Towards a Trusted Collaborative Medical Decision-Making Platform

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Abstract. Traditionally, shared decision-making has been considered as a one-off dyadic encounter between a patient and physician within the confines of the consultation room. In practice, several stakeholders are involved, and the decision-making process involves multiple rounds of interaction and can be influenced by different biopsychosocial, cultural, spiritual, financial, and legal determinants. Thus, there is an opportunity for developing an innovative digital platform for distributed collaborative medical decision-making. However, given the sensitive nature of data and decisions, there are several challenges associated with safeguarding the consent, privacy, and security of the contributors to the decision-making process. In this paper, we propose a conceptual framework and reference architecture for a trusted collaborative medical decision-making (TCMDM) platform that addresses some of these challenges by using a consensus building mechanism built on top of blockchain technology. We illustrate how the TCMDM platform functions by using a real-life use case scenario of an early stage breast cancer patient collaborating with other stakeholders to reach consensus on the best treatment plan.

Keywords: Shared decision-making · Clinical encounter · Consensus building · Privacy · Accountability · Trust · Blockchain

1 Introduction

As the number of diagnostic and therapeutic options increase, so does the complexity of medical decision-making. *Informed consent* and *shared decision-making* (SDM) are two important processes that promote patient participation and autonomy in such situations. Informed consent is a legal process that refers to an individual's explicit authorisation of a medical intervention, especially in treatments involving high risks. SDM is an ethical approach that seeks to enhance patient choice by incorporating their preferences into the healthcare decisions, particularly when multiple comparable medical choices exist [1,17]. Traditionally, SDM has been considered as a one-off dyadic encounter between patient and physician within the confines of a consultation room. However, in reality, there are several other stakeholders involved, and the decisions are influenced by different biopsychosocial, cultural, financial and legal determinants, and shaped over time as opposed to single, discrete encounters.

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As an illustrative scenario, consider an *early stage breast cancer* patient having to choose between mastectomy and lumpectomy with radiation [17]. Based on clinical evidence, both treatment options produce indistinguishable cure rates for early stage breast cancer. The patient can collaborate with a number of stakeholders including her family physician, surgeon, radiation oncologist, medical oncologist, family member/s, well-wisher/s and legal representative to select the option that best meets her emotional and situational needs. Enabling consensual and collectively accepted decisions is paramount to ensure that the patient gets the best possible medical option that encompasses her personal preferences while also considering the healthcare providers' recommendations and family members' wishes. This is not possible in a single clinical encounter and requires an **iterative consensus building process**. Moreover, the patient and other stakeholders may not want to reveal their preferences over the treatment options for a number of different reasons. Hence, the collaborative medical decision-making (CMDM) process has to be **secure, privacy-preserving and confidentiality-preserving**. The recent case of a new-born's death after "*lotus birth*"[1] further highlights the challenges associated with CMDM in such cases. It is believed that babies born through lotus birth have improved blood circulation and a stronger immune system however medical evidence does not support this [2]. Following the death, there were conflicting claims from the hospital and the parents. The hospital claimed that the mother rejected specifically suggested medical treatment options, including vaccinations of and transfer to a special care nursery for the baby, while performing alternative treatments on the baby without the knowledge of the hospital staff. This incident raises additional questions related to the way informed consent and CMDM are being implemented in practice including: (a) who takes responsibility if the selected treatment option does not yield the desired outcome, or worse still, results in an adverse outcome (**accountability**), and (b) which decision in the clinical encounter is the cause of the adverse outcome (**traceability and auditability**). Finding answers to such questions requires having documented evidence about the sequence of decisions taken over the entire clinical encounter (**provenance**).

We posit that there is a need for a practical, digital CMDM platform that (a) *supports multiple stakeholders'* participation, (b) *maintains privacy, confidentiality and security* of sensitive data and decisions, (c) *enhances trust* among stakeholders through transparent communication while permitting decisional authority to lie with one or more of them, (d) *maintains provenance, accountability and traceability*, and (e) *supports second or third opinions* to provide participants additional reassurance about the final decision. To the best of our knowledge, none of the existing CMDM models address all of the above. Therefore, we propose a novel conceptual framework and reference architecture for a trusted collaborative medical decision-making (TCMDM) platform that addresses some of these challenges. In particular, we propose a *consensus building mechanism* to support multiple stakeholders in reaching a consensual and collectively accepted decision that encompasses the patient's preferences, the healthcare provider's

[1] https://bit.ly/35yffK4.

recommendation and the family members' wishes. Integration of the consensus building mechanism with blockchain technology ensures trusted, secure, privacy-preserving and confidentiality-preserving interactions leading to the final decision. The digital platform shifts the CMDM process from the confines of a consultation room to a distributed digital environment in which stakeholders are able to freely express their preferences over the available treatment options.

The rest of the paper is organised as follows. Section 2 discusses related work on medical decision-making models and tools, consensus-building in group decision-making and blockchain technology in healthcare. Section 3 outlines the key requirements associated with CMDM. Section 4 discusses the proposed blockchain-based architecture of the TCMDM platform that addresses some of the challenges identified in Sect. 3. Section 5 concludes the paper with a discussion of future work.

2 Background and Related Work

In this section, we summarize the background and related work that provide the groundwork for this research study.

2.1 Medical Decision-Making Models

Medical decision-making models can be divided into four types based on the physician-patient relationship. In the *paternalistic* or *beneficience* model [12], the physician takes on a *directive, expert* role, while the patient has a *passive, dependant* role. The physician has full control of the clinical encounter and uses his skill and expertise to diagnose the patient, and recommend the tests and treatments without taking the patient preferences into consideration. The patients' participation is restricted to *providing consent* for the treatment.

In the *autonomous* or *informed* model, the patient takes on the role of autonomous decision maker while the physician's role is limited to that of a technical expert who provides relevant information to the patient but not their personal opinions. Having complete information about the treatment options, the patient determines the most appropriate medical intervention. The 'flip side" of this model is the *professional-as-agent* model in which the physicians either elicit the patients' preferences or assume that they are familiar with them. Having complete information about the patient's preferences, the physician becomes the sole decision maker without sharing any information with the patient. However, the physician's treatment preferences do not count. Both models were proposed to deal with the information asymmetry between patients and physicians.

In the *interpretive* model, the physicians not only share relevant information about the treatment options and the associated risks and benefits but also help the patients elucidate and articulate their preferences and make suggestions about what treatment options would help to realize those preferences. However, the physicians do not express their own treatment preferences and the final decision lies in the hands of the patients [8].

In contrast to the above models, *collaborative decision-making* involves information sharing, preference sharing and decision sharing between the physician, the patient, and any other participants, including family members and other physicians. The physician shares information about the patient's condition and the treatment alternatives (no treatment, non-surgical treatment, and surgical treatment) and may recommend the best course of action. The patient also shares preferences over the different treatment alternatives. All participants take steps to build consensus about the preferred treatment and a mutually acceptable agreement is reached between all parties on the treatment [4].

Of the four models presented, the collaborative decision-making model has the greatest emphasis on active participation by both parties and joint satisfaction and investment in the decision outcomes.

2.2 Medical Decision-Making Tools

Most medical decision-making tools that assist physicians and patients when using any of the previously mentioned decision-making models are either electronic or paper-based tools. The electronic tools can either be targeted at the physicians or at both the physicians and patients. The ones designed for physicians are aimed at providing decision-support based on state-of-the-art medical knowledge, evidence based medicine (EBM) or clinical practices guidelines (standard of care), or decision-automation and/or optimisation by generating patient-specific assessments and/or recommendations. They leverage Big Data, artificial intelligence and machine learning technologies to facilitate decision-support and decision-optimisation. Examples include sBest Practice (BMJ) (https://bestpractice.bmj.com/), Dynamed (https://www.dynamed.com/), and Up-to-date (https://www.uptodate.com/). Tools meant to be jointly used by the physicians and patients include decision-aids (https://decisionaid.ohri.ca/AZinvent.php), decision-boxes (https://dartmed.dartmouth.edu/spring08/html/disc_drugs_we.php), evidence summaries (https://www.uptodate.com/), question prompt lists (https://www.cancer.nsw.gov.au/patient-support/what-i-need-to-ask) and communication frameworks (https://askshareknow.com.au/). Some of these tools are aimed at providing information to patients (e.g., decision aids) while others provide ways of initiating or structuring conversations (e.g., question prompt lists and communication frameworks).

The main shortcomings of these tools are (a) they are predominantly designed for one-off clinical encounters taking place in a consultation room, (b) they make the assumption that CMDM is a dyadic encounter and only support the patient and the consulting physician. However, it should be noted that these tools can be used by some of the stakeholders (mainly the patient and physician) in different stages of the iterative CMDM process for making some of the interim decisions.

2.3 Consensus Building

Group decision-making (GDM) is a frequent, yet often challenging, human activity in which multiple stakeholders attempt to make a decision collectively.

Normally, GDM can be seen as the task of fusing the individual preferences of a group of decision makers to obtain the group's decision/s. In practice, the individual opinions may differ substantially, and therefore, the collective decision/s made in such conditions might not be positively accepted by all participants. Therefore, a *consensus building mechanism* is required to increase the agreement level within the group before proceeding to the selection phase, i.e., the last step in the decision-making process in which a selection criterion is applied to determine the final collective decision(s) [9]. Within this process, the individual preferences are first aggregated using an appropriate *aggregation operator* and the current level of agreement in the group is computed using a predefined *consensus measure*. The consensus degree is then compared with a preset minimum *consensus threshold*. If the consensus degree exceeds the threshold, the group moves on to the selection phase, otherwise, a procedure is applied to increase the level of agreement in the following consensus building round (e.g., an interactive feedback process to suggest modifying farthest opinions from consensus or through automatic adjustment of decision makers' preferences).

Different consensus reaching mechanisms have been developed in various decision contexts and many application areas are being actively explored such as education, manufacturing, resource management and energy planning [15]. Yet, to the best of our knowledge, there is little or no work on the use of consensus building for CMDM. A number of studies have suggested applying a GDM model to help patients, physicians, and their families collaboratively select a medical treatment among a set of available options [5]. However, such models limit CMDM to a single round of interaction, hence not guaranteeing that everyone's preferences are considered. Iterative CMDM is necessary to ensure that the final decision reflect the patient's personal preferences, their doctors' recommendations and their families' wishes.

2.4 Blockchain Technology in Healthcare

Blockchain technology is essentially a decentralized, distributed ledger that records the provenance of digital assets [10]. It has a number of inherent properties that address some of the challenges associated with CMDM. Transactions recorded on the blockchain are secured through the use of advanced cryptographic techniques (*security*). Once inserted in the blockchain, transactions become permanent and cannot be modified retroactively, even by the authors (*immutability*). Participants with authority have the ability to verify and track transactions recorded in the blockchain (*transparency*). The use of permissioned blockchains enables selective visibility of transactions by restricting access to the blockchain network to permitted users only (*privacy*). Smart contracts enable fine-grained access control to transaction data based on access rights, thereby further ensuring privacy of participants (*privacy*). Blockchain allows the tracking, and documenting in real-time, of complex interactions between numerous diverse stakeholders through a time-stamped workflow (*traceability & auditability*). It also supports the use of pseudo-identities to retain the anonymity of participants (*privacy*).

In recent years, several applications leveraging blockchain technology have been proposed in the healthcare domain. *Health record management* is one of the most popular blockchain-enabled healthcare applications, and includes the management of electronic health records, electronic medical records and personal health records. Specific solutions developed in this area include health data sharing between healthcare professionals [11], and providing patients a unified view of their health records across multiple healthcare providers [14]. Blockchain technology has also been proposed for *clinical trials* to ensure peer verifiable integrity of clinical trial data, improve the accuracy of data analytics and encourage data sharing and collaboration [16]. Blockchain-enabled trusted, privacy-preserving *wearable data marketplace* is another innovative healthcare application that enables the exchange of real-time, user-generated wearable data between wearable owners and health data consumers [6]. Recently, blockchain technology has also been proposed for *CMDM* using the notion of *Proof-of-Familiarity* [18]. However, similar to most traditional CMDM approaches, it also makes the very strong assumption that a clinical encounter is a one-off interactions. This limits its practicability in real-world clinical encounters.

3 Ecosystem

In this section, we analyse the major contributor roles to CMDM, and then discuss the main requirements that a **trusted** CMDM platform should fulfil.

3.1 Contributor Roles

- **Patient.** In the patient-centred approach, the patient is a key contributing role in the CMDM process. A competent adult *patient* always maintains final decisional authority in CMDM, i.e., the right to accept or reject any clinical intervention. In our scenario, this is the early stage breast cancer patient.
- **Core Medical Team.** As the complexity of the medical treatment increases, so too does the need for coordination of care and sharing of knowledge between multidisciplinary health professionals [7]. In our scenario, the core medical team comprises of one or more general practitioners, specialist nurses, pathologists, radiologists, surgeons, medical and radiation oncologists.
- **Non-Core Medical Team.** In addition to the core medical team, additional non-core contributors are also involved in CMDM, including genetic/hereditary counsellors, physiotherapists, psychiatrists, psychologists, plastic surgeons, palliative carers and social workers.
- **Power of Attorney.** In cases where the patient is not capable of making the decision (due to incapacitation or old age, or when the patient is a minor), the authority is delegated to a family member or surrogate [17].
- **Family Members/Carers.** While autonomy focuses on the notion of self-governance and the right of a patient to have final decisional authority (also referred to as *atomistic/individualistic autonomy*), the patient does not exist in isolation and is part of a larger relational network leading to the concept of

relational autonomy [3]. Therefore, any decisions concerning the patient have to incorporate the preferences of those who care for and support the patient, including family members and care givers.
- **Hospital Representative.** To ensure that there are no financial, logistical or legal obstacles to implement the CMDM process, the hospital (or clinic) should have an appropriate representative.
- **Insurance Agent.** The insurance company (represented by an agent) is a key stakeholder in CMDM since its policies can determine the medical decision that is acceptable to the patient, the patient's family and the medical team.
- **Fellow Patients.** The patients may communicate and gain experiential knowledge from *fellow patients* who are (a) either in or have been through similar medical conditions, and (b) have had successful or failed medical interventions.
- **Clinical Evidence Base.** In today's age of big data, insurmountable amounts of medical knowledge are being published and disseminated around the world. The aggregate state of this knowledge is referred to as *medical* or *clinical evidence*, and is used by doctors to deliver diagnosis, prognosis and treatment.
- **Unregulated Information Sources.** Patients have easy access to vast amounts of medical information, often unregulated and potentially inaccurate and clinically unsound, which can contribute to their decision preferences.

3.2 Requirements

- **Iterative CMDM.** Depending upon the complexity of the medical condition, there are multiple stakeholders involved in CMDM, and different biopsychosocial, spiritual and cultural determinants can influence the CMDM outcome, and several professional, clinical and legal guidelines that have to be adhered to. It is unlikely that a consensual, collectively accepted decision encompassing the patient's preferences, the healthcare providers' recommendations, and the family members' wishes, will be reached in one round of interaction. Therefore, CMDM should incorporate an *iterative consensus building mechanism*.
- **Privacy preserving CMDM.** Participants want assurance that their preferences are kept private during the CMDM process. For example, patients may not want to share their spiritual and cultural values with their doctor but may be willing to reveal it to their counsellor. Similarly, they may be willing to share their health data with the medical team but not with their family members. Family members may also not want to reveal their preferences over the different treatment options to the patient, or to other family members. Thus, the CMDM mechanism has to be *privacy-preserving* and participants should have assurances that their data and decisions are only shared with authorised parties in conformance to their sharing policies.
- **Confidentiality preserving CMDM.** Preference data as well as health data exchanged during the CMDM process are highly confidential. Hence, CMDM should be *confidentiality-preserving*, i.e., it should strictly enforce

data sharing on a *need-to-know* basis and only with the owner's consent. For example, if a physician attending to a patient wants a second opinion from another expert, he/she should share the health data only with the consent of the patient, and without revealing any personally identifiable information (PII). Similarly, if a patient wants a second opinion, they may only share the consultation outcome without revealing the PII about the consulting physician. This requirement is related to the above-mentioned privacy-preserving requirement.

- **Secure CMDM.** All contributors need assurance that the interactions will take place securely and there will be no tampering with the data/decisions exchanged during the CMDM process. Therefore, CMDM should eliminate any risks of confidential data leakage by implementing advanced mechanisms to enforce data protection and security. This requirement is also closely related to that of privacy/confidentiality-preservation.
- **Traceable and auditable CMDM.** It should be possible to audit the interactions between participants if and when required. Evidence-based medicine essentially relies on trial and error, and poor decision-making is unfortunately common in medicine [13]. Hence, in order to advance the state of knowledge, it is important to support audit of the CMDM process. Additionally, to deal with situations where the medical intervention does not yield the desired outcome, or worse still, results in an adverse outcome, it is important to have a *traceable and auditable CMDM.*

4 Proposed High-Level Architecture

This section outlines a high-level reference architecture for the proposed TCMDM platform and explains the main interactions involved in *consensus building.*

4.1 Platform Components

Figure 1 shows the high-level platform architecture. The platform is built on top of a *private* or *permissioned* blockchain owned by a trusted *consortium* of hospitals, insurance companies, pharmaceutical companies, medical research institutions and regulatory bodies. The key platform components are summarized below:

- **Identity Manager (IM).** IM provides interfaces for registration of the participants in the CMDM process including patients, core medical teams, non-core medical teams, family members, legal representatives, and insurance companies. It enables pseudo-identities to be used, where appropriate, to retain the anonymity of the participants. It also provides authorisation to these participants to access various functions on the blockchain such as which party has access to which transactions.

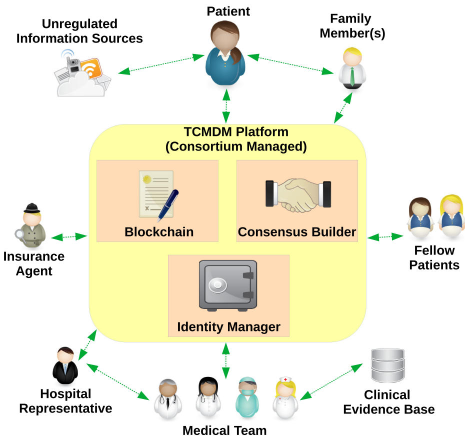

Fig. 1. High-level platform architecture.

- **Consensus Builder (CB).** CB is responsible for managing the entire CMDM life cycle including consensus building, selection and contracting. It uses an appropriate consensus building mechanism to generate a decision that is a consensual and collectively accepted decision.
- **Transaction Ledger (TL).** TL is responsible for recording the provenance of the CMDM process. Every interaction between the CB, the patient and all other contributors are recorded in the blockchain using a time-stamped workflow. This includes the interim group decisions as well as the final group decision that is acceptable to the patient. This ensures auditability and enables regulatory oversight or evidence for legal remedies in the case of negligence or an undesirable outcome resulting from the medical intervention.

4.2 Component Interactions

We refer to the first scenario presented in Sect. 1 to illustrate how the proposed TCMDM platform could be used in practice. We consider a case in which the patient goes through the CMDM process to decide the best possible treatment option. The key contributors and components are described below:

- **Patient** (*P*). P is an early stage breast cancer patient who has to select a treatment option in collaboration with PC, MCT, FP, and IC.
- **Principal Clinician** (PC). PC is the lead clinician who works closely with P and collaborates with MCT, FP, and IC to help P reach a medical decision.
- **Multidisciplinary Cancer Team** (MCT). MCT is a group of $m(\geq 1)$ health professionals including oncologists, radiologists, surgeons, and specialist nurses, that collaborates with PC, FP, and IC to help P with an expert medical decision. For simplicity, we consider MCT as a single entity.

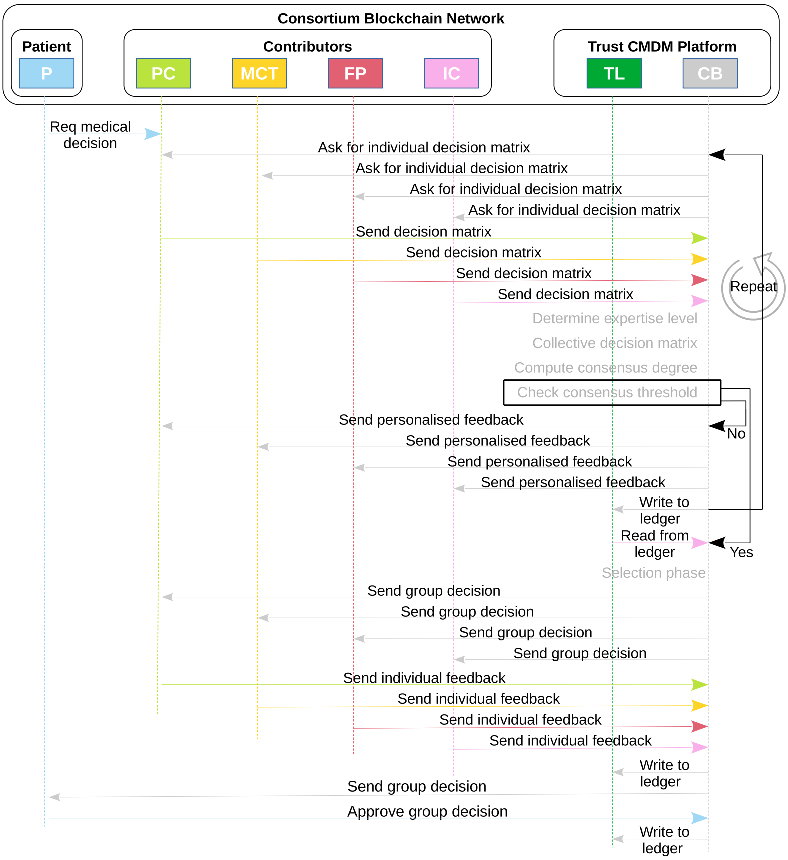

Fig. 2. Interaction diagram of the CMDM process using the TCMDM platform.

- **Fellow Patients** (FP). FP is a group of $n(\geq 1)$ (ex)breast cancer patients who have previously experienced at least one of the treatment options. FP helps P with a non-medical decision based on their own personal experience. For simplicity, we represent FP as a single entity.
- **Insurance Company** (IC). IC is responsible for analysing and finalising the health-related financial plans, and collaborates with PC, MCT, and FP to help P with the financial aspects of the medical decision.
- **Consensus Builder** (CB). CB is the main component that enables collaboration between PC, MCT, FP, and IC and supports them while deciding the best treatment option for P.
- **Transaction Ledger** (TL). TL is the permissioned blockchain integrated to enable trust between P, PC, MCT, FP, and IC, and give them comfort that the collaboration process is secure, their privacy is preserved, and only authorized entities have access to their personal interactions.

Figure 2 illustrates the main interactions using the expertise-based consensus reaching mechanism proposed in [15]. At the beginning of each interaction round, CB asks PC, MCT, FP, and IC to send their opinions and preferences in the form of *individual decision matrices*; rows represent treatment options, columns represent evaluation criteria, and each element represents the quantitative/qualitative value assigned to a treatment option against a criterion. A fixed deadline may apply for each round to prevent delays and ensure progress. CB analyses these decision matrices, determines the expertise levels, and uses this information to reflect the influence each contributor should have on the *collective decision matrix*, i.e., an aggregation of the individual decision matrices and represents the group's opinion. The collective decision matrix is used to compute the current *consensus degree*. If the *minimum consensus threshold* is met, the group moves to the selection phase; else, another discussion round is required and CB sends feedback to each individual contributor asking them to consider updating some of their preferences to help reach consensus. This process is repeated until either the group meets the minimum consensus threshold requirement or the number of consensus rounds exceeds the preset limit. At the end of each consensus building round, CB records all elicited and computed data on TL including contributors' identities, individual and collective decision matrices, expertise levels, consensus degree and feedback. If the group reaches agreement and moves to the selection phase, a ranked list of treatment options is presented to P to help her decide the best possible medical option that encompasses her personal preferences as well as the recommendations of PC, MCT, FP, and IC. The TL ensures that all data are kept secured and only authorised entities have access to them. This way, *the platform ensures that CMDM is iterative, trusted, secure, privacy-preserving, confidentiality-preserving and auditable.*

5 Conclusion

In this paper, we presented our vision for a trusted collaborative medical-decision making (TCMDM) platform that shifts medical decision-making from the confines of a consultation room and into a distributed digital environment. We enumerated the main requirements for realising practical CMDM including trusted, secure, privacy-preserving, confidentiality-preserving and distributed data and decision-sharing, as well as data and decision provenance. Based on these requirements, we proposed a conceptual framework and reference architecture that combines consensus building with blockchain technology to address some of the highlighted challenges. As future work, we will explore some of the human factors that might encourage or deter the uptake of digital health services such as the TCMDM platform.

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