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Methods to incorporate patient preferences into medical decision algorithms and models, and their quantification, balancing, and evaluation: a scoping review protocol

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ABSTRACT

Objective: The objective of this scoping review is to identify and map methods used to incorporate patient preferences into medical algorithms and models as well as to report on their quantification, balancing, and evaluation in the literature. The review will focus on computational methods for incorporating patient preferences into algorithms and models at an individual level as well as the types of medical algorithms and models in which these methods have been applied.

Introduction: Medical algorithms and models are increasingly being used to support clinical and shared decision-making; however, their effectiveness, accuracy, acceptance, and comprehension may be limited if patients' preferences are not considered. To address this issue, it is important to explore methods integrating patient preferences.

Inclusion criteria: This review will investigate patient preferences and their integration into medical algorithms and models for individual-level clinical decision-making. The scoping review will include diverse sources, such as peer-reviewed articles, clinical practice guidelines, gray literature, government reports, guidelines, and expert opinions for a comprehensive investigation of the subject.

Methods: This scoping review will follow JBI methodology. A comprehensive search will be conducted in PubMed, Web of Science, ACM Digital Library, IEEE Xplore, the Cochrane Library, OpenGrey, the National Technical Reports Library, and the first 20 pages of Google Scholar. The search strategy will include keywords related to patient preferences, medical algorithms and models, decision-making, and software tools and frameworks. Data extraction and analysis will be guided by the JBI framework, which includes an explorative and qualitative analysis.

Review registration: Open Science Framework https://osf.io/qg3b5

Keywords: decision-making; key concepts; medical algorithms; patient preferences; scoping review

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Introduction

Patient-centered care respects patients as unique individuals and addresses their needs and concerns regarding treatment in medical health care settings.[1] The shift toward a more patient-centric approach reflects the growing recognition of the importance of personalized health care and acknowledges the unique values and preferences of patients. Shared decision-making is a process in which health care providers and patients collaborate to make health care decisions, and it is increasingly acknowledged as a viable option for implementing patient-centered care approaches.[2] Shared decision-making integrates clinical evidence and expertise with a patient's individual values, beliefs, and lifestyle, leading to improved patient satisfaction, enhanced treatment adherence, and better health outcomes.[3] However, integrating shared decision-making into practice can

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be challenging. Obstacles to utilizing shared decision-making approaches can arise from lack of time in clinical settings.[3] Alternatively, obstacles may originate from a lack of experience or training in determining patient preferences or from unconscious biases influencing how health care providers discuss different treatment options.[4] Patients may lack understanding of the various alternatives or may be unfamiliar with medical jargon, leading them to defer their decisions to the health care provider.[5] This can be an issue, as health care providers may not accurately predict what a patient prefers in terms of the course of treatment, desired results, or acceptance of potential risks associated with the treatment.

One of the key elements in shared decision-making is understanding and incorporating patient preferences into medical decisions. *Patient preferences* is described as personal values and attitudes that drive personal choice.[5] While listening to the opinion of a patient should be central to making health care decisions, it is unclear whether the autonomy of the patient is always considered.[6] An example of the importance of including patient preferences in the decision-making process was reported in a study comparing functional electrical stimulation (FES) and conventional surgery for people with sixth cervical vertebra level motor group 2 tetraplegia.[7] While the rehabilitation team had a slight preference for FES over conventional surgery when considering upper limb interventions, overall, their preference for conventional surgery was slightly higher than that for FES. Conversely, potential recipients gave greater weight to burden of treatment and less weight to functional improvement, resulting in a slight preference for conventional surgery over FES, despite the rehabilitation team's overall preference for the latter.

Clinical decision support systems are applications that aim to help health care professionals and patients make treatment decisions based on the scientifically evaluated advantages and disadvantages of the treatment.[8] The effectiveness and accuracy of clinical decision support systems, which denote how well the results match the provided treatment outcomes and decision aids, still need to be improved. These parameters are significant for the acceptance and comprehension of decision support and its results, and existing implementations of decision support systems have already been viewed as an asset in modern health care settings.[9] This is evidenced by the World Health Organization describing the relevance of the development and integration of these systems.[10] Despite its importance, the question of how patient preferences can be integrated into such algorithms and models for clinical decision support systems has not been comprehensively addressed in the existing literature.

We will conduct a scoping review following the JBI methodology to examine this question.[11] Given the expansive and evolving nature of our research field, coupled with the significant variability in existing studies and our objective to explore and identify key concepts that require further investigation, we determined that a scoping review would be the most suitable methodology. Several methods have been proposed to capture and integrate patient preferences into medical algorithms and models,[12] which typically attempt to ascertain and quantify patient preferences related to various aspects of health care. This can include patient perspectives on different treatment options, health outcomes, or the balance between potential benefits and risks. However, the methods used to elicit, integrate, and quantify patient preferences can substantially differ in their approach and complexity. One method is a multi-criteria decision analysis, which is often used to create medical decision algorithms and models.[13] As an example, Tervonen *et al.*[14] published a study in which they used stochastic multi-criteria acceptability analysis to incorporate patient preferences into a drug treatment decision tool.

Striking a balance between patient preferences and other considerations, such as clinical evidence, cost-effectiveness, and resource allocation, often presents challenges. While patient preferences should undeniably play a central role in clinical decisions, they are just one part of a complex puzzle that includes evidence-based medicine, economic considerations, and ethical issues, among other factors.[15] A transparent approach to solving this puzzle involves using computational techniques to identify and quantify patient preferences. *Quantification* refers to the process of measuring and assigning numerical values to preferences, which allows us to rank treatment options in order of suitability for an individual patient. This ranking incorporates and balances various factors that are crucial to the decision-making process. After identifying the most suitable option, it is essential to conduct a thorough evaluation to ensure that this option aligns precisely with the patient's specific preferences. Quantifying, balancing, and evaluating

patient preferences is supported by various methods. Our goal is to document and map all the methods that have been utilized to integrate patient preferences into medical decision-making.

In this scoping review, we aim to provide a comprehensive overview of the methods used to incorporate patient preferences into medical algorithms and models, and report how these methods have been quantified, balanced, and evaluated. Our objective is to map the existing knowledge on computational methods that incorporate patient preferences for individual-level recommendations, and to identify areas that necessitate further research. Our goal is to contribute to a more nuanced understanding of how patient preferences can be integrated into clinical decision-making. By detailing the current methods and their evaluation, we hope to identify underlying limitations and areas for further development.

Review questions

i) What methods exist to incorporate patient preferences into computational medical decision algorithms and models at an individual level?
ii) How have patient preferences been quantified, balanced, and evaluated in existing methods?
iii) What are the reported limitations of these methods?

Inclusion criteria

Participants

The review will consider any type of patient.

Concept

The concept of patient preferences and their integration into medical algorithms and models is a multidimensional area of research that involves the examination of various methods. In the context of this JBI scoping review, the concept encompasses the current state of knowledge regarding the integration of patient preferences into medical decision algorithms and models, as well as techniques to quantify, balance, and evaluate patient preferences. In this context, *models* refers to structured representations of clinical scenarios or patient data, which are used to predict outcomes or support decision-making. *Algorithms* are step-by-step procedures or formulas designed to perform specific tasks, such as integrating patient preferences into these models to guide clinical decisions. This involves the incorporation of patient preferences into medical algorithms and models, which may involve the development of decision rules, weighting methods, or other methods that integrate patient preference data into the decision-making process.

Additionally, this concept involves the evaluation, balancing, and quantification of patient preferences, which may involve the use of utility measures, weighting methods, or other quantitative approaches to assess the relative importance or impact of different patient preferences on medical algorithms and models. It also includes evidence related to the evaluation, balancing, or quantification of patient preferences, which may provide information about the limitations and future research requirements associated with incorporating patient preferences into medical algorithms and models. We will summarize the limitations of methods as described by the authors in their publications, providing a comprehensive overview of the perspectives prevalent within the scientific community.

Context

This scoping review will focus on decision-making in clinical health care settings, emphasizing the integration of patient preferences into computational medical algorithms and models at an individual level, without geographical restrictions. These computational medical algorithms and models integrating patient preferences use advanced methods to tailor treatment options to individual values and needs, enhancing personalized medicine by aligning clinical decisions with patient-specific goals and preferences.

Types of sources

The scoping review will include a wide range of sources, such as peer-reviewed journal articles and gray literature. This will include original research articles, qualitative studies, quantitative studies, mixed methods studies, meta-analyses, conference abstracts, dissertations, theses, technical reports, relevant documents from reputable sources, clinical practice guidelines, reports, policy documents, online resources, and expert opinions obtained through personal communication. The inclusion of diverse sources provides a comprehensive overview of the evidence related to this research question.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews[11] and reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).[16] This protocol is registered in Open Science Framework (https://osf.io/qg3b5).

Search strategy

The search will aim to identify both published and unpublished research using a 3-step search strategy. An initial limited search of PubMed and Web of Science Core Collection databases was undertaken to identify articles on the topic. Pilot testing for a scoping review helps refine inclusion and exclusion criteria, ensure data extraction tools are effective, and assess the feasibility of the review process. This step is crucial for training team members and testing the search strategy. We decided to sample 100 random articles for the review, which will provide a broad yet manageable overview that will help ensure methodological consistency and identify procedural adjustments needed before conducting the full review. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles, were analyzed. Based on these keywords, a search query will be refined until it yields the smallest possible set of results while still including all relevant publications identified in the pilot. Subsequently, a comprehensive search using all identified keywords and index terms will be performed across included databases. Lastly, the reference lists of all the included reports and articles will be checked manually for additional sources of evidence.

The databases searched will include PubMed, Web of Science Core Collection, ACM Digital Library, IEEE Xplore, and the Cochrane Library. The search for gray literature will be conducted through OpenGrey, the National Technical Reports Library, and the first 20 pages of Google Scholar, encompassing conference abstracts, dissertations, theses, technical reports, relevant documents from reputable sources, clinical practice guidelines, reports, policy documents, online resources, and expert opinions obtained through personal communication. We decided to search the first 20 pages of Google Scholar, as it provides a broad overview of the key themes and areas of research without becoming unmanageable, and it is also a resource that is commonly used.

The search strategy will be tailored to each database to ensure that all the relevant articles are captured (see Appendix I). Systematic reviews and overview articles will be excluded, but the references will be screened for additional relevant publications. There will be no limitations regarding the year of publication or language. Where a translation of a publication is needed, a multilingual team member will translate the research or tools such as DeepL (DeepL, Cologne, Germany) will be used. Due to the broad definition of the included terminology, we expect a large number of results from our search.

Study selection

Following a pilot test, titles and abstracts will be screened against the inclusion criteria for the review by at least 2 independent reviewers. Inclusion criteria and data of interest will be identified based on a qualitative content analysis (as theorized by Mayring[17]) with included publications from the piloting test. Utilizing a qualitative content analysis at this stage provides a detailed and nuanced understanding of complex topics, offering a structured way to synthesize textual data across a broad range of sources. This approach may necessitate adjustments to the definitions of inclusion criteria and data of interest. Any changes to these definitions will be clearly documented in the scoping review. This method for qualitative content analysis will also be used for the data extraction process.

Following the search, all identified citations will be collated and uploaded to Rayyan (Qatar Computing Research Institute, Doha, Qatar), which will be used to conduct the blind screening of abstracts and titles and to remove duplicates. The full texts of the selected citations will be assessed in detail by independent reviewers based on the inclusion criteria. Reasons for the exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements between reviewers at each stage of the selection process will be resolved through discussion or with an additional reviewer. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA flow diagram.[18]

Data extraction

Data will be extracted from the papers included in the scoping review by 2 independent reviewers, using a data extraction tool developed by the reviewers (Appendix II). We will perform a pilot test of the data extraction tool on 10 full-text reports that utilize various research methods and approaches. This will allow data extractors to adjust and standardize the use of the tool, ensuring consistent application across studies. Following the pilot, we will refine the data extraction tool according to the feedback received. The extracted data will include specific details regarding the study details; aim/objective of study; methods of incorporating patient preferences; quantification, balancing, and evaluation of patient preferences; and limitations relevant to the review question. The draft data extraction tool was modified and will be revised as necessary during the process of extracting data from each included evidence source. These modifications will be detailed in the scoping review. Any disagreements between the reviewers will be resolved through discussion or with an additional reviewer. If necessary, we will contact the authors of papers up to 3 times via email and/or the social media application ResearchGate to request missing or additional data.

Data analysis and presentation

A qualitative content analysis will be utilized to categorize and interpret textual data, enabling the identification of gaps, patterns, and insights that inform the broader research questions of the study. The extracted data will be presented in a tabular format, offering an overview of the existing literature. A summary will detail the nature of the collected studies that focus on methods for incorporating patient preferences in medical algorithms and models and their quantification, balancing, and evaluation. Data categories for presentation will comprise the publication year; country; definition of patient preferences; methods for assessment and incorporation of patient preferences; methods for evaluation, balancing, and quantifying patient preferences; limitations; and implications for further research. The data will be categorized and analyzed using methods that are unified by a common underlying concept. A longitudinal chart with the year of publication will show when new methods have been invented and what current trends look like. Additionally, for each categorized method, a synthesis of limitations and implications for future work will be presented.

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Author contributions

JF wrote the main manuscript text; designed the study; and conducted data acquisition, analysis, and interpretation. VH and UM contributed to the protocol's conception and design, and significantly revised the manuscript. KS and IM assisted with data acquisition and analysis, and also made substantial revisions to the manuscript. All authors reviewed the manuscript.

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Appendix I: Search strategy

PubMed

Search conducted: July 20, 2023

Search	Query	Records retrieved
#1	("patient preferences"'[All Fields] OR "patient values"[All Fields] OR "patient choice"[All Fields] OR "patient-centered"[All Fields]) AND ("decision aid"[All Fields] OR "decision support"[All Fields] OR "collaborative decision making"[All Fields] OR "shared decision making"[All Fields] OR "treatment"[All Fields] OR "prediction"[All Fields] OR "multicriteria"[All Fields] OR "Multiple-Criteria"[All Fields] OR "Multi-Objective"[All Fields] OR "Multi-Attribute"[All Fields] OR "MCA"[All Fields] OR "MCDA"[All Fields]) AND ("tool"[All Fields] OR "app"[All Fields] OR "application"[All Fields] OR "model"[All Fields] OR "algorithm"[All Fields] OR "decision analysis"[All Fields] OR "framework"[All Fields] OR "system"[All Fields] OR "user interface"[All Fields] OR "user interaction"[All Fields])	7002

Appendix II: Draft data extraction instrument

Study details	
Authors	
Title	
Year of publication	
Journal	
Country	
Study design	
Aim/objective of study	
Aim of the study	
How does the study relate to the research question?	
Type of decision-making support	
Methods of incorporating patient preferences	
Medical condition	
Patient preferences incorporated	
Method used to assess patient preferences	
Description of how patient preferences were incorporated into the medical algorithms or models	
Tools, techniques, or frameworks used to incorporate patient preferences	
Patient involvement (criteria development, or scoring/weighting)	
Stakeholders involved	
Design of treatment options for decision-making	
Quantification, balancing, and evaluation of patient preferences	
Methods used to balance, quantify, and evaluate patient preferences	
Findings related to the quantification, balance, and evaluation of patient preferences	
User acceptance tested	
Conclusions	
Limitations	
Implications for future research	

