

the CHURCHILL fellowship

Artificial Intelligence and emerging technologies in palliative and end of life care – opportunities and challenges?

Hospice UK Conference, Liverpool 06/11/23



Lancaster University
Medical School



Liverpool University Hospitals
NHS Foundation Trust

Dr Amara Nwosu

MBChB FRCP PhD

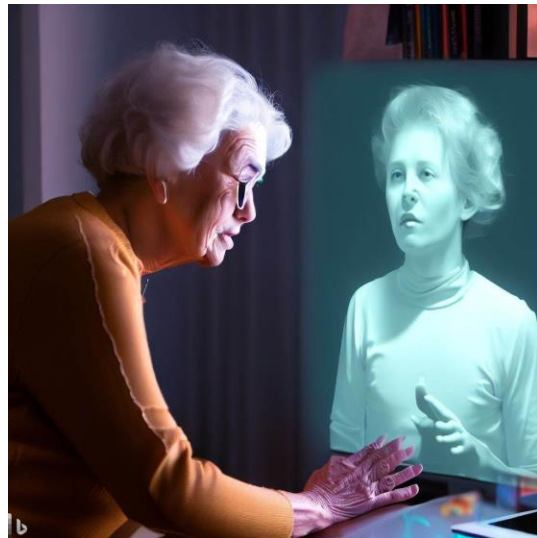
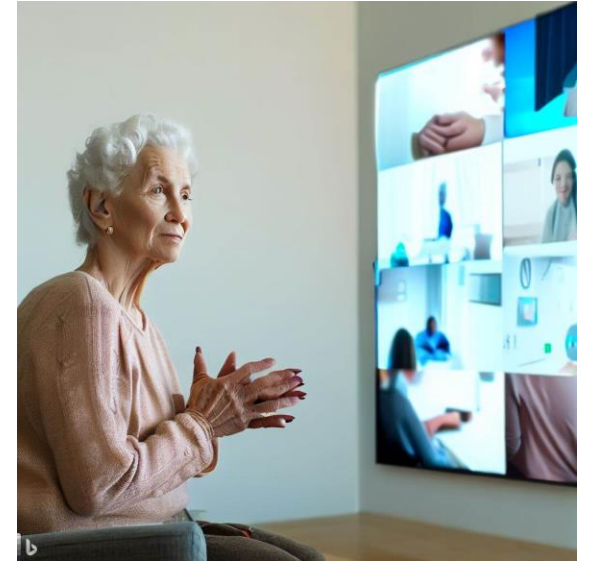
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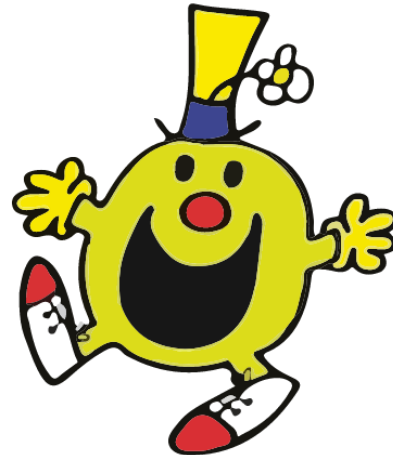
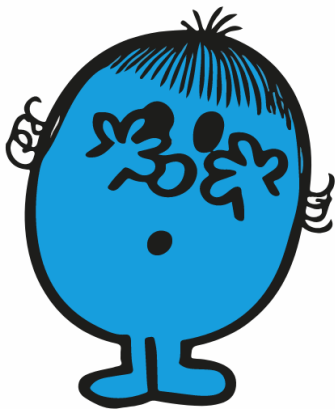
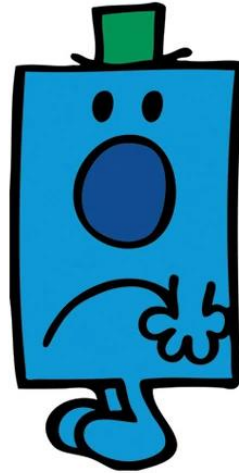
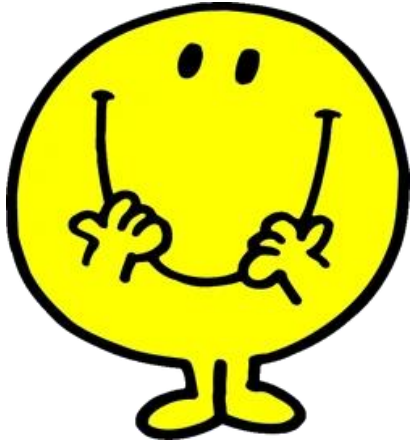
Imagine the future in 2060...



Emma in 2060



How does this make you feel?



Aims

- To provide an overview of my Churchill Fellowship to research palliative care technology
- Discussion of opportunities and challenges for artificial intelligence (AI) in palliative care
 - *Population level*
 - *Clinical management*
 - *The individual and digital legacy*

My interest in palliative care technology

Blog | BMJ Supportive & Palliative Care



Improving Palliative Care Through Digital Health Technology

Posted on [May 26, 2020](#)

Dr Amara Callistus Nwosu

*Lancaster University Faculty of Health and Medicine
International Observatory on End of Life Care*



Opportunities

- Innovation
- Remote care
- More choice

Challenges

- Does it work?
- Loss of human connection
- Inequalities

Published on 21.3.2022 in [Vol 5, No 1 \(2022\): Jan-Mar](#)

📌 Preprints (earlier versions) of this paper are available at , first published July 14, 2021.



Identification of Digital Health Priorities for Palliative Care Research: Modified Delphi Study

Amara Callistus Nwosu ^{1, 2, 3} ; Tamsin McGlinchey ⁴ ; Justin Sanders ^{5, 6, 7} ;
Sarah Stanley ² ; Jennifer Palfrey ⁸ ; Patrick Lubbers ⁹ ; Laura Chapman ² ;
Anne Finucane ¹⁰ ; Stephen Mason ⁴ 

Citation

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Identification of Digital Health Priorities for Palliative Care Research: Modified Delphi Study
JMIR Aging 2022;5(1):e32075
doi: [10.2196/32075](#)
PMID: [35311674](#)

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Article

Authors

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Tweetations (48)

Metrics

An abstract digital cityscape with glowing blue and red cubes and data streams, set against a dark blue background.

Priority Topics

- Telehealth & Telemedicine
- Big Data
- Mobile Devices & Wearables
- Virtual Reality
- Smart home
- Biotechnology
- Artificial Intelligence
- Digital Legacy

An abstract digital cityscape with glowing blue and red cubes and data streams, set against a dark blue background.

Priority Topics

- Telehealth & Telemedicine
- Big Data
- Mobile Devices & Wearables
- Virtual Reality
- Smart home
- Biotechnology
- Artificial Intelligence
- Digital Legacy

the CHURCHILL fellowship

- Overseas travelling fellowship for UK citizens to find innovative solutions for important problems.
- In 2020, I was awarded a Churchill Fellowship to visit the U.S.A and the Netherlands to research how technology, data and design can support palliative care.



Countries visited



The Netherlands



Delft University of Technology



USA



Artificial Intelligence (AI)

- Artificial intelligence (AI) describes the science and engineering of developing intelligent machines
 - Algorithms or a set of rules
 - Machine follows rules to mimic human cognitive functions
- Increasingly used in healthcare
 - For example; large datasets to recognise patterns and relationships, to identify proactive treatment solutions.
 - Electronic healthcare records (EHR)

Types of Artificial Intelligence

REACTIVE

Has no memory, only responds to different stimuli

LIMITED MEMORY

Uses memory to learn and improve its responses

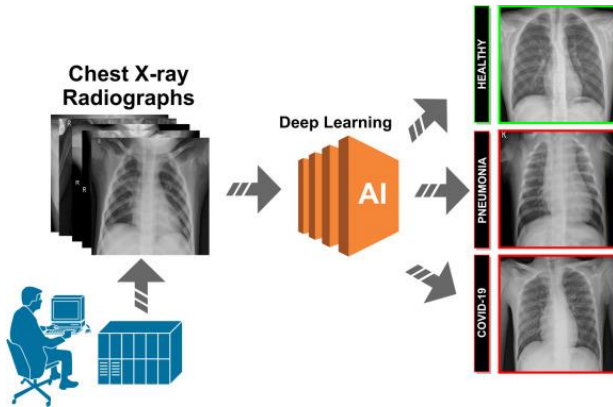
THEORY OF MIND

Understand the need of other intelligent entities

SELF AWARE

Has human-like intelligence and self awareness

Examples of AI methods



Learning



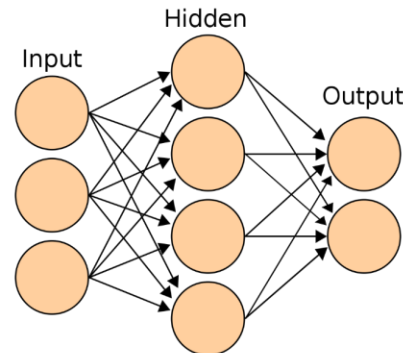
Natural language processing

2019: Generative pre-trained transformer (GPT) language models generate coherent text.

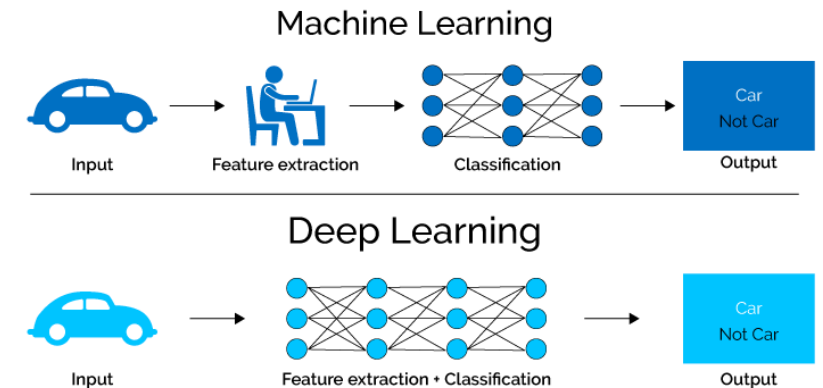
2023: ChatGPT achieves human level scores in professional exams



Perception

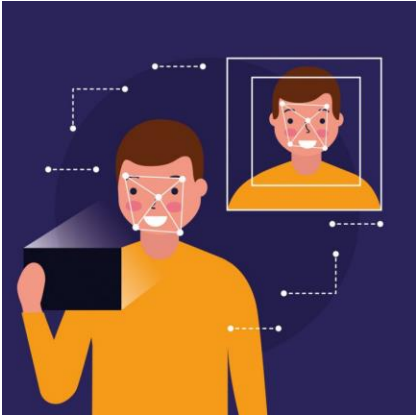


Artificial neural network



Deep learning

Day to day examples of AI



Facial recognition



Social media



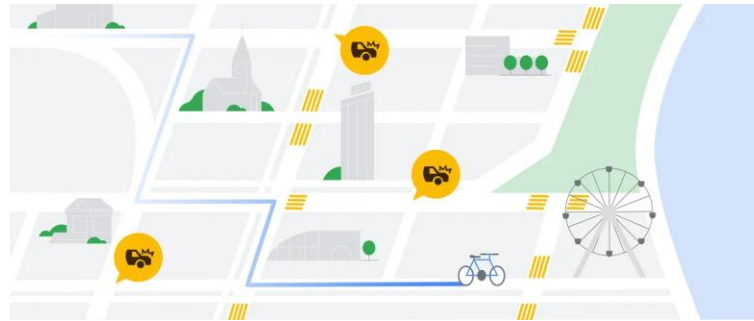
Email



Web search



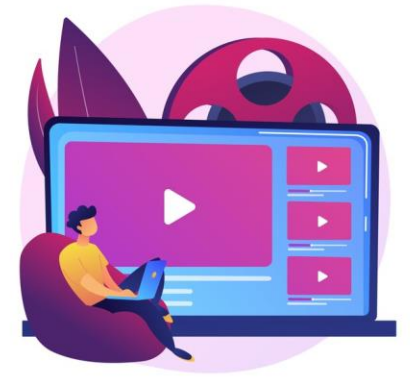
Voice assistants



Navigation apps



Banking



Streaming services



AI for Population level analysis



North Sea

UNITED
KINGDOM

GERMANY

Amsterdam o

The Hague o

NETHERLANDS

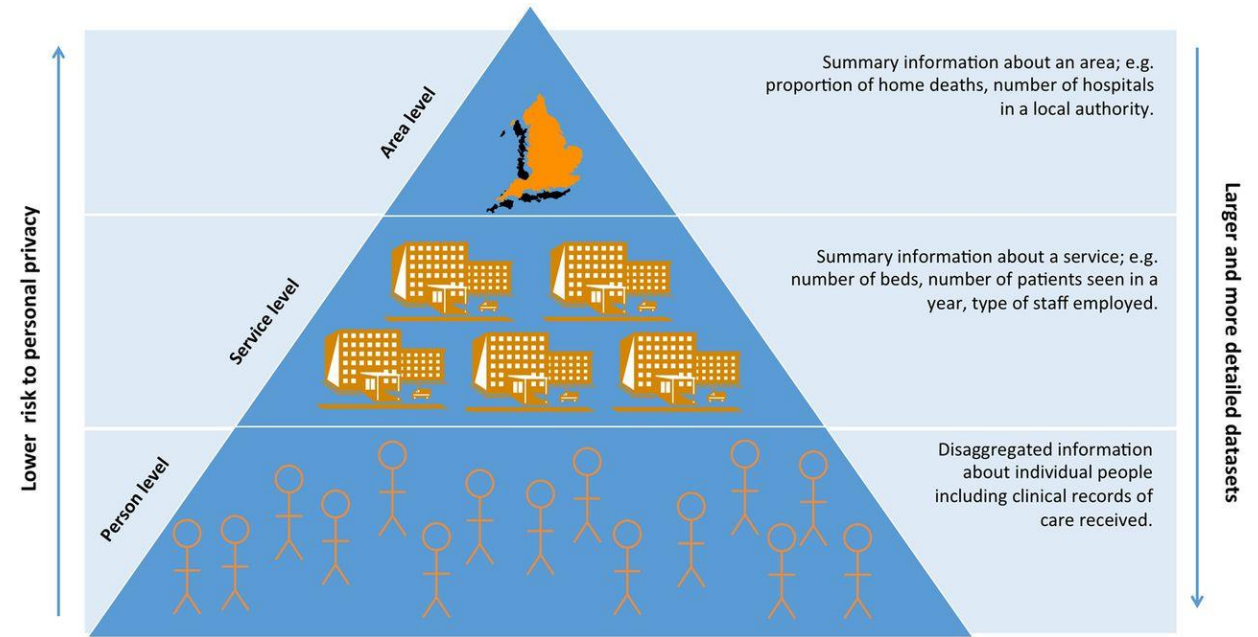
BELGIUM





Big Data in Palliative Care

Big data describes large amounts of (previously unmanageable) data that can now be processed by modern computer analysis techniques.



Davies JM, Gao W, Sleeman KE, *et al*
Using routine data to improve palliative and end of life care
BMJ Supportive & Palliative Care 2016;**6**:257-262.

Big Data has important potential in palliative care - EAPC 2022



Professor Joachim Cohen

End-of-Life Care Research Group of
the Vrije Universiteit Brussel.

1. Population needs assessment and monitoring.
2. Health care system and quality of care evaluations.
3. Addressing causality.
4. Evaluate policies interventions, programs in the real world.
5. Efficient data collection methods for palliative care trials.
6. Prediction and prospective decision support.

Using national data for healthcare decisions

Netherlands Cancer Registry (NCR)

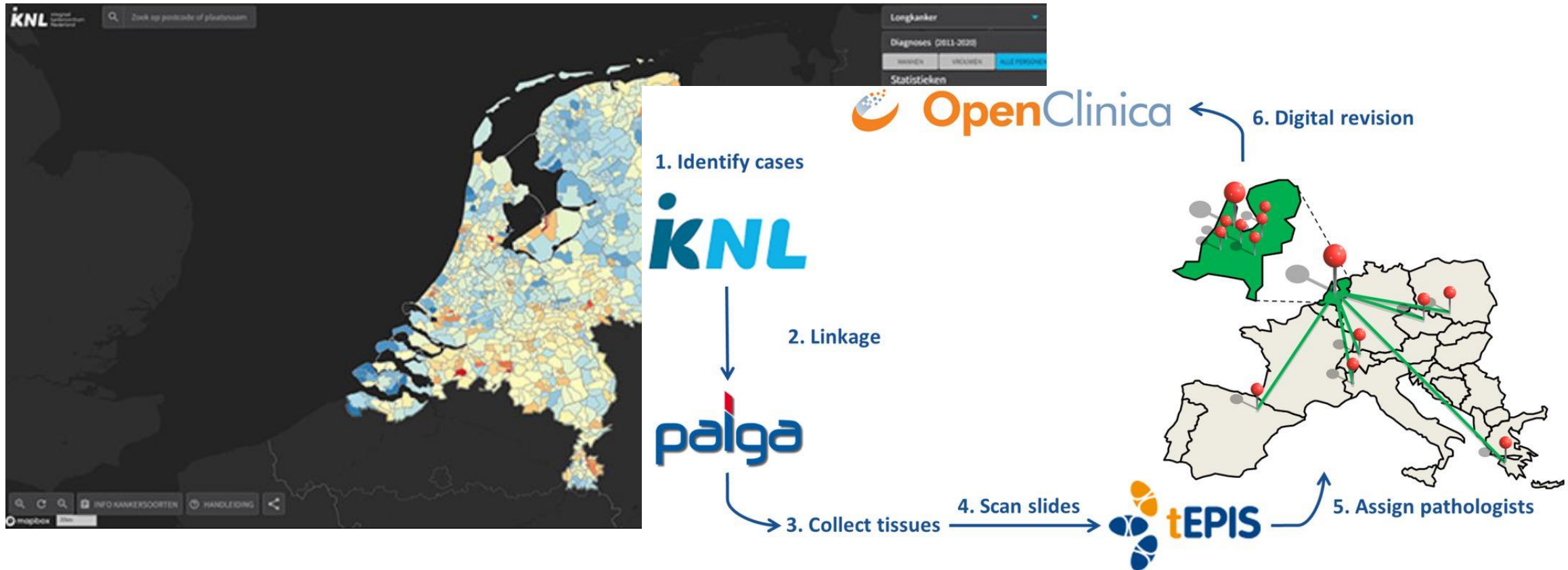
- Data of all Dutch cancer patients
- 2.7 million patients
- Open, international, anonymous dataset
- Netherlands Comprehensive Cancer Organization (IKNL)

Palliative care

- Realtime guidelines
- Cancer data on Google maps
- Visualising data in real-time
- Research and federated learning



Using national and international data to inform care

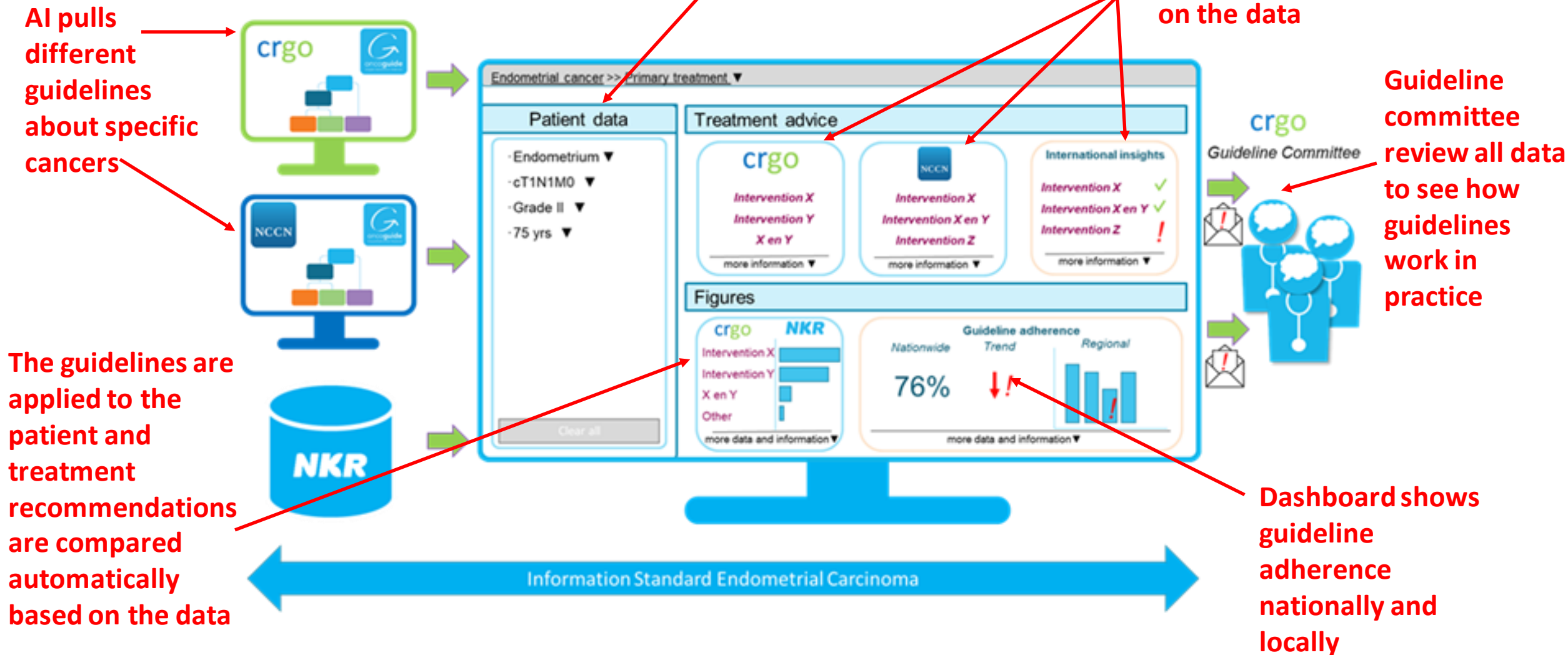


Mapping out cancer data for analysis and comparison

Sharing data to use international expertise

Dackus GM et al. Long-term prognosis of young breast cancer patients (≤ 40 years) who did not receive adjuvant systemic treatment: protocol for the PARADIGM initiative cohort study. *BMJ Open* 2017;7:e017842. doi: 10.1136/bmjopen-2017-017842

Using AI to visualise clinical outcomes



Federated Learning

Federated Learning addresses the problem of data governance and privacy, by training algorithms collaboratively without exchanging the data itself.

Analysis done rapidly on data recorded on standardized datasets



Liverpool



Rotterdam



Boston

Algorithm sent to local electronic healthcare database

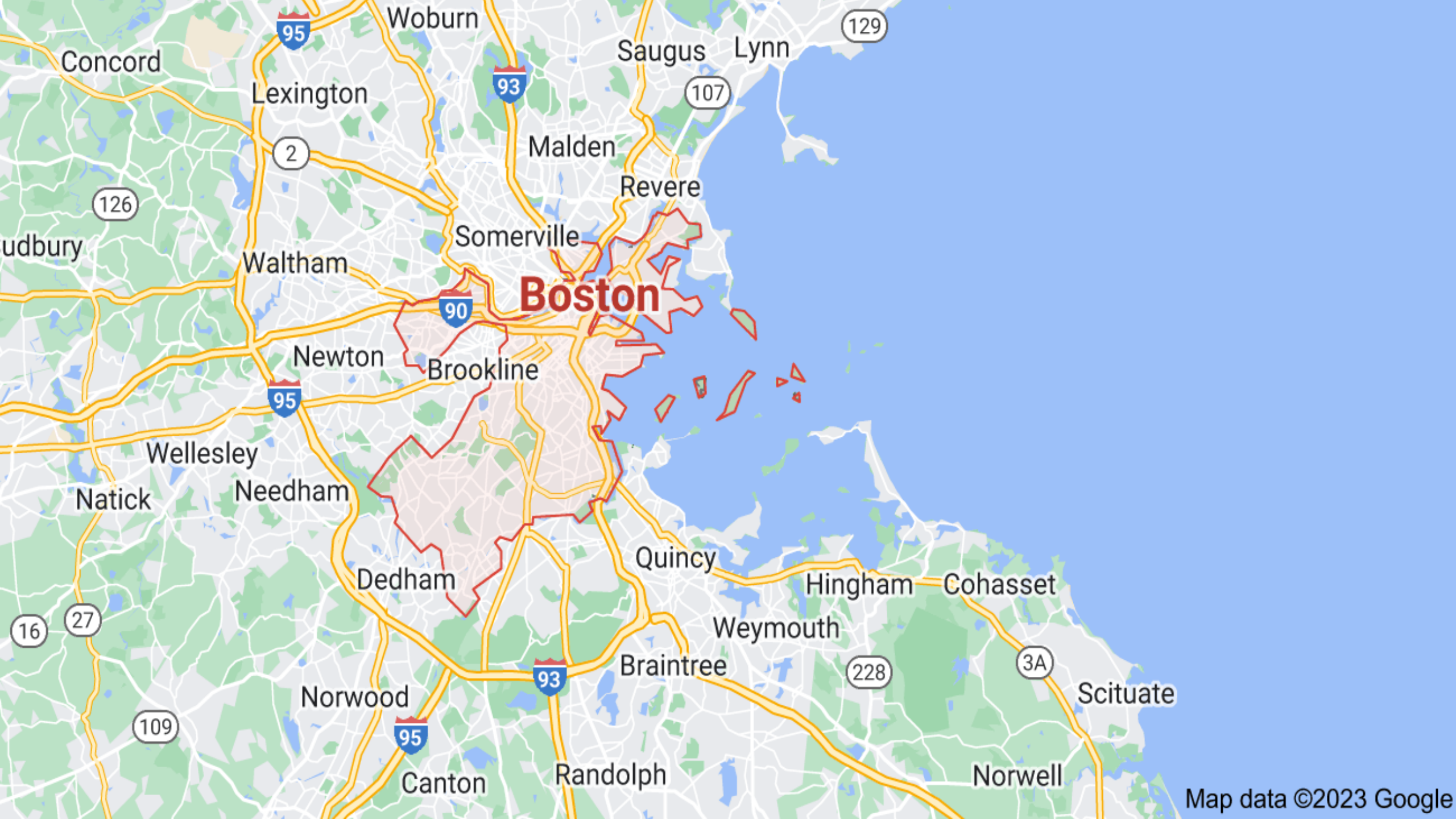


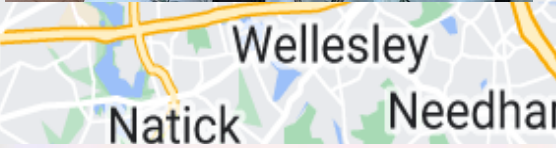
What is the survival data for adults with renal failure with metastatic cord compression after they receive radiotherapy?

Answer returned with no exchange of patient data



AI for clinical care





AI to identify palliative care need & estimate survival



Journal of Pain and Symptom
Management

Volume 63, Issue 5, May 2022, Pages 879-880



Randomized Trial of a Novel Artificial Intelligence/Machine Learning Model to Predict Palliative (

[Alisha Morgan DO, Jor](#)
[Jacob Strand MD FACP](#)
[Curtis Storlie PhD](#)

[Show more](#) ✓



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

Nishant Sahni, MD, MS¹, Gyorgy Simon, PhD², and Rashi Arora, MD¹

¹Division of General Internal Medicine, University of Minnesota, Minneapolis, MN, USA; ²Institute of Health Informatics, University of Minnesota, Minneapolis, MN, USA.

AI to analyse symptoms

Published in final edited form as:

Adv Data Min. 2015 July ; 9165: 56–68. doi:10.1007/978-3-319-20910-4_5.

Predictive Modeling for End-of-Life Pain Outcome using Electronic Health Records

Muhammad K. Lodhi¹, Janet Stifter¹, Yingwei Yao¹, Rashid Ansari¹, Gail M. Kee-nan²,
Diana J

Research and applications



Longitudinal analysis of pain in patients with metastatic prostate cancer using natural language processing of medical record text

Norris H Heintzelman,¹ Robert J Taylor,² Lone Simonsen,² Roger Lustig,²
Doug Anderko,¹ Jennifer A Haythornthwaite,³ Lois C Childs,¹ George Steven Bova^{4,5,6}

Natural Language Processing of healthcare records in palliative care



Lindvall Lab – Dana Farber Cancer Institute (DFCI)

Computational palliative care research

Dr Charlotta Lindvall

Developing and testing novel NLP-based approaches to capture palliative care quality measures.



Dana-Farber
Cancer Institute



HARVARD
MEDICAL SCHOOL

Evaluating interventions

Ann Surg Oncol (2019) 26:4204–4212
<https://doi.org/10.1245/s10434-019-07757-2>

Annals of
SURGICAL ONCOLOGY
OFFICIAL JOURNAL OF THE SOCIETY OF SURGICAL ONCOLOGY



ORIGINAL ARTICLE – HEALTH SERVICES RESEARCH AND GLOBAL ONCOLOGY

Deficits in the Palliative Care Process Measures in Patients with Advanced Pancreatic Cancer Undergoing Operative and Invasive Nonoperative Palliative Procedures

Brooks V. Udelsman, MD, MHS¹, Elizabeth J. Lilley, MD, MPH^{2,3}, Motaz Qadan, PhD¹, David C. Chang, PhD, MBA, MPH¹, Keith D. Lillemoe, MD¹, Charlotta Lindvall, MD, PhD^{4,5},

Analysis of administrative data to determine palliative care quality.

Vol. ■ No. ■ ■ 2020

Journal of Pain and Symptom Management 1

Brief Methodological Report

Identifying Goals of Care Conversations in the Electronic Health Record Using Natural Language Processing and Machine Learning

Robert Y. Lee, MD, MS, Lyndia C. Brumback, PhD, William B. Lober, MD, MS, James Sibley, BS, Elizabeth L. Nielsen, MPH, Patsy D. Treece, RN, MN, Erin K. Kross, MD, Elizabeth T. Loggers, MD, PhD, James A. Fausto, MD, Charlotta Lindvall, MD, PhD, Ruth A. Engelberg, PhD, and J. Randall Curtis, MD, MPH
Cambia Palliative Care Center of Excellence (R.Y.L., L.C.B., W.B.L., J.S., E.L.N., P.D.T., E.K.K., E.T.L., J.A.F., R.A.E., J.R.C.), University of Washington, Seattle, Washington; Division of Pulmonary, Critical Care, and Sleep Medicine (R.Y.L., E.L.N., P.D.T., E.K.K., R.A.E.,

Identification of goals-of-care discussions for people with serious illness.

of Psychosocial Oncology and Palliative Care (C.L.), Dana-Farber Cancer Institute, Boston, Massachusetts, USA

JOURNAL OF PALLIATIVE MEDICINE
Volume 22, Number 2, 2019
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2018.0326

Natural Language Processing to Assess End-of-Life Quality Indicators in Cancer Patients Receiving Palliative Surgery

Charlotta Lindvall, MD, PhD^{1,2}, Elizabeth J. Lilley, MD, MPH^{3,4}, Sophia N. Zupanc, PhD¹, Isabel Chien, BS^{1,5}, Brooks V. Udelsman, MD, MHS⁶, Anne Walling, MD, PhD^{7,8}, Zara Cooper, MD, MSc⁴ and James A. Tulsky, MD^{1,2}

Abstract

Background: Palliative surgical procedures are frequently performed to reduce symptoms in patients with

Identification of cancer patients receiving palliative gastrostomy and end-of-life documentation.

Vol. 59 No. 2 February 2020

Journal of Pain and Symptom Management 225

Original Article

Natural Language Processing Accurately Measures Adherence to Best Practice Guidelines for Palliative Care in Trauma

Katherine C. Lee, MD, MSc, Brooks V. Udelsman, MD, MHS, Jocelyn Streid, BA, David C. Chang, PhD, MPH, MBA, Ali Salim, MD, David H. Livingston, MD, Charlotta Lindvall, MD, PhD, and Zara Cooper, MD, MSc
The Center for Surgery and Public Health (K.C.L.), Brigham and Women's Hospital, Boston, Massachusetts; Department of Surgery (K.C.L.,

Identification of trauma patients receiving palliative care input.

Boston, Massachusetts, USA

NLP of automatic transcription in consultations for Advance Care Planning

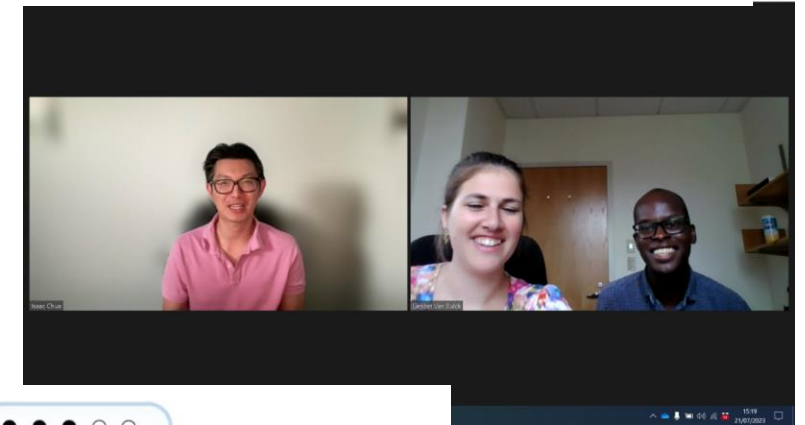
COMMENT OPEN

Enhancing serious illness communication using artificial intelligence

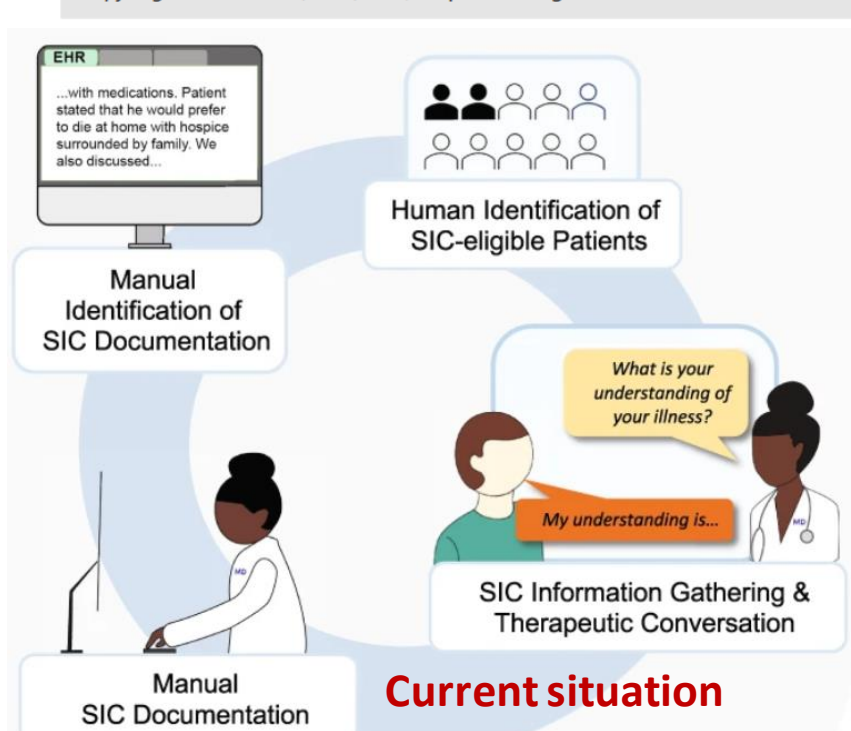
Isaac S. Chua^{1,2,3}, Christine S. Ritchie^{3,4} and David W. Bates^{1,3}

Delivery of serious illness communication (SIC) is necessary to ensure that all seriously ill patients receive goal-concordant care. However, the current SIC delivery process contains barriers that prevent the delivery of timely and effective SIC. In this paper, we describe the current bottlenecks of the traditional SIC workflow and explore how a hybrid artificial intelligence-human workflow may improve the efficiency and effectiveness of SIC delivery in busy practice settings.

npj Digital Medicine (2022)5:14; <https://doi.org/10.1038/s41746-022-00556-2>



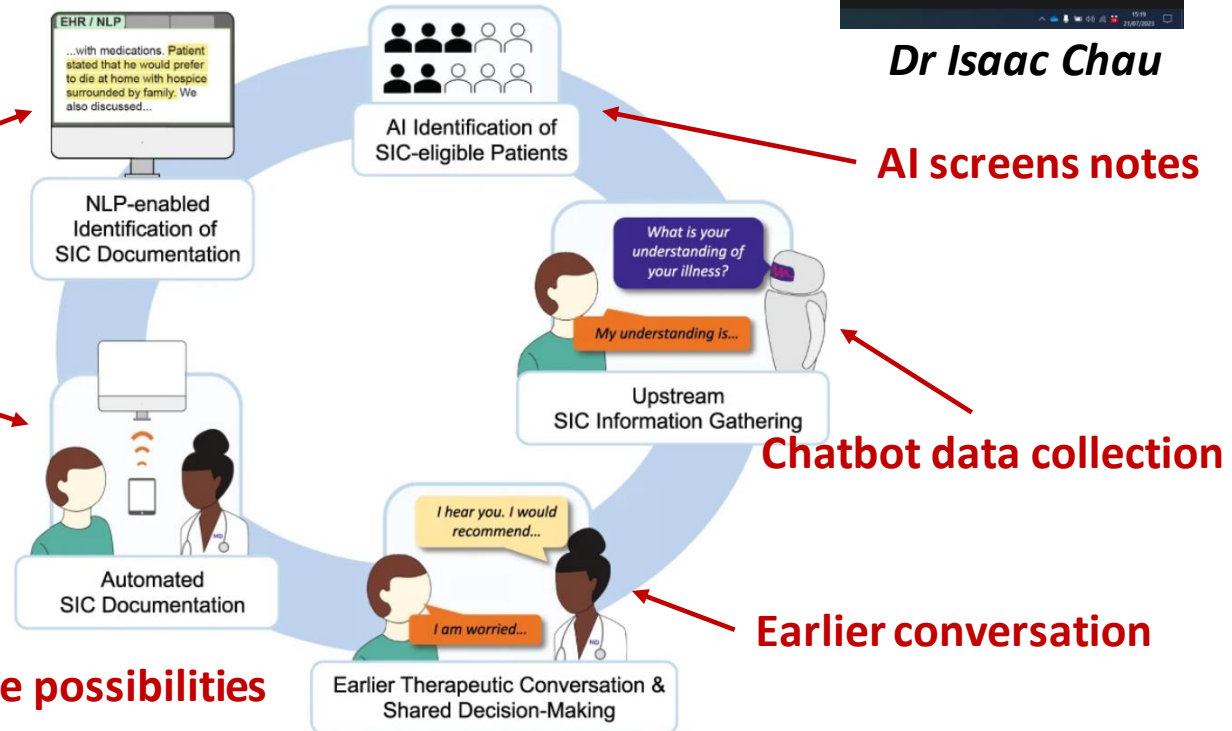
Dr Isaac Chau



NLP analysis, documentation and ACP sharing

Speech analysis – automatic transcription

Future possibilities

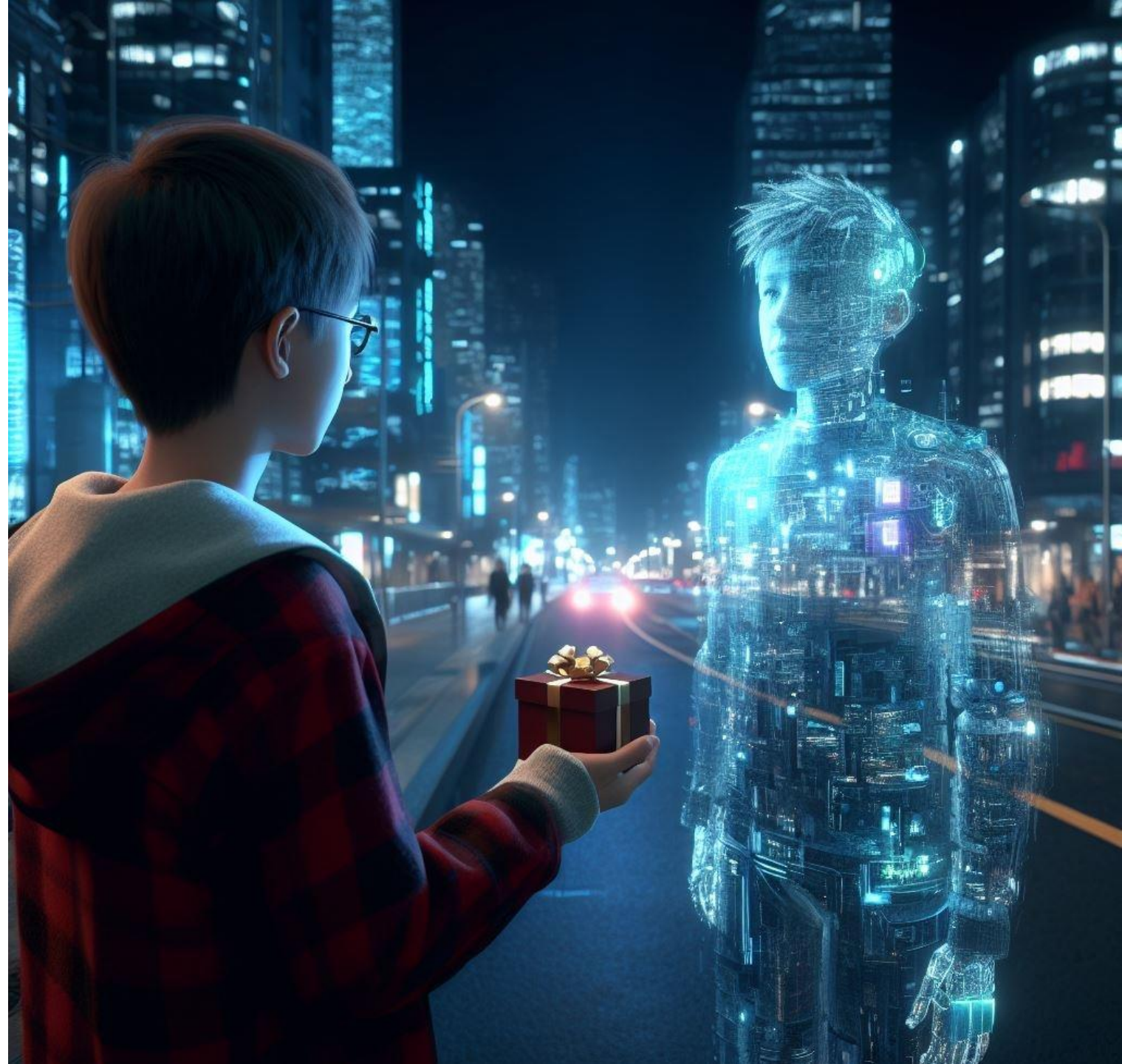


AI screens notes

Chatbot data collection

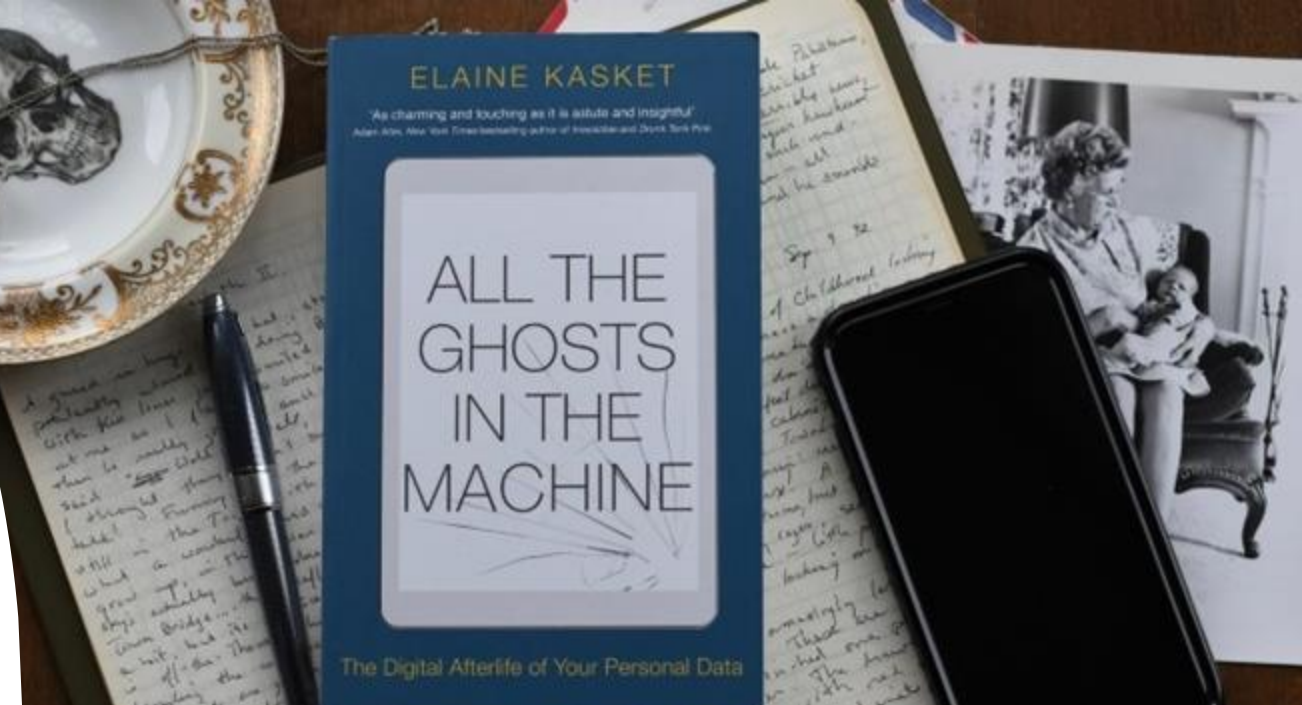
Earlier conversation

AI to support the individual and their digital legacy

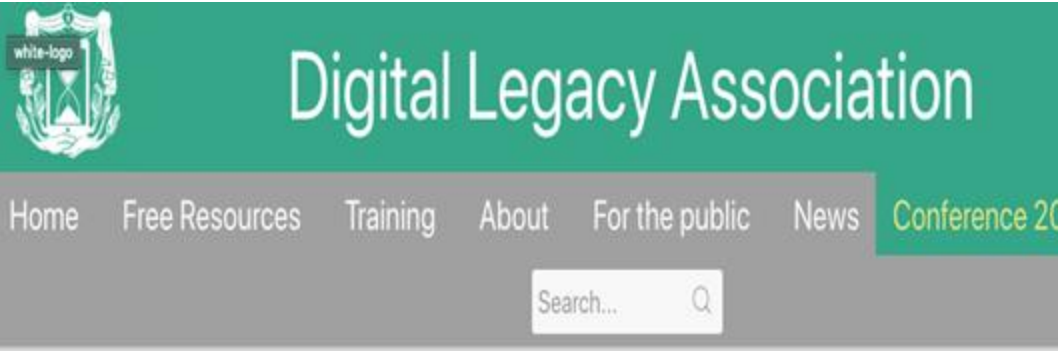


Increasing number of deceased users on social media

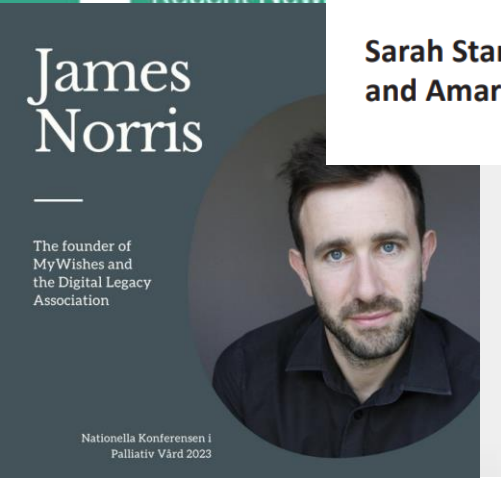
- Professor Elaine Kasket
- Who controls data of the dead?
- Expected 4.9 billion accounts of dead people on Facebook in the next century.
- How will you control your data?
- Opportunities & challenges?



Digital Legacy is increasingly important in Palliative Care



<https://digitallegacyassociation.org/>



James Norris

Original Article



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

Sarah Stanley^{1,2} , Karen Higginbotham², Anne Finucane^{3,4} and Amara Callistus Nwosu^{1,5,6}



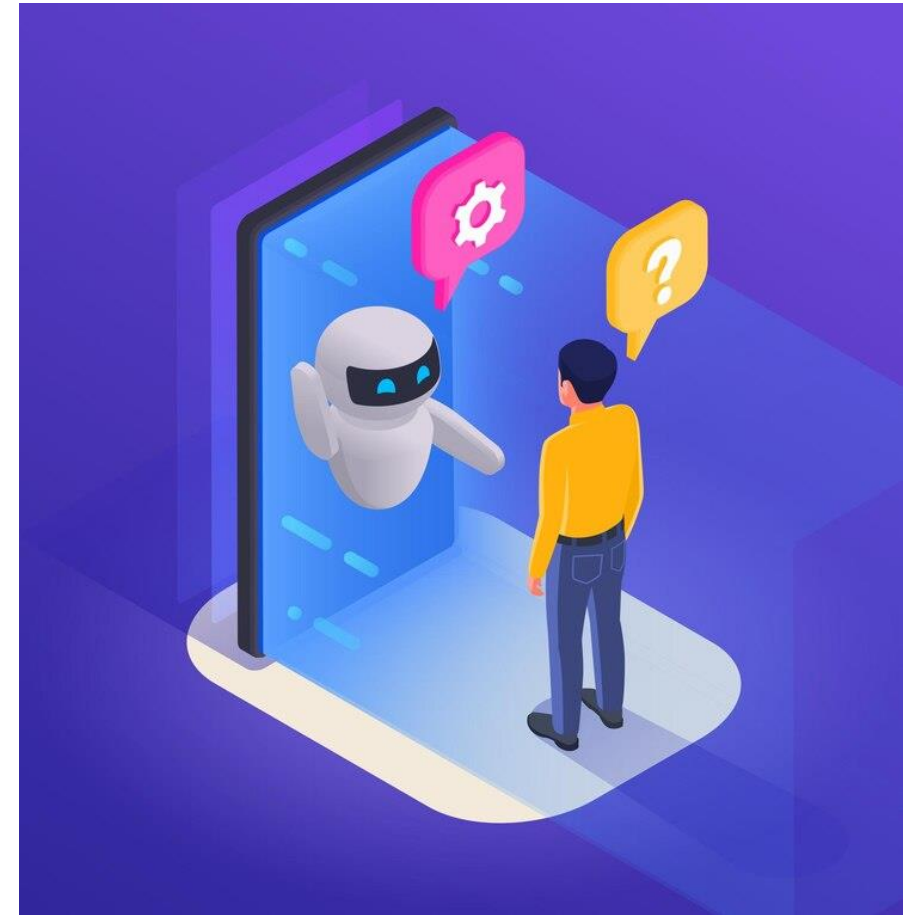
Sarah Stanley



Palliative Medicine
2023, Vol. 37(9) 1424–1433
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DOI: 10.1177/02692163231194198
journals.sagepub.com/home/pmj


Examples of AI technologies to influence digital legacy

- AI chatbots
- Holograms and avatars
- AI assistants



Chatbots in Palliative Care



*Dr Nathan Whitmore & Dr Ruby Liu
MIT researchers*

Living Memories: AI-Generated Characters as Digital Mementos

[Pat Pataranutaporn](#), MIT Media Lab, MIT, United States, patpat@mit.edu

[Valdemar Danry](#), MIT Media Lab, MIT, United States, vdanry@mit.edu

[Lancelot Blanchard](#), MIT Media Lab, MIT, United States, lancelot@mit.edu

[Lavanay Thakral](#), MIT Media Lab, MIT, United States, f20160566@goa.bits-pilani.ac.in

[Naoki Ohguchi](#), NTT DATA Corporation, Japan, naoki.ohguchi@nttdata.com



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.

Dame Cicely Saunders recreated as an AI chatbot



Home

Palliative Care: A Conversation with Cicely Saunders



Holograms of the dead



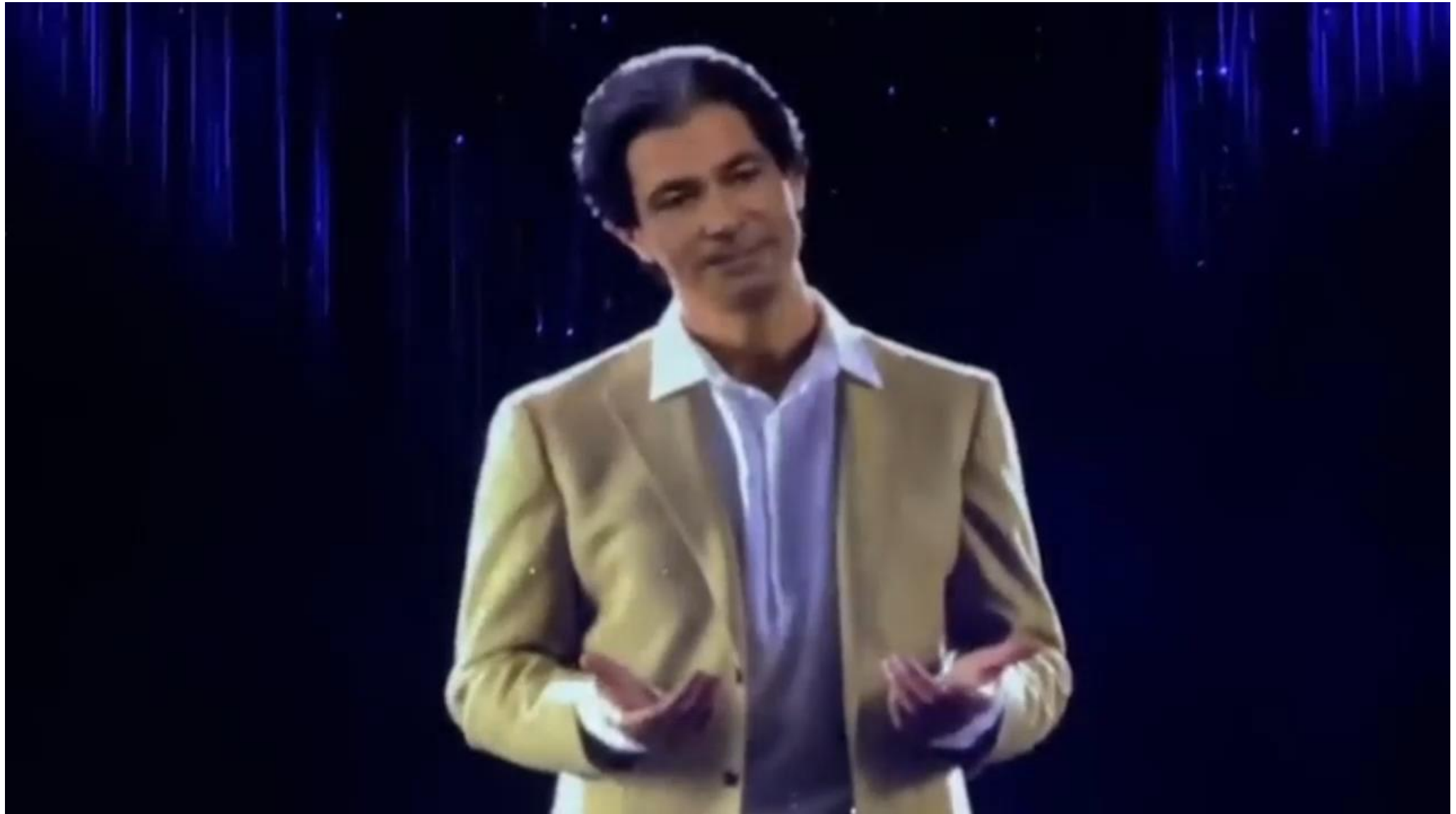
Copyright: 2014 Kevin Winter/Billboard Awards 2014



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Copyright: X, formerly Twitter, 2020



Designers & ethics in Palliative care AI



Professor Judith
Rietjens



Dr Euiyong Kim



Student Erasmus
Research Master
team

- Human centred design
- Decision-making
- Evaluation
- Ethics

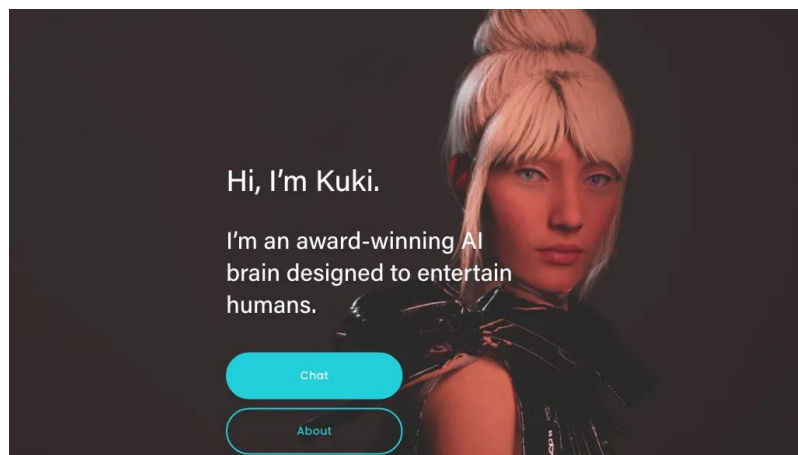


Dr Jiwon Jung



Ethical seminar about AI
in palliative care

Imagine your funeral in the future



Some opportunities...

- Personalised care to individuals and populations
- Improved efficiency
- Real-time data & analysis
- New interventions
- New forms of research
- Develop and curate digital legacies



Copyright -Bryan Lee O'Malley

Some challenges...

- Bias
- Risk of inequalities if not used well
- Lack of expertise
- Infrastructure
- Cost and maintenance issues
- Issues with trust/governance/ethics/ownership of data



Copyright -Bryan Lee O'Malley

Current work...



Digital Legacy Design & Technology Network

Next meeting:

- **Wednesday 20th March 2024
in Liverpool Science Park.**
- Contact me if you want further information.

Final thoughts – AI is already here



Conclusions

- AI is already present in various forms and there is potential to influence palliative care from population, clinical care level and individual & digital legacy level.
- Focus on the practical applications of AI in palliative care, rather than binary debates of its virtue.
- Interdisciplinary research is needed to explore how AI can be best used in palliative care.
- *More research is needed about the generic publicly available AI tools (e.g. ChatGPT)

Attributions - Images

- Google
- Freepik
- Chest X-Ray Ai image (de Moura, Joaquim, Jorge Novo, and Marcos Ortega. "Fully automatic deep convolutional approaches for the analysis of COVID-19 using chest X-ray images." *Applied Soft Computing* 115 (2022): 108190.)
- Perception AI image: By JonMcLoone at English Wikipedia, CC BY-SA 3.0, <https://commons.wikimedia.org/w/index.php?curid=44894482>
- 2014 Kevin Winter/Billboard Awards 2014
- Christopher Polk/Getty Images for Coachella 2012
- X, formerly, Twitter
- Google
- ImagineMe
- KukiAI
- Scott Pilgrim - Bryan O'Malley



Thank you!

- Dr Amara Nwosu
- MBChB FRCP PhD
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- a.nwosu@lancaster.ac.uk