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Data-driven shared decision-making: a paradigm shift

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Abstract: At first sight, shared decision-making and data science seem like two vastly different fields. Yet, despite their differences, both fields could, if combined, reinforce clinical utility for both. Here we describe a new paradigm called data-driven shared decision-making (dSDM), an extension of the existing shared decision-making paradigm. In dSDM, data's role and its interaction with the patient and doctor are made explicit. Furthermore, we describe the opportunities and challenges of combining data science and shared decision-making into this new paradigm. We believe that dSDM will bridge the gap between the need for patient empowerment and the need for more personalized medicine.

Keywords: shared decision-making, data-driven shared decision-making, paradigm, data science, personalized medicine.

At first sight, shared decision-making and data science seem like two vastly different fields. Shared Decision-mak- ing (SDM) is a well-structured consultation process where a patient and a doctor together decide which treatment option optimizes their joint value from seeking treatment [1]. In principle, it is a qualitative approach, both in the clinic and in research. On the other hand, data science appears to be the opposite since it focuses on objective data, quantitative sta- tistics and artificial intelligence.

Yet, SDM and data science should be seen as symbiotic and, if combined, could reinforce clinical utility of both. There is an increasing need for more personalized decision- making using data, but it is also important to maintain shared decision-making that is so effective for empowering pa- tients. Therefore, we believe that these two should be com- bined into a new paradigm that encompasses patient, doctor and data, to which we now refer as "data-driven shared de- cision-making" (dSDM).

A new paradigm

In dSDM, the emphasis remains on the collaborative process in decision-making between a patient and a doctor, but it explicitly introduces a third component: usable data for clinical decision-making. Here, data takes an advisory role, so to speak, in which it provides additional insights that are not readily available without the need for quantitative statistics or artificial intelligence and that relate to certain decisions that need to be made based on a patient's characteristics.

Introducing data as the third party in dSDM will consolidate the need for more inclusion of (digital) technology in healthcare and the persisting need for shared decision-making. It also applies to society's collective desire to move into the direction of personalised medicine [2].

In our new dSDM paradigm, the clinician involved in the SDM consultation has the additional task to guide the patient in understanding and interpreting the information that is provided by the data extracted by AI or statistics. The role of the patient does not change as they try to digest the information (including the extra information provided by the data), form their own opinions, and then make a decision together with their doctor. The third-party that is added to the paradigm is the data extracted by AI or quantitative statistics. Data's role is passive; it extracts and reports relevant condensed information based on health data that may be applicable to the patient. This condensed information can, for instance, take the form of individualized treatment outcome predictions, such as statistical risk estimates. In contrast to the data's passive role, the patient and doctor both take the active roles and decide (I) whether data's advice, report or prediction is valid and applicable, and (II) whether they want to use it as part of their decision-making process. The different roles of each player in the new dSDM paradigm are further explained in Table 1.

It is important to note that the way the data is incorporated in the clinical decision-making process, i.e., whether the patient consults outcomes on their own or together with their doctor, depends on the clinical situation. For instance, survival odds calculated by AI should not be shown to patients without guidance from an expert. In contrast, AI-based predictions of less impactful outcomes such as side effects in preference-sensitive situations [3] like localized prostate cancer or breast cancer can be provided to patients before a consultation.

particular patient could potentially give a better estimate of

Table 1
The roles of each party on the novel dSDM paradigm explained and compared to the original SDM paradigm published by Charles et al. [3]. The added roles of each party in dSDM compared to SDM are written in cursive.

	Shared decision-making	Data-driven shared decision-making
Role of the clinician	*Active:* Reports all information and treatment possibilities to the patient. Can recommend an option. Decides on the therapy together with the patient	*Active:* Reports all information and treatment possibilities to the patient. Can recommend an option. Decides on the therapy together with the patient *Leads the patient in understanding and interpreting the information provided by the data*
Role of the patient	*Active:* Receives all information. Forms their own judgement on harms and benefits of treatment options. Discusses his preferences with the clinician. Decides on the therapy together with the clinician.	*Active:* Receives all information. Forms their own judgement on harms and benefits of treatment options. Discusses his preferences with the clinician. Decides on the therapy together with the clinician.
Role of data	*NA*	*Passive:* *Condenses and reports all data-related information applicable to the patient's situation. Makes predictions of future health states given current health states and possible interventions.*
Information	Two-way: Patient ↔ clinician	*Multidirectional::* *Patient ↔ clinician* *Data ↔ patient* *Data ↔ clinician*
Deliberation	Clinician and patient (plus potential others)	Clinician and patient (plus potential others). *Data does not play a role in this as it only provides advice/extra information*
Who decides?	Clinician and patient	Clinician and patient

Opportunities

The strength of dSDM lies in its power to include multifactorial models of future treatment outcomes [4] into the shared decision-making framework that patients and doctors follow. By combining the two, we create opportunities to truly incorporate digital technology and data into clinical practice.

In fact, incorporating personal, objective, AI-based data- driven risks as part of the consultation and SDM process is one of the major strengths of dSDM. Generally speaking, information presented in the context of SDM currently revolves around population-based risks, for example "10 out of 100 people with this disease will develop this side effect". Based on this information, a patient (and their doctor) might decide to go with a less risky treatment. Yet, they may still end up with that side effect, because unknowingly they were already at risk. Personalized risk scores predicted by artificial intelligence based on the characteristics of that

that person's risk and prevent decisional conflict and regret in the long term.

Here we describe a few concrete examples of situations where dSDM could make a difference.

First, a low-threshold starting point is preference-sensi- tive decision-making, where reasonably clinically equipoise treatment alternatives exist that do not influence the patient's survival. Examples of this are certain types of prostate can- cer or breast cancer in which different treatments have simi- lar survival odds but different treatment-related toxicities [5]. Shared decision-making is already frequently used in these situations since it enables patients (and their doctor) to make a decision based on the patient's own personal situa- tion, in other words based on their preferences. Adding dSDM's data component into the mix will help patients and doctors to not only explore the impact of a decision on the patient's personal life, but also help them understand how likely and how severely a decision would affect their (daily)

life. Here, the data condensed by AI or quantitative statistics could describe a person's individual chances of good or bad outcomes as a result of the decision. For example, it could predict the odds of developing a side effect as a result of a treatment choice.

Similarly, the condensed data could help patients make health-related decisions in cases where the physician is uncertain about the risks related to certain treatments. This happens when treatment outcomes are dependent on a complex combination of factors and interactions that is only decipherable by machines. An example of this is the choice for mastectomy vs. breast-conserving therapy (BCT) of which the risks are mediated by age, genetic predispositions such as CHECK and BRCA, and the expression of estrogen, progesterone and HER2.

In other more dire situations such as terminal cancer, there may be the need to choose between receiving or not receiving treatment that lengthens the patient's life span at a high cost to their quality of life. In these cases, predicting the estimated survival of the patient by AI-models could be beneficial to determine whether they would even benefit from the long-term effects of that treatment. Patients with short-term survival can then, based on this information, decide together with their doctor to not take the treatment and live out the remainder of their life with a higher quality of life. It is imperative however that patients are informed by their doctor about the uncertainties and risks that come with statistical and AI-based models.

In addition to the personalized information, added trans- parency about risks and reducing risk of decisional conflict and regret, dSDM can help decrease the complexity and quantity of information both a physician and a patient need to process and comprehend in order to make a decision [6]. This can be achieved by providing a structured approach of the most relevant information for the patient with the option of drilling further into details when necessary.

Challenges

Despite these opportunities, there is also a lot of room for improvement due to a variety of challenges. Here we mention the most important ones.

As digital healthcare and personalised medicine are increasingly used to support and deliver healthcare, they require patients to become familiar with them as well as their disease [7]. Yet despite this surge of technology into healthcare, (digital) health literacy [8,9] is a major concern. Approximately half of the adult population in eight European countries have a poor or inadequate level of health literacy [10] and the average reading skills of an American

citizen lies at primary school level [11].

With personalised medicine and dSDM, the addition of data further complicates understanding for patients. Various patient demographics influence the level of digital health literacy, such as educational level, age and a minority background [12]. In order to combat this problem, the health

literacy research community has developed several (visualization) strategies for various target populations. A review of these strategies and their effectiveness can be found in [13]. It is imperative that developers of digital health tools consider health literacy and consult appropriate parties, such as the Dutch foundation "Stichting Makkelijk Lezen", which evaluates digital tools on their level of readability for people with low (health) literacy [14].

An extension of this challenge is the understanding of the physician of sometimes complex artificial intelligence algorithms that its developers sometimes even find difficult to understand. Poor understanding of the model during its use could lead to biased or inaccurate interpretation and as a result inaccurate decision-making and advice of the physician to the patient. To combat this problem, doctors need to be trained in how to understand, apply and explain AI- or rule-based algorithms. In addition, developers need to consider an algorithm's target population by providing understandable interfaces or using explainable AI [15].

Another challenge the health care community (and stakeholders beyond, including legislations) needs to reach is consensus on the appropriate extent, time and place to involve data in the SDM process. In fact, it is not desirable to have data alone make the decisions, just as it is not desirable that doctors alone make the decisions (as it was in paternalistic decision-making [16]). We believe that it needs to be clear to both patient and physician that data's role should merely be advisory and should simply become part of the variables that are already regularly taken into consideration to determine which treatment options to present to the patient.

It is also important for both patients and doctors to realise that data and thus recommendations based on that, are fallible. An AI model is only as good as the data it was derived from; the data, the derived model or both may be flawed [17]. In addition, AI cannot take into consideration every aspect of a patient's life or disease because not everything can be collected and quantified. Patients and doctors should therefore be given the liberty to disregard information presented by the third party “data” when there is doubt about its legitimacy for a specific individual.

An extension of this is a patient’s right to refuse the use of data and AI just as they would be able to refuse shared decision-making. In addition, privacy needs to be considered as a major factor in data-driven shared decision-making. There are various solutions to this dilemma, including federated data sharing or learning with distributed IT infrastructure systems like the Personal Health Train [15] or logistical solutions where patients receive the required information by phone or through a letter.

Conclusion

Personalized medicine and shared decision-making are both interesting developments in healthcare. Yet, thus far no attempt has been made to consolidate these two major developments. In this article we present a new and adjusted shared decision-making paradigm called data-driven shared decision-making where personalised medicine and SDM are both incorporated to provide patients with the best decision- making capabilities.

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