

# Leveraging patient decision aids and decision support systems

Citation for published version (APA):

Halilaj, I. (2024). *Leveraging patient decision aids and decision support systems: Towards more personalised medical treatments*. [Doctoral Thesis, Maastricht University]. Maastricht University. <https://doi.org/10.26481/dis.20240910ih>

## Document status and date:

Published: 01/01/2024

## DOI:

[10.26481/dis.20240910ih](https://doi.org/10.26481/dis.20240910ih)

## Document Version:

Publisher's PDF, also known as Version of record

## Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

## General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

[www.umlib.nl/taverne-license](http://www.umlib.nl/taverne-license)

## Take down policy

If you believe that this document breaches copyright please contact us at:

[repository@maastrichtuniversity.nl](mailto:repository@maastrichtuniversity.nl)

providing details and we will investigate your claim.

## IMPACT PARAGRAPH

---

## **Impact Paragraph**

In an era where patient participation in healthcare decisions is on the rise, the demand for decision support tools and collaborative processes like patient decision aids (PDAs) and shared decision-making (SDM) is steadily increasing. However, these innovations often encounter implementation challenges due to insufficient consideration of user perspectives and workflows. Therefore, the focus of this thesis was to delve into the patient experience, decision-making process, and the enhancement of patient-clinician communication.

## **Scientific Impact**

One significant outcome of this research is the development of a web-based PDA for lung cancer patients, which is publicly accessible. In the development of this PDA, predictive models have been used to provide valuable insights into individualized risk information, including the likelihood of experiencing specific side effects associated with various treatment options. The ongoing implementation of this augmented PDA aims to enhance SDM, increase patient knowledge, and reduce decisional conflict. Our work exemplifies the principles of user-centered design, fostering user-friendliness and clinician engagement, thus facilitating successful PDA adoption.

In the context of lung cancer, traditionally dominated by clinical guidelines, our exploration of SDM and decision support systems (DSSs) has contributed to a growing literature on SDM in this domain. Our findings underscore the importance of clinician involvement and reveal the potential benefits of incorporating artificial intelligence (AI) in decision-making. This research serves as a first step for future studies exploring the aspects of clinician trust and the comprehensibility of AI-driven predictions within data-driven shared decision-making.

### **Adapting PDA Format:**

This thesis provides insights into the challenges and advantages of digital PDAs. It highlights the potential of in-consultation paper PDAs in structuring SDM conversations, complementing digital PDAs. The integration of these formats offers a promising approach for more personalized decision support in both clinical and home settings.

## **Societal Impact**

Our research extends beyond academic boundaries, aiming to catalyze a profound transformation in patient-clinician interactions. The availability of our open-source PDAs to the public serves as a catalyst for informed healthcare decisions, reaching a broad audience of patients across diverse backgrounds and health conditions. This empowers individuals to gain a deeper understanding of their treatment options and fosters constructive conversations with their healthcare providers, potentially resulting in a better quality of life. In addition, as evidenced by the case of medication adherence, improving patient adherence to treatment may also help lower overall healthcare system costs.

Furthermore, there is a potential role that patient organizations can play as intermediaries in disseminating PDAs. These organizations could become valuable conduits for reaching patients and assisting them in preparing for shared decision-making (SDM) consultations, bridging the gap between research and practical implementation.

In tandem, involving clinicians in the development of PDAs and SDM training underscores the importance of healthcare providers in the implementation of patient-centered care. This engagement raises awareness among clinicians about the significance of patient perspectives and active participation in decision-making processes. The concept of hybrid PDAs, blending digital and paper formats, emerges as an adaptable tool that can cater to different healthcare contexts, especially the burgeoning realm of virtual healthcare.

Moreover, our findings advocate for the overhaul of patient pathways to accommodate individual preferences. This structural shift aims to respect patient choices and create an environment conducive to SDM. In this pursuit, stakeholders like health insurers can contribute significantly by recalibrating reimbursement structures, thus driving the adoption of SDM practices in the healthcare system.

In summary, our research transcends academia, directly benefiting a wide array of patients, healthcare providers, and intermediary organizations. By promoting patient-centered care, refining decision support tools, and facilitating collaboration among diverse stakeholders, we are collectively advancing the quality of healthcare decision-making, creating a healthcare ecosystem that respects individual preferences and empowers patients to actively engage in their care journey.

## Primary findings and products

In this thesis, we have explored the growing significance of medical apps in various clinical healthcare settings, highlighting their diverse applications ranging from research and education to triage and prescription of medications. Our analysis underscores the pivotal role of decision-support tools within these apps, particularly in the context of predictive modeling, clinical guidelines, and image analysis. While diagnostic DSS for prostate cancer have been readily accessible and well-validated, treatment selection DSS focused primarily on external beam radiotherapy, revealing an area for further development. Moreover, the underdeveloped field of PDAs faces cultural and language barriers but demonstrates improved patient satisfaction and mental well-being.

Furthermore, we introduced [AI4Cancer](#), an open-source repository for predictive models across various cancer types, emphasizing its role as a valuable resource for researchers and medical experts. We also created an online platform for COVID-19-related prognostic models, promoting collaboration and real-world impact within the medical community.

Although the iPDA for NSCLC has shown its effectiveness in aiding informed decision-making, there are still persistent challenges. These challenges include variations in information content, skepticism among physicians, and accessibility issues.

Additionally, we discussed the development and validation of a trial-specific PDA (tPDA) for the ImmunoSABR trial, with positive usability feedback from physicians, patients, and computer scientists. Nevertheless, we recognized the resource-intensive nature of tPDA development and the need for inclusivity across diverse patient groups.

Methodologically, our research adopted an interdisciplinary and mixed-methods approach, ensuring the reliability and applicability of our findings to real-world medical scenarios. However, limitations such as generalizability, ethical concerns, and implementation challenges were identified, underscoring the need for ongoing research and adaptation strategies in this dynamic field. Overall, this work has the potential to shape and improve healthcare practices across various medical disciplines.

## **Innovation**

Our research also contributes to innovation in the realm of healthcare decision support and shared decision-making. By developing and refining PDAs, we are at the forefront of enhancing patient engagement and informed decision-making. These innovative tools leverage technology to provide patients with accessible and personalized information, aiding them in understanding their treatment options, clarifying their values, and testing their knowledge.

Furthermore, our exploration of hybrid PDA formats, combining digital and paper-based components, represents a novel approach that promotes adaptability and convenience for both patients and clinicians. This innovation ensures that decision support can be seamlessly integrated into various healthcare settings, including in-person consultations and virtual care environments, aligning with the evolving landscape of healthcare delivery.

In the context of lung cancer decision-making, our research ventures into the application of AI and prediction models as decision support tools. This innovative approach opens new avenues for leveraging AI to assist clinicians and patients in making informed choices. It not only showcases the potential of AI in healthcare but also underscores the need for trustworthy AI-based predictions and their integration into data-driven shared decision-making.

Additionally, our work highlights the innovative potential of collaborations between healthcare institutions and stakeholders such as health insurers and medical technology companies. These partnerships demonstrate a proactive approach to aligning healthcare incentives with shared decision-making, ultimately driving positive change in the healthcare system.

In summary, our research is at the forefront of innovation in healthcare decision support and shared decision-making, with a focus on creating tools, processes, and collaborations that empower patients and clinicians to make informed and collaborative choices in the ever-evolving healthcare landscape.

## **Implementation**

While our research has generated valuable insights and innovations, successful implementation of these findings is essential to realize their full impact on healthcare practice. To facilitate the integration of PDAs and SDM tools into clinical workflows, it is crucial to collaborate closely with healthcare institutions, clinicians, and stakeholders. This includes providing comprehensive training and support to clinicians in effectively utilizing PDAs during consultations. Additionally, ongoing evaluation and feedback loops are vital to refine and adapt these tools to meet the evolving needs of patients and healthcare providers. A structured approach to implementing SDM, including changes in patient pathways and alignment of incentives, can help create a conducive environment for patient-centered care and informed decision-making. As we progress, our commitment lies in collaborating closely with healthcare systems to ensure the smooth integration and long-lasting effectiveness of these innovations in complementing decision-making processes in the healthcare domain. For example, we aim to collaborate with leading medical institutions and companies to deploy state-of-the-art AI-driven diagnostic tools, and we will interact with medical professionals to offer guidance and support on how to best use these tools in clinical practice.