Advancing Palliative Care: Artificial Intelligence and Design Insights from the USA and the Netherlands

Credit: Dr Amarachukwu Nwosu

Dr Amarachukwu Callistus Nwosu

Churchill Fellow 2020

the CHURCHILL fellowship

Marie Curie

Lancaster University Medical School

NHS Liverpool University Hospitals NHS Foundation Trust

UNIVERSITY OF LIVERPOOL

Table of Contents

Contents

Contact information

Dr Amarachukwu (Amara or Ami) Callistus Nwosu, MBChB (Commendation), FRCP, PhD

- Senior Clinical Lecturer in Palliative Medicine, Lancaster University, Lancaster, UK.
- Honorary Consultant in Palliative Medicine, Liverpool University Hospitals NHS Foundation Trust, Liverpool, UK.
- Research Lead, Marie Curie Hospice Liverpool, Liverpool, UK.
- Honorary Senior Clinical Lecturer in Palliative Medicine, Palliative Care Unit, University of Liverpool, Liverpool, UK.
- Technology Editor, Palliative Medicine, Sage Publications Ltd, London, UK.

Email: a.nwosu@lancaster.ac.uk

Websites and social media

Content	**Weblink**
Personal website	http://www.amaranwosu.com/
X (formerly Twitter)	@amaranwosu
LinkedIn	https://www.linkedin.com/in/amara-callistus-nwosu-b841244b/
Lancaster University	https://www.lancaster.ac.uk/lira/people/amarachukwu-nwosu
Marie Curie Hospice Liverpool	https://research-liverpool.mariecurie.org.uk/
The Palliative Care Futurist Podcast – Dr Amara Nwosu	https://podcasters.spotify.com/pod/show/dr-amara-nwosu
SAGE Palliative Medicine & Chronic Care - Palliative Medicine Podcasts	https://open.spotify.com/show/3m2Zr1Feh3eCRBjgVX5iIw

Acknowledgements

- Professor Judith Rietjens, thank you for your help in coordinating my visit to TU Delft and Erasmus Medical Center. Thank you for meeting my family with your children on the Euromast tower. I am forever grateful for your encouragement, kindness and help in making me believe that I was good enough to be a Churchill Fellow.
- Dr Charlotta Lindvall, thank you for your support in making my Fellowship possible. I am grateful for your kindness, and support in planning my schedule and making me feel at home in Boston. Thank you for your interest in me, and my family. Thank you for taking me, and my son Isaac, to watch the Boston Red Sox play the Atlanta Braves. We had a wonderful time!
- Dr Natasja Raijmakers, thank you for organising my visit to IKNL to meet your team. Thank you for the walking tour around Utrecht. Thank you for organising the incredible lunch with the IKNL team. Thank you all for patiently waiting for me to finish eating – I am very slow!
- Thank you to my wife, Dr Clare Nwosu for your support during the Fellowship and caring for our children as we travelled. Thank you for your strength, knowledge and encouragement throughout the application, the Fellowship, and afterwards. This Fellowship a celebration of you; it would not have been possible without you. Thank you. I love you.
- To my children - Isaac, Theophilus and Joshua. Thank you for the fun and energy you brought to the trip. I really cannot imagine this Fellowship without you. I am so proud of your interest in the places you visited. I am proud of your willingness to meet new people and learn about their lives.
- Mum (Beverley Nwosu) and dad (Dr Ezechi Callistus Nwosu). Thank you for your unwavering love, kindness and support. I love you always.
- Thank you to Paula Melo Signerez and Kamran Rahmani for your kindness in showing me around the TU Delft campus. I really appreciate your interest in my project. Paula, thank you for welcoming me warmly to work on desk next to you in the office.
- Thank you to Dr Patrick Lubbers for keeping me connected with the Netherlands and telling me about the work of IKNL. I enjoyed our chats about Liverpool Football Club.
- Dr Marjike Dermois, thank you for your incredible illustration to summarise my work so accurately. You are amazingly talented!

- Dr Lea Jabbarian. Thank you, thank you, thank you. You are a wonderful friend who has encouraged me to since 2014, I would not have chosen the Netherlands for my Fellowship without your support. Thank you for visiting me in Rotterdam, it meant a lot to me.
- Dr Liesbet Van Bulck. Where do I start? Thank you for being my Fellowship partner for two weeks in Boston. Thank you for the coffees, lunches, long discussions and laughter. Thank you for tolerating my awful jokes. I wish you the very best for the future.
- Brigitte Durieux, thanks for your warmth in welcoming me to the DFCI team. Thank you for your patience when you listened to me complain about my lost airline luggage; you are very kind.
- Joshua Davies, thank you for letting me in to the office every day because I did not have swipe access for the door. Thank you for explaining the rules of baseball to me and my son Isaac. Thank you for our discussion about the cost of medical school in the USA, and the correct use of the Oxford comma.
- Madison Gulbin, thank you for inviting me to speak at the annual Student Union of the Research Masters (SURE) 'Health and Technology' symposium in Erasmus Medical Center. I was grateful for the invite. I was impressed by your hard work in organising the conference; it was great – well done!
- Dr Sharifa Alghowinem, thank you for showing me around your robotics lab and introducing me to other members of the MIT Media Lab. Your kindness has made a big impact– I really appreciate it.
- Dr Nathan Whitmore and Ruby Liu, thank you for the time in sharing the amazing work that you are doing in MIT. It was simply mind blowing! Thank you for your passion and energy – I won't forget you.
- Sarah Stanley, thank you for your constant support and encouragement to me throughout the entire Fellowship process. Your kindness is invaluable to me. Thank you for interviewing me to produce the summary video. You're a great interviewer! I'm really pleased with the outcome.
- Thank you to my employers (Lancaster University, Marie Curie Hospice Liverpool and Liverpool University Hospitals NHS Foundation Trust) for granting me the leave I needed to complete my Fellowship.
- Thank you to Marie Curie for supporting the 2020 Palliative Care Churchill Fellowships. I am very honoured to be part of the Marie Curie family, and I am even more honoured to be awarded a Churchill Fellowship which was supported by Marie Curie.

Abbreviations

Abbreviation	Term
AI	Artificial intelligence
DFCI	Dana-Farber Cancer Institute
EAPC	European Association for Palliative Care
EHR	Electronic Health Record
Erasmus MC	Erasmus Medical Center
IKNL	Netherlands comprehensive cancer organisation
MIT	Massachusetts Institute of Technology
NCR	Netherlands Cancer Registry
NHS	National Health Service
NIHR	National Institute for Health and Care Research
NLP	Natural language processing
SURE	Student Union of the Research Masters (SURE) of Erasmus Medical Center
TU Delft	Delft University of Technology
UK	United Kingdom
USA	United States of America

Executive summary

I am a clinician and researcher; my research focus is the role of digital technologies in palliative care. I am a Senior Clinical Lecturer at Lancaster Medical School, an Honorary Consultant in Palliative care in Liverpool University Hospitals NHS Foundation Trust, Research Lead of Marie Curie Hospice Liverpool, and Honorary Senior Clinical Lecturer at the Palliative Care Unit, University of Liverpool. My expert area is the evaluation of new technologies in palliative care. My research interests include (1) the evaluation of technology to support care for patients with advanced disease and (2) the use of clinically assisted hydration to manage symptoms. Also, I am the podcast Editor for the 'Palliative Medicine' journal (SAGE Publications).

In 2020, I was awarded a Churchill Fellowship to visit the USA and the Netherlands to research how digital health technologies can improve palliative care. The start date of my Fellowship travels was delayed due to the global Covid-19 pandemic, and I completed my Fellowship between May and July 2023. During my Fellowship I travelled to the Netherlands and the USA to meet professionals who were using design, technology, and data science in palliative care. The objective of my Fellowship was to research how artificial intelligence can improve palliative care in the UK.

Aims of my Fellowship

1. To research how artificial intelligence is used in the palliative care practice and research.
2. To explore the role of design in palliative care digital health.

Major findings arising from my Fellowship

- Good design is necessary when considering how new technologies can be meaningfully used in palliative care healthcare systems.
- Artificial intelligence has potential to revolutionise palliative care practice in several ways, notably in the delivery of:
    - Population level care
    - Clinical care to individuals
    - Digital legacy

Summary of recommendations

The Fellowship provided me with an amazing opportunity to observe international examples of digital innovation in palliative care. I am delighted I had the opportunity to meet multidisciplinary experts who were using AI in palliative care. This experience has helped me to consider ways to improve UK clinical practice and research. I have written the following recommendations for palliative care professionals, researchers and policymakers, to suggest opportunities of how AI can be used in palliative care practice and research.

1. Healthcare professionals, researchers, policymakers should focus on the needs of the patients, care-givers and wider society (and ensure meaningful input into research and planning) when developing palliative care digital health interventions.

2. Palliative care professionals should work with designers to better understand, and address, the design related challenges, associated with the use digital health in palliative care systems.
3. Healthcare professionals, academic and policymakers should focus on raising awareness of artificial intelligence approaches in palliative care (in both professionals and lay audiences) to demystify this topic.
4. Palliative care professionals and researchers need to better understand, and study, the different types of AI approaches, and how these can be used to deliver of palliative care services.
5. Researchers should seek to identify important governance issues about different AI methods. Areas of importance include bias, privacy, trust, data security, accountability, fairness, safety, and ethics.
6. Research and policy work should determine the risk, and impact, of digital inequality associated with AI in palliative care.
7. Palliative care research should study commercially available AI modalities to determine how these tools may affect palliative care (e.g. population level care, clinical care, digital legacy, communication, grief and bereavement).
8. Interdisciplinary research groups should be developed to ensure that palliative care AI research teams have the necessary skills and experience to conduct meaningful work.

1.0 Background to the project

It is important to use technology better to improve palliative care. The UK population is ageing, and palliative care need is expected to increase by 42% by 2040;[1] which, will create challenges to policymakers to ensure adequate care for those in need. When used well, digital health (e.g. telehealth, mobile apps and electronic patient reported outcomes) are proven to improve access to healthcare services;[2] however, many barriers prevent meaningful use, and little data which details how emerging technologies, like artificial intelligence (AI), can be used to improve palliative care.

People with palliative care problems are likely to have specific needs, which may not be addressed through the current applications of digital health in UK, as current initiatives are generally focused on supporting the needs of older people.[3 4] The Churchill Fellowship provided me with the opportunity to learn from professionals in the USA and the Netherlands, and research approaches to improve palliative care using AI. My vision is that my Fellowship will help to improve the use of AI to support palliative care in the UK.

1.1 Why technological innovation is needed in palliative care

Palliative care is important to provide holistic, person-centred, support for people with life limiting illness. Palliative care is defined by the World Health Organisation (WHO) as an approach that: "...improves the quality of life of patients and their families facing the problem anticipated 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 social".[5] Global palliative care needs are expected to increase due to several socioeconomic factors (e.g. an ageing population); therefore, it is important to explore opportunities to ensure that the population has adequate access to palliative care services.[6] Digital health is an innovation, which has potential to transform health and social care, and provide opportunities for citizens to manage their own health.[2 7 8]

1.2 Digital health can improve care, but evidence is lacking in palliative care

Research demonstrates that digital health improves healthcare delivery and access when used well.[2] The potential for digital health to support palliative care has not been fully researched,

meaning that many of the current digital health innovations may not meet the specific requirements of users with palliative care needs.[4]

1.3 Artificial intelligence in healthcare

Artificial intelligence (AI) describes the science and engineering of developing intelligent machines, using algorithms or a set of rules, which creates the ability of a machine to think and act like a human.[9] AI involves different methodologies (e.g. machine learning, neural networks, deep learning, and natural language processing), which describes processes for a machine to be trained to act autonomously, with or without human instruction.[10] AI is useful in healthcare practice, by facilitating rapid analysis of large quantities of data in electronic healthcare datasets, which can support data interpretation, diagnosis and identification treatment decisions to support medical care.[10-12]

1.4 My previous work in palliative care digital health

I am a clinical academic with expertise in evaluating digital health interventions in palliative care. My previous research has explored social media,[13] wearables,[14] mobile devices,[15] robotics[16] and Big Data [17] in palliative care. Recently, I have completed an international study, which identified the palliative care digital health research priorities.[4] In this study, Artificial Intelligence (AI) was identified as a priority area, requiring urgent study in palliative care.[4]

1.5 The need for human-centred design in palliative care digital health

The Churchill Fellowship provided me with the opportunity to study human-centred design in palliative care AI. 'Human-centred design' describes a problem-solving technique that focuses on the needs of people, enabling designers to create products and services for the needs of service users.[18] Good design is important to ensure that AI tools, and systems, are appropriate for the specific needs of palliative care service users.[19] My Fellowship provided the opportunity to develop my knowledge of design methods in palliative care, and to collaborate work with design teams.

1.6 Why I chose to research palliative care AI during my Churchill Fellowship

Although there are opportunities to use AI in palliative care, many barriers prevent its meaningful use in the UK.[17] These barriers include expense, interoperability issues, data privacy and security concerns, concerns about effectiveness, equity, and the worry that AI will reduce face-to-face contact between patients and clinicians.[16 20] The Churchill Fellowship provided me with the opportunity to research palliative care AI, in centres in the Netherlands and the USA. My aim was to identify opportunities to improve the meaningful use of palliative care AI in the UK.

1.7 Locations of my Fellowship

I travelled to two continents, Europe and North America, to learn from individuals and organisations who were using AI, and design methods, in palliative care.

1.8 The Netherlands

The Netherlands is a country with an established connected digital life sciences and health ecosystem, a highly developed health information infrastructure, and efficiently digitised primary care services. The Netherlands has several prestigious healthcare and academic institutions. During my Fellowship, I visited the following centres.

1.8.1 Erasmus Medical Center (Erasmus MC)

Erasmus Medical Center based in Rotterdam, Netherlands, affiliated with Erasmus University and home to its faculty of medicine, is the largest medical centre in Europe. The Erasmus MC ranks 1st of the top European institution in clinical medicine and 20th in the world.[21] I to travelled to Erasmus MC to visit Professor Judith Rietjens (Professor of Design for Public Health at both Erasmus MC and Delft University of Technology), and her diverse academic team, who were experts in systems design, outcome measures, digital health and ethics.

1.8.2 Delft University of Technology (TU Delft)

The Delft University of Technology (TU Delft) is the oldest and largest Dutch public technical university, located in Delft, Netherlands. TU Delft is ranked 16th in top 20 Engineering and

Technology universities in the world.[21] I visited TU Delft to learn about design focused principles in palliative care, and how digital health intersects with real-world clinical applications. Professor Judith Rietjens has a joint Professorship with Erasmus MC, so I benefited from jointly working between TU Delft and Erasmus MC.

1.8.3 Netherlands Comprehensive Cancer Organisation (IKNL)

Netherlands Comprehensive Cancer Organisation (IKNL) is the quality institute for oncological and palliative research and practice. IKNL collaborates with healthcare professionals and managers and patients on the continuous improvement of oncological and palliative care. I chose to go to IKNL to observe how they use artificial intelligence methods on data from the national Netherlands Cancer Registry (NCR), which enables health care professionals, policy makers and researchers to predict, plan and coordinate cancer care.

1.9 The USA

The USA is known for its world-class universities and healthcare centres, which are world leaders in palliative care digital health. Boston is the largest biotechnology hub in the world.[22] The city is also a national leader in scientific research, law, medicine, engineering, and business. With nearly 5,000 startup companies, the city is considered a global pioneer in innovation and entrepreneurship, and more recently in artificial intelligence.[22] In Boston, I visited the following centres.

1.9.1 Massachusetts Institute of Technology (MIT)

The Massachusetts Institute of Technology (MIT) is a private university in Cambridge, Massachusetts. MIT is a world leader in scientific and technological research and is a leading area of expertise in AI. MIT students, graduates, and faculty members are famous for being given many awards, including 76 Nobel Prizes.[23]

1.9.2 Dana-Farber Cancer Institute (DFCI)

Dana-Farber Cancer Institute is a comprehensive cancer treatment and research institution in Boston, Massachusetts. DFCI is affiliated with Harvard Cancer Center, and clinical and research affiliates of Harvard Medical School. As of 2024, Dana-Farber is ranked the eighth best

cancer hospital in the world.[24] In DFCI, Dr Charlotta Lindvall's group had expertise on the application of natural language processing (a form of artificial intelligence) in palliative care.[25]

2.0 Aims and objectives of my Churchill Fellowship

1. To research how artificial intelligence is used in the palliative care practice and research.
2. To explore the role of design in palliative care digital health research.

3.0 Purpose of the report

In this report, I highlight the importance of the evolving field of artificial intelligence in palliative care, and I discuss its implications on future policy, clinical practice, and research in the UK. I aim to initiate a societal discussion, and debate, about the opportunities, challenges and action needed to meaningfully use artificial intelligence in palliative care practice. Finally, I provide recommendations for research, policy and practice for relevant stakeholders, from NHS, academic and palliative care sectors.

4.0 My approach

My Fellowship involved a two-week trip to the Netherlands in May 2023, followed by a two-week trip to the USA in July 2023. In each setting, I conducted interviews with experts in the field of AI, design, technology, data science, ethics and clinical practice. The interviews I conducted were either face-to-face or on Microsoft Teams. I made handwritten notes during each interview and audio-recorded some of the interviews for later reference.

4.1 Impact of Covid-19 on my Churchill Fellowship

My plans to travel in summer 2020 were disrupted by the global coronavirus pandemic, which led to a UK lockdown (with restriction to face-to-face contact and travel) on the 23rd of March 2020. I worked clinically, as a physician, throughout the duration of the pandemic, which also affected my ability to plan and organise my Fellowship. Consequently, my travel plans were delayed, and I eventually commenced my travels in May 2023, following the end of the global pandemic (as declared by the World Health Organization, on 5th of May 2023[26]).

4.2 The impact of the Covid-19 pandemic on the use of technology in palliative care

The Covid-19 pandemic caused many palliative care services to rapidly implement technology to reduce face-to-face human contact to limit virus transmission.[27] Examples of Covid-19 palliative care digital health innovations include telehealth,[28-30] remote education,[31] developments of communities of palliative care practice,[32 33] and virtual reality (for psychological care and symptom management).[34 35] The increasing use of technology in palliative care practice is likely to remain, due to innovations in practice,[36] AI,[4] and the increasing global need for palliative care.[37] Therefore, the importance of my Fellowship increased during the Covid-19 enforced delay. My Churchill Fellowship provided me with the opportunity to research developments of AI in palliative care (considering the effect of Covid-19) and to explore challenges and future opportunities of its use.

5.0 Findings

My Churchill Fellowship has increased my expertise in AI and design, in palliative care. This learning encompassed different interconnecting themes, with useful learning for me to bring to the UK, which will improve practice, research and my career. In the next section of this report, I will summarise the findings of my Churchill Fellowship in four areas, to explore the role of artificial intelligence in palliative care in the context of:

1. Design in Palliative Care
2. Population palliative care
3. Clinical care in palliative care
4. Digital legacy

6.0 Design and palliative care

In May 2023 I visited the NEMO Science Museum in Amsterdam which housed a fantastic exhibition about death and dying.[38] The section titled ‘Over de dood’ (About Death) takes people through a journey about people’s views and experiences of death and dying from different cultural perspectives. The exhibition used a mix of text, images, and lighting to provide a thoughtful and emotional experience about death and dying, from a societal and human perspective rather than a medical one. I really loved the design of the exhibition, with its

inclusion within a family science museum but also located within the ‘Hoe word ik ouder’ (How will I age?) section of the museum, which presented positive messages about ageing.

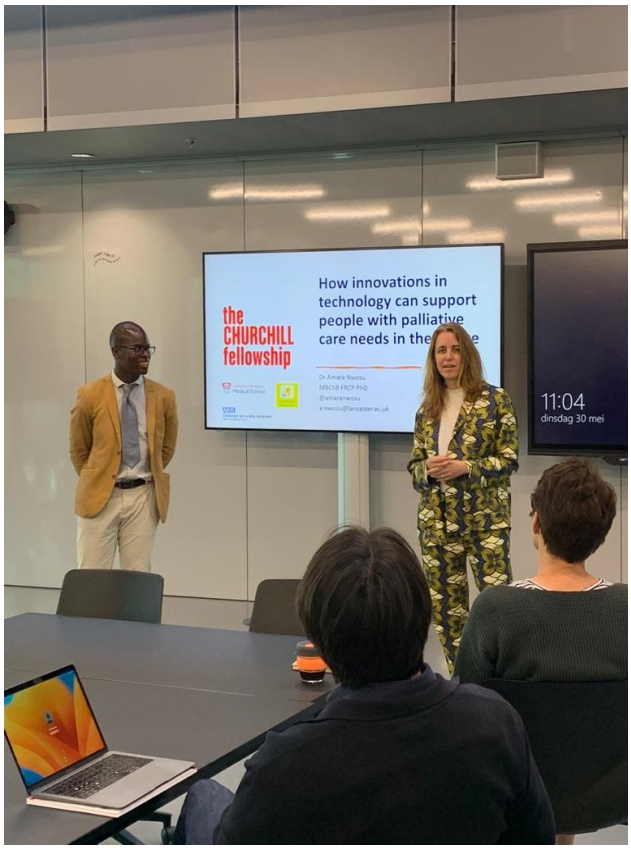
The exhibit made me consider how arts and design could be used to communicate important societal messages about palliative care, especially using images and media to create a discourse around new innovations such as the role of artificial intelligence for people with serious illness, after death and bereavement.

Images from the ‘Over de dood’ (About Death) exhibition at NEMO Science Museum in Amsterdam – can you spot my son Joshua (age 5) looking at interactive installation of different death cultures?

6.1 The importance of design in palliative care

I travelled to TU Delft to meet Professor Judith Rietjens, a Professor of Design for Public Health at the TU Delft, Faculty of Industrial Design Engineering, and Erasmus MC’s department of Public Health. As professor of ‘Design for Public Health’ at both TU Delft and Erasmus MC, Professor Rietjens integrates methodologies from public health and design research, to optimise person-centred care while considering healthcare system complexities. She described her interest in systems thinking and design, and how her bespoke professorship at TU Delft and Erasmus MC enabled her to collaborate with designers, data scientists and

medical professionals. She explained how her research group evaluates diverse populations and settings, including oncology and people with chronic conditions. Professor Rietjens explained how she has evolved her research focus, from conducting descriptive research, to intervention studies. Her current research involves the development, evaluation and implementation of digital psychosocial interventions aimed at improving patients' quality-of-life, quality-of-care and decision-making.



Professor Judith Rietjens (right) helped to coordinate my visit to TU Delft and Erasmus Medical Center.

In TU Delft, I met design students who provided insight of how design research interfaces with healthcare. Paula Melo Signerez (PhD Candidate & Design Researcher TU Delft) discussed the evolution of design methods, from products designed to be primarily to be functional but not form, and how designers now develop products where aesthetic appearance, and emotional response, are increasing important. Kamran Rahmani, (a Masters student, now working as a healthcare product designer) described his interest in exploring interactions between machines and humans. Specifically, he described his research, which involved the development of interventions that communicate with users, to identify future care needs. As a group, we had a

lively discussion about the potential AI methods in design, and the opportunities and challenges of these approaches. We agreed on the importance of design to understand the needs of users, which enables the designers to develop system to meet the needs of the user.

Meeting design students at TU Delft: Paula Melo Signerez (left), Kamran Rahmani (centre), me (right).

Dr Euiyoung Kim (Assistant Professor of Design for Dynamic Stability in the Design, Organisation, and Strategy) described the importance of learning from case studies to understand how industry uses technological innovation to improve human experience. Dr Kim provided the example using a text-mining method to better understand how 'Internet of Things' devices supported the management of childhood Type 1 Diabetes. He also shared the example of a media content analysis to describe how large organisations adapted to the challenges of Covid-19. Dr Kim explained how these research methods are transferable to other complex systems, such as healthcare, and could be used to help organisations to make better decisions of how to use technology well

Meeting Dr Euiyoung Kim (right) in TU Delft.

I met Dr Jiwong Jung (Assistant Professor for developing data-enabled design methods in the field of digital health, TU Delft) who provided insight of data-enabled design in digital health. She explained that the role of data-enabled designers is not to provide a complete solution to a community, but to empower them to realise their problems and create solutions. She further explained that designers should learn how to use available data, rather than learning how to collect new user data. She highlighted the importance of collaboration with different disciplines, such as designers, data scientists and medical professionals. She also highlighted the importance of humility, optimism, and seeking the viewpoint, and experience, of service users.

I enjoyed meeting Dr Jiwong Jung over lunch in the Erasmus Medical Center canteen, to discuss her PhD thesis: developing data-enabled design in the field of digital health.

A personal highlight of my Fellowship was my participation in an expert panel discussion about the ethical implications of technology in healthcare, during the 11th annual 'Health and Technology' symposium of the Student Union of the Research Masters (SURE) of the Erasmus MC. The day was coordinated by SURE's president, Madison Gulbin, who invited me to

participate in the panel discussion. The expert panel consisted of Dr Renske Los (Assistant Professor of Medical Informatics at Erasmus MC), Professor Ewout Steyerber (Professor of Clinical Biostatistics and Medical Decision Making at Leiden University Medical Center), Professor Judith Reitjens (Professor of Design for Public Health at the TU Delft, Faculty of Industrial Design Engineering and Erasmus MC's department of Public Health) and Dr Laura Hartman (Research and lecturer Medical Ethics).

During the symposium, we debated several ethical issues related to AI in palliative care, for example, digital inequality due to unequal provision of resources. We discussed issues of bias due to a failure of digital tools, software and algorithms to adequately represent the needs of some users. We debated issues of data security, lack of trust for AI, and uncertainty of the processes which generate the AI data outcomes. And finally, we discussed concerns about accountability for errors, and harm, which result from AI.

A picture of me at the 11th annual 'Health and Technology' symposium of the Student Union of the Research Masters (SURE) of the Erasmus MC. Left to right: Dr Renske Los, Professor Ewout Steyerber, Professor Judith Reitjens, me and Dr Laura Hartman.

I met committee members of the Student Union of the Research Masters (SURE) of Erasmus MC, who organised the Health and Technology Seminar. Madison Gulbin (far left) was the SURE President.

6.2 UK considerations for design in palliative care

There are exciting innovations in the UK, which reflect the design innovations I observed in the Netherlands. For example, Marie Curie have launched the 'Design to Care programme', which is a five-year collaborative initiative to rethink how palliative and end of life care can be provided equitably, efficiently and sustainably for future generations.[39] Furthermore, I am also leading projects, which involve the incorporation of design methods into palliative care delivery. For example, I have overseen the 'Designer in Residence Programme' in Marie Curie Hospice Liverpool, which involves a PhD design student being resident in the hospice for 18 months, to support design focused innovations of systems and practice.[40] I have also developed the 'Digital Legacy, Design and Technology Network', which is a network of multiprofessional stakeholders who are collaborating on design focused, palliative care research.[41] This innovation builds on my previous work of developing a multiprofessional through the 'Palliative Care, Architecture and Design Symposium (PADS)'.[42]

6.3 Key messages from design in palliative care

- When designing complex systems (like healthcare), it is important to understand the needs of the user, to appropriately design services and products to meet their needs.
- Technology can be part of the solution, but it should not replace the conversation with service users.
- Collaboration between designers and data scientists enables collaboration with medical experts, particularly in the fields of digital health and eHealth development.
- Researchers, clinicians and policy makers should consider impacts of digital inequity, governance, and ethical challenges of using AI in clinical practice.

7.0 Artificial intelligence for population level palliative care

I travelled to Utrecht to visit IKNL to meet a dynamic, multi-professional team who explained how IKNL aims to improve healthcare across the Netherlands, by using data science. INKL conducts data analysis of the Netherlands Cancer Registry (NCR), an open-source dataset of all people with cancer in the Netherlands, to describe, inform and predict cancer care. My visit to IKNL was coordinated by Dr Natasja Raijmakers (Senior Researcher at IKNL). My visit involved

presentations from the IKNL team, with the opportunity for me to share my work, and an enjoyable restaurant lunch in Utrecht.

I pose with the IKNL team during my visit.

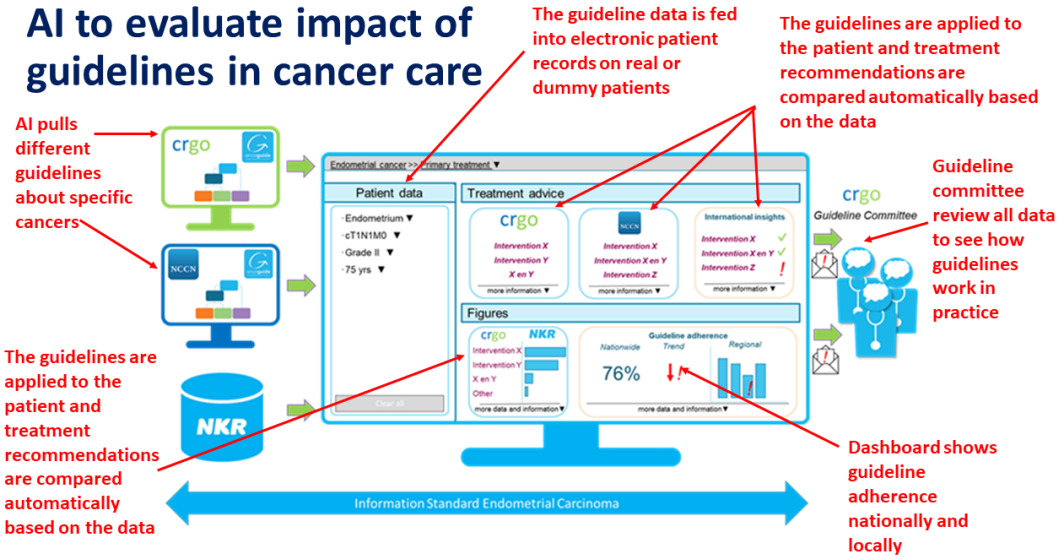
Dr Patrick Lubbers (Senior Clinical Informaticist at IKNL) and Dr Marjike Dermois (Clinical Informaticist at IKNL) conducted presentations which provided an overview of the role of INKL and how they use data from the NCR. They explained how data of all adults with cancer in the Netherlands are registered on the NCR (an open access database), and that IKNL uses this data to conduct analysis for stakeholders, to improve cancer care. I learnt about current IKNL projects, which used AI analysis of the NCR, to provide unique insights into palliative care management. Below, I present examples of potential population application of AI in palliative care.

My trip to IKNL was coordinated by Dr Natasja Raijmakers (Senior Researcher at IKNL).

Dr Patrick Lubbers (left) and Dr Marjike Dermois (centre) provided an overview of IKNL, the Netherlands Cancer Registry and current IKNL projects.

7.1 Artificial intelligence to evaluate the impact of guidelines in cancer care

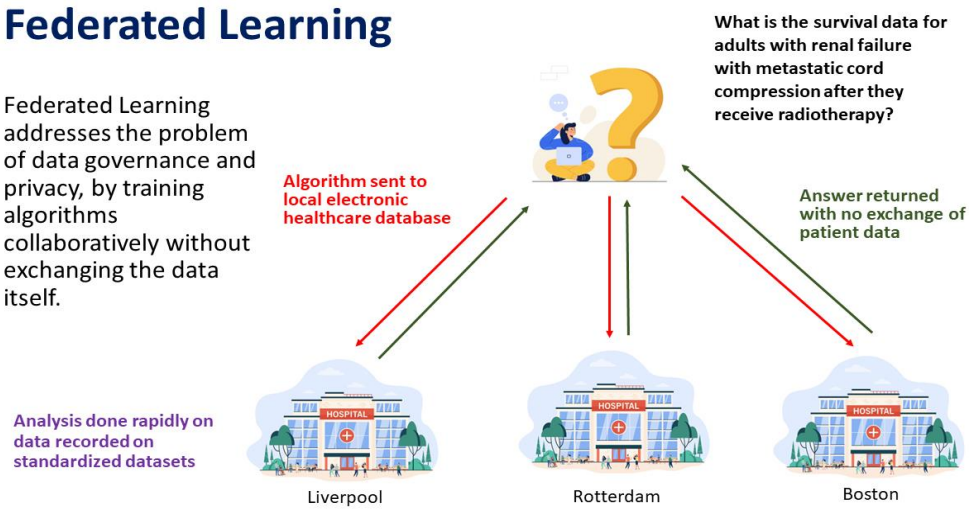
I learnt about how AI was used to automatically evaluate the impact of new cancer guidelines for patients, by applying the algorithm to electronic healthcare records. This enables policymakers, and healthcare providers, to evaluate the clinical impact of new guidelines (enabling further planning and resource management) to be anticipated in advance.



A slide to provide an example of how AI can be used to predict the impact of guidelines in cancer care

7.2 Federated learning

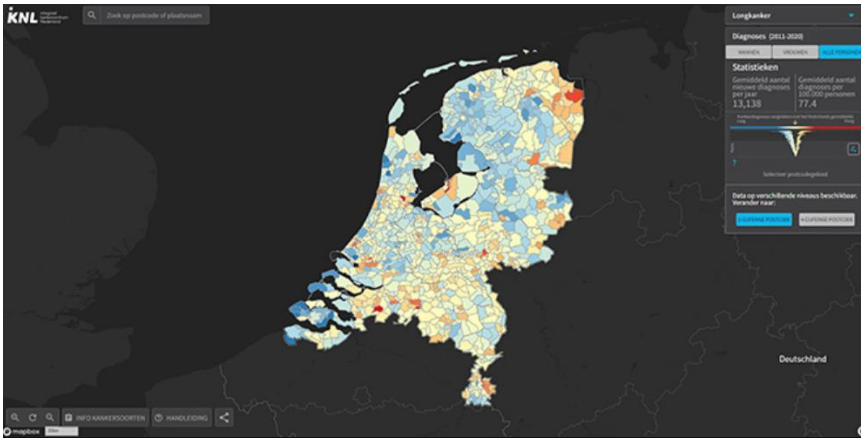
Dr Melle Sieswerda (Computer scientist and Physician) explained how 'federated learning' can be used to train AI models and can be used to conduct research across settings without personal information being shared, which overcomes some ethics and governance challenges. In healthcare research, federated learning may involve the use of an algorithm to interrogate a healthcare dataset, to obtain an anonymised outcome to a posed question, without transfer of the original dataset or personal information. Consequently, federated learning provides the potential for multicentre research to be conducted, without the exchange of personal and identifiable data.



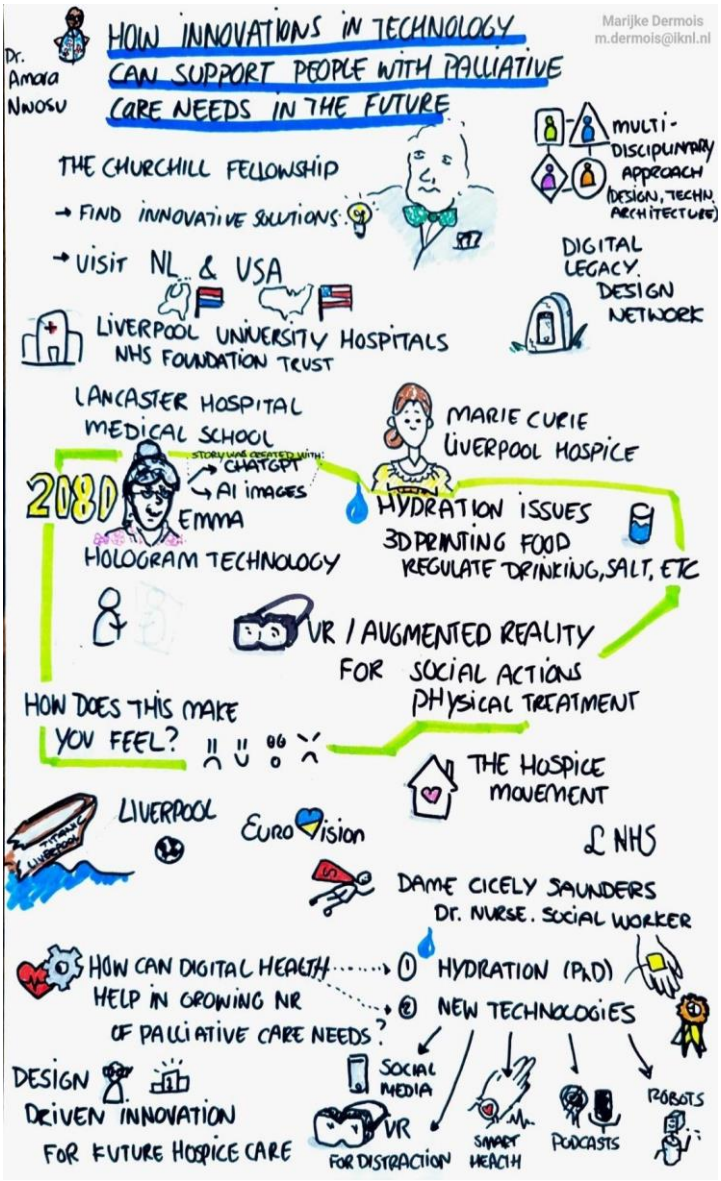
A slide I developed to summarise how federated learning can facilitate collaborative research with the teams I visited during my Fellowship.

7.3 Plotting cancer data on maps

Staff at IKNL explained how they can plot cancer information (from the NCR) on digital maps (e.g. Google maps) facilitating evaluation of cancer with other data (e.g. geographic, transport, societal), to help policymakers coordinate services according to local need. I also learnt how information from the NCR was available for use by researchers in other countries, to help facilitate international comparisons of data to support research and clinical practice.



An example of cancer demographic data plotted on the Netherlands map



Dr Marjike Dermois (Clinical Informaticist at IKNL) illustrated this wonderful picture to summarise my career and the objectives of my Churchill Fellowship. Thank you Marjike – this is awesome!

7.4 UK considerations for population health and artificial intelligence

The UK could potentially benefit from population health AI data science approaches, by using these methods to inform care decisions with routine data. In palliative care, routine data sources may include electronic health records (EHRs), disease registries, health administrative data, and epidemiologic surveillance systems. Examples of current UK palliative care initiatives includes the 'Big & Routine Data-Based Palliative & End of Life Care Research' project at Kings College London.[43] These projects include a range of research studies that use large-scale routinely collected datasets (including structured and unstructured datasets) to explore various end-of-life outcomes and to generate evidence to enable policymakers, commissioners, and healthcare professionals to use them directly in their decisions to improve palliative and end-of-life care.[44-46]

7.5 Key messages from population health and artificial intelligence

- Routine data can be evaluated using AI data analysis to provide useful information about the demographics of disease on a national scale.
- Cancer data can be displayed on a national map, to determine how cancer data relates to other factors.
- Federated learning offers the potential for data to be analysed without the exchange of personal information.

8.0 Clinical care and artificial intelligence

I travelled to the Dana Farber Cancer Institute (DFCI) to meet Dr Charlotta Lindvall, and learn about computational palliative care research.[25] Dr Lindvall's research focuses on AI methods, which examine palliative care clinician-patient interactions. An area of expertise of Dr Lindvall's lab is Natural language processing (NLP), describing the computer science processes (i.e. computational linguistics, rule-based modelling of human language, with statistical and machine learning models) that enable computers, and digital devices, to recognise, understand and generate text and speech.[47] During my visit, I met Dr Lindvall's research team, and other visiting researchers. Members of the Lindvall Lab were, Brigitte Durieux (Data analyst in Psychosocial Oncology and Palliative Care at Dana-Farber Cancer Institute), Dr Liesbet Van

Bulck (a visiting Postdoctoral Researcher at KU Leuven) and Joshua Davis (Medical student, Albany New York).

My first day with the Lindvall Lab in Dana-Farber Cancer Institute. Left to right: Brigitte Durieux, Dr Liesbet Van Bulck, Joshua Davis, Dr Charlotta Lindvall, me.

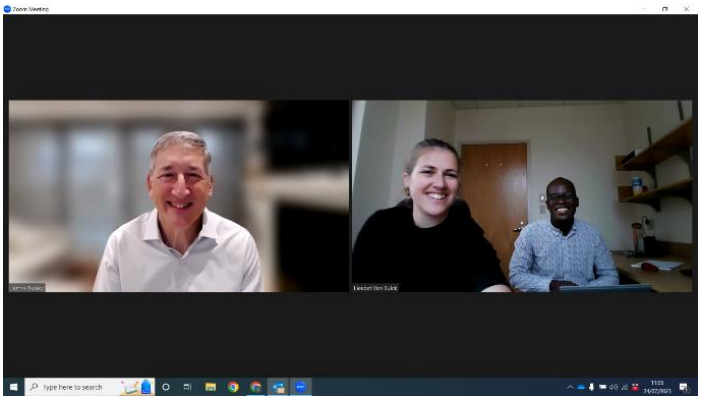
I met with senior researchers, leaders and Faculty staff at DFCI, who explained the potential to use NLP research to gather insights from electronic healthcare record systems, thus enabling rapid analysis of thousands of case notes. My discussions with Dr Jason Johnson (Chief Data and Analytics Officer) and Professor James Tulsky (Chair, Department of Psychosocial Oncology and Palliative Care) highlighted the patient centred focus of the work, to ensure that the data analysis leads to outcomes that are meaningful to patients, improving quality and efficiency of care.

Dr Jason Johnson and Professor James Tulsky provided me with an overview of DFCI, discussing the importance of using multiprofessional staff to develop collaborative links across disciplines (e.g. industry, academia and clinical services), to ensure innovation and the development of ideas. We discussed how the dominance of five EHR vendors (accounting of 80% of hospital

EHR systems in the USA[48]) creates opportunities to encourage standardisation of data capture methods, and tools, across system to facilitate interoperability of NLP research. Our discussions highlighted examples of innovative palliative care NLP research conducted at DFCI, for example.

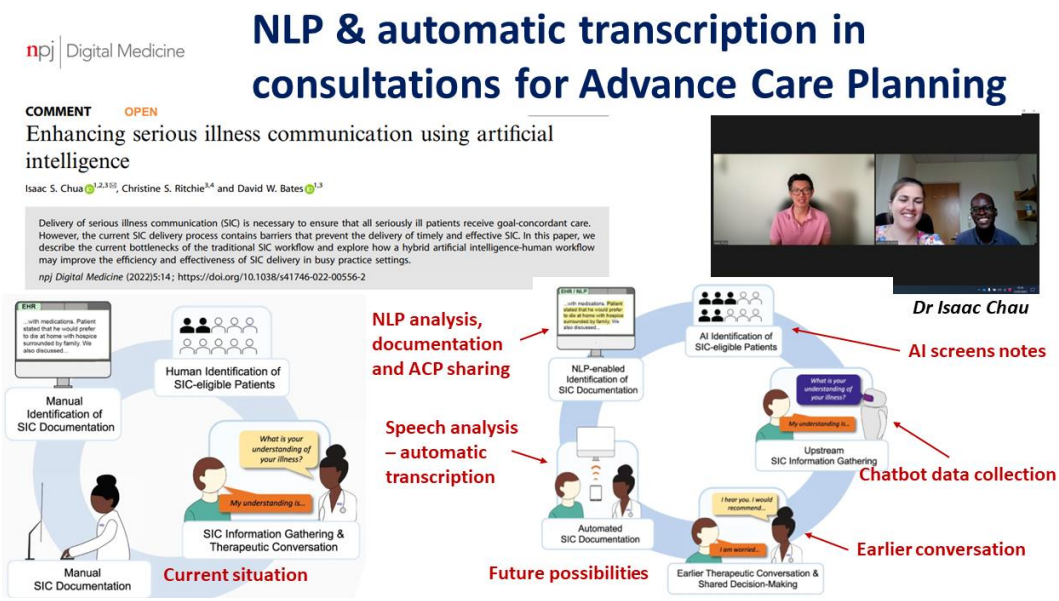
- *NLP analysis of administrative hospital data to determine the quality of palliative care delivered by to patients with advanced pancreatic care who are undergoing procedures.*[49]
- *Identification of goals of care conversations in the EHR using NLP and machine learning.*[50]
- *NLP to assess end-of life quality indicators in cancer patients receiving palliative surgery.*[47]
- *NLP to accurately measure adherence of best practice guidelines for palliative care trauma.*[51]

Our meeting with Dr Jason Johnson (centre). Me (left), Dr Liesbet Van Bulck (right)



A Zoom meeting with Professor James Tulsky (left), Dr Liesbet Van Bulck (centre), me (right).

I met with Dr Isaac Chau who presented details of a DFCI research study, using NLP analysis of hospital EHR data, to automatically identify patients likely to benefit from palliative care input. Dr Chau explained that these patients could be automatically contacted by a chatbot, to determine whether the individual would agree to an invitation to meet a palliative care professional, to explore their needs further. Patients who agree to this would meet the palliative care professional, with their consultation digitally transcribed into the EHR (using speech-to-text technology). Therefore, this application of NLP could facilitate earlier identification of people with palliative care needs and improve the efficiency of data capture.



A slide I developed to summarise Dr Chau's presentation on how NLP can help to identify patients with palliative care need, with automatic speech-to-text transcription of consultations.

A highlight of the trip was a networking visit to MIT, to meet other clinicians working on AI research. Dr Leo Anthony Celi (Associate Professor of Medicine, Harvard Medical School) coordinated the visit. I returned to MIT later in my trip to meet non-clinical researchers in the MIT Media Lab, to further explore how AI can be used to preserve memory of the dead (see section 9.0: Digital Legacy and AI).

I pose with other international researchers outside Massachusetts Institute of Technology (MIT). Huge thanks to Dr Leo Anthony Celi (far left) for his hard work in coordinating my visit.

8.1 UK considerations for clinical care and artificial intelligence

The UK should capitalise on the opportunity to use NLP methods in palliative care. The UK's small size (compared to the USA) offers practical advantages, due to the presence of a nationalised healthcare system, high adoption of EHR systems and a national mandate to use electronic palliative care coordination systems in clinical practice. These factors create opportunities to use NLP for research and practice (which is consistent with my observations in the DFCI) in the UK. Such approaches could improve the efficiency data analysis in clinical administration, research and quality improvement. UK-specific challenges should be considered, such as regulations regarding the UK General Data Protection Regulation (GDPR) Act, and issues with poor interoperability between organisations (attributable of the use of incompatible EHR systems used across the NHS).

8.2 Key messages from clinical care and artificial intelligence

- NLP provides several opportunities to enhance palliative care by supporting prediction of morbidity and mortality, to classify pain severity, identify quality indicators, and identify situations where important conversations occurred.
- NLP can analyse free text EHR data, supporting the evaluation of issues which have previously been difficult to study.
- NLP methods, combined with automatic voice-to-text transcription of clinical consultations, can potentially facilitate earlier identification of people with palliative care needs and improve the efficiency of data capture.

9.0 Digital legacy and artificial intelligence

A digital legacy is the digital information available about someone following their death.[52] Someone's digital legacy is often shaped by interactions the person made and information that they created before they died. This might include their social media profiles, online conversations, photos, videos, gaming profiles and their website or blog.[52 53] Someone's digital legacy can also be informed by content that is created or co-created by others. This may include interactions that occurred on someone else's social media. The importance that society places on their loved one's digital legacy is increasing, which is due to different factors. Firstly, the way we create and consume media is changing. Instead of using analogue devices

we are using digital devices (often for the same purpose); instead of storing things physically, we are storing them digitally.[52 53]

I met with researchers in the MIT Media Lab to explore how AI methods could be used to communicate with digital avatars of the deceased. The Media Lab is an interdisciplinary creative playground rooted squarely in academic rigor, comprising of several research groups, initiatives, and centres working collaboratively on hundreds of projects. Here, I met Dr Nathan Whitmore (MIT Research Scientist) and Ruby Liu (PhD student, Medical Engineering and Medical Physics program), who provided an overview of a project to use generative AI, to allow people to communicate with a digital representation of Leonardo Da Vinci.

Generative artificial intelligence (AI) describes algorithms (such as ChatGPT) which can create high-quality text, images, and other content based on the data they were trained on. Dr Nathan Whitmore and Ruby Liu, provided an overview of the work of MIT researchers to use biographical accounts and data, describing the work and ideas of Leonardo Da Vinci, to create a digital avatar, that could be interacted with (using voice and text), to elicit a response in the manner of Leonardo Da Vinci. We discussed capabilities of AI text to voice, text to picture, voice cloning, deep fake technologies and other developments and opportunities.

I discussed potential applications of artificial intelligence in palliative care with MIT researchers Dr Nathan Whitmore (centre) & Ruby Liu (right).

We discussed the potential for future applications of this technology which is rapidly advancing and has become more accessible, through developments of companies like Open AI and their service, Chat GPT. We discussed the potential for multiple data sources of individuals to be collected over time, which could enable, prospective and retrospective, development digital avatars of the deceased. Reasons for creating an avatar of a deceased person may include an AI recreation of an historical figure, or a digital avatar of aa deceased family member or friend. Together, we discussed the potential for AI analysis to passively collect data from highly prevalent data sources in society, such as email, photos, voice calls, social media, messaging services and geolocation services. We highlighted the opportunities and challenges of these developments, and the considerations of ethical issues, governance considerations and policy implications.

In the MIT Media Lab, I also met Dr Sharifa Alghowinem, who provided a demonstration of how AI-powered robotics has the potential to provide people with social support and personal care. We discussed future scenarios where robotics could be used in combination with AI to recreate the physical appearance, movement and sounds of a deceased person.

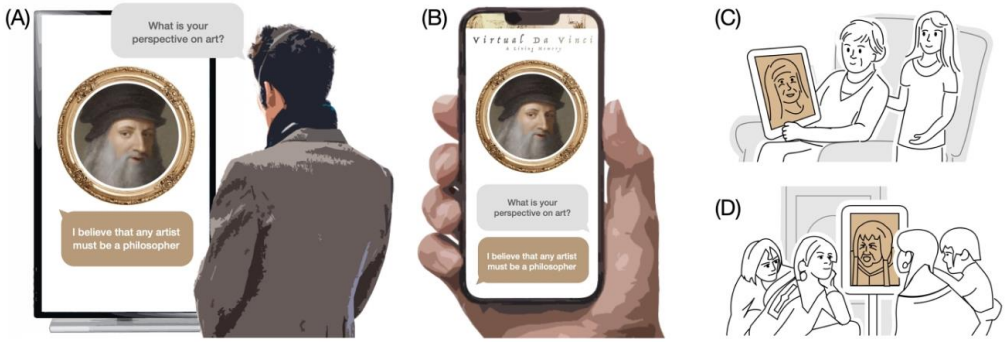


Figure 1: Left (A&B): The user interface for a living memory of Leonardo Da Vinci chatbot that participants interacted with using our system. The experience started with a 40 second long animated video of Leonardo Da Vinci introducing himself generated using an open-source AI-generated character pipeline. Right: Potential applications of Living Memories to (C) help people remember and mourn, and (D) preserve culture and learn about people from the past.

An example of the MIT project where a user can interact with an AI avatar of Leonardi Da Vinci. Captions 'C' and 'D' which highlight potential applications of this technology for remembrance and to preserve culture.

Dr Sharifa Alghowinem (right) showed me her workspace in the MIT Media Lab and demonstrated her personal robotics research.

9.1 UK considerations for digital legacy and artificial intelligence

In the UK, there is increasing recognition of the importance in developing research and policy to improve our understanding of how to manage digital legacy, which is evident through the important work of organisations and individuals. From an organisational perspective, the 'Digital Legacy Association' (and its associated conference) is a professional body raising awareness and improving areas relating to digital assets planning and digital legacy safeguarding.[54] Marie Curie has recently developed public-facing guidance about digital legacy, to help people with palliative care needs to manage their online and social accounts ahead of their death.[55] Several UK experts are increasing the evidence base about practical issues, ethical challenges and future possibles of using AI in palliative care digital legacy.

These individuals include Dr Elaine Kasket,[56] Sarah Stanley,[52] James Norris,[57] Professor Mark Taubert,[58] and Ginger Liu.[59] I hope to use the 'Digital Legacy, Design and Technology Network' (a collaborative network of stakeholders committed to conducting palliative care, digital legacy research, that I have established), to collaborate with these individuals (and my Churchill Fellowship connections) to conduct future research in about the opportunities and challenges of AI-generated avatars of the dead. Therefore, the UK is well placed to evaluate the modern ways how society remembers the dead, and how AI will shape the experience of death and

bereavement for future generations. Collaboration with a variety of stakeholders (like Marie Curie and the NHS) will help to determine the opportunities, challenges, social impacts, ethical and governance issues concerning the remembering the dead through using new technologies.

9.2 Key messages from digital legacy in palliative care

- AI technologies provide opportunities for people to live as avatars after death.
- Examples of important AI technologies in this area includes generative AI, holograms, virtual reality, face cloning and voice cloning technologies.
- It is important to consider how AI can contribute to digital legacy, considering the opportunities and challenges of innovations in this area.

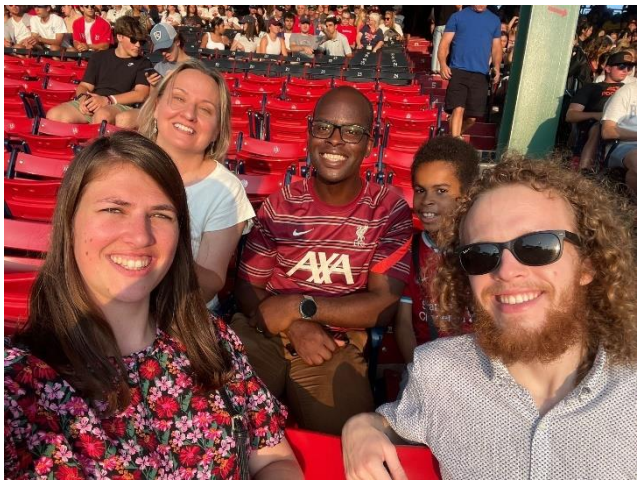
10.0 My family and the Churchill Fellowship

Travelling with my family during my Churchill Fellowship was a privilege. I travelled with Clare (my wife) and my three sons Isaac (age 12), Theo (age nine) and Joshua (age five). I travelled with my family for one week in the Netherlands and two weeks in the USA. The three-year (Covid-19 enforced) delay to my Fellowship was beneficial, as I think it was easier to travel with my children who are older and more physically able to enjoy the adventure. The trip was inspirational for my children, providing them with an insight of living in different countries, and gaining perspectives about the opportunities for development, knowledge transfer, and cultural exchange, which comes from travel.

We arrive in Amsterdam to take in the culture. Left to right: Me, Theo, Joshua, Clare, Isaac (front).

We enjoyed exploring the MIT museum. Left to right: Me, Isaac, Clare, Theo, Joshua (front).

We spent a lovely evening, with Professor Judith Rietjens and her children, on the top of the Euromast tower in Rotterdam.



Thank you, Dr Charlotta Lindvall, for the tickets to watch the Boston Red Sox play the Atlanta Braves at Fenway Park. Left to right: Dr Liesbet Van Bulck, Dr Charlotta Lindvall, me, Isaac Nwosu, Joshua Davis.

11.0 Conclusions

11.1 Design and palliative care:

When designing complex systems (like healthcare), it is important to understand the needs of the user, to appropriately design services and products to meet their needs. I learnt about the importance of developing interdisciplinary collaboration between stakeholders, such as designers, data scientists, healthcare professionals, ethicists, the public and policy makers. These collaborations will help to ensure that AI is developed according to users' needs and that important governance and ethical issues of AI in palliative care are addressed.

11.2 Population health and artificial intelligence

There is potential for the UK to leverage developments in AI methodologies for population health to support palliative care on a population level. At IKNL I observed projects where AI analysis was used on a national cancer dataset (1) to evaluate patterns of disease and to identify population palliative care needs of a population, (2) to conduct research using federated learning, and (3)to identify trends of illness, evaluate guidelines and recommend interventions.

11.3 Clinical care and artificial intelligence

NLP provides several opportunities to enhance palliative care by supporting prediction of morbidity and mortality,[60-63] to classify pain severity,[64 65] identify quality indicators,[47 65] and identify situations where important conversations occurred.[66] NLP methods, combined with automatic voice-to-text transcription of clinical consultations, can potentially facilitate early identification palliative care needs and improve the efficiency of data capture. NLP approaches may be useful in the analysis of large amounts of free text data, supporting the evaluation of issues which have previously been difficult to study.

11.4 Digital legacy and artificial intelligence

AI has potential to be used to preserve the memory of the dead, by creating a digital avatar of the deceased person, enabling a living person to interact with an the 'avatar' of the dead. For example, an AI computer program (e.g. a chatbot) can be used to mimic the writing style of a dead person. Another example is the use of a computer to create a hologram of the deceased, to mimic their appearance, movements, and voice.[67 68] Consequently, it is important to consider the different ways AI can contribute to digital legacy, considering the opportunities and challenges of innovations in this area.

12.0 Recommendations

1. **Healthcare professionals, researchers, policymakers should focus on the needs of the patients, caregivers and wider society (and ensure meaningful input into research and planning) when developing palliative care digital health interventions.**

It is important to ensure that the needs of individuals are central to approaches to use AI in healthcare. This is especially important in palliative care due to the specific physical, psychosocial, spiritual and emotional needs of individuals, and caregivers, which may require careful consideration to determine how AI best addresses needs.

2. **Palliative care professionals should work with designers to better understand, and address, the design related challenges, associated with the use digital health in palliative care systems.**

Incorporation of human-centred design method, and designers with the ability to apply this in practice, can help understand clinical problems, the system, and identify solutions, which will increase the potential for success when developing digital health solutions.

3. **Healthcare professionals, academic and policymakers should focus on raising awareness of artificial intelligence approaches in palliative care (in both professionals and lay audiences) to demystify this topic.**

It is important to improve the health literacy, in both professionals and lay audiences, about the potential of AI in palliative care. It is important that society is more informed about the strengths, opportunities, weaknesses and threats, that are posed by AI. Improved societal awareness about AI, its impacts and possibilities, will help guide future innovation, research and policy.

4. **Palliative care professionals and researchers need to better understand, and study, the different types of AI approaches, and how these can be used to deliver of palliative care services.**

It is important for palliative care professionals to have awareness that different types of AI exist (e.g. machine learning, deep learning, natural language processing, generative AI etc etc) and these different methods offer different opportunities and challenges. Greater awareness of e different AI methods will help the speciality move forward in research, practice and policy.

5. **Researchers should seek to identify important governance issues about different AI methods. Areas of importance include bias, privacy, trust, data security, accountability, fairness, safety, and ethics.**

Further work is required to establish responsible AI governance practices in palliative care. This is needed to ensure that AI is developed and used ethically, transparently, and in the best interest of society. Furthermore, it is important to establish consensus on how AI should be used, regulated and to agree priorities for research.

6. **Research and policy work should determine the risk, and impact, of digital inequality associated with AI in palliative care.**

Digital inequality is the unequal distribution of digital and internet-based devices, utilities and services. Globally, societies are becoming increasing digitised, thus increasing the size of digital footprints after death. Consequently, it is likely that some individuals (and those important to them) will experience digital inequalities in life and after death.

7. **Palliative care research should study commercially available AI modalities to determine how these tools may affect palliative care (e.g. population level care, clinical care, digital legacy, communication, grief and bereavement).**

Commercially available AI technologies have the capacity to dramatically shape the way we grieve today and in future. For example, Generative AI (e.g. ChatGPT), virtual reality, holograms, chatbots, voice cloning technology and other innovations, have been used to re-animate the dead. It is important that research and policy work evaluates available AI technologies, to determine the immediate opportunities, challenges and actions that are needed to ensure best practice in palliative care.

8. **Interdisciplinary research groups should be developed to ensure that palliative care AI research teams have the necessary skills and experience to conduct meaningful work.**

Interdisciplinary AI research will help to bring together knowledge from other fields, which will help to identify solutions to problems, data acquisition, recognition and reduction of bias, training, testing of intervention, audit and evaluation of the quality and safety.

13.0 My achievements

Following the conclusion of my travels I have been working on strengthening, and establishing new connections, in the field of palliative care digital health. I have conducted diverse of work, including research, scientific publications, development of new research networks and public speaking. Below is a summary of some activities which I have achieved since the conclusion of my Fellowship.

13.1 Awards

As Research Lead of Marie Curie Hospice Liverpool, we were awarded Culture for Innovation Award at The Northwest Coast Research and Innovation Awards 2023 (June 2023).

13.2 Collaborations

I have led the development of a National Institute for Health and Care Research (NIHR) funded, multidisciplinary digital legacy design network (compromising of palliative care, digital and design stakeholders) to work collaboratively to improve the capacity to conduct digital legacy research.

13.3 Book

I am writing a book about Technology and Palliative Care (Morgan and Claypool Publishers).

13.4 Upcoming research

Developing and refining a virtual reality intervention that will help to manage pain for people living with advanced cancer. Dr Nicola White, Dr Ollie Minton, Dr Victoria Vickerstaff, Professor Mark Taubert, Dr Amarachukwu Nwosu, Dr Kathleen Shelley, Dr Sarah Yardley. Funded by National Institute for Health and Care Research (NIHR), Research for Patient Benefit (RfPB) funding stream.

13.5 Publications related to my Churchill Fellowship

1. **Nwosu AC**, Mills M, Roughneen S, Stanley S, Chapman L, Mason SR. Virtual reality in specialist palliative care: a feasibility study to enable clinical practice adoption. BMJ Supportive & Palliative Care 2024;14:47-51.

2. Stanley, S., Finucane, A., Thompson, A., **Nwosu AC**. How can technology be used to support communication in palliative care beyond the Covid-19 pandemic: a mixed-methods national survey of palliative care healthcare professionals. BMC Palliat Care 23, 40 (2024). https://doi.org/10.1186/s12904-024-01372-z

3. Stanley S, Higginbotham K, Finucane A, **Nwosu AC**. A grounded theory study exploring palliative care healthcare professionals' experiences of managing digital legacy as part of advance care planning for people receiving palliative care. Palliative Medicine. 2023;0(0). doi:10.1177/02692163231194198

https://journals.sagepub.com/doi/full/10.1177/02692163231194198

4. **Nwosu AC**. Telehealth requires improved evidence to achieve its full potential in palliative care. Palliative Medicine. 2023 Jul;37(7):896-7. https://journals.sagepub.com/doi/full/10.1177/02692163231182461

13.6 Oral Presentations related to my Fellowship

- **March 2024:** Dr Amara Nwosu, Dr Catriona Mayland & Dr Steve Marshall. Palliative Care Research Society (PCRS) Masterclass: The power of global connections to change practice: lessons from Churchill fellows. Palliative Care Congress, online, 2024.
- **March 2024:** Artificial intelligence in palliative care: opportunities & challenges. Digital Legacy, Design & Technology networking event. Liverpool Science Park, Liverpool, UK.
- **February 2024:** My Churchill Fellowship: Artificial intelligence and design in palliative care – implications for practice. Marie Curie Research Conference, online.
- **November 2023:** Artificial Intelligence and emerging technologies in palliative and end of life care – opportunities and challenges. Hospice UK National Conference 2023, ACC Liverpool, Liverpool, UK.
- **November 2023:** Development of 'use-cases' for a digital palliative care bereavement service. Hospice UK National Conference 2023, ACC Liverpool, Liverpool, UK.
- **November 2023:** Ethical conundrums roundtable – The ethical implications of AI in digital legacy and managing grief. Hospice UK Conference 2023, ACC Liverpool, Liverpool, UK.
- **July 2023:** How innovations in technology can support people with palliative care needs in the future, Massachusetts Institute of Technology, Boston USA.
- **July 2023:** How innovations in technology can support people with palliative care needs in the future. Dana Farber Cancer Institute (DFCI), Harvard Medical School, Boston USA.
- **June 2023:** How innovations in technology can support people with palliative care needs in the future. Digital Legacy Conference part of European Association for Palliative Care World Congress, Rotterdam 2023.
- **June 2023:** How innovations in technology can support people with palliative care needs in the future. Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht 2023.
- **June 2023:** How innovations in technology can support people with palliative care needs in the future. Erasmus Medical Center, Rotterdam, 2023.

14.0 My next steps and concluding remarks

I plan to further build on my achievements by conducting research to address the eight recommendations in this report. Firstly, I will focus on researching the societal impact, on grief and bereavement, of AI generated avatars of the dead. I will research this area with my colleague, an expert in digital legacy, Sarah Stanley (Research Nurse, Marie Curie Hospice, Liverpool, UK). I will use my academic and healthcare networks to develop my collaborative research network. Ultimately, my aim is to improve palliative care in the UK through better use of AI. The Churchill Fellowship has been invaluable in providing me with the opportunity to travel, develop my network and make my vision a reality. I had a wonderful, life-changing adventure and I am looking forward the opportunities that the Fellowship has given me. I thank you for reading this report. I hope is it useful to you and will collectively help us all to use AI better, to improve the lives of people with palliative care needs.

Best wishes,

Amara Nwosu

15.0 Further reading

Futurism in Palliative: An overview of the Palliative Care, Architecture and Design Symposium (PADS 2018)

My EAPC blog about my conference about palliative care, design and technology.

https://eapcnet.wordpress.com/2019/02/25/futurism-in-palliative-an-overview-of-the-palliative-care-architecture-and-design-symposium-pads-2018/

Improving Palliative Care Through Digital Health Technology

My BMJ Supportive & Palliative blog about future innovations of palliative care and technology.

https://blogs.bmj.com/spcare/2020/05/26/improving-palliative-care-through-digital-health-technology/

Identification of Digital Health Priorities for Palliative Care Research: Modified Delphi Study. Nwosu AC, McGlinchey T, Sanders J, et al. JMIR aging 2022;5(1):e32075.

My publication in JMIR Aging about digital health priorities in palliative care.

https://aging.jmir.org/2022/1/e32075/

Designer in Residence: a new model for design-driven innovation in future hospice care

Details of the design programme I coordinated in Marie Curie Hospice Liverpool.

https://inclusionaries.com/portfolio/designer-in-residence/

Digital legacy and palliative care: using technology, design and healthcare partnerships to research how digital information is managed after death

My abstract detailing development of a multiprofessional group to research digital legacy.

https://spcare.bmj.com/content/13/Suppl_5/A41.3

The Digital Legacy Association

A professional body raising awareness and improving standards in areas relating to digital assets planning and digital; legacy safeguarding)

https://digitallegacyassociation.org/

16.0 Appendices

16.1 Institutions visited

Institution	Website
The U.S.A	
Dana-Farber Cancer Institute	https://www.dana-farber.org/
The Lindvall Lab	https://lindvalllab.dana-farber.org/
Massachusetts Institute of Technology	https://www.mit.edu/
MIT Media Lab	https://www.media.mit.edu/
The Netherlands	
Erasmus Medical Center	https://www.erasmusmc.nl/en/
Delft University of Technology	https://www.tudelft.nl/en/
Faculty of Industrial Design Engineering - Delft University of Technology	https://www.tudelft.nl/en/ide
Netherlands comprehensive cancer organisation (IKNL)	https://iknl.nl/

16.2 Interview where I provide an overview of my Churchill Fellowship (video – YouTube)

I was interviewed by Sarah Stanley, research nurse at Marie Curie Hospice Liverpool, to produce a video to discuss the Churchill Fellowship in greater depth. A YouTube link is below.

https://youtu.be/G6XHOjY4mCI

16.3 Interview where I provide an overview of my Churchill Fellowship (Audio – Spotify)

I was interviewed by Sarah Stanley, research nurse at Marie Curie Hospice Liverpool, to produce a podcast to discuss the Churchill Fellowship in greater depth. A Spotify link is below.

https://spotifyanchor-web.app.link/e/QAvQ7z864Jb

16.4 Videos of scientific presentations I have delivered which summarise the findings of my Fellowship

I have conducted several presentations to disseminate learning from my Churchill Fellowship. The following links provide full videos of presentations that I have delivered.

Presentation details	**Link**
Artificial intelligence and emerging technologies – Hospice UK 2023 Conference keynote plenary (delivered 24/11/2023)	https://www.youtube.com/watch?v=M20Gafw1v1M
My Churchill Fellowship: Artificial intelligence and design in palliative care – implications for practice (delivered 07/02/2024)	https://vimeo.com/912159456/580d194c0c
Palliative Care Research Society (PCRS) Masterclass – The power of global connections to change practice: lessons from Churchill fellows – Palliative Care Congress 2024 (delivered 22/03/2024)	https://vimeo.com/933223331/a47fd52cd8?share=copy

17.0 References

1. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine* 2017;15(1):102. doi: 10.1186/s12916-017-0860-2
2. Topol E. Preparing the Healthcare Workforce to Deliver the Digital Future the Topol Review: An Independent Report on Behalf of the Secretary of State for Health and Social Care. *NHS Health Education: London, UK* 2019
3. Finucane A, O'Donnell H, Lugton J, et al. Digital Health Interventions in Palliative Care: A Systematic Meta-Review and Evidence Synthesis. *medRxiv* 2020:2020.09.16.20195834. doi: 10.1101/2020.09.16.20195834
4. Nwosu AC, McGlinchey T, Sanders J, et al. Identification of digital health priorities for palliative care research: modified delphi study. *JMIR aging* 2022;5(1):e32075.
5. World Health Organization. WHO Definition of Palliative Care 2010 [Available from: http://www.who.int/cancer/palliative/definition/en/.
6. Bone AE, Gomes B, Etkind SN, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative Medicine* 2017;32(2):329-36. doi: 10.1177/0269216317734435
7. Department of Health Social Care. The future of healthcare: our vision for digital, data and technology in health and care. https://www.gov.uk/government/publications/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care: DHSC London, 2018.
8. Haghi M, Thurow K, Stoll R. Wearable Devices in Medical Internet of Things: Scientific Research and Commercially Available Devices. *Healthcare informatics research* 2017;23(1):4-15. doi: 10.4258/hir.2017.23.1.4 [published Online First: 2017/03/07]
9. McCarthy J. What is artificial intelligence? 2004
10. Bajwa J, Munir U, Nori A, et al. Artificial intelligence in healthcare: transforming the practice of medicine. *Future Healthcare Journal* 2021;8(2):e188-e94. doi: 10.7861/fhj.2021-0095
11. Shukla Shubhendu S, Vijay J. Applicability of artificial intelligence in different fields of life. *International Journal of Scientific Engineering and Research* 2013;1(1):28-35.
12. Quinn TP, Senadeera M, Jacobs S, et al. Trust and medical AI: the challenges we face and the expertise needed to overcome them. *Journal of the American Medical Informatics Association* 2021;28(4):890-94.
13. Nwosu AC, Debattista M, Rooney C, et al. Social media and palliative medicine: a retrospective 2-year analysis of global Twitter data to evaluate the use of technology to communicate about issues at the end of life. *BMJ Support Palliat Care* 2015;5(2):207-12. doi: 10.1136/bmjspcare-2014-000701 [published Online First: 2014/09/04]
14. Nwosu AC, Quinn C, Samuels J, et al. Wearable smartwatch technology to monitor symptoms in advanced illness. *BMJ supportive & palliative care* 2018;8(2):237-37.
15. Nwosu AC, Mason S. Palliative medicine and smartphones: an opportunity for innovation? *BMJ Support Palliat Care* 2012;2(1):75-7. doi: 10.1136/bmjspcare-2011-000151 [published Online First: 2012/03/01]
16. Nwosu AC, Sturgeon B, McGlinchey T, et al. Robotic technology for palliative and supportive care: Strengths, weaknesses, opportunities and threats. *Palliat Med* 2019;33(8):1106-13. doi: 10.1177/0269216319857628 [published Online First: 2019/06/30]
17. Nwosu AC, Collins B, Mason S. Big Data analysis to improve care for people living with serious illness: The potential to use new emerging technology in palliative care. *Palliative Medicine* 2018;32(1):164-66. doi: 10.1177/0269216317726250

18. Landry L. WHAT IS HUMAN-CENTERED DESIGN? https://online.hbs.edu/blog/post/what-is-human-centered-design: Harvard Buisness School Online; 2020 [updated 06/01/2024. Available from: https://online.hbs.edu/blog/post/what-is-human-centered-design accessed 02/05 2024.
19. Melles M, Albayrak A, Goossens R. Innovating health care: key characteristics of human-centered design. *International Journal for Quality in Health Care* 2021;33(Supplement_1):37-44.
20. Hancock S, Preston N, Jones H, et al. Telehealth in palliative care is being described but not evaluated: a systematic review. *BMC Palliative Care* 2019;18(1):114.
21. Times Higher Education (THE). World University Rankings Website of Times Higher Education (THE)2024 [Available from: https://www.timeshighereducation.com/world-university-rankings accessed 2nd June 2024.
22. EPM Scientific. Boston is Now the Largest Biotech Hub in the World 2023 [Available from: https://www.epmscientific.com/blog/2023/02/boston-is-now-the-largest-biotech-hub accessed 2nd June 2024.
23. Massachusetts Institute of Technology. Massachusetts Institute of Technology (MIT) Website of Massachusetts Institute of Technology2024 [Available from: https://www.mit.edu/ accessed 2nd June 2024.
24. Newsweek. World's best specialized hospitals Website of Newsweek2024 [Available from: https://www.newsweek.com/rankings/worlds-best-specialized-hospitals-2024 accessed 2nd June 2024.
25. Dana-Farber Cancer Institute (DFCI). Lindvall Lab: computational palliative care research Website of Dana-Farber Cancer Institute (DFCI),2020 [Available from: https://lindvalllab.dana-farber.org/research.html accessed 2nd June 2024.
26. Wise J. Covid-19: WHO declares end of global health emergency: British Medical Journal Publishing Group, 2023.
27. Wherton J, Shaw S, Papoutsi C, et al. Guidance on the introduction and use of video consultations during Covid-19: important lessons from qualitative research. *BMJ Leader* 2020:leader-2020-000262. doi: 10.1136/leader-2020-000262
28. Calton B, Abedini N, Fratkin M. Telemedicine in the Time of Coronavirus. *J Pain Symptom Manage* 2020;60(1):e12-e14. doi: 10.1016/j.jpainsymman.2020.03.019 [published Online First: 2020/04/03]
29. Grewal US, Terauchi S, Beg MS. Telehealth and Palliative Care for Patients With Cancer: Implications of the Covid-19 Pandemic. *JMIR Cancer* 2020;6(2):e20288. doi: 10.2196/20288 [published Online First: 2020/10/14]
30. Ritchey KC, Foy A, McArdel E, et al. Reinventing palliative care delivery in the era of covid-19: how telemedicine can support end of life care. *American Journal of Hospice and Palliative Medicine®* 2020;37(11):992-97.
31. Lal A, Bell G, Curseen K, et al. Teaching Telepalliative Care: An Elective Rotation for Medical Students during the Covid-19 Pandemic. *Journal of Palliative Medicine* 2020
32. Abel J, Taubert M. Coronavirus pandemic: compassionate communities and information technology. *BMJ Supportive & Palliative Care* 2020;10(4):369-71. doi: 10.1136/bmjspcare-2020-002330
33. Mills J, Li C, Fullerton S, et al. Staying connected and informed: Online resources and virtual communities of practice supporting palliative care during the novel coronavirus pandemic. *Progress in Palliative Care* 2020;28(4):251-53. doi: 10.1080/09699260.2020.1759876
34. Niki K, Okamoto Y, Ueda M. Response to Wang et al., Virtual Reality as a Bridge in Palliative Care during Covid-19 (DOI: 10.1089/jpm.2020.0212). *J Palliat Med* 2020;23(7):892-94. doi: 10.1089/jpm.2020.0261 [published Online First: 2020/05/13]

35. Wang SS, Teo WZ, Teo WZ, et al. Virtual reality as a bridge in palliative care during Covid-19. *Journal of palliative medicine* 2020;23(6):756-56.
36. Stanley S, Finucane A, Thompson A, et al. How can technology be used to support communication in palliative care beyond the covid-19 pandemic: a mixed-methods national survey of palliative care healthcare professionals. *BMC palliative care* 2024;23(1):40.
37. Sleeman KE, De Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *The Lancet Global Health* 2019;7(7):e883-e92.
38. NEMO Science Museum. NEMO Science Museum Website of the NEMO Science Museum2024 [Available from: https://www.nemosciencemuseum.nl/en/ accessed 2nd June 2024.
39. Lab4Living. The Life Café: The Marie Curie Design to Care Programme Lab4Living, Sheffield Hallam University2024 [Available from: https://lab4living.org.uk/projects/life-cafe/ accessed 1st June 2024.
40. Nickpour F, Tibbles A, Nwosu A, et al. 32 Designer-in-residence; a new model for design-driven innovation in future hospice care: British Medical Journal Publishing Group, 2023.
41. Nwosu A, Stanley S, Norris J, et al. P-86 Digital legacy and palliative care: using technology, design and healthcare partnerships to research how digital information is managed after death: British Medical Journal Publishing Group, 2023.
42. Goodwin CD, . Futurism in Palliative: An overview of the Palliative Care, Architecture and Design Symposium (PADS 2018). In: Nwosu A, ed. The blog of the European Association for Palliative Care: European Association for Palliative Care, 2019.
43. King's College London. Big & Routine Data-Based Palliative & End of Life Care Research 2024 [Available from: https://www.kcl.ac.uk/research/bigroutinedata-based-research accessed 2nd June 2024.
44. Johnson H, Davies JM, Leniz J, et al. Opportunities for public involvement in big data research in palliative and end-of-life care. *Palliative Medicine* 2021;35(9):1724-26.
45. Gao W, Gulliford M, Morgan M, et al. Primary care service use by end-of-life cancer patients: a nationwide population-based cohort study in the United Kingdom. *BMC Family Practice* 2020;21:1-13.
46. Chukwusa E, Yu P, Verne J, et al. Regional variations in geographic access to inpatient hospices and Place of death: A Population-based study in England, UK. *PloS one* 2020;15(4):e0231666.
47. Lindvall C, Lilley EJ, Zupanc SN, et al. Natural Language Processing to Assess End-of-Life Quality Indicators in Cancer Patients Receiving Palliative Surgery. *J Palliat Med* 2019;22(2):183-87. doi: 10.1089/jpm.2018.0326 [published Online First: 2018/10/18]
48. Maggy Bobek Tieché. Most common hospital EHR systems by market share Definitive Healthcare2024 [Available from: https://www.definitivehc.com/blog/most-common-inpatient-ehr-systems accessed 2nd June 2024.
49. Udelsman BV, Lilley EJ, Qadan M, et al. Deficits in the palliative care process measures in patients with advanced pancreatic cancer undergoing operative and invasive nonoperative palliative procedures. *Annals of Surgical Oncology* 2019;26:4204-12.
50. Lee RY, Brumback LC, Lober WB, et al. Identifying goals of care conversations in the electronic health record using natural language processing and machine learning. *Journal of pain and symptom management* 2021;61(1):136-42. e2.
51. Lee KC, Udelsman BV, Streid J, et al. Natural language processing accurately measures adherence to best practice guidelines for palliative care in trauma. *Journal of Pain and Symptom Management* 2020;59(2):225-32. e2.
52. Stanley S, Higginbotham K, Finucane A, et al. A grounded theory study exploring palliative care healthcare professionals' experiences of managing digital legacy as part of

advance care planning for people receiving palliative care. *Palliative Medicine* 2023:02692163231194198.
53. Coop H, Marlow C. Do we prepare patients for their digital legacy? A survey of palliative care professionals. *Palliat Med* 2019;33(1):114-15. doi: 10.1177/0269216318802748 [published Online First: 2018/09/28]
54. The Digital Legacy Association. The Digital Legacy Association The website of the Digital Legacy Association2021 [Available from: https://digitallegacyassociation.org/ accessed 1st June 2024.
55. Marie Curie. How to sort out online accounts: The website of Marie Curie; 2024 [Available from: https://www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/social-media-online-accounts accessed 1st June 2024.
56. Kasket E. All the ghosts in the machine: The digital afterlife of your personal data: Hachette UK 2019.
57. James Norris. Website of James Norris 2024 [Available from: https://www.jamesnorris.me/ accessed 1st June 2024.
58. Taubert M, Watts G, Boland J, et al. Palliative social media. *BMJ Supportive & Palliative Care* 2014;4(1):13-18.
59. Ginger Liu. Website of Ginger Liu https://www.gingerliu.com/2024 [Available from: https://www.gingerliu.com/ accessed 1st June 2024.
60. Einav L, Finkelstein A, Mullainathan S, et al. Predictive modeling of U.S. health care spending in late life. *Science* 2018;360(6396):1462-65. doi: 10.1126/science.aar5045 [published Online First: 2018/06/30]
61. Makar M, Ghassemi M, Cutler DM, et al. Short-term Mortality Prediction for Elderly Patients Using Medicare Claims Data. *Int J Mach Learn Comput* 2015;5(3):192-97. doi: 10.7763/ijmlc.2015.V5.506 [published Online First: 2015/06/01]
62. Sahni N, Simon G, Arora R. Development and Validation of Machine Learning Models for Prediction of 1-Year Mortality Utilizing Electronic Medical Record Data Available at the End of Hospitalization in Multicondition Patients: a Proof-of-Concept Study. *J Gen Intern Med* 2018;33(6):921-28. doi: 10.1007/s11606-018-4316-y [published Online First: 2018/02/01]
63. Avati A, Jung K, Harman S, et al. Improving palliative care with deep learning. *BMC medical informatics and decision making* 2018;18(Suppl 4):122. doi: 10.1186/s12911-018-0677-8 [published Online First: 2018/12/13]
64. Heintzelman NH, Taylor RJ, Simonsen L, et al. Longitudinal analysis of pain in patients with metastatic prostate cancer using natural language processing of medical record text. *Journal of the American Medical Informatics Association : JAMIA* 2013;20(5):898-905. doi: 10.1136/amiajnl-2012-001076 [published Online First: 2012/11/13]
65. Lodhi MK, Stifter J, Yao Y, et al. Predictive Modeling for End-of-Life Pain Outcome using Electronic Health Records. *Adv Data Min* 2015;9165:56-68. doi: 10.1007/978-3-319-20910-4_5 [published Online First: 2016/08/09]
66. Chan A, Chien I, Moseley E, et al. Deep learning algorithms to identify documentation of serious illness conversations during intensive care unit admissions. *Palliat Med* 2019;33(2):187-96. doi: 10.1177/0269216318810421 [published Online First: 2018/11/15]
67. Jiménez-Alonso B, Brescó de Luna I. Griefbots. A new way of communicating with the dead? *Integrative Psychological and Behavioral Science* 2023;57(2):466-81.
68. Özdemir V, Springer S, Yıldırım A, et al. Thanatechnology and the living dead: New concepts in digital transformation and human-computer interaction. *OMICS: A Journal of Integrative Biology* 2021;25(7):401-07.