Patient Engagement in AI Development in Healthcare:

Where are we and where are we going?

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Thank you for the support and space for growth.

Territory and Land Acknowledgment

I would like to acknowledge the traditional territories of the Mississauga of the New Credit First Nation, Anishnawbe, Wendat, Huron, and Haudenosaunee Indigenous Peoples on which the University of Toronto now stands. I am thankful to work, play, love, and grow on this land.

Learning objectives

1) Understand the scope of the literature to date on patient engagement in the development of artificial intelligence applications in healthcare.

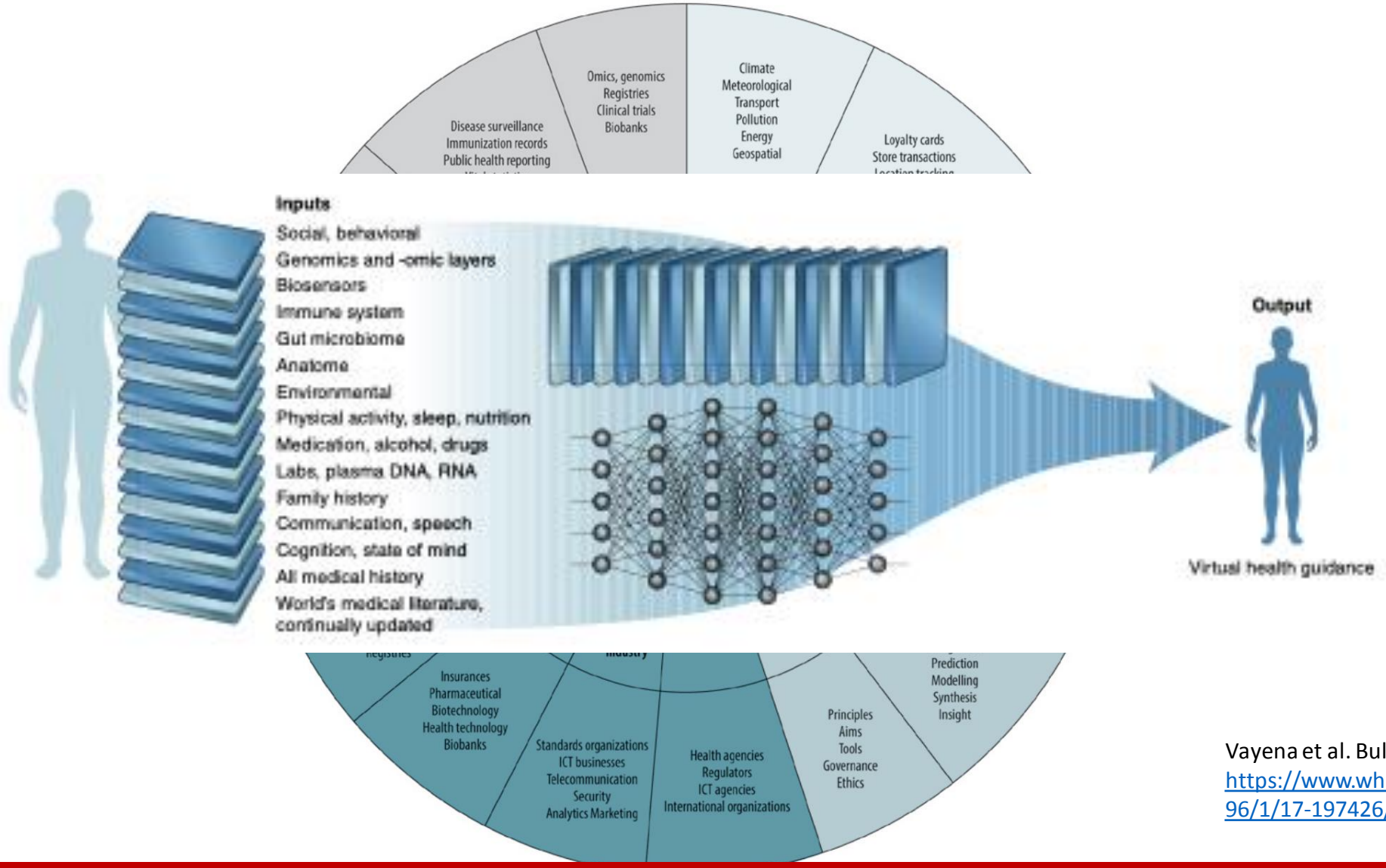
2) Explore, from multi-disciplinary perspectives, the facilitators and barriers to patient engagement in AI, and the methods to be used in the future.

3) Reflect on how to ensure patients will have a seat, from the start, in AI development conversations in healthcare.

Artificial Intelligence (AI)

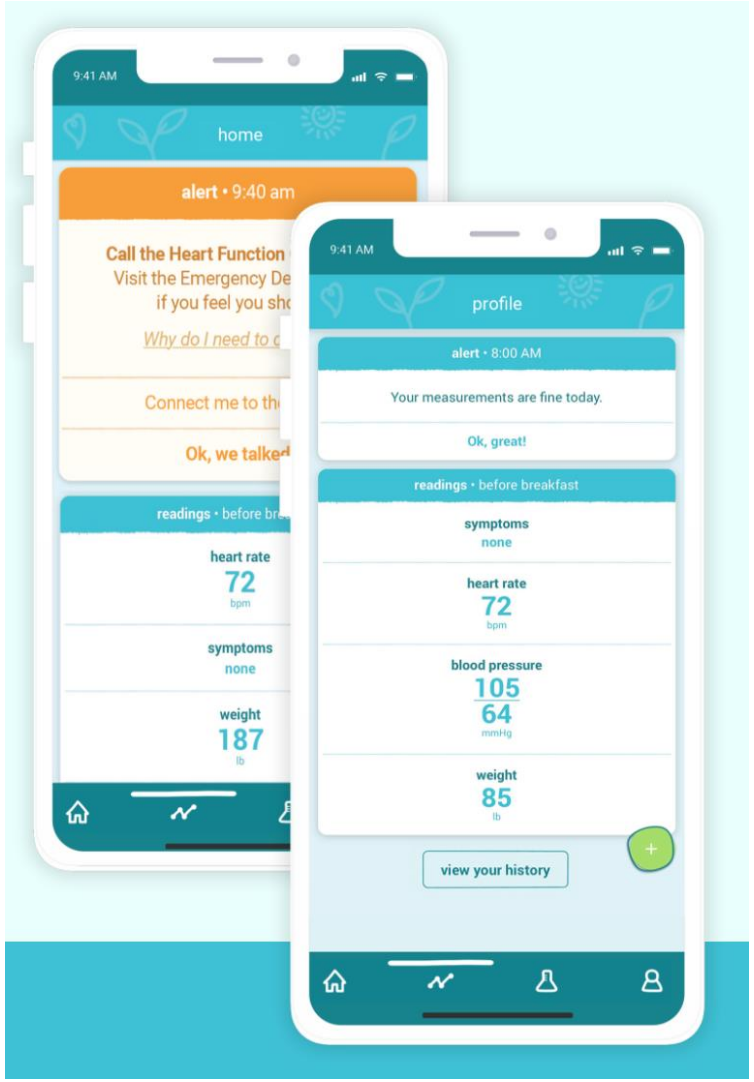
- A broad term first introduced in 1956 by John McCarthy
- AI can be simply defined as **a "machine behaving in ways that would be called intelligent if seen by a human"**
- AI is a broad field of study, including computer scientists but also psychologists, philosophers, linguists and many others

Big Data for Health



Vayena et al. Bull WHO 2018; 96: 66-68
https://www.who.int/bulletin/volumes/96/1/17-197426/en/

Machine Learning Example: Medly

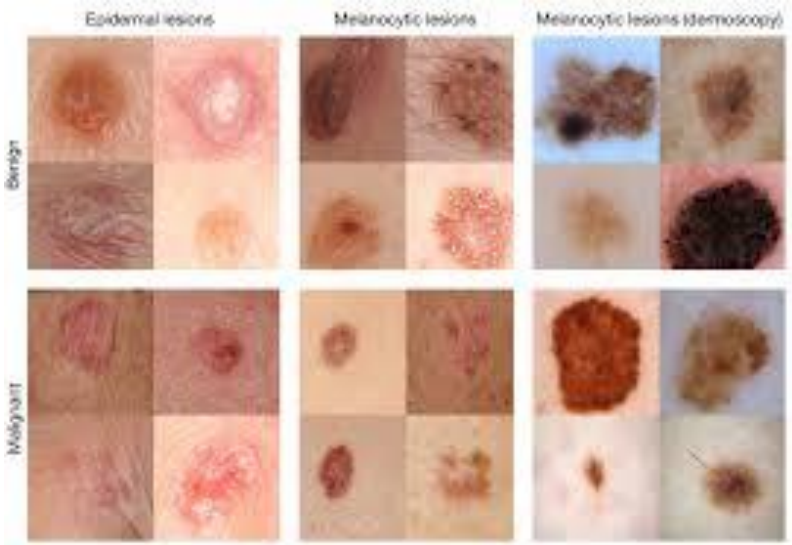


Where a model **learns from experience** acquired from engaging in certain tasks, and where its performance on these tasks **improves** with more experience

www.medly.ca

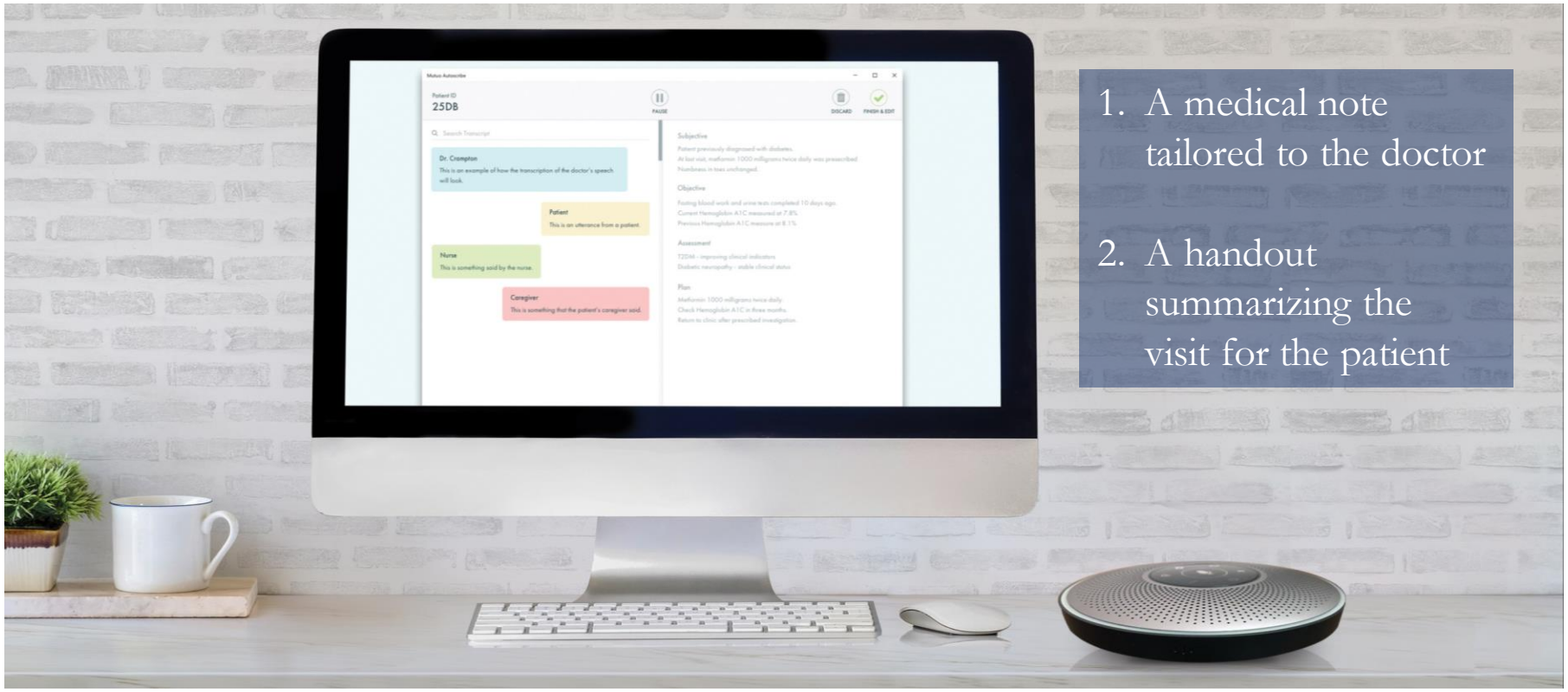
Deep Learning Example: Melanoma Diagnosis

"Deep learning uses deep networks with many intermediate layers of artificial "neurons" between the input and the output, and these artificial neurons learn a hierarchy of progressively more complex feature detectors"



Esteva *et al. Nature. 2017.*

Natural Language Processing (NLP) Example: Autoscribe



https://medicine.utoronto.ca/news/autoscribe-ambition-50-less-screen-time-docs

Concerns? Questions? Ethical Dilemmas?

- Algorithms that are biased towards certain groups (e.g., Black vs White skin)
- Did patients consent to their data being used to train these algorithms?
- How does it feel for a patient and clinician to use an algorithm they don't really understand ("The Black Box")
- How do we ensure AI applications made by the private sector are safe to use in the public healthcare sector?
- What are the most pressing needs of the healthcare system that AI can improve?
- How do we ensure patients have an understanding where their data is going?

For us to answer many of these questions, patients should be at the forefront of the conversation.

Defining Patient Engagement

"occur[ing] when patients **meaningfully** and **actively** collaborate in the **governance**, **priority setting**, and **conduct of research**, as well as in summarizing, distributing, sharing, and applying its resulting knowledge"

- Canadian Institute for Health Research's Strategy for Patient Outcome Research (SPOR)

Co-Build | Inclusiveness | Support | Mutual Respect

Benefits of Patient Engagement

- Patients setting priorities and goals of care in the setting of innovation
- Reduction to health care costs
- Fewer hospital admissions
- Increased patient outcomes
- Increased quality of life
- Improvements in patient safety
- Patient empowerment

Boivin A, Lehoux P, Lacombe R, Burgers J, Grol R. **Involving patients in setting priorities for healthcare improvement: A cluster randomized trial.** *Implement Sci.* 2014;9(1):1-10. doi:10.1186/1748-5908-9-24

Shimmin C, Wittmeier KDM, Lavoie JG, Wicklund ED, Sibley KM. **Moving towards a more inclusive patient and public involvement in health research paradigm: The incorporation of a trauma-informed intersectional analysis.** *BMC Health Serv Res.* 2017;17(1):1-10. doi:10.1186/s12913-017-2463-1

Adams L, Burall S. **How to stimulate effective public engagement on the ethics of artificial intelligence.** 2019:1-19.

Achieving Success in Patient Engagement

Box 1 Successful engagement approaches for patient engagement in health research [15, 30]

1. Engage patients as early as possible and continue engagement throughout
2. Clearly define patient engagement plan; be clear on roles, duties and expectations between patients and researchers
3. Provide orientation and education about research and patient engagement
4. Provide ongoing support, encouragement and recognition for patient contributions
5. Facilitate mutual respect and valuing of patients' expertise based on knowledge gained through experiences
6. Ensure a trusting and positive environment by providing structural support
7. Include a plan for evaluation of engagement

Box 2 Shared characteristics of successful patient engagement in health research

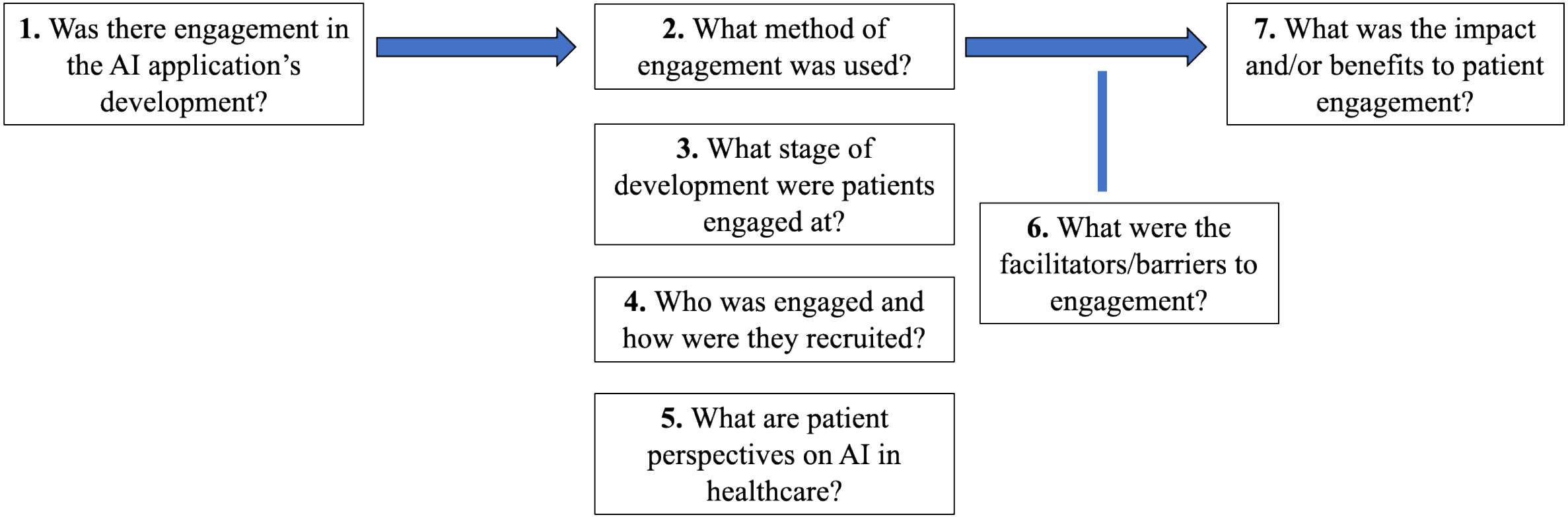
• Clear purpose, role and structure for engaging patients [26, 55]
• Initiate and maintain partnerships between researchers and stakeholders [24, 42, 44, 55]
• Take the time required to foster relationship-building as the most critical component in establishing trust [55,56,57]
• Clear leadership from principal investigator and/or wider culture of involvement [56]
• Promote the need for facilitation of cross-communication among all groups [37, 44, 55]
• Capture and optimise patient perspectives across all phases of research [44, 55, 58]
• Ensure meaningful patient influence on research by validating the need for respect and support for patients [37, 44, 59, 60]
• Ensure adequate training for researchers and patients [44, 59]
• Share and promote research learnings, including evaluation efforts [37,59,, 44, 55, 58–60]

Source: Manafo, E., Petermann, L., Mason-Lai, P. *et al.* **Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research.** *Health Res Policy Sys* **16,** 5 (2018). https://doi.org/10.1186/s12961-018-0282-4

Objective 1: Systematic Review

- In consultation with two patient partners, we studied whether patients were engaged in the development of AI applications in healthcare, and if so, how the engagement happened.
- Searched MEDLINE, Embase, Web of Science, and CINAHL as well as grey literature from January 2000 to March 2020, with a refresh in April 2021.
- Looking for English articles globally that described the development/design of an AI application in healthcare as part of a patient care delivery in any healthcare setting.
- Of those, we then looked for ones that had active patient engagement during any developmental stage of the application.
- Analyzed using meta-narrative approach

Systematic Review



Findings (General)

- Of 8697 unique citations, we identified 704 eligible articles on AI healthcare application development.

- **Of those identified, only 37 studies (approx. 5%) that reported any form of patient engagement.**

- Most frequently in USA and UK
- 75% done 2018 onwards

- Variety of applications (mobile coaching, mobile telemonitoring, clinician decision support, communication support, diagnostic support, and other)
- 35% of applications in chronic illness management (most common)

Findings (Engagement)

- 45% of engagement was using survey methodology (satisfaction, acceptability, usability)
- Other methods included interviews, design workshops, observation of application use – but only 1 justified reason for use of method
- Only three studies used inclusive patient engagement language, such as "CO-design", "CO-create" or naming patients as experts
- 8 studies included caregivers in the definition of patient engagement
- Spread of engagement activities along the continuum of development stages: idea conception (10), development (12), pilot/feasibility (12), validation (2), implementation (5), evaluation (5), and dissemination (0).
- 50% of the studies reported demographic information (majority reporting on age and sex, many studies on ethnicity, education level, and income level, and few studies on the patient's familiarity with technology, language, religion, urban/rural setting)

Findings (Engagement)

Patient Perspectives:

- Mixture of hope and skepticism; one study reported only 20% of patients considered the benefits of AI to outweigh the risks
- **Biggest perceived benefits:** alerts at home, accurate diagnoses, take on mundane administrative tasks for more time with clinician
- **Biggest concerns:** lack of empathy, ”explainability”, information privacy

Facilitators/Barriers/Impact

- Not reported facilitators to engagement
- **Main barriers:** digital divide, unwell patients, technology literacy
- Five studies reported **impact**: made application more accessible, user-friendly, patient-centred, more widespread adoption

Our Recommendations

Patient Engagement Recommendations

1. Increasing Patient Engagement Research Rigor
2. Continuing Patient Engagement Beyond Piloting Stages
3. Comparing Clinician and Patient Engagement Findings
4. Ensuring Equal Opportunity in Patient Engagement

Rationale for Objective 2

Patients are often identified as key stakeholders in the design of AI healthcare applications, but we have seen from our literature review that they have not been engaged appropriately.

The method of patient engagement in AI development in healthcare has not been previously studied, and currently no guidelines exist.

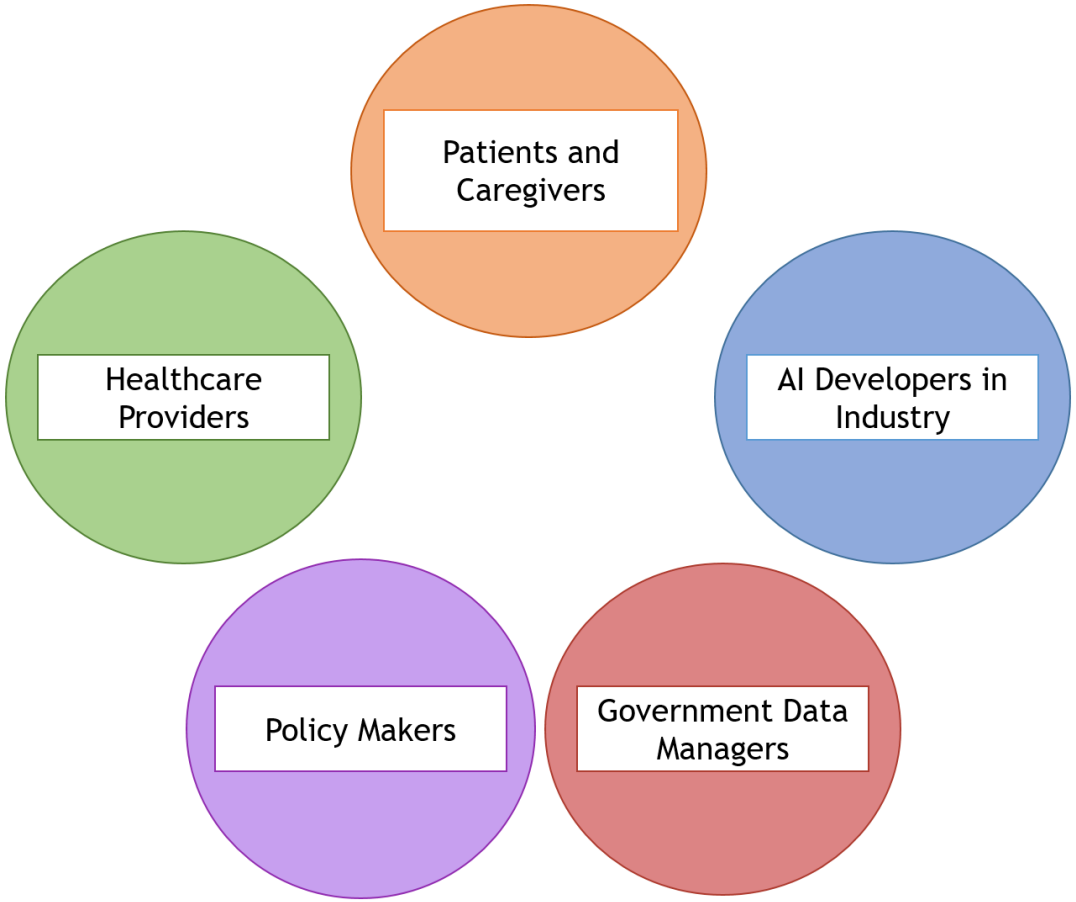
In order for patients to have meaningful participation in the eventual development of guidelines for patient engagement in AI health research, we must thoroughly understand what methods are best suited for engagement in the first place.

Objective 2: Focus Groups

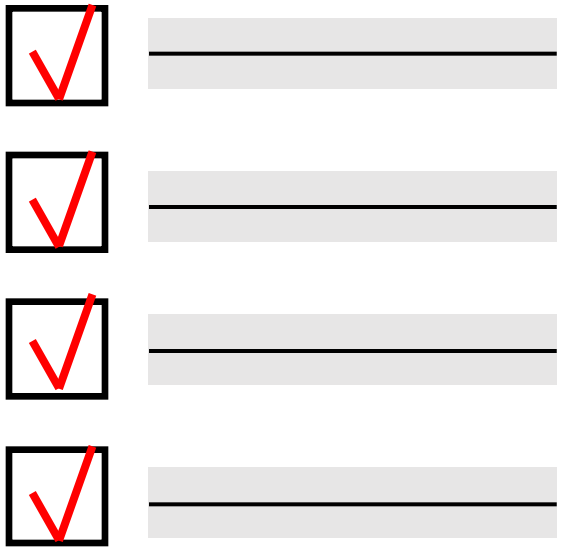
This study seeks to understand, from multiple perspectives, the most effective, feasible, and preferred method to engage patients in the development of guidelines for patient engagement in AI health research.

This study utilizes an exploratory qualitative design using focus groups to engage various stakeholders in their perspectives on how best to engage patients in the development of AI in healthcare.

Understanding Patient Engagement from Multiple Stakeholders Perspectives



Guideline Development



Centering Education

Welcome to the artificial intelligence educational module.

1. Introduction

What is the purpose of this module?
You have received this module because you are participating in the research study: Exploring multiple perspectives on how patients can and should be involved in the development of guidelines for patient engagement in artificial intelligence (AI) health research.

You do not need to know anything about artificial intelligence (AI) to participate in this study.

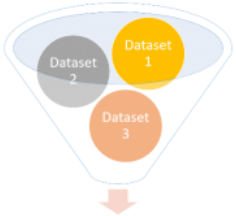
This module was created to provide you with background knowledge on AI prior to participating in the study. We aim to equip all participants with a baseline level of AI knowledge to encourage participation during our focus groups. You are not expected to be an expert on AI, and you will likely have further questions after reading this module. At the end of this module there will be a list of resources for further learning; however, this is optional for the purposes of this study.

This module will:
- Define AI and describe computer programming methods that underlie AI technologies
- Broadly explore the applications of AI in medicine
- Describe ethical considerations when applying AI in the context of health care
- Review the findings of our systematic review on AI and patient engagement

What is Big Data? How is it related to AI?

Big Data is a term used to describe data produced by a variety of sources in large volumes at a fast pace. Big Data has grown across industries in the last three decades because of advances in computer processing power and storage, widespread adoption of mobile devices, and increased internet availability (6). AI methods allow us to condense and make sense of these datasets. These datasets can also be used to program a specific AI task. Advances in machine and deep learning in the last 10 years have depended on the availability of large, labelled "Big" datasets.

A **dataset** is a collection of data gathered using the same criteria for a specific purpose. Datasets from different sources can be shared and combined to create **linked datasets**. Linked datasets contain a broad range of information that can be analyzed to shed light on complex issues.



Linked-dataset

Initial Patient Perspectives

- Not surprised about the literature findings that there is very little engagement in this space
- AI complexity is intimidating and why many patients have not pushed to be engaged; too short of time to ask their clinician about it
- Patients want to be engaged from the very beginning, with brainstorming and prioritizing ideas on what we can tackle with AI
- Round table of patients, clinicians, and leaders is necessary for guideline development, but ensuring patients have their voice
- Need to survey patients to understand why type of training or resources they need to be able to engage

What is Next?

- Concurrent data collection and analysis with interpretive description, an inductive analytic approach to create ways of understanding clinical phenomena that leads to practice implications in healthcare; often used for multi-disciplinary perspectives.
- Inviting some participants to a collaborative planning meeting this spring with other stakeholder groups and academic to review focus group findings, discuss future work, and a plan a gran to support formal guideline development of how to engage patients at each phase of the development process.
- Really the first instance of studying engagement methods in the context of AI development in healthcare, and forming this multi-disciplinary patient-oriented network in this space.

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