Leveraging patient decision aids and decision support systems

Summary

The rapid growth in clinical decision-support software presents significant opportunities for improving healthcare accessibility and quality. However, the proliferation of app technology and its applications may be impacting the effectiveness of clinical trials, patient participation, and healthcare delivery. To fully harness the potential of app technology and digitalization, the healthcare industry may need to reconsider its approach and adoption criteria, possibly incorporating predictive modeling into its strategies. Like any therapeutic tool, prioritizing patient safety and establishing suitable conditions is crucial, especially considering the early stages of data-driven app regulations.

Newly diagnosed cancer patients are faced with an expanding array of treatment options, each with distinct impacts on their lives. In cases where no single treatment option is clinically superior, the patient's choice relies on their assessment of benefits and drawbacks in light of their unique circumstances. Initiatives like shared decision-making (SDM) and patient decision aids (PDAs) aim to empower patients and improve satisfaction and clinical outcomes. However, implementing these initiatives requires addressing various barriers at different levels (PDA-specific, patient/clinician, and organizational) to develop effective implementation strategies.

The primary focus of this thesis is to advance patient participation in SDM through two key objectives:

1. **Objective 1**: To develop and validate individualized PDAs to ultimately improve patient involvement in SDM for lung cancer.

2. **Objective 2**: To review and facilitate the clinical utility of DSS in oncology by providing an overview of machine learning-based models for predicting outcomes.

To guide this research, several fundamental questions were explored:

1) **Research question 1**: What are the critical elements that need to be incorporated into a PDA to ensure clarity, comprehensibility, and personalization of early-stage NSCLC treatment decisions?

2) **Research question 2**: In what ways can trial PDAs be optimized to effectively convey trial information and support informed decision-making by NSCLC patients?

3) **Research question 3**: What evaluation methods and interfaces can be established to assess the accuracy and clinical relevance of predictive models for DSS in real-world oncological settings?

These research questions aim to explore challenges, assess effectiveness, and enhance the usability of patient decision support tools within the context of NSCLC treatment and oncology as a whole, while also addressing methods for optimizing PDA design and implementation.

In reflection on the primary findings, Chapter 2 underscores the increasing prevalence of medical apps in various clinical healthcare settings. These apps typically focus on predictive modeling, clinical guidelines, or image analysis to aid healthcare decision-making. However, their potential must be rigorously validated and assessed.

The development of personalized patient decision aids (iPDA) for non-small cell lung cancer (NSCLC) patients, aligned with Objective 1 and research questions 1 and 2, has achieved success by offering information on treatment options through a multimedia approach encompassing video, animation, and text. This tailored content caters to individual patient preferences and addresses potential side effects. An initial pilot study demonstrated the effectiveness of the initial lung iPDA version in conveying information and influencing decision-making [9]. Nonetheless, certain challenges persist, including the incorporation of predictive models intended for clinicians and the need to standardize information content across hospitals to overcome language barriers for international use. Clinical integration faces hurdles such as physician skepticism and the need for enhanced training, while some patients may encounter barriers to access due to

factors like age. Nevertheless, a systematic review has indicated positive outcomes, particularly for elderly patients using patient decision aids [10]. Ongoing development, integration, and maintenance are essential, with a particular focus on predictive models and overcoming challenges related to the clinical implementation of iPDA tools.

Chapter 3 survey results underscore the iPDA's positive reception among respondents from diverse backgrounds, including doctors, patients, and computer scientists. The majority of respondents found the tool to be user-friendly and easy to navigate. Notably, there was widespread agreement on the clarity and effectiveness of the videos and written information pertaining to treatment options, with high levels of consensus among doctors, patients, and computer scientists. The tool was perceived as successful in conveying comprehensive and clear information about treatment options, including the advantages and disadvantages of surgery and radiotherapy. The written information provided by the tool was widely regarded as useful and easily understandable. Furthermore, the tool was seen as fulfilling the requirement of providing sufficient details for making informed decisions. Respondents unanimously agreed that the tool assists patients in the treatment selection process and esteemed it as a valuable iPDA. Positive feedback also extended to the tool's design. These findings underscore the iPDA's efficacy in empowering patients, facilitating informed decision-making, and providing valuable information and comfort [9].

In Chapter 4, which aligns with research question 2, the development and validation of a trial-specific patient decision aid (tPDA) for the ImmunoSABR trial are described. This tPDA aimed to inform patients about the innovative clinical study and assist them in deciding whether to participate [11]. Evaluations involving physicians, medical students, patients, and computer scientists, conducted through System Usability Scale (SUS) questionnaires, yielded a favorable SUS score of 79, placing it in the 85-89 percentile range and indicating strong overall usability. Feedback from computer scientists on the initial prototype was largely positive, with some suggestions to address interface disparities across devices, textual inconsistencies, and visual cues for interactivity. Subsequent evaluations by physicians on the improved prototype emphasized the need for multilingual video translations, enhancements in text and animation content for clarity, and system improvements to retain user inputs. The majority of patients

navigated the tPDA within 30 minutes and rated its content and clarity highly, while also suggesting areas for improvement, such as more nuanced response options. This study directly addresses the gap identified in the 2015 Cochrane review regarding trial-specific PDAs, shedding light on the potential benefits and challenges associated with these digital tools. While tPDAs offer a consistent method of information delivery, their development can be resource-intensive. Challenges encountered include timing the tPDA's development with the ImmunoSABR trial recruitment and a patient engagement rate that was lower than expected. Moreover, the digital nature of tPDAs may limit accessibility for specific patient groups, such as elderly individuals or those with limited digital literacy. As tPDAs become increasingly prevalent, it will be crucial to ensure their inclusivity and accessibility across all demographic groups.

Chapter 5 follows Objective 2 and research question 2, discussing the development of AI4Cancer as an open-source repository for predictive models. This platform serves multiple disease types and aids researchers and medical experts. However, it's essential to emphasize that these models should support research rather than replace clinical judgment.

During the pandemic, Chapter 6 focuses on the creation of an online platform serving as a repository for COVID-19-related prognostic models, assisting doctors in decision-making. The platform welcomes new models from researchers, promoting collaboration and enhancing the accessibility of validated models for medical professionals.

Implementing PDAs, SDM, and DSS in clinical practice presents several challenges. These include time constraints for clinicians, low health literacy among patients, conflicts in decision-making due to patient preferences, cultural and linguistic barriers, technological challenges, integration with clinical workflow, and cost considerations. Addressing these challenges necessitates collaboration among stakeholders to ensure accessibility, effectiveness, and integration of these tools into routine clinical care.

The future of PDAs, SDM, and DSSs holds promise, with emerging trends such as personalized tools catering to individual patient needs, integration with electronic health records (EHRs) to

streamline clinical use, improved user interfaces for enhanced usability, and the development of mobile apps and digital tools for greater accessibility. These advancements aim to enhance patient engagement and enable informed decision-making, ultimately leading to improved healthcare outcomes and quality of life.

In conclusion, this work showcases a persistent commitment to advancing patient-centered care in the ever-evolving healthcare landscape. The development and validation of PDAs for lung cancer, the establishment and maintenance of open-source predictive modeling repositories for oncology, and the introduction of predictive modeling tools all contribute to the enhancement of clinical decision support and patient engagement, especially in oncology and broader medical decision-making. These contributions offer valuable insights and solutions to the healthcare community as the medical field continues to progress and innovate, paving the way for improved clinical decision support, patient empowerment, and a healthcare system that prioritizes patient preferences and needs. This thesis not only represents significant progress but also underscores an ongoing dedication to patient-centered care and the facilitation of shared decision-making.