if music has a positive effect on feelings of stress.

The Zen Hospice Project in San Francisco has an ongoing collaboration with a local art college which involves students undertaking a module of their studies at the hospice working with patients and families. At the time of my visit the students had helped create decorative fabric door partitions which allowed for patients to have privacy if the partition was closed, but also feel more involved with the goings on in the hospice if the partition was open.

There is a great deal of potential from initiating projects with students and groups of patients and their loved ones as the benefits for all parties involved are multiple. This model also often offers opportunity for research to be carried out whilst the projects are ongoing. Most communities have colleges, universities, hospitals, nursing homes as well as people receiving palliative care at home. If connections can be made between these organisations there is the opportunity to learn, create and build relationships between people who otherwise may stay separate.

Key Findings

- Involving artists and musicians in projects offers the opportunity for unique and creative approaches to legacy work.

- Bringing different communities together in legacy projects can result in multiple benefits for all parties involved.
Digital Legacy

The internet has revolutionised how we interact and communicate, and many people now have social media accounts as well as videos, audio and photographs stored digitally. The Digital Legacy Association\(^{22}\), a collaboration between healthcare professionals, scholars, technologists and patients, was created in order to assist healthcare professionals with addressing digital end of life planning and digital legacy with the general public. Their framework\(^{23}\), published in 2015, writes of digital legacy; “when we die the interactions that we made (also known as our digital footprint) often remain and help to create our digital legacy. When we die our digital footprint plays a big part in determining our digital legacy.” Digital assets “can be of sentimental, or monetary value, or both. For example, many people now use digital photography and video devices. These include mobile phones, tablets and digital cameras. Most of these photos are no longer printed. Instead they are stored and saved on devices (such as hard drives) and uploaded on platforms like Facebook, Instagram and DropBox.”

Whilst many people actively use social media accounts and store memories digitally, it could be said that there is still a lack of knowledge around how to manage these accounts and collate digital memories when someone is at the end of life or after they have died. The guidance provided by the Digital Legacy Association around advising the general public on how to safeguard their digital assets and shape their digital legacy is a valuable and much needed resource for most healthcare professionals.

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\(^{22}\) http://digitallegacyassociation.org/

During my travels around the USA and Canada researching legacy projects I was introduced to several different apps designed to address the idea of legacy within a digital format. Having an awareness of digital legacy can enable healthcare professionals signpost people to digital legacy apps, or use apps as part of a legacy project which they are facilitating.

**Case Study**

**StoryCatcher App**

I attended a legacy dinner and workshop at the John Muir Medical Centre in Walnut Creek, outside of San Francisco, with personal historian and co-founder of StoryCatcher App, April Bell. StoryCatcher is a free app for iPhones which enables people to record, edit and share their stories, life lessons and messages for present and future generations without the need for a facilitator or expensive recording equipment. The workshop was an opportunity for April to explore the idea of legacy and what this may mean for different people, whilst showcasing StoryCatcher and encouraging people to preserve and document their own legacies through the app. April is extremely proud of StoryCatcher and was recently profiled in an article in the New York Times about revamping ethical wills for the digital age. Ethical wills are non-legal documents which pass on wisdom to future generations, and were traditionally handwritten or typed. Advances in technology now present people with a wealth of different methods to capture this wisdom, and StoryCatcher is one of several methods which combines a traditional idea with modern technology.

Other websites and apps for recording legacy include ‘My Time to Say’ which charges a monthly fee to ‘create a time capsule of what makes you, you’ and which enables people to send and leave messages for loved ones which can be timed to be received even after death. The opportunity to record and time messages for loved ones full in the knowledge that they will be received after death is an increasingly common theme with digital legacy websites and apps.

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25 [https://mytimetosay.co.uk/](https://mytimetosay.co.uk/)
Safe Beyond\textsuperscript{26} has been described by The Washington Post as ‘the world’s first posthumous message delivery system’ and is specifically designed to enable people to record messages which can be timed to be sent on special dates such as birthdays and anniversaries, or events such as graduations or weddings. There is even an option to send a message when a loved one reaches a certain destination such as Paris or New York. Safe Beyond’s website offers users the chance to ‘be around forever’ and ‘allow your digital identity to outlive you.’ It may take a while for people to adjust to the idea of receiving video or audio messages from dead relatives or friends, and indeed for people to record these messages knowing they will only be viewed or heard after death. The promotional video on the Safe Beyond website shows a healthy looking active father recording messages for his wife, daughter and son to be received on his daughter’s wedding day, as he watches his present day daughter and son play by the sea as children. In the video his family are equally moved and thrilled to receive messages from him beyond the grave, however in real life there is no guarantee that everything will work as smoothly. Technology now provides people with the ability to create legacies in ways that may not have been considered before. While the option to send and receive messages from beyond the grave may appeal to some, for others it may take some time for societal ideas around death to catch up with technological possibilities.

**Self-directed Legacy Projects**

Some legacy work can be as simple as suggesting different legacy activities or signposting people to different websites or apps where they can then carry out their own legacy project. If clinicians are made more aware of these activities and where to signpost people, legacy projects can still be part of end of life conversations within healthcare settings. At Seasons Hospice in Baltimore, Maryland, I was shown a list of ‘Legacy Ideas’ which can help prompt clinicians into discussing legacy projects - some of which could be self-directed by patients and their loved ones.

Self-directed projects may appeal to certain people who would prefer to consider their legacy without an outside facilitator being involved. There may also be a way to include legacy projects indirectly within clinical practice without the need for facilitators, which would obviously require less time and financial resources. In order to ensure consistency when considering legacy activities, clinicians may require some kind of toolkit which would enable them to operate within a framework when suggesting and signposting around legacy projects.

\textsuperscript{26} https://www.safebeyond.com/
Digital legacy is becoming more relevant as an increasing number of people have social media accounts and online lives. Healthcare professionals may be required to help guide their patients through safeguarding their digital assets and creating a digital legacy.

A number of legacy projects, digital and otherwise, can be completed by people without the need for a facilitator. People may require signposting to these projects.

Clinicians or those working with patients and their loved ones may benefit from a toolkit which enables them to work within a framework when recommending or facilitating legacy activities.
It is important to view legacy projects in the context of the society in which these projects are taking place. Each society has its own norms and taboos around death and dying, and it is often reported that we live in a ‘death denying’ society in the Western World\(^2\). It is also important to view legacy projects in the context of an individual’s understanding and acceptance of their own mortality when discussing legacy projects specifically designed for those near end of life. There is an emphasis within palliative and end of life care of the need for timely conversations around advance care planning which include people’s wishes around preferred place of care, preferred place of death and ceilings of care including discussions around cardiopulmonary resuscitation, however this is not always the case within other areas of healthcare or within society as a whole.

If the concept of creating a legacy is introduced to someone who has not begun to contemplate their own death and has not been involved in any advance care planning discussions, there could be some breakdown in the relationship between clinician and patient. It could be said that if there was a greater acceptance of the inevitability of death on an individual and societal level, these conversations could be taking place between people earlier on, with greater ease and to greater effect, and the concept of legacy could be introduced as part of an individual’s advance care planning.

During my time in the USA I met with several people and learned about organisations who are attempting to normalise these types of conversations and innovate around end of life care in an attempt to redesign how we think, talk and inevitably go about ‘the art of dying.’

Ned Buskirk and the ‘You’re Going to Die’ Movement.

On a human scale one of the certainties that connects all of us, no matter how divided we may be in terms of culture, geography, economics or belief systems is the fact that death will come to all of us. It’s with this thought in mind that Ned Buskirk began the movement simply called ‘You’re Going to Die’. I met Ned in a cafe in San Francisco to learn more about his project. Ned is a wonderfully open, creative and positive force who was inspired to begin You’re Going to Die (often abbreviated to YG2D) following the death of his mother from cancer in 2003. With a background in theatre, Ned found that he was missing a ‘safe space’ to share writing, poetry, spoken word or music around themes of mortality - so he created one. Now YG2D is a hugely successful project in San Francisco which recently collaborated with artist Claudia Bicen (discussed previously) whose portraits and recordings of hospice patients have gained international acclaim. Ned believes that when people are allowed to be vulnerable in a carefully curated, yet also spontaneous environment, magic can happen. He encourages and stimulates communication and thinking around what it is to be human, to have suffered loss, and to find freedom and acceptance in the fact that one day you’re going to die. Ned hopes that one day other cities and countries will go on to host YG2D events, as the movement unlocks a need inside people to confront their own mortality.

Dr Dawn Gross and ‘Dying to Talk’ Radio Show.

If people are more able to think and talk about death and dying early on in life, when they are actually confronted with the inevitable they should hopefully be more able to discuss choices at end of life and achieve the ‘good death’ that is often spoken about. It is this idea, coupled with professional expertise and personal experience that prompted palliative care physician Dr Dawn Gross to begin a ground-breaking radio show called ‘Dying to Talk’, broadcast on KALW 91.7 FM. I was fortunate to spend some time with Dr Gross in San Francisco and found that her main passion is simple: to get people talking about what is important to them, so that life can be lived in full and death can be faced with dignity. As simple as this may sound, Dr Gross finds that it still so often goes against the medical model of ‘doing everything possible’ - a model that is tied up with the complex American insurance-based health care system, and one which Dr Gross is trying to reshape from her own unique angle.

28 http://www.yg2d.com/
29 http://kalw.org/post/dying-talk-1-until-death-it-all-life#stream/0
‘Dying to Talk’ is a phone-in talk show in which Dr Gross invites listeners to call in and ask questions about advance care planning, death, dying and all things in between. Her gentle and human approach to the subject and the callers makes for a very moving and enlightening listening experience. Dr Gross hopes that her radio show can reach into people’s homes so that conversations can begin naturally and could even be part of a family dinner discussion.

Redesigning End of Life Care

The Zen Hospice Project in San Francisco is a leading light in innovation around end of life care. Millions of people have viewed the TED talk by BJ Miller\(^30\), palliative care physician and senior director of the Project, and have been inspired by the philosophy around how life is celebrated even when death may be imminent. There appears to be an understanding within The Zen Hospice Project that one way to innovate and grow is to collaborate with experts from different fields of practice outside of healthcare. This has recently resulted in a partnership with San Francisco ideas-based design lab OpenIDEO\(^31\) around ‘redesigning end of life care.’ OpenIDEO proposes challenges and opens them up to the general public in order to draw from a vast well within all sectors to redesign current systems in a variety of fields. They have turned their attention to end of life care following the experience of OpenIDEO’s founder Paul Bennett, who found that his father’s death from bone cancer had a certain ‘inelegance’ to it.

The challenge to redesign death is now it’s ‘impact’ phase, after the top 10 ideas have been whittled down from 363 contributions. Interestingly both Ned Buskirk and Dr Dawn Gross have proposed ideas which have made it to the top 10 (my own idea around legacy projects made it to the final 50 ideas). Ned’s idea is called ‘Music at the End of Life’ and is based around musicians offering their talents at the end of life including playing music and writing songs to honour the dying and the dead. Dr Gross has proposed an idea called ‘Death-Ed: because abstinence is not an option’ which aims to normalise and prepare young people for the inevitability of death and dying. Other ideas include a global peer-to-peer digital platform that taps all the experience individuals have from going through the end of life experience in order to share with other users, and a platform called ‘InMyHands’ which is described as ‘a creative way for independent types to capture and update end-of-life wishes, without navigating complex systems and forms.’

\(^31\) https://challenges.openideo.com/challenge/end-of-life/impact
Another partner involved in the OpenIDEO redesigning end of life care challenge is the HELIX Centre. HELIX is short for ‘Healthcare Innovation Exchange’ and is a unique collaboration between the Royal College of Art, Imperial College and Imperial College Healthcare NHS Trust in London. The HELIX Centre has placed designers in the same space as clinicians, researchers and the public at St Mary’s Hospital in Central London with the idea of turning healthcare issues into design solutions.

HELIX is involved in several different projects one of which is focussing on end of life care, which aims to ‘research and design innovative solutions that improve the quality of care, alleviate suffering for dying people and transform the support their families receive.’

End of life care innovation being thrown open as a global challenge by a design laboratory is an encouraging step in the larger discussion around our acceptance of death and dying. It makes sense to invite ideas around death and dying from everyone, because everyone is involved. It also makes sense to bring different people’s expertise to something that is not a solely healthcare related issue - it is global issue which often happens to be played out in a healthcare setting. Legacy is part of the wider conversation around advance care planning and if more people begin talking about their wishes - regardless of if they have a life-limiting illness or not - then more people may have the opportunity to take part in shaping their own legacy.

32 http://www.helixcentre.com/
Legacy projects do not stand alone within an end of life care context and are reflections of the society in which they are taking place, and of the individual’s understanding of their illness and mortality.

Innovative thinking around death and dying may help break taboos and encourage discussion around advance care planning as part of ‘everyday’ conversations. Considering your legacy may become part of these conversations.
My trip to the USA and Canada demonstrated that there are various existing legacy projects within palliative and end of life care which have the potential to be adapted for the healthcare system in the UK. I had several questions which I kept in mind throughout the trip and which I considered when I observed each different type of project. As shown in the table below, I found that in essence each different type of project could be carried out in the UK and could be adapted for hospital, hospice and community.

I was very encouraged by the different types of practice I witnessed whilst in the USA and Canada, particularly the innovation around end of life care at The Zen Hospice Project in San Francisco. Incorporating legacy projects within practice is often a case of creative thinking and viewing the idea of legacy as part of wider advance care planning conversations. The Zen Hospice Project is at the forefront of attempting to begin global conversations around what it is to be human and how be can improve the experience of living whilst acknowledging death and dying.

I found that there is still a lack of research being carried out around the benefits of legacy projects, other than Dignity Therapy, though I was very encouraged by the results of the Compassionate Allies project and feel that this has potential to be adapted for medical students in the UK. Overall, I found that there was a lack of guidance for clinicians and facilitators around how to identify if someone would be eligible to take part in a legacy project, or which type of project could be matched to an individual to suit their needs.

I was introduced to the idea of ‘Digital Legacy’ and the development of apps and websites which allow people to begin collating and curating their lives on digital platforms. These platforms have the capacity to allow users a digital afterlife, which is a relatively new concept and which may take time to adapt to as a society.

Overall, my trip has shown me the possibilities and benefits of legacy projects, and has ignited many different sparks of inspiration around how legacy projects can be developed and integrated into palliative and end of life care within the National Health Service in the United Kingdom.
<table>
<thead>
<tr>
<th></th>
<th>Is the project local, national or international?</th>
<th>Who carries out the projects?</th>
<th>Is there a tool that helps people identify those who may be eligible for legacy projects?</th>
<th>How is the project evaluated?</th>
<th>Could this be adapted for practice in the UK and in which setting?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>StoryCorps Legacy Initiative</strong></td>
<td>National</td>
<td>Facilitated by clinicians/Allied Health Professionals</td>
<td>No</td>
<td>Recent evaluation by independent agency</td>
<td>Yes. Suitable for Hospital, hospice and community.</td>
</tr>
<tr>
<td><strong>Legacy projects by Art/Music therapists</strong></td>
<td>International</td>
<td>Trained Art/Music Therapists</td>
<td>No specific tool - discussed in MDT and if felt appropriate then offered.</td>
<td>Ongoing professional evaluation and ad hoc feedback.</td>
<td>Art Therapists and Music Therapists already practice in the UK however not part of every MDT</td>
</tr>
<tr>
<td><strong>Dignity Therapy</strong></td>
<td>International</td>
<td>Trained Dignity Therapists</td>
<td>No</td>
<td>Often part of research projects so effectiveness of Dignity Therapy intervention is measured as part of research.</td>
<td>Yes - however time/resource constraints may limit how many people would be able to benefit from Dignity Therapy. Could be carried out in all settings - may be more difficult in hospital.</td>
</tr>
<tr>
<td><strong>Healing Through Art at CSU Institute of Palliative Care</strong></td>
<td>Local</td>
<td>Artists</td>
<td>No</td>
<td>Part of ongoing evaluation at CSU Institute of Palliative Care</td>
<td>Yes. Arts projects can be carried out in all settings.</td>
</tr>
<tr>
<td><strong>Compassionate Allies</strong></td>
<td>Local though organised through national hospice organisation</td>
<td>Medical Students</td>
<td>No specific tool - potential participants identified by hospice staff</td>
<td>Yes - evaluation carried out as part of research</td>
<td>Yes. Could be carried out in all settings</td>
</tr>
<tr>
<td><strong>Digital Legacy websites/apps</strong></td>
<td>International</td>
<td>Self-directed by individual</td>
<td>No</td>
<td>No</td>
<td>Yes. Could be carried out in all settings.</td>
</tr>
<tr>
<td><strong>Leaving a Legacy Program at Seasons Hospice</strong></td>
<td>National</td>
<td>Social workers/nurses/volunteers/doctors</td>
<td>No</td>
<td>Some local evaluations carried out.</td>
<td>Yes. Could be carried out in all settings.</td>
</tr>
</tbody>
</table>
1. Legacy Projects can aid with psychosocial, spiritual and physical symptoms for those near end of life, and may help the bereavement process for loved ones. There should be greater awareness around legacy projects amongst those working in palliative and end of life care and greater opportunity to partake in legacy projects as part of advance care planning for patients and their loved ones.

This may require:

- Piloting and researching legacy projects in different settings eg: hospital, hospice and community, with a view to building an evidence base for benefits of legacy projects. This may also help to raise awareness of legacy projects from a funding and policy perspective.

- Education around legacy projects for those working in palliative and end of life care. It is my experience that legacy work is not widely carried out in palliative settings often due to lack of knowledge around different types of projects and benefits of legacy work.

- The development of a ‘Legacy Toolkit’ which can help guide facilitators and clinicians around the identification, facilitation and evaluation of legacy projects. A National Survey of Children’s Hospital Legacy Making Activities carried out in the USA in 2012 concluded that: “An assessment tool could assist professionals in screening and identifying patients that could benefit from legacy-making opportunities. Further research is also needed to develop educational tools for staff and identify multidisciplinary roles (physician, nurse, child life specialist, social worker, psychologist, etc.) in regards to legacy-making activities.” I believe that developing such a tool would help to provide a consistent approach to legacy projects.

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2. Each community offers a wealth of opportunity with regard legacy activities. An effort should be made to identify possible collaborations between palliative patients, their loved ones and relevant members of the community such as artists and art students. These types of projects can prove beneficial for all parties involved and can allow legacy to be explored from a creative perspective. Collaborations between medical students and patients have shown to develop greater communication skills and feelings of empathy amongst the students who took part. This can help to develop compassionate clinicians of the future.

This may require:

- Developing partnerships with local Medical Schools and Art Schools and demonstrating potential benefits of collaboration for those involved.
- Tapping into local communities to find artists and musicians or other community groups who may want to facilitate legacy projects.

3. Digital Legacy and digital assets should be considered when discussing advance care planning with patients and their loved ones. Many people now have an online presence and lack of knowledge around this area could lead to difficulties for patients or their loved ones when trying to access or preserve digital assets before or after death. There is a growing trend for digital platforms to curate legacy and clinicians may need knowledge of these platforms when considering legacy activities for patients and their loved ones.

This may require:

- Further education around Digital Legacy and awareness of the Digital Legacy Association and their framework.
- Considering digital legacy and digital assets when developing end of life care plans and documents in all end of life care settings.
Since returning from the Fellowship I have:

- Disseminated my findings through education sessions within the Palliative Care Team at Central North West London NHS Healthcare Trust.

- Been invited to talk about my research at the Centre for Death and Society at the University of Bath in November 2016.

- Taken part in a King’s College Cultural Institute’s Arts, Health and Wellbeing Workshop which introduces clinicians to artists in order to facilitate collaborations. I am planning follow up meetings from connections I made at the workshop with a view to discussing collaborations around legacy projects.

- Made contact with the HELIX Centre and have been invited to sit on their advisory panel around end of life care innovations. I am also involved in a project to design a digital platform to facilitate better conversations around advance care planning for healthcare professionals.

- Made contact with the editor of BBC Radio 4’s ‘The Listening Project’, which is the UK version of StoryCorps. I hope to arrange a meeting to discuss the potential for piloting a version of the StoryCorps Legacy Initiative within the NHS.

- Contributed to a local care plan for people at end of life in Camden and Islington to include a section around healthcare professionals and service users being aware of digital legacy and digital assets.

- I am in discussions with an illustration tutor at Nottingham Trent University to develop a module which involves students carrying out a project in their local hospice.

I plan on holding further education sessions to raise the profile of legacy projects, and hope to attend conferences in order to reach larger audiences. Eventually I hope to undertake further education which would enable me to carry out research around legacy activities with a view to developing a legacy toolkit which could be used across settings in the NHS.
# Itinerary

<table>
<thead>
<tr>
<th>Date</th>
<th>City/Country</th>
<th>Place/Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>20th April</td>
<td>Baltimore, Maryland, USA</td>
<td>Johns Hopkins Medical Centre. Meeting with Dr Lauren Brooks about StoryCorps Legacy Initiative. <a href="http://www.hopkinsmedicine.org/">http://www.hopkinsmedicine.org/</a></td>
</tr>
<tr>
<td>25th April</td>
<td>Washington DC, USA</td>
<td>Smithsonian National Portrait Gallery <a href="http://npg.si.edu/">http://npg.si.edu/</a></td>
</tr>
<tr>
<td>26th April</td>
<td>Baltimore, Maryland, USA</td>
<td>Anne Hansen, Director of Supportive Care, Seasons Hospice. <a href="http://www.seasons.org/">http://www.seasons.org/</a></td>
</tr>
<tr>
<td>Date</td>
<td>Location</td>
<td>Event</td>
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</tr>
<tr>
<td>28th April</td>
<td>New York City, New York, USA</td>
<td>StoryCorps Headquarters. Meeting the StoryCorps Legacy Team.</td>
</tr>
<tr>
<td>3rd May</td>
<td>New York City, New York, USA</td>
<td>Mount Sinai Hospital Palliative Care Unit. Shadowing Art Therapist Sarah Yazdian.</td>
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<tr>
<td>5th May</td>
<td>New York City, New York, USA</td>
<td>Professor Rita Charon, Director of the Department of Narrative Medicine, Columbia University, New York.</td>
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<tr>
<td>7th May</td>
<td>Los Angeles, California, USA</td>
<td>Museum Of Death.</td>
</tr>
<tr>
<td>Date</td>
<td>Location</td>
<td>Activity Description</td>
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</tbody>
</table>
| 10th May   | Los Angeles, California, USA     | Psychotherapist and Personal Historian Ellie Kahn  
| 12th May   | San Francisco, California, USA   | Zen Hospice Project. Meeting with Director of Marketing Geoff Dunlop  
[https://www.zenhospice.org/](https://www.zenhospice.org/)                                                                                                              |                                                                      |
| 12th May   | Walnut Creek, California, USA    | Legacy dinner hosted by April Bell, Director, Tree of Life Legacies  
[http://aprilbell.com/](http://aprilbell.com/)                                                                                                                                                             |                                                                      |
| 14th May   | San Francisco, California, USA   | Meeting with Ned Buskirk, founder of 'You’re Going to Die’ movement  
| 14th May   | San Francisco, California, USA   | Meeting with Dr Dawn Gross, palliative care physician and host of ‘Dying to Talk’ radio show  
[http://www.drasyouwish.com/about/](http://www.drasyouwish.com/about/)                                                                                                   |                                                                      |
| 16th May   | San Diego, California, USA       | Meeting with Professor Sharon Hamill, Faculty Director, California State University Institute for Palliative Care at California State University, San Diego  
[https://csupalliativecare.org/](https://csupalliativecare.org/)                                                        |                                                                      |
| 17th May   | San Diego, California, USA       | Meeting with Professor Lori Montross, Psychiatry & Psychosocial Services, Moores Cancer Center, University of California, San Diego  
[https://health.ucsd.edu/specialties/cancer/Pages/default.aspx](https://health.ucsd.edu/specialties/cancer/Pages/default.aspx) |                                                                      |
| 19th May   | San Diego, California, USA       | Long Term Care Facility with Chaplain from Mission Hospice to observe Dignity Therapy session.                                                                                                                                 |                                                                      |
| 25th May   | Winnipeg, Manitoba, Canada       | Dignity Therapy Workshop  