Digital Technologies Supporting Shared Decision-Making in Oncology Consultations: Barriers, Enablers, and Recommendations for Improvement

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SUPERVISOR'S CERTIFICATE

This is to certify that the thesis entitled ***"Digital technologies to improve shared decision-making in oncology consultations"***, submitted by Alan Yung in fulfilment of the requirements for the degree of Doctor of Philosophy, is in a form ready for examination.

Date: 27 September 2025

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STATEMENT OF ORIGINALITY

I certify that the work in this thesis, entitled

"Digital technologies to improve shared decision-making in oncology consultations"

has not been previously submitted for a degree to any university or institution other than the University of Sydney. I also certify that the thesis is an original piece of research and that it has been written by me. Any help and assistance that I received in my research work and the preparation of the thesis itself have been appropriately acknowledged.

Name: Alan Yung

Date: 27 September 2025

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Planning and implementation	AY, JK, PB, KG, TS	AY, JK, AJ, PB, KG, TS	AY, AJ, JK, TS
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As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Professor Tim Shaw

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GENERATIVE AI STATEMENT

While working on this thesis, I used both Writefull and Grammarly software.

I did not use ChatGPT or Microsoft Copilot Artificial Intelligence.

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ABSTRACT

Background

Medical decision-making is a complex process, and the need to increase patient participation in planning and managing their care has been widely accepted worldwide. When patients are not involved in the planning of their care or do not collaborate with their physicians to decide on their preferred therapy for their health situation, they may receive treatments that they or their families do not value. This can lead to poorer health outcomes and dissatisfied health consumers. Today, shared decision-making is recognised as an effective framework in health care to involve patients more in the planning and management of their own care. However, its incorporation into the workflow of medical consultations has been challenging and slow. This difficulty may be due to the numerous challenges that impact communication between patients and physicians throughout the patient's journey through the healthcare system.

Many healthcare organisations claim to operate as paperless clinical environments; however, they still rely on various paper-based processes. A common problem for healthcare professionals is the difficulty in locating crucial information from other healthcare professionals about patients, such as letters from surgeons that have been scanned into electronic health records as PDFs. Challenges persist in accessing pathology and imaging results that are often performed at off-site locations. Laboratory test requests are often printed from computers for patients to bring to the laboratory to receive specific diagnostic tests. Follow-up consultation requests are often documented on paper forms, for which patients present at the front desk to book their next appointment. This ongoing fragmentation of the healthcare system at the micro level hampers effective communication between healthcare providers and patients. As a result, patients who seek care often become frustrated with a system that is cumbersome and difficult to navigate.

The integration of digital tools for shared decision-making into routine medical practice has been promoted for decades as a potential way to improve shared decision-making and involve patients in the management of their care. However, there is still limited evidence that this strategy has been effective in providing the promised benefits.

Research aim

This research aimed to explore how technology is used to support shared decision-making in oncology consultations, to understand the barriers and enablers to using existing technologies such as electronic health record systems for shared decision-making, and to provide recommendations for improvement.

Methodology

To answer this research aim, three studies were undertaken: (1) A systematic review of the literature on computer-based shared decision-making was carried out to assess the current maturity level of the digital tool to support shared decision-making in the practice of medical oncology; (2) an ethnography study of how medical oncologists currently use shared decision-making and electronic health records in their consultations was carried out at outpatient medical oncology clinics of a cancer centre; (3) human-centred co-design techniques were applied to guide the realisation of a prototype to identify and validate the needs and requirements to design a future shared decision-making digital tool to improve treatment consultation decisions for patients diagnosed with cancer.

Results

The results of the studies presented in this thesis suggest that many of the features of current, routinely used health technologies, such as Electronic Medical Records (EMRs), do not support shared decision-making or teamwork in oncology practice. Where tools have been specifically developed to support shared decision-making, there are few examples of them being used in routine practice.

This thesis proposes and tests ways to enhance existing technologies, such as EHR systems, to improve decision-making, and how tools such as patient portals can be used to support shared decision-making with patients, families and carers. A key finding is that any modification to existing tools must be compatible with the complex clinical workflows of oncologists, and any new technologies need to be integrated into existing platforms and workflows.

Oncologists are interested in the emerging capabilities of new technologies, such as generative artificial intelligence for supporting oncology practice and shared decision-making. These capabilities include automatically generating reports about patients or writing letters to other healthcare professionals, provided they can trust the outputs of these tools.

Conclusion

There are many opportunities for technology to support shared decision-making in oncology practice. This thesis provides a roadmap for how existing digital platforms can be enhanced to better support shared decision-making in oncology practice and provides suggestions for the development and integration of new tools.

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PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS PHD

PEER-REVIEWED PUBLICATIONS:

1. Yung, A., Kay, J., Beale, P., Gibson, K. A., & Shaw, T. (2021). Computer-Based Decision Tools for Shared Therapeutic Decision-making in Oncology: Systematic Review. JMIR Cancer, 7(4), e31616. https://doi.org/10.2196/31616

2. Yung, A., Shaw, T., Kay, J., & Janssen, A. (2025). Examining How Technology Supports Shared Decision-Making in Oncology Consultations: Qualitative Thematic Analysis. JMIR Cancer, 11, e70827. https://doi.org/10.2196/70827

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ABBREVIATIONS

ASCO:	American Society of Clinical Oncology
COVID-19:	Coronavirus disease 2019
EHR:	Electronic health record
EHRs:	Electronic health record system
EMR:	Electronic medical record
JMIR:	Journal of Medical Internet Research
MDT:	Multidisciplinary team
NCCN:	National Comprehensive Cancer Network
SDM:	Shared decision-making

GLOSSARY

This glossary presents the key terms and concepts that appear in the thesis.

Artificial intelligence	Computers are performing tasks that typically require human intelligence.
Barrier	Challenges can be linked to resources, infrastructure, or systems within an organisation that impede successful implementation, including insufficient funding or inadequate facilities.
Cancer	A collection of circumstances where cells grow uncontrollably and can spread to different parts of the body.
Care partner	A care partner collaborates with a person receiving care to manage their health and daily activities, emphasising a mutual relationship in which the individual actively participates in decision-making, rather than the traditional caregiver role.
Care team	A team of healthcare professionals and support personnel guides a patient through coordinated diagnosis, treatment, and recovery, with the patient at the centre of the team.
Caregiver	A caregiver is someone who supports individuals unable to care for themselves due to illness, disability, or old age. Caregivers can be family, friends, or hired professionals.
Carer	A carer is an individual who provides unpaid, informal care and support to a family member, partner, or acquaintance who needs assistance due to physical illness, disability, mental health conditions, or age-associated functional decline.
Case	The text describes a detailed examination of specific cases within the context of oncology consultations.
Clinic	A clinic is a healthcare facility that provides medical services, typically on an outpatient basis, in which patients do not stay overnight. Clinics can provide a range of services, from routine examinations and preventive treatments to care for specific health conditions. Generally smaller than hospitals, clinics often focus on particular specialties, such as cancer management.
Clinical decision	A clinical decision is a judgement made by a healthcare provider, such as a physician, nurse, or therapist, based on the evaluation of a patient's symptoms, medical history, and diagnostic test results. These decisions guide treatment, including the selection of the therapies, medications, or interventions most appropriate for the patient's condition.
Clinical decision support system (CDSS)	Access to electronically stored knowledge to aid patients, caregivers and healthcare providers in making healthcare decisions.

Clinical document	A clinical document is any written or electronic record that contains information about a patient's health status, treatment, and care. These documents are used by healthcare providers to communicate patient data, track progress, and make informed decisions about care.
Clinical information systems (CIS)	Digital systems used by healthcare providers to capture, store, manage, and retrieve clinical patient information, and to support clinical workflows and decision-making, including clinical documentation, electronic health records, computerised provider order entry (CPOE), medication management, and results reporting.
Clinician	In healthcare, a clinician is a formally trained and licensed health professional who provides direct, hands-on patient care. Clinicians assess, diagnose, treat, and manage diseases, disorders, and other health conditions over time. This group typically includes physicians, nurses, and other comparably qualified practitioners involved in independent or supervised clinical decision-making and patient care.
Computer desktop	A desktop is the primary screen or workspace on a computer where users interact with files, applications, and system functions. It typically includes icons, a taskbar, and a background image, providing a central place to organise and access resources.
Computer network	The connection among a group of computers.
Computer screen	A computer screen (or monitor) is a display device that shows visual output from a computer. It allows users to interact with the operating system, software, and applications through a graphical user interface (GUI).
Computer-based	Computer-based refers to processes, systems, or activities that are primarily powered or managed by a computer. It involves the use of software, hardware, or digital technologies to perform tasks, store information, or run operations.
Custom-made	Systems developed within the hospital or clinical setting are used.
Decision aid	Decision aids are tools (paper-based or digital) that help patients and clinicians compare treatment options, understand benefits and risks, and clarify patient values and preferences to support shared decision-making.
Decision talk	Decision talk refers to discussions or conversations focused on making choices, typically involving the evaluation of options, risks, and outcomes. It often occurs in settings in which decisions are made collaboratively, such as in healthcare, business, or personal contexts.
Deductive analysis	Deductive analysis is a method of reasoning in which conclusions are drawn from general principles or premises. It begins with a broad theory or hypothesis and tests it against specific observations or data.

Digital ecosystem	Designing and integrating the hardware and software of computer systems.
Digital health tool	A digital health tool is any technology or software designed to improve health outcomes, track wellness, or manage healthcare services. These tools often include mobile apps, wearables, or online platforms that collect and analyse health data.
Digital technology	Digital technology encompasses electronic devices, systems, or tools that use digital data to perform tasks, store information, or enable communication. It includes everything from computers and smartphones to software, apps, and the internet.
Digital transformation	Digital transformation is the process of integrating digital technologies across all areas of a business or organisation, fundamentally changing how it operates, delivers value, and interacts with customers.
Digitisation of healthcare	Digitisation of healthcare refers to the use of technology to convert healthcare processes, records, and services into digital formats. This includes electronic health record systems, telemedicine, digital diagnostic tools, and health apps.
Electronic health record (EHR)	An individual patient's health record in digital format.
Electronic health record (EHR) system	An Electronic Health Record (EHR) system is a digital platform that stores and manages patients' medical records. Healthcare providers use it to document, access, and organise patient information, including diagnoses, treatments, medications, and test results.
Electronic prescribing	Electronic prescribing (ePrescribing) is the process of generating and transmitting prescriptions electronically from a healthcare provider to a pharmacy, replacing traditional paper prescriptions.
Enabler	A factor, condition, resource, or process that facilitates the successful adoption, implementation, sustainability, or scaling of an intervention within a system.
Ethnographical methodological study	Investigations into people's practices.
Evaluation	Determination of the quality, value or importance of something.
FHIR	FHIR (Fast Healthcare Interoperability Resources) is the global standard for exchanging electronic health data, using modular Resources and RESTful APIs to enable secure, seamless interoperability across systems.
Formative evaluation	An evaluation conducted during the development of a system to provide information on the processes involved, often to support the system's operational success.

Healthcare consumer	An individual, family member, or caregiver who uses, is affected by, or participates in healthcare services and whose needs, preferences, and behaviours influence the implementation and outcomes of health interventions.
Indicator	A statistic or unit of information that reflects the performance of a system.
Inductive analysis	An analytical approach that derives concepts, themes, or theories from observed data rather than applying predefined frameworks, allowing implementation factors and system dynamics to emerge from empirical evidence.
Integrated	The degree to which an intervention, process, or role is embedded and coordinated within existing system structures, workflows, and relationships to operate as a cohesive whole.
Medical assessment report	A structured clinical document that summarises patient health status, assessments, and recommendations, informing decision-making and supporting the implementation, coordination, and evaluation of care within a healthcare system.
NCCN	The National Comprehensive Cancer Network (NCCN) is a non-profit coalition of prominent cancer centres that develops clinical practice guidelines widely used by healthcare professionals worldwide.
Observation	Data collection method based on the researcher's observations, listening, and recording of events.
Oncologist	A medical specialist in cancer care whose clinical expertise, decision-making, and practice context influence the adoption, delivery, and outcomes of oncology interventions within healthcare systems.
Oncology	The branch of medicine concerned with the study, diagnosis, treatment, and prevention of cancer.
Oncology Information System (OIS)	Oncology Information System (OIS) (also referred to as an Oncology Management Information System) is a specialised clinical information system (CIS) designed to coordinate, manage, and document cancer care throughout the treatment pathway. It supports key oncology workflows, including patient assessment; treatment planning and delivery (chemotherapy and radiotherapy); protocol or regimen management; scheduling; medication ordering and verification; and monitoring of toxicity, outcomes, and follow-up care.

Open Notes	A practice model, originating in the US, in which patients are given online access to clinicians' consultation notes (often via an EHR portal). In Australia, Open Notes is not mandated by a specific "Open Notes law," but aligns with patients' legal right to access their health information under the Privacy Act 1988 and the Australian Privacy Principles, subject to limited exceptions, for example, a serious threat to safety.
Option talk	A stage of shared decision-making in which available treatment or action options are clearly presented and explained to the patient.
Pathology	The branch of medicine that studies diseases by examining tissues, cells, and bodily fluids to understand their causes and effects.
Patient	An individual who receives medical care, diagnosis, or treatment from a healthcare professional.
Patient journey	The complete sequence of experiences and interactions a patient has with the healthcare system, from initial contact through diagnosis, treatment, and follow-up.
Patient management	The coordinated planning and delivery of healthcare services to monitor, treat, and support a patient's condition over time.
Patient progress note	A clinical record documenting a patient's current status, care provided, and response to treatment at a particular point in time.
Patient-reported information	Health data provided directly by the patient about their symptoms, experiences, or outcomes, without interpretation by clinicians.
Person centred	An approach in healthcare, social care, or services that focuses on the individual's unique needs, preferences, values, and experiences, ensuring they are actively involved in decisions about their care or support.
Physician	A medical professional who diagnoses, treats, and helps prevent diseases in patients, typically holding a medical degree and a licence to practise medicine.
Portal	A centralised online (web-based) platform that provides access to a variety of resources, services, or information through a single interface, often tailored to specific users or organisations.
Process	A series of structured steps or actions undertaken to achieve a specific goal or outcome.
Qualitative research method	Research conducted in natural settings is largely non-statistical.
Real-world	Referring to situations, data, or evidence that arise in everyday, practical settings rather than in controlled experiments or simulations.

Registrar	A medical oncology registrar in Australia is an advanced trainee physician who delivers and coordinates systemic cancer care under consultant supervision, assessing referrals, determining treatment suitability, initiating and monitoring chemotherapy, targeted therapy, and immunotherapy, managing toxicities and oncologic emergencies, and implementing MDT decisions across inpatient, outpatient, and on-call settings, ensuring safe, patient-centred care.
Shared Decision-Making	A collaborative process in healthcare in which patients and healthcare providers work together to make treatment decisions, considering the patient's preferences, values, and the best available evidence.
SMART	SMART on FHIR is a framework that leverages OAuth 2.0 and OpenID Connect to allow third-party applications to securely and uniformly connect to electronic health records. It utilises scopes for permissions and launch context to ensure the appropriate patient or user is pre-selected when opening.
Sociotechnical	Interdependence and interrelation of social and technical factors.
Team talk	A communication approach in healthcare where healthcare providers collaborate and discuss treatment options, patient care, and goals to promote clear understanding, shared decision-making, and coordinated action within the team.
Temporally	In clinical contexts, temporally refers to time, sequence, or duration. In professional use, it typically describes how events or biological processes are arranged on a timeline.
Thematic analysis	A qualitative research method used to identify, analyse, and report patterns or themes within data, often from interviews, surveys, or texts, to gain insights into a particular subject or phenomenon.
Triangulation	The use of multiple research methods as a validation and data analysis technique.
Usability	The degree to which a product, system, or service is easy to use, efficient, and satisfying for its intended users, with a focus on user experience and functionality.
Vendor system	A commercially made computer system, comprising hardware or software purchased from a computer system developer.
Wireframe mock-up	A visual blueprint or skeletal representation of a website or application's layout, focusing on structure, navigation, and functionality, without detailed design elements.
Workflow	A series of tasks or steps that are systematically organised to achieve a specific goal or process, often involving multiple people, tools, or systems.

CHAPTER 1: INTRODUCTION

1.1 THESIS RATIONALE

The digital transformation of many industries worldwide has transformed business models and impacted the user experience [1, 2]. In the same way, healthcare organisations are under pressure to provide value to end users of their services [3]. Digital transformation is particularly important in healthcare delivery, especially in hospital settings [4]. While the digitisation of healthcare holds the promise of providing value to end users of healthcare services, this promise has yet to be fully realised [5]. To quote Atul Gawande, a leading advocate for digital change in healthcare, "I've come to feel that a system that promised to increase my mastery over my work has, instead, increased my work's mastery over me" [6].

Despite technological advances in Australia, the digital transformation of hospital care is still in early stages in many ways [7]. This thesis was motivated while I was a business analyst on a team that installed an oncology management information system in a major hospital in metropolitan Sydney in Australia. The hospital administration initiated this project in response to the recommendations of the New South Wales legislative council to implement oncology management information systems and multidisciplinary healthcare teams in cancer care practices across the state of New South Wales [8]. During this project, I was struck by the challenges that physicians faced with an existing oncology management information system that was already installed in a cancer centre, where the task flow of the electronic health record system was not aligned with the clinical practice workflow. Other researchers have reported similar observations in other cancer centres [9]. Additionally, there was a noticeable lack of enthusiasm and expectation among the managers, physicians, and healthcare consumers at another cancer centre we visited regarding how the proposed installation of the oncology information system would improve the system user experience in their clinical setting.

Oncology is the branch of medicine that specialises in the diagnosis and treatment of cancer [10], a complex disease that places patients and physicians in inherently stressful situations. In this process, diverse sets of information must be combined and utilised to make a shared decision on a course of treatment that satisfies patient preferences while maximising the best use of evidence in line with best clinical practice.

This introduction outlines the shared decision-making process in oncology presentations, which is a collaborative, consultative process and a bidirectional exchange of information between the physician and the patient [11]. It then summarises oncology practice in metropolitan Sydney in Australia, and how digital technology supports cancer care decision-making processes, specifically when the electronic health record system is involved.

1.2 RESEARCH AIMS AND OBJECTIVES

This research aimed to explore how technology is used to support shared decision-making in oncology consultations, to understand the barriers and enablers to using existing technologies, such as electronic health record systems for shared decision-making and to make recommendations for improvement.

1.2.1 What is decision-making in the context of healthcare?

Decision-making is a systematic process that people use every day to arrive at their choices to solve problems [12]. This process may be applied to both simple and complex problems. Decisions may be influenced by decision-makers' past lived experiences, biases, age, preferences and beliefs, in addition to environmental, political and social structures and information flow [13]. To facilitate the selection of decision strategies, the use of models that break down the decision-making process into stages has been proposed [12]. In healthcare, the decision-making process for medical decisions is particularly complex [14-16]. Therefore, physicians have developed models that help them in making these complex medical decisions.

The Calgary-Cambridge guide described the workflow undertaken in a consultation [17]. At the beginning of a patient's visit, the physician collects information from patient statements, observations, interviews, referral letters, medical records, and carer reports. At this stage, the physician begins to formulate the initial concepts of the patient’s problem and quickly develops several hypotheses in their working memory. Physicians use these hypotheses to guide their search for more information. With additional information, they mentally verify all hypotheses in parallel against the accumulated information. The physician then focuses on specific hypotheses. Further investigations of the patient's history, symptoms, and physical evaluations provide more information, especially vital information, to help them iteratively rank or modify their previously established hypotheses until they reach a satisfactory decision [17-21]. As a result, the physician has collected a large amount of significant information that they need to remember [22]. Consequently, physicians must organise and consolidate the available information so that they can recall the necessary information from their working memory [23]. When sufficient information has been collected or all information obtained at that time has been considered, the physician can decide to manage the patient medically, surgically, and psychologically, order additional diagnosis tests, or refer the patient to other specialists for further consultation [24]. Thereby, the patient progresses to the next point of care in their clinical journey [25]. However, if a physician is uncertain about the appropriate medical intervention for a patient and cannot determine whether the risks of a medical intervention outweigh its potential benefits, they may hesitate to recommend a course of action [26].

In addition to collecting sufficient key patient health data, physicians have recognised the importance of involving patients, their family members, or carers in the medical decision-making process [27] In collaboration with the patient and their family, physicians should correctly diagnose patients' needs and preferences as a key part of decision-making regarding the most appropriate medical intervention to address the patient's health problems and conditions [28, 29]. Together, as a result, the patient and the physician can co-create care plans that meet the patient's needs and make sense for them in a collaborative environment [30]. Hence, medical decision-making processes should be chosen based on the individual patient's circumstances to fit their personal needs, not only their medical needs. This strategic approach is at the heart of person-centred care [31, 32].

Proponents of the person-centred model of care have further advocated that patient care can be enhanced by applying the concepts of shared decision-making [33]. They believe that by adopting a shared decision-making framework, physicians and patients can navigate complex medical decisions more efficiently and effectively, thereby improving patient engagement and ultimately enhancing patient outcomes [34]. The quality, safety, and value of health services provided, as well as the positive effects on the people involved and the health systems, and the level of patient satisfaction with the care they receive, can thus increase [35-41].

The concept of a shared decision-making model has been developed over several years and continues to evolve. Legare et al. [42] stated that with the guidance of one or more physicians or nurses, the patient and family members decide on their preferred care pathway in a shared decision-making process. Elwyn [43] further clarified that shared decision-making is a model for sharing decisions in clinical settings that involves combining communications between the physician, the patient, and family members or caregivers, health and personal information, and collaborations between associated stakeholders to arrive at an appropriate clinical decision.

In its basic form, the shared decision-making model requires at least one patient and a physician to exchange information and ultimately agree on a decision [44]. Further elaboration produced the second major approach, the SHARE model, which promotes a five-step process to seek patient participation, help the patient explore and compare treatment options, assess their values and preferences, make a collaborative patient and physician decision, and evaluate the patient's decision [45]. A third model was produced by Elwyn et al., consisting of three main stages: 'team talk', 'option talk', and 'decision talk' [46]. The first stage, 'team talk', describes the possibility of choices, provides support, and asks patients about their goals [46]. The second stage, 'option talk', discusses alternative therapies [46]. The final third stage, 'decision talk', collects information about patient preferences and makes preference-based decisions [46].

Studies indicate that employing patient decision aids positively impacts medical decision-making, such as enhancing patient involvement in the process [47]. Despite these positive benefits and proven effectiveness, along with strong promotion, advocacy, and policies from health service organisations [48], standards institutions [37, 49], and legislation [50], incorporation of the shared decision-making process into usual medical practice remains slow and difficult [43, 51]. Insufficient infrastructure support has been recognised by researchers as a key barrier, while the utilisation of online platforms and the inclusion of end users in development teams act as facilitators for implementing patient decision aids in engaging patients in the decision-making process [47].

1.3 Cancer as a disease

Cancer is a disease of the genes. When mutations occur, cells in the body can divide, multiply without control, and spread to other areas of the body [52, 53]. Cancers can be non-solid, such as those in the blood, or solid tumours, which are large bodies of cancer cells that do not contain any liquid. Solid tumours, for example, breast, colorectal, or lung cancers, may be treated by surgery, cancer drugs, radiation, or a combination of modalities [52].

The concept of ‘cancer medicine’ originated in ancient Greece [54]. In that era, several Greek physicians, notably Hippocrates, Celsus, and Galen, treated patients with cancer [55]. During the Second World War, physicians experimented with nitrogen mustard as a cancer therapy [56]. In December 1942, doctors gave a patient with cancer a dose of nitrogen mustard, and the tumour disappeared [57]. Since then, ‘cancer medicine’ has evolved into a medical specialty known today as medical oncology [58].

The incidence of cancer is increasing all over the world. In 2020, worldwide, there were 19.3 million new cases [59]. In 2024, the number of diagnosed cancer cases was expected to reach approximately 169,500 in Australia [60]. From 2016 to 2020, approximately 71% of individuals who received a cancer diagnosis survived to the five-year mark following their diagnosis [60].

1.4 SHARED DECISION-MAKING IN CANCER CARE PRACTICE

With the shared decision-making approach or model of care now recognised as a key component of the patient- or person-centred care, this approach is well-suited for making medical decisions for patients with complex healthcare needs, especially in oncology settings [61]. Shared decision-making is especially critical when a lack of evidence, high uncertainty, or conflicting opinions among physicians prevent an informed choice, as can be the case in cancer care [62].

In this context, shared decision-making serves several important purposes. If one applies the shared decision-making three-talk model to oncology consultation, it first allows the physician to engage the patient in a collaborative discussion about cancer care options, providing support while exploring the patient’s goals. Second, it creates an opportunity for the physician to present the available alternative cancer treatments, along with their potential risks and benefits. Finally, in the third stage, the physician takes the patient's preferences into account and works together with the patient to select an appropriate treatment or care that aligns with their wishes [46].

Research has shown that women are comfortable using the shared decision-making process in advanced breast cancer treatment [63]. Similarly, most men diagnosed with prostate cancer prefer to actively participate in shared decision-making process when considering treatment options [64]. Patients with colorectal cancer also seek involvement in shared decision-making during their care [65]. In contrast, a study on lung cancer patients found minimal involvement in the decision-making process within shared decision-making [66]. Nonetheless, further research has highlighted a persistent gap in awareness of shared decision-making among some healthcare providers [11]. These researchers recommend using patient decision aids in conjunction with clear communication strategies.

1.5 ROLE OF TECHNOLOGY IN SHARED DECISION-MAKING WORKFLOW

Healthcare system design experts have suggested embedding shared decision-making tasks into clinical practice workflows through the application of digital technologies to streamline the delivery of healthcare services [41, 67]. A review of literature on incorporating shared decision-making procedures into the electronic health record system highlights the improvements in lifestyle, increased discussions between patients and physicians, and reduced decision-making conflicts [68]. However, studies also showed that only a small number of patient decision aids were put into practice in clinical settings [47].

Several digital tools have been developed for cancer care management, aiming to tackle decision-making challenges and enhance interactions between patients and physicians. These include electronic health record systems, oncology management information systems, patient Web portals, mobile software applications, artificial intelligence-based systems, and custom-made clinical decision support systems. However, the lack of integration between these digital solutions and existing electronic health record systems in cancer clinics hampers the widespread adoption of shared decision-making in practice [69, 70]. An example of a digital tool for shared decision-making helps patients choose cancer treatments. The tool called Watson for Oncology was developed and trained on more than 100 years of clinical cancer treatment data in the United States. It was designed to recommend appropriate chemotherapy regimens for specific patients with cancer [71]. Another example helps individuals decide whether to accept to undergo cancer screening [72]. However, the adoption of digital tools for decision-making assistance in cancer treatment has been limited, and only a small number of studies have evaluated systems that facilitate medical decision-making in oncology [73]. As a result, further research is needed to investigate how digital technologies can be developed to enhance current practices by facilitating the integration of shared decision-making into the patient cancer care journey at their oncology clinic point of care.

1.5.1 Electronic health record systems

Electronic health record systems in countries like Norway and the USA have been introduced to support shared decision-making, including improving patient access to clinical information and documentation. For example, consultation notes, and decision-support functionality [74, 75]. In principle, electronic health record systems could support shared decision-making in any setting where they have been adopted. However, the extent of this support is shaped by national policy and access rules, system configuration and interoperability, clinical workflow integration, and patient and clinician uptake. Electronic health record systems are enterprise-wide systems that manage the longitudinal patient record across specialties, whereas oncology information systems, also termed oncology management information systems, are specialised systems or electronic health record system modules designed to support oncology-specific workflows and manage high volumes of cancer-care data [76, 77]. Oncology information systems support clinical decision-making by enabling oncology physicians to access and share oncology-relevant documentation and data, for example, progress notes, assessments, summaries of consultations, laboratory test results, and reports and by facilitating protocol or regimen management, electronic prescribing, scheduling, and charting of cancer therapies [78, 79]. In practice, oncology information systems may be integrated into or interfaced with electronic health record systems, thereby extending the broader electronic health record with oncology-specific functions to support decision-making in oncology consultations [76-79].

In Sydney, Australia, many public and some private hospitals have implemented hospital and healthcare organisation-wide electronic health record systems and oncology information systems to support patients with cancer throughout their cancer care journey from admission through to discharge, as well as to support physicians in managing their patients' medical oncology records. As a result, physicians can remotely access and view their patients' medical reports, test results, and manage their prescribed medication on a computer screen at any point on their hospital organisation's computer network [80].

Furthermore, other healthcare organisations outside Australia have also opened their electronic health record systems to provide patients with access to the clinical notes written by their medical specialists who are responsible for managing their ongoing care. For example, in the USA, the 21st Century Cures Act Interoperability and Blocking Rule requires healthcare organisations to provide patients with access to their health information, including their medical progress notes, stored in the healthcare organisation's electronic health record system [81]. The goal of this legislation, which was signed into US law in 2016, is to modernise the healthcare system in the USA. It mandated that patients must be given immediate access to their clinical information once it is entered into the electronic health record system. However, existing electronic health record systems in the USA were not designed to provide patients with access to their clinical information, such as their radiology reports, without a certain amount of time delay [82]. Consequently, electronic health record systems in the USA will need to be redesigned or upgraded to enable oncologists to share their documented clinical notes with patients without the usual delays, in line with the Open Notes Law [83, 84].

1.5.2 Clinical decision support systems

Beauchemin et al. [85] found that some clinical decision support systems in general offer recommendation guidelines to assist physicians in therapeutic decision-making, while others also incorporate patient-reported information. Some systems help to diagnose and manage diseases, prescribe treatments, and control drug doses [16], and alert or remind physicians of potential clinical problems, like adverse reactions [86], while others prompt physicians to deliver recommended care processes [87]. Therefore, clinical decision support systems vary in their degree of automation, accessibility, usability, and how well they are integrated with existing hospital clinical information systems and electronic health record systems [73, 87].

1.5.3 Standalone custom-made clinical decision support systems

Some clinical decision support tools have been developed as standalone applications. Chapter 2 of this thesis presents a systematic review of computer-based decision aids that have been specifically designed to support shared decision-making in an oncology consultation.

For example, Adjuvant! Online is a computer program designed to help physicians and their patients make informed decisions about adjuvant therapy for early breast cancer [88]. The creators of Adjuvant! Online believed that such tools can help personalise medicine by clearly communicating test results to patients, allowing them to become active partners in choosing their preferred treatment from various options [89].

Another customised online clinical decision tool, developed to assist shared decision-making in breast cancer care, is the Predict web-based software application [90]. This custom decision tool has been recognised as being advantageous in forecasting and treatment modelling [91]. It has also been shown to effectively predict the 5-year overall survival rate for older breast cancer patients and has been shown to be more accurate than the Adjuvant! Online tool for estimating 10-year survival rate [92].

1.5.4 Web-based patient portal Systems

Patient portals are digital platforms that enable patients to access their personal health information stored in electronic health record systems of healthcare organisations [93]. These systems linked to electronic health record systems facilitate shared decision-making and have been found to be feasible and acceptable to patients and their families, thereby improving healthcare outcomes [94]. Patients can securely access their blood test results, radiology imaging reports, physicians' consultation notes, and medication lists via patient portals s [95]. Patients can also view appointment times, send and receive secure messages with their healthcare team, request prescription refills, and participate in video consultations where available [93].

Overall, the innovation of patient portals can facilitate shared decision-making and engage patients in the management of their care by improving accessibility and information exchange, thereby strengthening the patient-physician relationship for patients living with chronic health conditions such as cancer [96].

1.5.5 Artificial intelligence-based systems

Artificial intelligence-driven digital platforms, utilising technologies such as machine learning and neural networks, potentially act as a gateway to the next frontier of cancer therapy by transforming large and varied data into actionable treatment strategies [97]. Nevertheless, delivering personalised, data-driven healthcare for individual patients continues to be challenging. Artificial intelligence has demonstrated significant potential in enhancing healthcare precision, improving patient outcomes, facilitating risk evaluation, enabling early disease detection, enhancing prognosis, and aiding in the selection of appropriate treatments [98].

However, when physicians decide to adopt artificial intelligence-driven systems in their practice, they must choose one that values patient autonomy and shared decision-making, supporting patient-centred care and respecting each individual patient's values and uniqueness [99]. Conversely, developing effective artificial intelligence tools for clinical decision support is difficult without first identifying the key clinical needs that remain unmet and the related research questions. These needs highlight the challenges physicians face when making decisions and are essential for designing artificial intelligence-based tools that enhance patient care, particularly for individuals with cancer [100].

1.6 INCENTIVES TO ENCOURAGE THE SHARED DECISION-MAKING METHOD OF CARE

While many governments have introduced financial incentives, there is limited evidence that these effectively change how physicians interact with patients [50]. Shared decision-making, emphasised in clinical guidelines, such as the NCCN clinical guidelines for colon cancer [101], and considered essential for safe and high-quality healthcare practice [102], is often inconsistently implemented [103]. Despite global pressures, like the COVID-19 Pandemic, encouraging healthcare professionals to reassess their care delivery methods and focus on shared decision-making, obstacles such as time constraints, limited staff [49, 104], and a lack of decision-support tools still persist [67]. Consequently, certain governments are enacting laws to mandate that healthcare providers implement shared decision-making to ensure patient-centred care is delivered [67, 104, 105].

1.7 RESEARCH QUESTIONS

As Borycki et al. [106] reported, qualitative methods address the questions of ‘how’ and ‘why’ in using health information systems, which quantitative methods cannot provide. To understand how technology can support the shared decision-making process in cancer care, it is essential to understand the detailed clinical decision-making workflows and the sociotechnical needs of physicians and patients.

Therefore, this research adopted a qualitative methodological paradigm to explore the operations of digitally enabled healthcare systems that enable physicians to guide and empower patients to engage in decision-making about their cancer care. To accomplish its vision and goals, the research explored several issues related to digital health technology, oncology consultations, and the cancer patient’s journey by addressing the following questions:

RQ1. What digital technology-based tools are available to support shared decision-making workflows in oncology consultation practices?

RQ2. How is shared decision-making actually carried out in real-life oncology consultations?

RQ3. How do physicians use digital technology-based tools in consultations to support patients in shared decision-making in their routine oncology consultations?

RQ4. What are the barriers and enablers for physicians to use digital technology-based tools for engaging patients with cancer in shared decision-making conversations?

RQ5. How can existing and emerging technologies be adopted and enhanced to support further incorporation of shared decision-making as a method of care in oncology consultations?

1.8 THESIS OUTLINE

The first chapter of this thesis explains the objectives and purpose of the study. It covers various topics, including the concept of shared decision-making as a model of care and the definition of digital tools in the context of oncology. The chapter also explores the scope and background of the research, as well as the possible barriers and facilitators to implementing digital technology-based shared decision-making in oncology practice. Additionally, it identifies key issues in the digital technology-enabled management of patients diagnosed with cancer, outlines the research objectives, and provides a roadmap of the thesis. Chapter 1, the introduction, concludes with a brief description of each remaining chapter, from Chapter 2 to Chapter 5, and summarises the logical flow of the thesis in Figure 1.

Chapter 2, the article '*Computer-Based Decision Tools for Shared Therapeutic Decision-Making in Oncology: Systematic Review',* was published by the journal JMIR Cancer. It presents a structured examination outlining the current adoption maturity of computer-based decision tools to support shared decision-making conversations for treatment decisions in medical oncology consultation services.

Chapter 3, '*Shared Decision-Making in Oncology Consultations and the Role of Technology'*, provides the initial real-world workflows for oncology practice as developed and documented during brainstorming sessions with a senior oncologist in a series of workshops. The second part of this chapter presents the findings from a two-hour interview with the senior oncologist on site at a major tertiary hospital's oncology clinics. The aim of the interview was to gain a deeper understanding and clarification of the actual oncology consultation processes and challenges faced by oncologists in real-world settings. The third and final part of Chapter 3 is an article to be submitted for publication by the journal JMIR Cancer. The article discusses observations from real oncology consultations at a large cancer centre. It presents the results of a study that examined how oncologists undertake shared decision-making and how digital technologies support shared decision-making at a cancer centre in Sydney, Australia. The three sections of this chapter offer a triangulated overview of the investigation, confirming the current clinical workflows used in planning care for patients with cancer.

Chapter 4 begins by outlining the principles and techniques used to apply human-centred design when creating wireframe mock-up prototypes for a digitally enabled shared decision-making tool, which can be integrated into electronic health record systems. The chapter concludes with the publication of '*Examining How Technology Supports Shared Decision-Making in Oncology Consultations*' in the journal JMIR Cancer. The article presents the perspectives of oncologists from several cancer centres in metropolitan Sydney, Australia, on the relevance of digitally enabled shared decision-making tools in their oncology practices. It also highlights the oncologists' suggestions for enhancing the system's design and expanding the availability of future electronic health record systems to better assist physicians and patients in making informed, shared decisions during consultations.

Chapter 5, *Discussion and Future Perspectives,* is the final chapter of this thesis. It summarises the findings from previous chapters, discusses the significance and limitations of the research, and explores the implications of the results for future research. It examines the digitally enabled shared decision-making model of care to promote person-centred care, healthcare policy development, digital transformation of oncology consultation practices, and the design of future electronic health record systems that incorporate shared decision-making workflows. The suggested improvements in this final chapter could help to strengthen future shared decision-making processes and the effectiveness of digital tools to support shared decision-making in cancer care clinics. The chapter concludes with suggestions for ongoing future research, including the investigation of artificial intelligence-based digital health tools.

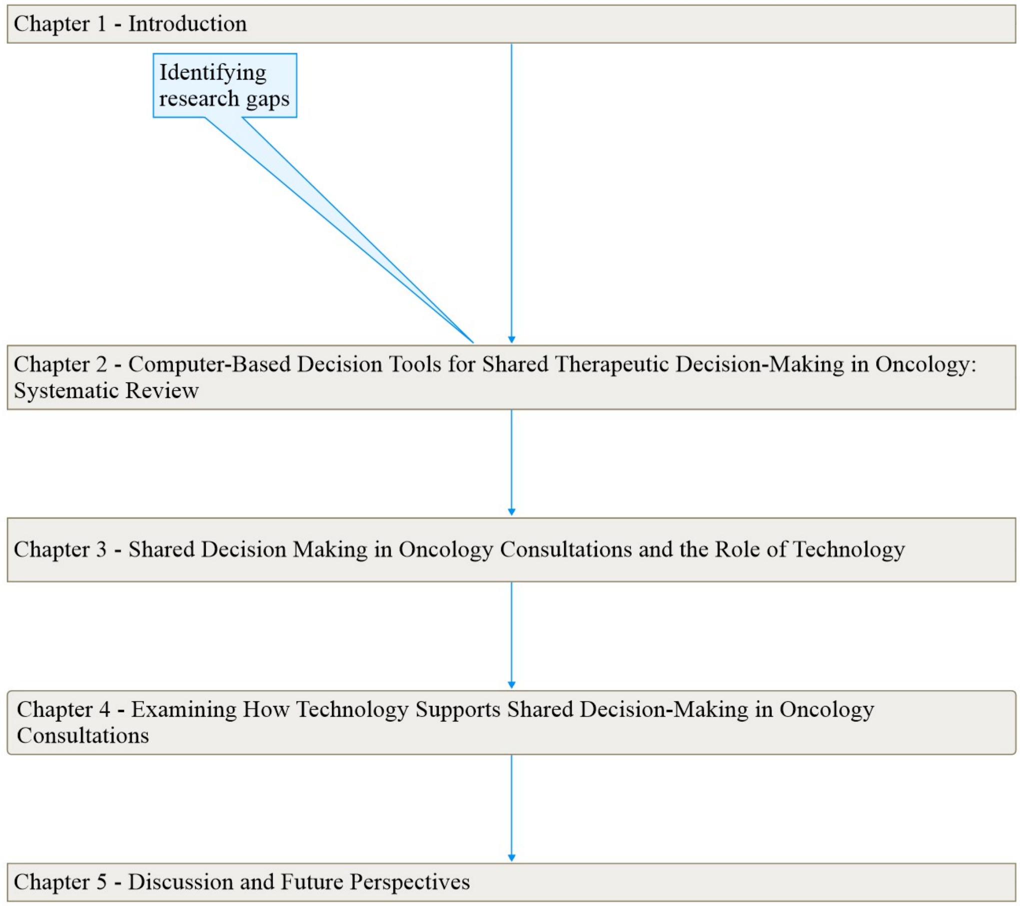

Figure 1: The thesis logical progression flow chart.

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CHAPTER 2: COMPUTER-BASED DECISION TOOLS FOR SHARED THERAPEUTIC DECISION-MAKING IN ONCOLOGY: SYSTEMATIC REVIEW

The following publication is based on the work in this chapter.

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- conception and design of research
- experimental data collection
- data management
- analysis and interpretation of the findings
- writing the manuscript

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Review

Computer-Based Decision Tools for Shared Therapeutic Decision-making in Oncology: Systematic Review

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Abstract

Background: Therapeutic decision-making in oncology is a complex process because physicians must consider many forms of medical data and protocols. Another challenge for physicians is to clearly communicate their decision-making process to patients to ensure informed consent. Computer-based decision tools have the potential to play a valuable role in supporting this process.

Objective: This systematic review aims to investigate the extent to which computer-based decision tools have been successfully adopted in oncology consultations to improve patient-physician joint therapeutic decision-making.

Methods: This review was conducted in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 checklist and guidelines. A literature search was conducted on February 4, 2021, across the Cochrane Database of Systematic Reviews (from 2005 to January 28, 2021), the Cochrane Central Register of Controlled Trials (December 2020), MEDLINE (from 1946 to February 4, 2021), Embase (from 1947 to February 4, 2021), Web of Science (from 1900 to 2021), Scopus (from 1969 to 2021), and PubMed (from 1991 to 2021). We used a *snowball* approach to identify additional studies by searching the reference lists of the studies included for full-text review. Additional supplementary searches of relevant journals and gray literature websites were conducted. The reviewers screened the articles eligible for review for quality and inclusion before data extraction.

Results: There are relatively few studies looking at the use of computer-based decision tools in oncology consultations. Of the 4431 unique articles obtained from the searches, only 10 (0.22%) satisfied the selection criteria. From the 10 selected studies, 8 computer-based decision tools were identified. Of the 10 studies, 6 (60%) were conducted in the United States. Communication and information-sharing were improved between physicians and patients. However, physicians did not change their habits to take advantage of computer-assisted decision-making tools or the information they provide. On average, the use of these computer-based decision tools added approximately 5 minutes to the total length of consultations. In addition, some physicians felt that the technology increased patients' anxiety.

Conclusions: Of the 10 selected studies, 6 (60%) demonstrated positive outcomes, 1 (10%) showed negative results, and 3 (30%) were neutral. Adoption of computer-based decision tools during oncology consultations continues to be low. This review shows that information-sharing and communication between physicians and patients can be improved with the assistance of technology. However, the lack of integration with electronic health records is a barrier. This review provides key requirements for enhancing the chance of success of future computer-based decision tools. However, it does not show the effects of health care policies, regulations, or business administration on physicians' propensity to adopt the technology. Nevertheless, it is important that future research address the influence of these higher-level factors as well.

Trial Registration: PROSPERO International Prospective Register of Systematic Reviews CRD42021226087; https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021226087

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KEYWORDS

oncology; cancer; computer-based; decision support; decision-making; system; tool; machine learning; artificial intelligence; uncertainty; shared decision-making

Introduction

Background

As patients continue to play a more active role in the management of their health, the person-centered model of care has been promoted as a strategy to improve the quality of health care systems [1]. Along with ensuring that all clinical decisions are guided by the patient's values, the goal of the person-centered model is to respect and respond to the individual's preferences and needs. This motivates physicians and patients to coordinate their activities, share information, and reach shared therapeutic decisions [2]. This review takes a person-centered approach for the important and challenging case of consultations involving patients with cancer. Patients have come to expect their treating physicians to explain the benefits, as well as the risks, of the therapies recommended to them. Furthermore, patients prefer to be engaged in the therapeutic decision-making process [3,4], except when they are very ill [5,6], rather than permitting their physicians to choose therapies for them. Patients may also want to be given the chance to consider their options and to choose between accepting or refusing a therapy.

Medical consultations in oncology are a multipart process that involves shared decision-making between the patient and the physician. Bomhof-Roordink et al [7] have articulated this process in their model of shared decision-making. A physician starts the anticancer treatment recommendation process by learning about the patient's preferences, before or during consultations, which they need to consider along with the evidence of efficacy of each potential treatment option. Next, the physician needs to engage the patient in reviewing the potential benefits and risks of the key therapeutic choices available. After collaboratively and carefully examining the situation, the physician provides treatment recommendations. However, the ultimate course of action may be chosen by the patient alone or by the physician when the patient does not want to decide [7].

As the choice of diagnostic modalities and therapies grows, the clinical decision-making process has become extremely complex [8]. Faced with large volumes of fragmented information, physicians must reconstruct, identify, and consider the portion of information that they share with their patients. In addition, physicians need to decide how to best inform their patients and obtain their consent [9]. Hence, physicians need clinical information that is organized and presented in a way that is easy for them to interpret and share in discussions with their patients.

Once physicians have determined what they need to share, they need to be able to show the relevant information to their patients in such a way that the patient can understand the meaning of the different benefits and risks of each therapeutic choice [5,10]. When physicians can summarize information that is relevant to patients' diseases and their survival, explain highly uncertain situations, and manage their interactions with patients well, then patients can more easily understand their physicians' recommendations and choose their preferred therapy or care pathway. This step establishes the foundation for informed consent in shared therapeutic decision-making.

With the intention to support patients, as well as physicians, in this challenging therapeutic decision-making process, paper-based decision tools have been developed [8]. They have been designed to enhance patient-physician communications and interactions. In addition to the incorporation of research results, for example, evidence from clinical trials, paper-based decision tools inform both physicians and patients of the risks, benefits, and outcomes of the available therapies [6,11,12]. Furthermore, paper-based decision tools have a long tradition in supporting clinical decision-making. They have been shown to improve patients' knowledge, accuracy of perceived potential risks, understanding of prognosis, treatment goals, and health outcomes [8]. Moreover, in practices where paper-based decision tools are used, they are well accepted [11]. However, paper-based decision tools can be difficult to update when new therapies are rapidly being developed and adopted. Furthermore, increasing the use of genetic testing and the introduction of advanced molecular medicine in routine clinical practice has generated an expanding body of knowledge that increases the complexity of the decision-making process [2]. Thus, it is recommended that physicians and patients use computer-based decision tools to improve the process outlined above [2].

Hunt et al [13] defined a computer-based decision tool as follows: "any software designed to directly aid in clinical decision-making in which characteristics of individual patients are matched to a computerized knowledge base for the purpose of generating patient-specific assessments or recommendations that are then presented to clinicians for consideration."

Research to create computer-based clinical decision tools has a long history. For example, as far back as 1973, Shortliffe et al [14] published a paper on this topic. Shortliffe [15] believed that with computer-based decision tools, knowledge can be integrated and disseminated to physicians. Similarly, computer-based decision tools may aid in packaging relevant clinical information and therapeutic choices for presentation to individual patients [16]. They may also simplify patient-physician communications [8]. On the basis of these perceived benefits, several computer-based decision tools have been developed to assist therapeutic decision-making during oncology consultations [17].

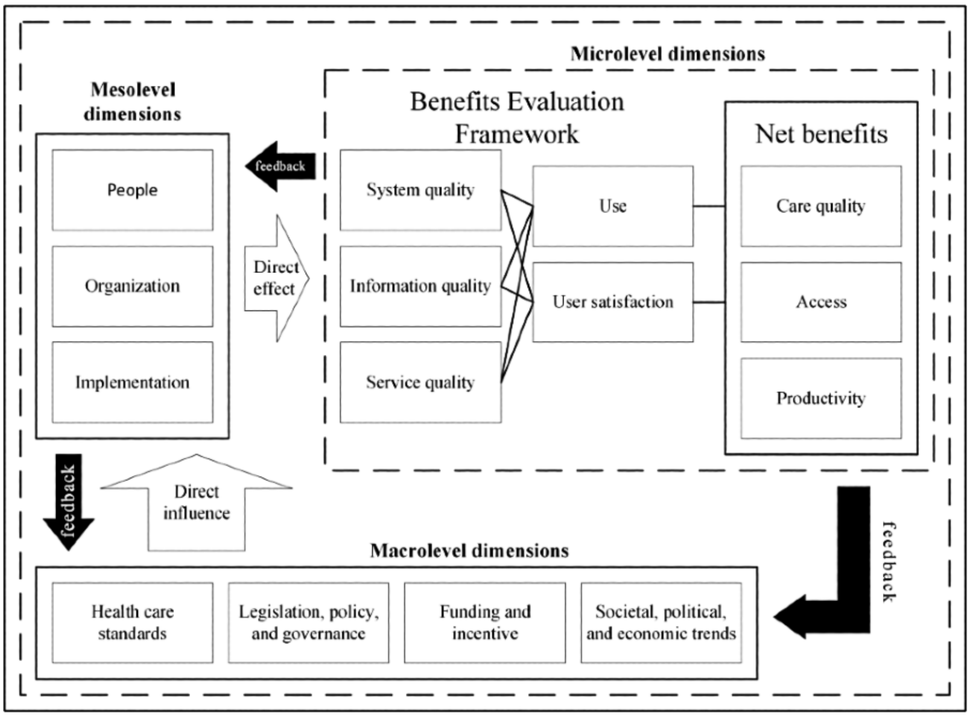
For example, Shortliffe et al [18] developed a computer-based decision tool to guide physicians treating patients with cancer. The technology consists of a computer user interface that enables physicians to review patients' historical data and test results, enter new information about patients, and query the computer system for anticancer therapy recommendations. The implemented computer technology was initially based on the IF-THEN rule algorithm: for example, "IF: there is evidence of disease extension THEN: refer the patient to lymphoma clinic" [18]. However, more recently, computer-based decision tools have been redeveloped for oncology consultations by applying artificial-intelligence–based machine learning software technologies to improve the accuracy of the recommended anticancer therapies [16].

It is unclear at what level computer-based decision tools are adopted by oncology physicians. There have been a small number of reviews about computer-based clinical decision tools [19-21]. Pawloski et al [21] reported patients' outcomes from a treatment delivery viewpoint. Beauchemin et al [20] described decision tools broadly and included nursing care delivery in their study. In contrast, Mazo et al [19] provided an overview of decision tools for breast cancer. However, none of the reviews addressed physicians' propensity to adopt computer-based decision tools during oncology consultations. The aim of this review is to identify and categorize the factors that influence physicians' propensity to adopt computer-based decision tools in oncology consultations by using the Clinical Adoption Framework (CAF) [22,23].

Conceptual Model

The CAF, as shown in Figure 1, is an extension of the Benefits Evaluation Framework (Canada Health Infoway), which was adapted from the DeLone and McLean information system success measurement model, as cited in the study by Lau et al [22].

Figure 1. Clinical Adoption Framework with the micro-, meso-, and macrolevel dimensions, which could influence the successful adoption of health information systems, and the associated conceptualized feedback loops [22,24].



Conceptually, the CAF is made up of micro-, meso-, and macrolevels. At the microlevel, the focus is on the dimension of quality, which measures success factors such as information completeness, accuracy, relevance and comprehension, system features, performance, security, responsiveness, support services, and leadership; user behavior, intention to use the technology, and user satisfaction; and net benefits, which refer to patient safety, risk, effectiveness, compliance, health outcomes, efficiency and capability, cost and savings, availability and access to services, and patient and clinician participation [24].

The mesolevel dimensions directly influence microlevel users' propensity to adopt the technology. It addresses people's characteristics and their expectations, roles, and responsibilities; technology system and organizational fit, strategy, culture, structure or processes, information infrastructure, and return on value; and implementation stages, project management approaches, and technology fit with present and future operations [24].

The macrolevel dimensions directly affect the mesolevel factors, which in turn affect the success of adoption at the microlevel. At the macrolevel, governance, legislations, regulations, and policies; health care and professional practice standards; funding and incentive payments; and trends in public expectations as well as sociopolitical and economic climates with respect to technologies and the whole health care system influence adoption [24].

In addition, as indicated in Figure 1, there is a feedback loop at each level of the CAF. The results of each level are fed back to higher and lower levels of the conceptual model, that is, the outcomes of microlevel factors influence the meso- and macrolevel factors. Similarly, mesolevel factors influence higher macrolevel and lower microlevel factors, and macrolevel factors affect mesolevel factors [24]. Consequently, the CAF represents a technical, social, political, and economic system that must contend with constant internal and external forces that dynamically affect propensity to implement and adopt computerized information systems in health care settings.

The research questions are as follows: (1) What is the extent of adoption of computer-based decision tools in oncology consultations? (2) Is there a difference in levels of adoption by country and period? (3) What factors may have influenced the adoption of the technology? (4) What are the lessons learned to improve adoption of the technology?

Methods

This systematic review was registered on PROSPERO (CRD42021226087), the International Prospective Register of Systematic Reviews [25].

Search Strategy and Inclusion Criteria

This study was conducted in accordance with the Cochrane Handbook for Systematic Reviews of Interventions [26] and followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 checklist, guidelines, and statements [27]. In addition, with the assistance of medical sciences librarians, the search strategy was constructed by applying the PICOC framework [28,29]:

- P (population): only physicians treating patients with cancer were included. Other clinicians such as nurses, pharmacists, or supportive care professionals were excluded.
- I (intervention): only computer-based decision tools used to assist oncology consultations were included. Paper-based tools or digital tools such as websites that are used solely and independently by patients who seek information outside consultations with their treating physicians were not included.
- C (comparison): usual care, which means health care based on traditional paper pamphlets, video recordings, or using standard data collection in electronic health record systems.
- O (outcomes): adoption of the technology for use during oncology consultations, that is, physicians use the information provided by computer-based decision tools as part of their routine medical practice to deliver oncology care.
- C (context): assisting shared decision-making during the selection of anticancer therapy, that is, physicians and patients use the information provided by the technology to collaborate and discuss the benefits and potential harms of each treatment option before agreeing on a final treatment plan. In this context, use of the technology does not mean only the physician needs to physically operate or view information on the computer screen. The physician may provide access to the technology to the patient or another care provider to assist the patient enter personal information or understand the information provided. The physician can then use the additional information provided by the patient to facilitate discussions and decision-making during the consultation.

On February 4, 2021, 1 reviewer (AY) used the OvidSP platform (Health First) to search the following databases: Cochrane Database of Systematic Reviews (from 2005 to January 28, 2021), Cochrane Central Register of Controlled Trials (December 2020), MEDLINE (from 1946 to February 4, 2021), and Embase (from 1947 to February 4, 2021). In addition, on the same day, the databases of Web of Science (from 1900 to 2021), Scopus (from 1969 to 2021), and PubMed (from 1991 to 2021) were searched. After relevant articles were selected for inclusion in this review, the reference list and citations of each article were inspected for additional articles. The *snowball* search was conducted using Scopus and Google Scholar. Further searches for relevant articles were conducted by browsing the *BMC Medical Informatics and Decision Making* journal website, along with searches of gray literature websites [30-33]. The detailed Boolean expressions of the search strategy are provided in Multimedia Appendix 1.

Study Selection

A single review author (AY) removed duplicates and screened the titles and abstracts of all retrieved articles for relevance in accordance with the criteria of the research questions. Similarly, another 2 review authors (JK and TS) independently assessed the eligibility of a randomly selected sample of articles from a subset of the retrieved articles to judge their eligibility for inclusion or exclusion in the review. Disagreement among the 3 review authors was resolved through discussion.

First, guided by the evidence-based medicine pyramid [34], articles that used a study design within the categories of randomized controlled trials, cohort studies, case-control studies, and case series or reports were included for review, whereas articles that were published as conference papers or abstracts, protocols, commentaries, editorials, letters, or opinions were excluded because of their perceived low quality. No limitation on language was imposed. For articles that were not published in the English language, attempts were made to translate them into English by using a web-based translator [35]. Second, studies that met the following key criteria were included: (1) the study was conducted in an oncology consultation setting, (2) it involved distinct real-world computer-based decision tool use by oncology physicians, (3) a computer-based decision tool assisted patient-physician communications to share information and to agree on an anticancer therapy; and (4) the elements of the effectiveness of a computer-based decision tool in oncology consultations were reported.

Data Extraction

A data extraction spreadsheet to capture study information was developed a priori by 3 reviewers. The selected studies were then screened by 1 review author, and relevant qualitative data were extracted. The spreadsheet was populated in accordance with the requirements of the review questions. As more experience was gained with data extraction, the review authors iteratively adjusted the required variables in the spreadsheet. The final set of data variables required to answer the review questions was as follows: study; study design and participant sample size; computer-based decision tool versus comparator; clinical setting context and country; primary objective; and study outcomes (Table 1).

Table 1. Overview of the included studies, ordered with the most recent first (N=10).

Study	Study design and participant sample size	Computer-based decision tool versus comparator	Clinical setting context, country	Primary objective	Study outcomes[a]
Wyatt et al [36], 2019	Pre- and postsurvey patients (n=290), postsurvey patients (n=447)	TakeTheWind versus no comparison	Breast cancer clinic (n=1), United States	To assess utility, ease of use, and impact of decision tool	*Patients preferred shared decision-making* and written material, disliked tablet computers, and had trouble navigating and accessing the tool.
Yao et al [37], 2019	Longitudinal, prospective before-and-after study; CDT[b]-arm patients (n=63), surgeons (n=2); UC[c]-arm patients (n=57), surgeons (n=3)	In-visit decision aid versus UC	Breast surgery clinics (n=5), institution (n=1), United States	To measure impact on knowledge, preferences, and involvement	*Patients had more discussions regarding their treatment with surgeons and had less surgery.* (Anxiety, distress, fear, quality of life, and concerns regarding body image were unchanged) compared with UC.
Cuypers et al [38], 2019	RCT[d]; CDT-arm hospitals (n=9), UC-arm hospitals (n=9), academic medical center (n=1)	Prostaat versus UC	Prostate cancer hospitals (n=18), academic medical center (n=1), the Netherlands	To understand implementation and use of CDT	*Improved physician-patient communication about preferences and values*
Raj et al [39], 2017	Controlled before-and-after study; before-implementation patients (n=80), after-implementation patients (n=134)	COMBAT versus paper	Pain management at outpatient cancer clinic, Norway	To evaluate improvement in pain management	(No change in physicians' behavior and no improvement in pain management)
Yao et al [40], 2017	Prospective pre-post study; CDT-arm patients (n=97), UC-arm patients (n=114)	In-visit decision aid versus UC	Breast surgery at hospitals (n=3), United States	To examine effects on shared information and treatment choice	*Higher knowledge levels in the CDT group than in the UC group*
Miles et al [41], 2017	Mixed-methods randomized trial; patients (n=13)	Openclinical versus no comparison	Colorectal cancer outpatient oncology department, United Kingdom	To examine acceptability, usefulness, and areas of improvement	*CDT was accepted and found useful by patients* but needed improved presentation of information.
Henton et al [42], 2017	Usability study; patients with prostate cancer (n=7), patients with colorectal cancer (n=7)	SEER*CSC[e] versus no comparison	Prostate and colorectal cancer centers (n=4), United States	To understand patients' information needs and preferences	CDT lacked features to facilitate patient-physician discussions and was time consuming for data entry.
Morgan et al [43], 2015	Prospective study; patients (n=25)	Morgan versus no comparison	Breast cancer center, Canada	To assess satisfaction and knowledge retention	*Knowledge retention was high, and patients were highly satisfied.*
Siminoff et al [44], 2006	RCT; physicians (n=58), patient-physician pairs (n=405)	Adjuvant! versus UC pamphlet	Breast cancer oncology practices (n=14), United States	To examine impact on treatment decisions and practice	CDT added 5 minutes to total consultation time *and was found more useful than a pamphlet.*
Peele et al [45], 2005	RCT; physicians (n=56), CDT-arm patients (n=250), UC-arm patients (n=182)	Adjuvant! versus UC pamphlet	Breast cancer practices, academic (n=5), community-based (n=9), United States	To examine impact on women's adjuvant therapeutic decision	*Fewer women with low tumor severity chose adjuvant therapy.*

[a]To represent the key outcomes of each study, the following formatting has been adopted: *italic text* represents positive outcomes, normal text represents negative outcomes, and normal text within parentheses represents neutral outcomes.

[b]CDT: computer-based decision tool.

[c]UC: usual care.

[d]RCT: randomized controlled trial.

[e]SEER*CSC: Surveillance, Epidemiology, and End Results Cancer Survival Calculator.

Risk-of-Bias Assessment

Using the Cochrane risk-of-bias tools for randomized controlled trials and nonrandomized studies, 1 review author assessed the risk of bias of the included studies [26]. The tool for randomized controlled trials [46] assesses studies on each of these 6 domains: (1) randomization processes, (2) identification or recruitment of participants into clusters, (3) deviations from the intended intervention, (4) missing outcome data, (5) measurement of the outcome, and (6) selection of the reported result. The tool for nonrandomized studies [47] assesses studies on each of these 7 domains: (1) due to confounding, (2) selection of participants into the study, (3) classification of intervention, (4) deviations from the intended intervention, (5) missing data, (6) measurement of outcomes, and (7) selection of the reported result. Finally, the judgment in each domain is carried forward to an overall risk of bias for each study. The tools highlighted some risk of bias in all the selected studies.

Data Synthesis

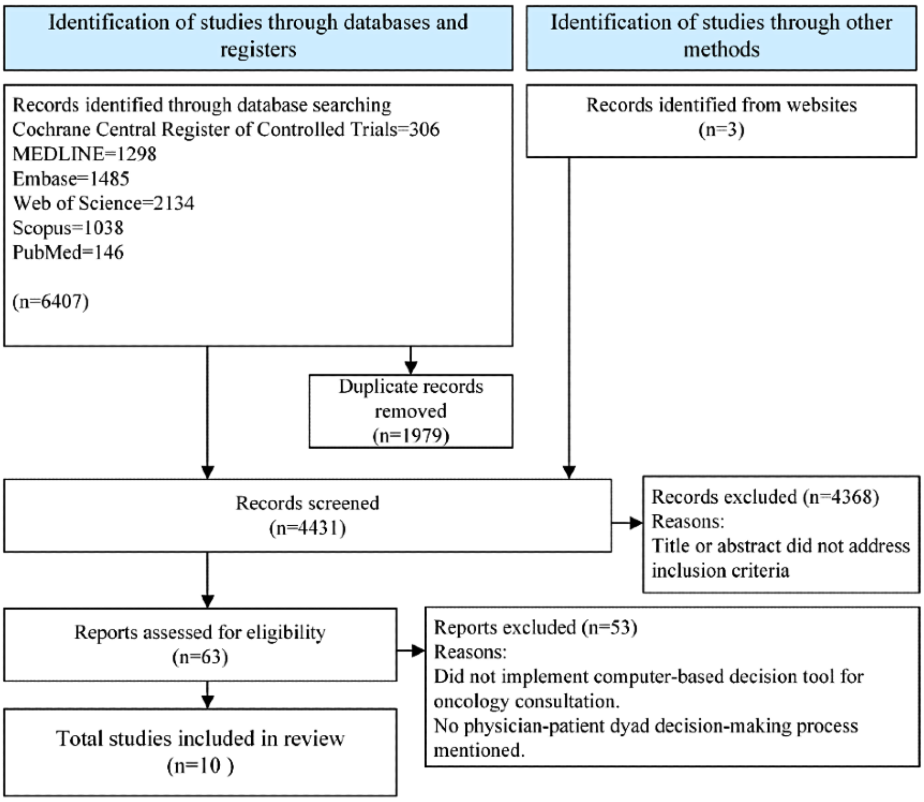
The articles included in this study reported a high diversity of functionalities and features of computer-based decision tools. Therefore, the reported outcomes of the studies were grouped according to the dimensions of the CAF [22]. The results within each group were subsequently assessed and combined into a common set of factors that directly affect physicians' propensity to adopt computer-based decision tools in oncology consultations.

Results

Search Results and Study Characteristics

The initial searches in the aforementioned databases retrieved 6407 articles (Figure 2). Browsing searches and inspections of reference lists and citations identified 3 additional articles. Of the 6407 articles retrieved through database search, 1979 (30.89%) duplicates were removed. Of the remaining total 4431 articles, 4368 (98.58%) were excluded after titles and abstracts were screened. Next, the full-text articles were assessed for eligibility, and of the 63 articles, 53 (84%) were excluded. A total of 10 studies were thus included in this review.

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 flowchart of the study selection process and results.



When the 10 selected studies for review were assessed by using the Cochrane risk-of-bias tools, they all exhibited some level of risk of bias. Of the 10 studies, 3 (30%) were randomized controlled trials [38,44,45], and 1 (10%) was a mixed-methods randomized study [41] (Multimedia Appendix 2, Table S1 [38,41,44,45]). All (4/4, 100%) the randomized studies included a high risk of bias because of the practices observed when assigning participants, adhering to the intervention, and accounting for missing outcome data. Of the 10 studies, 6 (60%) were nonrandomized studies (Multimedia Appendix 2, Table S2 [36,37,39,40,42,43]). Of these 6 nonrandomized studies, 1 (17%) [39] included a moderate risk of bias, whereas the remaining 5 (83%) [36,37,40,42,43] included serious risk of bias due to confounding [36,37,40], bias in selecting participants [43], bias in accounting for missing data, and measurement of outcomes [42].

Table 1 includes significant details gathered from the reviewed studies. Of the 10 studies, 6 (60%) were conducted in the United States, and 1 (10%) each was conducted in Canada, the Netherlands, Norway, and the United Kingdom. In all, 8 different computer-based decision tools were used across the 10 studies.

A summary of the identified computer-based decision tools from the review is provided in Table 2. The details include the name of the computer-based decision tool, country where each evaluation was conducted, categories of disease that were handled, types of decision that were settled, number of studies that were conducted for each computer-based decision tool, and bibliographical references. Of the 8 computer-based decision tools, 4 (50%) were evaluated for breast cancer consultations; 1 (13%) each for colorectal, prostate cancer, and cancer pain; and 1 (13%) for breast or colorectal cancer.

Table 2. Summary of 8 identified computer-based decision tools from 10 reviewed studies.

Name of computer-based decision tool	Country	Disease category	Type of decision	Number of studies	Reference
Adjuvant!	United States	Breast cancer	Take adjuvant chemotherapy or not	2	[44,45]
In-visit decision aid	United States	Breast cancer	Choose surgical option	2	[37,40]
Morgan	Canada	Breast cancer	Educate patients about adjuvant systemic therapy	1	[43]
TakeTheWind	United States	Breast cancer	Choose surgical option	1	[36]
SEER*CSC[a]	United States	Breast or colorectal cancer	Estimate patient prognosis	1	[42]
Openclinical	United Kingdom	Colorectal cancer	Take adjuvant chemotherapy or not	1	[41]
COMBAT	Norway	Cancer pain	Choose opioid dose and pain management option	1	[39]
Prostaat	Netherlands	Prostate cancer	Choose surgical and radiotherapy or no treatment	1	[38]

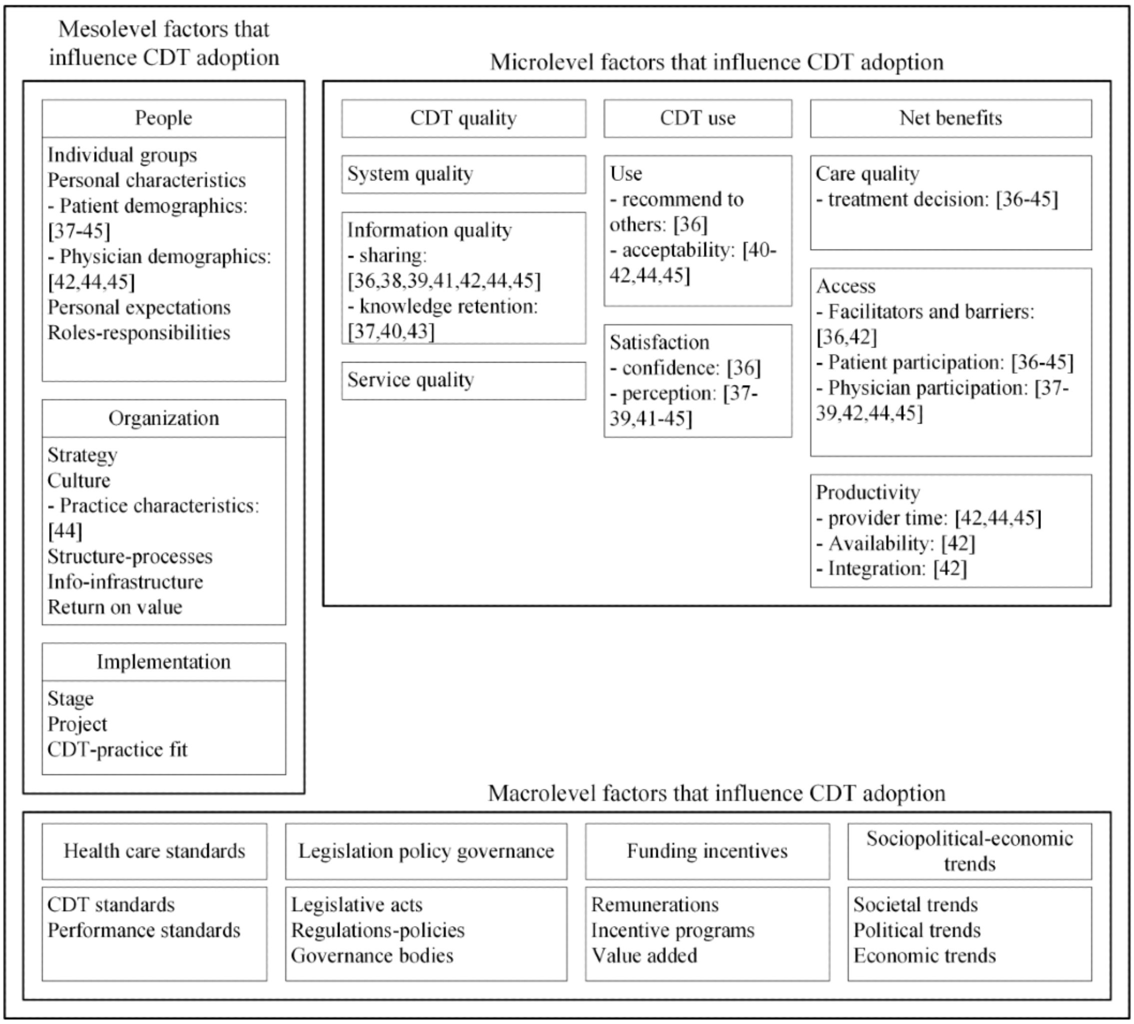
[a]SEER*CSC: Surveillance, Epidemiology, and End Results Cancer Survival Calculator.

Factors Influencing Adoption of a Computer-Based Decision Tool

Levels of Impact

The factors that influenced the adoption of computer-based decision tools during oncology consultations were identified from the 10 selected studies. An initial 16 distinct influential factors were collected from the review and mapped to the categories of the CAF as shown in Figure 3. Afterward, these 16 factors were expanded to show their levels of impact on adoption as shown in Multimedia Appendix 3 [36-45] and in the following sections [22].

Figure 3. Micro-, meso-, and macrolevel factors that influence computer-based decision tool adoption [22]. CDT: computer-based decision tool.



Microlevel

Quality of System, Information, and Service

At the microlevel, no system or service quality factors were identified. However, information quality factors included information-sharing and knowledge retention. Transfer of information between patients and physicians was assessed by 30% (3/10) of the studies, which reported that patients retained a high level of treatment knowledge after consultations with physicians who used a computer-based decision tool [37,40,43]. Of the 10 studies, 5 (50%) assessed the level of information-sharing. Of these 5 studies, 1 (20%) found that 81.4% of the physicians considered the information provided by the computer-based decision tool useful [44], 2 (40%) reported that patients found the information about treatment options useful [36,41], and the remaining 2 (40%) reported that physicians did not use the information provided by the computer-based decision tool [39,42]. Of the remaining 5 studies, 1 (20%) reported that 65% of the patients read all information provided about treatment comparisons, and 71% of the patients indicated that they discussed the summary that was provided by the computer-based decision tool in consultation with their physicians [38]. A few physicians believed that some patients were made more anxious by the information, did not understand key information [44], were confused by the information provided, or felt that the information provided was conflicting [41]. In addition, some physicians did not value or benefit from the information provided by the computer-based decision tool [39].

Use and User Satisfaction

All 10 reviewed studies discussed use and user satisfaction. The use factors included recommendation and acceptability of use. Of the 10 studies, 1 (10%) [36] reported that when patients were introduced to the technology, 92% indicated that they liked it and would recommend its use to other patients. The feature that they liked the most was the *presence of helpful information*, followed by *ease of navigation* and *confidence in the treatment plan*. After consultations with physicians who used the technology, patients experienced a positive increase in confidence by an average of 0.8 points on a 10-point scale compared with when the technology was not used, and this was statistically significant [36]. However, the study also pointed out that some patients found navigating the technology difficult, disliked the use of tablet computers, and preferred written or printed material [36]. Similarly, another study (1/10, 10%) reported that 22% of the patients preferred consultations with paper-based decision tools [38]. In other cases, physicians provided patients with external access through web technologies to educate and prepare them for discussions about therapeutic choices during consultations. In these cases, other care providers such as nurses were also able to help by walking patients through the information provided by the technology and helped them increase their understanding of the benefits and risks of the different therapies on offer. Of the 10 studies, 4 (40%) reported that this practice was positively acceptable to both physicians and patients, although patients reportedly found the language of computer-based decision tools too complex [41,42,44,45]. Physicians found that their patients communicated better and engaged more in discussions. They felt that they were able to refine their understanding of their patients' preferences, whereas patients felt that their perspectives were made clearer and reflected more accurately [44]. Patients' satisfaction with consultations and clinic visits when computer-based decision tools were used was estimated to have a mean satisfaction score of 4.53 (SD 0.1) out of a maximum score of 5 [43]. However, of the 10 studies, 3 (30%) disclosed that computer-based decision tools did not improve therapeutic decision-making or found no statistically significant difference between decisions made using the technology and usual care and did not change physicians' usual behavior [37,39,40].

Net Benefits in Terms of Care Quality, Access, and Productivity

Of the 10 studies, 8 (80%) referred to care quality factors as net benefits of computer-based decision tools. The studies [36-41,44,45] measured the proportion of patients who received various types of treatment. Siminoff et al [44] indicated that the difference in the proportion of patients receiving various types of therapy was statistically insignificant but stated that the adoption of computer-based decision tools during oncology consultations influenced 86.2% of the patients' treatment decisions. The authors also declared that 84.6% of the patients in technology-assisted consultations accepted treatment compared with 89.5% of the patients in usual care. Furthermore, Peele et al [45] reported that only 58% of the women in consultations with technology accepted adjuvant therapy, an additional treatment to enhance the effectiveness of an initial medical treatment, compared with 87% of the women in usual care, and Yao et al [37] reported that 15.9% of the patients with low tumor severity in technology-assisted consultations accepted treatment compared with 24.6% in usual care. Similarly, Miles et al [41] reported that when technology was used in consultations, 11 out of 12 patients declined chemotherapy.

In contrast, of the 10 studies, 3 (30%) reported that patients in consultations with computer-based decision tools received more treatments than those in usual care. In a computer-based decision tool study for prostate cancer, 71% of the patients received treatment [38]. In a study for breast cancer treatment, 21.7% of the patients underwent surgery compared with 15.8% in usual care [37]. In addition, significantly more patients with high tumor severity chose adjuvant therapy in the computer-based decision tool group [45].

Of the 10 studies, 1 (10%) examined the effects of technology-assisted consultations on cancer pain intensity [39]. The authors observed no significant difference in pain intensity when technology was used compared with before its introduction. In addition, after 3 weeks of follow-up care, the authors noted that there was a lack of efficacy when the technology was used.

Of the 10 studies, 2 (20%) discussed access factors. The first study collected information on the facilitators and barriers to local adoption and implementation of a computer-based decision tool [42]. The study mentioned that the facilitators or barriers included existing channels, processes, and provider preferences. Users revealed that they did not access the technology because of lack of incentives or infrastructure, time, information about treatment, integration with the electronic health record system, availability of the technology on their desktops, and their own habits or preferences [42]. The second study produced a nonprioritized list of the facilitators and barriers to access [36]. The study identified that users needed to enter their username and password to log in, or they encountered technical issues every time they tried to use the technology; users had difficulty connecting wirelessly to the internet; and users were being provided information that they had already received on paper or during consultation [36].

Productivity factors covered the length of consultations. Of the 10 studies, 1 (10%) measured physicians' productivity in terms of the effect of a computer-based decision tool on the length of consultations [44], and it found that an average of 5 minutes was added to the length of consultations.

Meso- and Macrolevels

Of the 10 studies, 9 (90%) identified patient demographics, 3 (30%) identified physician demographics, and 1 (10%) identified practice characteristics as mesolevel factors. However, there were no factors identified that explicitly influenced adoption at the mesolevel. At the macrolevel, there were no health care standards; legislations; policies; governance; funding incentives; or societal, political, or economic factors identified that explicitly influenced adoption.

Summary of Key Findings

The results of this review showed that of the 8 identified computer-based decision tools, 4 (50%) were developed and studied in the United States, as shown in Table 2 [36,37,40,42,44,45]. Next, to determine whether a study was positive, negative, or neutral, the greater than or equal (≥) 50% rule, as cited in the study by Lau et al [22], was adopted. Consequently, of the 10 studies, 6 (60%) reported positive results for computer-based decision tools [37,38,41,43-45], whereas only 1 (10%) reported negative results [42]; 3 (30%) were neutral [36,39,40].

The CAF was extended to accommodate factors that influenced physicians' propensity to adopt computer-based decision tools in oncology consultations. Of the 83 factors at the microlevel, 20 (24%) were identified as influential (Multimedia Appendix 3). Of these 20 factors, Textbox 1 reports 11 (55%) that were identified as positively affecting physicians, Textbox 2 reports 7 (35%) that negatively affected physicians, and Textbox 3 reports 2 (10%) that had no effect on physicians.

The studies did not explicitly provide evidence of meso- and macrolevel factors that influenced physicians' propensity to adopt computer-based decision tools.

Textbox 1. The positive factors that influenced physicians' propensity to adopt computer-based decision tools (N=11).

Factors that were identified as positively affecting physicians

- Access
  - Factor 1: treatment decisions were influenced by recommendations from physicians.
  - Factor 2: information provided by the technology was given to patients by physicians.
  - Factor 3: treatment information and the relationship with survival were included to facilitate conversation with patients.
  - Factor 4: technology helped physicians to understand patients' treatment preferences.
  - Factor 5: information provided by the technology was useful to physicians.
  - Factor 6: a copy of the information produced by the technology was used for reference during consultations.
- Information quality
  - Factor 7: physician-patient communication about preferences and values was improved.
  - Factor 8: physicians reviewed information provided by the technology with patients during consultations.
- Satisfaction
  - Factor 9: physicians believed that patients became more engaged in discussion and understood the information.
- Use
  - Factor 10: physicians reported that the technology was useful for their patients.
  - Factor 11: the technology was used in routine practice in academic and community practices.

Textbox 2. The negative factors that influenced physicians' propensity to adopt computer-based decision tools (N=7).

Factors that were identified as negatively affecting physicians

- Access
  - Factor 12: the technology did not provide all the information that the physicians wanted.
  - Factor 13: the technology was not readily available on the physicians' desktop.
  - Factor 14: the technology was not integrated with the electronic health record.
- Information quality
  - Factor 15: physicians did not take advantage of the information conveyed through the technology.
  - Factor 16: physicians were not able to share information and treatment alternatives with their patients.
- Productivity
  - Factor 17: the technology added 5 minutes to total consultation time.
- Satisfaction
  - Factor 18: some physicians perceived that the technology made patients somewhat more anxious.

Textbox 3. The factors that showed that the use of computer-based decision tools had no effect on physicians' propensity to adopt the technology (N=2).

Factors that were identified as not affecting physicians

- Access
  - Factor 19: no significant change in physicians' behavior.
- Care quality
  - Factor 20: no significant change in prescribed drug dosage between preintervention and intervention periods.

Discussion

Making Sense of the Adoption Success of Computer-Based Decision Tools in Oncology Consultations

This review has 3 aims: (1) to understand the different levels and periods of adoption of computer-based decision tools during oncology consultations across the world, (2) to identify the factors that influenced the adoption of the technology by physicians, and (3) to learn how to guide future implementation and adoption of the technology in the context of shared therapeutic decision-making during oncology consultations [48].

This review showed that the development and studies of computer-based decision tools were primarily conducted in North America and Europe in the last 16 years. Although 10 studies were specifically selected for review based on the topic of computer-based decision tools that were used by physicians in oncology consultations, only 60% (6/10) of the studies addressed some aspects of the perspectives of physicians. Most of the studies focused on patients' views. Our findings of low adoption of computer-based decision tools converged with similar patterns in previous studies [49].

In all, 2 computer-based decision tools—Adjuvant! and an in-visit decision aid—were used across 40% (4/10) of the studies. Adjuvant! provided the strongest evidence of user satisfaction, information-sharing, care quality, and productivity measures. The in-visit decision aid was assessed for users' perception, knowledge retention, and treatment decision. A summary of the 8 identified computer-based decision tools is provided in Table 2.

By extending the CAF to computer-based decision tools in oncology consultations, these findings suggest that of the 20 factors, there are 11 (55%) that can facilitate physicians to adopt the technology and 7 (35%) that can stifle adoption, whereas 2 (10%) may have no effect on physicians' propensity to change and adopt the technology.

Along with helping physicians to understand their patients' treatment preferences, computer-based decision tools enable physicians to refer to information and to provide treatment information and recommendations that are related to their patients' survival. Some physicians used the technology in routine practice in academic and community practices to review information with patients during consultations. They believed that the technology is useful for their patients because their patients become more engaged in discussions and understood the information. Thus, the conversation between the physician and the patient was facilitated during consultations, and the patient-physician communication about preferences and values improved.

In contrast, some physicians perceived that computer-based decision tools made patients more anxious and added 5 minutes to their total consultation time. The study by Siminoff et al [44] gave the impression that an additional 5 minutes was insignificant. The effect, however, was subjective, depending on each physician's expectation. For a 1-hour consultation, an additional 5 minutes may be acceptable. However, the impact of adding 5 minutes to a 10-minute consultation in usual care may become objectionable. Furthermore, when the technology does not provide all the information that physicians want, is not readily available on their desktop, or is not integrated with the electronic health record, then physicians are not able to take advantage of the information conveyed through the technology. Consequently, they are not able to share information and treatment alternatives with their patients.

The findings of this review advance our understanding of the extent to which computer-based decision tools have been successfully adopted in oncology consultations. The evidence suggests that there have been very few studies that address physicians' propensity to adopt computer-based decision tools in routine oncology consultations. This review provides a starting point and direction for further investigations to incorporate computer-based decision tools in usual oncology consultations. This review also provides a guide and key lessons—as shown in Textboxes 1, 2, and 3—for the design and development of new computer-based decision tools. In addition, the review highlighted some important areas that need to be improved in future computer-based decision tools, such as integrated access with electronic medical records (Textbox 2). Some studies have reported negative outcomes with computer-based decision tools [50,51], whereas others have shown benefits [52]. In our review, of the 10 selected studies, 6 (60%) were positive, with only 1 (10%) being negative, whereas 3 (30%) were neutral. Consequently, the impact of computer-based decision tools on oncology consultations is unclear. Taken together, our findings and the findings of similar past studies [19-21,53-56] point to the need for further research in several dimensions of the CAF to uncover the value of computer-based decision tools in oncology practice.

Looking at Figure 3, it is obvious that the studies included in this review have addressed only a small set of factors among the numerous factors that could influence the adoption of computer-based decision tools in oncology consultations. Therefore, future studies will need to address additional dimensions at the meso- and macrolevels to gain a better understanding of what factors lead to successful implementation and adoption of computer-based decision tools in oncology consultations.

Review Limitations

This systematic literature review includes some limitations. First, only 10 studies were included in this review because of the dearth of studies that addressed the issues with computer-based decision tools from the perspectives of physicians. Second, the literature search was conducted by only 1 reviewer, which could have introduced bias and limited the findings. Third, the selected studies for review included a high risk of bias. Furthermore, most of the studies were conducted at nontraditional cancer centers or at health care organizations affiliated with academic institutions, which limit generalization. Fourth, our review covered a wide range of health information systems' issues, which might not have been explored sufficiently and fully explained. Future researchers should refine the search strategy to identify additional potentially relevant studies that may have been missed and allocate more reviewers to search the literature databases to minimize potential biases.

Conclusions

In this review, we investigated the extent to which computer-based decision tools have been adopted in oncology consultations and physicians' propensity to adopt the technology. The results of the investigation suggest that the adoption of computer-based decision tools in oncology consultations remains low. Of our 10 reviewed studies, 6 (60%) showed positive outcomes, whereas 1 (10%) showed negative outcomes, and 3 (30%) were neutral. To date, improvements have been made in communication and information-sharing between patients and physicians. However, unavailability of the information that physicians need, lack of access to the technology on physicians' desktops, and lack of integration with existing electronic health record systems are some of the findings that stifle successful adoption. Therefore, this review shows that, in addition to improving communications between physicians and patients, technology is needed to streamline the flow of information that physicians need to better inform patients. Notwithstanding the 5 minutes that would be added to the overall time of consultations, this review indicates that it is possible to create leaner oncology practices by adopting computer-based decision tools. The technology would eliminate the need to track paper-based information, making the decision-making process more streamlined and eliminating the risk of missing hard-copy paperwork. Hence, in the long run, physicians would have more time to dedicate to their patients. As a result, patients may engage more in discussions during consultations, may be better informed, and they may be more apt to provide consent for treatment.

The CAF provides the capacity to make sense of complex multidimensional factors that influence the adoption of computer-assisted decision-making in oncology consultations. Furthermore, it provides a starting point as well as a sense of direction for research in the design and development of new computer-based decision tools. Thus, this review provides a set of key factors that need to be addressed to enhance the possibility of successfully implementing and adopting computer-based decision tools in oncology consultations. However, although the review shows that it is possible at the microlevel for patients and physicians to improve their communication by using computer-based decision tools, the effects of meso- and macrolevel factors remain understudied. It is therefore important to conduct additional studies in real-world oncology consultations to understand the impact of higher-level factors on physicians' propensity to adopt computer-based decision tools.

Authors' Contributions

This review was conceived and designed by AY, PB, KAG, JK, and TS. AY performed the data collection. The data were analyzed and interpreted by AY, JK, and TS. The paper was drafted by AY, JK, KAG, and TS. Critical revision of the paper was performed by AY, JK, KAG, and TS. All authors approved the final version for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Article search results and screening.
[DOCX File , 16 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Risk of bias in individual randomized controlled trials and nonrandomized studies of interventions.
[DOCX File , 30 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Datasheet of microlevel factors extracted from 10 reviewed studies.
[DOCX File , 58 KB-Multimedia Appendix 3]

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Abbreviations

CAF: Clinical Adoption Framework
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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CHAPTER LINK

Chapter 2 provided a systematic review of the literature on the role of computer-assisted decision-making processes in oncology clinics, emphasising the enhancement of conversation and information exchange between healthcare physicians and patients. These computer-based tools help physicians navigate complex patient health information, the latest medical knowledge base and chemotherapy regimens, thereby supporting informed consent and patient involvement in treatment decisions. The computer-based tools help physicians to align their prescribed cancer treatments, such as chemotherapy, with patients' preferences, values, and objectives. However, the use of these computer-based digital tools in oncology consultations remains limited, with few studies demonstrating their implementation in routine clinical settings. Studies that reported positive outcomes highlighted improvements in communication and information sharing. Nevertheless, some physicians have noted that the digital technology-enabled tools might increase patient anxiety and extend consultation times by around five minutes.

Chapter 3 presents an ethnographic study aimed at understanding how digital technology, particularly electronic health record systems, is integrated into medical oncology clinics that provide treatment consultations to cancer patients at a major cancer centre in metropolitan Sydney, Australia. This study aimed to examine how computer-based digital systems facilitate oncology consultations, with a particular focus on comparing shared decision-making practices in this setting against existing research results. The goal was to evaluate oncology consultation services to identify current challenges and explore opportunities to improve digital tools for supporting shared decision-making in hospital-based cancer care. The study aimed to provide insights into clinical practices related to the care of patients diagnosed with cancer and seeking care. The study aimed to highlight opportunities for using current as well as emerging digital technologies such as generative artificial intelligence capabilities to support shared decision-making efforts, thereby increasing patient participation in the planning and managing of their cancer care.

CHAPTER 3: SHARED DECISION MAKING IN ONCOLOGY CONSULTATIONS AND THE ROLE OF TECHNOLOGY

3.1 CHAPTER PREFACE

The previous chapter examined the scholarly evidence on computer-based decision tools used to support the therapeutic decision-making process in oncology consultations. It highlighted the factors that can help clinicians adopt digital decision support tools while also pointing out the obstacles to their adoption. It described the current state of the available technology to assist in decision-making during oncology visits. These findings revealed various levels within the healthcare system, including the healthcare provider organisation, the clinical setting, communication between clinicians and patients, and time-based tasks in oncology consultations that influence the use of digital technology.

The foundational knowledge described in Chapter Two, regarding how clinicians' needs affect different types of cancer treatment consultations and how digital tools can be designed to improve patient participation in the care pathway, treatment planning, and medical decision-making processes, is drawn upon in this chapter. This chapter has two components: 1) This preface, which provides context and preliminary work undertaken to prepare to undertake ethnographic work undertaken in the second section and 2) A research publication prepared for submission presenting findings from the ethnographic study observing how digital technology-driven decision-making processes impact oncology consultations, with a focus on clinical workflows and the patient centred decision-making model of care within the medical oncology department.

3.1.1 Field work planning, preparation and logistics.

Prior to undertaking observations as part of the ethnographic study, a number of preparatory and logistical tasks were undertaken to ensure the researcher had a high-level understanding of the setting in which the observations would take place. This process involved a two-pronged approach consisting of 1) Exploratory workshops to understand the complexities of clinical workflows and how technology is embedded within them; 2) a clinical domain expert interview to understand the oncology decision-making process.

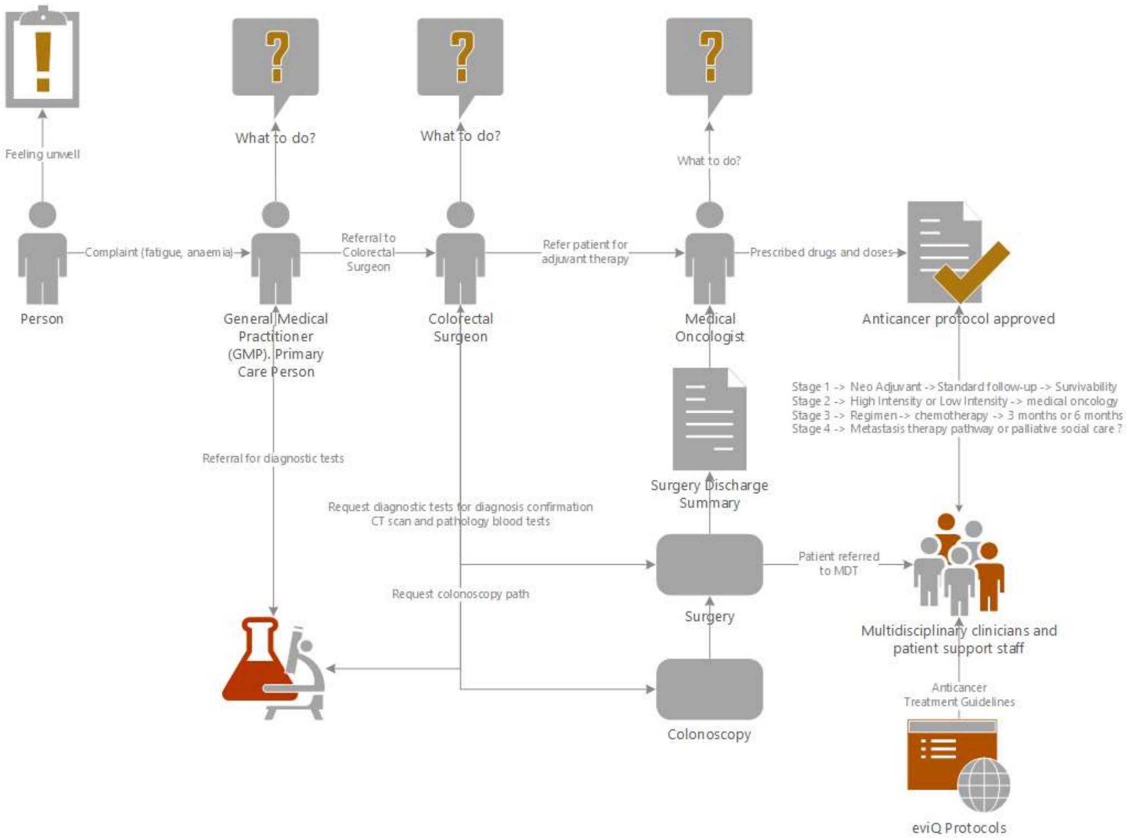
3.1.1.1 Exploratory workshops.

The first component of fieldwork planning consisted of three separate two-hour brainstorming workshops. The workshop sessions were conducted in an unstructured format to promote free-flow discussions and brainstorming about the consultation process and patient journeys through medical oncology clinics. The subject matter experts included a senior medical practitioner, an experienced senior medical oncologist, a senior professor specialising in digital health technology implementation in cancer care, a senior professor in human-centred design, and a business analyst with expertise in designing and implementing digital health tools in hospitals across New South Wales. Example cancer cases were used during the workshops to guide discussion, prompt questions from the researchers and raise points for discussion on issues such as what clinical workflows look like in oncology. Emerging concepts and relationships illustrating potential pathways through cancer services were visualised on a whiteboard to inform future discussions. The study participants iteratively validated and refined the emerging conceptual map until reaching a final version agreed upon by all. The end goal was to develop concept maps of common clinician task flows, care delivery points, and data collection processes for cancer presentations likely to be observed during the ethnographic study.

The colorectal cancer (CRC) workflow was discussed first in the workshops, as a large number of patients with this diagnosis were referred to the organisation where the ethnographic study was being undertaken. Breast cancer cases were also discussed because this was another common type of cancer that the subject matter experts anticipated would be observed during the ethnographic study.

Colorectal cancer case scenario.

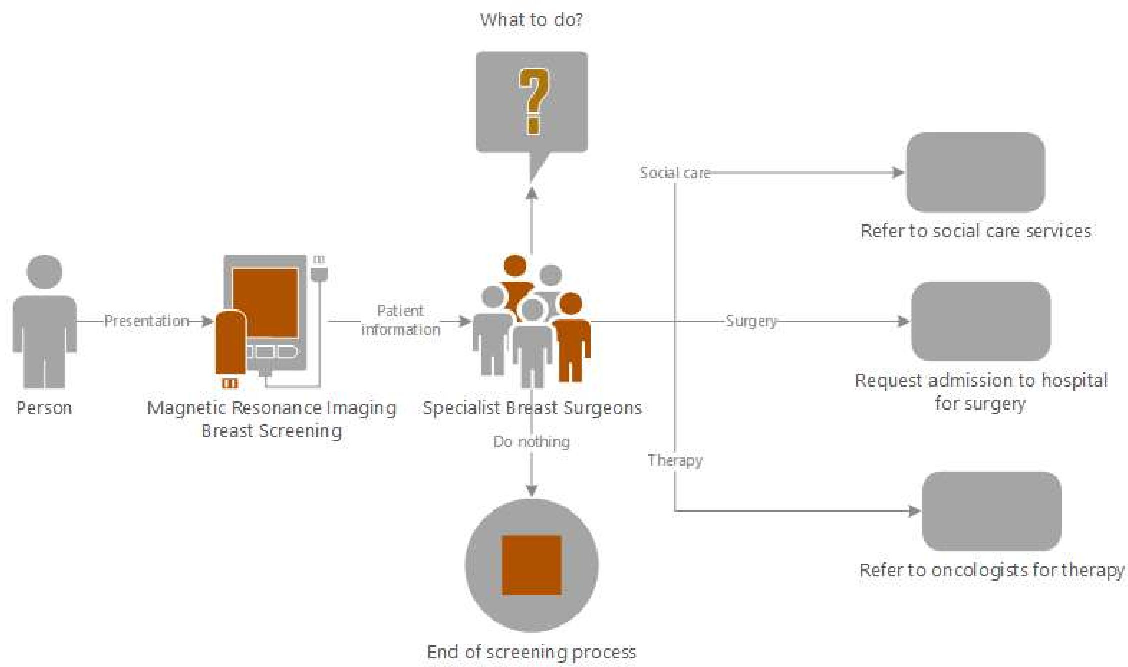
In cases of colorectal cancer, as shown in (Concept Map 1), the patient journey usually begins when an individual decides to see their general practitioner after experiencing symptoms such as fatigue or anaemia. The general practitioner then orders laboratory tests; once reports suggest colorectal cancer, they refer the patient to a colorectal surgeon. The colorectal surgeon may decide to order further, more specific diagnostic tests to confirm the presence of colorectal cancer in the patient. Depending on the patient's health situation, if the patient is referred to a medical oncologist after surgery by the surgeon, the medical oncologist may choose to prescribe a treatment recommended by a multidisciplinary clinical team or follow the standardised, evidence-based eviQ treatment protocol [1, 2].



Concept map 1 – Patient with colorectal cancer journey through cancer care.

Breast cancer case scenario

In cases of breast cancer, the individual may have undergone a screening for breast cancer, and based on the test results, they may be referred to a breast surgeon for further assessment. The surgeon may recommend no action, refer the patient to social care services, admit them for surgery, or refer the patient to an oncologist.



Concept map 2 - Patient with breast cancer journey through cancer care.

3.1.1.2 Clinical Domain Expert Interview.

To augment the learnings from the exploratory workshops conducted with experts from a range of fields, a two-hour in-depth interview was undertaken with a senior medical oncologist to gain a more granular understanding of decision-making in cancer care and patient involvement in the process. This interview also explored some of the technologies that were used to support cancer care at the ethnographic study site, to provide the researchers with context for what they would observe during their observations. The interviews were conducted face-to-face, recorded and transcribed into text for rapid analysis. Key insights identified through this interview are described below.

Prerequisites for decision-making.

The issue is not just reviewing a patient's electronic health record on the computer before inviting them into the consultation room. It involves recalling the patient's history and health status, while considering multiple issues, including the patient's past expressions of preferences or life wishes, and evaluating possible treatment options simultaneously. For example, in one case, when the available treatments could no longer control the cancer, the director was contemplating the questions

> "…how are we going to care for her…"
>
> "…what resources do we have. So, I spoke with one of our teams, who is to support patients…"
>
> (Chief Medical Oncology Director)

Sharing information prior to selecting treatment.

The director reviewed blood markers and scans, including CT scans and ultrasounds, to monitor patients' progress and guide treatment decisions. They also ask patients for feedback and inquire about any other health concerns. The director records all treatments in the electronic health records. Additionally, the director is considering the potential next lines of treatment, taking treatment guidelines into account or checking protocols at this stage. The director uses charts showing blood response to treatment that are displayed to patients to share information because

> "…visual and visualisation is very credible for patients…"
>
> (Chief Medical Oncology Director)

Deciding after sharing information.

The director explained that the goal is to make all the necessary information available to the medical oncologist. However, he said that there are times

> "…when I make decisions, I don't have everything, but I've got about 90% of it…"
>
> (Chief Medical Oncology Director)

Moreover, although he might be certain that he knows which treatment the patient should receive, on many occasions, he would say to a patient that he is taking the patient's case

> "…to my meeting for review, because I want to be sure about this. This is why I'm planning and I'm booking you into my MDT or my Imaging meeting so that I can be as sure as possible, as this is what the report is saying, and I trust my radiologist…, I want to have that second pair of eyes …"
>
> (Chief Medical Oncology Director)

Involvement of third parties in decision-making processes.

The director explained the involvement of registrars and nurses in the decision-making process. The registrars are learning how to develop treatment and management pathways while caring for the director's patients. However, the director mentioned

> "…I am relying on another doctor to give me things, obviously I work out whether or not I can feel very confident about their information they give me or know I need to check on certain things…I'll check things that I think are most important, and then I'll use that information they have given to me…" (Chief Medical Oncology Director)

Clinical Nurse Consultants also gather information about patients and provide it to clinicians. For example, in treatment scheduling,

> "…planning as in the chemo suite as in the chairs…"
>
> (Chief Medical Oncology Director)

Facilitators and obstacles in shared decision-making.

The most notable facilitator observed during the consultation, as noted by the chief medical oncology director, was when a patient's family member participated in the decision-making process. This was evident when a family member asked questions during the consultation about the possibility of giving the patient another line of chemotherapy. The chief medical oncology director explained during the interview what the patient told him privately,

> '…she said to me... "…look, I don't really care if I live or die. You know, it doesn't matter to me. I am 80 years old…" '…type of thing…' "…I've lived a good life. It doesn't really matter…"'
>
> (Chief Medical Oncology Director)

The main barriers to shared decision-making were identified in the analysis of the interview transcript. The chief medical oncology director discussed the challenges faced with the electronic health record (EHR) system. He said,

> "…scanned document might be a letter from another specialist, and that may be sitting in your EMR, but it's not; you can't tell where it is. Could be in one of 20, 30, 50, a hundred documents that have been scanned into the EMR, and you don't know the date, well you go um, and even then, the date may not be …, because it might

have happened, you know today, and the letter has been generated, and then that arrived in the system, and then someone uploads it three months later…"

(Chief Medical Oncology Director)

3.1.2 Key learnings to inform the ethnographic study.

The exploratory workshops highlighted the complexity of cancer care, including different types of cancer, which leads patients to follow unique care pathways through healthcare services. This includes providing the researchers with an understanding of how the workflow was influenced by the specific cancer type with which the patient was diagnosed. Variations could include more or fewer laboratory tests needed to confirm diagnoses and determine the patient's eligibility for available treatments. There are also various levels of treatment intensity. The suitable treatment recommended by a medical oncologist depends on the stage of the cancer, which also affects other hospital departments or healthcare areas involved in supporting the patient.

The clinical domain expert interview provided insights into decision-making in routine cancer care. The main challenge identified was issues with the electronic health record system. It is challenging to obtain information, particularly letters from clinicians outside the hospital, regarding patients. This work highlighted the need to undertake a more structured observation of the use of technology in individual consultation in the subsequent ethnographic study.

3.2 Ethnographic Study Publication

The earlier parts of the study involved the preparatory work undertaken to undertake a robust ethnographic study in a complex clinical setting. This section presents the findings of the ethnographic study. The results of the work conducted in this section of the chapter are included in the article that will soon be submitted for publication in JMIR Cancer.

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Candidate Name: Alan Yung

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As the research supervisor of the above candidate, I confirm that the candidate has made the following contributions to the above paper:

- conception and design of research
- experimental data collection
- data management
- analysis and interpretation of the findings
- writing the manuscript

Name: Tim Shaw

Date: 27 September 2025

SHARED DECISION-MAKING IN ONCOLOGY CONSULTATIONS AND THE ROLE OF TECHNOLOGY: AN ETHNOGRAPHIC STUDY

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Abstract

Background: Discussions during oncology consultations about cancer care are complex and challenging. Several frameworks have been developed to aid medical decision-making. However, there is still limited evidence on how technology can be used more effectively and efficiently to support shared decision-making (SDM) during cancer care consultations.

Objective: This paper aims to gain insights into the dynamics of cancer care consultations in order to inform the design of future potential roles of technology within the framework outlined in the shared decision-making (SDM) 3-talk model [1].

Methods: Cancer care consultations were observed at a major tertiary hospital in Sydney, Australia. Written field notes were taken to describe observations, primarily noting when technology was used to support information retrieval, sharing, or discussions. Data from these notes were analyzed deductively by two researchers to categorize them according to the SDM 3-talk model and inductively, based on the nature of decisions made during consultations. A third researcher reviewed the qualitative coding process and the final classification of themes and subthemes to ensure consistency of the analysis and results.

Results: A total of 55 consultations were documented, including 9 initial consultations and 46 follow-up consultations. Four decision categories emerged during these consultations. 55.7% of decisions involved administering chemotherapy, 20% involved considering alternative care, 14.3% involved monitoring patients' health, and 10% resulted in delaying the final decision. In only 3 cases, the standard chemotherapy protocol was modified. Physicians primarily used the electronic health record (EHR) system to access patients' medical records. They also accessed evidence-based chemotherapy protocols from a website and printed copies to give to patients.

Conclusions: This study highlights major ways in which technology can support the shared decision-making (SDM) process in oncology consultations. These opportunities can enable more effective and satisfying decision-making. It is essential to integrate such SDM considerations into the design of oncology information systems and clinical decision support tools within electronic health record (EHR) systems.

Keywords: Shared Decision Making; Patient Centered Care; Person Centered Care; Professional Patient Relationships; Physician Patient Relationships; Medical Oncology; Hospitals; Tertiary Care Centers; Electronic Health Records; Decision Support Systems; Clinical; Cancer Care Professional; Care Partner

Introduction

Background

In medical oncology, as the number of treatment options increases, choosing the appropriate care pathway for a patient diagnosed with cancer becomes more complicated [2, 3]. For more than a decade, societal changes have encouraged more patients to participate in deciding their treatment [4]. This shift in attitudes has led to shared decision-making (SDM) being regarded as the preferred approach for making therapeutic decisions in cancer care planning [5]. SDM focuses on understanding patients' needs, desires, and preferences [6]. During cancer care visits, medical oncologists now routinely encourage patients and their families or care partners to collaborate in selecting therapies that best fit the individual patient's needs and preferences [7].

Involving patients in their cancer care journey promotes a personalized approach to decision-making while considering their unique situations [8]. SDM has become a vital, integral part of patient-centered care in oncology, emphasizing the importance of patients being involved in discussions about their treatment preferences [9]. Studies show that when patients are actively involved in decision-making, they tend to feel more confident and satisfied with their treatment choices, which also increases their trust in healthcare providers [10]. As a result, oncologists tailor their clinical practice to each patient’s specific health circumstances by considering clinical guidelines, personal preferences, and the complexity of each patient's situation [11].

Digital technologies, such as electronic health record (EHR) systems, are increasingly adopted by healthcare organizations and used in clinical practice [12]. The Institute of Medicine has noted that using computers can promote safe and high-quality care that aligns with each patient's preferences, needs, and values [13]. Ultimately, technology can help healthcare providers improve the quality of healthcare services, increase efficiency, and boost patient satisfaction [14]. However, significant gaps remain in understanding how computers are used in cancer care consultations to enhance patient-centered care.

Lenert et al. proposed a technological model to support SDM through EHR systems [15]. First, integrating technology into SDM workflows enables healthcare providers and patients to identify situations in which patients' preferences can be leveraged to influence healthcare decisions. Second, combining technology with SDM helps select information sources to view details, assess option availability, and enables patients to evaluate their treatment choices. Furthermore, technology plays a significant role in SDM, especially since EHR systems contain essential patient information that facilitates conversations between patients and healthcare providers. Similarly, digitized online treatment protocols are important for enabling physicians to refer to the most current and evidence-based clinical best practices when determining treatment options. Third, after reviewing patient information on the computer, healthcare providers may need support to adjust treatments to align with patients’ reported preferences and goals. They may also need assistance when facing challenges in personalizing care and managing patients’ therapeutic reluctance. The fourth step involves continuously monitoring care outcomes to ensure that current treatments match patient preferences [15]. Friedberg et al. also examined a system to communicate patient preferences and self-reported values to healthcare providers. They found that a lack of communication facilities is a significant deficiency that can hinder the effective implementation of SDM in real-world situations [16].

Politi et al also emphasized that specific ways in which technology may improve SDM in oncology include the use of clinical practice guidelines to help healthcare providers access and personalize the latest evidence-based best practices for optimal treatment options, leading to better patient health outcomes [17]. Using validated evidence-based protocols with technology may also improve consultation decisions and the quality of cancer care, as suggested by Moja et al. [18]. However, research has not definitively shown how these integrated digital information systems benefit clinical decision-making processes [19]. Challenges related to unstructured critical health data and misaligned decision-support tools created by computer-based workflows in cancer care, as outlined by Berger et al. [20], may also impact the current ability of technology to support SDM. There are a number of examples where digital tools have been specifically designed to support SDM, but there are few examples of these being routinely used in practice [21]. Researchers have therefore proposed that more effective organizational and technical innovations are needed to improve patient-centered care and address ongoing concerns about collaboration and communication efficiency [22].

Therefore, in this study, our goal is to understand the interactions that happen when physicians involve patients in shared cancer care decision-making processes and how they use technology to support this clinical workflow. The results of this study establish a foundational understanding of how to improve digital information systems to better facilitate SDM in oncology consultations.

Methods

Study Design

This study applied an ethnographic methodology to observe SDM processes in medical oncology consultations and how technology is used to support this clinical decision-making workflow [23]. This qualitative research was conducted in outpatient oncology clinics, where an observer, not involved in the consultations, watched the SDM interactions between physicians and patients, along with the interactions between physicians and digital technology-enabled tools [24]. Details of the consultation room configuration and the technologies used are provided in Multimedia Appendix 2.

Setting

Data were collected from outpatient oncology clinics at a tertiary referral public hospital in metropolitan Sydney, Australia. This facility offers comprehensive, advanced medical care and serves as a training and research center for physicians specializing in cancer treatment. The chief medical director, a senior medical oncologist, of the medical oncology department, selected the outpatient clinics for data collection through convenience sampling.

Participants and Data Collection

The chief medical director, a senior medical oncologist, an experienced researcher in cancer care, supervised the observations conducted by (AY), who had no clinical training background. Without predefined behaviors to monitor or prior expectations upon entering the cancer clinical area, AY adopted an unstructured observation approach to make discoveries [25]. The director identified suitable upcoming patient visits for observation. Some consultations were assigned to registrars in training. The director informed each assigned registrar of the planned observation when their consultation was selected for inclusion in the research. AY assigned a random number to each observed consultation to de-identify individuals present in the consultation rooms and to protect their privacy. Before allowing AY to enter the consultation room, the physician in charge sought permission from the patient and, if present, from their family or care partners to observe their consultation.

During the consultations, AY took brief handwritten notes to record observations. Immediately after completing the observation of each encounter, AY expanded these shorthand notes into more complete sentences to detail the observations. The field notes were then typed into Microsoft Word, a word-processing program readily available on the authors' computers.

Data Analysis

The data analysis followed the qualitative content analysis principles outlined by Hsieh and Shannon [26] and Elo and Kyngas [27]. Two researchers (AY and JK) independently coded the field notes and resolved interpretive differences through discussion.

The authors based the coding process on the components of the SDM 3-talk model developed by Elwyn et al. [1] as outlined in Table 1. The content analysis process involved several steps: first, AY and JK read the field notes from the first five observed consultations to familiarize themselves with the data. Second, AY performed an initial line-by-line coding of these five field notes. Third, after the initial phase, JK independently coded the same field notes using the SDM 3-talk model. AY and JK then compared their coding results. After extensive discussion, they agreed on an initial set of codes for independently coding the remaining field notes. Fourth, both researchers continually reviewed and refined the codes iteratively during the process. After multiple reviews and discussions, they finalized the code set; subsequently, all field notes were independently coded. Finally, the two researchers compared their coding, engaged in further discussion, and refined their codes to develop a unified coding scheme. A third researcher (AJ) reviewed the coding process, data analysis, and results to ensure consistency and reliability throughout. All codes and results were subsequently organized and documented in Microsoft Excel worksheets.

Table 1: The components of the shared decision-making (SDM) model [1].

<table>
<tr><th>COMPONENTS</th><th>BASIC DEFINITION</th><th>ELABORATION OF THE SDM COMPONENTS</th></tr>
<tr><td rowspan="3">TEAM TALK</td><td>Indicate choice.</td><td>Collaborate, explain options, and provide support.</td></tr>
<tr><td>Provide support.</td><td>Let's work together to determine what works best for you.</td></tr>
<tr><td>Identify goals.</td><td>Inquire about goals.</td></tr>
<tr><td rowspan="2">OPTION TALK</td><td>Compare alternatives.</td><td>Discuss alternatives based on risk communication principles.</td></tr>
<tr><td>Discuss the harms and benefits.</td><td>Let's evaluate the available options.</td></tr>
<tr><td rowspan="2">DECISION TALK</td><td>Get to informed preferences.</td><td>Determine informed preferences and make decisions accordingly.</td></tr>
<tr><td>Make-preference-based decisions.</td><td>Tell me what matters most to you when making this decision.</td></tr>
</table>

Throughout the coding process, memos were used to clarify codes and track ideas and thoughts. For the presentation of the results in this article, the themes of the qualitative analysis were organized into a hierarchy. These headings represent the highest level of the inductive categorization system, while subthemes were derived deductively from the research questions and theoretical background. In addition to qualitative analysis, descriptive statistics were calculated to determine the number of consultation types and the variety of clinical decisions made during those consultations.

Results

Overview

There were 55 oncology consultation observations. The majority of consultations were undertaken by the director, as described in Table 2 . A small number of consultations were led by oncology registrars (medical specialist trainees). However, all these consultations concluded with a team meeting with the director to finalize the consultation decisions.

Table 2 - Overview of observation characteristics (N=55 consultations).

Consultation Characteristics	Proportion of observations with a characteristic	Observation Number (see summary in Multimedia Appendix 1)
Healthcare professional leading the consultation	Director -- 40 (72.7%)	(#1 to #15, #18 to #21, #24 to #29, #31 to #33, #39, #40, #42, #44, #45, #46, #47, #49, #51, #52, #53, #55)
	Oncology registrars (doctors in specialist training) -- 15 (27.3%)	(#16, #17, #22, #23, #30, #34, #35, #36, #37, #38, #41, #43, #48, #50, #54)
Consultation Type	Initial -- 9 (16.4%)	(#1, #14, #17, #21, #23, #35, #37, #38, #41)
	Follow up -- 46 (83.6%)	(#2 to #13, #15, #16, #18, #19, #20, #22, #24, #25 to #34, #36 to #40, #42 to #55)
Number of times any patient was observed	Only one observation (one initial or one follow-up visit)	54
	Two observations (one initial and one follow-up visit)	1 (#1 and #45)

Observations of the consultations identified four main categories related to the primary decisions made during the encounters: 1) Alternative Care; 2) Chemotherapy; 3) Deferred Decision Making; 4) Monitoring. Each major decision category was further divided into two or more sub-categories, as described in Table 3. In 55.7% of consultation decisions, chemotherapy-related issues were addressed. Decisions to monitor patients' issues accounted for 14.3% of consultation decisions, whereas alternative care decisions accounted for 20.0%. The final decision was delayed in 10.0% of observed consultations. It is also worth noting that, during the observed consultations, only three decisions were made to modify the standard chemotherapy protocol due to patients' health issues. The majority of consultations observed were for patients attending follow-up visits (83.6%). In 16.4% of the consultations, patients encountered their oncology physician for the first time. The fact that only four consultations were observed when the decision was made to start chemotherapy for the patient highlights the limited opportunities that were available to observe initial consultations.

Table 3: A description of consultation decisional types that emerged through analysis of observation data (N=55 consultations). Note that several consultations resulted in multiple decisions.

Consultation decision category		Description	Count of consultations where the category was observed and IDs of those cases.	%
Alternative Care	Supportive care	Supportive care involves assisting with daily activities such as cooking, bathing, and maintaining personal hygiene; supporting social and personal needs; and administering medications for other health conditions.	5 (#8, #16, #20, #26, #48)	20.0
	Pain therapy	Pain therapy involves using medications, either in pill or injection form, to manage cancer-related pain.	5 (#7, #15, #22, #47, #53)	
	Referral to another healthcare specialist	When services from other healthcare specialists, such as surgeons, pulmonologists, psychologists, or physiotherapists, are required, the	1 (#53)	

		patient is referred to another care facility.		
	Consult a multidisciplinary medical (MDT) specialist team	The MDT team comprises clinical specialties, such as surgeons, radio-oncologists, and medical oncologists. In MDT meetings, the team reviews and recommends patients' treatment plans.	3 (19, #28, #48)	
Chemotherapy	Beginning new chemotherapy	Decision-making and consultation for newly-intake, referred patients.	4 (#34, #37, #38, #41)	55.7
	Continuing chemotherapy	Chemotherapy treatments can be continued for a variety of reasons. For example, when chemotherapy effectively controls or shrinks the tumor, the decision is made to continue administering the same chemotherapy drugs to the patient.	25 (#3, #4, #6, #8, #9, #10, #11, #15, #16, #17, #18, #20, #22, #27, #29, #30, #40, #43, #47, #48, #49, #50, #51, #52, #53)	
	Modifying the chemotherapy protocol	Changing chemotherapy protocols for reasons such as poor patient tolerance of treatment.	3 (#12, #25, #39)	
	Stopping chemotherapy	When chemotherapy fails to control cancer or causes severe side effects or adverse effects, the decision is made to discontinue treatment.	1 (#5)	
	Rescheduling chemotherapy	When the timing of chemotherapy doesn't align with the patient's schedule or health status, the administration period is adjusted.	1 (#39)	
	Assessing care outcomes	After a patient undergoes chemotherapy, tests such as blood tests and imaging are performed to assess the treatment's effectiveness and impact.	5 (#47, #50, #51, #52, #54)	
Deferred Decision Making	Considering options and planning	Delaying decision-making for reasons such as high risk of making the patient ill, requiring emergency or hospitalization, or affecting the patient's quality of life makes it prudent to wait to start chemotherapy or give the patient time to think about their options.	4 (#1, #23, #28, #45)	10.0
	Waiting for diagnostic test results or specialist review	Delaying decision-making due to delayed results, the need for additional tests or specialist review, difficulty locating the correct report in the EHR, or missing key paper-based patient information.	3 (#14, #24,#55)	
Monitoring	Monitoring patient progress	For some patients who have completed a set of treatments and been cancer-free on recent tests, are between treatments, or need time to recover after surgery. When the outcomes of treatment pathways are uncertain, the decision is to monitor patients' health progression over time, thereby providing additional information to guide the next decisional step.	10 (#2, #8, #21, #32, #33, #36, #44, #46, #54, #55)	14.3

Thematic Analysis

Observational data were deductively analyzed with respect to each component of the SDM 3-talk model. In the following section, data are presented for these three components, with subthemes incorporated throughout the framework to demonstrate how the four consultation decision-making categories described in column 1 of Table 3 fit within the SDM 3-talk process flow. The recurring themes across the four decision categories reveal a cyclical pattern of wishes, discussions, deliberations, and good intentions that occur during real-life conversations about cancer care planning and service delivery management.

Team Talk

In this study, 83.6% of cases involved follow-up consultations focused on patient progress, management of chemotherapy side effects, evaluation of test results, cancer progression, and assessment of chemotherapy effectiveness.

Occasionally, physicians were observed accessing the EHR to review the patient's medical details prior to the appointment. For patients receiving chemotherapy at the infusion center, physicians would also contact the oncology nurse for pertinent updates on the patient's status or for access to the patient's chemotherapy records. Furthermore, for some cases, the physician referenced evidence-based clinical practice guidelines and chemotherapy protocols available in the eviQ online database [28, 29]. After reviewing and refreshing their memory of the patient's information, physicians invited the patient and, if present, their family into the consultation room. The consultation commenced with the physician reviewing the information in the EHR and discussing key points with the attending patient.

During the initial phase of a consultation, known as ‘team talk' in the SDM 3-talk framework, physicians worked closely with patients and their families or care partners. They engaged in discussions to understand their perspectives on health, reviewed the patient's overall condition, and discussed laboratory results, using digital or printed documents. Sometimes, physicians retrieved specific data, such as tumor growth charts, from the EHR system. In several cases, physicians and patients, in addition to reviewing the patient’s tumor growth charts, also examined the latest vital signs, CT scans, or magnetic resonance images (MRI) using the EHR system.

When healthcare providers outside the hospital referred patients to the medical oncology clinics, physicians typically reviewed patients’ results from paper records. Physicians had to open paper files that contained referral letters and paper copies of laboratory results and reports. Patients whose tests were conducted at private laboratories often brought paper copies of their results to their appointments. One patient brought a CD-ROM containing their radiology images to their consultation, but did not bring the associated laboratory report. As a result, the consultation had to be rescheduled because the oncologist could not properly assess the patient’s health status.

Physicians took patients’ medical histories, including their medications and surgeries, and performed physical examinations. They discussed the patient’s broader life circumstances, including financial difficulties and social conditions at home.

When physicians had all the necessary patient health data available in the EHR system or in a supplemental paper file, including materials the patient brought to their medical appointment, they proceeded with their information-gathering by evaluating issues such as pain or lung problems. This information helped them explain the patient’s health status and available care options to the patient while establishing shared therapeutic goals, considering different concerns, and identifying medical interventions that required joint decision-making. The physicians documented the information gathered from the patient in the EHR system during or after the consultation, or at the end of the day when the clinic was quiet, after all appointments.

Alternative care objectives

Across 14 consultations, the discussions focused on explaining and offering assistance with ‘Alternative Care’, including options such as supportive care, palliative care, social worker support, and home care. Support was offered to manage pain, comorbidities, physical limitations, and psychosocial problems. Physicians, patients, and their family members would discuss the patient's quality of life and daily living challenges together. 'Alternative Care' discussions also involved offering patients referrals to other healthcare professionals, such as physiotherapists or psychologists, for additional healthcare services. In more complex situations, physicians informed patients that they were referring their cases to a multidisciplinary team (MDT) of medical specialists, who would review their health information, collaborate to assess their condition, and offer recommendations on the most appropriate treatment or care plan. Physicians were often observed using traditional methods, such as telephone, fax, and verbal communication, to communicate the need for alternative patient care with the patient and other cancer care professionals.

Chemotherapy objectives

In 39 consultations, physicians involved patients and, when appropriate, their families in the 'Chemotherapy' decision-making process. During meetings with newly admitted cancer patients, discussions of initial chemotherapy decisions typically included an explanation of the referral letter from the patient’s physician, surgeon, or primary care provider, as well as the possible chemotherapy options. For all patients, the conversations also involved explaining diagnostic test results, symptoms, and the effects of chemotherapy on quality of life.

Deferred decision-making objectives

In seven consultations, the primary focus was on 'Deferred Decision Making’. Physicians and patients conducted detailed assessments of various factors, including social, mental, and physical functioning; medical and surgical histories; pathology and radiology results; overall health conditions, persistent symptoms, or other health issues; and their indicators. Both physicians and patients recognized the need to discuss postponing the treatment plan or taking further action, as proceeding with care planning was impractical without additional investigation, time for recovery from surgery, or reflection.

Monitoring objectives

During ten consultations, the primary goal was to decide on ‘Monitoring’ the patient's health progression. The physicians involved the patients in this discussion when the results showed that the patient was cancer-free, eliminating the need for further treatment, but requiring surveillance. Patients referred to the medical oncology clinics after surgical procedures by a surgeon discussed their ongoing follow-up needs with the cancer care physician (the oncology clinics’ director or the registrar) during recovery. This was done to prevent potential health issues that could lead to rehospitalization. Other patients who needed time for education and preparation before starting chemotherapy or between treatment cycles required a careful explanation of available support to prevent potential setbacks. In cases with uncertain treatment outcomes, physicians emphasized the need to observe the patient’s disease trajectory over time to gain insight before making a final decision on medical intervention.

Accessing patients’ test results in the EHR system and chemotherapy protocols via the evidence-based eviQ database, with standardized care pathways, facilitated collaborative conversations, and joint goal setting. These tools made clinical information immediately available to physicians. However, when critical health data were difficult to obtain, both physicians and patients struggled to develop a shared understanding of the patient’s health situation and to make informed clinical decisions.

Option Talk

Once essential clinical details were clarified, and a shared understanding of the patient’s health status was established with the patient and their family, physicians evaluated potential treatment options and appropriate medical interventions tailored to the patient's specific needs. This phase in the SDM 3-talk model is called the 'option talk'. The physicians engaged in a thorough discussion of treatment options, involving the patient and their family or care partners whenever possible. They cited clinical guidelines, such as those from the National Comprehensive Cancer Network [30]. They provided their expertise on the recommended standard care pathway for patients in similar health situations. They reviewed treatment protocols from the online eviQ database [28], printed relevant chemotherapy protocols from their computers, and handed them to the patient during the consultations in the secure consultation room. The physicians explained the procedures, risks, and benefits of each protocol to the patient and their care partners. Often, the director discussed sensitive patient matters, such as end-of-life planning, privately with the patient. Occasionally, the physicians invited the oncology nurse into the consultation room to clarify the procedures for each chemotherapy protocol. Physicians also used online resources to display images of the chemotherapy infusion pump to patients. The nurse additionally discussed potential discomforts and which procedures might be less uncomfortable for the patient. Finally, the physicians asked the patients about their preferences.

Alternative care options

When patients with a certain stage of cancer have used up all available and appropriate treatments, leaving no other medical options, the remaining choices for these patients were 'Alternative Care'. For patients eligible for enrolment in clinical trials of new drugs or treatment methods, the director explained the procedures for such trials. For some patients, the discussion included supportive care, home assistance, palliative care, hospice, or end-of-life services. Their conversations about supportive care interventions and related health services included pain management strategies, physiotherapy, psychotherapy, consultations with orthopedic or palliative care experts, as well as treatments for other issues not associated with cancer. Additionally, they addressed the management of side effects and the coordination of ongoing hospital care.

Chemotherapy options

When making decisions about ‘Chemotherapy’, physicians often referred to the eviQ protocols displayed on their desktop computers to guide conversations about available chemotherapy options, while patients followed along with their printed copies in hand. They discussed the number of chemotherapy cycles, their duration and dosages, the techniques for administering the drugs, the expected outcomes for each recommended chemotherapy regimen, and the potential benefits and side effects associated with each option. For patients who met specific criteria, physicians included other potential treatment options, such as surgery, radiation therapy, or immunotherapy, in their discussions about chemotherapy. However, physicians also emphasized to patients that, when adopting a combination treatment approach, the chosen strategy would require additional consultations and coordination with other cancer care physicians, including surgeons and other medical specialists.

Deferred decision-making options

In situations involving 'Deferred Decision Making', physicians explained the justification for postponing the decision and verified the patient's agreement. Among the reasons cited was the need to wait for crucial diagnostic test results that had not yet arrived by the scheduled consultation time. Physicians needed complete information to assess the options because they were concerned about the patient's health stability. Physicians mentioned the risk that treatment could trigger the need for the patient to require emergency care or hospitalization, as well as concerns about adverse effects on patients’ quality of life. In some situations, decisions were postponed to allow patients time to return home and discuss their choices with their family. Reasons for delaying decisions also included the need to obtain additional tests, such as biopsies or genomic tests from private laboratories, or to consult other cancer care professionals for specialized expertise or to assess patients’ health indicators.

Monitor options

During consultations, it was particularly important to highlight 'Monitoring' of patient progress for individuals who had either recovered from cancer, were in the interim between treatments, or required recuperation after surgery. These patients did not undergo chemotherapy or other cancer-related therapies. Instead, they needed regular follow-up appointments with oncology specialists to maintain their health. Physicians advised periodic monitoring of patients' health over time, especially when treatment outcomes were uncertain. This approach was designed to collect comprehensive data on cancer progression, providing concrete evidence to guide future decisions on the most effective care plans to optimize patient benefits from cancer care.

After reviewing the findings, the physician and patient discussed the advantages and disadvantages of the proposed treatment plan. No particular technology or decision-support aid, such as a nomogram or other statistical tool, was employed to assist the patient in selecting a treatment option.

Decision Talk

For newly referred patients to oncology clinics for ongoing cancer treatment, 'Decision Talk' focused on developing a personalized care plan that addressed each patient's unique needs. In the final stage of the SDM 3-talk framework, both physicians and patients aimed to reach an agreement on the most suitable care option. This involved considering factors such as the availability of chemotherapy drugs; patients' health status; their home situation; existing family support and involvement in their care; the distance they need to travel to the hospital for routine treatments; and patients' personal views on the treatment options presented. When the expected outcomes of different treatments were unclear, physicians and patients decided to conduct additional diagnostic tests and wait for the results to better inform their decisions on the most effective treatments. The additional information helped reduce uncertainty and risk. When patients requested additional time to discuss and consider their options with family at home or to seek second opinions from other cancer care professionals, the physicians provided their contact details. The physicians provided patients with their direct phone numbers, particularly to prevent delays. The physicians encouraged patients to ask questions for clarification and to inform them of their decisions. Physicians informed patients that once they decided to proceed with treatment, there was no need to wait until their next follow-up visit. They could simply call to inform them. During the ‘Decision Talk’ phase, the physicians were not seen using any special digital tool for documenting the planned care beyond using the EHR system during the consultations.

Alternative care decisions

When patients opted to consider the 'Alternative Care' pathway, physicians assisted them in understanding their options through private, one-on-one discussions. A physician described a specific conversation with a patient about their wishes and expectations, where the patient acknowledged that all treatment options had been tried and that the cancer had been managed for some time. However, the patient recognized that the cancer returned as expected, although it remained stable longer than anticipated. Having exhausted all treatment options, the patient concluded that the remaining course of action was supportive care and end-of-life planning. Once the patient agreed, the physician began organizing supportive care. At that point, the physician requested specific support to improve the patient's quality of life and ensure their comfort. The physician contacted the supportive care team by telephone to inform them of the patient's needs. The physician involved the patient and her family in developing a care plan that considered the patient’s broader health needs. This included routine hospital visits for ongoing supportive care, such as draining fluid buildup in the abdomen caused by cancer, pain relief, and addressing personal challenges like financial problems. The physician worked with the supportive care team to organize and to schedule the patient's ongoing hospital care. The physician fostered a shared decision-making environment that respected the patient's personal life and preferences by advocating for her choices.

For cases discussed in an MDT, physicians then discussed the MDT’s recommendations with the patient. During discussions of the MDT’s recommendations, physicians were observed not using any specific digital technology to support their dialogues with patients, document their discussions, or provide patients with a summary of the MDT's decisions. They used their existing desktop computer to document the agreed-upon care plans in the patient's clinical notes section of their EHR.

Chemotherapy decisions

During discussions about chemotherapy administration, physicians and patients developed and confirmed their treatment plans. These plans included starting chemotherapy immediately for some patients to control cancer progression or adjusting doses based on observed side effects and patient-reported results. In some cases, physicians had to temporarily stop chemotherapy until the patient was physically strong enough to continue. For patients who needed to regain strength, physicians provided signed request forms to obtain specific pathology or radiology imaging tests at a diagnostic laboratory. Once the laboratory completed the tests and uploaded the results to the hospital's clinical information system, the results were stored in the patient's medical record within their EHR. Physicians then accessed the patient's digitized medical record to review the results of their blood tests and, via the picture archiving and communication system (PACS), also reviewed their radiologic imaging scans. When the results of their diagnostic tests showed that the patient's health and conditions had returned to safe, normal levels, physicians allowed the prescribed chemotherapy to resume. Physicians stopped treatments entirely when chemotherapy failed to halt tumor growth or caused adverse side effects that made the patient feel ill. Physicians considered patients' wishes and concerns while ensuring that their preferences were understood. One physician shared an example of a patient who insisted on continuing chemotherapy despite experiencing pain so that he could spend as much time as possible with his daughters.

Deferred decision-making decisions

During discussions focused on 'Deferred Decision Making', both physicians and patients agreed to pause the decision-making process for a period. For some patients, the break allowed them to review the information provided by the physician, consult other cancer care professionals, gather more information, or obtain additional diagnostic test results. This helped reduce uncertainties and risks or allowed recovery after surgery. The physicians gave the patient signed request forms to bring to the laboratory for additional diagnostic tests. When the new test results were available, the physicians explained the expected treatment outcomes to the patient. Sometimes, physicians and patients agreed to set specific timelines for follow-up visits, such as when medication needed to be pre-ordered from an external pharmacy. The physicians provided patients with a paper form to submit to the front desk staff to request a scheduled follow-up appointment. When the patient decided to proceed with the agreed treatment, or when more specific tests, such as biopsies or radiologic images, provided the necessary information, physicians and patients agreed on clear next steps.

Monitoring decisions

The decision-making process for 'Monitoring' patients in cancer care underscored the importance of continuous, meticulous observation. For those patients who were cancer-free after treatment, it was crucial that physicians detect early signs of recurrence. For others, assessing the success of chemotherapy for their unique health conditions was essential. For all patients monitored, timely and appropriate intervention was required if their health status changed. Physicians issued signed orders for diagnostic tests, including blood tests and imaging modalities such as CT and MRI, to monitor tumor growth. After receiving test results in the EHR, physicians reviewed patients' health data and advised them on the next steps in their cancer care journey.

Ongoing EHR access supported the final SDM phase by enabling physicians to document patients' chosen care plans and to coordinate follow-up consultations or referrals to other care providers within the hospital health service network. Physicians also used phone contact with nurses and other hospital staff to implement the patient's preferred care plan, and sometimes they faxed referrals to external specialist care providers.

Discussion

This study describes an SDM process and the associated role of technology observed during medical oncology consultations at a major tertiary hospital in metropolitan Sydney, Australia, which provides cancer care services. A director conducted the majority of consultations at the outpatient oncology clinics, accounting for 72.7% of all the observed consultations. The director also led a team of registrars who initiated 27.3% of the remaining consultations, which the director then finalized with patients. In this study, four key decision categories were identified as outcomes of the SDM process in the medical oncology clinics: 'Alternative Care', 'Chemotherapy', 'Deferred Decision Making', and 'Monitoring'.

During the observed consultations, the main activities included discussing test results and patient health conditions; exploring treatment options; planning and preparing treatments; weighing treatment choices; prescribing treatments; coordinating patient support; monitoring progress; assessing treatment outcomes; and referring patients to other healthcare professionals for specialized care. The standardized medical interview framework outlined by Kurtz et al. [31] doesn't fit well with the complexity of the observed medical oncology consultation workflow in this study. The standardized medical interview workflow typically involves a physician and a patient working together. In practice, the medical oncology consultation workflow involves the physician collaborating with internal and external healthcare professionals and service providers, such as diagnostic laboratories, as well as patients' care partners or families who are actively involved in the decision-making process for developing the patient's care plan. A more appropriate approach to cancer care would involve a model that combines the efforts of a multidisciplinary team, as reported by Nic Giolla Easpaig et al. [32].

This study examined SDM by focusing on exploring the intersection of technology and decision-making, contrasting with previous research that focused on the barriers and facilitators of SDM [33-35], or healthcare professionals' perspectives, attitudes, experiences, or factors influencing their use of decision aids [36]. For example, Shepherd et al. [37] discussed factors affecting decision aid use, while other studies examined communication barriers in SDM [33]. Most research on the technological aspect of SDM has focused on the 'option talk' component of the SDM 3-talk model. Researchers developed and tested tools, such as decision aids, to support patients' independent decision-making outside of clinical visits [38, 39]. Some studies created decision tools like option grids [40, 41] to assist physicians in presenting treatment options during consultations, while considering the effects of different medications or therapies on patients' health conditions. Several healthcare services integrated these option grids into their EHR systems to facilitate SDM [42]. However, these tools have struggled to represent the complexity of chemotherapy or different treatment strategies and quickly became outdated compared to the regularly updated, evidence-based eviQ protocols available online [28, 29]. The value of the eviQ protocols as a shared decision-making digital tool is supported by observations of physicians' use of the protocols during the 'option talk' phase of consultations. The physicians also used the desktop computer to print the eviQ chemotherapy protocols, which they provided to their patients to facilitate shared decision-making. Patients and their care partners often took time after team and option talks with their physician to deliberate on issues related to 'Chemotherapy' or 'Deferring Decision Making' and to reflect on the information they had received. They often consulted further at home with family or sought additional opinions from other medical professionals. These patients' behaviors outside their main oncology consultations further expanded the shared decision-making team.

In this study, the EHR system, the primary digital tool, was used to support SDM during oncology consultations. The EHR system allowed physicians to access, for example, patients' referral letters, blood test results, and radiology images. Physicians used a desktop computer to document their observations and additional findings during patient interviews and physical examinations. The desktop computer also enabled physicians to display pathology charts and radiology images, allowing them to share health information and discuss potential care options with patients. This study aligns with the four-phase model of technology support proposed by Lenert et al., which states that EHR systems: (1) enable healthcare providers and patients to identify situations where patient preferences can influence healthcare decisions; (2) allow patients to assess their treatment options and facilitate conversations with their providers; (3) support the adjustment of treatment plans; and (4) enable ongoing monitoring of care and alignment with patient preferences, as a starting point. In most consultations in this study, the physician had to gather patient information from the patient's EHR and other systems. This process was time-consuming and required the physician to combine data from multiple sources. Additionally, the study results confirm that the medical oncology consultation workflow reflects a team-based process. After consultation, patients were often assigned multiple care pathways to follow concurrently throughout their cancer care. Therefore, the technology model supporting SDM needs to be expanded to include a care model that facilitates collaborative, multidisciplinary teamwork grounded in SDM principles.

Analyzing documented actions and decision categories from medical oncology consultations, using the SDM 3-talk model, shows that a digital technology platform is essential beyond EHR systems to support a collaborative, team-based SDM approach to improve oncology consultations. Several existing digital tools can support team-based SDM in cancer care. For example, a digital decision dashboard can help patients visualize their key health information, better understand their health status, and become more involved in their treatment decisions and care planning [43, 44]. The decision dashboard clearly and systematically presents information on treatment options, potential outcomes, and probabilities, fostering informed and collaborative decision-making between patients and healthcare professionals. Patients and physicians can access the decision dashboard digitally, online, or in the consultation room. This allows real-time updates to be communicated directly to individual patients without delay. Patient web portals [45] can enable patients to access their clinical notes and information written by healthcare professionals, as well as details on the treatment protocols of various options under consideration, which have been preloaded and stored on their patient portal. In addition, educational materials can be saved on the patient portal. Both patient web portals with integrated decision dashboards would enable patients to access and review their health information and test results online. Without waiting for their next consultation, they may also be able to ask their physicians questions for clarification between appointments.

In addition, several technologies incorporating artificial intelligence (AI) have been developed to help determine a patient's cancer profile and match the most suitable chemotherapy protocol or therapeutic option to their individual health condition [46]. However, caution is necessary, as many of these platforms have fallen short of expectations for various reasons, including a lack of specificity and prediction bias [47]. The ability of generative AI, for example, through electronic scribes, to record and provide plain-language interpretations of conversations during consultations is increasingly recognized as highly valuable [48-50]. Generative AI's ability to interpret and present data in different languages and at various levels of health literacy [51] may offer clear benefits in helping patients and families make decisions between visits. Furthermore, intelligent or conversational agents, such as chatbots, can help patients with cancer and their care partners collaboratively make decisions at home [52]. For example, conversational prompts in generative AI could facilitate SDM by asking a series of questions (prompts) that generate responses (answers). A summary of the discussions above and potential improvement areas through technology at every stage of the SDM workflow, in the future, is provided in Table 4.

Table 4 – Present and future use of technology in medical oncology consultation for decision-making.

SDM 3-talk model phases	**Current state of the use of technology for decision-making**	**Future state of the use of technology for decision-making**
Team talk	Present and share information on the computer screen in the consultation room.	Future EHR systems must be able to collect and integrate information from multiple sources and present it in the context of a specific patient journey. It should support access to information and team-based cancer care, and it should allow patients to access their health information online, enabling them to view their results and ask questions.
Option talk	Oncologists need to retrieve standard treatment protocols from an external website. They need to verbally explain the protocols to patients. They need to explain the benefits, harms, and side effects of each recommended treatment option. They need to consult other experts to reach a consensus on the appropriate treatment for the individual patient.	Technologies such as artificial intelligence (AI) could help determine individual patients' cancer profiles and match the most suitable chemotherapy protocol or therapeutic option to their specific health condition.
Decision talk	In this study, no specific technology was observed to support discussions about finalizing the consultation decision. Beyond the existing EHR system, this part of the decision-making process was primarily conducted verbally.	A variety of integrated decision aids should be integrated into new EHR systems. For instance, a computer-based decision board can help patients understand and participate in treatment decision discussions. The digital board would display information on treatment options, potential outcomes, and survival probabilities in a clear, organized manner, supporting informed, shared decision-making between patients and their oncologists. The digital decision board would be accessed online and in the consultation room by both patients and oncologists.

This study highlighted three essential design principles for effective clinical SDM tools. First, seamless integration into current clinical workflows to enhance efficiency and promote adoption. Traditional approaches such as phone calls, faxes, and informal handoffs were widely used to initiate referrals, clarify details, and coordinate follow-ups in outpatient oncology clinics. However, these methods carry operational risks, lack traceability, consume valuable clinical time, and do not support robust governance, auditing, or performance monitoring. To establish a unified, reliable, and fully traceable referral process in future oncology clinics, it is essential to replace these manual methods with an electronic system that provides transparent, comprehensive visibility of referral statuses from initiation to completion.

Second, concise, easy-to-understand summaries of vital information to support quick comprehension and decision-making. In oncology, key clinical documents such as specialist letters, referral notes, and treatment summaries are stored in the patient's EHR as scanned images or uploaded files. Physicians struggled to determine when these documents were originally written, when they were added to the patient's medical record, who authored them, or whether they reflect the patient's current condition because they were created, sent, and uploaded at different times. Important information was scattered across multiple files, which increased safety risks, caused workflow delays, and raised cognitive burdens. Therefore, there is a need for a unified longitudinal timeline that consolidates all referral-related correspondence and scanned documents, clearly showing authorship, transmission, upload dates, and sources or origins.

Third, content parity between physician and patient materials, ensuring that both receive accurate, relevant, and appropriately personalized information. Oncology clinics often faced a significant gap between the information provided to physicians and that provided to patients regarding referrals, diagnostics, and care coordination. Physicians had access to detailed, up-to-date EHR data, whereas patients received incomplete, delayed information via letters or other communication channels. This disparity led to misunderstandings, hindered shared decision-making, increased administrative burdens, and exacerbated inequities in access to cancer care, where accurate data are crucial. The goal of future digital health systems is to achieve content parity in oncology consultations, ensuring that both clinicians and patients receive timely, relevant, and personalized information from a single authoritative source while adhering to standards for clinical governance, informed consent, patient privacy, health data security, and patient health literacy.

Limitations

The observations in this study were made opportunistically in a single cancer center, where only a director and a small number of oncology registrars were available to participate. However, few studies have reported more than 50 consultation observations, and the objective of this study was to gain a deeper understanding of the processes physicians use during oncology SDM.

The study site and the outpatient oncology clinical facility are part of a university medical school; therefore, they may not reflect oncology practice in a cancer center in nonacademic healthcare settings.

Although longitudinal studies of patient cases were not feasible, the lack of opportunities to track patients' visits over time during their cancer care journey did not prevent data saturation from revealing diverse consultation objectives and decisions achieved. Only a snapshot of their circumstances was recorded at the time of the observed consultations. However, the large number of consultations observed ensured that patients at all stages of their oncological care were well represented, thereby providing a comprehensive understanding of the SDM process and the technologies employed.

Conclusion

The traditional view of SDM, in which a physician and patient collaborate to select a treatment from equally effective options, needs to be broadened to reflect the complexity of medical oncology consultation workflows. In cancer care, many decisions must often be made simultaneously to guide patients through multiple clinical care pathways. Throughout their journeys, patients interact with various healthcare professionals at different points of care in cancer care. There are several possible combinations of intervention pathways that may be necessary for a patient diagnosed with cancer, beyond just one physician in medical oncology clinics managing their chemotherapy. Additional medical interventions may include surgery, radiation therapy, immunotherapy, management of other medical conditions, and addressing personal physical, mental, or social issues. Patients may also visit diagnostic laboratories for tests to confirm diagnoses, conduct further investigations, or undergo routine monitoring of their health status. These actions complement hospital visits for treatments like chemotherapy. For a physician managing a patient's treatment in medical oncology, obtaining this essential information from other clinics, healthcare providers, patients, and care partners is crucial for informed decision-making at each stage of the patient’s cancer care journey.

The use of technology in consultations is often limited to digital functions for storing, retrieving, accessing, displaying patients’ health information, and writing clinical notes. There are clear opportunities to improve SDM in medical oncology consultations. For example, integrating health data across public and private healthcare systems and incorporating patient web portals, mobile devices, and AI technologies. A healthcare system-wide integrated digital infrastructure can enable more efficient and effective multidisciplinary teamwork in delivering cancer care services. Healthcare professionals and patients can continue to communicate effectively by accessing and sharing information digitally between clinic visits. Patients would be able to access and review the accuracy of their physicians’ clinical notes and the care plans they collaborated on with their physicians. A digitally enabled clinical teamwork approach would help patients ask questions online and obtain clarifications about their treatment options, enabling them to make better-informed decisions about their healthcare.

A digitally connected cancer care team can also boost healthcare professionals' satisfaction with the healthcare system and help patients feel more satisfied with the care they receive. This would help build more trust between patients and their healthcare providers. All healthcare professionals, patients, and their care partners would be empowered to access the patient's test results as soon as they appear in the patient's EHR within the hospital information system and the integrated patient web portal. Patients would also be able to monitor their scheduled appointments and stay up to date on their progress.

As a result, an integrated EHR system equipped with AI-powered decision-support tools would promote an informed, team-based SDM approach. Furthermore, the growth of generative AI offers new opportunities to develop patient-specific cancer profiles and create more effective, personalized care tailored to each individual patient, rather than providing generic care programs for all patients within a population with a similar cancer type.

In conclusion, a comprehensive and enhanced EHR system that incorporates patient web portals and validated AI tools would help identify patients at risk, not only for cancer, and alert their healthcare team and healthcare providers promptly. The new SDM teamwork approach to providing cancer care would foster greater patient engagement in decision-making and their cancer care management processes, thereby enhancing the quality of medical oncology practice and the delivery of hospital cancer care services.

Multimedia Appendix 1

Table 5: Summary of the study observed consultations.

Consultation case number	Summary of the observed consultation
1	This was an initial consultation with a male patient, around 50 years old, who was diagnosed with bowel cancer. After surgery, he was advised to undergo chemotherapy. During his consultation with the medical oncologist, he provided paper copies of his laboratory results. The patient was accompanied by his care partner, who actively participated in the consultation session by discussing the recommended chemotherapy medications and their possible side effects. The oncologist told the patient that his recovery was going well. Together, the oncologist, the patient and his care partner decided that the next step would be to prepare for participation in a clinical trial. No computers or digital devices were used during this consultation.
2	A man around 60 years old diagnosed with cancer came in for a follow-up consultation after being discharged from the hospital and completing his radiation therapy. The patient discussed his diet, overall health, exercise habits, weight, and social issues. The oncologist emphasized the importance of future follow-up visits and additional blood tests. During this consultation, the oncologist used the EHR system to review the patient's medical records.
3	A woman in her sixties diagnosed with cancer attended her follow-up appointment. The oncologist observed an improvement in her overall health and recommended that she continue with the existing treatment and dose. During this consultation, the oncologist reviewed the patient's medical records on the EHR system.
4	A man in his sixties diagnosed with colorectal cancer attended a follow-up appointment. The oncologist informed him that his condition was stable and advised him to continue with the treatment. The oncologist reviewed the patient's medical record in the EHR system.
5	A woman in her 80s diagnosed with ovarian cancer attended her follow-up appointment. During this visit, the oncologist discussed her cancer recurrence, noting that medical treatment was no longer effective and that supportive care was needed. The oncologist reviewed the patient's tumor growth chart in the EHR system.
6	A 60-year-old man diagnosed with cancer attended a follow-up visit. The oncologist evaluated the impact of chemotherapy, observing a reduction in tumor growth and stabilization. Skin issues and their pertinent treatments were also discussed. The oncologist utilized the EHR system to review the patient's results and recommended further chemotherapy and diagnostic tests.
7	A woman diagnosed with cancer consulted her oncologist after receiving chemotherapy to discuss her health status in a follow-up visit. During their appointment, the oncologist performed a physical examination and reviewed her medication list. They also reviewed her medical records, including diagnostic images stored in her EHR, and updated her health information. The oncologist then contacted Medicare by phone to get approval for prescribing certain medications for long-term pain management and advised her to seek guidance from the cancer council.
8	At a follow-up appointment, a female patient diagnosed with cancer discussed her laboratory test results, current health condition, ongoing treatment, and medication plan with her oncologist. They scheduled a future follow-up visit and arranged for ongoing necessary regular blood tests. No technology was observed in this consultation.
9	A male patient, around 50 years old, diagnosed with lung cancer, attended a follow-up appointment with his oncologist to review his CT scan results and plan his treatment. The oncologist prescribed medications and new chemotherapy cycles on paper, no technology was observed in this consultation.
10	A woman in her fifties diagnosed with neuroendocrine cancer visited her oncologist for a follow-up appointment. They discussed her treatment outcomes, planned future tests and treatments, and organized her ongoing care. No technology was observed in this consultation.
11	A man in his sixties diagnosed with cancer had a follow-up appointment with his oncologist. They discussed the patient's results and health status. The oncologist utilized the EHR system to access the patient's health data. They decided to proceed with the current treatment plan and scheduled follow-up visits.
12	A woman in her sixties diagnosed with ovarian cancer attended a follow-up appointment with her oncologist. They discussed her test results, ongoing chemotherapy, and possible side effects. They also talked about home care support and allied health services. No technology was observed in this consultation.
13	A man in his eighties diagnosed with prostate cancer visited his oncologist for a follow-up consultation. They reviewed his chemotherapy results, scheduled future tests, and arranged further appointments. No technology was observed in this consultation.
14	During a follow-up consultation, a male patient diagnosed with pancreatic-liver cancer and the oncologist reviewed the chemotherapy results and discussed future treatment plans. No technology was observed in this consultation.

15	A woman in her fifties diagnosed with cervical cancer attended her follow-up appointment after chemotherapy. During the visit, she discussed her test results, health condition, and medication use with her oncologist. They planned the continuation of her chemotherapy along with monitoring her progress. No technology was observed in this consultation.
16	A man in his fifties diagnosed with colorectal cancer attended a follow-up appointment where, together with the oncologist, they reviewed the results after chemotherapy and discussed treatments for other medical complaints. The oncologist retrieved the patient's medical records through the EHR system. They agreed to keep the current treatment plan and to continue monitoring the patient's progress.
17	A woman in her fifties diagnosed with colorectal cancer visited her oncologist for a follow-up appointment. The oncologist reviewed her test results and discussed her health condition. Using the EHR system, the oncologist accessed her CT scans through the Picture Archiving and Communication System (PACS). They agreed to continue with the current treatment plan and the oncologist recommended that the patient to also contact social support services.
18	A woman diagnosed with cancer returned to her oncologist for a follow-up appointment, during which they discussed the results of her treatment and her current health status. They concluded to proceed with additional chemotherapy. No technology was observed in this consultation.
19	A patient diagnosed with colorectal cancer presented for a follow-up appointment after treatment. During the meeting, the patient and the oncologist discussed the treatment results. They agreed to consult with the multidisciplinary team to decide on the next steps. No technology was observed during this consultation.
20	A female patient diagnosed with breast cancer visited her oncologist for a follow-up appointment to evaluate her health. The oncologist discussed her treatment results. To review her MRI images, the oncologist used the EHR system. They agreed to continue with more chemotherapy and regular CT scans. Additionally, the oncologist requested specific injections for the patient by obtaining approval from Medicare over the phone.
21	A woman in her 70s was diagnosed with bowel cancer and attended a follow-up appointment to discuss her test results. Her care partner inquired about the scans and their implications. The team opted to continue testing and monitoring the patient. The oncologist utilized the EHR system to examine the patient's results.
22	A man in his 60s was diagnosed with colorectal cancer and attended a follow-up appointment after receiving chemotherapy. A registrar was also involved in the consultation. Together with a senior consultant, they assessed the patient's results and other health issues. A decision was made to continue with chemotherapy and ongoing monitoring. The patient's care partner was also present. The EHR system was used to review the patient's results.
23	A man in his 60s diagnosed with colorectal cancer attended an initial medical oncology consultation after surgery at the hospital. The registrar collected the patient's information and discussed his condition. The oncologist outlined treatment options and scheduled a follow-up visit to finalize the patient's treatment plan. The EHR system was used to review chemotherapy protocols.
24	A female cancer patient attended a follow-up appointment. During this visit, she and the oncologist discussed her health issues as she was recovering from surgery. They decided to schedule additional tests and a follow-up assessment before beginning chemotherapy. The oncologist used the EHR system to review the patient's test results.
25	A man, aged 42, received a diagnosis of advanced pancreatic-liver cancer. During a follow-up consultation, the patient and the oncologist reviewed the test results. The oncologist advised maintaining chemotherapy but at a lower dose and suggested monitoring the patient's progress. No technology use was observed during this consultation.
26	A man who was diagnosed with colorectal cancer went to a follow-up appointment. During the visit, they discussed the test results and his health progress. No technology was observed being utilized during this meeting.
27	A man in his 50s diagnosed with colorectal cancer attended a follow-up appointment. During this visit, he discussed his ongoing health issues and progress with the oncologist. They planned to continue his treatment regimen. Additional tests were ordered to help determine the next course of action. The oncologist wrote new prescriptions. No technology was observed in use during the consultation.
28	A 78-year-old woman with ovarian cancer attended a follow-up appointment. During this session, her recovery after surgery and chemotherapy was reviewed. The discussion also covered potential future treatments, including participating in clinical trials. Recommendations from the multidisciplinary team were needed, and her progress was to be monitored before finalizing the upcoming treatment plan.
29	A woman diagnosed with breast cancer went to a follow-up visit. During this appointment, her test results were reviewed, and the oncologist informed her that a change in her treatment plan was necessary due to a continued increase in her cancer growth marker. No technology was observed in use during this consultation.
30	A woman diagnosed with breast cancer visited for a follow-up appointment. She carried her test results on paper form and discussed her current health problems with the oncologist. The treatment plan stayed the same. The oncologist issued requests for further tests and scheduled the next follow-up on paper. No technology was utilized during this consultation.

31	A woman diagnosed with breast cancer attended a follow-up appointment. During the session, they discussed her treatment results and the ongoing treatment plan. No technology was used during this consultation.
32	A woman in her 60s, who was diagnosed with gallbladder cancer, attended a follow-up appointment. The oncologist reviewed her test results and informed her that, although they indicated no additional treatment was needed, continued monitoring would be necessary. The oncologist utilized the EHR system to examine her medical record.
33	A woman in her forties who has breast cancer reviewed her test results and health status with her oncologist, who recommended a follow-up to decide on the subsequent course of action. The consultation was conducted without the use of any technology.
34	A woman in her 40s, diagnosed with breast cancer, attended a follow-up appointment with her oncologist. A registrar reviewed her medical results, discussed her current condition, and addressed other health issues. The oncologist explained her treatment options and advised her to contact support services. To prescribe specific pain relief, the registrar telephoned Medicare. The registrar accessed the patient's results and reports via the EHR system.
35	A woman in her seventies, diagnosed with colorectal cancer, attended her initial consultation. The registrar reviewed her test results, discussed her condition, and addressed additional health concerns. They also talked about treatment options and possible side effects of chemotherapy. The oncologist recommended reducing the doses of the chemotherapy drug and stated that they would discuss treatment options with the multidisciplinary team (MDT). The patient was accompanied by her care partners. The registrar used the EHR system to access the patient’s information.
36	A man in his 80s with colorectal cancer attended a follow-up appointment. During the consultation, they reviewed the results and agreed that chemotherapy was no longer needed, although they would continue monitoring his health. The oncologist examined the full-body scans in the EHR system.
37	A man in his 70s diagnosed with colorectal cancer attended his initial consultation. During the appointment, the registrar discussed the patient's health concerns, previous treatments, and possible future options. The oncologist recommended new chemotherapy to slow the cancer's growth and suggested ongoing testing. The patient was accompanied by his care partners, and no technology use was observed during the visit.
38	A man in his 50s, who has been diagnosed with neuroendocrine cancer, attended his initial consultation. The registrar examined the patient's test results and current health issues. The oncologist discussed the available treatment options and next steps in the patient's care management. During the consultation, the EHR system was utilized. Chemotherapy protocols were accessed from an online database.
39	A woman in her sixties visited her oncologist for a follow-up appointment. During the visit, they reviewed her test results, discussed her health issues, and decided to continue her treatment. The oncologist accessed her medical records in the EHR system.
40	A woman in her 60s with ovarian cancer attended a follow-up appointment. The oncologist reviewed her post-chemotherapy results and decided to proceed with additional treatment. No technology was used during this appointment.
41	A man in his 50s with colorectal cancer attended his first consultation. The registrar reviewed the reported results and discussed the outcomes of the patient’s recent surgery. The oncologist arranged chemotherapy with assistance from an oncology nurse and referred the patient to a dietitian. The EHR system was used during this consultation.
42	A woman diagnosed with ovarian cancer presented for a follow-up appointment. The oncologist reviewed her chemotherapy results and decided to continue with additional treatment. No technology was used during this consultation.
43	A woman in her 50s with ovarian cancer attended a follow-up appointment. The registrar reviewed her treatment and test results. The oncologist suggested further treatment and testing. No technology was used during this appointment.
44	A woman in her 40s was diagnosed with stomach cancer. After her treatment was completed, the oncologist reviewed her results. The oncologist recommended additional tests for ongoing monitoring. No technology was utilized during this consultation.
45	A man in his 50s, recently diagnosed with colorectal cancer, attended a follow-up appointment. During this visit, the oncologist reviewed the patient’s postoperative recovery. The patient's reported outcomes were vital in shaping the ongoing treatment plan. Additionally, the patient considered participating in a clinical trial. No technology was used during this consultation.
46	A woman diagnosed with appendiceal mucinous cancer attended a follow-up appointment. The oncologist discussed ongoing monitoring of her health after her colon surgery. She was accompanied by her care partner during the visit. No technology was used in this discussion.
47	A woman with colorectal cancer attended a follow-up consultation. The oncologist discussed the patient's postoperative progress and results, as well as the ongoing need for tests and monitoring. No technology was used.
48	A male in his sixties with colorectal cancer attended a follow-up appointment. The registrar reviewed the patient's results and current health concerns. The oncologist informed the patient that his case would be presented at the MDT to help plan his future treatment. Technology was not used.

49	A patient diagnosed with cancer attended a follow-up appointment. During the visit, the oncologist reviewed the patient's treatment results and decided to continue with the current treatment plan. Technology was not involved.
50	A female cancer patient attended a follow-up appointment, during which the registrar reviewed and discussed her treatment results. The oncologist recommended further tests and addressed her ongoing health concerns. Plans were made for her to restart chemotherapy after her vacation. The registrar accessed the patient's results and reports in her EHR and typed notes in the system during the discussion.
51	A woman in her 40s attended a follow-up appointment where she talked about her continuing health problems. She and the oncologist reviewed her ongoing treatment, tests, and the methods used to track her progress. No technology was employed during this consultation.
52	A man in his 60s with a neuroendocrine cancer attended a follow-up appointment after surgery. The oncologist informed him that his case would be reviewed by the MDT and that additional tests were needed. The oncologist also recommended continuing treatment with higher doses of chemotherapy drugs and emphasized the importance of further testing and follow-up appointments. No technology was used.
53	A man diagnosed with cancer attended a follow-up appointment. During this visit, the oncologist reviewed his test results, gave him a paper copy, and discussed his health concerns. They discussed his progress and potential treatments. The oncologist referred him to a specialist for further care. The patient shared his preferences. The oncologist reviewed his laboratory results in the EHR system.
54	A woman in her 70s, diagnosed with colorectal cancer, attended a follow-up appointment. The registrar reviewed her test results, discussed her health concerns, and coordinated with the oncology nurse to plan her treatment. The oncologist also addressed her questions and clarified the indicators of her health progress, emphasizing the importance of regular tests and follow-up visits. Her care partner accompanied her to the appointment. The EHR system was used to review the laboratory results.
55	A woman in her 60s diagnosed with ovarian cancer brought a CD with her test results to her follow-up appointment for evaluation. During the visit, they discussed her health progress and concerns after chemotherapy. They also discussed potential additional treatments, such as clinical trials. The oncologist planned ongoing monitoring and scheduled more follow-up appointments. The EHR system was accessed to review her information.

Multimedia Appendix 2

Study Design

Before conducting observations, the chief medical director of the medical oncology department was contacted. The physicians at the outpatient medical oncology clinics were also informed about the project and discussed the planned observational study.

Configuration of the Consultation Room and Technologies Used

The cancer center is an integrated healthcare service in metropolitan Sydney, Australia. The center provided multiple consultation rooms, each equipped with a desktop computer for accessing digitized patient medical records and online health information sources. A telephone was also available on the physician's desk. The center provided the Cerner PowerChart Millennium EHR system alongside paper-based clinical files in its chemotherapy infusion center. In 2019, the cancer center adopted the Cerner Oncology module to standardize evidence-based oncology treatment protocols. The EHR system supported physicians by enabling them to access and retrieve patient diagnostic test results, clinical notes, and assessment reports, such as physical fitness scores from other healthcare providers. However, requests for pathology and radiology diagnostic tests, as well as scheduling for follow-up consultations, were handwritten and signed on paper forms by the physician. The ordering of treatment followed a hybrid system in which some chemotherapy protocols were ordered via the Cerner Oncology Module, while others were ordered on paper forms. Each physician-patient encounter occurred in one of the secured consultation rooms. In addition to the consultation rooms, several private rooms were made available in the clinical area for physicians and nurses to meet discreetly to discuss patient care, if needed.

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3.3 CHAPTER 3 CONCLUSION AND CHAPTER LINK

The study in Chapter 3 examined the consultation process in medical oncology clinics, using an electronic health record system for support. To understand the workflow of oncology consultations when using an electronic health record system, an ethnographic approach was adopted. The qualitative study involved meeting with subject matter experts, interviewing a senior oncology consultant, observing physicians and patient encounters, and reviewing literature databases for articles on the medical consultation process. By coding the qualitative data collected, a conceptual model of the oncology consultation process was developed (Figure 1).

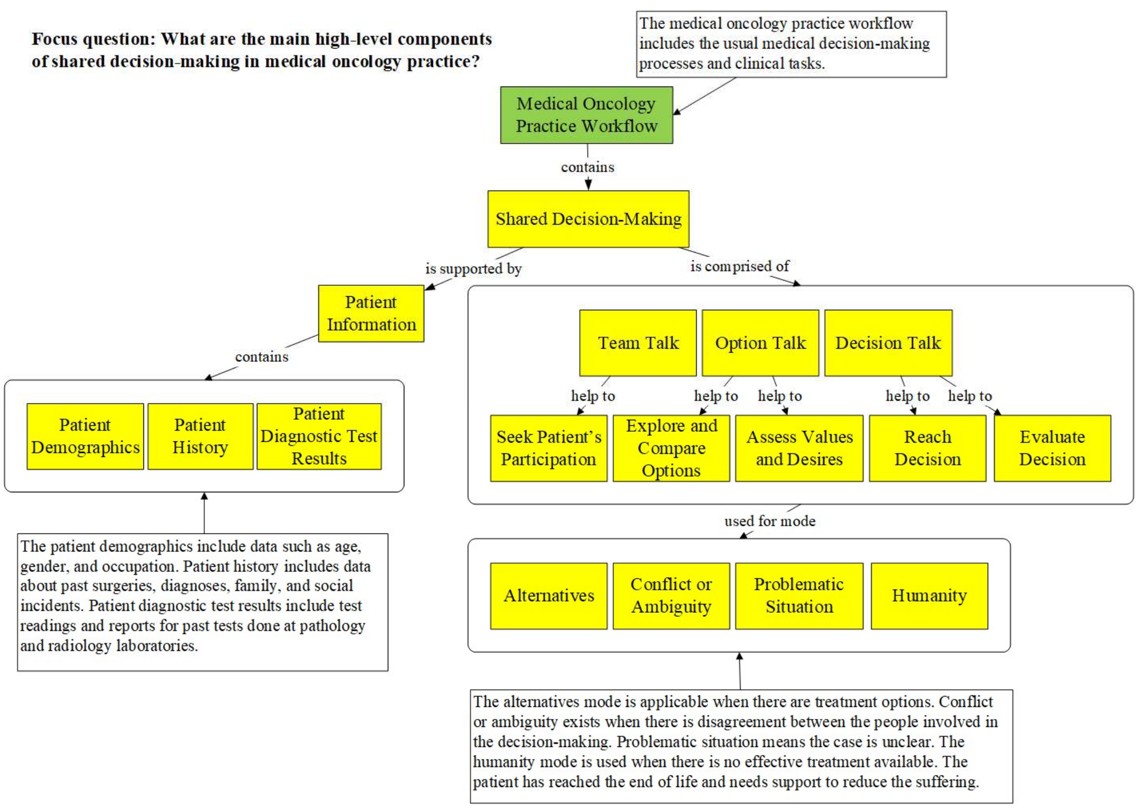

Figure 1 - Conceptual model showing the components of shared decision-making embedded within the oncology consultation workflow.

As shown in Figure 1, and in line with Hargraves et al. [3] findings, there are potentially four different types of decision-making workflows involved. These workflows relate to managing chemotherapy, selecting alternative treatment options, assessing patient progress, and scheduling follow-up reviews of the patient's health progression.

Building on the conceptual model created in Chapter 3, Chapter 4 presents the results of a co-design, prototyping, and desktop evaluation of a technology-driven shared decision-making system integrated into the electronic health record system. This envisioned future integrated system aims to enhance patient engagement in the shared decision-making method of care, thereby helping patients choose their preferred treatment and collaborate with their oncologist to manage their own care in a manner that suits them best, and remain engaged in the teamwork nature of cancer care.

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CHAPTER 4: EXAMINING HOW TECHNOLOGY SUPPORTS SHARED DECISION-MAKING IN ONCOLOGY CONSULTATIONS

4.1 CHAPTER PREFACE

Chapter 3 provided context on the way digital tools were used as part of shared decision-making processes for cancer care. It centred on consultation procedures in outpatient medical oncology clinics within a major metropolitan hospital in Australia. Specifically, it examined the patient journey and decision-making processes during outpatient oncology patient visits within the local health district's cancer services. The study uncovered the complexities and various possible care pathways a patient with cancer might follow, ranging from consulting a general medical practitioner to seeking treatment at the local cancer centre with a medical oncologist. The findings presented in Chapter 3 suggest that oncology consultations are complex, often involving multiple oncologists and medical specialists advising on appropriate care pathways.

Based on the insights gained in Chapter 3, this chapter explores a mock-up for a shared decision-making tool for use in cancer care. The focus of this chapter is on the design of an early concept for a tool to visualise information, targeting specific patient goals, along with user feedback on the strengths and weaknesses of the mock-up. This chapter has two components: 1) This preface, which describes the early design of the shared decision-making tool from concept to mock-up and 2) A research publication presenting feedback from co-design workshops with cancer care professionals about the mock-up and the role of technology in cancer shared decision-making more broadly.

4.1.1 Creating the mock-up shared decision-making system.

The digital shared decision-making tool concept was developed in accordance with the principles and recommendations of Human-Centred design principles [1], Scenario-Based design [2], and Human-Centred software engineering [3]. These principles include understanding and defining the context of use, specifying the user and organisational requirements, creating design solutions, and assessing designs against requirements to ensure the system meets the specified user and organisational needs [3, 4].

The mock-up shared decision-making tool was created by the PhD candidate in this thesis, a clinical business analyst who had over five years of experience implementing clinical information systems in hospitals. The initial development and content of the digital shared decision-making concept were concentrated on the characteristics of oncologists and their needs. The researcher used the Ottawa Decision Support Framework as the starting point for developing the prototyped digital shared decision-making system [5]. The development process then focused on two main areas. First, it determined the data elements required by oncologists during each patient visit. Next, the relationships between the cancer workflow concepts developed previously (Chapter 3) were used to organise and display the data, supporting the oncologists' decision-making process with information.

The digital tool user interface prototypes were created using online, hosted web-based rapid prototyping software. The Balsamiq wireframing software was used by the researcher remotely for creating the user interfaces and for sharing with remote representatives of end-users of the digital shared decision-making system [6]. The researcher assessed the feasibility of the prototyped computer user interfaces through simulated consultation scenarios, workflows, and standardised or idealised patient cancer cases.

4.1.1.1 Idealised simulated patient with a cancer case scenario.

During the initial development of the prototype, the researcher reviewed previous patient cases (Chapter 3) and selected one as the ideal example for replaying the consultation scenario. This case was chosen because it provided sufficient clinical data and included the oncologist's actions and interactions with the computer, the patient, and their family, which were observed and recorded in field notes. Figure 1 illustrates the oncologist's consultation office setting, where treatment options were discussed and decisions were made.

Figure 1 - The oncologist is talking with the patient and family about the patient's health situation.

The patient's cancer care journey through the oncology consultation follows a similar pattern to that shown in Figure 2. In the consultation room, the oncologist, the patient, and the family established a relationship and rapport, setting the stage for a crucial conversation about how to proceed with the patient's care.

In the scenario presented (Figure 2), the decision-making process was assumed to be ideally linear and follows the shared decision-making three talk model and the standard Calgary-Cambridge medical interview framework that is taught in medical schools. However, in real oncology practice, the consultation may progress in a circular manner. Participants involved in the consultation may revisit a previous step for clarification before proceeding to the next stage in the process.

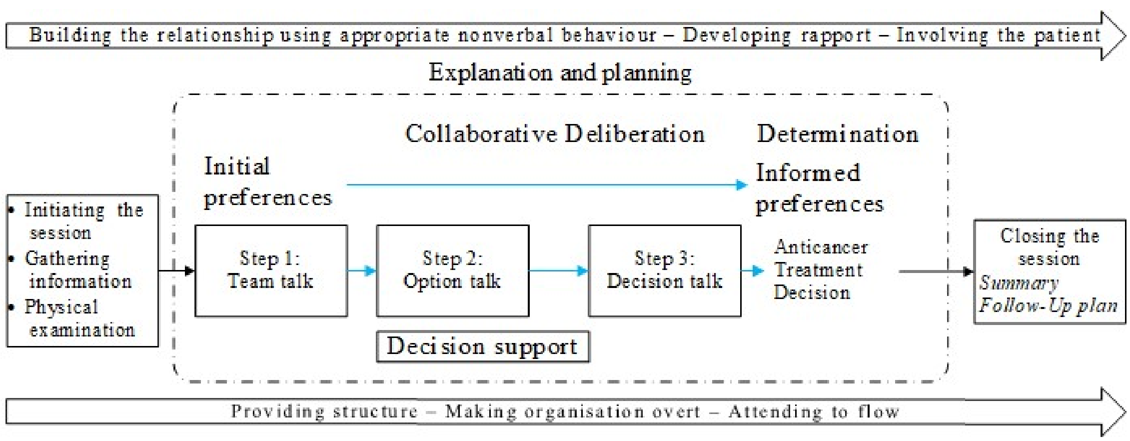

Figure 2 - Idealised patient-centred oncology consultation with the three types of conversations of the shared decision-making method of care. The diagram illustrates a simplified version of the workflow of an oncologist, as provided in Chapter 3 and referring to the standard Calgary-Cambridge medical interview framework.

The details in Table 1 were used to create the mock-ups of the computer user interface for the prototype. The interfaces were designed to guide users through the three stages of the shared decision-making model. The development followed the patterns and consultation task flow outlined in Table 1.

Table 1 - Events and oncologist's actions during a simulated oncology consultation. Note: The data used in this table may be clinically inaccurate. The dataset used here is solely for case simulation purposes.

Event descriptions	Consultation phases	Oncologist task steps	Oncologist's actions	Oncologist-patient dialogues
The nurse or clinical support staff entered the patient's information and attached documents to the patient's health records on the computer.	Initiating the session (Phase I)	1	Open the patient's electronic health record	Silent
Simulated patient: Name: Test One Age: 49 years old Sex: male		2	Review the patient's health records	
Diagnosis: stage IIIA CRC (cT2N1M0) adenocarcinoma rectum		3	Review the referral letter	
The patient was referred to the Department of Medical Oncology.		4	Review relevant evidence-based guidelines and protocols.	
		5	Call the patient into the clinic	Test One
		6	Greet patient (and family members and friends if present)	Hi, Mr One. Come in and have a seat. Nice to meet you and your family. My name is Mr Stephens, and one of the oncologists here.
		7	Confirm the patient's name, date of birth, sex, and address	Mr Test One? Can I confirm your address and your date of birth?
Patient problem(s): The patient presented symptoms of rectal bleeding. The referring physician diagnosed the patient with stage IIIA CRC (cT2N1M0) adenocarcinoma rectum.		8	Review the patient's chief complaint and diagnosis	I see that you've been referred to me by Dr Ben due to a finding in your recent laboratory test results. May I ask what you already understand or what has been explained to you so far? Based on the pathology report, it appears that you have colorectal cancer. This type of tumour is usually more or less aggressive and tends to spread. Based on the imaging findings, you have stage three colorectal cancer.
The patient's history, including medical, social, and family, was entered into the health records by the oncology registrar or nurse: No history of smoking, hypertension, dyslipidaemia, diabetes mellitus, or renal disease, and no family history of colorectal cancer. The patient has no known drug allergies, denied any previous alcohol, smoking, or herbal agent intake, and was a self-employed architect.	Gathering information (Phase II – Part 1)	9	Review the patient's history and vaccination records to determine if there are any vaccinations the patient needs prior to treatment	Can I confirm your medical, social, and family history? Do you smoke or drink alcohol? Any issue with hypertension or diabetes, dyslipidaemia, or renal disease? Any family history of cancer? Any allergies to drugs or herbal agents? What is your occupation? Can you please confirm which vaccinations you have received?

The registrar entered the following data: General status: conscious, responsive, aware of surroundings. Eyes: No changes in vision, no double vision, no blurry vision; wears glasses. ENT: No congestion, changes in hearing; not wearing hearing aids. Normal findings, the nasal septum is on the midline with no changes. Uvula on the midline with no tonsil hypertrophy or hyperaemia. Skin: No rashes, dry skin with loss of turgor due to dehydration, no erythematous areas. Neck: no noticeable or palpable swelling, redness, or inflammation around the throat or on the face.	Gathering information (Phase II – Part 2 Physical examination	10	Review the physical examination	Do you have any issues with your vision, breathing, or hearing? Any skin issues or rash? May I check your neck for any swelling or rash? May I take your blood pressure and listen to your heart and breathing?
Data were entered into health records by the pathology laboratory: Complete blood count, blood chemistry, coagulation profile, and urinalysis. Carcinoembryonic antigen (CEA) = 5.3 ng/ml; carbohydrate antigen 19–9 (CA 19.9) = 43 U/ml.	Explanation (Phase III – Part 1)	11	Review the pathology lab results and explain them to the patient	As the charts and your test results show, your tumour continues to grow.
Data were entered into health records by the radiology laboratory: PET-CT scan: A positron-emission tomography (PET) CT scan was performed to assess the staging. CT scan revealed increased fluorodeoxyglucose (FDG) concentration in the thickening involving the rectum and upper anal canal (standardised uptake value (SUV) 15.6), multiple discrete mesorectal, right obturator, and inferior mesenteric lymph nodes (SUV 2.0), indicative of metastases. There was no evidence of hepatic, pulmonary, or skeletal metastases. Additionally, the involvement of a few discrete retroperitoneal lymph nodes was noted.	Explanation (Phase III – Part 2)	12	Review radiology diagnostic imaging scans and explain them to the patient	Your scans show there are changes. The cancer is progressing. It would help if you started treatment soon to control the progression.
The registrar indicated that the case would be added to the register for the next multidisciplinary team meeting.	Planning (Phase IV – Part 1) Team Talk	13	Work with the patient, describe choices, offer support, and ask about goals.	Let's work together to make a decision that suits you best. We have a team of clinicians to support you. In general, who will help care for you at home?
The nurse recorded the patient's goals, values, preferences, and circumstances in health records.		14	Review the patient's goals, values, preferences, and life situation.	What would you like to see achieved from your treatment?
The nurse provided the patient with education pamphlets, videos, and supportive care contact information on the patient portal.		15	Review patient education materials provided on the patient portal.	Can I confirm that you have received the educational materials to assist you in deciding on your preferred treatment?

		16	Document Team Talk	Record the conversation (voice recognition, handwriting to typed text or direct keyboard typing)
Treatment options: 1. Long-course chemoradiation therapy with capecitabine or infusional 5-fluorouracil followed by chemotherapy for 12-16 weeks with FOLFOX or XELOX protocol, or 2. Short course radiation therapy followed by chemotherapy for 12-16 weeks with FOLFOX or XELOX Chemotherapy for 12-16 weeks with FOLFOX protocol, or 3. XELOX protocol followed by long course chemoradiation therapy with capecitabine or infusional 5-fluorouracil or short course radiation therapy, or 4. do nothing	Planning (Phase IV – Part 2) Option Talk	17	Discuss survival estimates using a prognosis calculator and alternatives, utilising the Option Grid to effectively communicate the benefits and risks of each treatment option. Explain the findings of some landmark studies and side effects, if any.	We cannot estimate your survival. It will depend on how well you respond to treatment. Your overall survival estimates are based on previous studies, as shown in this tool. Now, let's talk about the possible treatment options. What I can tell you is that: *Read the answers from the Option Grid for each option for each question*: What does the option involve? What are the similarities between these treatment options? What are the expected adverse effects of the treatment? What is the predicted response rate of the chosen treatment? How many sessions or clinic visits are needed for the treatment plan? Will surgery be required after chemotherapy? When can the patient expect to return to work? Will cancer come back anywhere? How will the patient be monitored?
The physician provides the patient with the Option Grid on the patient portal.		18	Share the Option Grid with the patient	Could I also suggest that you receive a copy of the treatment options on the patient portal to review at home and discuss with your family and friends?
Get informed preferences and make preference-based decisions.	Planning (Phase IV – Part 3) Decision Talk	19	Make decisions based on the information the patient provided about their preferences	Please tell me what matters most to you in this decision.
The patient and the medical oncologist agree on which treatment protocol to implement.	Planning (Phase IV – Part 4) Treatment decision	20	The medical oncologist includes the chosen therapy in the care plan	You don't need to select a treatment today. You can go home and think about it, discuss it with your family and let me know. I'll give you my mobile phone number, and you can contact me directly if you have any further questions.

The physician provides the patient with a summary of the clinical consultation notes on the patient portal.	Closing the session (Phase V – Part 1)	21	Summarise the outcomes of the consultation for the patient and the family members	Can I summarise what may be a plan for now? We talked about the blood test and CT scan results. We can arrange new tests for you for your next visit. Some information has been sent to you via the patient portal for you to read at home. Read the information with your family and think about the treatment options. It is essential to maintain a balanced diet and engage in moderate exercise. In terms of alternative treatments, extensive clinical trials do not back up supplements or herbal medications.
The physician provides the patient with the treatment management plan on the patient portal.	Closing the session (Phase V – Part 2)	22	Add the consultation summary and treatment management plan to the patient portal	I have added the summary of our conversation and the goals we discussed as of today to the patient portal. Read the information with your family and friends and consider the treatment options.
1. Treatment decision 2. Blood test 3. PET CT scan	Closing the session (Phase V – Part 3)	23	Give the patient and family members the chief medical oncologist's mobile phone number and inform them about the next steps	Can we schedule you to return here next week to see me again? Here is my mobile phone number, along with the requests for blood tests and a CT scan. Take the test before your next visit to have the results available by then. We'll discuss what's happening and whether things are improving or not, and then we can make a more informed decision about which way you want to go next. Whether that's chemotherapy or not. How does that sound? Do you have any other questions for me? Good, see you in one week then. Nice to meet you, Mr One. Bye now.

The treatment options grid in Table 2 is a decision-making tool designed to help oncologists inform patients of the various treatment choices available to manage their illness. The treatment options grid in this scenario is for an oncologist to determine, together with the patient, the best approach for managing their diagnosis of rectosigmoid junction cancer. Management of their cancer stage condition usually involves a combination of chemotherapy, radiotherapy, and surgery. Various approaches and regimens are available depending on the patient's needs and preferences. This options grid will assist the patient in deciding with their oncologist.

Table 2 - Example of a treatment option grid for cancer of the rectosigmoid junction. Note: No claim is made to the accuracy of the clinical information or data provided in the table. The dataset is used solely for case simulation purposes.

The dataset was extracted from Willett CG, Ryan DP. Neoadjuvant chemoradiotherapy and chemotherapy for rectal adenocarcinoma. UpToDate. Accessed on August 17, 2022.

Frequently asked questions	**Long course chemoRT with capecitabine or infusional 5-fluorouracil followed by chemotherapy for 12-16 weeks with FOLFOX or XELOX**	**Short course RT followed by chemotherapy for 12-16 weeks with FOLFOX or XELOX**	**Chemotherapy for 12-16 weeks with FOLFOX or XELOX followed by long course chemoRT with capecitabine or infusional 5-fluorouracil or short course RT**	**No treatment**
How much is the cost of the treatment?	Because long-course chemoRT requires more RT sessions, it is more costly compared to short course RT (this includes not only the actual RT cost but also incidental expenses such as transportation). In addition, long course chemoRT requires the administration of capecitabine or infusional 5-fluorouracil during RT days, which will entail additional expense. Chemotherapy for 12-16 weeks after long course RT depends on the regimen, i.e., whether FOLFOX or XELOX. Since FOLFOX warrants admission and consists of more sessions, it costs more than XELOX, which is outpatient and has fewer sessions.	Short course RT is cheaper than long course chemoRT because it consists of fewer RT sessions, and it does not warrant the administration of capecitabine or infusional 5-fluorouracil during RT days. Chemotherapy for 12-16 weeks after short course RT depends on the regimen, i.e., whether FOLFOX or XELOX. Since FOLFOX warrants admission and consists of more sessions, it costs more than XELOX, which is outpatient and has fewer sessions.	Costs are similar with the other two preceding options because it is only the sequence of modalities which changed, i.e., chemotherapy first before either long course chemoRT or short course RT.	No treatment means no costs from chemotherapy or RT aside from costs incurred from supportive measures such as pain medications.
What are the expected adverse effects of the treatment?	Long course chemoRT has fewer side effects related to radiation (such as dermatitis, colitis, and bleeding) because it uses a smaller radiation dose distributed over a longer period. However, the concurrent administration of capecitabine or infusional 5-fluorouracil causes additional chemo-related side effects including diarrhea, dermatitis, abdominal pain, nausea, vomiting, anemia,	Short course RT has more side effects related to radiation (such as dermatitis, colitis, and bleeding) because it uses a higher radiation dose distributed over a shorter period. It has no adverse effects related to chemotherapy because it does not involve the concurrent administration of either capecitabine or	Expected adverse effects are similar with the other two preceding options because it is only the sequence of modalities which changed, i.e., chemotherapy first before either long course chemoRT or short course RT. As such, the patient will experience the adverse effects related to the chemotherapy first before those related to radiation.	Since there is no treatment modality used, there are no expected adverse effects. However, the patient may experience symptoms related to the worsening cancer such as constipation, diarrhea, abdominal pain, rectal bleeding, anorexia, weight loss, nausea, vomiting, etc.

	leukopenia, and thrombocytopenia. FOLFOX and XELOX also has a different adverse effect profile. FOLFOX, because of its intravenous administration can cause more side effects related to the infusion site such as redness, inflammation, and pain. In contrast, XELOX has more gastrointestinal adverse effects such as abdominal pain, diarrhea, nausea and vomiting because of its oral route of administration.	infusional 5-fluorouracil. FOLFOX and XELOX also has a different adverse effect profile. FOLFOX, because of its intravenous administration can cause more side effects related to the infusion site such as redness, inflammation, and pain. In contrast, XELOX has more gastrointestinal adverse effects such as abdominal pain, diarrhea, nausea and vomiting because of its oral route of administration.		
What is the expected response rate of the chosen treatment?	The expected response rate among the options is comparable. According to studies, rates of local recurrence, disease free survival, distal recurrence, and overall survival are comparable. In some institutions, long course chemoRT is preferred for most patients, particularly those with T4 and/or bulky tumors or if the circumferential resection margin (CRM) or complete resection status are predicted to be at risk.	The expected response rate among the options is comparable. According to studies, rates of local recurrence, disease free survival, distal recurrence, and overall survival are comparable. Short course RT is usually preferred in selected patients, such as those thought not to be able to tolerate long course chemoRT or those who cannot go to the hospital/center daily for a prolonged period.	The expected response rate among the options is comparable. According to studies, rates of local recurrence, disease free survival, distal recurrence, and overall survival are comparable. This is usually preferred in patients in patients who do not have immediate access to a center capable of radiotherapy.	Because of the absence of treatment, it is expected that the tumor may continuously grow and metastasize to other organs.
How many sessions/clinic visits are needed for the treatment plan?	Long course chemoRT usually consists of 25 days of RT sessions, Monday to Friday concurrent with capecitabine or infusional 5-fluorouracil. This will then be followed by 12-16 weeks of FOLFOX or XELOX. FOLFOX entails 12 inpatient sessions every 2 weeks while XELOX entails 8 outpatient sessions every 3 weeks.	Short course RT consists of only 5 days of RT, Monday to Friday with no concurrent chemotherapy. This will then be followed by 12-16 weeks of FOLFOX or XELOX. FOLFOX entails 12 inpatient sessions every 2 weeks while XELOX entails 8 outpatient sessions every 3 weeks.	This is similar with the preceding two options; only the sequence of modalities is changed, i.e., chemotherapy with either FOLFOX or XELOX first before long course RT or short course RT.	Even in the absence of treatment, regular clinic visits are still warranted. Depending on the status of the patient, this may be scheduled every 3-6 months or even more frequently at every month or every 2 weeks if the patient's condition warrants closer monitoring.
Will I still need surgery?	Yes. After or during this treatment option, surgical resection will be recommended. Surgery is usually recommended after long course chemoRT and before adjuvant chemotherapy.	Yes. After or during this treatment option, surgical resection will be recommended. Surgery is usually recommended after short course RT and before adjuvant chemotherapy.	Yes. With this option, surgical resection is recommended after chemotherapy and long course chemoRT or short course RT. This is the reason why this option is called total neoadjuvant treatment. This is	Surgical resection can be an option for patients who do not consent for chemotherapy or radiation. However, there is an increased risk of local or systemic

			recommended for most patients with locally advanced rectal cancer who are at high risk for a margin-positive resection (i.e., T4 disease or an involved mesorectal fascia, extramural venous invasion), as well as for those with clearly node-positive disease and a low-lying rectal tumor.	recurrence. Other surgical procedures such as placement of a colostomy may also be done such as in patients with an enlarging tumor which may lead/have led to colonic obstruction.
How will we monitor the patient?	Monitoring is usually done with history, physical examination, imaging tests and tumor markers. Repeat imaging and serum CEA is usually requested every 3 months during treatment. After completion of treatment, surveillance consists of: O History and physical examination every 3-6 months for 2 years, then every 6 months for a total of 5 years O CEA every 3-6 months for 2 years, then every 6 months for a total of 5 years O Chest, abdominal, pelvic CT scan every 6-12 months for a total of 5 years O Colonoscopy in 1 year after surgery except if no preoperative colonoscopy due to obstructive lesion, colonoscopy in 3-6 months			Depending on the goals of the patient and family, monitoring may instead involve monitoring for the progression or worsening of symptoms.

4.1.1.2 Feedback and iterative design of the mock-ups.

Feedback sessions were conducted with the designer of the interface and two senior academic researchers. The senior academic researchers each had over 10 years of experience in designing and implementing digital health solutions across various healthcare districts. The senior academic researchers in digital health technology were tasked with assessing the prototyped computer user interfaces and providing feedback to the designer. The senior academic researchers representing the end-users regularly met with the clinical business analyst in face-to-face and online meetings to review the progress of the prototype development. These sessions enabled the designer to refine the computer user interfaces and iterate on them.

While the end-user proxies examined the prototyped computer user interface mock-ups, they focused on the designs and usability, identifying gaps and elaborating on their requirements.

During reviews and walkthroughs of the prototyped functions, the end-users used the 'Think Aloud' technique to share insights into their thought processes with the researcher. Their further clarification included feedback on the quality of the oncology or patient health information presented by the digital tool, the types of decisional information required, and how the clinical information should be displayed on the computer screen to inform the end-users of the shared decision-making steps. For example, whether the information should be provided via video, infographics, text, or other formats, or tabulated in more clinically logical ways. After fifteen meetings conducted via MS Teams, Zoom, or face-to-face, and several iterations of the prototyped computer user interface mock-ups, the end-users reached consensus on the final version to present to practising oncologists, who are the potential ultimate end-users.

4.1.1.3 Final mock-ups for the co-design workshops.

After multiple cycles of testing and improvements with the end-users' proxies and the researcher, the final set of interface concepts for the shared decision-making tool was ready for end-user review. As described in previous sections, multiple reviews were conducted to refine the tool concept into a mock-up. The version of the mock-ups that was used in the co-design workshops described in the next section of this chapter is shown below. Figures 3 to 8 below display examples of wireframes shown to end-user proxies for review, evaluation, and feedback during testing and iterative refinement.

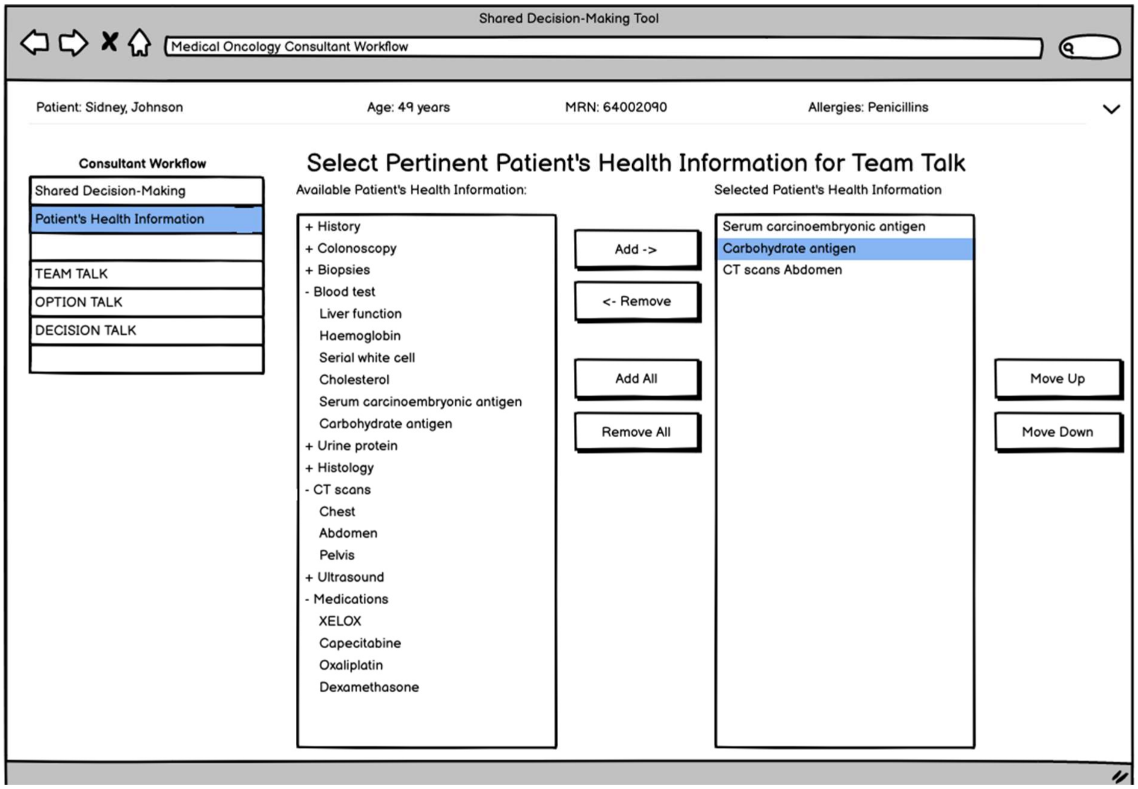

Figure 3 - Computer user interface mock-up for data gathering from the electronic health records.

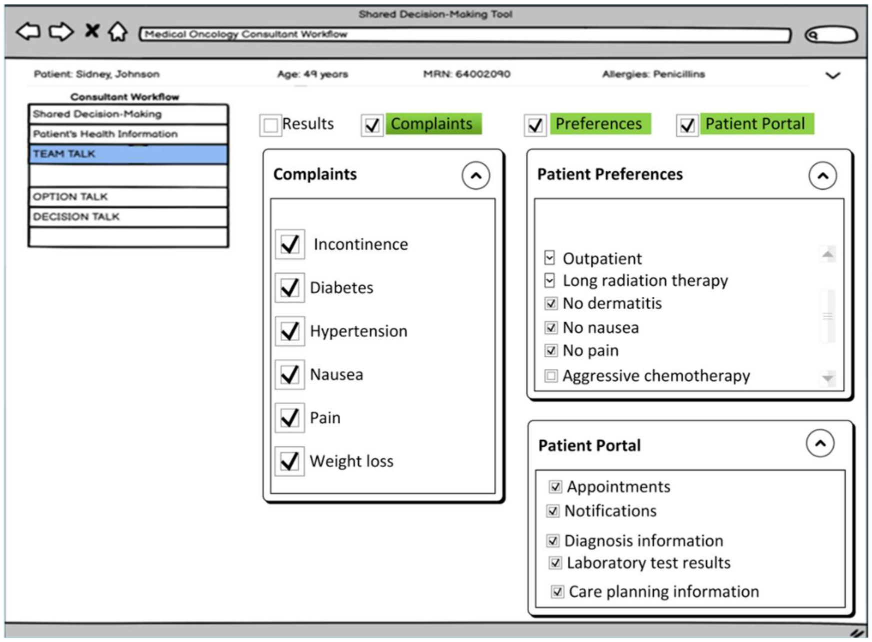

Figure 4 - Computer user interface mock-up for team talk during shared decision-making conversations.

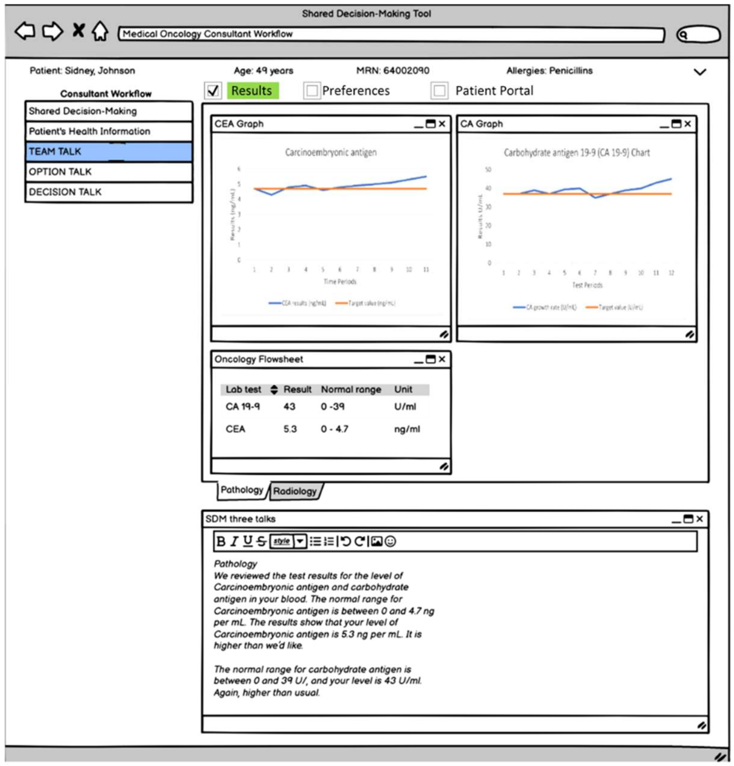

Figure 5 - Computer user interface mock-up for team talk during shared decision-making conversations about the patient's laboratory test results.

Figure 6 - Computer user interface mock-up for team talk during shared decision-making conversations about the patient's radiology imaging test results.

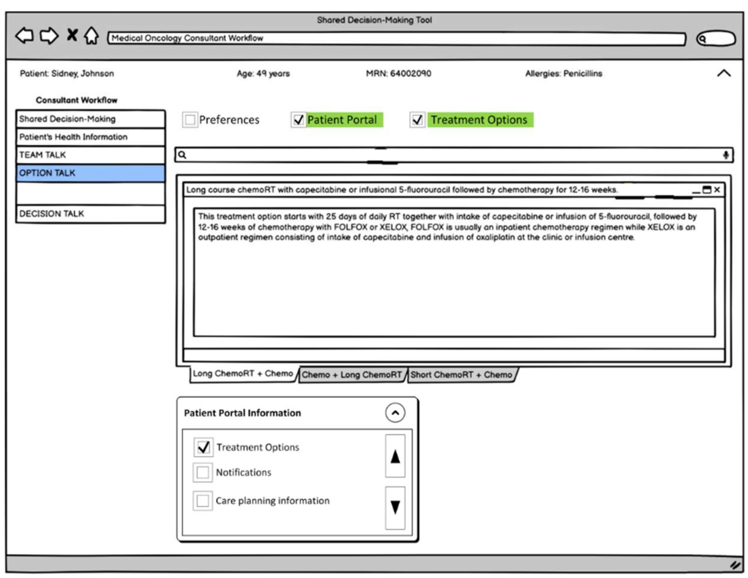

Figure 7 - Computer user interface mock-up for option talk during shared decision-making about potential risks and benefits of different available treatment options.

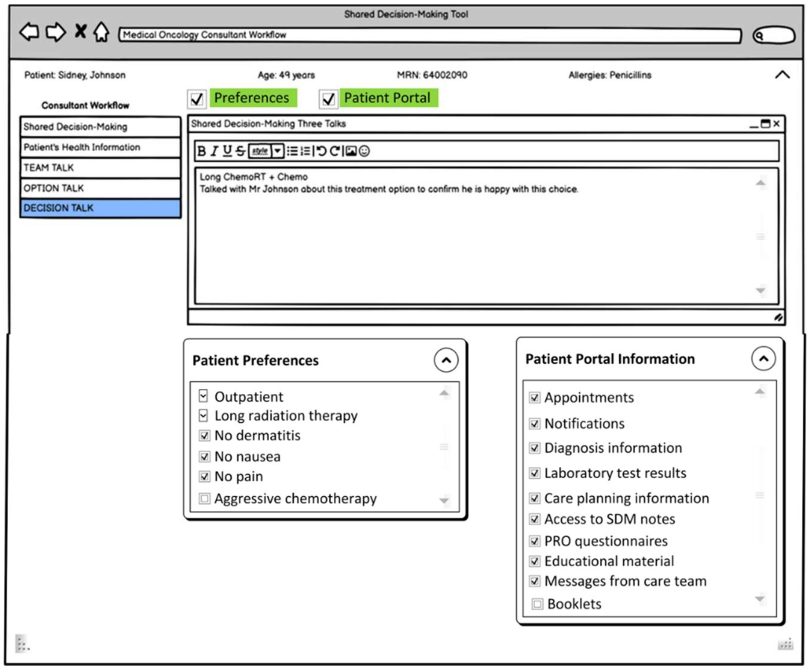

Figure 8 - Computer user interface mock-up for decision talk during shared decision-making conversations about the patient's preferences, goals, and wishes while creating a care plan for the patient.

4.2 Co-design Study Publication.

The final concepts described in the chapter preface were used to prompt discussion in a series of co-design workshops with healthcare professionals specialising in cancer care. The results of these workshops are provided in this section. The article has been published in an academic journal.

Yung, A., Shaw, T., Kay, J., & Janssen, A. (2025).

Examining How Technology Supports Shared Decision-Making in Oncology Consultations: Qualitative Thematic Analysis. *JMIR Cancer*, *11*, e70827.

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Original Paper

Examining How Technology Supports Shared Decision-Making in Oncology Consultations: Qualitative Thematic Analysis

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Abstract

Background: Commonly used digital health technologies, such as electronic health record systems and patient portals as well as custom-built digital decision aids, have the potential to enhance person-centered shared decision-making (SDM) in cancer care. SDM is a 2-way exchange of information between at least a clinician and the patient and a shared commitment to make informed decisions. However, there is little evidence in the literature on how technologies are used for SDM or how best they can be designed and integrated into workflows and practice. This may be due to the nature of SDM, which is fundamentally human interactions and conversations that produce desired human outcomes. Therefore, technology must be nonintrusive while supporting the human decision-making process.

Objective: This study examined how digital technologies can help cancer care professionals improve SDM in oncology consultations.

Methods: Health care professionals who treat patients with cancer were invited to participate in online co-design focus group meetings. During these sessions, they shared their experiences using digital technologies for SDM and provided suggestions to improve their use of digital technologies. The session recordings were transcribed and then analyzed using qualitative thematic analysis. The 3-talk SDM model, which consists of 3 steps—team talk, option talk, and decision talk—was used as the guiding framework. This approach was chosen because the 3-talk SDM model has been adopted in Australia. The researchers walked the participants through the SDM model and discussed their routine clinical workflows.

Results: In total, 9 health care professionals with experience treating patients with cancer and using technologies participated in the study. Two focus groups and 2 interviews were conducted in 2024. Three themes and 7 subthemes were generated from the thematic analysis. The findings indicated that various digital technologies, such as electronic health record systems, mobile devices, and patient portals, are used by cancer care professionals to help improve patients' understanding of their disease and available care options. Digital technologies can both improve and undermine SDM. Current systems are generally not designed to support SDM. Key issues such as data integration and interoperability between systems negatively impact the ability of digital technologies to support SDM. Emerging technologies such as generative artificial intelligence were discussed as potential facilitators of SDM by automating information gathering and sharing with patients and between health professionals.

Conclusions: This research indicates that digital technologies have the potential to impact SDM in oncology consultations. However, this potential has not yet been fully realized, and significant modifications are required to optimize their usefulness in person-centered SDM. Although technology can facilitate information sharing and improve the efficiency of consultation workflows, it is only part of a complex human communication process that needs support from multiple sources, including the broader multidisciplinary cancer team.

(JMIR Cancer 2025;11:e70827) doi: 10.2196/70827

KEYWORDS

digital health; patient-centered care; person-centered care; shared decision-making; cancer care; oncology; artificial intelligence; AI

Introduction

Background

Shared decision-making (SDM) is defined as a collaborative approach in which patients and health care providers work together to make medical decisions [1]. SDM emphasizes a cooperative relationship between the patient and the physician, characterized by a 2-way exchange of information and a shared commitment to making informed medical decisions [2]. During the SDM conversation, patients and clinicians share information, express preferences, participate in discussions to gain insights, negotiate conflicts, solve problems, and ultimately make decisions [3]. Through this approach, patients can play an active role in their care [4], while physicians gain a better understanding of the unique needs of each patient. Physicians can then make informed and collaborative recommendations that aim to improve patient health outcomes [5]. The use of SDM is particularly crucial in oncology consultations, as the results of treatments are often uncertain. This uncertainty makes treatment decisions complex for patients who often have to choose between aggressive disease management and maintaining their quality of life [6]. Therefore, SDM has been implemented in oncology consultations in several hospitals around the world, and perceptions of its use by cancer care specialists in hospitals have been studied [7-9]. Despite the integration of SDM into health policies and practice standards [10,11], the benefits of SDM are slow to materialize at the operational level [12], and a fragmented health care system can complicate the implementation of SDM.

Efforts have been made to integrate decision aids into electronic health record (EHR) systems used by oncologists [13]. Current EHRs used in oncology practices in hospitals may include functions to facilitate the scheduling of patient consultations and follow-ups, history taking, review of examination results, electronic medication management systems, and care planning [14,15]. However, existing EHRs often do not provide complete details about patients' health values and preferences [16]. This lack of patient details can cause clinicians to misunderstand patient preferences when patients experience cognitive difficulties or when their health conditions worsen too quickly to participate in SDM, which can have significant adverse consequences [16]. The introduction and integration of additional digital tools, such as cancer care dashboards, into EHRs that display patient treatment outcomes and other clinical measurements to monitor patient health status have been developed to increase the ability of both clinicians and patients to visualize results and aid decision-making [17] and to aid the stakeholders during SDM to improve cancer care delivery [18].

Research is ongoing to understand how digital health tools and EHRs can be combined in innovative ways to improve the SDM process [19]. In particular, we need to collect more detailed information to pinpoint where additional digital technology could be developed and used to help the SDM process in the delivery of cancer care. This paper examines how EHRs and other digital tools are used in practice to inform possible future improvements in applied digital technology to facilitate SDM in oncology consultations.

Objectives

Hence, the objective of this study was to explore how health care professionals use digital technology to support SDM in oncology consultations, understand the barriers to technology that support SDM in oncology consultations, and understand the opportunities for future technology to improve SDM in oncology consultations.

Methods

Study Design

This study design was informed by the 3-talk SDM model and the approach of previous studies to develop digital tools to support SDM [20]. The 3-talk model incorporates the principles of team-based collaboration throughout a multistage consultation process and is highly recognized in the health care sector. This model has 3 main components: team talk, option talk, and decision talk [21].

Therefore, to investigate the role of digital technology in SDM in oncology consultations and to achieve the study objectives, we applied the design thinking framework [22]. Design thinking is a creative approach that has been used effectively to address problems in the health care sector [23,24]. It helps to collect user insights to develop efficient products, services, and experiences [23]. Ideas are quickly prototyped and improved through continuous iterations [25]. This study design was chosen because it emphasizes collaboration with end users throughout the problem-solving process. We developed low-fidelity wireframe prototypes of EHRs. This technique was chosen to investigate the potential of EHRs to help oncologists and patients with cancer collaborate on decisions because it has been suggested to be effective in health care management and innovation [26]. Low-fidelity prototypes (Multimedia Appendix 1) were quickly created using affordable graphic software, allowing feedback to be gathered without consuming significant time and resources. We applied co-design and low-fidelity prototyping methods with study participants in focus groups and one-on-one interviews.

Participants and Settings

Health care professionals with opinions on the role of digital technologies in oncology consultations were invited to participate in this study. Specialists in medical and radiation oncology, as well as physicians in training programs, were included. Through existing university connections and local cancer networks, participants were purposefully recruited from 5 cancer care centers in Sydney, Australia. A researcher (TS) initially contacted key potential participants who collaborated on previous research projects in oncology via email and introduced them to AY. AY then followed up on the communication by providing an information package about the research project and suggesting focus group schedules. The focus groups and interviews were scheduled on Microsoft Teams for remote videoconferencing, and the participants' attendance was recorded.

Data Collection

Guided by the core components of the SDM 3-talk model—team talk, option talk, and decision talk—a focus group and interview topic question guide were developed in advance to shape study inquiries in alignment with the SDM model. The researchers (AY, JK, AJ, and TS) iteratively developed the topic question guide. The topic guide was pretested by running pilot focus group sessions with researchers working on other health care projects within the department. Their feedback helped to refine the topic questions and focus group process. The final version of the topic question guide is shown in Multimedia Appendix 1. The topic questions were used to ask participants about their experience with how technology is used to support SDM within each component of the 3-talk SDM model, particularly if they used the 3 SDM core components in their usual medical practice. The focus groups and interviews were semistructured and guided by the topic questions. The low-fidelity prototypes were presented to participants after discussing the application of technology in their practice, and feedback was sought on the usefulness of the concepts included in the prototype design. The prototypes also served as a trigger for further discussion.

Each focus group and interview concluded by summarizing and reflecting on the discussion and confirming the accuracy of the researcher's understanding of the information provided by the participants while they were still present. This final concluding step was necessary because scheduling busy, working health care professionals providing cancer care to patients for study reviews is difficult.

All interviews and focus groups were recorded in video and audio formats. They took place online between April and May 2024. Author AY led all the focus groups and interviews.

Data Analysis

Three researchers (AY, AJ, and TS) analyzed the qualitative data collected using the reflexive thematic analysis as a framework by Braun and Clarke [27-30]. This method guided the initial coding process applied to the focus group meetings and interview recording transcripts, which were deidentified and anonymized. The researchers first read through the transcripts to fully understand the data. They then proceeded with line-by-line coding, collaboratively compiling and discussing the codes. After completing the coding, the codes were inductively arranged into themes and subthemes. Researcher AY created a codebook, and the researchers engaged in multiple discussions to agree on the identified themes and subthemes. The codebook was tested on 1 transcript. Iterative discussions and consensus resulted in a refinement of the codebook. The final codebook was then used to code the remaining focus groups and interview transcripts. Then, AY used the codebook to code the content of each remaining transcript. Columns in an Excel (Microsoft Corporation) sheet were created to represent different themes and subthemes. AY analyzed the content of each transcript line by line and coded the text. The coded chunks of text were extracted and added to the Excel table according to their alignment with the themes. As new knowledge was found, the codes were refined accordingly. Afterward, AJ reviewed, modified, and confirmed the recategorization of the codes. Eventually, AY finalized the recorded data in the Excel sheet.

Ethical Considerations

The Human Research Ethics Committee of the University of Sydney approved this study (project number: 2023/790). All participants provided written informed consent. Data collected were anonymized and deidentified, and the research data were stored in the university's secure computer systems. All the participants provided their time and information freely without receiving financial compensation.

Positionality of the Research Team

Our research team (TS, JK, and AJ) has extensive experience conducting research on the implementation of digital technologies in health care organizations in Australia from an academic point of view. On the other hand, author AY is a practicing professional with experience in developing and implementing computer software in hospital settings for clinicians. We believe that digital technologies can improve health care. Thus, we are driven to implement the latest innovations in health care.

Results

Participants

The study involved 9 participants who participated in different co-design focus groups and interview sessions. One focus group was attended by 5 (56%) participants; another focus group was attended by 2 (22%) participants. Two interviews were conducted one-on-one. Each session lasted between 30 and 60 minutes. The participant demographics are presented in Table 1.

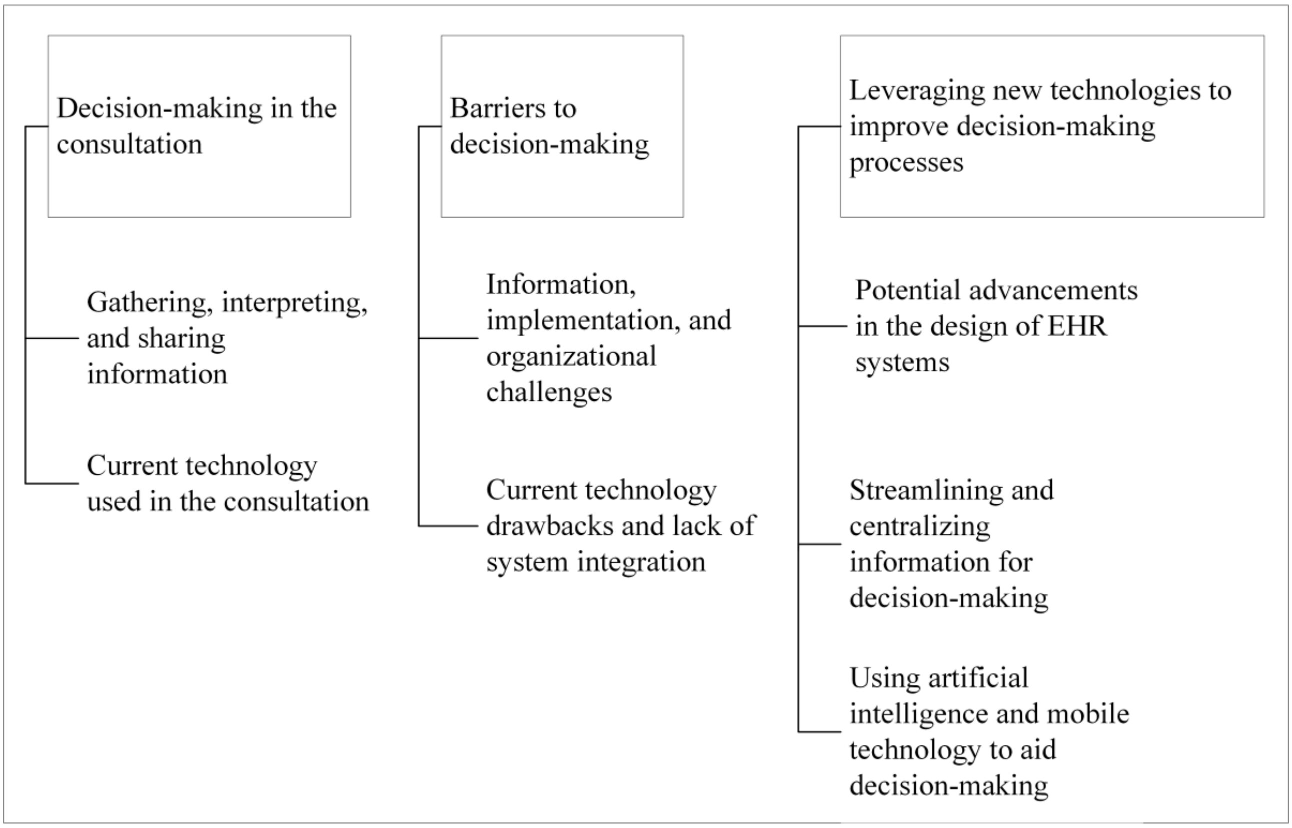
Table 1. Individual participant characteristics.

Participant ID	Session ID	Cancer Care Center ID	Sex	Cancer care stream	Level of experience
P1	A	C1	Female	Breast and lung	Radiation oncologist (consultant)
P2	B	C1	Male	Breast and lung	Radiation oncologist (consultant)
P3	B	C1	Male	Breast and lung	Radiation oncology registrar (in training program)
P4	B	C2	Male	Prostate	Radiation oncology registrar (in training program)
P5	B	C2	Female	Prostate	Radiation oncologist (consultant)
P6	B	C2	Female	Prostate	Radiation oncology registrar (in training program)
P7	C	C3	Male	Lung and head and neck	Medical oncologist (senior consultant and hospital executive)
P8	C	C4	Male	Perioperative	Anesthetic registrar (in training program)
P9	D	C5	Female	Lung	Respiratory specialist (consultant)

Overview of Themes and Subthemes

Three themes and 7 subthemes were generated from the thematic analysis. The three themes are (1) decision-making in the consultation, (2) barriers to decision-making, and (3) leveraging new technologies to improve decision-making processes (Figure 1).

Figure 1. Overview of themes and subthemes. EHR: electronic health record.



Theme 1: Decision-Making in the Consultation

Overview

Participants discussed their decision-making process during consultations and how they felt their clinical workflow aligned with the 3-talk SDM model while being prompted by the wireframe prototypes. The participants appreciated the 3-talk SDM model for breaking the clinical decision-making process into 3 core components:

> *...in general,...this is quite similar to what my approach is in the clinic.* [Participant P4 B C2]

> *...it's interesting, and I appreciate this model...breaks it into three pieces.* [Participant P7 C C3]

> *...I like team, option, and decision...I hadn't heard of it, but it's exactly how I structure my consultation.* [Participant P9 D C5]

On the basis of their experience, participants highlighted that they did not differentiate between the option talk and the decision talk components:

> *I...in the real world, don't differentiate between option talk and decision talk. So, option talk and decision talk, for me, is the same process. So, as I'm discussing options...I don't sit there and say here are all the options. Now, let's stop and have a discussion about the decision. I blend those two conversations together.* [Participant P7 C C3]

Participants described how they collect information by talking to their patients directly rather than having them fill out responses to a list of questions in advance:

> *I'm actively, kind of, discussing what would be involved in making a decision to go down this pathway. What further information would be needed? So, the implication for digital technology is that it's the same technology I use while discussing options. I don't sort of stop and say now, here's another one I prepared earlier. And let's talk about it this way.* [Participant P7 C C3]

Some participants were concerned about patient privacy:

> *...in the waiting room, I'm not sure...I don't know that I can see an easy way to get personalized digital information in the waiting room, in a safe way. I think that...needs some human and clinical inputs...it could be like a nurse coordinator, someone like that could meet with the patient before going to the consultation. So, there's all those sorts of very personalized differences.* [Participant P9 D C5]

Another important step, in their view, is that the participants noted that they plan activities before patients visit for their consultations:

> *So firstly,...these patients would have been discussed by the multidisciplinary team before they saw me with the surgeons and medical oncologists,...and we would have a plan of action from the MDT.* [Participant P1 A C1]

After the multidisciplinary team planning discussions, the participants described how they would discuss the situation with the patient and involve other professionals in the patient model of care:

> *So, we've looked at performance status, frailty, and pulmonary function. We identified things that are needed. We discussed that at the consultation and asked the care coordinator to link up.* [Participant P1 A C1]

The subthemes of decision-making in consultation include gathering, interpreting, and sharing information through digital and analogue communications.

Subtheme 1.1: Gathering, Interpreting, and Sharing Information

Participants said that decision-making often occurred in multidisciplinary team meetings without input from the patient:

> *...some of our decisions or, you know, consensus, optimal decisions are also influenced by our MDT meetings...in most MDT meetings, the patient is not there....we think we are arriving at a decision that can be communicated to patients, but often, it actually doesn't align with their preferences.* [Participant P5 B C2]

When reflecting on the decision-making component of consultations, participants noted that patient wants and expectations at the point of care they were at were shaped by their previous experiences along the way. Participants remarked that some patients may be ready to decide after meeting with the physician, while others may be hearing about their condition for the first time and feel overwhelmed. The participants know that this approach takes longer. Yet, they prefer having the ability to understand the patient's wishes better:

> *...there's a huge variation in what patients want at this point and what they expect, and it also probably is not independent of what specialty you're in and how they've gotten to you. So, you know, for me, by the time a patient's gotten to me, they may well have been through two or three specialists already. They've got...cancer and, so sometimes, they're already primed. They're ready to make a decision. Other times, it's the exact opposite, and this is the first time they've heard they might have cancer.* [Participant P7 C C3]

> *I use the time when I'm talking to patients, collecting...information to kind of just get to know the person...it takes longer than if they fill in a list of questions in advance and I'm just looking down the list...I'm building a relationship. If I look at a screen...that's not the same as asking those questions and, kind of, building a rapport with a patient.* [Participant P7 C C3]

Different approaches were described for different patient situations and desires for information. Participants said that some patients want to know their treatment plan, while others seek detailed explanations of the decision-making process. The preference for the type of clinical workflow in consultations can also depend on the physician's training, work style, and personality:

> *They've got no idea what's going on....it's the opposite conversation, where they absolutely need to go away and think about it....and I think the things you do to help them in those situations are somewhat different. The first one, those people often already have the information they need. The second one, they absolutely don't.* [Participant P7 C C3]

Several important points related to patient care were covered in the participants' discussions. Participants highlighted the challenges of bringing bad news to patients, the need for better participation of patients in decision-making, and the importance of documentation following decisions:

> *I see them at the start...usually, the person who sees them earlier then has to break the bad news, and then...all the referrals afterward...that's where things fall apart a little bit...they'll get discussed in MDT...but sometimes that's a little bit delayed. Sometimes, the patient doesn't always get the right*

information. The right time is the other problem. [Participant P8 C C4]

The reliability of clinical information sources was raised. It is crucial to always refer to a trusted source of information:

> *...and look, the very important thing in clinical medicine is you go to the primary source for the information; you never make, you should never make a significant clinical decision based on anything but firsthand information.* [Participant P9 D C5]

The value of having care coordinators share the patient care to address patient needs and support them throughout their treatment journey was emphasized:

> *...the need for a care coordinator to triage the patient's care needs, ...it's helpful to have the prostate care nurse who can talk to patients about the radiation therapy and the surgery...they [the patients] get time to make the decision about what they want. We refer them to the men's health physiotherapist as well.* [Participant P6 B C2]

Understanding the specific concerns of the patient is key. It is important to begin the decision-making process with the patient's desired outcome and then work out the appropriate care pathway:

> *...you need to work out the patient's goals first...then work backward from that... "Well, I think it isn't that…" "I definitely don't want radiotherapy" or "I definitely do want radiotherapy because my sister had it. It was good."…you might not get the decision if the patient is still sort of weighing things up...the decision is going to be informed by the goals. It's coming back to the quality of life versus the quantity of life.* [Participant P1 A C1]

The information gathering step is followed by reviewing the patient's results and interpreting the situation before the patient arrives for their visit. One participant described this step as follows:

> *...what I'm talking about is more around interpreting patient results...like the pre-three-talk process...is having the information available...when I prepare for the clinic, I like to have an opportunity to read everything in the pile, and everything is there...that I'm not chasing stuff. So, I'll usually look at my clinic two days ahead of time and make...notes in chronological order to try and figure out firstly whether there is any missing information. Umm…then ensuring that it's adequately documented in a way that is more meaningful to me.* [Participant P2 B C1]

After interpreting the available information step, the participants discussed how they communicated the medical information to patients. They like the way visual aids, as suggested in the wireframe prototypes, help them to clarify and make information more understandable, improving patient understanding and facilitating informed decision-making through effective communication:

> *I find, you know, drawing diagrams and having pictorial, sort of, explanations of things help...I think it breaks through language barriers and understanding of things. Anyway, I'm scrolling through the images and going through the results with the patient, pointing things out, simplifying things, maybe drawing...handwritten...document...to help explain things.* [Participant P4 B C2]

Information and knowledge sharing was discussed in addition to visual aids. Participants mentioned that they often explained results using prognostic calculators that can assess life expectancy, especially in older patients. One participant explained how they discuss different options with patients to help them make treatment decisions:

> *...in some lung cancer patients where there are some poor prognostic factors, and even though they've got technically localized disease that could be curable, you might be a bit worried whether this patient can get through six weeks of umm daily treatment. So, sometimes, we do discuss more palliative options...You give the options; you discuss the harms and benefits of options...but I don't...use the EMR [electronic medical record] apart from the imaging information....I do use...e-prognosis calculators to calculate life expectancy, particularly in older persons.* [Participant P1 A C1]

The participants also discussed the idea of summarizing the consultation decisions:

> *...you know, I appreciate that we don't do it today, but you could imagine a summarized transcript of the consultation generated.* [Participant P7 C C3]

Subtheme 1.2: Current Technology Used in the Consultation

Some participants explained that they do not use digital technology extensively in their consultation workflows. Digital technology is only sometimes used to show patients their medical images or to show images of medications. Videos have been used, but the participants found them too slow. They currently do not have interactive digital tools, but the technology would be useful for discussing treatment options:

> *...in terms of the team talk, how do I use digital technology at this point...mostly show people images, ...I show a lot of scans and X-rays. I usually find the videos are a bit slow for the consultation,...the patients get bored.* [Participant P9 D C5]

Decision aids were discussed. Tools to help predict outcomes of cancer treatments are available on the web for physicians to calculate patients' life expectancy and survival rates. Participants described how they use the decision aids in practice:

> *...I use a predictive tool...I will plug the patient numbers in and print them out for the patient. ...we often use it before we see the patient...in medical oncology, there's one for adjuvant systemic therapy... " ...without adjuvant chemotherapy, this is your 5 or 10-year survival or recurrence, and with...it's..."*

they'll show the magnitude of benefit. Then, the patient can decide. [Participant P1 A C1]

Information sharing was emphasized. Participants described how they provide patients with information about advocacy and treatment protocols and search the internet for basic information, such as images, models, or videos. They share the information they find with patients to educate them. These web-based resources are then used to explain treatment procedures and complex equipment operations, saving them time and effort. The patients are then expected to be able to access and review the same web-based information that they have been introduced to and recommended when at home:

> *...radiation therapy is a technology that most people don't know anything about, ...they get confused....the value of images, models, or video to actually just show what a radiation linear accelerator machine is...you don't have to draw a picture of it. You don't have to waste time taking somebody around to look at the machine...trusted website resources.* [Participant P5 B C2]

> *I found myself doing a lot of...very basic Google images search...the information can be so basic...I think we get lost in explaining things.* [Participant P3 B C1]

Theme 2: Barriers to Decision-Making

Two subthemes were identified under the barriers to decision-making theme. The first subtheme, "information, implementation, organizational challenges," focuses on the participants' perceived challenges regarding access to and the quality of information. The second subtheme, "current technology drawbacks and lack of system integration," deals with the participants' difficulties related to the limitations of the EHRs and the lack of information integration.

Subtheme 2.1: Information, Implementation, and Organizational Challenges

Participants pointed out challenges such as experiencing difficulties when communicating with patients from different cultures and non–English-speaking patients in communities. They also mentioned challenges with patients' lack of health literacy:

> *...meeting patients of non-English backgrounds and cultural and health literacy issues; uh, very significant, and that's very hard together in a very quick clinical environment.* [Participant P2 B C1]

The involvement of the family and interpreters was also raised as a challenging area due to the time needed to understand the needs and priorities of the individuals:

> *...family care as support, and...the interpreter as well, ...can be part of the communication process, which can either assist or umm or slow down dramatically the process...It's hard to think of a solution because it takes time to talk to people and find out what's important to them.* [Participant P5 B C2]

Gathering precise patient information during visits, as patients often forget details, was expressed as a difficulty. Participants noted the need to improve communication methods and understand each patient's needs:

> *There are even times when a patient has had a test done, and it's not until they're, literally, sitting in the clinic room before me, and I go, where did you have this done? Sometimes, I have to ask them three questions to clarify...Umm, it's a common assumption of the patients as well. "Don't you have this information?" And the answer is often no, I don't.* [Participant P6 B C2]

Verifying the accuracy of the information patients provide can be time-consuming, as one participant pointed out the following:

> *...patients come in...and say, oh yes, I had a scan. ...you spent 5 minutes searching all the providers...then you Google where they live and what radiology practice is in their town, and then you find out they did have a scan, but it was an MRI of their ankle. It wasn't actually their chest, but they don't remember.* [Participant P9 D C5]

Subtheme 2.2: Current Technology Drawbacks and Lack of System Integration

Manual processing of information and uploading data into the EHRs is problematic for physicians, especially under time pressure:

> *At the moment, when we upload imaging, it's not the actual images themselves,...to, just, get the image in, I take a screenshot and paste it into a document in the EMR, or I am literally, highlighting and copying the text from the report and pasting it in,...when you are time-pressured, that's just how you get it done.* [Participant P6 B C2]

Obtaining and merging data from various sources presents additional challenges to physicians. Especially the lack of integration among older information systems for data sharing was considered a drawback. This situation caused difficulties in accessing different systems for decision-making tasks:

> *...needing multiple passwords in multiple different information systems or not having access to all the patient results. ...unfortunately, most hospitals, including ours, rely so much on a technology called fax.* [Participant P2 B C1]

The participants said the systems could not provide integrated results even when patients had medical tests conducted in public hospitals:

> *There are already difficulties in accessing scans and results...done even in other public hospitals...patients have blood tests done by multiple providers. Imaging from multiple different providers.* [Participant P6 B C2]

Besides the lack of system integration, 1 participant pointed out that their hospital does not have full access to the facilities of EHRs:

> *I sit in a hospital that does not use an EMR or has a partial EMR. So, the medical notes don't go, for the*

> *most part into an EMR, it does in the oncology clinics, but that's not where I work anymore. So, we mostly write on paper in the private clinic. I use my own digital interface and I'm always zooming around to different portals, external radiology, different pathology providers, et cetera.* [Participant P9 D C5]

Poor wireless digital communication network connectivity was also mentioned as another drawback:

> *...it's again getting onto another website, potentially getting password...Terrible Wi-Fi in most cancer centers...I think that is a big barrier.* [Participant P5 B C2]

Theme 3: Leveraging New Technologies to Improve Decision-Making Processes

The theme "leveraging new technologies to improve decision-making processes" encompasses the following subthemes: (1) participants' interest in implementing potential improvements to advance the design of EHR systems; (2) making data more accessible and understandable by streamlining, centralizing, and communicating information for collaborative decision-making; and (3) helping to share evidence data and decisions with patients' care team members outside consultations, as well as analyzing patients' data using artificial intelligence (AI) and mobile technologies.

Subtheme 3.1: Potential Advancements in the Design of EHR Systems

Participants expressed their interest in improving the design of the EHRs. They highlighted the need for improved access to laboratory diagnostic test results and recommended automatically providing reliable medical information from different systems:

> *...if there was some magic like a digital resource that could do all of that detection for me and link me to multiple different providers and go to clinical labs...and pull it all in, I would love it...If it was as good as me, it would be transformative. But you'd have to really be sure and be able to trust it...and then...the reliability of information.* [Participant P9 D C5]

There is interest in decision-making tools to help patients make treatment decisions. Participants said they do not need additional electronic devices to replace what they already have. They want decision-making tools to help patients choose their preferred treatments according to their desires and goals, especially when treatment options are risky:

> *...some, sort of decision tool may help in those situations where radiotherapy is high risk or trying to help people decide about quality versus the longevity of life or some sort of tool where you...answer to some questions..."quality of life is more important to me or length of life is more important" ...it would be good to have a tool where you can...help guide the patients to...their priorities...and...help the decision-making...I don't want any extra devices. I'd do it on the computer and then, maybe, print it out for the patient rather than an iPad type stuff.* [Participant P1 A C1]

Subtheme 3.2: Streamlining and Centralizing Information for Decision-Making

Centralizing and systematically organizing medical information to make it more accessible and easier to interpret is important to some participants. These participants were interested and emphasized that providing the right information to the physician at the point of care would help:

> *...one thing I found very helpful is the centralization of information. ...things like scans, test results from clinics or centers outside of the...health system...something that aggregates that information into...something to sort of centralized or funnel information to us...having patient information presented in a way where...making things more centralized, it would be helpful to us.* [Participant P3 B C1]

Other participants stressed the importance of obtaining comprehensive patient information before the consultation:

> *...I guess what I'm talking about is more around interpreting patient results, which is almost...preempted to the whole three-talk process, really...is having the information available.* [Participant P5 B C2]

The introduction of a patient portal for sharing information with patients is seen as a benefit. This would enhance physicians' ability to maintain communication with patients outside of consultations as they consider treatment options:

> *...if there's a patient portal, they can log in and see things, that could be nice. ...if I could say to them... "I've put all these in...I've put in the options...when you go home, you can log into your patient portal..." I could even imagine they could post some questions.* [Participant P9 D C5]

Subtheme 3.3: Using AI and Mobile Technologies to Aid Decision-Making

The potential use of generative AI was discussed to streamline medical documentation and improve patient care. Participants suggested using basic AI to generate patient reports that can be shared with medical colleagues:

> *...information can be more easily extractable...we use very basic artificial intelligence in our practice where we can generate a patient report, for example, where we pull information from different parts of...and combine it with text that we put in the record and that then goes to the general practitioner. So, I can do a treatment summary on a radiotherapy patient in about a minute, and I only have to type a line or two, and yet, a complex report goes back to the general practitioner, and we do that in medical oncology as well.* [Participant P2 B C1]

However, one other participant disliked the idea of using AI for report writing:

Wouldn't use it. I write better than generative AI. I think the kind of language that generative AI produces is boring and opaque, and I'm better than that. So, I wouldn't do it yet. [Participant P9 D C5]

Discussion

Key Findings

This research examined how health care professionals in Sydney use digital technology to support SDM during oncology consultations. It sought to understand the difficulties they encounter when using technology for SDM and explore potential developments of new technologies that could improve the implementation of SDM in clinical oncology settings. First, the findings of this study emphasize the critical need for oncologists to consolidate health information from patients with cancer to facilitate SDM in oncology consultations. The results also highlight a significant misalignment between the current operations of existing EHRs and the clinical practice workflow in oncology clinics to help clinicians follow the SDM process. Second, the study draws attention to the challenges of access to information due to outdated technologies and communication barriers due to language and the lack of knowledge of the patient about health. Nevertheless, the study participants were interested in developing new technologies that could streamline access to health information and automate administrative processes, thus supporting SDM and ultimately improving the delivery of cancer care.

Current Use of Technology to Support SDM in Oncology Consultations

The study participants stressed the importance of consolidating medical information to improve decision-making in oncology consultations. Studies in similar data-driven cancer care management reinforce these findings of the investigation [31]. Similar to other studies on cancer care, participants in this research study have emphasized the critical role that information and data play in driving SDM processes and improving health service outcomes [18]. As digital technologies transform the health care sector, cancer care is also being transformed [32].

Discussions between health care professionals during the study addressed the 3 key components of the SDM model: team talk, option talk, and decision talk [21]. The prototyped EHRs used to investigate the feasibility of supporting SDM with EHRs demonstrated that some components of the SDM model of care, such as option talk, could be implemented to match established oncology consultation practices and workflows where patients and oncologists usually discuss treatment options. However, the phase sequence of the SDM model did not fit fully into the typical consultation procedures or workflow patterns of the study participants. The health care professionals who participated in this study appreciated the SDM model but stated that, in their routine clinical practice, they frequently combined option and decision discussions. This means that EHRs must be flexible to support cancer care workflows to accommodate the iterative nature of the oncology decision-making process.

Study participants highlighted the importance of direct patient communication to foster relationships and ensure complete information collection before choosing treatments or health care options. Previous research in this area has also emphasized the importance of the relationship and communication between oncologists and patients beyond consultation visits in cancer care management [33]. Several study participants have pointed out that a key to the successful implementation of SDM is the integration of digital systems and EHRs, ensuring accessibility to digital information when needed at the correct point of care for the right patient. However, some participants have also stated that they do not use their digital systems or EHRs extensively to support patient discussions. They may use only part of the system to show diagnostic images to share information with the patient. Other participants use EHRs only to look up patient results or document consultations.

Future Use of Technology to Support SDM in Oncology Consultations

Cancer treatment is based on data, involves multiple disciplines, is a lifelong process, and is increasingly dependent on the smooth digital exchange of clinical information [34]. In this study, the participants identified several key obstacles to SDM in their clinical oncology settings related to access to information, implementation, organization, and limitations of current technology, specifically EHRs. In addition, the participants mentioned communication challenges due to language barriers, emotions, comprehension, low health literacy, participation of patients, difficulties in accessing and integrating patient data, lack of information that often leads to poor data quality and inefficient processes, time pressure, and lack of privacy. Similar barriers have been reported by Steenbergen et al [35]. The participants informed the research about the absence of integrated systems and their continued dependence on outdated technologies in their clinical settings, which hinders information exchange between cancer care facilities. Furthermore, during the investigation, some health care professionals who participated in the study described that their hospitals do not have comprehensive EHRs, leading to a greater dependence on paper records and personal digital interfaces. Researchers in Canadian health systems have also reported on clinician experiences with outdated, ineffective, or inefficient technologies that do not fit their clinical workflows [36]. Therefore, the implementation of better information and communication technologies could eliminate some technological barriers and improve the overall efficiency of cancer care provided by oncologists.

During the study, health care professionals said that they use the information from the EHRs to help in their decision-making process to treat cancer. They focused on integrating digital resources to improve efficiency and support patient care. However, integrating quality health data remains challenging due to the lack of guaranteed interoperability, even between EHRs from the same vendor, as reported in a previous study in the United States [37], although the requirement to improve interoperability among digital health systems was legislated in the United States in 2016 [38], and the Fast Healthcare Interoperability Resources specifications were approved by the Health Level 7 International in August 2019 [39]. In June 2024, the Canadian government introduced Bill C-72, which requires health IT systems to be interoperable [40]. Therefore, the stated goal of the health care professionals, which is to be able to securely access all the health information of their patients in integrated EHRs, is expected to be achieved in Canada in the future [40]. Therefore, future EHRs in the North American health care systems, designed to make health care information more accessible and transparent to patients and the health care team [41], are expected to be available to provide oncologists with critical cancer care data needed to support the SDM process in oncology consultations.

Furthermore, the study participants were interested in the potential benefits of an integrated web-based portal driven by clinical information designed to simplify access to data from private laboratory tests and automate various clinical documentation processes, such as generating interclinician letters and managing patient diagnostic test results. Petrovskaya et al [42] performed an evaluation of web-based patient portals and emphasized the elements that the study participants seek to help improve patient participation in SDM. The researchers stated that the patient portal is connected to the EHRs of health organizations, providing patients with functionalities such as secure and convenient access to medication lists and the ability to arrange and verify appointment availability and communicate with their health care team securely through SMS text messaging, in addition to access to their laboratory test results [42]. However, in a recent patient portal implementation initiative, Grewal et al [43] found that there are technical challenges in enrolling patients to use the patient portal, but involving nurses in the patient education and enrollment process is a promising approach and reinforces the value of multidisciplinary methods in improving patient care.

During the study, the participants explored the concept of a patient web-based portal that can consolidate health information from multidisciplinary treatment journeys. They emphasized the need for sophistication and proper allocation of resources. The participants envision a web-based portal where patients can access information about care options, ask questions, and review details such as their therapeutic plans and preferences. They believe that this would lead to more streamlined communication, better decision-making, and automation that uses AI capabilities. They perceive that AI innovations could help reduce the double handling of information and miscommunication, as well as prevent patients from falling through the cracks in their care. However, trust in AI systems and the data provided emerged as a significant concern among some participants. In an article on digital transformation in cancer care, Papachristou et al [32] emphasized that ensuring the safety, accuracy, and ethical application of data-driven interventions requires building trust among health care professionals, patients, family members, caregivers, and other stakeholders. Nevertheless, integrating AI into the cancer management workflow has been shown to transform individual treatment planning by accurately predicting responses of patients with cancer to different therapies [44].

Efforts to improve EHRs for better cancer care management are ongoing around the world. Two international workshops focused on technology in cancer care management were held in 2019 and 2020 in Europe [31] and one in 2022 in the United States [38]. These workshops addressed SDM processes, data integration and management, analytics, EHRs, and AI-based clinical decision-making [31,38]. While significant progress has been made in implementing EHRs in public hospitals in Sydney for cancer care [15,45], the full potential of EHRs to consistently improve cancer care quality and patient outcomes has not yet been fully realized [38,45]. Similar to the challenges that the participants of this study encounter with poor EHR usability, lack of fitness with clinical workflows, fragmented data sources, and large amounts of data, researchers from other health care jurisdictions have also described similar experiences [31]. The participants suggested that in addition to using technologies, nurses and other health care professionals could also assist in patient engagement. These additional clinical resources have skills, such as patient education and effective communication, crucial to facilitating patient participation in SDM during clinical oncology consultations and can help improve patient outcomes [46]. The effectiveness of SDM is maximized when health care professionals have experience, strong relationships with patients, and sufficient time for treatment discussions [35]. As reported by Steenbergen et al [35], the exchange of knowledge and the efficient flow of health information between clinicians and patients are essential to facilitate SDM in oncology. Consequently, technological opportunities are tailored to support human interactions [31,38].

Barriers to the effective digitalization of information in oncology have been identified. However, continuous innovations and technological improvements have helped minimize the effects of several major barriers. Technological innovations such as Health Level 7 Fast Healthcare Interoperability Resources [47], the Minimal Common Oncology Data Elements [48], and the Systematized Nomenclature of Medicine–Clinical Terms [49] when combined with legislation, such as the Connected Care for Canadians Act in Canada, make better access to health information possible. Therefore, digital health data in oncology can be shared across health care organizations in a more standardized way that all stakeholders can understand.

Conversely, although AI technologies have been introduced in oncology over numerous decades, a persistent distrust exists toward the suggested technology. The level of trust in AI systems influences the acceptance of these technologies. Therefore, frameworks and guidelines have been suggested to tackle the issues related to the reliability of AI-powered health care systems, such as the FUTURE-AI framework, which defines 6 requirements for trustworthy AI [50]. Accepting AI systems in health care depends on ethical principles, trust dynamics, and rigorous evaluation processes [51].

Tools and protocols are available globally to support SDM in oncology consultations. For example, in the United States, tools include Watson for Oncology [52] and the Adjuvant! Platform [53]. In Australia, EVIQ chemotherapy protocols are available nationally [54,55]. In the United Kingdom, the PREDICT tool aids in breast cancer treatment decisions [56]. In Canada, standards for SDM tools have been developed and are often used as a reference by international researchers [57-59]. Despite multiple trials, the integration of these tools and protocols into practice remains nonroutine, and several programs, such as IBM Watson for Oncology, have failed to meet expectations [60]. These examples illustrate the ongoing challenges.

In summary, various oncology specialists and health care professionals perceive the usefulness of technology in supporting SDM in oncology consultations differently. A senior medical oncologist preferred face-to-face conversations with patients. In contrast, an anesthetic registrar preferred a high level of computerization and welcomed the possibilities of driving health care delivery with data. Other specialists, especially radiation oncologists, did not see the need to use technology extensively when helping patients make treatment decisions, as their oncology specialization typically involves only one treatment modality. However, they do want technology to accurately and promptly share information provided by other health care professionals. However, young health care professionals are ready to adopt more digitalized medical practices. Most health care professionals recognized the value of technology in supporting access to information for consumers, thereby facilitating informed decision-making.

Limitations and Future Research

The first limitation of the study was that only 9 health care professionals were available to participate in the co-design sessions. The second limitation was that no surgeon was identified to potentially participate in the co-design sessions. It is difficult for practicing physicians to allocate time for research projects and to attend co-design sessions when they are already working overtime and long hours providing patient care. Therefore, physicians who participated in the study may not have fully represented the larger oncology practice community. Only their views and practices on SDM were collected. The third limitation was that oncology consultation involves patients, other oncology specialists, and other health care providers. However, they were not invited to participate in this study due to time constraints. Patients and other health care providers may have provided different perspectives on their experience with SDM and the use of digital technology.

A larger group of oncology specialists, including surgeons, would have represented the larger oncology community and provided more generalized views. Furthermore, patients who have had oncological consultations would have provided their views on decision-making processes, particularly SDM. To mitigate the limitations of this study and obtain more generalizable results, our approach should be replicated in future studies with a larger and more diverse group of cancer health care professionals. This diversity would include many specialty dimensions, including surgeons and other health systems specialists. Furthermore, similar future studies should include patients who have experienced oncology consultations.

Conclusions

The findings of this study indicate that digital health technologies can assist in SDM in oncology consultations. This includes providing concise and consolidated information to support decision-making, tools such as multimedia resources to support patient understanding of cancer and treatments, and patient access to information and data outside of the consultation through tools such as patient portals. Emerging technologies, such as generative AI, may assist SDM by consolidating and personalizing information.

Nevertheless, care needs to be taken to ensure that technology does not erode the development of rapport and trust between a clinician and patient. Although EHRs and other systems are continually improving, there are substantial barriers to realizing the potential of technology to improve SDM, including the lack of data integration between systems and integration of new tools and resources into clinical workflows. However, continuous technological innovations and government efforts through new legislations are eliminating some of the digital system integration and data interoperability difficulties.

In conclusion, the study shows that digital technology can facilitate the exchange of information between independent health care organizations and individual health care providers, thus increasing the efficiency of oncology consultation workflows. However, technology is only part of the support needed for the complex human communication process in oncology. Oncology consultation services need support from a multidisciplinary cancer team, which includes other health care professionals and the patient's family. Health care professionals, such as nurses, must educate and prepare patients for consultations. Allied health professionals are often needed to help with language difficulties. Only through an ecosystem that is fully integrated, interoperable, and seamlessly fits in with the human and social interactions of numerous stakeholders involved in the care of a patient with cancer can the goals of the person-centered model of care be achieved through the implementation of SDM in cancer care.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus group and interview topic guide questions and low-fidelity prototypes.
[DOCX File , 517 KB-Multimedia Appendix 1]

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Abbreviations

AI: artificial intelligence
EHR: electronic health record
SDM: shared decision-making

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4.3 Chapter 4 Conclusion

Chapter 4 described the human-centred design process used to create prototype mock-ups of computer user interfaces for an envisioned integrated digital application with electronic health records. This system aims to help oncologists involve their patients in care decisions during shared decision-making conversations in future oncology consultations.

While the oncology consultations discussed in Chapter 3 focused on medical oncology clinics within a single cancer centre in a local health district of Sydney, Chapter 4 involved a sample of oncologists from radiotherapy oncology practices across different local health districts in New South Wales, Australia. Chapter 4 also examined the broader applicability of the shared decision-making approach within oncology consultation services across the Australian cancer care sector, supported by an integrated digital technology system based on electronic health records.

To better understand the experiences and perceptions of oncologists regarding the impact of the digital shared decision-making system on their usual clinical workflows and tasks, a co-design research study was conducted. The study included semi-structured interviews and online workshops with remote participants, who reviewed and evaluated the prototype of the proposed digital shared decision-making system. This final part of the study is documented in the published article in this chapter.

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CHAPTER 5: DISCUSSION AND FUTURE PERSPECTIVES

5.1 RESEARCH SUMMARY

5.1.1 Context and Background

Recent advances in cancer treatments, such as immunotherapy and combination therapies, have been effective strategies for improving outcomes for people diagnosed with cancer, leading to increased survival rates and better quality of life [1]. However, this progress has also made selecting the most appropriate cancer care pathway more complex, considering each patient's unique health situation, variable responses and resistance to treatments, and personal preferences [2]. As a result, cancer care providers worldwide are seeking more effective and efficient tools and methods to support and improve patient engagement and care coordination, and satisfaction with the cancer care services they provide [3]. In the complex process of managing patients' health journeys with chronic diseases, such as cancer, the shared decision-making approach and digital technological solutions are promoted as key strategies to enhance the quality of healthcare [4].

Yet, integrating digital tools into routine clinical workflows requires ongoing careful investigation of the factors that shape the dynamic nature of medical consultations in specific settings, such as cancer services, to design and implement suitable digital technologies into standard clinical procedures. This research aimed to understand how physicians make decisions during consultations and how they utilise electronic health record systems and digital tools to support these decisions. Issues related to decision-making in oncology consultations, technology utilisation, and clinical oncology workflows were analysed to understand how information flows through oncology consultation tasks. Communication was also examined to identify opportunities to develop future digital health interventions tailored to patients with cancer. As a result, the steps that physicians and patients take to create a jointly tailored care pathway for the specific patient were highlighted. Understanding the context of use, user requirements, and task flow is essential for enhancing the digitally enabled health system [5]. Ultimately, the goal was to identify chokepoints and opportunities in which technologies such as the electronic health record system could be utilised to enhance the productivity and effectiveness of oncology consultation services. This chapter provides a brief overview of the research findings from the studies presented in this thesis, contextualised within the wider scholar literature. It highlights the implications for implementing digital health systems in oncology. It also suggests how the research findings can be applied to enhance patient engagement in shared decision-making, thereby delivering patient-centred care in cancer care services. In this final chapter, the thesis also offers suggestions for future research directions.

5.1.2 Summary of Research Findings

This thesis addressed the following research questions:

Research Question Number	**Question**	**Conclusion**
RQ1	What digital tools are available to support shared decision-making in oncology practice?	Digital tools can enhance communication between patients and physicians. The impact of organisational and management factors remains less explored. Electronic health records on desktop computers remain the most widely used digital tools supporting shared decision-making processes in oncology consultation practice.

RQ2	How is shared decision-making carried out in oncology consultations?	Most decisions made during consultations focused on the stages of chemotherapy, including the prescription and management of chemotherapy protocols, as part of the medical decision-making process. Physicians monitored patients' progress, health status, and the effectiveness of the prescribed treatment on the cancer. This also involved referring the patient to other healthcare professionals or specialists for further assessment. Additionally, decisions included providing alternative healthcare options, waiting for additional information before making a choice, and adjusting the standard chemotherapy protocol to suit the individual patient's unique health characteristics or physical functioning.

RQ3	How do physicians use technology in consultations to support shared decision-making in routine consultations?	Physicians currently utilise computers to access patients' electronic health records. They use desktop computers during oncology consultations to share information, thereby supporting shared decision-making with patients and their families. They access evidence-based protocols and cancer care guidelines for various chemotherapy options online via a Web browser and print hard copies to hand to patients. Nevertheless, physicians were not seen using any specialised tools, whether on paper or digital devices, specifically designed to facilitate shared decision-making in oncology consultations.
RQ4	What are the barriers and enablers to using technology for shared decision-making?	Physicians are keen to adopt new technologies for improving information sharing and patient involvement in decision-making. However, these tools must integrate seamlessly into existing clinical workflows without creating additional tasks for physicians. Key requirements include access to electronic health records from a single point, an organized presentation of patient information, and adaptability to support dynamic consultations. The technology should facilitate navigation and enable physicians to adjust their decision-making goals during discussions with patients and families.

RQ5	How can existing and emerging technologies be enhanced to support shared decision-making?	A first step toward enhancing shared decision-making with digital technologies is to leverage new functionality in existing digital tools to support this purpose, as physicians are already trained in these systems and use them regularly in their clinical workflows. Existing technologies, such as electronic health records, could be gradually made more effective and efficient if data, particularly test results, from various healthcare providers and laboratories could be accessed instantly upon generation through integrated hospital departments and relevant external organisations, such as private diagnostic laboratories outside the hospital information systems. Patient portals [6] and electronic health records [7] offer patients significant opportunities to be more actively involved in shared decision-making. Additionally, generative artificial intelligence [8] provides additional potential to support shared decision-making.

Overall, this study confirms that shared decision-making in cancer care is a conversational process that emerges from interactions among patients and care partners, physicians, and other healthcare professionals. In cancer care, digital technologies, such as electronic health record systems, are useful only when they are patient-centred, facilitate clear and effective communication, and reduce rather than increase physicians' workload. Although this sociotechnical environment is organised around clinical systems and protocols, it is fundamentally a human endeavour to identify and evaluate clinical care options, weigh trade-offs, and choose cancer care pathways that align with well-informed patient preferences. These decisions are often shaped and refined in multiple clinical visits rather than finalised in a single consultation.

The uptake of dedicated computer-based decision-support tools in cancer care consultations appears to be limited [9]. Nonetheless, when such tools are used, for instance, via electronic health record systems, they can change the dynamics of communication. Physicians' actions, including computer screen use and typing, may diminish eye contact and emotional engagement, potentially influencing the doctor-patient relationship by introducing an additional factor into their interaction [10].

At the same time, displaying patient data on a computer screen during consultations can support patient participation in care planning, either by connecting clinical perspectives with their daily realities or by allowing them to verify information independently. However, many patients in research studies still perceive the consultation computer screen as largely under the physician's control, underscoring the need to redesign both electronic health record systems' interfaces and the conventions surrounding their use to make their shared character more explicit [11]. Nevertheless, the current body of evidence does not yet allow a comprehensive understanding of their effects on hospital efficiency. Focused research remains necessary to close these knowledge gaps and to optimise the use of electronic health record systems. Incoming studies should take precedence in examining the direct influence of electronic health record systems on patient outcomes and in analysing how specific functionalities of these systems can enable patients and encourage their active participation in cancer care processes. Therefore, additional research is required to clarify these complex, multiparty interactions in the hospital oncology consultation setting [12].

5.2 Discussion of the Research Outcomes

Physicians are responsible for identifying the most appropriate cancer treatment or care option for each individual patient requiring ongoing cancer care. The primary objective of this thesis was to address knowledge gaps in digitally supported cancer care. To do this, it was essential to first understand the current workflows of physicians when managing patients with cancer. Afterwards, the challenge was to understand how physicians utilise existing technologies to select the most suitable care options for each patient, based on their specific personal characteristics and health conditions, within the oncology consultation practice workflow.

5.2.1 Discussion of key findings

This section provides a brief overview of each chapter, emphasising its key findings and comparison with published literature.

Chapter 1 – Introduction.

The first chapter of this thesis introduced the topic and provided an overview of the research questions and overall approach.

Chapter 2 - Systematic review of shared decision-making tools.

Summary of key findings

In chapter 2, a systematic review of the literature was conducted to examine the use of digital tools in oncology consultations. Few studies have been published on this topic. Most of the studies were conducted in the USA. The findings indicate that these digital tools enhance communication between physicians and patients, improving information sharing.

However, physicians do not modify their usual clinical workflows or working methods to accommodate the task flows or features of the software. The study found that the adoption of digital tools in oncology consultation was low. The key recurring issue is the lack of adequate system integration. However, the studies included in the review did not investigate the management or policy factors that might be influencing the implementation of these digital tools in oncology clinical practice.

Comparison with published literature

The review in Chapter 2 found that research studies primarily focused on the perspectives of patients from North America and Europe. In particular, the majority of articles were written about research conducted in the USA, with a small number also conducted in the UK, the Netherlands, Norway, and Canada [9]. Consequently, the findings of this study may not be generalizable to other population centres or regions of the world with different demographics or genetic mix, like Sydney, Australia. Moreover, most research articles were focused on breast cancer, which is the most reported type of cancer incidence in women, with a few articles considering colorectal cancer, which is the third most reported type of cancer incidence for both sexes globally [13]. The use of digital tools for decision-making was found to be low. Similarly, researchers at an Australian hospital reported low adoption rates among care providers for electronic clinical decision support tools, highlighting the need to increase their usage [14]. The study in Chapter 2 found that custom-built decision tools were the primary area of focus for many researchers. Two digital decision tools, Adjuvant! and In-Visit, were the most cited in the literature [15, 16]. Nonetheless, the limited number of studies on digital health tool interventions has indicated positive outcomes for various measures, although other research studies have found both neutral and negative impacts.

Overall, the research reported in Chapter 2 highlighted that improving communication and information sharing between patients and physicians is a realistic goal. However, barriers such as limited access to necessary data, restricted technology availability on physicians' desktops, and poor integration with existing electronic health record systems have been reported to hinder successful implementation. In addition, in their review article, Jacobs et al. [17] identified that misclassifying a digital tool according to its intended purpose can lead to poor decisions and that high data security is crucial for establishing trust and fostering collaboration. Jacobs et al. [17] also stated that digital tools should be developed based on tailored data relevant to the target population. Interoperability should be enabled to facilitate data sharing across platforms, thereby preventing the creation of isolated data silos and fragmented systems [17]. Ensuring compatible designs and compliance with standards to ensure smooth data flow, which supports a patient-centred approach [17]. Patients need access to resources and education to use digital tools effectively, while healthcare professionals should be trained to build confidence and show commitment [17]. Simplified interfaces and streamlined interactions promote consistent use [17]. Digital tools must also comply with relevant regulations [17], including those for medical devices such as the EU medical device regulation [18] and the US Food and Drug Administration [19] and the Australian Therapeutic Goods Administration [20]. Developing, maintaining, and updating these solutions requires significant funding, which should be considered with the aim of providing the target population with equitable access to healthcare [17].

Chapter 3 - Observations of oncology consultations.

Summary of key findings

In Chapter 3, the workflow in medical oncology practice and the cancer care journey experienced by patients were examined, with a focus on how technology is currently used to involve patients in a collaborative decision-making process, specifically the three-talk shared decision-making model for improving cancer care delivery. The study also explored how technology could support physicians' needs to engage patients in the three-talk shared decision-making model approach.

It was found that patients with different types of cancer are referred to the medical oncology clinic for ongoing treatment. It was also emphasised that physicians need to collaborate with other healthcare professionals both within and outside the hospital setting to gather and discuss information about each patient in their care. They need to deliver treatments in consultation with other healthcare professionals, care partners, and the patients as a team. During a consultation, multiple decisions can be made, ranging from prescribing chemotherapy and monitoring patient progression to coordinating alternative and supportive care. The care plan is developed in collaboration with the patient, caregivers, and other healthcare professionals, often through joint meetings, but sometimes via separate reports, such as laboratory results or referral letters.

However, the multidisciplinary team of healthcare professionals meeting to discuss and develop a treatment strategy for the patient is often inefficient, as it is challenging to present patient information in a timely and logical manner. The current electronic health records and other online digital systems that provide patients with information about treatment protocols are also fragmented and inefficient.

Comparison with published literature

The study presented in Chapter 3 demonstrated that when physicians are involved in making decisions with patients being treated for diagnosed cancer, the decision-making process involves many considerations beyond just choosing treatment options. In this study, four main categories of decisions were identified. The primary types of decisions were 'Alternative Care', 'Chemotherapy', 'Deferred Decision Making', and 'Monitoring'. The outcome of a consultation may include one or more decisions, which means that consultation decisions may overlap. For example, a decision to administer chemotherapy might be followed by a decision to monitor the patient's response to the drugs in the care plan. At the same time, the physician and the patient may decide to address other health issues, such as a skin rash or refer the patient to another healthcare professional for further evaluation. Sometimes, the physician and the patient may decide to defer their final decision about which chemotherapy to administer, allowing the patient and family more time to reflect on their options.

In comparison with a study conducted by Driever et al. [21], the authors categorised the consultation decisions into main decisions and other decisions. The main decisions relate to medical and surgical interventions, while the other decisions cover diagnostics, treatment, follow-up, and advice [21].

Although the terms used by Driever et al. [21] are slightly different from those used in this study; however, their meanings align with the findings presented in Chapter 3.

Alternative care or other decisions, as observed, involve referrals to other healthcare professionals, such as allied health professionals, general medical practitioners, or surgeons, to discuss the patient's health information and issues. The cancer care team in the study, including the patient and care partners, collaborates to determine the most appropriate therapy for the patient. Similarly, as Doughty et al. described [22], patients receive care from clinics, infusion centres, and radiation departments. The patient shares information with different healthcare professionals they encounter on their journey [22]. Patients may be receiving other treatments concurrently, such as chemotherapy and radiation therapy [22]. Their teamwork efforts result in the creation of comprehensive care plans for patients, leading to improved patient outcomes [22].

Chapter 4 - Prototype design and physicians' workshops.

Summary of key findings

Chapter 4 involves workshops and interviews with end-users to co-design and develop a digital platform for team-based shared decision-making. The workshops were conducted with physicians to validate the requirements gathered in Chapter 3.

A medium-fidelity mock-up prototype of the digital platform was developed to allow end users to critique the proposed ideas. The users identified three main themes: decision-making in consultation, barriers to decision-making, and leveraging new technologies to enhance decision-making processes. The physicians noted that their current practice workflow aligns with the three-talk shared decision-making model, which serves as the foundation for the prototype's design. However, they emphasised the importance of holding multidisciplinary team meetings. They also suggested the need for a care coordinator to triage patient needs.

The physicians confirmed their need to continue using their existing electronic health record system, as they are familiar with it and do not want to introduce additional technology. Therefore, the new technology must integrate seamlessly with their current computer system. They also identified a need to provide facilities such as a patient web portal, which would allow patients to review their results, view educational videos and post their questions. The integration of mobile devices would assist patients on the move, whether they are at home or waiting in the clinics, provided they have privacy. However, they did not see artificial intelligence as a priority, as some physicians believe artificial intelligence functions cannot match their own writing abilities.

Therefore, physicians in this study expressed the need for a digital platform that can aggregate key clinical data points and support integrated, team-based consultations. They also emphasised the importance of online collaboration features and seamless integration with existing electronic health record systems used in consultation rooms.

Comparison with published literature

During the study, insights were gained through co-design workshops about how shared decision-making actually occurs during oncology consultations in practice. The participants agreed with the concept of the shared decision-making process, which often involves physicians and patients making choices about chemotherapy, including prescribing and managing treatment plans. Physicians assess patient progress, overall health, and the effectiveness of current treatments. They might also refer patients to other healthcare professionals or specialists for further assessment. Additionally, the shared decision-making process may involve offering alternative treatment options, waiting for additional information before deciding, and tailoring standard chemotherapy protocols to suit the patient's specific characteristics and health status. The participants' view of their oncology workflow aligns with Montori et al. [23], who described shared decision-making as a healthcare approach where the physician gathers the patient's history, performs physical examinations, selects and interprets diagnostic tests, educates and counsels the patient, and engages in a discussion to develop an action plan for the patient's issue. This description in the literature aligns with the findings of the firsthand studies conducted with practising physicians as participants.

Across the included studies, physicians demonstrated the use of digital technologies during observed consultations. They also reported, in co-design workshops and interviews, that these technologies are routinely integrated into their clinical workflows to support shared decision-making. They use computers to access patients' electronic health records. During consultations in their clinics, most also use desktop computers to share information and involve patients in decisions. Thereby fostering shared decision-making conversations that follow task patterns similar to those of the three-talk shared decision-making model. This process involves patients and their families in the discussions, if they are present. Some of the physicians also mentioned that they employ a type of specifically designed decision aid called 'nomograms' to support shared decision-making discussions with their patients. However, although decision aids can improve the shared decision-making process, Salwei et al. [24] illustrated that integrating decision aids into the clinical workflows of existing routine cancer care is complex. Other decision aids, called 'option grids', have also been developed and found useful for facilitating shared decision-making conversations about different treatments [25, 26]. However, when the physicians were shown an example of an 'option grid' during the co-design sessions, one physician mentioned that she had experience in building an 'option grid' once. She informed the workshop participants that the process was very time-consuming. In addition, research has shown that it is very challenging to keep the 'option grids' up to date because treatment procedures change often. For example, Scalia et al. have reported that integrating 'option grids' into existing electronic health record systems requires major hospital-wide efforts to maintain consistency across the healthcare organisation [27]. Therefore, integrating shared decision-making digital tools into existing clinical workflows remains a significant challenge.

The physicians participating in the study recognised that technology and shared decision-making digital tools must integrate seamlessly into their cancer care workflows, preserve communication, and maintain workload balance. Key patient details must be displayed clearly and logically to support information sharing and decision-making.

In contrast, Peters et al. [28] have reported that integrating digital technologies for shared decision-making often encounters sociotechnical barriers. The researchers have identified obstacles, including physicians' unfamiliarity with shared decision-making principles and challenges in using digital tools [28]. These issues can impede the adoption of technology-driven shared decision-making. Additionally, poor planning in deploying digital tools and difficulties in integrating them into existing electronic health records [28], can make their usability unacceptable and contribute to stress and burnout [29]. A lack of effective communication among healthcare team members can further obstruct integration. Moreover, concerns regarding the quality of patient care delivery may also prevent the adoption of digital systems designed to support shared decision-making [28].

Conversely, when physicians are aware of the shared decision-making processes enabled by digital technology, such as electronic health record systems, familiarity with the process encourages easier adoption of the new technology [7]. Facilitating physicians in eliciting patients' preferences was also regarded as an important facilitator [28]. When the shared decision-making digital system is integrated with electronic health records, it is regarded as a facilitator of adoption by physicians [28]. Thus, digitally embedding the shared decision-making process within the electronic health record system has been confirmed as a key implementation requirement.

The physicians have informed the study that they prefer not to have additional functions that could disrupt their clinical workflow. Therefore, the initial strategy for enhancing technology in shared decision-making is to avoid creating a new digital tool separate from the existing system. A separate system would create another silo or disconnected set of data. The goal is to integrate the new shared decision-making digital components within the existing electronic health record system. The physicians are already trained to use the electronic health record system and do so regularly in their oncology clinics. As a result, any existing and emerging technologies being considered to improve the system should be enhanced to support shared decision-making. The electronic health records would become more effective and efficient if data, especially laboratory test results, from various healthcare providers and laboratories could be accessed instantly when generated through integrated hospital departments and relevant external organisations, like private diagnostic laboratories outside the public hospital information systems.

5.2.2 Contributions to the literature

Shared decision-making workflow components in healthcare should not be viewed as an extra task added to a clinical workload during a consultation, pointed out by Montori et al. [23]. It is a collaborative process where a physician and patient work together to decide on health care choices [30]. The physician and the patient discuss potential cancer treatment options, considering the potential benefits and harms, while taking into consideration the patient's preferences, goals, values, and personal and health circumstances [31].

This study demonstrates that creating digital decision support tools for shared decision-making in oncology consultations is feasible and can enhance communication among patients and physicians, and other members of the patient's cancer care team. However, in the literature, Elwyn [32] pointed out that there is no evidence indicating that the interests of organisations and management in these digital decision tools will lead to their widespread use in clinical practice. Similarly, in the studies conducted for this research, although at least three senior oncology consultants who are directors of oncology clinics participated, they did not provide evidence that they are readily interested in implementing the integrated digital decision tools in their respective organisations. In fact, one of the participating senior oncology consultants, who is also the chief operating officer of a hospital, stated that implementing the digital decision tool for shared decision-making is not a priority for them. They actually have more pressing issues to solve first. Currently, the most commonly used digital technology in oncology clinics to support shared decision-making is the electronic health record system. This was observed during clinical practice and confirmed by participants in the codesign workshops and interviews, and it is typically accessed via desktop computers. Although most hospitals in metropolitan Sydney, Australia, have electronic health record systems, one physician participating in the research claimed that she does not have access to the electronic health records in her clinic. Hoffmann et al. [30] observed that Australia lags considerably behind many other countries in all facets of shared decision-making. It appears that significant progress is still needed to improve the implementation of shared decision-making in oncology consultations in hospitals based in metropolitan Sydney, particularly through the support of modern integrated team-based digital technology infrastructures.

Research in electronic health record interoperability has shown that current and emerging technologies can be improved to better support shared decision-making [33]. Patient portals and digital decision support systems have demonstrated the potential to enhance patient understanding and facilitate information exchange between patients and physicians by emphasising system integration, software usability, and digital alignment with clinical workflows and the task flow of electronic health record systems [33]. According to Yung et al. [33], the current systems often lack design features specifically tailored to support shared decision-making. These researchers believe that these shortcomings limit the effectiveness of digital shared decision-making tools in clinical practice.

Improvement activities should therefore focus on interoperability and data integration across systems to enable seamless information sharing, which is vital for supporting shared decision-making processes [29]. Using Health Level Seven International Fast Healthcare Interoperability standards, the digital shared decision-making system can be integrated within electronic health record systems, thus improving oncology clinics' efficiency and compliance with evidence-based clinical guidelines [29].

The findings of this research are supported by Pierce et al. [7], who reported that using the electronic health record system to support shared decision-making is an effective way to incorporate the shared decision-making method of care into routine clinical workflows. Similar to the observed consultation decisions in oncology, in their review, Pierce et al. [7] also identified that the main goals of shared decision-making often involve planning care, preparing for visits in advance, making end-of-life arrangements, enabling patients to manage their health independently, reconciling medications, assessing risks, and adhering to treatment. Key shared decision-making digital functions could include patient risk calculators, data visualisation features, alerts, and tools for comprehensive consultation documentation. Pierce et al. [7] also found that including patient portals as part of shared decision-making processes within electronic health record systems provides patients with access to their clinical records, which in turn encourages patient engagement.

5.3 IMPLICATIONS OF INTEGRATING DIGITAL TEAM-BASED SHARED DECISION-MAKING TOOLS INTO OUTPATIENT ONCOLOGY ELECTRONIC HEALTH RECORDS

The research studies presented in this thesis offer valuable insights into a digitally enabled team-based shared decision-making system and its role in improving the efficiency and effectiveness of consultation services in outpatient oncology clinics. The shared decision-making method of care has been recognised by the Australian Commission on Safety and Quality in Health Care [34], as a goal for healthcare services. This research highlights the importance of integrating components of the shared decision-making process with digital technological support into oncology consultation workflows. The findings in this thesis highlight several technological implications for digital health-enabled oncology consultations. These implications suggest that a model of care focusing on the healthcare of an individual and utilising a team-based, digitally enabled, shared decision-making system, combined with electronic health record computer systems, is both practical and acceptable to practising physicians at public hospitals in metropolitan Sydney in Australia.

Research findings emphasise the importance of ensuring that digitally enabled shared decision-making systems do not interfere with or disrupt the usual oncology consultation workflows. These digital health systems should support patient involvement in the therapeutic decision-making process and continuity of care, customised to their needs, goals, and preferences. This digital system facilitates the co-creation of a specific care plan for each individual patient seeking care for their type of diagnosed cancer.

The shared decision-making three-talk model for providing person-centred care was viewed positively by the physicians involved in the research [31] . To enhance implementation and uptake among physicians, the cancer care process flow should be integrated into existing electronic health record systems, aligning with the physicians' usual oncology practices.

The implications of the research findings for consultation workflows suggest that patient-centred, team-based shared decision-making processes can be used to engage patients with cancer through a digital health-enabled approach.

Furthermore, digital shared decision-making can feasibly be offered to patients with cancer through patient portals and Internet-based tools, particularly those who require more time to decide on their preferred treatment, need to consult with other cancer care specialists, or individuals who want more time at home with family to evaluate their choices before deciding.

Implementing these suggested digital shared decision-making functionalities would require a coordinated approach to designing and developing digital tools, involving patients, physicians, other healthcare professionals, oncology clinic management, hospital administrators, and health systems funders. The research findings suggest that integrating digital shared decision-making systems into consultation workflows is crucial for enhancing the overall quality of life and patient satisfaction with the cancer care they receive.

5.3.1 Critical Interpretation of Empirical Findings from Sociotechnical and Human-Centred Perspectives

Sociotechnical systems theory

This section reinterprets the study findings through the lens of sociotechnical systems theory, which conceptualises technology implementation as a dynamic interaction between technical artefacts and social and organisational structures. Within this framework, the outcomes of digital health technology implementations are understood to emerge from interdependent relationships among eight sociotechnical dimensions merged into four broader domains: (1) Technology (hardware, software computing infrastructure, and human-computer interface), (2) People (physicians, patients, and other stakeholders), (3) Tasks (clinical content and administrative workflows, and communication), (4) Environment (internal organisation features and governance procedures, external rules and regulations, measurement and monitoring) [35, 36]. Sociotechnical systems theory proposes that organisational effectiveness depends on optimising the interaction between technical elements and social subsystems, rather than maximising each component in isolation.

Technology domain

In a recent scoping review by Pierce et al., the authors found that incorporating shared decision-making tools into the electronic health record system improved their integration and accessibility [7]. In contrast, this thesis reports that the mere availability of digital shared decision-making solutions does not ensure sustained use in oncology practice [37]. Together with findings from the literature, this thesis indicates that although embedding technology into cancer care services is a critical step, it is insufficient on its own to secure long-term adoption.

People domain

Acceptance of and alignment with professional identity strongly influence both the initial use and ongoing utilisation of the shared decision-making tool. Pierce et al. found higher adoption of decision aids embedded unobtrusively in existing communication routines and workflows [7]. In line with previous research, this thesis shows that oncology teams' perceptions of trust, legitimacy, and professional authority significantly shape their willingness to engage with and consistently use the tools [37]. Together, these findings highlight that human agency remains central to the effectiveness and long-term success of technical interventions and technology implementation.

Tasks domain

The incorporation of shared decision-making into established clinical workflows is a critical determinant of its effective implementation. The imposition of additional documentation requirements for administrative reporting, along with perceptions of prolonged consultations due to additional tasks in computer software applications, has been associated with diminished physician engagement and reduced willingness to utilise digital health technologies in shared decision-making and pre-existing clinical processes [7, 37]. Furthermore, discrepancies between tasks related to shared decision-making and pre-existing clinical processes have emerged as a principal barrier to the widespread adoption of shared decision-making in cancer care.

Environment domain

Organisational governance frameworks and site-specific variability had a pronounced influence on implementation outcomes. Pierce et al. conducted a systematic description of dominant documentation practices and institution-level constraints [7]. Whereas the present thesis underscore the crucial role of contextual variability in the oncology consultation environments [37]. Collectively, these findings indicate that environmental determinants are fundamental to shaping both the scalability and the validity of technology-based interventions and digital health implementation.

Through a sociotechnical analysis of the studies' results, the findings indicate that the digital tools currently deployed to support shared decision-making within the cancer care centre function predominantly as repositories of clinical data designed to align with and be integrated into existing physician-led oncology clinic workflows. Consequently, these current electronic health record systems offer only limited support for bidirectional planned communication processes, which are fundamental to enabling meaningful patient engagement in shared decision-making.

Hence, the core issue can be conceptualised as a “conversation gap". Current technologies neither systematically elicit, encode, nor operationalise the values and preferences of individuals diagnosed with cancer and seeking treatment. In addition, concerns about the validity and reliability of patient-generated data persist. These concerns demonstrate the enduring caution among healthcare professionals regarding the integration of such data into critical clinical decision-making processes and routine cancer care workflows.

Human-Centred design principles

This thesis adopts a human-centred design methodology, beginning with an in-depth examination of the clinical setting and the patterns of consultation interactions, rather than immediately developing software or introducing new shared decision-making tools. In line with ISO 9241-210, human-centred design is treated as an iterative process grounded in a detailed understanding of users persona, their activities, and the contexts in which these occur throughout the lifecycle of the system [38]. Norman's human-computer interaction framework highlights cues (mental model alignments), mappings, and feedback loops as key determinants of a system's usability and comprehensibility [39]. Furthermore, experience-based co-design participatory workshops with representatives of the user community underscore emotional touchpoints as crucial for shaping the user experience and for pinpointing opportunities to enhance services [40]. Drawing together these perspectives, this thesis formulates four core design principles: (1) interactional integrity, (2) structured value representation, (3) workflow tempo alignment, and (4) trust architecture.

Interactional integrity principle

Interactional integrity refers to the preservation of a coherent conversational rhythm and ongoing relational involvement between participants. This thesis highlights that shifts of attention towards computer screens interfere with mutual gaze (eye contact) and disrupt the continuity of narrative development. Pierce et al. demonstrated that physical embedding of systems enhances the efficiency of information retrieval. Nevertheless, this form of structural representation fails to capture or quantify the dynamic, temporal, and sequential properties of conversational interaction. Accordingly, the authors identified workflow integration as the central practical implication of their findings [7]. The present thesis systematically documented the variability in consultation patterns and the associated interactional constraints. On this basis, the thesis proposes a redesign of the current system to one that is aligned with the sequence of steps of consultation processes and cancer care workflows.

Structured value representation principles

Patient values must be explicitly represented as structured clinical products. The central problem is that patient values are currently insufficiently formalised and inadequately expressed as visible, interoperable clinical artefacts within electronic health records. The scoping review by Pierce et al. emphasised the availability of tools and focused on mechanisms for eliciting and documenting patient preferences. The proposed solution in that work is the deployment of structured preference-capture models systematically integrated into clinical documentation workflows [7]. In contrast, the present thesis demonstrates that, in routine cancer care practice, patient preferences are operationalised in a highly inconsistent manner. The empirical findings indicate substantial heterogeneity and a lack of standardisation in how patient preferences are conceptualised, encoded, and applied within clinical decision-making processes. Accordingly, the overarching system must be redesigned to accommodate and robustly manage variability in the human user behaviour.

Workflow tempo alignment principle

Temporal constraints within clinical consultations substantially influence the nature and depth of physician-patient engagement. A key challenge is that additional documentation requirements by the healthcare system governance exacerbate the perceived temporal burden on physicians. Pierce et al. identified the importance of integrating documentation processes into clinical workflows, but did not fully address the need to align them with the pace of real-time consultations [7]. Although Pierce et al. emphasised potential gains in documentation efficiency, the present thesis emphasises that documentation-related time burden constitutes a significant barrier arising from consultation time pressures. As a potential mitigation strategy, the thesis proposes using advanced digital technologies, such as generative artificial intelligence, to automate documentation systems and generate high-level sophisticated summaries, reducing cognitive and time demands during oncology consultations.

Trust architecture principles

The trust physicians place in patient-generated data within digital health systems is a crucial determinant of long-term adoption and sustained integration of such data into routine clinical practice. The persistent reluctance among physicians to assess the reliability and validity of patient-generated health data remains a key barrier to its effective clinical use. In an evidence-based scoping review conducted by Pierce et al., the conceptual and methodological frameworks required to foster and evaluate this trust, here termed "trust scaffolding", were found to be insufficiently developed. Although the authors engaged with the construct of trust, their analysis was comparatively narrow, emphasising variability in relational trust rather than describing systematic mechanisms for trust calibration and assurance. However, the findings of this thesis underscore the need to address this deficit by specifying, designing, and operationalising both technical and procedural infrastructures to support the framing of trust. The results of the thesis suggest that such trust infrastructures include, but are not limited to, rigorous data provenance tracking, structured and auditable verification workflows, and formal proof processes. Physicians believe that, if implemented collectively, these mechanisms can enhance transparency, enable more robust evaluation of data quality, and thus reinforce their confidence in using patient-generated data to inform shared clinical decision-making processes in their oncology practice.

5.3.2 Conceptual Architecture for Digitally Enabled Shared Decision-Making

A digitally enabled shared decision-making environment requires four interdependent layers: (1) Data Integration to establish longitudinal informational coherence; (2) Value Representation to encode patient goals and preferences; (3) Deliberation Interface to align documentation with consultation tempo; and (4) Governance and Trust to sustain accountability and standards alignment. These layers define the structural preconditions for embedding shared decision-making as a routine capability within the digital healthcare system.

A detailed technical elaboration of interoperability mechanisms, workflow automation processes, artificial intelligence-supported documentation, and standards alignment is provided in Appendix A.

5.4 FUTURE RESEARCH

This thesis presents a key component of research examining the feasibility and acceptability of introducing digital shared decision-making support systems in oncology consultations by physicians practising at oncology clinics in public hospitals across metropolitan Sydney in

Australia. The following section will discuss future research to build on the findings of this thesis.

1. *Extend this research to investigate the current state of the electronic health record systems to support shared decision-making for the entire cancer care team.*

Future research should include the construction and piloting of a high-fidelity artificial intelligence-driven prototype to facilitate the observations and interviews with medical specialists and experts in oncology and haematology who employ various therapeutic methods, including emerging immunotherapy. The study should also include several other cancer centres and oncology clinics in other healthcare districts outside metropolitan Sydney, Australia, and other countries. The future study should also be extended to include observations of patients and their families' or caregivers' interactions with the system, both in and out of consultations, as well as interviews to obtain their perspectives on the use of digitally shared decision-making support systems during and in between consultations. This additional research would provide a broader understanding of the interactions and behaviours among patients, physicians, and computers, and crucially, the needs of the patients for ongoing communications, support, and continuity of care.

Continuous advancements in digital technologies for managing clinical data, combined with the decreasing cost of powerful computer hardware, have driven the expansion of artificial intelligence across multiple sectors, including healthcare [41]. Artificial intelligence is anticipated to continue to transform the healthcare business significantly, especially in the area of cancer treatment services [42]. Artificial intelligence will also likely play a crucial role in cancer therapy management by integrating extensive and diverse datasets to produce actionable insights and to support the creation of personalised treatment plans that combine various therapeutic methods [43].

Despite thousands of potentially relevant artificial intelligence-based models having been published in recent years, Hope et al. [41] pointed out that only a few have been incorporated into intelligent clinical decision support systems that are regularly used in clinical settings. The researchers reported that the most common reason given for not adopting the artificial intelligence-based clinical decision support systems is that these systems are seen as ‘black boxes’, whose internal logic is very hard to understand from the outside [41]. Therefore, in line with similar findings about how physicians perceive artificial intelligence-driven software in this thesis, further research is needed to identify the unmet clinical needs and the relevant clinical decision-making questions that must be addressed. This research is crucial for effectively implementing artificial intelligence-driven software, which is in high demand to help manage the care of patients with cancer. It is only after these clinical questions have been answered and clearly defined that artificial intelligence-driven software applications, which physicians will find useful, can be developed and realised to support their clinical decision-making tasks.

2. *Assess how patient engagement with digitally integrated systems in electronic health records improves shared decision-making in oncology clinics and explore prospects for future systems enhancements.*

Electronic health record systems were originally designed to handle clinical data, rather than involve patients in care decision-making, as noted by Lyles et al. [44]. However, Tolotti et al. [45] have demonstrated that engaging patients in their health journeys after receiving a cancer diagnosis encourages them to take ownership of their care management, leading to better decision-making and behavioural changes that can improve their health outcomes. Active patient involvement in managing their disease progression is becoming more essential to improve patient satisfaction and help lower treatment costs [45].

Many healthcare provider organisations have been offering patient portals and other digital health applications that allow patients and their care partners to access their electronic health records and communicate with their healthcare specialists online for several years. One example is the MyChart platform at Sunnybrook Hospital [46]. Despite the widespread availability of patient portals in healthcare, studies indicate that only a small to moderate proportion of patients actually use these patient portals [44]. Still, the growth of digital health tools, such as mobile health applications and virtual healthcare platforms, is increasingly being used for patient engagement, reflecting an acknowledgement of their potential to improve healthcare delivery, especially in managing chronic conditions, and enhancing patient outcomes [47]. However, the effectiveness of these digital tools is often limited by various barriers, such as a lack of suitable information and communication technological infrastructure to support the new digital technologies [48], patients' inadequate health literacy and a lack of the necessary skills to utilise digital resources effectively, especially in rural Australia [49], and health system limitations, such as inadequate funding, lack of robust data security and privacy management systems [50].

Therefore, this research will be expanded to explore opportunities to leverage existing digital health assets, such as the integrated national digital health infrastructures and electronic health records, and the Australian national digital health record system [51], and physicians' clinical information systems to connect patients, physicians, and other healthcare providers, forming the digital patient care team. This integrated digital system will establish a continuous and seamless digital cycle of care for patients. The patient and their care team members can then access the patient's clinical notes, laboratory test results, update their medical history, and health outcomes, thus communicating regularly and seeking advice from their healthcare professionals remotely at any time. The system would also enable patients and their care partners to access online resources through digital assets such as patient web portals, including self-help supporting groups tailored to their specific health conditions. Self-help care groups are also known as ePatients [52]. Additionally, tools such as prognostic calculators and digital educational resources can be provided for patients and their care partners to assess their situations based on their own values, preferences, and life goals, helping them make informed decisions before more specific discussions with their treating physician.

3. *Explore the impact of including genomics data and the Human Leukocyte Antigen (HLA) information into clinical shared decision-making support systems to improve patient selection for emerging cancer treatments such as immunotherapy.*

Clinical decision support systems for selecting cancer therapies are increasingly relying on advanced technologies that integrate multiple data sources to improve treatment outcomes. In addition to chemotherapy and radiation therapy, immunotherapy has become a vital approach for treating various cancer types by harnessing the body's immune system to target tumour cells [53]. However, the unpredictability of how patients respond to treatment, along with the opportunity costs of using ineffective drugs that allow cancer tumours to continue growing and complicate future cancer management, mean that optimising patient selection for specific therapies such as immunotherapy is essential [54]. Including Human Leukocyte Antigen related information in treatment planning can help develop personalised therapeutic strategies and potentially improve patient outcomes. A research article by Vanguri et al. [55] highlighted significant advances in combining diverse diagnostic laboratory test data. This strategy of combining different types of data has shown promise in more accurately predicting patient responses to immunotherapy [55]. As a result, an artificial intelligence-driven data platform has been created in Europe to support personalised treatment decisions by analysing complex interactions within the tumour microenvironment and patient behaviour, thereby improving patient outcomes and resource utilisation efficiency in healthcare systems [56]. Knowledge of cancer biology and the immune system continues to expand alongside technological progress in computers, leading to promising cancer immunotherapy that can improve patient outcomes and their quality of life [57].

5.5 Ethical, Policy, and Equity Implications

Digitally mediated shared decision-making in oncology carries ethical, governance, and equity implications that shape its responsible implementation in public clinical settings.

Data privacy and information governance

Oncology consultations involve sensitive personal health information. Digital systems that structure or document shared decision-making operate within existing privacy legislation, institutional governance frameworks, and clinical documentation standards. Data minimisation, role-based access controls, audit logging, and clear documentation boundaries are required. Recorded patient values form part of the clinical record and support, but do not replace, professional judgement.

Fairness and bias

Where rule-based logic, triage categorisation, or algorithmic summarisation is incorporated, attention must be given to potential differential effects across demographic groups, communication styles, cultural contexts, and levels of health literacy. The framework advanced in this thesis assumes clinician mediation. Decision authority and accountability remain with the cancer care team, with the patient at the centre.

Equity and access

Digital mediation intersects with variation in age, socioeconomic position, language proficiency, digital literacy, disability, rurality, and device access. Implementation therefore occurs within preexisting structural inequities in public oncology services. The proposed design principles are embedded within clinician workflows and do not depend on patient-owned technology, reducing the risk of technology-mediated exclusion.

Policy alignment

Deployment must align with institutional clinical governance structures, digital healthcare strategies, informed consent standards, and multidisciplinary review processes. Digital augmentation remains subordinate to established healthcare professional obligations.

5.6 Strengths and Limitations

A key strength of this thesis was the opportunity to observe a large number of oncology consultations led by the director, a senior medical oncology consultant, and his registrars in training. In addition, the director was interviewed in depth, and an initial series of brainstorming sessions was conducted to explore and map cancer care journeys. Sufficient data were collected to appreciate the dynamic nature of oncology consultations and the varied nuances in the types of patient cases and the different task flow patterns that are needed for physicians to be flexible in actual busy oncology clinics. Another key strength is that the conceptualised shared decision-making models, based on real oncology consultation workflows, were realised into mock-up prototypes by the active participation of subject matter experts in the fields of digital health software implementation and human-centred design techniques. Through a series of prototyping development workshops, dozens of iterations and reflection sessions over several years, a final refined prototype with sufficient high fidelity was produced for verification and validation by another group of actively participating practising physicians in co-design workshops. The co-design workshop sessions included several senior oncology consultants and one chief executive officer of a major hospital in metropolitan Sydney. These domain experts provided insights into the thinking and directions of healthcare system design and management. They provided guidance on the digital system's functional possibilities and addressed the immediate needs of the physicians. Therefore, this group of high-level management decision-makers provided the necessary insights into the future steps and directions, as well as the roadmap, for developing the digitally enabled team-based shared decision-making system platform.

Limitations in this thesis include that only one senior oncology consultant and trainee oncologists under his supervision were observed, meaning the research data reflected only one oncology clinical setting. It is not possible to generalise the findings to all oncology consultation services. It is unknown whether other oncology clinical settings follow the same practice workflow patterns or use similar software applications. Further observations of oncology consultations and interviews with physicians at other cancer centres and oncology clinics should be conducted. The research project was undertaken during the COVID-19 Pandemic, which limited some aspects of clinical data collection.

This study did not include interviews with patients undergoing cancer treatment or survivors to gather their insights on shared decision-making and the role of technology in improving communication with healthcare providers. This key limitation will be addressed in future research.

5.6.1 Research Quality and Reflexivity

This study is guided by Lincoln and Guba's criteria for trustworthiness: credibility, transferability, dependability, and confirmability [58], and adheres to the Consolidated Criteria for Reporting Qualitative Research and the Standards for Reporting Qualitative Research [59, 60]. Credibility was ensured through the triangulation of four data sources: a systematic literature review, direct observation of oncology consultations, interviews with physicians, and participatory codesign workshops. Themes and decision categories were cross-checked across these sources and verified by physicians. Transferability is facilitated by a rich description of the clinical environment, including workflows, governance structures, and digital infrastructures, allowing readers to assess the applicability of findings to comparable oncology contexts. Dependability is evidenced by a staged research design—encompassing review, observation, thematic analysis, prototype development, and iterative refinement-underpinned by documented coding procedures and versioned iteration records that together provide an audit trail from raw data to final conclusions. Confirmability was strengthened through triangulation, participant validation, and alignment with existing literature, ensuring that the findings are anchored in observed clinical practice and physician feedback. Reflexivity was maintained by continuously checking interpretations against empirical data and digital healthcare subject matter experts' and clinicians' critiques, while considering the researcher's expert knowledge of digital healthcare systems engineering. The thesis contributions are therefore based on systematically gathered, rigorously analysed, and validated evidence.

5.7 ORIGINAL CONTRIBUTIONS OF THIS THESIS

This thesis advances the field of digitally supported shared decision-making in cancer care by providing substantial contributions in the theoretical, empirical, methodological, and design domains.

First, this study reconceptualises shared decision-making processes in oncology consultations as a dynamic, multi-decisions, workflow-integrated, and time-related distributed points-of-care process, rather than as a single discrete clinical visit and treatment choice. Drawing on prolonged direct observation of oncology consultations conducted in a major metropolitan public hospital in Sydney, Australia, the research presents four empirically derived cancer care decision categories: Chemotherapy, Monitoring, Alternative Care, and Delayed Decision-Making, demonstrating that cancer care clinical decisions are iterative, overlapping, and frequently distributed between multiple hospital visits and healthcare professionals. In doing so, the analysis extends the traditional shared decision-making models by situating them within actual clinical task flows and multidisciplinary structures to coordinate cancer patient care.

Second, the thesis offers an original, workflow-oriented, and sociotechnical analysis of oncology consultation environments. It presents the trajectories of information as it circulates across multidisciplinary teams, external diagnostic test providers, and referral networks for medical specialists' services, and electronic health record systems, thereby identifying structural bottlenecks in information sharing, presentation, time-related sequencing, and data aggregation. This contribution advances scholarly understanding of how technical artefacts, professional role configurations, institutional governance arrangements, and the time sensitive dynamics of consultations collectively condition the feasibility and method of integrating digital shared decision-making tools.

Third, the research reconceptualises shared decision-making as a distributed sociotechnical phenomenon. It extends the conventional physician-patient dyad into a digitally mediated team-based configuration that incorporates care coordinators, multidisciplinary clinicians, informal care partners, patient web-based portals and interoperable digital infrastructures as integral representatives within the decision-making ecosystem. This reorientation positions shared decision-making not only as an interpersonal clinical communication strategy but also as an organisationally and technologically embedded methods of care delivery within the wider healthcare system.

Fourth, drawing explicitly on sociotechnical systems theory and ISO 9241-210 human-centred design principles, the thesis formulates four original design principles to guide the implementation of digital shared decision-making systems: interactional integrity, structured value representation, workflow speed alignment, and trust architecture. These principles provide a theoretically grounded yet practically actionable framework for redesigning digital healthcare systems to preserve conversational rhythm, formally encode patient values, align documentation with the pace of real-time consultation, and build professional trust in patient-generated data.

Fifth, the thesis identifies and theorises a critical 'conversation gap' in current electronic health record systems. While existing clinical information systems effectively store and retrieve clinical data, they fail to capture, structure, and operationalise patient values, preferences, and thought through reasoning. By conceptualising this gap as a design and governance problem, rather than merely a lack of technology, the research reframes the central implementation challenge within the strategic digital shared decision-making model of care delivery.

Sixth, the thesis proposes a detailed concept of operations for an integrated, artificial intelligence-enabled team-based shared decision-making platform embedded within existing electronic health record digital infrastructures. Rather than advocating standalone decision aids, it demonstrates how interoperable components that take advantage of SMART and FHIR standards can be integrated into routine workflows to support data aggregation, multidisciplinary coordination, automated documentation, and patient participation online via web-based portals. This provides a feasible and adoption-sensitive pathway for implementation.

Finally, through participatory codesign workshops with practising oncology physicians and consultants and senior hospital leaders, the thesis provides empirical evidence of feasibility and contextual acceptability within public hospitals in metropolitan Sydney in Australia, thereby addressing a gap in the literature, which is dominated by North American and European studies. Collectively, these contributions establish the shared decision-making model of care in hospital-based cancer services as a digitally mediated, team-based, workflow-sensitive, and governance-aware phenomenon, and provide a scalable strategy for embedding shared decision-making processes within existing electronic health record ecosystems without requiring a comprehensive redesign of existing cancer care systems.

5.8 OVERALL CONCLUSIONS

This thesis defines the structural conditions under which digitally mediated shared decision-making can operate as a sustained and integral component of oncology practice. Its central contribution is the demonstration that the principal limitation is not technological capacity, but the configuration of digital infrastructures in relation to clinical reasoning and problem-solving processes. Where electronic health record environments fail to formally encode and operationalise patient values and preferences within routine workflows, shared decision-making remains based on the discretion of individual physicians rather than embedded within system architecture.

The analysis shows that meaningful advancement does not require the wholesale replacement of existing clinical information systems but rather disciplined structural refinement. By clarifying the organisational, workflow, and trust conditions that govern adoption, this research establishes a practical implementation pathway for integrating person-centred thought into established electronic health record ecosystems. In this sense, digital innovation in cancer care is reframed as an exercise in structural alignment rather than technological proliferation.

More broadly, this thesis moves shared decision-making from prescriptive advocacy to operational realisation. It advances a framework that is theoretically integrated and properly implemented to strengthen digitally supported team-based cancer care through a context-responsive system transformation that is aligned with standards.

APPENDIX A

Technical Supplement to the Conceptual Architecture for Shared Decision-Making

This appendix provides a unified technical clarification of the layered conceptual architecture described in Section 5.3.2. Its purpose is to outline possible implementation configurations that could operationalise digitally enabled shared decision-making processes within electronic health record systems. The discussion is intended to clarify feasibility considerations while preserving the analytical and theoretical focus of the main chapter.

A.1 Aggregation of Longitudinal Clinical Data

As presented in Section 5.3, information fragmentation was identified as a structural barrier to effective shared decision-making in oncology consultations. A pragmatic intervention would involve systematic aggregation of relevant cancer care clinical artefacts across diagnostic laboratory results, referrals, and treatment domains within existing electronic health record systems. This multilevel strategy is consistent with sociotechnical models of healthcare work systems, such as the System Engineering Initiative for Patient Safety (SEIPS) framework [61, 62], and is consistent with information infrastructure theory, which emphasises the layered, emergent, and continuously evolving nature of integration processes [63, 64].

Rather than relying on fragmented and heterogeneously maintained documentation distributed across multiple information systems, implementing a dedicated data aggregation layer enables the integration of temporally dispersed clinical information into a coherent, consultation-oriented context. This aggregation mechanism does not generate novel clinical data; instead, it systematically restructures, harmonises, and recontextualises existing artefacts to more effectively support longitudinal clinical reasoning processes. This may involve structured retrieval, collation, and presentation of recent laboratory parameters, imaging findings and reports, longitudinal treatment pathways, and previously collected patient reported outcome measures. This design is consistent with contemporary shared decision-making models, which emphasise structured deliberation, explicit elicitation and clarification of patient values, and transparent communication of available care options within clinical oncology consultations [65, 66].

In contexts where digital tools based on artificial intelligence technologies are employed, their function is restricted to structuring and summarising information rather than making autonomous clinical judgements. For example, automated transcription solutions can convert consultation conversations into organised documentation, but clinicians must review these outputs and comply with institutional governance requirements. This framework is consistent with sociotechnical perspectives on the safety and implementation of health information technology, highlighting the need for human supervision, responsibility, and robust system governance [36, 67].

Any visualisation or dashboard created from aggregated data should be viewed as an informational tool rather than a decision-making authority. Its main purpose is to facilitate coherent information sharing during clinical consultations by presenting relevant artifacts in a clear, time-ordered, and clinically understandable way. The key design goal is to minimise cognitive fragmentation and prevent information overload, not to replace, automate, or supplant expert clinical judgement.

Specifically, data aggregation mechanisms must operate within existing institutional information security architectures and demonstrate compliance with relevant data governance frameworks, statutory provisions, and regulatory standards and mandates. The practical feasibility of implementing such configurations depends on high levels of interoperability among clinical information systems, comprehensive end-to-end auditability, and strict adherence to medicolegal documentation requirements, including criteria governing evidentiary admissibility, authenticity, and integrity.

Figure A1, as shown below, presents a layered conceptual framework designed for aggregating longitudinal clinical data to enhance shared decision-making in cancer care. This model integrates sociotechnical systems theory [61, 62, 68], information infrastructure theory [63, 64], and frameworks for shared decision-making delivery in oncology [65, 69], illustrating how clinical data integration, value representation, deliberation interfaces, and governance safeguards function as interrelated layers within electronic health record ecosystems.

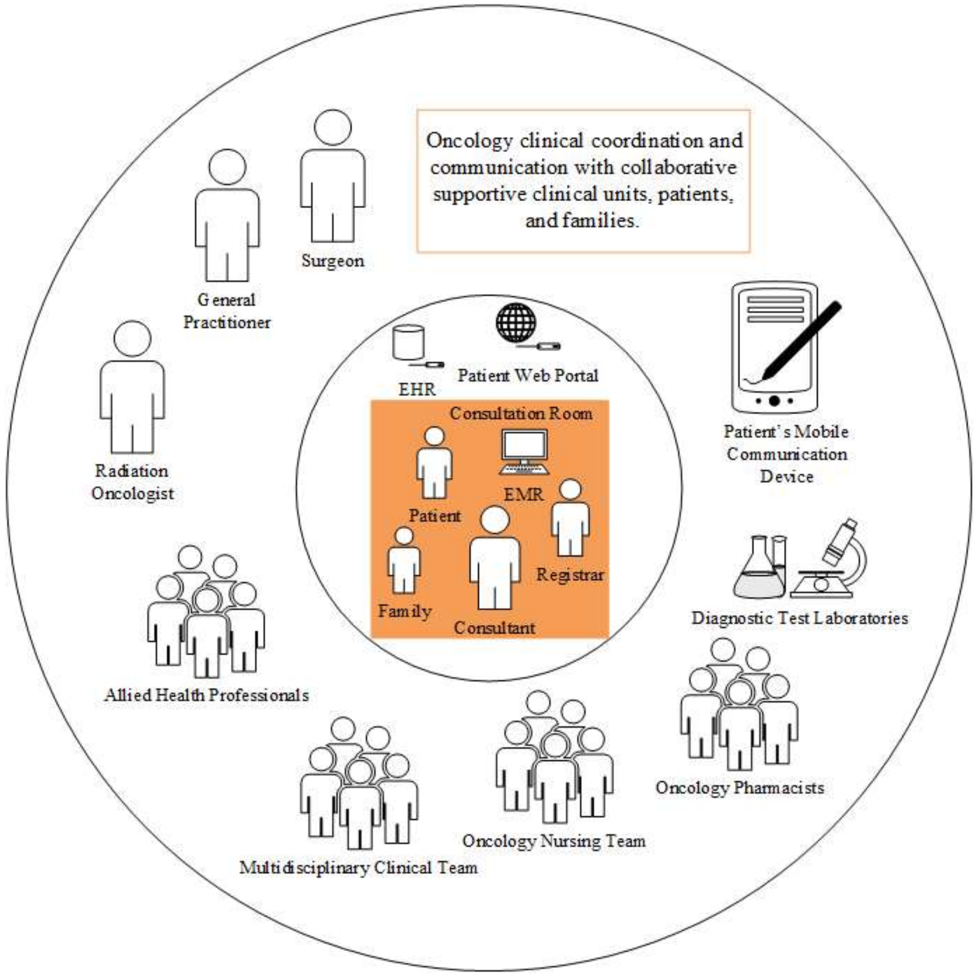

Figure A1: Layered conceptual framework for longitudinal aggregation of clinical data to support a shared decision-making model of care in oncology.

A.2 Care Coordination, Documentation Structures, and Multidisciplinary Information Flow

Chapter 5 established that shared decision-making in oncology extends beyond discrete clinical consultation and routinely involves multidisciplinary clinical specialities collaboration. Therefore, any technical implementation of the conceptual architecture must incorporate formalised mechanisms to represent task delegation, care coordination, and interprofessional communication within existing electronic health record infrastructures [36, 62]. Rather than relying on informal communication channels or disjointed scheduling solutions, structured workflow fields could enable physicians to document intended follow-up actions, referrals, and care coordination needs in a transparent, traceable, and reviewable manner. These mechanisms should be conceptualised as documentation aids rather than as autonomous workflow management systems. Their primary purpose is to improve the visibility of clinical actions agreed on across the cancer care team, with the patient at the centre, while preserving professional judgement and discretionary authority [67, 70].

Where digital tools are used to support scheduling or referral documentation, their operation should be embedded within established institutional governance frameworks and remain dependent upon the review and verification of the physician. Any introduction of automation would require the explicit delineation of decision-making authority and the establishment of robust audit trails for all recorded actions [36]. The overarching objective is not only to increase clinical performance, but to reduce administrative fragmentation that may hinder shared deliberation and collaborative planning.

Consultation documentation may adhere to established clinical formats, such as Subjective–Objective–Assessment–Plan (SOAP) or Assessment–Plan–Subjective–Objective (APSO) [71-73], in alignment with institutional policies. Structured digital templates may facilitate compliance with these documentation standards while enabling systematic capture of patients' values, goals, and stated preferences [74, 75]. Interprofessional information exchange, including communication with members of the multidisciplinary team, should be framed as a component of maintaining longitudinal coherence of the health record rather than as a discrete technical subsystem. Infrastructure theory highlights that integration succeeds when layered incrementally within existing institutional arrangements [63, 64]. Secure digital dissemination of clinically relevant summaries may strengthen information continuity, provided it complies with applicable data protection regulations and medicolegal requirements.

Patient-facing communication tools, when deployed, should be regarded as supportive modalities for information access and clarification rather than replacements for direct physician-patient consultation and interaction. Research on patient web-based portals and digital engagement has demonstrated improved transparency when such tools were integrated correctly into clinical workflows [76-78]. Their integration into electronic health record systems must be consistent with national regulatory requirements governing privacy, informed consent, and data security.

Collectively, these coordination and documentation structures demonstrate how the conceptual ecosystem architecture outlined in Section 5.3.2 may be extended beyond individual oncology consultation events to enable longitudinal, team-based shared decision-making, while upholding governance standards and integrity, and preserving clinician accountability.

A.3 Patient Access, Communication Infrastructure, and Interoperability Standards

Shared decision-making in oncology is increasingly placed within digitally mediated communication ecosystems. Patient-facing web-based portals and secure electronic messaging platforms have been associated with greater transparency of information and higher levels of patient engagement, particularly when they provide structured access to clinical test results and facilitate bidirectional communication with clinicians [76-79]. Nonetheless, the mere availability of a patient web-based portal does not inherently ensure high-quality deliberative processes. The influence of these systems on decision-making processes depends on their degree of integration into clinical workflows and on the robustness of the institutional and regulatory governance structures that oversee their use by clinicians.

From a sociotechnical standpoint, patient-facing communication tools are more appropriately conceptualised as extensions of the value representation and deliberation interface layers presented in Section 5.3.2, rather than as unconnected engagement technologies [61, 62]. Within the overall architecture, their primary role is to maintain the continuity of information access across consultation episodes. Thus, enabling patients to revisit their recorded preferences, treatment choice rationales, and longitudinal clinical trajectories.

Interoperability standards, including Substitutable Medical Applications and Reusable Technologies (SMART) and Fast Healthcare Interoperability Resources (FHIR), establish formalised frameworks for the integration of heterogeneous clinical information systems across institutional boundaries [80-82]. These standards enable modular application development and secure standards-based data exchange, thereby supporting the multi-layered aggregation of oncology-specific data elements without requiring comprehensive architectural replacement or decommissioning of pre-existing legacy systems.

The feasibility of achieving this kind of interoperability has been empirically demonstrated in multiple clinical domains, including oncology settings [83, 84]. Still, consistent with the assumptions of infrastructure theory, integration should be conceptualised as a gradual, path-dependent process and conditional on organisational governance arrangements, rather than as a solely technical accomplishment [63, 64]. In this context, interoperability functions both as a critical enabler of informational coherence and as a boundary condition, whose scope and operation are delimited by institutional policy frameworks, data governance rules, and regulatory compliance requirements.

Accordingly, communication platforms and interoperability mechanisms should be evaluated not only in terms of their technical capabilities, but also in their capacity to preserve longitudinal, auditable, and retrospectively reviewable representations of shared decision-making processes. This conceptualisation further supports the central thesis that the digital augmentation of oncology consultations necessitates rigorous alignment among technical standards, clinical workflows, and institutional governance frameworks.

A.4 Clinical Decision Support, Documentation Infrastructure, and Artificial Intelligence Assistance

Clinical decision-support instruments, including prognostic calculators and evidence-based nomograms, are being increasingly embedded within electronic health record systems to support oncology clinical consultations [74, 85, 86]. Within the conceptual framework defined in Section 5.3.2, these instruments should be seen as additional analytical aids that inform and strengthen clinician judgement, rather than as autonomous or supreme decision-making authorities.

Standards-based interoperability mechanisms, including SMART on FHIR architectural frameworks, enable modular clinical decision-support applications to programmatically access structured patient data while preserving a clear delineation between clinician-mediated judgement and algorithmic or computational outputs [83, 87]. This stratified integration paradigm facilitates robust data exchange and utilisation without requiring substantial reengineering or replacement of the underlying electronic health record infrastructure.

Artificial intelligence-enabled documentation systems have the potential to further support physicians by transforming unstructured consultation conversations into structured clinical representations. Automated speech recognition, structured summarisation, and computational extraction of clinically relevant decision variables have shown promise in mitigating the documentation burden within complex healthcare settings [88-90]. Nevertheless, in accordance with sociotechnical safety frameworks, such systems must function under explicit clinician oversight and verification, and remain subject to robust mechanisms for auditability, regulatory compliance, and governance oversight [36].

In this configuration, artificial intelligence operates as an assistive infrastructural component intended to enhance the clarity, coherence, and standardisation of clinical information and documentation. It does not replace clinician judgement, does not autonomously produce diagnostic or therapeutic recommendations. Preserving professional responsibility and explicitly attributing decision-making authority remain fundamental to maintaining trust within the physician-patient relationship.

A.5 Governance, Accountability, and Trust Mechanisms

Governance coherence constitutes a fundamental structural precondition for sustainable, digitally supported shared decision-making. Sociotechnical analyses of the implementation of health information technologies underscore that both safety and successful adoption depend on clearly explained accountability frameworks, robust audit trails, and systematically designed role-based access controls [36, 67].

Within this stratified conceptual framework, governance is conceptualised as an autonomous structural layer rather than as a subsidiary or purely compliance-oriented function.

Consequently, technical architectures must be designed to ensure that value articulation, documentation of decision-making rationales, and subsequent follow-up actions are systematically reviewable, clearly attributable to responsible agents, and rigorously aligned with institutional medicolegal standards and regulatory requirements.

Empirical and theoretical research on technology adoption indicates that trust in digital systems is determined not only by their functional usability, but also by the presence of salient sociotechnical safeguards that ensure sustained human oversight and reinforce the perceived legitimacy of the governing institutions [67, 91].

A.6 Implementation Boundary Conditions and Organisational Alignment

The realisation of the proposed conceptual architecture is conditional upon multiple interrelated factors, including organisational readiness, the maturity and scalability of the supporting infrastructure, the prevailing regulatory and policy environment, and the extent and quality of stakeholder engagement. From the perspective of infrastructure theory, the integration of digital systems is typically characterised as a path-dependent, incremental process that unfolds within pre-existing institutional configurations, rather than as a discrete, disruptive transformation [63, 64].

Codesign methodologies that systematically engage both clinicians and patients have the potential to improve contextual fit and minimise disruption to established clinical workflows. Within the health information technology implementation literature, iterative pilot testing and phased or staged deployment strategies are frequently recommended as means to reduce implementation risks and to facilitate long-term, sustainable adoption [62, 67].

These boundary conditions substantiate the core thesis that technical feasibility, in isolation, is inadequate for the effective integration of the shared decision-making methods of care into the oncology consultation practice. Achieving sustainable implementation necessitates coherent alignment across sociotechnical systems, governance architectures, and institutionalised rules.

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