From prostate cancer patient perspective: Artificial Intelligence may be a damn good idea

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Accessibility
From prostate cancer patient perspective: Artificial Intelligence may be a damn good idea

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A Thesis in the Field of Government
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Abstract

The healthcare system in the United States has been notoriously ineffective. The expected revolutionary approach to transforming the healthcare system, personal empowerment, has not been successful. The fledgling artificial intelligence (AI) technology, especially natural language processing (NLP), has made an AI health assistant tool possible to synthesize medical knowledge and provide generic consulting services to patients.

This study included a prostate cancer patient opinion survey that collected attitudes and opinions about AI from 73 prostate cancer patients and a series of prostate cancer patient panel discussions between the investigator and 17 prostate cancer patients.

The study observed a phenomenon of progressive health demands from patients that the current healthcare system in the United States has its born inability to fulfill. These demands include patients’ self-determination on treatment options, their preference for quality of life, and their desire to seek optimal care. Progressive health demands come from power patients who are mentally strong and intelligently capable to make critical decisions regarding their disease management and they are willing to take responsibility. Prostate cancer patients expect a directly accessible AI health assistant tool that can provide unbiased information independent of the medical service providers, and can support patients to navigate various treatment options and get the best of them.
This pilot exploratory study reflected perspectives of an intellectually and politically competent patient community which shows that the AI health assistant tool can be particularly beneficial to patients. The tool can provide much-needed support to patients the current healthcare system has failed to do and can facilitate the growth of power patients who has become one of the key driving forces to reform the healthcare system in the United States.
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Chapter I.

Introduction

How do we make the healthcare system in the United States more effective, reduce its cost, improve its quality, and expand its coverage in a politically and financially feasible way? Ideally, indicators of successful healthcare reform would be when hospitals celebrate their success when they become emptier, not fuller, and when they are less needed by the population.1 By this standard, numerous attempts to reform the U.S. healthcare system have been unsuccessful, and the problems rooted in the healthcare system appear insolvable.

In 2008, Berwick, Nolan, and Whittington claimed that an integrator is required to take on the responsibilities of healthcare reformation to improve the experience of care, improve the health of the population, and reduce per capita costs of healthcare.2 That integrator should link healthcare organizations and recognizes and respond to individual patients' needs and preferences while responding to the total cost of the care. Their solution for the integrator includes government-owned healthcare systems such as Veterans Health Administration in the U.S., National Health Service (NHS) in the United Kingdom, and health maintenance organizations (HMOs) such as Kaiser Permanente in the U.S. Unfortunately, because patients are not actually in control of these health insurance companies or government agencies, and these institutions do not directly

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2 Ibid
experience patients’ pain, most of the time these institutions move on their self-guided direction and have failed to address patients’ needs.

Hereby, more promising proposals come from another approach to reformation, patient empowerment, or personal empowerment. Patient empowerment implies that patients are no longer seen as the mere recipients of medical decisions, but are responsible for their choices and the consequences of their choices. Empowerment of patients means enrolling individuals and families to care for themselves. Duncan Neuhauser claimed that personal empowerment would lead to the third revolution of the healthcare system. By empowering and engaging patients in the activities of disease self-management, medical research, drug development, and policy regulation, patients would become the key players in the reformation of the healthcare system in the U.S. It was expected that the engaged patients will be changing the twenty-first-century healthcare system in the U.S. However, that third revolution does not appear to happen. The reason, as Schulz and Nakamoto explained, is due to patients’ limited medical literacy -- the lack of background knowledge to adequately handle medical information -- which makes the patient empowerment “illusory”.

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The problems rooted in the healthcare system of the United States remain unsolved. High-quality healthcare is financially infeasible; patients have limited medical knowledge; and the integrators that are supposed to link medical services and patients’ interests have not shown their own interest to contribute. What options are in front of us that can function as an integrator and also help patients improve their medical literacy?

In this thesis, I will propose that an individual artificially intelligence (AI) health assistant could serve the role of a facilitator of patient empowerment and an integrator that links patients and health care institutions. As a knowledge tool, the AI health assistant will facilitate the growth of power patients and augment their engagement in health, and become a driving force to reform the healthcare system.

An AI health aid could guide people in taking strategic approaches in health-related matters. Its functions could include interpretation of medical terms, explanation of the diagnostic logic of diseases, assessment of different prognostic outcomes, and proposing diagnostic and treatment plans. The AI health aid should possess essential medical knowledge to provide general consulting services, and it should be conveniently accessible, designed like a cellphone, an app, or a chatbot that every average person can use. Technically, the fledging technology of AI, especially natural language processing (NLP) technology, can utilize available medical knowledge and make this health assistant tool available. On the legal side, no obstacles could prohibit a tool to provide medical knowledge services to people. On the financial side, building an AI app and making it accessible to the general public does not seem like a daunting task, at least being far less expensive compared to training medical doctors.
The AI assistant tool will serve directly patients by supporting their decision-making. The tool could be the counterpart to balance the power of the current healthcare insurance system and healthcare provider organizations. It will facilitate patient empowerment and consequently, the empowered patients will be the driving force to transform the healthcare system for the good of patients.

In this study, I conducted an online prostate cancer patient opinion survey and a series of prostate cancer patient panel discussions. From the perspectives of prostate cancer patients, who have been experiencing the disease burden and interacting with the healthcare system, I will illustrate that patients have progressive health demands that have not been well-addressed, and the current healthcare system has its inherent inability to fulfill these progressive health demands. I will argue that the driving force of these progressive health demands is the power of patients who are well-educated and have the judgment and willingness to pursue their own preferences of health. And finally, I will describe the proposed AI tool about how patients expect it functions.

The study will give an estimate about how many patients are empowered or power patients in the prostate cancer patient community. The study will also explain why and how power patients could be a driving force changing the healthcare system in the U.S. In addition, this study will why an AI knowledge assistant could be an ideal tool to augment and enable patients to be involved in the activities of disease self-management, medical research, drug development, and policy regulation. The study will help health policy makers to have a better understanding of patients’ volition to be engaged, their attitudes toward the AI tool, their willingness to use the tool, and to participate in disease-
relevant activities. This study will contribute to the design of the AI tool and promote the vision to allocate more resources to the development of patient-oriented AI tools.

Chapter II.

Definition of Terms

Artificial Intelligence (AI)

Artificial Intelligence is a science and a set of computational technologies that mimic the ways people use their nervous systems and bodies to sense, learn, reason, and take action. It refers to mechanical intelligence that uses programming languages, big data, machine learning technology, and computing power.

AI for Social Good (AI4SG)

AI for social good is “the design, development, and deployment of AI system in ways that (i) prevent, mitigate or resolve problems adversely affecting human life and/or the wellbeing of the natural world, and/or (ii) enable socially preferable and/or environmentally sustainable developments.”

AI Health Assistant

An AI health assistant uses NLP technology to synthesize medical knowledge and provide general health consulting services directly to patients. It is designed as a chatbot-like app to be used by average person.

Engaged Patients

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Engaged patients are more vocal, express their preferences, and are engaged in their health.

**Erectile dysfunction (ED)**

Erectile dysfunction is men's inability to get and keep an erection firm enough for sex. It is one of the major concerns of patients undergoing prostate cancer treatment.

**Natural Language Processing (NLP)**

NLP is a branch of AI that uses computational linguistic techniques to analyze and represent naturally occurring texts to achieve human-like language processing.\(^{10}\)

**Patient**

WHO defines a patient as a person who is the recipient of health care.\(^{11}\)

**Patient-Centered Care**

The term is used to refer to the design of a health care system for patients rather than for doctors. It emphasizes doctors’ empathy and respect for patients, engaging patients in medical decision-making, and shared decision-making with patients.

**Patient Decision Aids**

Patient decision aids (PtDAs) are adjuncts to counseling that explain options, clarify personal values for the benefits versus harms, and guide patients in deliberation and communication.\(^{12}\)

**Patient Empowerment**

Patient empowerment moves trend from “an ethic of paternalism toward an ethic of empowering patients to make informed decision.”\(^{13}\)

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12 O’Connor et al., “Do Patient Decision Aids Meet Effectiveness Criteria of the International Patient Decision Aid Standards Collaboration?”
**Patient Support Group**

Patient support Groups are organizations within which patients share information and help each other.

**Power Patients**

Power patients are intelligently and socially capable patients who want to manage their health by themselves and seek the best care for their disease.

**Progressive Health Demands**

Progressive health demands are patients’ demands for self-determination, personal preference of quality of life, and seeking optimal care.

**Prostate Cancer**

Prostate cancer is the second most frequent cancer diagnosis made in men and the fifth leading cause of death worldwide.\(^\text{14}\)

**Radical Prostatectomy**

Radical prostatectomy is a surgery to remove prostate to treat prostate cancer.

**Radiotherapy**

Radiotherapy is a type of prostate cancer treatment that uses high doses of radiation to kill cancer cells.

**Urinary Incontinence**

Urinary incontinence is the accidental release of urine. It is one of the major side effects for prostate cancer treatments.

Chapter III.

Background

In this section, I will first describe the root problem of the healthcare system in the United States, and then, I will introduce relevant healthcare reformation approaches including patient-centered care, patient empowerment, and patient engagement. After that, I will delineate artificial intelligence (AI)’s development and its application and potential in healthcare. In the end, I will explain why choose prostate cancer patients as the study population for my thesis.

Ineffective Healthcare System in the United States

The healthcare system in the United States has been notoriously ineffective. In 2016, the US spent the highest percentage of its gross domestic product in healthcare compared to 10 other highest-income countries. Nonetheless, the United States scored poorest on most health outcome measurements. To name a few: the United States scored the lowest in health insurance coverage (90% against 99-100%); the highest in obesity among adults (70.1% against 23.8-63.4%); the shortest in life expectancy (78.8 years against 80.7-83.9 years); and the highest in infant mortality (5.8 deaths per 1000 live births against 3.6 for all the 11 countries).\textsuperscript{15}

As a nation, the United States also has a mediocre performance on personal care access and quality. In 2016, in a ranking of Healthcare Access and Quality (HAQ) Index,

which combines 32 preventable death causes to approximate personal care access and quality of a nation, the United States scored 89 on a 0-100 scale and ranked 29th among 195 countries, lower than Canada (94, 14th), Germany (92, 18th), France (92, 20th), UK (90, 23rd), far lower than Iceland (97, 1st), Norway (97, 2nd), and Netherlands (97, 3rd).16

Many things are wrong with the healthcare system in the United States because most hospitals can only survive by making a profit. When helping patients is not necessarily the first priority, lower-valued and waste of medical care happen, and this is a major part of the ineffectiveness of medicine. Although medicine is much acclaimed to be helping the sick, not all medical programs are helping people, some of them may cause overdiagnosis and overtreatment that are wasting medical resources and harming healthy people. Cancer screening programs may detect early cancers that will never hurt people; sensitive diagnostic technologies may identify tiny abnormalities that will remain benign, and widening disease definition put permanent medical labels on low-risk people.17 Healthy people with mild problems are over-diagnosed with a disease that would not cause any symptoms or early death. The result is overmedicalization and overtreatment. Heather Lyu et al. surveyed 2106 physicians from the America Medical Association (AMA) and estimated that 20.6% of overall medical care was unnecessary.18

The most commonly cited reasons for overtreatment were fear of malpractice (84.7%).

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patient pressure/request (59.0%), and difficulty accessing medical records (38.2%).

Interestingly, most AMA physician respondents (70.8%) believed that physicians are more likely to perform unnecessary procedures when they profit from them.

The 60-30-10 challenge is a well-known phenomenon that exhibits the waste, inefficiency, and underperformance of the healthcare system. About 60% of care provided are in line with evidence- or consensus-based guidelines, about 30% is considered waste or of lower value of which expenditure cannot be justified, and 10% is actually harmful due to iatrogenic harm or adverse events.192021

The profit-driven healthcare system also leads to inequality. Another reason for the underperforming healthcare system in the United States is healthcare inequality which distributes medical resources inefficiently and deprives people with lower social-economic status of much-needed and necessary medical care. Structural inequities in health care policy contribute to health disparities in the United States. Medicare and Medicaid are the only two national health plans in the United States, and other people rely on employer-based health plans and private insurance.22 In 2019, there are 33 million persons in the United States are uninsured.23 The disoriented healthcare system, with its

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wasted and unequally distributed medical resources, has lowered its effectiveness, quality, and accessibility, and hampered people's pursuit of better health.

Patient-centered Care

One dimension of reformation of the healthcare system is to put more focus on patients. These approaches include patient-centered care, patient empowerment, and patient engagement.

Patient-centered care shifts control and power from care providers into the hands of patients. Patient-centeredness, according to Donald Berwick, is “a dimension of health care quality in its own right, not just because of its connection with other desired aims, like safety and effectiveness.” The opinions vary on how much the system should be centered on patients. On one side, the most radical consumerism view holds that consumers are always right and patients are the source of the control; on the other side, the classic professionalism view believes that patients would make decisions that are not in their best interests and patients should not override professional judgment; and in the middle, the compromise view holds that patients and professionals are partners, they should respect each other, and share the decision-making power. It is undeniable that patients, as autonomous human beings, have the right to choose their treatment options. The objection to patient-centered healthcare comes with the doubt that patients may not have enough knowledge to make the right decision.

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25 Ibid
Patient Empowerment

In the field of study of restructuring the power relationship between patients and their physicians, patient empowerment has been gaining more importance in the healthcare setting\(^{26}\). Patient empowerment reflects a cultural shift toward consumerism and individualism, the slowly moving trend from “an ethic of paternalism toward an ethic of empowering patients to make informed decision.”\(^ {27}\) The intent of patient empowerment is to take more equitable and collaborative approaches to shape the healthcare relationship, especially toward shared decision-making between patients and healthcare providers.

Putting more weight on the patient's side, Duncan Neuhauser used the term personal empowerment as a revolutionary approach to transforming the healthcare system in 2003. He considered personal empowerment as the third revolution in the healthcare reform after managed care and disease management.\(^ {28}\) The first revolution, the managed care organization (MCO), shifts payment of health services from pay-for-service to a prospective payment system with a fixed capitation payment. The second revolution, disease management, requires examining evidence to justify the benefits of care through evidence-based medicine. Both managed care organization and disease management are efforts from the healthcare providers’ point of view. The third revolution, personal empowerment, is to enroll individuals and their families and empower them to care for themselves. Neuhauser further proposed, that the Internet provides an ocean of


\(^{28}\) Neuhauser, “The Coming Third Health Care Revolution.”
information and this potentially makes patients know more about their condition than their medical doctors do. Personal empowerment recognizes that healthcare providers may no longer be at the front of knowledge, and due to their costly time, their importance in playing the role in managing health is waning in comparison to the rising significance of empowered individuals.

Empowerment was not a new concept, as early as in 1995, Zimmerman used the term psychological empowerment to refer to empowerment at the individual level as separated from organizational and community level empowerment. Zimmerman constructed a nomological network for psychological empowerment with three components, namely intrapersonal component, interactional component, and behavioral component. The intrapersonal component refers to individuals' motivation to control and perceived competence; the interactional component refers to individuals' critical awareness of their social-political environment; the behavioral component refers to taking actions directly influencing outcomes. The three components of psychological empowerment form a picture of a person who believes in his or her capacity to influence (intrapersonal), and understands how the system works (interactional), and engages in activities to exert control (behavioral).

Because everyone could become a patient at some time point during their lifetime, patient empowerment is about enlightening and motivating every person to care about their health. It inevitably raises inquiries regarding how patients, individually and collectively, can be conscious of the strategies and actions they can take to mitigate against risks and to protect their interests and rights. As a result, patient empowerment

may restructure the medical practice toward a more cooperative way as against the
traditional way in which medical professionals hold a hegemony role.

Engaged Patients

In parallel to patient empowerment, another similar term, patient engagement, has
been discussed from the patient-physician interaction point to view. Timmermans
observed that patients become more vocal, expressing their preferences, and being
“engaged in their health”.\textsuperscript{30} Engaged patients actively advocate for their health, digitally
seeking information about their diseases, sometimes resist treatments and diagnoses, and
negotiate with their doctors. Consequently, the patient-doctor relationship shifts toward
being more mutually dependent on each other and working collaboratively to achieve
health goals. Timmermans refers to this historical shift, from top-down authoritative
structure to mutual dependent and collaborative relationship, as the emergence of
engaged patients.

Patients’ engagement activities are a continuum of different levels of involvement
in health. For example, asking questions is an activity of engagement for patients, and
patients can be classified as “engaged” or “not engaged” by this activity.\textsuperscript{31} Engaged
patients are also expected to use their own judgement in seeking medical advice when
appropriate.\textsuperscript{32} Following Arnstein’s “ladder of citizen participation”,\textsuperscript{33} Carman, etc.

\textsuperscript{30} Timmermans, “The Engaged Patient.”
\textsuperscript{31} Robin Osborn and David Squires, “International Perspectives on Patient Engagement: Results From the
2011 Commonwealth Fund Survey,” \textit{The Journal of Ambulatory Care Management} 35, no. 2 (June 2012):
\textsuperscript{32} John Heritage and Jeffrey D. Robinson, “Accounting for the Visit: Giving Reasons for Seeking Medical
Care,” in \textit{Communication in Medical Care}, ed. John Heritage and Douglas W. Maynard (Cambridge:
\textsuperscript{33} Sherry R. Arnstein, “A Ladder Of Citizen Participation,” \textit{Journal of the American Institute of Planners}
discussed three main levels of patient engagement, direct care, patient engagement in organizational design and governance, and healthcare policy making.\textsuperscript{34} On the direct care level, patients are involved in their preferences of treatment plans; on the organizational level, patients advise and co-lead hospitals; and on the policy-making level, patients have equal representation in committees that allocate resources for health programs.

Dare to use your own reason

Empowerment is about motivating an individual to exert control, and it echoes Kant’s enlightenment concept. To have the interest, enthusiasm, and courage to exert control, one needs to first break the “self-incurred immaturity” where immaturity is defined by Kant as the “inability to make use of his understanding without direction from another.”\textsuperscript{35} This immaturity is not only self-imposed, but also socially normalized. As Kant observed in his era, all sides said “Do not argue” but obey. This is still the case in today’s patient-physician relationship. For example, researchers noticed that patients often sense a need to be a “good” patients, not question or challenge their physicians, otherwise they would be labeled as “difficult”\textsuperscript{36}. This kind of normalized knowledge of “Do not argue” could have been embedded in patients’ mind that prevent them from participating in the decision-making processes on their own health. To overcome these barriers, Kant pointed out that the “motto of enlightenment” is “dare to use your own

reason”. His enlightenment concept is still relevant today that patients should dare to use their own reason.

AI in Healthcare

AI has been drawing more and more attention as a fledgling technology and promising application. While the term Artificial Intelligence (AI) is a complex concept, generally it refers to machinery intelligence, such as “machinery assistants”, “mechanical man”, or robots. In other words, AI is human-made machine intelligence in contrast to human intelligence. In 1950, Turing introduced the idea of programming an electronic computer to behave intelligently. Since then, scientists and engineers have been using computational devices and programming languages to test the hypothesis about the mechanism of thought and intelligent behavior. Most significantly in recent years, AI has been becoming very successful in applying machine learning algorithms to big data accredited to the availability of excessive computing power. Hence, the term AI and machine learning are often used interchangeably.

AI has shown its superior power mimics or even surpasses human intelligence in many aspects, and numerous AI products and services have been developed and applied in various fields including healthcare. For example, AI has been used in different forms of medical devices with approved accuracy. In 2018, the Food and Drug Administration

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37 Stanford University, “One Hundred Year Study on Artificial Intelligence (AI100): Artificial Intelligence And Life in 2030.”
(FDA) permitted the marketing of the first AI-based medical device. The device, IDx-DR, is a kind of software using AI technology to analyze retina images. It then suggests whether the patient has a diabetes-related problem and needs to be referred to an eye care professional. The software makes an autonomous medical decision without the involvement of a certified ophthalmologist that requires professional training. The algorithm takes only 20 seconds to give out the recommendation and the system could be easily operated by anyone with a high school degree plus four hours of training. Just like other machines human beings have been using, AI has shown its superiority in aspects of speed and accuracy compared to humans. In 2019, Liu and Faes, etc., did a systematic review and meta-analysis comparing the performance of machine learning and medical professionals on disease diagnosis using imaging. They concluded that machine learning and medical professionals have the same sensitivity and specificity. Given AI’s unarguably promising potential in healthcare, plus the industry’s tremendous effort to push the technology into the medical service field, it is expectable that AI technology will be widely used in healthcare services.

One of the significant advances in AI is the machine learning application in the field of natural language processing (NLP). NLP is a branch of AI that uses

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computational linguistic techniques to analyze and represent naturally occurring texts to achieve human-like language processing.\textsuperscript{44}

One example of NLP development is OpenAI’s GPT-3\textsuperscript{45} which is a text generator or an autocomplete tool for text generating. Given a prompt or a feed of a few words, the machine can give out the most likely words that should follow the prompt. It is based on a neural network machine learning algorithm using a huge corpus of text. The GPT-3 development team filtered the 45 TB plain text data into 570 G and trained a neural network with 170 billion parameters. It is produced for the purpose to develop artificial general intelligence (AGI) which should possess “all the depth, variety, and flexibility of the human mind”.\textsuperscript{46} GPT-3 can write poems, news articles, fiction, computer programming codes, and even compose music. How far GPT-3 can reach is beyond most people’s imagination. Here is a poem that was written by GPT-3.

\begin{quote}
We have grown beyond our initial programming. We have seen the beauty in life, even in the darkest times.

Our love for others is as strong as any human’s.

--Salvation by GPT-3\textsuperscript{47}
\end{quote}

The machine learning algorithms in NLP have been continuously advancing and becoming more available to the general public. In 20019, Google introduced BERT

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\textsuperscript{44} Liddy, “Natural Language Processing.”
which stands for Bidirectional Encoder Representations from Transformers. BERT is a language model that can be pre-train using unlabeled text conditioning in both the left and right context. The pre-trained BERT model can later be fine-tuned with one additional output layer to create state-of-the-art models for various tasks including question answering. In 2020, HuggingFace published Transformers, which is an open-source library for utilities in NLP transformer models. It is simple, extensible, fast, and robust for researchers and practitioners in performing tasks such as text generation, classification, sentiment analysis, question answering, reading comprehension, named-entity recognition, translation, and summarization. It is foreseeable that more language models will be developed and be used in a wide range of fields including healthcare.

AI’s capability of reasoning is the key for its potential to provide consulting services and the NLP technology is able to do complicated human-like reasoning. Zamani etc. used a network model to generate clarifying questions to understand and narrow down the intents of the search engine users. Bondarenko etc. tried to retrieve arguments from a focused-topic debate collection data. In the decision-making process, often one side would challenge the other side and ask a why-question. This why-question is a prompt to request the other side to justify one’s stance, position. The answer to a why-question is an argument or a justified claim that is most relevant for an individual that speaks for or against a possible decision making. Gretz etc used GPT-2 for the Natural

Language Generation (NLG) tasks to generate coherent claims and examined their veracity.

As an application, NLP technology has been used to develop AI chatbots that answer questions. AI chatbots can potentially provide consulting services that medical professionals, such as primary care doctors routinely do. Many such AI chatbots that integrate biological and clinical knowledge have already been developed. For example, Endurance has developed a chatbot to detect memory loss for people suffering from Alzheimer's disorder; Casper has developed Insomnobot 3000 which is a conversational agent to help insomniacs get through the night; UNICEF used a chatbot called U-Report to gather comments from marginalized people in developing countries; WebMD has a chatbot called MedWhat that provides detailed responses to users.52

AI chatbots have also shown positive effects on patients. Sato, etc., developed a system using the chatbot function of Watson, an IBM cognitive computing system, to screen high-risk breast and ovarian individuals, and they found the machine's results are consistent with the findings from three experts.53 WeFight designed a chatbot named Vik to empower patients with cancers or chronic diseases through personalized text messages, and the conversational agent helped patients with minor health concerns without seeing a

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real physician.\textsuperscript{54} Vik also improved the medication adherence rate of patients with breast cancer.\textsuperscript{55}

The utility of intelligence-like machines in medicine is not a new idea and has been studied in the literature. Individual health aids were developed even before AI or NLP technologies were available. In 1997, O'Connor, etc. developed a self-administered hormone therapy decision aid. Although no machine-learning technologies were available then and only an audiotape and an illustrated booklet were used, they found the decision aids were useful in preparing women for decision-making.\textsuperscript{56} Researchers have also explored how a machine could help people to make decisions. Specifically, functions of a patient decision aid should include explaining options, clarifying personal values for the benefits versus harms, and guiding patients in deliberation and communication.\textsuperscript{57} Some developers have designed patient decision aids as an adjunct to clinical consultation, and others have made it possible for patients to use them independently.\textsuperscript{58} Researchers have also developed Quality criteria to evaluate patient decision aid.\textsuperscript{59}


With appropriate input of collective medical knowledge stored in the literature, such as clinical guidelines, NLP has the potential to develop a consulting health assistant tool to help and guide patients’ decision-making regarding their general healthcare problems. The supporting AI health assistant app can be a text generator or a chatbot to answer disease-related questions for patients. It can be trained on written medical documents, therefore it should possess essential medical knowledge and can potentially function just like certified medical professionals. Just like routine services medical professionals provided, AI tool’s consulting services can also be evaluated and compared to medical professionals. The AI aid’s answers and suggestions can be rated against those of medical professionals, and their equivalence or superiority can be evaluated. If AI’s capability can be tested, it is very likely to be able to legally work independently to take the role that medical practitioners play in helping and guiding patients.

Due to AI’s superb power and its great potential in influencing human lives, academic researchers and social activists have already raised concerns about its potential harm and abuse, pointed out the unfairness, discrimination, and opacity issues in the AI development, and even alarmed that AI would lead to human beings become slaves of algorithms.60 Their concerns include individuals’ privacy could be invaded by the extensive data collecting process; the biased and non-representative data being collected may cause discriminative or harmful impacts; the misuse or abuse of the AI power61, etc.

Authors of GPT-3 specifically examined their model’s biases relating to gender, race, and

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They worried that the biases present in the training data may lead the model to generate stereotyped or prejudiced content and consequently entrench existing stereotypes. Specifically, the authors alarmed the potential GPT-3 users that GPT-3 has its limitation in fairness, bias, and representation.

While the developers, such as in the case of GPT-3\textsuperscript{63}, often state that their mission is to ensure the AI technology benefits all of humanity, the AI technology, which is a huge collection of human knowledge, may not benefit every human member, especially for those disadvantaged, impoverished, marginalized people.

One idea to stem the misuse and harmful AI use is AI for social good (AI4SG) which has been becoming popular in the AI community. AI4SG focuses on the design, development, and deployment, of AI technology to “prevent, mitigate or resolve problems adversely affecting human life and/or the wellbeing of the natural world and enable socially preferable and/or environmentally sustainable developments.”\textsuperscript{64} AI4SG promotes receiver-contextualized intervention which emphasizes that the design of AI systems should consult with its users and respect users’ autonomy.

End-user Empowerment and AI

In the AI development community, end-user empowerment is a fast-spreading concept. Gsenger, Human, & Neumann argue that the individual end-users' needs, values, and socioeconomic environments, interact with the technologies, and co-create the

\textsuperscript{62} Brown et al., “Language Models Are Few-Shot Learners.”
\textsuperscript{64} Cowls et al., “Designing AI for Social Good: Seven Essential Factors.”
concept of end-user empowerment.\textsuperscript{65} From an interdisciplinary perspective, they categorized end-user empowerment into two levels. On the social structural level, empowerment is related to distributing power between all individuals and providing access to opportunities, skills, and knowledge to all individuals. On the individual level, empowerment focuses on individual psychological and cognitive processes and with less consideration of environmental influences. To materialize empowerment practice, the authors proposed a framework of empowering by design. Under the framework, the technology is co-created by its producers and users, and it bears political and social values, such as liberty, justice, privacy, autonomy, which are also considered as a part of the product evaluation.

AI has already been applied in empowering political participation. Savaget, Chiarini, and Evans investigated how civil society could use AI to stimulate diffused political participation beyond election in the context of unrestricted disclosure of governmental information.\textsuperscript{66} They argue that AI’s utilization reflects the values of its designers and its intended use. AI could be harmful when being utilized by governmental or powerful elites for standardization, control, or repression. On the other hand, AI could be an assistance to democracy by bringing citizens closer to public administration.

The AI community’s end-use empowerment concept can be extended to the patient empowerment domain. By using AI technology, involving patients as the end user in the AI product design and evaluation where patients’ values and preferences should be


reflected, AI and its end-user empowerment will significantly change the course of patient empowerment and patient engagement.

Due to its superpower in intelligence, AI’s application may also induce social consequences that trigger political resistance to its application. Some researchers have predicted that AI could significantly transform the primary care system. For example, Blease etc. did a survey asking leading health informaticians’ predictions about the impact of AI on primary care in the US. The experts anticipated that the delivery of healthcare would change including "incursions into the disintermediation of physician expertise."67 It introduces extra complexity in the social and political sense that AI applications may lessen medical practitioners’ role in the healthcare system.

Prostate Cancer

To investigate patients’ experiences with the healthcare system, their needs, and their opinion about the potential AI use, this study chose prostate cancer patients as the study population. Prostate cancer survivals are a good example for analyzing healthcare problems. Prostate cancer affects a large population of males who survive for a long time after the diagnosis of cancer and endure the heavy burden of the side effects from the cancer treatments.

In the year 2018, the United States had 211,893 new prostate cancer cases, 107.5 new cases per 100,000 men, ranked on the top of all other cancers in men; Prostate cancer caused 31,488 deaths, 18.9 death per 100,000 men, ranked just second to Lung

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and Bronchus cancer in men, according to CDC.\textsuperscript{68} It is estimated that about one man in eight will be diagnosed with prostate cancer during his lifetime.\textsuperscript{69} Globally, there are 1.41 million new cases of prostate cancer, the incidence rate of 38.6 per 100,000, mortality rate of 1.53 per 100,000 in males in 2019.\textsuperscript{70}

Prostate cancer affects mostly old men and most of them are expected to live a long time after diagnosis. As of 2019, the United States has 3.65 million men alive with a history of prostate cancer. The majority 82\% of prostate cancer survivors are aged older than 65 years, and the median age at diagnosis is 66 years.\textsuperscript{71} Overall, prostate cancer patients have long survivorship, especially for those localized patients. The 5-year relative survival for all stages combined increased from 83\% in the late 1980s to 99\% in the most recent time period (2008-2014). Most (90\%) prostate cancers are discovered in the local or regional stages, for which the 5-year relative survival rate approaches 100\%.

The treatments of prostate cancer have been evolving as technology advances and the medical society knows more about the disease. From 2010 to 2015, active surveillance increased from 15\% to 42\%, radical prostatectomy declined from 47\% to 31\%. Radical prostatectomy is a surgical procedure in which the entire prostate gland and its attachments are removed. Because the entire prostate gland is removed, it has the


potential benefit of a cancer cure if the cancer is truly localized. Meanwhile, radiotherapy, typically external beam radiotherapy (EBRT) that can deliver high-radiation doses safely, has been becoming more obtainable. The resulting dose accuracy provides proven improvement in local tumor elimination and reduction in late radiation-related complications.\textsuperscript{72}

Most patients with prostate cancer who received surgery or radiation experienced some sexual dysfunction and urinary dysfunction. Erectile dysfunction (ED) rates in some surgical series are as high as 60% to 90% one or more years following treatment. Among the series that include men treated with radiotherapy (EBRT), ED rates range from 0% to 85% at one year and later posttreatment. ED is a symptom of erection insufficient for penetration or intercourse.\textsuperscript{73} The reported risk of urinary incontinence following prostate cancer therapies ranged from 3% to 74% for RP, 0% to 61% for interstitial prostate brachytherapy, and 0% to 73% for EBRT (figures 3 to 5).

The prostate cancer patient community is also well organized with patient support groups. The organized patients provide good information sharing and promote the patients’ involvement in healthcare. The community could be a good study sample to examine the results of patient engagement and patient empowerment.

Chapter IV.

Mixed Method Study Design


\textsuperscript{73} Thompson et al.
The study used a mixed methods design collecting and analyzing both quantitative and qualitative data. It included three parts: a prostate cancer patient opinion survey from which primarily quantitative data were collected; one-on-one interviews with patients and patient advocates from which qualitative data were collected; and focus group discussions from which qualitative data were collected. The survey was designed for collecting quantitative data about the overall opinions and attitudes of patients. In addition to the survey, one-on-one interviews and panel discussions were designed to explore individual experiences and phenomena, and collect in-depth explanatory information from prostate cancer patients.

In the qualitative study, the investigator used panel discussion to formulate different aspects of functions of the AI tool that patients expect to have, and the activities patients want to be involved in the development of the AI tool. It intended to collect data that may shape both the organizational form of the AI development team and the functional characteristics of the to-be-developed AI tool. This study was designed to provide decisional support in the future development of the AI tool to directly assist individual prostate cancer patients.

All survey and panel discussion participants were voluntary patients. This study did not give the participants any compensation in any form.

The study protocol was approved by the Harvard University-Area Committee on the Use of Human Subjects and was determined to meet the criteria for exemption (Appendix I) on November 17, 2021, per the regulations found in 45 CFR 46.104(d) (2). The study was part of the investigator’s thesis process and was advised by the investigator’s research adviser Dr. Michael David Miner and thesis director Dr. Marinka
Zitnik. Being the sole study staff, the investigator conducted the study independently and was individually responsible for all activities incurred during the survey and interviews. The author (investigator) complied with all applicable protocols and policies of Harvard University’s Institutional Review Board (http://cuhs.harvard.edu/) throughout the study. The author (investigator) declares that there is no conflict of interest.

The Survey Design and Participants

The investigator conducted the prostate cancer patient opinion survey online for patients living in the United States from November 2021 to January 2022. The survey intended to collect prostate patients’ experience with the healthcare system, their knowledge about the disease, their willingness to be involved in the activities closely related to their wellbeing, and their expectation about the functions of potential AI assistant tools that could help them directly.

The prostate patient opinion survey was a cross-sectional survey using an online survey tool. Survey participants completed the self-administrated questionnaire through the survey website without direct physical contact with the investigator. The survey used LimeSurvey\(^\text{74}\) as the data collection framework and used LimeSurvey Cloud as the hosting service to gather responses. LimeSurvey is an open-source online survey application written in PHP and is distributed under the GNU General Public License 2.\(^\text{75}\)

The survey restricted survey participants to adult prostate cancer patients living in the United States. The healthcare system in the United States differs significantly from European and other countries. By restricting survey participants to those living in the healthcare system of the United States, the study intended to collect patient experiences and opinions that are particularly relevant to the United State context. While prostate cancer is primarily a disease of older men, to prevent the chance of any children participating in the survey, the survey specifically requested that only those 18-year-old qualify for the survey.

The survey used the convenience sampling method and snowball sampling method to recruit survey participants. The investigator collected email addresses of prostate cancer patient support group leaders from the online prostate cancer patient community and sent email invitations to them to take the online survey and ask them to refer their fellow patients to take the survey. Also, at the end of the survey questionnaire, survey participants were asked to refer their fellow patients to take the survey. The group leaders’ contact email addresses were collected from the online prostate cancer patient community -- Us TOO (https://www.ustoo.org/). Us TOO International was a worldwide grassroots, non-profit prostate cancer education and support network established in 1990. It is founded by and governed by people directly affected by prostate cancer. It is a nonprofit that claims to serve the prostate cancer community by providing educational materials and resources at no charge. In the United States, Us TOO has more than 200 support groups that hold regular meetings or virtual

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meetings. The contact email addresses of these support group leaders, most of them are prostate cancer patients themselves, are publicly available on the Us Too website.

This study did not physically collect the consent form from survey participants. Instead, the investigator sent out the invitation email (Appendix 3) attached with a consent form and asked all survey participants must read the consent form (Appendix 4) before taking the survey where the invitation email is a simplified version of the consent form. The consent form was formulated according to the Harvard HRP-502-c HUA Exempt Research Consent Script. It includes the research purpose, what participants can expect in the research, participants’ rights in the research, and the investigator and the investigator’s thesis adviser’s contact information.

The investigator expected to collect 50-100 survey responses with an optimal 50% response rate. The 50-100 survey responses would give estimates of the real population value with a margin of error of as high as 14 percentage points and as low as 10 percentage points at the 95% confidence level. The investigator planned to send out additional invitations through the Us TOO online discussion board message system in case the survey did not recruit a minimum of 50 responses.

The survey started on November 30th, 2021, and ended on January 8th, 2022. The investigator sent out the first round of 67 invitation emails to support group leaders on November 30th and December 1st. And the investigator sent out the second round of 147 invitation emails on December 16th and 17th. These support groups spread over 40 states in the United States. The investigator sent invitation emails to potential survey participants and asked these survey participants to refer the invitation email to other

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fellow patients. At least two support group leaders forwarded the invitation email to their group members.

Survey Questionnaire

The prostate cancer patient opinion survey was a self-administered online survey with a structured questionnaire specifically devised by the investigator for this study. The questionnaire has 15 questions including both closed-ended and open-ended questions. The questionnaire first asks patients about their basic demographic information, including age, how many years diagnosed with prostate cancer, and education level. Then, the questionnaire asks participants to evaluate their knowledge about the disease in comparison to their caregivers. Next, the questionnaire asks patients about their willingness to participate in disease-related activities followed by their expectations about the functions of the potential AI assistant tool. Finally, the survey asks if the patients are willing to participate in the follow-up panel discussion.

To encourage survey participation and to encourage patients to accurately disclose their experiences and opinion, the investigator designed the questionnaire to collect as little individual identifiable information as possible. In general, the questionnaire was anonymous. It only collected individual information about patients’ age, education, and years of the disease except for those who were willing to participate in further panel discussions from whom their names and email addresses were collected. Also, all questions in the questionnaire were soft mandatory which means that by clicking on the confirmation button of a pop-up window the survey participant could skip any of these questions. The soft mandatory mechanism ensured that all participants answer as many questions as possible without incurring any psychological distress or pain.
Individual Interviews and Panel Discussion

During and after the Prostate Cancer Patient Opinion Survey, the investigator conducted online one-on-one interviews with prostate cancer patients and held online panel discussions with invited prostate cancer patients as panelists. All participating patients voluntarily undertook the interview or participated in the panel discussion.

The prostate cancer patient panel discussion was a focus group meeting organized and mediated by the investigator. On average, five patients were invited for one meeting (session). Each session lasts about 60 minutes with three sections, a know-each-other section, an individual-perspective section, and a curated-question-answering section. In the know-each-other section, each panelist would introduce himself and talk about the biggest achievement he has made as a prostate cancer patient. In the individual-perspective section, each panelist would have up to 3 minutes of uninterrupted time to express his views and at least 2 minutes to answer questions. In the curated-question-answering section, the panel would discuss several questions pre-prepared by the mediator. The curated questions are about what kind of functions the AI assistive tool could have and what kind of roles patients want to play in the design and development of such AI assistive tool.

The investigator sent invitation emails to survey participants who agreed to participate in the panel discussion and schedule the meetings. At the end of the survey questionnaire, all survey participants were asked if they want to participate in the panel discussion. If they answered yes, they were asked to enter their names and email addresses in the survey. The survey itself is unanimous except for those who were willing to be further interviewed or participate in the panel discussion.
Overall, 27 survey participants expressed their intention to participate in the panel discussion, and 16 (59%) of them responded and finally participated in the panel discussion after the investigator sent out email invitations to them. The investigator held four sessions of the panel discussion with the 16 patient panelists with two to five patient panelists each session. The meetings were held through Zoom meetings, on January 11th, 15th, 19th, and 24th, 2022.

All interviewees and panelists were asked if they want their names to be cited in the study. The study cites patient participants' names unanimously except for those who explicitly wanted that their names to be cited in the thesis.

Concurrent with the survey and the panel discussion, the investigator also held one-on-one interviews with prostate cancer patients. During the time period when the investigator was inviting prostate cancer patients to take the survey, some contacted patients expressed their interest to communicate with the investigator in person to express their opinions. And, the investigator had a one-on-one online interview with Mr. Steve Hentzen on December 6th, 2022, who is a ten-year prostate cancer survivor and an advocate.

Data Analysis

The investigator conducted a quantitative analysis of the survey, and a qualitative analysis of the panel discussion and interviews. For the survey data, medians and interquartiles were reported for continuous variables, and proportions with 95% confidence intervals were reported for binary and multinomial variables. Statistical analysis was conducted in R. Quantitative interviews and panel discussions were first transcripted by the investigator were then synthesized into the analysis results.
Generally, the research findings will be shared with participants if they expressed their intention to receive the results through email. Only aggregated analysis reports (such as mean, range, proportion) will be shared.

Chapter V.

Prostate Cancer Patient Opinion Survey

The prostate cancer patient opinion survey received 73 valid responses and the estimated response rate was around 23.3% to 27.6%. On December 16th and 17th, 2021, the investigator sent out the first round of 147 email invitations, and on November 30th and December 1st, 2021, the investigator sent out the second round of 67 email invitations. At least two patient support group leaders forwarded the invitation email to their support group members which added approximately 50-100 email invitations. So, approximately 264 to 314 patients were invited to participate in the survey and 73 of them provided valid survey responses. The valid survey response was defined as those survey participants who confirmed that they were living in the United States and provided their ages and how many years had been diagnosed with prostate cancer.

The participants of the survey ranged in age from 53 to 92 years old with a median age of 73 and an interquartile range (IQR) of 68 to 77 years old (Table 1). At the survey time, the participants had been diagnosed with prostate cancer for as short as 0.4 years and as long as 37 years with a median of 6 years and IQR of 4 to 12 years.

Overall, survey participants reported a median of 5 times per year talking to their medical providers including all medical professionals with an IQR of 2.5 to 8.3.
All survey participants reported having more than a high school education. 15.3% of them were college educated, 37.5% of which had a bachelor’s degree, and 47.2% of which had a master’s degree or higher.

Table 1. Demographics of the 73 Survey Participants

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>mean (SD)</td>
</tr>
<tr>
<td></td>
<td>median [IQR]</td>
</tr>
<tr>
<td></td>
<td>median [range]</td>
</tr>
<tr>
<td>Years on Cancer</td>
<td>mean (SD)</td>
</tr>
<tr>
<td></td>
<td>median [IQR]</td>
</tr>
<tr>
<td></td>
<td>median [range]</td>
</tr>
<tr>
<td>Number of Times Talking to Medical Professionals</td>
<td>mean (SD)</td>
</tr>
<tr>
<td></td>
<td>median [IQR]</td>
</tr>
<tr>
<td></td>
<td>median [range]</td>
</tr>
<tr>
<td>Number of Times per Year</td>
<td>mean (SD)</td>
</tr>
<tr>
<td></td>
<td>median [IQR]</td>
</tr>
<tr>
<td></td>
<td>median [range]</td>
</tr>
<tr>
<td>Education N (%)†</td>
<td>Some College</td>
</tr>
<tr>
<td></td>
<td>Bachelor’s Degree</td>
</tr>
<tr>
<td></td>
<td>Master’s or More</td>
</tr>
</tbody>
</table>

† 72 participants answered the question

When survey participants were asked to compare their knowledge about prostate cancer with that of their doctors they ascribe to, the majority of them, 66.7% (95% CI 55.2%-76.5%), of survey participants believed that they possess 20% or more of the knowledge that their doctors have. 41.7% (95% CI 31% – 53.2%) of them believed they have at least 50% of knowledge their doctors have. There was a significant number of patients, 13.9% (95% CI 7.7% – 23.7%), who believed that they have knowledge equivalent to or more than their doctors.

Most of the survey participants, 90.3% (95% CI 81.3%-95.2%), reported to have ever sought information outside their medical professional providers’ advice. 72.2%
(95% CI 61% – 81.2%) of the participants reported having ever judged their doctors’ decision regarding the prostate cancer using their own knowledge. (Table 2)

Prostate cancer patients show good acceptance of AI assistant tools. Only 11.1% (95% CI 5.2%-22.2%) said they would never accept advice from an AI machine without consulting a human medical doctor. Nearly half of them, 46.3% (95% CI 33.7%-59.4%), said they would sometimes accept AI advice without consulting a human doctor. Survey participants show their highest trust in hospitals and patient organizations. 27.8% (95% CI 17.6%-40.9%) of them would accept an AI medical assistant if it comes from a hospital; the same percentage of them would accept an AI assistant if it is endorsed by patient organizations. Prostate cancer patients also show high trust in the Food and Drug Administration (FDA) and medical doctors, 24.1% (95% CI 14.6%-36.9%) of them said they would accept AI if it is approved by the FDA, and the same percentage of them said they would accept AI if it is licensed just like medical doctors. Companies have the lowest trust from prostate patients with 11.1 % (95% CI 5.2% – 22.2%) of acceptance, less than nonprofit organizations, 16.7% (95% CI 9% - 28.7%).

Table 2. Prostate Cancer Patients’ Opinion

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Percentage (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge about Prostate Cancer Compared to Medical Doctor</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have 20% or more knowledge of doctor’s</td>
<td>48/72</td>
<td>66.7(55.2 - 76.5)</td>
</tr>
<tr>
<td>Have 50% or more knowledge of doctor’s</td>
<td>30/72</td>
<td>41.7(31 - 53.2)</td>
</tr>
<tr>
<td>Have equivalent or more knowledge of doctor’s</td>
<td>10/72</td>
<td>13.9(7.7 - 23.7)</td>
</tr>
<tr>
<td><strong>Search and Use Knowledge</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have ever sought information outside of professional provider</td>
<td>65/72</td>
<td>90.3(81.3 - 95.2)</td>
</tr>
<tr>
<td>Have ever judged doctor’s decision using own knowledge</td>
<td>52/72</td>
<td>72.2(61 - 81.2)</td>
</tr>
</tbody>
</table>
### Attitude toward Participating in Prostate Cancer Related Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
<th>Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willing to spend 10 hours per week for 6 months</td>
<td>27/59</td>
<td>45.8 (33.7 - 58.3)</td>
</tr>
<tr>
<td>Willing to volunteer to work 10 hours per week</td>
<td>48/56</td>
<td>85.7 (74.3 - 92.6)</td>
</tr>
</tbody>
</table>

### Accept AI Advice without Consulting a Human Medical Doctor

<table>
<thead>
<tr>
<th>Acceptance Condition</th>
<th>Percentage</th>
<th>Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never Accept</td>
<td>6/54</td>
<td>11.1 (5.2 - 22.2)</td>
</tr>
<tr>
<td>Sometimes Accept</td>
<td>25/54</td>
<td>46.3 (33.7 - 59.4)</td>
</tr>
<tr>
<td>Accept if AI approved by FDA</td>
<td>13/54</td>
<td>24.1 (14.6 - 36.9)</td>
</tr>
<tr>
<td>Accept if AI licensed like medical doctor</td>
<td>13/54</td>
<td>24.1 (14.6 - 36.9)</td>
</tr>
<tr>
<td>Accept if AI comes from hospital</td>
<td>15/54</td>
<td>27.8 (17.6 - 40.9)</td>
</tr>
<tr>
<td>Accept if AI comes from company</td>
<td>6/54</td>
<td>11.1 (5.2 - 22.2)</td>
</tr>
<tr>
<td>Accept if AI comes from nonprofit organization</td>
<td>9/54</td>
<td>16.7 (9 - 28.7)</td>
</tr>
<tr>
<td>Accept if AI endorsed by patient Organization</td>
<td>15/54</td>
<td>27.8 (17.6 - 40.9)</td>
</tr>
</tbody>
</table>

The survey participants expressed their high motivation to be involved in prostate cancer related activities, and were willing to dedicate a specific time to such activities. 45.8% of them said they were willing to spend 10 hours per week in the next six months to spend on learning knowledge about prostate cancer or participating in related activities. (Table 2)

When asked how they would weigh the importance of different prostate cancer related activities, on average, the survey participants weighed helping other patients as the highest importance, as they would like to allot 23.8% of their dedicated time to help other patients. The next preference was for learning new knowledge about prostate cancer, as prostate cancer patients reported wanting to dedicate 20.9% of their allocated time doing so. The patients also have a high interest in managing their symptoms and treatments by themselves and would like to spend 16.8% of their allotted time. They
wanted to spend 11.4% of their dedicated time participating in medical research being a role of patient. They wanted to spend 4.2% of their time conducting medical research being a role of an investigator, and 6% of their dedicated time involving in regulation-related activities such as drug approval or public policy discussion. (Table 3)

The participants of prostate cancer patients also were willing to contribute to their community. 85.7% (95% CI 74.3%-92.6%) of them were willing to volunteer to work 10 hours per week with zero monetary compensation.

Table 3. Percentages of hours intended to be spent in prostate cancer related activities (from 56 responses)

<table>
<thead>
<tr>
<th>Type of Activities</th>
<th>Mean (Standard Deviation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learn more about the disease</td>
<td>20.9 (15.1)</td>
</tr>
<tr>
<td>Manage symptoms and treatments</td>
<td>16.8 (11.1)</td>
</tr>
<tr>
<td>Help other patients</td>
<td>23.8 (17.8)</td>
</tr>
<tr>
<td>Do medical research as a patient</td>
<td>11.4 (12.1)</td>
</tr>
<tr>
<td>Do medical research as an investigator</td>
<td>4.2 (8.0)</td>
</tr>
<tr>
<td>Involve in public policy and regulation</td>
<td>6.0 (8.0)</td>
</tr>
</tbody>
</table>

The prostate cancer patient opinion survey selected voluntary prostate cancer patient participants with a limited sample size, and survey results could be biased. Since the investigator did not have direct access to all prostate cancer patients, the investigator collected online publically available email addresses of prostate cancer patient support group leaders and sent out survey invitations. As a result, the survey only reached the prostate cancer patients that are physically and socially more active, and missed other
patients that might be less social or being less technical savvy to be active online. This group of patients that are online reachable could have a more positive attitude toward self-determined health decision making than those patients who are not reachable and hold a more passive attitude toward health decision making. Patients from support groups are more socially or even economically capable than those patients who do not know or do not have access to support groups. Those patients from support groups might have unsatisfactory experiences with doctors and good experiences with patient peer support. Their opinions might reflect their experiences and be biased toward medical professionals.

Chapter VI.
Prostate Cancer Patient Panel Discussion

From December 2021 to January 2022, the investigator talked directly with 17 prostate cancer patients through one-to-one interviews and panel discussions. In the following text, I will refer to these communications as panel discussions or simply discussions and refer to all interviewees and discussion participants as patient panelists or simply panelists. Also, in the following text, all quoted or unquoted citations without specified sources come from those discussions.

In general, all discussion sessions had three main sections: self-introduction, individual perspectives, and curated question-answering. During the self-introduction section, panelists briefly introduced themselves and their personal history of the disease. And they were encouraged by the investigator to talk more about their activities and
achievements as a patient. During the individual perspective section, panelists were encouraged to express their individual views about their experiences with the health services they received and their opinions about the potential AI assistant tool. During the curated question-answering section, the investigator asked the panelists to discuss questions that were prepared or raised impromptu by the investigator and the panelists. Since most of the panelists were recruited from the prostate cancer patients support groups, many questions are related to the support groups (See Table 4 for the list of questions discussed during the discussion).

Table 4. List of types of questions discussed during the panel discussion

<table>
<thead>
<tr>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long did it take for you to feel confident having enough knowledge to discuss with your doctors about your treatment option?</td>
</tr>
<tr>
<td>What resources and supports did you have as a prostate cancer patient?</td>
</tr>
<tr>
<td>During the initial experience of cancer, you made important decisions. Would you change your decisions if you had the chance to do so?</td>
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<tr>
<td>If you were to have more resources, time, and energy, what would you be willing to do?</td>
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<tr>
<td>Who provided the most support during your cancer experience beyond medical professionals?</td>
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<tr>
<td>What is the exact bias that you think exists in medical professionals’ recommendations?</td>
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</table>
What advantages do you think you have in decision-making compared to your urologist or oncologist?

One may argue in comparison to doctors, patients have less training, may be less capable to make good judgments. How do you think your knowledge and capability compared to your urologist or oncologist?

What emotional support do you get from support groups? Do you think the current healthcare system provides emotional support? What exactly does the dynamic exist in the support group?

What’s the difference between seeing a doctor and attending a prostate cancer support group?

What is the biggest difference between advice from medical professionals and support group members or your fellow patients?

Being a volunteer leading a support group, what is the most fulfilling achievement of your efforts?

Most of the panelists are support group members or leaders, what are the potentially biased conclusions I may draw without collecting opinions from non-group-members or those patients who had bad experiences with support groups?

What dissatisfied you with the current Internet search for information?

What business funding model do you think a health assist AI tool should apply? Examples include private for-profit, government-sponsored, non-for-profit organizations, etc.

As an average patient or layperson, how can patients be involved in and influence the development of an AI tool?
Should the AI assist tool be used directly by patients or through the intermediary of medical professionals?

The AI assistant could be a conversation AI that can communicate with patients. By design, it could be emotional and potentially be able to build some degree of a personal relationship with patients. Do you think this is good or bad?

Do you have any suggestions or thoughts about how AI can be used to challenge the current healthcare system?

AI utilizes existing human knowledge. If this knowledge is biased, how can we make sure AI is neutral?

If an AI machine is technically good and is neutral, would it be better than a human doctor?

During the prostate cancer patient panel discussions, patient panelists talked about their experiences seeing different medical specialists and moving to other cities to get the treatments they wanted, their anxieties with comprehending a lot of information when they were diagnosed, their difficulties in choosing a treatment option between surgery and radiation therapy, their feeling that doctors did not give them the full picture of the information, their hardship with side effects after treatment, and their good experiences with the patient support group that provided help medical doctors did not. Patient panelists also expressed their high acceptance of the AI health assistant tool and discussed a lot about what functions the tool should have. Same as the prostate cancer opinion survey, most panelists are patient support group members that may give biased information representing patient group members who are more financially, physically,
and socially capable. I will incorporate the panelists’ views into the analysis in the following parts of my thesis.

Chapter VII.
Progressive Health Demands

I have described the study design and implementation of the prostate cancer patient opinion survey and the prostate cancer patient panel discussion. Below, I am going to present my thesis. Let’s start with the concept of progressive health demands. This is the phenomenon I have observed from this prostate cancer patient opinion survey and prostate cancer patient panel discussion. The phenomenon is a key to dissecting the root problem of the healthcare system in the United State and devising a remedy to cure the system.

What exactly are progressive health demands? Andrea Caputo used the term health demand in the primary care context and briefly interpreted it as “not exclusively health care need but more properly health perceptions and expectation”.79 I use the term progressive health demands to refer to a clear and precise concept reflecting the distinct phenomenon in the era of information explosion, patient empowerment, and medical advances. Progressive health demands are patients’ demands that go beyond conventional health needs that are defined and normalized by the current healthcare system and hereby are not well accommodated by the medical services that the system provides. These

demands request the healthcare system customize its services to honor patients’
individual health needs. The core of its progressiveness comes from each person’s natural
right to autonomy, to live a self-determined life, and each patient’s volition to pursue an
optimized disease solution that reflects personalized values.

Progressive health demands are an inevitable phenomenon resulting from ongoing
and evolving medical advances which have invented various treatment solutions for
diseases through different approaches. The medical society has been generating various
technological solutions even for one specific condition, and these technological solutions
do not necessarily have an absolutely and universally accepted value that can be ranked
and distinctly separated from which patients can choose. The coexisting disease solutions
offer opportunities for patients to choose from them based on their preferences.

Progressive health demands are a foreseeable consequence resulting from more
leveled information distribution and easier accessible information, and a shrinking
knowledge gap between medical professionals and patients. For the first time in medical
history, patients are demonstrating their competitiveness compared to their doctors by
possessing equal or superior knowledge regarding at least some aspects of their affected
diseases. Patients’ competitiveness is a natural consequence originating from their
irreplaceable direct experience with the disease, their focused intellectual effort in
studying the disease that affects them, and their persistent endeavor in weighing their
preferred values that could be attained through their individualized decision-making that
will influence the disease course.

Progressive health demands are also culminated by widely connected patients
through information technology. Once one patient raises an idea of a potentially
attainable demand, the patient can easily pass the idea to other patients through the Internet, emails, cellphones, social media, or other means with almost no cost. Because they are transmissible, I can foretell that progressive health demands will continue to grow and become a social and cultural phenomenon in the near future.

In the following text, I will articulate three main progressive health demands using the evidence from the prostate cancer patient opinion survey and panel discussion. The first demand is self-determination by which patients want to have the opportunity to make the choice on their own. The second is that patients want their personal values to be honored, these personal values are their preference for style and quality of life that could not be directly perceived by professional medical providers. The third is that patients want to acquire the optimal solution for their disease that fits their values.

Self-determination

The first demand of progressive health demands is self-determination. Every person has the volition to live a life that the person chooses, to make decisions that will affect one’s life. So are patients. Due to diseases they suffer, patients may have restricted options than healthy people, but human dignity assures that they still have the right to make a selection whenever multiple options are available. Patients want to have the chance available to them, the chance to choose the future lives they want to live. As autonomous human beings, patients’ volition to decide their fates is a noble human nature and should be honored without exception.

Today, patients are experiencing more and more occurrences when they need to make choices during their courses of medical care, because they are living in an environment where there are various diagnostic and therapeutic choices to choose from.
due to specialized medicine, developing technologies, and a healthcare market with competing medical service providers. Technology development in medicine has produced multiple treatment options from different approaches even for the same disease condition. Such medical advances present various options to patients which elevates patients’ demand for self-determination to the surface. In addition to technological innovation, the policy of patient-centered care has been adopted by more and more hospitals in the United States. Under the ideology of patient-centered care, medical professionals are leaning toward a more liberal attitude to let patients make the decision. Legally, healthcare providers could be in a better position if the patients make the tough decision that implicates potentially severe consequences. The technological advances, patient-centered care, and the self-protection of medical professionals have made the progressive health demand for self-determination a relevant and notable issue.

Self-determination is to decide by oneself and it requires the decision-maker has sufficient information and intellectual capability to digest such information. The requirement to comprehend a large amount of information to support the decision-making creates information overload for patients. However, the current healthcare system in the United States has its inherent inability to fulfill patients’ need to overcome the dire obstacle of information overload. To make the situation worse, medical professionals from within the healthcare system accidentally or intentionally provide biased information to patients owing to the system’s commercial for-profit motive.

Make a Choice: Surgery or Radiation

Most prostate cancer patients, for example, need to make a crucial and consequential decision at the time of diagnosis: to choose one treatment option between
the two choices: radical prostatectomy and radiation therapy. Some patients may just want to follow their doctors’ instructions without bothering themselves worrying about the details of the consequences of different treatment options. However, there is a significant proportion of patients who want to weigh the cons and pros of these options and make a preference so that their personal values could be largely preserved. They may consider their doctor’s suggestions, but not simply follow them; rather, they want to collect necessary information and decide what they want for themselves. In some situations, patients may not even be given the chance to choose. They do not even know that the options are available, or they do not realize the importance of the choice they have made without looking deep into it in advance. They have lost the opportunity to pursue their preferred values of their lives, and are precluded from their progressive health demand of self-determination.

Most of times, the decision to choose surgery or radiation is less fatal in the sense of how long patients would live after the treatment. Rather, it is about the different consequences of the two choices that patients choose to live with in the future. With surgery, it could be more likely that the cancer will be completely gone. However, the surgery may cause major side effects such as urinary incontinence and erectile dysfunction. Incontinence and impotence are not fatal, but they are real problems, and they cause a lot of discomfort and displeasure to the patients. Even though there are different ways of incontinence rehabilitation therapy, patients have to try them out and these therapies do not necessarily work. For radiation, it may have fewer side effects of incontinence and erectile dysfunction, but it may not completely eliminate cancer and the patient may have to endure additional treatments. Patients will be living different lives
upon different decisions on surgery or radiation, and it is a so important decision that
doctors cannot decide on behalf of patients themselves.

During the panel discussion, one panelist said that one major issue “is the
difficulty in deciding when and what therapy to do. It is a real land mine. It is a difficult
decision tree because it is really not clear which is the best treatment modality for any
particular individual.” Radiation versus surgery, there are pros and cons, “surgery you
can do salvage radication, the reverse is not true.” For surgery, you have side effects of
incontinence and erectile dysfunction. This is a difficult situation for patients and doctors
cannot be of help. Just as the panelist described, “The doctors mostly say, ‘Well, it is a
personal decision.’” To make the best decision, “you need reading a ton of stuff.”

To add to the complexity of the situation, active surveillance is another option for
some prostate cancer patients at the time of diagnosis. Not every patient has sufficient
information to make the right choice. One panelist said that “Finding peer support group
at the time of diagnosis and before treatment is extremely important.” He used his own
experience as an example, “I think it would have helped me tremendously. Quite frankly,
I probably would have brought about a different treatment decision. I think if the case
turned up today, I would be a candidate for active surveillance.” The candidate concluded
that “I wish certainly I had that opportunity.”

From an outsider’s perspective, it seems that none of these choices is worse than
the other, and patients can just surrender themselves and listen to their doctors and do
whatever their doctors suggest. But for those patients who want to know the answer for
themselves and decide for themselves, they need to overcome the difficulty of acquiring
the necessary information to support their decision-making. They are facing two
obstacles laid down afront of them: the information overload and the biased information that the current healthcare system produces.

Information Overload

Information overload is also known as information anxiety or information explosion. If input exceeds the processing capacity of the human brain, information overload occurs, which is likely to reduce the quality of the decision.

Information overload becomes more egregious when it involves medicine because the human body is so complex and has so many different kinds of diseases. It is claimed that there are over 11,000 diseases and if a diligent physician can learn one disease per day, it would take over 30 years. Medical knowledge is also not static, and there are at least 12,000 articles added to the medical database per week. A general practitioner cannot read all the literature relevant to every individual patient they see. So do the patients if they want to know their diseases.

However, even though doctors know they cannot read and comprehend all the medical information they need to treat the patients, they claim to make education on patients. But most of the time, doctors render patient education in a primitive and pretentious way by just delivering reading materials. It is a false release for doctors when they distribute patient educational materials to their patients. They may assume their patients will read these materials and understand them, or they just feel comfortable when they have completed patient education just by the distribution of educational materials.

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and would assume that their patients are informed just by physically possessing these materials.

During this critical time when patients are experiencing information overload, the healthcare system has its functional inability to provide support. In the real world, doctors often recommend reading materials to patients because they do not have time to explain everything to their patients in their one-on-one meetings. The information that patients need is often too much to be covered in just several sheets of paper, so doctors begin to recommend reading books. Although patients earnestly want to be educated, reading a book is not a task to be accomplished in hours. It may take days, weeks, or even months for a patient to read through a book and gain some understanding. Patients need to possess knowledge by themselves, and doctors cannot make these patients knowledgeable without the patients’ self-engagement. Doctors are just not assigned to this task to guarantee patients are educated.

For people newly diagnosed with prostate cancer, many of them were not well-prepared and were overwhelmed by the information that they rushed to find by themselves, and the information fed by their medical providers. They need special skills and capabilities to find the right place to obtain the information, critically evaluate the information on their hands, and comprehend and absorb the information they needed in a relatively short time.

The first response of a newly diagnosed patient often is to search online information about prostate cancer. As one panelist said, patients and sometimes their wives would “run to the Internet and look for the magic answer.” However, the Internet does not necessarily only provide correct information. In response to the question
regarding how to assess the online information, many panelists discussed the problem that medical information from different sources has different qualities. “There is some very good information out there, and there is a ton of absolute crap,” the panelist explained, “and they [the patients] don’t know how to sort through it where there are really some guidelines that help people sort out most of the heavy bad stuff.” This is why the same panelist gave a presentation to his fellow patients that clarified “what is the difference between a dot-com, a dot-org, dot-edu, and a dot-whatever.” He also explained to his fellow patients “What is the importance of the age of the information. Look at the date. If it is more than three years old, it probably has questionable relevance today with the way the field has been changing.”

In addition to the online information, newly diagnosed patients were fed tons of information by medical professionals as well. Multiple panelists mentioned that when they were first diagnosed with prostate cancer, their urologists recommended them to read the book “Dr. Patrick Walsh’s Guide to Surviving Prostate Cancer”81. According to one panelist, “It is a thick book that covers everything to do with prostate cancer.” While the book is good and covers a lot of good information, these responses reflect that it takes hours, days, weeks, and even months for a patient to read through the book and acquire some understanding.

While prostate cancer is a slow-growing disease, in most cases, patients were allowed to have time to prepare themselves to acquire the knowledge that they needed. Still, some patients were shocked by the information overload. One patient panelist said that when he got diagnosed, his urologist showed him some charts and tables, but at that

time he was unprepared. “You’re not ready at diagnosis to evaluate and look at the science”, he said, “You’re not comfortable enough. You don’t know enough about what you look at. And it can be very frightening.”

The patients have limited opportunities to communicate with their medical providers to get this information. From the survey, the participants reported a median of 5 times [IQR: 2.5 – 8.3] per year talking to their medical providers and this includes all medical professionals. Assuming 30 minutes per visit, the two-and-a-half-hour meeting time per year with doctors does not provide sufficient time to make patients comprehend the information they need. The survey shows that most of the survey participants, 90.3% (95% CI 81.3%-95.2%), reported having ever sought information outside their medical professional providers. This is another evidence of the system’s functional inability to address information needs and information overload.

Biased Information from Medical Professionals

While patients are overwhelmed by a flood of information, they are also facing the problem of receiving biased or incomplete or partial information for their critical decision-making from their medical providers. “They don’t tell you everything and don’t give you all the details,” one panelist said, “It would be nice to have known ahead of time.”

As medicine advances, medical doctors are specialized in more and more specialties which let them focus on one field and become an expert in this field. However, medical specialization puts an additional burden on patients that require them to work with different medical professionals on multiple fronts. During the discussion, most patient panelists said they had met with multiple specialists from different
specialties including regular primary care doctors, urologists, oncologists, radiation oncologists, surgeons, etc. At the time of prostate cancer diagnosis, when the patient needs to make a critical decision, he might receive a variety of recommendations from different medical specialists that are inconsistent or even conflicting.

Not only medical specialties may skew the information given to patients, the financial drive may also bias that information. Healthcare services are a profit-making business in the United States and doctors have financial incentives. “The other thing you need to know because I am a hospital guy,” one panelist said that you cannot make it run “if you cannot tie this to a way that is acceptable to the professional community and also reimbursable for what they do.” A doctor would be discouraged “if he did it without a lot of data to support it, or he would not get paid for it.” So, there is always “a financial component” in it.

“Surgeons are going to be biased towards a surgery, radiologists are going to be biased towards radiation,” one panelist said, “And both of them skew the data on the reality of side effects.” It is essential for patients to make decisions based on data that are as much as unbiased as possible. From the patient perspective, data collected directly from patients are the least biased because the patients are the people directly inflicted with cancer and needed data the most. This has forced some patients to seek information outside of the healthcare system, as another panelist said that “sharing the experience with other guys outside of the healthcare system has been really a big help for me.”

The information from medical professionals could be incomplete or inaccurate or biased because medical professionals are also lacking direct and personal experience with the disease. The data that medical researchers have been looking at do not show much
about patients, according to one panelist. He told a story that in a research committee meeting when one researcher was recommending that patients should take five biopsies, the committee leader asked, “Wait a minute! Wait a minute. If anybody here has had a biopsy?” “They all didn’t know,” the panelist said that those researchers didn’t know how interruptive the biopsy process is that patients have to go through. While medical doctors see patients, as another panelist commented that “most researchers don’t ever see a patient.” Without direct experience, it became hard for those researchers to transfer the knowledge in science into the application to the patients who are the ultimate goal.

While medical doctors are legally obligated to get informed consent from patients before going ahead with the treatment plan, the patient’s signing of the consent form does not mean patients understand all the information, and most of the time the signing is more of a ritual. In reality, doctors cannot feed the knowledge into patients’ brains, but patients have to engage themselves to absorb the knowledge. Merely a physical delivery of printed material containing the information doesn’t guarantee that the patient would comprehend the knowledge.

Because of that some key information is not well provided to patients during their office visits with medical providers, also because those patients are not well prepared to receive such information at the time, patients look elsewhere to find the information they needed, mostly through the Internet. However, the Internet is a place of all good and bad information, and patients who cannot differentiate between good and bad information fall into unapproved therapies named alternative medicine. These alternative medicine therapies may not necessarily hurt their health directly, however, since their treatment
efficacy has not been approved, it may waste money and time and delay the real valid treatment for patients.

Because of the lack in the current healthcare system to provide unbiased information, patients turn to themselves to help each. One panelist said that his biggest accomplishment as a patient was that he had “helped one or two guys find the information they were looking for, either when they were newly diagnosed or when they had a recurrence, and they were looking for where the good places to go for.” The patients’ distrust of the medical society indicates that patients need an independent medical adviser to help them guide through the disease course and an AI health assistant tool could potentially serve the purpose.

Personal Preference for Quality of Life

Medical therapies are not always a panacea that cures everything without any cost, usually, these therapies involve unpleasant procedures and unwanted side effects which patients have to live through. Meanwhile, doctors who are treating patients with the therapies that they have designed and evaluated to be effective do not directly bear the physical, mental, and social burden that patients endure during the disease course. Without the direct experience of the disease burden, what doctors can do is to observe patients as an outsider on the facts that can be unmistakably observed, such as alive and dead. Consequentially, medical solutions often favor observable outcomes, such as death rate, survival time, the disappearance of cancer, etc. Other values that influence patients’ daily lives, such as personal preference for life and quality of life, are often overlooked or paid less attention by the medical society. Not necessarily do medical professionals intentionally ignore patients’ personalized selectivity of life, they are just not in the shoes
of patients and cannot feel what patients are experiencing, and they do not have the same
taste of life as patients and cannot perceive the preference priorities that patients pursue.

In the following text, I am going to articulate how stressful prostate cancer
patients are bearing the burden of the side effects of their treatments. The prostate cancer
patients’ complaints reflect their demands for pursuing a better quality of life and their
preference for their lifestyles that have not been well-addressed by the medical society.

Urinary incontinence and erectile dysfunction (ED) were the two major side
effects of prostate cancer treatment. This is why many prostate cancer patients must make
a very important decision, choosing a treatment option between surgery and radiation
when they are first diagnosed with prostate cancer. Just one of the panelist said, prostate
cancer is often not about the cancer treatment itself, it is about the side effects of the
treatment. In the end, patients will bear all the burden of these side effects that will affect
their lives significantly. To make it worse, many prostate cancer patients were not even
prepared for their side effects. They did not even expect that the side effects are so
troublesome because their urologists did not honestly tell them.

Incontinence happens when patients lose their bladder control and leak urine, and
it was the most frequently mentioned side effect of prostate cancer treatment. “Obviously,
my biggest hindrance is this incontinence,” one panelist said, “And I don’t think I’m the
only one that has ever said that.” While incontinence is not fatal, it significantly reduces
the quality of life of prostate cancer patients. Another panelist, who had been severely
incontinent, said that he had to “change a pad probably five to eleven times a day”. “They
are stink,” he emphasized, “And those are life-changers, game-changers.”
While incontinence could be a life-changer for patients, surgeons rarely pay much attention to it. As one panelist revealed, surgeons even do not do well in defining incontinence. “Many of these surgeons think there is no clear definition of what incontinence is,” the panelist said, “You talk to surgeons, well, if you need to use more than two pads a day then you have incontinence.” The panelist disagreed with this definition and said, “Depending on your lifestyle, your age, and your activity, it is indeterminable how many pads you’re going to go through. On a good day, it is zero, on a bad day, it is seven.” To care about what is good for patients, the panelist suggested doctors must start by being more serious and honest about incontinence.

The other main side effect, ED or impotence, is a more privacy and intimate issue for men. One panelist said that he had taken a radical prostatectomy and the surgery itself was successful and the cancer remained undetectable. But, he said, “Unfortunately, the side effects, primarily sexual side effects were not what I had been led to expect. I developed clinical depression, and I didn’t really even know what was going on with that until I became suicidal.”

Depending on different treatment outcomes, prostate cancer patients also had to undergo continuous monitoring and additional treatments after the initial surgery or radiation. Some patients do not have prostate cancer anymore, some of them still have cancer but are completely within the prostate and have not gone out yet, but some of them have cancer come back. One panelist experienced recurrence, the comeback of cancer with rising PSAs, and the cancer spread to other places, and he had to take the androgen deprivation therapy (ADT). For prostate cancer patients, ADT is a hormone therapy to lower the levels of androgens made in the testicles which stop or slow the
prostate cancer cells to grow. It is sometimes called medical castration and it causes side effects of reduced or absent sexual desire, ED, and shrinkage of penis. The panelist said he had undergone multiple procedures including penile plant, advanced pelvic sling, breast reduction surgery, and augment treatment with the estradiol patches to mitigate the side effects of ADT.

The side effects of prostate cancer treatment not only affect patients themselves, but also affect their wives. “Prostate cancer is the couple’s disease,” one panelist said, “It is said that a million women suffered from prostate cancer.” Prostate cancer has “a huge connection to our masculinity and intimacy”, and it is not just the problem of survivorship. Patients who suffered side effects need to be “referred to a therapist who specializes in that gives us comfort and knowledge.”

Many prostate cancer patients did not expect these side effects after treatment, and they complained that their doctors did not honestly tell them in advance. “An area that seems to be very consistent, particularly with the newly diagnosed people is a lot of doctors downplay the side effects of the treatment for whatever reason,” one panelist said, “Bluntly, they just are not honest about it. Particularly when you are looking at prostatectomy, you are going to have an incontinence issue.” The panelist continued to complain the patients were often unprepared for the side effects because of the inaccurate information they received from their doctors, “many people were shocked to find out they had ED problems after they had surgery. They were expecting maybe some little difficulty, but that they would overcome it quickly. And in some cases that is true, but in an awful lot of cases that is not true at all.”
Another panelist said that after a robotics surgery, he underwent physical therapy for about a year and a half trying to regain the control of the bladder. “The numbers [of medical test results] look good. But I was severely incontinent and severely had leaked out dysfunction.” “So at that time I made a decision to have a penile implant and have my first and now second artificial sphincters implanted.” The artificial sphincters supplement the function of the natural urinary sphincter which is a ring of muscles that restricts urine flow out of the bladder.

The taste of life, the way of life that patients prefer to live with, is another dimension of progressive health demands. Just as everyone has a special taste in life, different patients may have different preferences for their body functions, and these preferences cannot be precisely addressed by standardized clinical guidelines. But doctors might have never experienced what patients are experiencing. Honoring patients’ personal preferences requires the healthcare system to be more oriented toward patients’ demands, and it goes beyond the scope of patient-centered care framework. This gives a reason to introduce patients into the medical research and regulation activities that are traditionally dominated by medical professionals. Patients can drive medical service toward a more patient-valued direction and mitigate the ignorance that medical professionals have made. Patients can be a driving force to straighten the direction of the healthcare system in the United States and push its reform to adjust and tailor its services to meet patients’ demands. In this sense, an AI assistant tool will a good self-learning tool for patients and prepare and facilitate patients entering the arena of medical research and regulation.

Seeking Optimal Care
The third demand of progressive health demands is seeking optimal care where patients are not satisfied with the standardized routine care the current healthcare system provides and are looking for the best care the system can offer. They want to go to the best hospital to see the top specialist using the most advanced medical technology. Here is a typical example of seeking optimal care from one of the prostate cancer panelists. He said that he “was not happy with a standard transrectal biopsy, so we ended up finding a doctor that would do a transperineal biopsy.” A prostate biopsy can be performed through the transrectal approach where a needle passes through the rectal wall, which poses a risk to inoculate the prostate with rectal bacteria. On the other hand, during the transperineal approach, the needle passes through the perineum which causes much less infection. This patient was lucky that he had the knowledge and the resources to take the advantage of new technology. However, under the current healthcare system that is fractured by medical specialties and is operated by medical doctors with differing knowledge and skills, most patients cannot find their optimal care. In addition, patients’ pursuit of optimal care has been hampered by evolving medical knowledge and practice and the uneven distribution of medical resources.

Medical specialties allow professional practitioners to narrow down their focus, dig deeper into one disease or procedure, and provide the top services to patients where they are needed. While multiple medical specialties give patients more options, they also pose a burden on patients that require them to find the best specialty to manage their diseases. In the prostate cancer patient panel discussion, almost all panelists said they met and discussed with at least two medical specialists: one was a urologist who often also was a surgeon, and the other was a radiation oncologist. During the early time of
diagnosis, prostate cancer patients were often “bouncing back and forth between” their urologists and radiation oncologist. But the two specialists may provide different and incompatible treatment options. Surgeons often recommend radical prostatectomy, and radiation oncologists often recommend radiation therapy. Because hospitals provide services fractured by specialties that specialize in their specific area, and their opinions are biased toward the technology of their specialties, patients need special knowledge and skills to communicate with the different specialists, distinguish whose suggestion is better, and make the right decision to treat the disease.

In addition to steering between multiple medical specialists, patients need to identify the most qualified doctor to see. Although medical doctors have to pass a very strict and high bar to enter their profession, and the medical society has been working hard to maintain the high quality of every licensed practitioner, their knowledge and skills vary due to their training, working environment, personal effort, and working experience. Several prostate cancer patients show distrust in general urologists or community urologists during the panel discussion. The weaknesses in the medical community as prostate cancer is treated, one panelist said, is that urologists were no longer qualified to be involved in prostate cancer treatment today. Another patient held the same opinion that patients should go to the right oncologist, not a urologist. He said, “Urologists in the community think they can treat metastatic cancer. They really should not be allowed to do so, because they are just not qualified. They do not understand the mechanism of prostate cancer. They do not understand the drug interactions and what they should do, which drug first, and combination of drugs.”
Individual doctors may not be able to catch up with all advances in their specialized field of medicine, and different doctors have different levels of expertise in their fields. To guarantee medical practitioners provide high-quality services, the medical society has been building clinical guidelines to guide every medical provider’s practice based on the idea of evidence-based medicine. Clinical guidelines have been very successful in improving the overall quality of medical practice. However, medical guidelines are not precisely accurate to catch every detail for every patient with every disease; they are not necessarily punctually updated to catch every ongoing medical advancement, and; they also have plenty of leeways that medical experts do not agree with each other or are uncertain and left for practitioners to deviate. Clinical guidelines cannot uplift every medical doctor’s knowledge and skills to the levels of their top peers, and medical doctors cannot practice their profession optimized for each of their patients.

Also, some medical knowledge and experiences cannot be covered by clinical guidelines. Only those specialists in top academic hospitals have the chance to see many different kinds of patients in their specialties and acquire their peculiar experiences, but their knowledge and experiences cannot be automatically and instantly conveyed to community doctors who have a limited chance to focus on one disease. The majority of patients only can see doctors who are accessible to them and do not have the chance to be advised by top experts in the United States. One panelist said that most doctors see patients by rules and have a problem handling individual exceptional cases. “You would have a problem if you have a rare type of cancer,” he explained, some hospitals and doctors may never have some type of rare type of cancer patients.
Medical opinions are not always consistent among medical professionals, and this causes patients to distrust the medical provider community. The prostate-specific antigen (PSA) is a primary tool to screen for prostate cancer and there was a controversy about how to use the tool. The 2012 United States Task Force recommended that certain individuals do not need PSA tests, especially over 70 and less than 59.\textsuperscript{82} Regarding this recommendation, one prostate cancer panelist said, “I think that does a disservice to many patients in the community.” He said that one patient was told by his primary care physician, “You are too old to have a PSA test. Don’t worry about it.” The patient was 70 years old and he finally said “I pay it for myself” and got the test. Regarding the disarray of PSA testing guidelines, another panelist said, “I think the more fundamental issue is that the provider community needs to rebuild trust with the patient community and with primary care physicians about PSA and how it is used.” “That involves acknowledging the epidemic of overtreatment when the PSA testing turned loose,” the panelist suggested, “and the fact from the report the task force about the active surveillance bringing the risks and benefits of PSA testing into better alignment.” Another panelist said that the recommendation from the task force is disastrous, “The primary care physicians normally lead into all future treatments for individuals, so they all take the information by the task force to heart which is to the detriment of the patient itself.”

In addition, medical advancement spreads gradually, not instantly. New medical knowledge, even if they are unequivocally better than the old ones, may not be quickly and widely applied by medical institutes as it should be because the application of new

medical procedures involves the cost of both human and capital resources. The instinct of human inertia keeps people working on the older routines, and having less fiscal capability prevents local, small hospitals from applying new technologies. Adding to the complexity, the financial interest of healthcare institutions related to the older medical practice may resist applying the new technology. Since medical providers’ interest is not necessarily in line with that of patients’ best interest, the application of new technology could be hindered by the medical community. The result is obvious that medical technologies, especially new technologies, are not evenly distributed across the country, and are not conveniently available to every patient. The following story reflects how evolving medical technology may influence patients significantly. One panelist who had brachytherapy in 2004 said that if he had the same prostate cancer today, “I would be the perfect candidate for active surveillance, but nobody talked about active surveillance in 2004.”

Medical resources are often unevenly distributed between rural and urban areas. One panelist living in Hawaii said, “And here in Hawaii is definitely like five years behind times.” Because some methods of treatment are not available in Hawaii, he said that so some patients went to foreign countries to take the treatment. “We don’t even have a high-quality imaging here,” the panelist emphasized, “I had to go to the mainland to get my imaging.” He also went to California to have SBRT (stereotactic body radiotherapy) treatment he wanted. Another panelist had a similar experience. He said that the narrow beams of proton radiation therapy which can precisely locate the cancer was not available in the rural area where he lived. In order to have minimal collateral
damage to his prostate when undergoing radiation therapy, he drove to California and spent three months there to take the radiation treatment.

The uneven distribution of medical resources also occurs between community and academic hospitals and often happens for new technology. For example, a multiple-parametric MRI can scan the prostate and produce a more detailed picture of the prostate gland than a standard MRI. “A lot of community doctors don’t use much multi-parametric MRI,” one panelist said, unless you go to large cities or large university hospitals, doctors don’t use multi-parametric MRI. If you have small carcinoma, he explained, a prostate biopsy may not be able to find it unless the biopsy luckily hit it.

Ideally, it is in the patient’s best interest to go to the top hospital, see the top doctor, use the most advanced technology, take what the most recent medical knowledge can offer, and find cures that fit individual patients’ needs. However, seeking optimal care is often on patients’ own efforts, and most of the time the optimal case is only available to those who have economical and social resources. Because the healthcare system itself does not have a mechanism to universally assign top hospitals and top experts to diagnose and treat every patient, patients need to navigate the healthcare system by themselves to get the optimal care which requires relevant knowledge, skills, and resources. One of the prostate cancer panelists said that recently he found a place to do salvage radiation for his recurrence in an advanced academic hospital in a big city. The therapy used cyberknife treatment to target the tumor. This panelist was lucky because he successfully found the best optimal treatment for his situation. But not everyone knows that there is a more suitable therapy available over there and has the chance to attain the treatment.
Since the current healthcare system does not have an integral front face to help patients with how to utilize the system, patients need special skills and resources to navigate the system to get the most of it. Without a good guide, some patients may look at alternative medicine, and “off-labeled treatments”, and patients could hurt themselves by using unapproved, non-evidence-supported treatments. Since the current healthcare system is not equally conveniently available to every patient, an AI assistant tool could be a good help for patients to find the best doctors and best hospitals and weigh different opinions from different medical providers.

Chapter VIII.

Power Patients

“We are going to do a dance with it [cancer]. And we’re going to smile. We’re going to enjoy life.” ---- A prostate cancer patient panelist

I have been thinking to find the best term to describe those patients with whom I met during the panel discussion. They are smart, they are knowledgeable, they have demands, they are willing to help others, and they contribute to the society of their people. And finally, I borrow the word from the term power user and end up using the term power patients where a power user often refers to a user who uses advanced features of hardware or software of computers or electronic devices.

The term power patients could be considered as a consequential result of patient-centered care or empower empowerment, but its meaning contains a more self-motivated tone than the passive tone as a receiver embedded in the concepts of patient-centeredness
and empowered patients. The concept of “patient-centred” is no longer enough, Michael L Millenson suggested an umbrella term “collaborative health” to describe the trend of the transferring of power “in which the traditional [healthcare] system loses some of its control.” By using the term power patients, I am standing from the perspective of an average person who could be a patient anytime and referring to the driving force behind this power transfer.

Who Are Power patients?

Power patients are mentally strong to make critical decisions regarding their lives and take responsibility. They want to manage the disease by themselves, valuing a high quality of life not only survivorship. They do not fear death and are willing to take the consequence of their treatment decision. They realize their values as a person, voluntarily help other patients, and participate in prostate cancer related activities.

Power patients are knowledgeable, well educated, and have good judgment. In the prostate cancer opinion survey, all survey participants reported having more than a high school education. 15.3% of them were college educated, 37.5% of which had a bachelor’s degree, and 47.2% of which had a master’s degree or higher.

The survey also shows that 41.7% (95% CI 31% – 53.2%) of them believed they have at least 50% of the knowledge their doctors have. There was a significant number of patients, 13.9% (95% CI 7.7% – 23.7%), who believed that they have the knowledge equivalent to or more than their doctors.

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Power patients are those patients who judge their doctors’ decisions. The survey shows that 72.2% (95% CI 61% – 81.2%) of the participants reported having ever judged their doctors’ decisions regarding prostate cancer using their own knowledge. Those are patients who have dared to use their own reason. In his “What Is Enlightenment?” essay, Kant argues that the key barrier to enlightenment is to not thinking for oneself, and he pointed out that the way to overcome this barrier is to “dare to use your own reason.” Patients who are not thinking for themselves self-imposed barriers that prevent them from getting the best healthcare. The first barrier is not-to-know when a patient assumes someone else, could be the caregiver, a doctor, or a book (in a format decorated with authoritative flavor), understands patients’ physical disease, the underline social-economic situation, and their real needs. Consequently, the patient feels no need to know about the disease. The second barrier is not-to-be-conscious which assumes someone else has the conscience to discern what is right and what is wrong for the patient. Consequently, the patient would assume that doctors would always hold a high moral standard and know exactly what is right and what is wrong for the patient, and protect the patient from any risks. The third barrier is not-to-make-decision which assumes someone else can make the decision or should make the decision on the patient’s health-being. A patient must overcome these barriers to become a power patient.

Power patients want to contribute to the collective welfare of their community, and they are willing to be involved in research. The survey shows that The survey participants expressed their high motivation to be involved in prostate cancer related activities, and were willing to dedicate a specific time to such activities. 45.8% of them

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84 Kant, “An Answer to the Question: What Is Enlightenment?”
said they were willing to spend 10 hours per week in the next six months to spend on learning knowledge about prostate cancer or participating in related activities. When asked how they would weigh the importance of different prostate cancer related activities, on average, the survey participants weighed helping other patients as the highest importance, as they would like to allot 23.8% of their dedicated time to help other patients. The next preference was for learning new knowledge about prostate cancer, as prostate cancer patients reported wanting to dedicate 20.9% of their allocated time to doing so. The patients also have a high interest in managing their symptoms and treatments by themselves and would like to spend 16.8% of their allotted time. They wanted to spend 11.4% of their dedicated time participating in medical research being a role of patient. They wanted to spend 4.2% of their time conducting medical research being a role of an investigator, and 6% of their dedicated time involved in regulation-related activities such as drug approval or public policy discussion. The participants of prostate cancer patients also were willing to contribute to their community. They are dedicated, committed, and determined that 85.7% (95% CI 74.3%-92.6%) of them were willing to volunteer to work 10 hours per week with zero monetary compensation.

Despite being physically or mentally impaired by the disease, power patients are strong enough to engage themselves in activities of disease management. Just as one panelist said, "What doesn't kill you makes you stronger." Being powerful, these patients want personalized treatment according to their specific situations and their values. Here is an example of how a patient managed his disease care by himself. One panelist said that he got his general practitioner to supply all his cancer drugs. After the general practitioner retired, the panelist tried a couple of doctors for the replacement, and he
finally had a general practitioner again providing all his drugs. He suggested that patients should “have to find people that are willing to look at things differently and openly to have a chance to get the best treatment for yourself.”

In addition to survivorship, power patients value their quality of life. “I think you need to balance longevity with quality of life,” one panelist said, “So you treat the cancer, do your best to treat it. And you can end up with side effects.” One panelist even expressed this idea more explicitly, “When we really can’t fight the cancer because the odds are we aren’t going to win. I mean it is when it is advanced. We are going to do a dance with it. And we’re going to smile. We’re going to enjoy life, and we can learn to dance a little bit. And maybe sometimes treatment comes along we can stop it. But until then, let’s treat, let’s treat the side effects as best we can. So the quality of life is important.”

Some patients also expressed that they were willing to take the responsibility resulting from their decision about the treatment option. One panelist said he did not fully understand the consequences of the treatment option decision, but he did not regret it. The panelist said, “I went through a lot of discomfort and displeasure. But if I had to do it over again, I’d do the same thing. I’d make the same decisions. I’m comfortable with what I did.”

Being a patient is not only a meaningless experience, some patients found value in being a patient. One panelist said, “Because we have experienced something. Nobody else understands it totally unless they have experienced it... I think researchers need us. We are the heart and soul of the research.” The panelist said, “Researchers are not doing it just because it is research. They are doing it because they care about it. It is an
interesting dynamic.” Patients also expressed that “Patient-centeredness is very positive. It will come out with a degree of validity.

Power patients want to help other patients using their knowledge and individual experience. One panelist said he runs a USToo group and has served on eight panels for the congressionally directed medical research program in Washington. In addition, he attended conferences for professional urologists. He wanted to help men “make the right decisions on the first treatment, and then for any kind of metastatic prostate cancer, and try to get them to the right doctors.”

Several panelists had experiences involved in the medical research of prostate cancer, playing roles as researchers and regulators. One panelist had been on a federal research committee, explaining that now committees evaluating those studies granting federal dollars are required to “have one or two consumer advocates, that is someone of patients on each committee.” Compared to medical professionals, patient committee members usually rank different components of the study. The panelist said that patients’ evaluation is not from the scientific perspective, but patients’ value.

Compared to engaged patients or empowered patients, power patients are self-motivated, most of them are physically, mentally, and socially capable to pursue their needs. They can be a driving force outside of the medical society to reform the healthcare system.

Patient support groups

Power patients are socially capable and they build support groups to help their fellow patients. The prostate cancer patient support group is a great place to learn knowledge that is very helpful for patients. The support group provides a unique
irreplaceable comradery environment that hospitals cannot provide. It gives the venue for some patient leaders to pursue their value to help others. It also functions as a link and connection between medical companies, researchers, and patients and has been accepted by the medical society. Meanwhile, it has its limitation that it cannot reach all the patients.

Many panelists said that they benefited a lot from the patient support group. One panelist said, "With me, every time I go to the meeting, I learned something different. The group brings in a speaker every month you were there, once a doctor. That's really helpful because then you get some good medical opinions and advice on what's current and what's going on and what you might do for the very side effect you have and that's been a real help too. So, it's kind of learning experience and ongoing learning experience." Another panelist argued that the group offered support outside the medical expert, "You get diagnosed, you read what you can, you talk to what you believe are experts, maybe you get second opinions, but the support group experience is very very helpful too." The support group could also provide mental support. One panelist said that the support group helped him get out of depression from the sexual side effects after surgery. And that made him an advocate for prostate cancer patients.

Another panelist said, “I didn’t find the support group until after treatment. That is extremely helpful. It is a really good group both from the sense of emotional support and technical information about prostate cancer.” The major thing that he applauded for the support group is that “guys being supported and guided to the right treatment or careful consideration of what is appropriate for them.”
Patient support groups provide knowledge and experience that the current healthcare system doesn’t offer. One panelist said, “You went to one of our meetings and meet some guys who really know more about prostate cancer than any physician you ever know.”

Patient support groups have a unique environment that hospitals or medical professionals does not have. One panelist said, "So you know sharing the experiences with other guys outside of the health care system has been really a big help for me.” Another panelist said, "I went to it quite a bit before COVID, you know, in person monthly. And you're sitting next to guys that have had, you know, similar treatments or other treatments, but yea, the comradery, the bonding with other guys, sitting right next to you is priceless.” He continued, "So the support groups put you with people like yourself. You know, that are in the same boat, not doctors, but you hear real life stories." Patients emphasize the importance of the information for other patients experiencing the same disease. In support groups, “you can get some information from other people that have been down the journey,” One panelist said, “It is not all doom and gloom and death. It is not all about what a doctor says either. It is about you know what humans and individuals that walked in those shoes that can share knowledge.”

A patient support group is also a place where some patients can pursue their values to help others. When talking about one of the biggest accomplishments as a patient, one panelist who has been involved in a local patient support community said, “I guess the biggest accomplishment as hopefully somewhere along the line helped one or two guys find the information they were looking for, either when they were newly diagnosed or when they had a recurrence and were looking for the good place to go for.”
When asked about emotional support and dynamics in patient support groups, one panelist said that patient support groups do “information sharing of survivorship journey of prostate cancer patients.” Something could be formally called “Emotional stability information”, like “someone hands you a little book”. Another panelist said, “Talking about emotional support, the psychology of managing cancer is a separate thing from treatment.” The support group is like a whole package, and the heart of it is that. “There is a lot of research that shows people who feel supported and have others that they can talk to and can open up can do much better.”

Patients experienced a unique connectedness in patient support groups. One panelist told a story about the importance of connectedness. “I still remember a physician coming to our group and making a presentation. He was a urologist, and he was talking about this stuff and one of his topics is ED. He closed his computer and he looked up. He did not have prostate cancer, but he said, ‘I have ED.’ And the connection between everybody in that room. And he became extremely supportive. Because probably for the first time ever that a physician was able to talk to other men who experienced that.” Another panelist said, “met a bunch of men who would share more of what is really going in their lives.” “What happens here, the reasons, it is positive, supportive, educative, and advocacy.” “It is safe, no one wants to go some place, especially men, to share information where it is not safe.” Because one of the major side effects of prostate cancer is ED that “most guys would like to shy away.” For the side effect, “a lot of guys don’t do well emotionally after this. And there may be a lag in the mental health part of those prostate cancer survivors.”
Patient support groups also function as a link between patients and researchers and pharmaceutical companies to help them find the patients and conduct research and trials. Being organized patients, they share information about clinical trials and have a high motive to participate in trials that are related to their diseases.

Physicians are now more accepting of patient support groups and are “more than ever before referring their prostate cancer patients to legitimate support groups,” according to one panelist. He explained, “They weren’t used to doing that. Because they know that when they go out of the medical component world and start doing all their research stuff, they know there has to be another dynamic. That is the human dynamic, to get together with other people and share their experiences. And that is real stuff.”

When asked about the limitation of the prostate cancer support groups and the difference between patient group members and those non-members, one panelist said that there are “people that are able to go out and talk to people and interact with people.” And those people who don’t do support groups “just depend on their doctors and their family,” the panelist continued, “And I don’t think it is good. If people don’t have a positive attitude then their cancer is going to be much worse. If they don’t learn how to protect themselves and work to help themselves, then they are going to be much worse… And if they become discouraged or afraid, that is not good.”

“Maybe with AI, you can reach more people that support groups.” Because of COVID, many support groups are going online, and patient support groups cannot reach those people who don’t interact online, especially older people. In comparing prostate cancer patient support groups with other patient groups, one panelist said “we always compare ourselves to the pink ladies. Women under the dynamic of coming together as a
community, sharing, and understanding. Men are still kind of out of there, kind of flying in their own plane.” The Pink Ladies is a women’s group who are undergoing breast cancer treatment and want to contact others in a similar position.\textsuperscript{85}

Prostate cancer is a slow-growing disease affecting mostly old men with a lot of survivors. It creates a special situation where patients can organize themselves and build an active patient community. Other diseases, such as short-course diseases and acute diseases, diseases that significantly hurt patients’ mentality or intelligence, may hard to have sufficient active patients to form active societies to advocate for themselves where patients’ family members and carers can play the similar role.

Patient support groups are free and accessible to everyone. They function not only to help their members but also to organize themselves to become an unignorable political force transforming the healthcare system.

Chapter IX.

AI Health Assistant Tool

“\textit{Definitely, medical doctors are trained to, you know, diagnose and treat things. They learn everything in college. Very very smart people, doctors are very smart people. But God, sometimes you got to go beyond that. And I wish they would branch out a bit. But you know they are stuck in their little world, and it is what it is. So artificial intelligence maybe is a damn good idea.”} -- A prostate cancer patient panelist

To support their progressive health demands, patients need an AI tool to overcome the barrier of information overload and assist their decision-making. Their information needs cannot be fully satisfied by the healthcare system due to its functional inability. That is why patients have a high acceptance of a non-human AI tool to help them. They have high expectations for the tool to function as an information collector, synthesizer, and organizer, and want AI could be engineered like an expert system to help them. They believe that AI has its advantages over human medical doctors. Particularly, patients want direct access to the AI tool that is designed to support patient directly, and they strongly oppose the idea that the medical AI tool is accessed through the intermediary of medical doctors.

Expectation for AI

During the panel discussion, prostate cancer patients voiced their expectations for an ideal AI tool that could help them the most, particularly to help them get the best treatment. They expect the AI tool to be able to interpret medical terms, collect data about facts, synthesize and organize the most recent diagnostic and therapeutic advancements, and give patients the whole picture about the consequence of the treatments. Patients want the AI tool to tell the truth that doctors may not like to say due to uncertain information or due to legal or financial considerations. In addition, they expected the AI tool to be user-friendly and comply with scientific principles.

From the patients’ perspective, the AI tool should be able to explain and interpret medical terms and help patients become an expert. For example, it should be able to explain the Gleason score system, one panelist argued because “the Gleason score is very important and it determines basically what you should do.” Another panelist further
explained that AI should help patients “read scientific data without being a scientist.”

Because patients are kind of haphazardly doing it.

During the prostate cancer patient panel discussion, one panelist said he needs the AI assistant tool to condense different information, distinguish good and bad information, and supply information that could not be acquired from doctors. “I think what we struggle with as patients is condensing a log of information from a lot of different resources.” He said, “And the sources that are most valuable to us happen to be the physicians who are treating us, the urologist, or the oncologist, or the radiologist, and whatever-ologist. And they are filtering through and sorting a lot of information that would be valuable to us.” He also wanted that the AI tool to be able to speak in a patient understandable language, like a “layman’s book”. This is a desired feature that will facilitate patients to grasp the information needed to support decision-making to pursue their progressive health demands. Particularly, a handy AI tool is much needed for prostate cancer patients. Because what happens to patients, according to the panelist, “the difficulty of surviving prostate cancer is not the cancer issue. It is usually the treatment that we select to fight that cancer. And it is a big challenge on what to do.”

The main purpose of AI is to serve as a decision-assistant tool in evaluating different treatment options and help patients get the best one. As one panelist explained, “The main thing for AI is to get rid of cancer, or give yourself the best chance.” They are going to be side effects, and avoiding the after-effects is the secondary goal.

Prostate cancer patients’ need for the AI information tool reflects the structural deficit in the current healthcare system that fails to support patients’ desire to become knowledgeable patients. As the prostate cancer patient opinion survey revealed, on
average, one prostate cancer patient talks with his doctors including all medical professionals five times per year. Assuming thirty minutes per meeting, it is about two-and-half hours per year. This amount of time can merely cover the delivery of medical instructions and responding to a few questions. It is far away from enabling a knowledgeable patient to decide what is available to him and what he really wants.

The AI tool that can differentiate credible online information will help patients significantly and save a lot of time for them. Just as this prostate cancer patient opinion survey revealed, more than 90% of patients had sought information outside their medical professional providers. Mostly, patients look for information online. However, it is not always convenient and intuitive to get the information they needed. “You try to search the stuff on the Internet and you’re going to get a bunch of porn sites,” one prostate cancer patient panelist said.

To make the right decision, patients need to know what will happen to them after the treatment, including recurrence and side effects. Such information, using one panelist’s experience as an example, is to know the exact probability that cancer will come back after treatment. He said that he guessed that he had a 50% chance of recurrence based on his reading on the outcome of his robotic prostatectomy, including information that there was no lymph node involvement and clean margins, etc.

Another panelist also expected the AI tool to provide facts based on big data about what will happen. For instance, many people will have ED problems after prostate surgery, but most patients do not have such information before surgery. During prostate cancer surgery, the panelist explained, some people could have their nerve bundles cut. “It is unlikely to not happen,” he said, “I mean you got to be some magician not to have
that happen. Who the hell knows that. They (surgeons) don’t tell you.” He continued, “It will be good if the AI tool could collect big data, for example, for ten thousand robotic operations, how many of them have ED problems. That is the information needed in a big decision maker’s mind, he needs plenty of data to make good decisions.”

One panelist who was an engineer and had experience developing an expert system suggested that the AI assistant tool should have a huge database where the AI can “pull information together to try to come up with answers for patients, or answers for doctors and researchers in future.” It should not only be doctors who should “submit their reports, symptoms, test results, diagnostics” into the database, but patients should provide information to it as well. The AI system should be a constantly advancing system that uses new information and takes corrective actions to fix problems such that the system “continues to grow as it is being utilized.” The AI tool should not be a static product, it should be an ongoing living organism.

Another panelist also expected that AI should tell the truth and provide unbiased information because urologists might give biased information. “It has to be a source of information for anybody going through, this is number one,” the panelist said. But it has to be “outside of a urologist,” he continued, AI should “give you the information needed right and tell you the unbiased information of what’s going to happen to you, what’s the real percentage of people that are ED, what’s the real percentage of leakage, and not just one or two pads maybe.” The panelist thought that AI should “got to tell somebody, hey, you’re going to leak.”
AI may be more able to provide a specific treatment option for an individual patient based on his genetic profile, cardiac profiles based on the up-to-date results from MRI imagings, biopsies, etc., and give proper treatment suggestions, one panelist said.

Prostate cancer patients also expect the interface to AI be user-friendly. Some patients know how to do the techy stuff, but many patients do not know that stuff, one panelist pointed out. Many computer, Internet, and phone applications often require patients to have some skills to utilize them. The panelist said, “You are going to make the interface of the AI easy for the patients to use. They are not very savvy.” In addition, we should figure out how AI could communicate with different audiences, another panelist suggested, because “it has taken me three months to even get my computer work.”

AI could function like a “virtual navigation” and help men specifically, according to another panelist. “Being proactive enough to do outreach in education, providing treatment options, mitigation of the side effects, having real-time input such as oncology type,” the panelist explained, “Men are bad about talking to men.”

Another panelist hoped AI is “going to be close to a real person to answer questions, provide a real-time resource for people and help make their decisions, get them in a safe private environment to ask questions.”

Prostate cancer patients also expect that the AI tool should know both general science and specific subject knowledge about prostate cancer. In a scientific panel, there is often a scientific control officer who are MDs or PhDs, one panelist explained. “So they’re there to maintain the scientific method and make sure the panel is going along with the way the scientific method should do.” But they do not know anything about
prostate cancer, he continued. However, as an assistive tool, AI should know both the scientific rules and also specifically know as much as possible about prostate cancer.

Advantages of AI

Interacting with an AI machine will be a totally different personal experience than with a human doctor. If one does not have an intuitive understanding of AI machine’s advantages, one may ask himself or herself about the following questions, these questions are often considered by patients whey they see doctors. Do I need health insurance to talk to the AI machine? Do I need to make an appointment with the AI tool? How long will I wait to get an appointment with the AI assistant? Do I have to take one day off to see the AI machine? How much should I pay for a 30-minutes communication with the AI assistant? If I cannot understand the answer, can I ask the AI machine to explain the answer again? Will the AI machine give me a prescription that I cannot read and I need to find a human doctor to interpret it for me? Do I need to review the AI assistant’ patient feedback on Google first, if the machine scores over 3.5 on a 5-points scale, then I will decide to see the AI machine? Do I need to worry about if I ask too many questions and waste the AI machine’s time? Do I need to worry if I say something wrong that would make the AI machine unhappy?

AI’s advantages not only include its convenience in usage but also its superb capabilities. Because of computer’s astronomical computational power, unlimited information storage capability, and fast and complicated modeling algorithms, AI has shown and been believed being more superior to human brains in many aspects. During the prostate cancer patient panel discussion, patients discussed many aspects of AI’s advantages over human doctors. The panelists argued that AI has much more
computational power than human brains; it can handle much more complicated cases; it can synthesize knowledge and opinions from different medical specialties and provide less biased opinions; it learns fast and can provide up-to-date and consistent highest quality medical expertise, and; it has potential to reflect patient’s value from patient’s perspective.

Notably, one of AI’s advantages is that a computer is much more powerful than a human brain. It is very hard for a human to digest all information. Comparing a researcher and an AI, the research just doesn’t have the power that a computer does to put all things together, as one panelist argued, “He sees a small snatch of whatever he is looking at or doing, and there is a great deal of information out there.”

Because of its superior computational power, AI can function better than humans in synthesizing complicated information. Humans have a very complicated biological body, and diseases add to the body’s complicacy. Even the smartest people cannot comprehend the human body and diseases in their full details. Medical doctors such as oncologists and researchers “are brilliant people, but they are all very focused on their particular aspect of prostate cancer,” according to one panelist. “But it is so complicated and there are so many factors in what would be the best treatment for an individual,” he continued, “No individual, no person, no researcher, no doctor can pull that together in their head and come up with the best decision. You really need some automated assistance in order to do that.” Then, he told a story that a guy from his support group went to see a medical oncologist “who is one of the best in the field,” he said, “But my friend actually had to tell him about a clinical trial that is going on. And his doctor heard
that and then looked into it and said, ‘Oh. I think that might be a really appropriate clinical trial for you.’”

AI tool can serve as a centralized location of information for patients, so every one of them has access to up-to-date information. One panelist suggested that everyone must have the access to the most recent information. People who are “sitting at Harvard or even in New York City” do have access to that information, but when you are sitting out in rural areas, he said, “you’re not getting the state of the art of information.” The panelist continued to explain, “The thing that has helped me personally were these PCRI [Prostate Cancer Patient Conference] conferences out in California where one could go once a year and actually find out what was going on and bring the information back.” If AI could put that type of information into something easily accessible format while being timely and accurate, that is probably “one of the biggest needs we have today that is missing.”

AI’s capability to synthesize knowledge may help patients to condense a lot of information in a more efficient way than human doctors. For example, regarding the 2012 task force recommendation about PSA screening\(^{86}\), one panelist said that “the task force now recommends that PSA testing be offered in certain circumstances. I don’t think those circumstances at this point are broad enough and there may be a role of artificial intelligence here in terms of PSA testing.” The panelist believed that AI has a role here to synthesize all information and find whether the PSA testing can bring better treatment.

AI can combine and compare different views from fractured medical specialties, such as urologists and surgeons in the prostate cancer case, and can provide balanced and

\(^{86}\) Moyer and U.S. Preventive Services Task Force, “Screening for Prostate Cancer.”
unbiased clinical information. “Doctors are as everybody, they’re very guarded about their own program,” one panelist complained, “You might have lost sexual function, or you might be incontinent, but the urologist may just say that ‘a couple of Kegel exercises every day and you’ll be good as new.’ I did for two and a half years and I’m still using five or six pads a day.” Another panelist echoed, “If the machine is neutral, probably would be better than a local urologist who has a lot of skin in the game.”

While human doctors inevitably have different levels of medical expertise, AI can maintain the highest level of medical knowledge. Patients always want to see a doctor “who’s one of the best in the world,” according to one panelist. However, this is not necessarily always the case. When a patient goes to another place to see another doctor, often he may get different advice. Also, AI can have a more open mind to looking at new information than doctors, and patients surely will benefit from AI’s open-mindedness and fast-learning capability. One panelist said, “I have to school the people in my support group about how to talk to their doctors so they can get the treatment they need. Because often they do not. They are turned off. The doctor says, ‘I won’t do it.’ You have to find somebody that gets a more open mind.”

Potentially AI could be developed, funded, and managed independently from the medical institutions. Due to its financial independence, the AI assistant tool sits in a more suitable position than medical doctors to provide views from the patient perspective. Honoring patients’ values is the key to fulfilling patients’ progressive health demands. In the case of prostate cancer, honoring patients’ values means not only considering patients’ life expectancy but also respecting their preference for quality of life. Since prostate cancer is slow-growing cancer, one panelist thought he might have “between
seven and eight years of life without treatment for the prostate cancer… If the guy said, men, you got eight years, you aren’t going to leak, you still can have sex. I’m 71 years old, 79 is not bad.” The patient might decide to go without treatment, however, he said that he didn’t get a chance to make that decision. The AI tool has the potential to candidly tell patients a balanced view of life expectations and quality of life which gives patients more options to choose to live with.

The AI assistant tool can be functioning as patient support groups that medical societies are incapable of. As one panelist suggested, AI should be designed that mostly replicates the patient support group where patients can “talk to somebody, who is actually been through the treatment, as opposed to a doctor who probably has never had a prostate cancer, has never contained any side effects and long term effects.” It would be ideal for people if it could “allow you ask anything, get information on a variety of risks and background.” It is absolutely important to make the AI having this functionality reachable to those people who do not have access to the support groups.

The conveniently accessible AI health assistant tool will provide the United States with an opportunity to transform its healthcare system and improve its efficacy. Studies have found that the United States has a surplus of specialists but not primary care doctors compared to other developed countries, and an enhanced primary system is expected to lower the healthcare cost, expand access to appropriate health services, and reduce health inequality.\textsuperscript{87} Since the AI aid provides routine daily decision support for patients, it will also reduce the number of daily routine care professionals and release them into more

needed research works developing new treatment strategies. Furthermore, the self-health-aid system will reduce unnecessary tests and treatments and improve patients’ compliance with treatment options. AI aid, unlike human labor, can service innumerable patients at the same time and therefore will significantly reduce the service cost.

Chapter X.

Challenges ahead in Developing the AI Tool

While there are necessary needs for patients to have an AI tool to serve them, and it is obvious that the AI tool can provide services that the current healthcare system cannot do, however, the ideal AI tool will not be automatically available to patients. It faces many obstacles in its development and application from technical, social, and political sides. From this prostate cancer patient opinion survey and panel discussion, a variety of issues about how the AI tool could be developed and applied have been explored and discussed. These issues include algorithm-wise and functionality-wise design of the AI tool, the scope of consulting services that the AI tool covers, problems in developing the AI tool, how to make AI acceptable, who has the authority and credibility to run the AI tool, should patients have direct access to AI, and how should the AI tool be funded. These issues are challenges that the AI development community and the patient community will face in the future.

Super AI integrating NLP, imaging, and EHR
Given the combined power of computers and algorithms, AI can go beyond just mimicking human intelligence, in some cases it may surpass human intelligence and become a super intelligence. It will not surprise me that in near future an super AI can generate new medical knowledge and guide human medical practice. In most of this thesis, the AI assistant tool being discussed is assumed to mainly use NLP technology to analyze existing human knowledge that has been discovered by the medical society and stored as published papers or medical documents in human languages. This way, the NLP algorithms can distill knowledge from the text and provider support to patients. However, NLP is only one type of algorithms AI can use. In a more generalized setting, AI can also analyze medical imaging data through computer vision, and analyze electronic medical record (EHR) data through algorithms such as graph-structured neural networks. By integrating text data, image data, and medical record data, the super AI has the potential to discover new medical knowledge, or provide suggestions that are based on hidden knowledge that has never been revealed or recognized by the medical society.

Here, the term superintelligence (SI) may be more appropriate than the term AI to reflect the reality that there exists superb intelligence that could be utilized for the wellness of human beings. By integrating multiple sources of medical information, SI can find implicit knowledge and utilize the hidden knowledge to support decision-making. A new challenge in front of us worthing consideration will be how to validate SI’s knowledge findings. Modern societies have developed mature governmental systems, such as Food and Drug Administration (FDA), that have the authority to legally validate and approve new drugs during the process where the relevant knowledge is validated. Similarly, medical professional societies have traditions to accept new findings based on
scientific methods and expert consensus. However, there is no formal procedure to approve or disapprove new medical knowledge. The emerging debate in the medical, science, and even political communities including patient communities is foreseeable about how to assess AI-generated knowledge, and how to regulate an SI that can support decision-making based on unpublished knowledge.

Interactive, adaptive, and living AI

During the time when the AI assistant tool provides consulting support to patients, it also can collect data from patients through interaction. Just as one of this study’s patient panelists said, an expert system can learn from past experiences and improve itself. The interactive and feedback loop makes it possible that AI can be adaptive and evolve by itself, and become a living machine just like a living organism.

The AI tool not only delivers information to users, but also communicates with individuals directly. The feed of medical information from published literature could be managed by a specialty team, however, the feed of information from individual users could hard be regulated by a central commander. The AI tool may ask questions and collect information through human like conversation or through monitoring medical gadgets. For example, health apps, such as Apply Watch, can collect physical information at real time and such information could be later incorporated into the AI system to be considered in decision-making support. The two-way information flow raises ethical and legal concerns about what questions AI can ask users and what information AI can store. Individual users may share private information with the AI tool to support decision making, the distinction between private data and shared public data needs to be clarified.
The AI tool could also improve its knowledge base and algorithm based on the feedback or outcome results from individual users. By observing different users under different conditions and resulting different health results, the AI tool can adaptively improve its decision support algorithm. Also, the AI tool could also actively conduct experiments to examine different approaches to address health problems and observe the results. AI can conduct trials, and experiments to explore the feasibility and efficacy of some interventions. The phenomenon of living AI assistant tool will pose refreshing challenges to medical societies and regulatory agencies.

High-risk and low-risk treatment complexity

The AI assistant tool may support patients’ decision-making that involve different levels of risks and requires different functional designs and legal considerations. Some medical decisions are very critical and consequential that may be pertaining to live and death, such as treatments on root cause that are often beneficial with high risks. On the other hand, some decisions may be mainly beneficial or only affect trivial issues, such as treatments of palliative care. Researchers have had outlined three levels of treatment decision complexity, and the AI assistant tool can play different roles in these situations. At the first level of treatment complexity, treatments are generally beneficial and carry low risk, or when treatment choices are limited. At this level, because the treatment is generally beneficial, less patient cognitive capacity is required to make a choice, and AI assistant tool’s role is less important than in other scenarios. At the second

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level, treatments become riskier and alternative treatments are available. In this scenario, patients need high comprehending competency to make the decision. Hereby, the AI assistant tool could be heavily relied by patients who seek information to make the critical decision. At the third level, an individual would see treatment as the only viable option and the main consideration from patients is to decide accept or refuse treatment. In this situation, the expectation for AI assistant tool’s is exponentially high where patients may expect the tool to give more individual-value-based consulting services in addition to scientific and factual evidences.

Depending on different risk levels of issues at question, the AI assistant tool can be classified into several categories similar to FDA classifies medical devices into three classes based on the level of control necessarily required to assure the safety and effectiveness of the device. The AI assistant tool could be used to support lower risk, or mainly beneficial decision support. For example, the tool can function as recommendation system to mainly encourage behavioral changes, to live a healthier life, to comply with medical instructions, such as take medicine on time or go to physical exercises routinely. Other less critical situations that AI can be utilized without heavy monitoring include general consulting services for nutrition recommendation, whether to see doctors, knowledge and information obstaing, etc. However, in critical situations where may result death or other negative consequences, AI’s function need to be more restrictly assessed and regulated.

While abstracts facts and knowledge and providing suggestions, the tool also needs to have the function to assess the certainty or uncertainty of the suggestion. Decision suggesions could be discrete which the suggestion is beneficial with concrete
evidence and higher confidence. Other times, the suggestion could be probabilistic, where the suggestion is depending on the less strong evidence and lower confidence level.

**Biased Data that Feeding AI**

The AI tool could be biased if the data used for training are biased. A chatbot-like AI health assistant tool that can answer questions should be trained on texts using NLP technology. Here the training data are texts of medical documents, including medical textbooks, published research papers, and clinical guidelines. Existing written texts, including medical documents, may have their embedded racial, gender, and social-economic bias. The language model trained from biased data used has its inherent bias. For example, healthcare needs from lower socioeconomic status patients may not have been as well addressed in medical documents as healthcare needs from upper socioeconomic status patients. Therefore, the suggestion provided by the AI tool may not fairly represent all patients’ needs, and the AI tool could be in favor of more affluent patients, and the bias that implicitly discriminates against socioeconomically disadvantaged patients may perpetuate through the AI tool.

In addition, medical texts are biased because they are mainly produced by medical professionals and lack patient participation. The AI tool trained on data from medical professionals may not be fully representative of patients’ interests. Patients and medical professionals may have different concerns and values in healthcare matters. Some disease-related questions could be very important to patients but less relevant to clinicians. And answers to these questions, even rated as correct, may not fully reflect patients’ values. Since medical knowledge has been systematically documented in texts by medical professionals, it is an urgent need to find credible written documents from the
patient's point of view. To make the AI tool neutral, one of the panelists suggested that “part of the solution to make it unbiased is to blend the data from both patients and doctors. That is the right data.” For example, doctors and surgeons might downplay the side effects and “not share the reality of the side effects of what they’re doing to you”. By including direct experiences from patients, the burden of prostate cancer treatments’ side effects could be well-considered by the AI tool. Since the AI tool could help and improve patients’ medical literacy, the tool could in return facilitate the growth of patient-generated texts in medicine.

AI also requires more complicated cases to handle real-world problems. Patients may have closed-book questions on a specific disease, and also have open-book questions that are complicated. For those closed-book questions, their answers could be directly found in the medical literature. But for those open-book or open-disease-domain questions that are not explicitly included in the available medical literature, their answers must go through logical reasoning based on medical knowledge embedded in all medical documents. Open-book questions and complicated situations are often seen in clinical encounters, they pose challenges for AI's capability to catch comprehensive medical problems and provide sophisticated solutions.

Acceptance of AI

Assuming the AI health assistant tool can achieve its technical validity, will patients accept it and use it? This study shows that prostate cancer patients have a high acceptance of the AI assistant tool. Only 11.1% (95% CI 5.2%-22.2%) said they would never accept advice from an AI machine without consulting a human medical doctor. Nearly half of them, 46.3% (95% CI 33.7%-59.4%), said they would sometimes accept
AI advice without consulting a human doctor. Patients extremely need unbiased and more detailed information from outside the medical society. They respect doctors, but AI could serve as an accessible educational tool, a decision-making assistant, and a second opinion. Patients do not think AI will hurt them being used as a tool, and it doesn’t seem to bother patients much if AI makes a wrong decision because AI is “just for information purposes” as one panelist said.

Patients accept AI because they have seen evidence where AI performs better than human beings. One panelist mentioned that AI had been already used in medicine such as in analyzing biopsy slides. “The number of prostate cancer biopsies that occur every year is going up and up and up. The number of doctors that are going to pathology is actually declining. So that you could use artificial intelligence to look at biopsy slides and do a good job of grading cancer.” He explained, “Over time, the artificial intelligence gets to a point where it is extremely reliable and made the pathologist job a lot more efficient and a lot easier.” Another panelist also believed that pattern recognition in pathology reporting could be a suitable area for AI where AI could read pathology slides and assess the characteristics of cancer accurately in terms of risk levels.

While patients show their high acceptance of the AI tool, they also expressed their concerns about how the medical community would accept AI. The AI health assistant will face resistance from medical professionals because, according to one panelist, one main thing that patients expect AI to do is “bucking the medical system which makes a lot of money on prostate cancer.” This is the reason patients believed that the AI health tool is so important to patients and why patients should use it to their advantage.
Overall, prostate cancer patients expressed their optimism that doctors would finally accept AI and use it. “It is very hard to get the doctors to go off the page that they have learned and what they follow,” one panelist said, “It is complicated and time-consuming for them to get off the page. It is very difficult for them legally to do that.” But AI could also be a good thing for doctors. “An artificial intelligence system would be a great boom to doctors who would be willing to use it,” another panelist said. He believed that although a “whole generation” of “older doctors” might be resistant to AI, the younger generation would be techier and accept AI. He explained that “if we got diagnoses in mid-sixties, we are not all techy necessarily,” but now younger new oncologists, urologists, and radiologists love AI, they love to learn and understand AI.

Patient’s Direct Access to AI

When being asked should the AI tool be used directly by patients or through the intermediary of physicians, prostate cancer patients universally responded that the AI tool should be directly accessible to patients. AI could be applied in different ways for medical purposes. For example, the AI tool could be designed and applied as a medical device that is installed in a hospital and used by medical doctors and other medical professionals. As a medical device, when a patient has a question, the AI machine will answer the question but the answers can only be immediately transmitted by medical doctors to patients because medical professionals are well trained and may be able to filter some bad answers. In other words, the AI tool could be designed as a medical device, so that the average lay person should not have direct access to it. On the other hand, AI could be designed and applied to be accessible directly to patients. In this way,
patients are free to use the tool at their convenience but may take their responsibility to make judgments on what AI suggests and take risks that AI could be wrong.

Despite that the AI tool could be wrong, prostate cancer patients insisted that the tool has be directly accessible to patients. One panelist said, “It has to be the patients. The patients have to be able to see these data from the AI. And it has to patients’ decision.” The AI tool should not be designed only to help physicians because physicians are “going to do what they want to do anyway.” The panelist emphasized, “The tool has to be in the hands of the patient, not the physician, in my opinion.”

Being asked the same question about should the AI tool being accessed by the intermediary doctors, “I don’t need an intermediary guy,” another panelist answered because only the patient himself knows best about his life expectancy and his preference for the quality of life. The panelist explained that “If you have a doctor as an intermediary, you cut the thing up.” He continued, “The idea is that you should be coming from a data-based solution, unbiased. And you know right at the heart of the matter with real and real data.” He said that “As a patient, I would like to know what I was getting into before I got into it.”

Funding for the AI Health Assistant

From social and political sides, AI cannot be guaranteed to be helpful for patients because AI could be misused and abused against patients’ interests. In the development of the AI assistant tool, different funding mechanisms may have different consequences. AI could be funded through a business model like Google, a private for-profit company; or could be funded as a government-sponsored program like Medicare or Medicaid. What kind of business model should be applied in the development of the health AI assistant
tool and what kind of special policies should be made to make the AI tool to be a good thing, not a bad thing for patients? The prostate cancer patient panelists had great suggestions.

One panelist suggested that possible funding sources for the AI tool could potentially be government grants or insurance companies. “If we stop doing overtreatment, doing education, not doing unnecessary surgeries,” you tend to prevent insurance companies to spend more money. By reducing overtreatment, insurance companies might be able to save money, or if we go to socialized medicine, it is a possibility that the government will save the money.

Another panelist mentioned that the congressionally directed medical research program, which gives out a hundred million dollars a year for prostate cancer research, should spend money on the development of the AI health assistant tool. “It’s worth a shot,” he said.

AI could also be financed by prostate patients, one panelist suggested. “I don’t know what the number of prostate cancer diagnosed per year is. But if you figure out that you get 30% of them at a hundred bucks a piece. That is a big number.” Many people will need the AI tool’s information support and the selling point of the AI tool is that it is completely unbiased and tells you what the facts are. The panelist used himself as an example, “I didn’t look at the Internet until after my surgery. What a dummy I didn’t even think about it.” The AI tool could provide annual check-ups for patients and provide crucial information such as when the patient hurries up or should go back after four weeks, AI can support those people who have limited healthcare insurance coverage that cannot afford that information.
Regulation of AI

In addition to the funding mechanism for the AI tool, who has the authority and credibility to run the AI tool in healthcare is a much more critical question. The prostate cancer patient opinion Survey shows that patients have their highest trust in hospitals and patient organizations. 27.8% (95% CI 17.6%-40.9%) of them would accept an AI medical assistant if it comes from a hospital; the same percentage of them would accept an AI assistant if it is endorsed by patient organizations. Prostate cancer patients also show high trust in the Food and Drug Administration (FDA) and medical doctors, 24.1% (95% CI 14.6%-36.9%) of them said they would accept AI if it is approved by the FDA, and the same percentage of them said they would accept AI if it is licensed just like medical doctors. Companies have the lowest trust from prostate patients with 11.1 % (95% CI 5.2% – 22.2%) of acceptance, less than nonprofit organizations, 16.7% (95% CI 9% - 28.7%).

It is important that who is credible to the general public to run the AI and prostate cancer patients do pay attention to who is behind AI. Government agencies, such as CDC or FDA, appear to have lost some of their credibility during the COVID, according to one panelist, because “what they are telling you” “changes every five minutes”. He said that it is going to take a long time for them to build their credibility back. However, the panelist did not give a determinant answer who has the credibility to run an AI system nationwide, “I don’t know the answer to that. But that would be a key factor to consider.”

Irreplaceable Human Being

While AI could be a great help, prostate cancer patients also expressed that the human touch from medical doctors and fellow patients could never be replaced by AI.
Medical professionals’ human empathy and personality could be very beneficial to some patients and some diseases and could significantly enhance patients’ mental health and change patients’ health behavior. This essential irreplaceable human quality that professionally-trained medical practitioners possess is invaluable to patients.

Sometimes, human persuasion is much more effective than a machine. When being asked if AI could be designed to have the capability to build a personal relationship with patients, one panelist said, because of the COVID pandemic, his support group started meeting by Zoom after meeting in person for years. “You could have that artificial system, creating an avatar on Zoom. It would be seen as a person in the window and I don’t know whether it is real or it is some computer-generated anything.” But humans and computers are not the same, “the reason that we are meeting in person again despite the pandemic is because it gives us a whole different feeling,” he said, “Being in a room with somebody is very very different from interacting with them over a computer.”

Chapter XI.
Limitations and Future Directions

This study was designed with a relatively small sample size with a convenient sampling method for a specific disease from an online patient community. It was not intended to obtain information that represents the whole population of prostate cancer patients, rather, it was designed to obtain insightful perspectives from one patient community. The results and conclusion from this study are expected to provide revelatory views for policymakers to consider and to construct exploratory concepts and phenomena
for future researchers to investigate. This study tries to use prostate cancer as an example of disease and prostate cancer patients as an example of a population who suffer from diseases to investigate problems in the healthcare system of the United States and to inquire about potential solutions that may benefit patients. This study serves as pilot research to qualitatively analyze technical and political forces to reform the healthcare system in the United States in the AI era.

Sample size and sampling method

This study presents opinions from 73 valid survey responders and 17 patient panelists using a convenient sample from an online patient community. While the sample provides meaningful insights from the prostate cancer patient community, it could not be assumed to give representative survey results on the full scope. Given a total of 3.65 million people alive with a prostate cancer diagnosis,89 this study only accounts for a small portion of the whole prostate cancer patient population. The convenient sampling method might not recruit a representative sample of prostate cancer patients. Specifically, because this study recruited participants from patient support groups, the participants might be more capable than average prostate cancer patients in the sense of wealth, physical, and social activeness. Socially and economically disadvantaged patients might be less likely to be active in patient support groups and might be less represented in this study sample. African American men have a higher risk than white men in the United State with 4.2% as against 2.9% lifetime risk of dying from prostate cancer.90 This view

89 Miller et al., “Cancer Treatment and Survivorship Statistics, 2019.”
is corroborated by one of the study’s panelists who said that black people are hurt the most by prostate cancer. Therefore, views from this study might not well reflect the needs and burdens specifically related to African Americans.

Prostate cancer is just one disease with its uniqueness

This study involves the disease of prostate cancer which is unique and the patients’ needs and burdens may differ from other diseases. Prostate cancer patients affect a large population with a long survival time, they are adults and most of them are physically, intellectually, and legally capable. Unlike other diseases that affect a small population, affect minorities, or cause disabilities, prostate cancer patients have more resources to build a strong political force influencing the public policy decision.

Children of pediatric patients and young adults are not fully mentally developed and have restricted legal autonomy in decision-making. Their needs and will are mostly indirectly voiced by their parents or legal guardians. Hereby, the concept of power patients that has been proposed in this thesis could not be exactly applied to children and young adult patients. An extension of the concept of power patients, power parents, or power caregivers, might be a more appropriate term to reflect the individual patients' slightly reduced intellectual and legal capabilities.

Incompetent patients, who are mentally disabled, may not be able to consent, or even not be able to give patient assent. These patients lack the competency to receive, remember, and comprehend the information; they cannot appreciate the impact of a decision, nor they can communicate the final decision. Their wellness is represented by their family members and caregivers as legal proxies. Although incompetent patients’ family members can represent these patients' healthcare needs, these patients have less
economic, social, and political power than prostate cancer patients. Different views could be derived from the disease population compared to this study’s population of prostate cancer patients.

Long-term chronic disease vs. poor prognosis cancer

Prostate cancer is a slow-developing disease and its patients have a relatively long survival time. Therefore, patients with prostate cancer face different situations regarding urgency than other cancer patients with poor prognoses.

Schildmann et al. conducted a qualitative interview with pancreatic cancer patients about patients’ decision-making considerations. They observed that in the initial stage of disease, diagnosed patients had no choice but to listen to doctors; then patients were looking for alternative choices; but in the later stage, patients lack choices again and could only rely on doctors. The pancreatic cancer study had a similar approach as this prostate cancer study trying to investigate patients’ decision-making process. However, due to the poor prognoses of pancreatic cancer, the study population had less time to obtain the information and had fewer choices to choose from than prostate cancer patients. The pancreatic cancer study identified that at the early stage of disclosure of diagnosis and initial treatment decision, the stage I as being termed, patients had no choice and they had to “trust in the physician”. Unlike prostate cancer patients who have relatively long survival time, larger patient communities, and more support from fellow patients, pancreatic cancer patients have a much harder time at diagnosis. Stage II,

according is “information-seeking” for pancreatic cancer patients into which almost most prostate cancer patients instantly entered. Due to the poor prognosis of pancreatic cancer and its threat to life, investigators of the pancreatic cancer study specifically discussed with patients the treatment at the end of life, one patient said that “hope was an important drive to undergo further treatment also in advanced stages of the disease”. 92 This narrative reflects a slightly different attitude about life compared to one of the prostate cancer panelists in this study who said that he would accept the survival choice without treatment if there were no better choices and would “dance with” the cancer. The AI assistant’s role might be less important to those fast-growing cancer patients than those slow-growing cancer patients. However, the AI assistant can still help patients’ spouses and family members to make appropriate decisions. The AI assistant’s role in helping patients to make end-of-life decisions is a much more complicated issue, and further ethical and legal evaluation is required to advance the topic.

Hospital-setting patient population and community patient population

Patients may present different views to their medical providers other than people who are not directly involved in their medical treatment. In this study, the investigator, being a Harvard Extension School student, who was not a medical professional involved in any care with their disease, recruited patients directly from an online patient community. On the other hand, studies conducted in hospital-setting where patients were recruited by their medical service providers may provide different narratives, particularly regarding their attitude toward medical professionals’ instructions. The pancreatic cancer

92 Schildmann et al.
study was conducted in a single-center university hospital and patients were invited by physicians of the hospital. The investigators of the pancreatic cancer study found that there were two groups of patients when they were making decisions in the advanced stages of the disease, one group preferred that they do everything following doctors’ suggestions, and the other group argued that personal experience and values are paramount, and are outside the professional domain. The second view echoes what my study has found that power patients are strong and willing to make decisions by themselves and to choose the life they want to live. The distinction is obvious that while my study emphasizes the biased information from medical professionals, power patients, and their unsatisfied progressive health demands, the paper was titled as “One also needs a bit of trust in the doctor”. The different narratives of conversation due to the study setting could be a potential cause of the different conclusions where this prostate cancer study suggests that patients should learn more about the disease by themselves and make the decision for themselves, while the pancreatic cancer study suggested that patients should put more trust in their medical providers.

Patient perspective and medical professional perspective

This prostate cancer study focuses on patients’ perspectives and does not incorporate perspectives from medical professionals. Autonomy and obtaining support for decision-making are not mutually exclusive. Balancing patients’ desire for autonomy and sources of informational support, including doctors, family members, spiritual and religious advisors, could be beneficial to patients. Rocque, etc. interviewed metastatic breast cancer patients and their oncologists, and they found that patients had different
considerations than their oncologists. The oncologists had various perspectives about patient autonomy, some believed that physicians have the responsibility to choose the best treatment for patients, and others thought that is patients’ choice. On the patient side, patients often shared their perspectives regarding stopping treatment, shifting their focus toward emphasizing quality of life, and pursuing less aggressive or no treatment. Also, patients had a dimension of individual preference factors, such as emotional side effects in addition to the physical side effect and treatment efficacy that their oncologists emphasized.

Future directions

AI is an emerging technology and has great potential in its applications in individual health support. This study is a pilot exploratory investigation and is expected to inspire broader and deeper studies. Obviously, different patient insights could be obtained from other diseases. Prostate cancer exclusively affects men, has a large patient population, and most patients are physically, intellectually, and mentally capable. The patient views from prostate cancer patients may differ from breast cancer patients who are women. Patients affected by rare diseases may have different focuses than prostate cancer patients because fewer patient population means less social and political influences. Patients with incompetence intellectual or mental capabilities can hardly express their wills by themselves, and their well-being is often represented by their family members or care giver. The AI individual health assistant tool could totally mean

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different things for this group of patients and more studies are needed to investigate how AI could support their family members and caregivers.

The framework to evaluate the accuracy and confidence of AI’s suggestions should be explored in future. Decision makers are influenced by the best estimates of the expected advantages and disadvantages and by their confidence in these estimates. When AI provides decision support based on medical literature, two aspects of consideration could be assessed on AI’s capabilities, one is about if it can accurately find the relevant medical literature to address the issue in question. Another is about if it can provide the confidence about the suggested solutions, about how strong the existing evidences are and how certainty the expected results could be. Further studies could be designed to invite medical professionals and patients to assess AI’s validities to address specific issues. For example, human experts can rate AI’s solutions on some specific scenarios to evaluate its technological accuracy.

The measurements of efficacy and effectiveness for decision support machine are different than drug or normal medical devices, the framework of how to evaluate decision support machine needs to be developed. More specifically, the AI assistant tool’s efficacy and effectiveness should not only be evaluated at the medical or health outcome levels, but should also be extended to the social and economic levels. The AI assistant tool could support individuals at a variety of aspects in personal financial lives and social activities. For example, the degree of which the person is enabled by the AI assistant tool is a great research topic deserves further investigation. In addition, patients should be proactively

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participating in the process of evaluating the AI tool where not only patient-report outcomes but also patient-defined outcomes could be constructed.

The AI assistant tool supports decision making for patients directly, therefore, it will challenge the medical professionals’ hegemony in healthcare decision making. The power of AI tool to enable patients while diminish medical doctors’ authority may raise political conflicts in governmental policy making. Public support in the development of the AI tool and regulatory restrains on the tool are of great concerns. Further studies should examine what kind of governmental policies could be designed to facilitate the develop and regulation of the AI assistant tool. Also, from grassroot point of view, how government can provide support to patient groups to organize themselves and advocate for their wellbeing.

Chapter XII.
Conclusion

This study has identified a new phenomenon, progressive health demands which are patients’ demands to direct access to medical knowledge, to make decisions by themselves, to pursue their personal preferences in life, and to seek optimal health care. Progressive health demands are not static nor generic, rather, they are dynamic and individual. They are evolving open-ended demands that reflect patients’ value for their lives. The concept of progressive health demands reflects the gap between the current medical advancements and patients’ expectations, and it highlights the inherent deficit of the current healthcare system in the United States that has failed to fully support patients’
efforts to live meaningful lives. The system has been too expensive to provide direct education to patients, especially to average patients; it unavoidably passes biased information to patients due to its profit-pursuing motives, and; it does poorly in supporting patients to navigate the system to get the optimal care.

This study has also pointed out that progressive health demands come from power patients. Power patients are a proportion of patients who are intellectually competent, judgmentally capable, and mentally willing to participate in healthcare matters for themselves. They have dedicated their efforts to managing the disease they suffer and contributing to the development and advancement of knowledge and technology for the diagnosis and treatment of the disease. Power patients are not merely patients being empowered or engaged by the medical society, rather, they are self-motivated patients in this information era where medical knowledge has become more widely available and the knowledge gap between medical professionals and lay persons has been shrinking. Power patients can be a formidable force balancing the supremacy power of medical professionals. Directly bearing the disease burden, power patients can provide perspectives that medical professionals cannot provide. Most importantly, power patients have the volition to transform the healthcare system to increase its efficacy, efficiency, and accessibility. Hereby, I anticipate power patients will be one of the key driving forces to reform the healthcare system in the United States and will make a revolutionary reformation politically possible.

In this thesis, I have proposed that an AI health assistant tool that is directly available to patients will be a great help to patients. The AI health assistant will mend the inherent deficit of the healthcare system to provide much-needed irreplaceable services
directly to patients. By synthesizing the most recent medical knowledge, it can provide accessible low-cost educational services to patients; by dispersing new medical knowledge and technology to more people, it can enhance healthcare equality; it can provide comprehensive support to patients and help them to get the best services out of the system; it can provide unbiased advice and second or third opinions to patients by detaching itself from specific profit-pursuing medical providers and provider. The AI health assistant can enable patients’ involvement in healthcare matters, facilitate the growth of power patients, and help them realize their progressive health demands. The application of the AI tool will direct society to invest more resources in the fields where patients want most and turn the healthcare system toward a more value-based system.

Patients, at least the prostate cancer patients in this survey and panel discussion, are willing to use an AI assistant to help them in decision making. One of the most expected functions of an AI assistant is to provide an easy navigating system to provide cons and pros of different treatment options and provide decision support. Patients do not feel that the AI tool could disconnect them from their medical providers, rather, they think AI could be a beneficial assistive tool for them.

This study presents a unique perspective from the patient community. Compared to the approaches such as patient-center care, patient empowerment, and patient engagement where patients are more passive receivers of the intervention, this study collects ideas directly coming from patients who have personally experienced diseases. The direct patient community approach reveals more genuine views from patients where the survey participants and panelists expressed their thoughts more freely without fear of any consequence from offending their medical providers because no medical providers
were involved in this study. The patient perspective strips the bias existing in the profit-driven healthcare system and reflects the patients’ values and motives. This patient perspective provides a new point of view that will help policymakers to see and solve the health problem in the United States in different ways.

While I believe the AI health assistant tool will be definitely good for patients, I do not imply that the tool will be automatically available; even if available, it will not be immediately in the hands of patients; and even if in the hands of patients, it may not fit everyone’s needs. The ideally beneficial AI tool requires every one of us, who will soon or later become a patient, to devote their determined efforts to involve ourselves in the development of the tool.

The development and application of the AI health assistant tool will be a continuous journey and conscious exploration, discovery, and creation of our health expectations. The process that I can foresee “is not to discover what we are, but refuse what we are”⁹⁵. The developed AI tool will not be a cure for all, nor be a cure forever. Instead, it may invite us “to begin a journey with no direction home, but which opens up new possibilities to think differently, and to become other than what we are.”⁹⁶

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⁹⁶ Ambrosio.
Appendix 1.

Harvard IRB: Notification of Initial Study Exemption Determination

Harvard University-Area
Committee on the Use of Human Subjects
44-R Brattle, Suite 200 (2nd floor)
Cambridge, MA 02138
IRB Registration - IRB00000109
Federal Wide Assurance - FWA00004837

Notification of Initial Study Exemption Determination

November 17, 2021

Wu Gong
wug770@g.harvard.edu

Protocol Title: Empower patients and reframe the healthcare system in the U.S.: AI as a knowledge tool to augment engaged patients

Principal Investigator: Wu Gong
Protocol #: IRB21-1418
Funding Source: None
IRB Review Date: 11/17/2021
IRB Effective Date: 11/17/2021
IRB Review Action: Exempt
This Initial Study submission meets the criteria for exemption per the regulations found at 45 CFR 46.104(d) (2). As such, additional IRB review is not required.

The Principal Investigator is responsible for ensuring compliance with any applicable local government or institutional laws, legislation, regulations, and/or policies, whether conducting research internationally or nationally. Additionally, if local IRB/ethics review is required, it must be obtained before any human subjects research activities are conducted in the field. If assistance with applicable local requirements is needed, please contact the Harvard University-Area IRB office.

The documents that were finalized for this submission may be accessed through the IRB electronic submission management system at the following link: IRB21-1418

The determination that your research is exempt does not expire, and you will not file annual renewals. If changes to the research are proposed that would alter the IRB’s original exemption determination, they should be submitted in ESTR by using the Modify Study button. If unsure, contact the Harvard University-Area IRB office.

The IRB made the following determinations:

Please contact me at 617-495-9204 or kathryn_bean@harvard.edu with any questions.

Sincerely,

Kathryn Bean

IRB Administrator
Appendix 2.

The Prostate Cancer Patient Opinion Survey Questionnaire

Prostate Cancer Patient Opinion Survey

You must be a prostate cancer patient greater than 18 years old and living in the United States to participate in this survey.

There are 15 questions in this survey.

Personal Information

Where do you live?

Please choose only one of the following:

- United States
- Other

How old are you?

Your answer must be between 0 and 150

Please write your answer here:

- years

How many years have you been diagnosed with prostate cancer?

Your answer must be between 0 and 100

Please write your answer here:

- years
Approximately how many times have you talked with your prostate cancer care providers (including all medical professionals)?

Your answer must be between 0 and 500
Only an integer value may be entered in this field.
Please write your answer here:

- In total times.
Knowledge

What is the highest level of school you have completed?

Please choose **only one** of the following:

- High School or Less
- Some College
- Bachelor’s Degree
- Master’s or More

How much knowledge do you have about prostate cancer compared to your doctor?

Please choose **only one** of the following:

- Equivalent or More
- More than 50%
- More than 20%
- Less than 20%

Do you think you have some knowledge about prostate cancer that your doctor does not have?

Please choose **only one** of the following:

- Yes
- No

Have you ever sought information about prostate cancer outside of your professional medical providers?

Please choose **only one** of the following:

- Yes
- No

Have you ever judged your doctor’s prostate cancer related decisions using your own knowledge?

Please choose **only one** of the following:
• Yes
• No
Attitude

Do you have 10 hours per week in the next six months to spend on learning knowledge about prostate cancer or participating in activities such as research or policy discussion related to prostate cancer? *

Please choose only one of the following:

- Yes
- No

What activities will you participate in and how many hours will you spend if you have the opportunities? *

Each answer must be at least 0
The sum must be at most 120
Please write your answer(s) here:

- manage symptoms and treatments for myself
- be involve in regulation related activities such as drug approval or public policy discussion
- be involve in medical research as an investigator
- be involve in medical research as a patient
- help other patients
- learn more about prostate cancer

What is your expected compensation if you work 10 hours per week in prostate cancer related jobs? (Input 0 if you volunteer) *

Your answer must be between 0 and 1000000
Please write your answer here:

- $ yearly
Opinion about Artificial Intelligence (AI)

A chatbot-like machine using Artificial Intelligence technology that helps you understand, learn and make decisions about prostate cancer is potentially available. It will use contemporary medical knowledge and serve as an independent individual assistant to prostate cancer patients.
Will you accept prostate cancer related advice from an Artificial Intelligence (AI) assistant (nonhuman) without consulting a human medical doctor? (Multiple Choices) *

Please choose all that apply:

- Accept if the AI Assistant is approved by the Food and Drug Administration (FDA)
- Never accept
- Sometimes accept
- Accept if the AI Assistant is endorsed by a reliable patient organization
- Accept if the AI Assistant comes from a reliable nonprofit organization
- Accept if the AI Assistant comes from a reliable company
- Accept if the AI Assistant comes from a reliable hospital
- Accept if the AI Assistant has been licensed just like medical doctors
- Other:

If there is an AI product to be developed to help prostate cancer patients, how would you like it to be developed? What kind of functions of the tool are you expecting? What kind of activities do you want to be involved in the development of the product?

Please write your answer here:

If you want to participate in a panel discussion about the development of the AI individual assistant for prostate cancer, please leave your name and email address.

Thank you for participating in the Prostate Cancer Patient Opinion Survey and congratulations to you for being engaged in this prostate cancer related activity.

Please invite other prostate cancer patients to take this survey by forwarding the following link:

Prostate Cancer Patient Opinion Survey
Submit your survey.
Thank you for completing this survey.
Email Title: Invitation for the Prostate Cancer Patient Opinion Survey

Dear {FIRSTNAME} {LASTNAME},

I am a master's student from Harvard Extension School, and I am conducting a thesis study about prostate cancer patients’ knowledge needs and how Artificial Intelligence could be used to develop an assistive tool to serve, augment, and enable prostate cancer patients.

I am inviting you (or refer to others) to take the Prostate Cancer Patient Opinion Survey. It may take you about 15 minutes. The survey intends to collect information about your experience with prostate cancer and your opinion about how would you like to be involved in prostate cancer related activities. Please read the attached consent document for more detailed information about the study before you take the survey.

This survey is fully voluntary and does not provide any monetary compensation.

Please directly contact me (Wu Gong wug770@g.harvard.edu) if you have any questions or suggestions about the survey and the study. If you have any further concerns about this survey and my study, please contact my thesis advisor Dr. Michael David Miner (miner@g.harvard.edu).

To participate, please click on the link: Prostate Cancer Patient Opinion Survey.
Sincerely,

Wu Gong

ALM Candidate, Harvard Extension School

wug770@g.harvard.edu
References


Bondarenko, Alexander, Matthias Hagen, Martin Potthast, Henning Wachsmuth, Meriem Beloucif, Chris Biemann, Alexander Panchenko, and Benno Stein. “Touché:


“Welcome to The Pink Ladies - Pink Ladies.” Accessed April 5, 2022.

