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Blockchain Enabled Patient-Centred Care for Inflammatory Bowel Disease: 4 Principles for Socio-Techical and Clinical Alignment

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Abstract. Inflammatory bowel disease (IBD) is a chronic relapsing and remitting illness. The presentation, diagnosis and management IBD are complex, and involve multi-disciplinary care with complex information requirements. The lack of an accurate and comprehensive patient record is often a stumbling block for optimal patient care. Blockchain technology therefore appears to be the perfect solution to improve IBD patient care. Blockchain technology can provide comprehensive and secure data transmission. Many current projects using blockchain for IBD care focus on information delivery. Recently, clinical research has shown that patients have different perceptions of what constitutes high-quality care, compared to healthcare professionals. Patient-centred care in IBD has increasingly taken central stage. Concurrently, blockchain in healthcare has shifted focus to argue for allowing the patient to be in the driver's seat for information access, facilitated by blockchain-enabled patient-driven interoperability and patient-driven care. This paper dissects the risks and benefits of these two approaches in using blockchain in IBD patient care. This paper then explores the socio-technical and clinical considerations in using blockchain in IBD patient care. Finally, this paper presents four key principles in using blockchain to improve IBD paper care, using collaborative participatory design involving patients, healthcare professionals, and health systems.

Keywords. Blockchain, patient-centred design, inflammatory bowel disease.

1. Introduction

Inflammatory bowel diseases (IBD) are chronic diseases typically involving relapsing and remitting periods of gastrointestinal tract inflammation. The diagnosis and management of IBD are complex and often require multiple different investigations and therapeutic interventions. The management of patients with IBD often involves multiple visits to different healthcare professionals. There are also ongoing surveillances due to increased risks of malignancies, thrombotic events and serious infections [1,2]. Active IBD has significant impact on quality of life, work productivity and financial burden on the health care system [1,3,4]. The management of IBD has evolved over the years, with objective endoscopic remission through tight disease monitoring shown to predict steroid

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free remission, reduced hospitalisation and surgical rates [4,5]. The medical model of care is well established in IBD and traditionally patients have been passive recipients of care. More recently, patient-centred care has been promoted to improve patient well-being. The priorities from patients, are differ from traditional medical care [4,6,7]. The lack of adequate access to information and health care, symptom control and shared decision making are some of the key aspects that have been highlighted as patient concerns [4]. Due to the chronic and complex nature of IBD, a health care model prioritizing effective communication, patient oriented interactions and shared decision making between patient and practitioner, has been shown to improve patient outcomes [8].

2. Digital health and IBD care

Digital health has the potential to transform patient care, especially delivering an interactive platform for patients and healthcare professionals. The use of digital health in chronic complex conditions such as IBD has been shown to improve health outcomes and quality of care [9]. Technologies such as telehealth, mobile health applications, machine learning and artificial intelligence (AI) can improve accessibility and efficient delivery of health care [9]. This digital future, however, is based on the traditional patient care model, and is focused on healthcare professionals and healthcare systems. Some mobile health applications do have the ability to involve patients more in monitoring of diseases, but their designs have so far been centred around medical specialist model. Blockchain technology, touted as the 4th industrial revolution has provided an opportunity to re-consider the ability for digital health as the driver to transform healthcare to focus on patients. The characteristic of blockchain has allowed much better focus on consumers and users in other industry and raises hope that blockchain can have a transformational effect on patient centred healthcare. This paper presents the case of blockchain in IBD care, the complexity associated with patient-centred blockchain and proposes 4 principles to guide blockchain design and implementation to improve IBD patient care.

3. Blockchain, patient-centred care and patient-driven care in IBD

Blockchain technology is disrupting traditional industry in many fields, such as finance, logistic, and healthcare. Some features of blockchain will help solve major issues associated with healthcare information delivery. Blockchain allows chronological documentations of information with comprehensiveness and integrity. It is almost impossible to hack, thereby providing data security, essential for healthcare [10].

In IBD, due to the complexity of patient care, the availability of comprehensive information regarding previous symptoms, investigations and management is essential to plan for future care. Reactions to treatment and side effects are also important to define future care. As such, there is a proliferation of projects using blockchain technology, including in IBD care, such as a project by Mount Sinai Hospital in New York which claimed blockchain technology will “enable seamless information exchange between care providers” for IBD care [11]. When these projects are analysed in detail, the main theme of using blockchain in current work is related to storage and transfer of information to facilitate care using the current traditional model of care.

In our initial work on conceptualisation of the impact of blockchain in healthcare, the main transformational effect is when blockchain is used in parallel with clinical transformation of care, therefore achieving a socio-technical alignment [10]. Blockchain should be seen as the innovation and driver necessary to transform patient care, rather than a new and perhaps a better way of delivering information. The assumption of better information leading to better care is problematic. Multiple previous technologies and projects have shown that information delivery is only part of the equation of better patient care. This is especially important in the care of patients with IBD as recent focus has shifted from medical-centric innovation to patient-centred care.

Patients with IBD, currently have information stored and managed throughout the healthcare system via individual silos. This could potentially be changed by having the patient at the centre of the blockchain specifically designed for IBD through patient-driven interoperability, allowing the patient to determine and control information access [12]. Furthermore, while smart contract is often discussed in the context of data access, a patient-centred clinical-oriented smart contract could allow for adjustments in treatment without clinician review [10]. While blockchain is known as the latest disruptive innovation, its hype needs to be balanced with the risks of changing the therapeutic relationship between patient and doctor, potentially leading to patient harm.

We face an important dilemma when considering these two models of using blockchain in IBD patient care. If we adopt the healthcare service centred model, without transforming clinical care, blockchain is just a different way of delivering the mantra of "more information is better". Many interventions with information communication technology adopting this mantra fail to achieve desirable outcomes, and sometimes, lead to patient harm. It is likely that blockchain will face the same fate. The patient-driven care model, while unique to blockchain, might prove too disruptive, and does not take clinician autonomy, therapeutic relationship, risk and benefit analysis and the dynamic nature of healthcare into account. This will similarly lead to failure and potential harm.

4. Four key principles for blockchain in IBD care.

How can we resolve the dilemma of two different model of using blockchain in the care of patients with IBD? We propose four key principles to achieve alignment of socio-technical and clinical transformation using blockchain in our research:

Key principle 1: The design process must involve all users in a collaborative participatory process. Patients, clinicians and healthcare systems need to work together to achieve optimal benefits. The design process not only needs to involve all users but also need to consider an equal participation process. It is essential that all parties are involved from the very beginning in order to achieve better buy-ins from all parties and to eliminate significant design flaw in the system [13].

Key principle 2: All information is presented via a new common user-centred information architecture. While information is essential for patient care, unfiltered large volumes of information might create more harm than good [14]. This is especially a concern with blockchain technology over the life-time of a patient's IBD. Current chronological documentation will not be adequate to facilitate blockchain enabled care. A new common information architecture, designed based on user-centred technique and provides a snapshot summary of a patient relevant to clinical decision making is essential for healthcare professionals and patients if blockchain is going to help in patients with IBD.

Key principle 3: Automated smart contract execution for patient care is governed by an agreed safeguard mechanism. Clinically based smart contract, such as automatic reminder of investigations and adjustment in treatment based on certain pre-set criteria in the management of IBD does have the biggest potential transformative effect on patient care [10]. The design and implementation of this step requires careful ethical, clinical and regulatory considerations with adequate clinical safeguard to ensure safe patient care. An escape mechanism will need to considered especially for patients who might not have full capacity to actively drive and/or participate in care.

Key principle 4: The implementation process allows dynamic-interactive changes. The implementation phase of blockchain for patients with IBD care is a complex and dynamic process between patients, healthcare providers and health systems. A single step implementation will be too disruptive to the current healthcare delivery model for both patients and healthcare professionals. An incremental approach whereby response and feedback are considered in a dynamic feedback loop [15] is essential to ensure patents and healthcare professionals are on board.

5. Conclusion

This paper delivers a clinical and digital health vignette in patients with IBD care in order to present the argument for blockchain to transform patient care with IBD. This paper argues that to achieve the best clinical outcome, blockchain should serve as a driver for patient-centred care transformation. There are complex socio-technical and clinical issues to consider and this paper proposes 4 key principles to achieve that alignment.

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