
Abstract

Introduction

Medical data is economically valuable and there have been wide scale leaks and breaches in multiple jurisdictions. Role of insiders in these leaks have been significant. At the same time medical and external entities with access to patients' medical data act with much more discretion in areas of secondary usage and often prioritize monetization and consumer engagement. This study explores the possibility of medical data ownership by patients. It intends to act as an enabler for wider conversation in this regard. It takes a look at benefits, concerns and solutions towards this goal. And consider these themes in legal, economic and social settings.

Methodology

Comprehensive literature review is conducted to understand the existing landscape better and conduct a qualitative study with 16 participants. 10 non medical and 6 medical professionals. Emphasis is made to include a diverse set of non medical i.e. patient participants and to reach to a diverse roles of medical professional participants. Based on the literature review different set of questions for two groups with some overlapping questions were created. There underlying themes and observable patterns are identified and discussed.

Results

Research shows that there's a disagreement between two groups about who is medical data owner. Although medical professionals are legally owners, patients consider themselves as owners and have hosts of assumptions about their control. Both patients and medical professionals lack awareness on data leaks and data privacy laws. This might be a contributing factor towards high number of medical data leaks. The issue of secondary usage and implied consent for monetization and further sharing was raised by patients and concerns about selective sharing by patients were raised by medical professionals. Both groups contributed towards identifying solutions for medical data ownership that are shared in detail.

Conclusion

Implications, challenges and solutions for medical data ownership by patients were identified. It is acknowledged that there are number of glaring issues surrounding medical data ownership. It is also learned that it's a multifaceted problem with social, economic, legal and technical challenges. Current ownership regime is not ideal and more control should be granted towards patients. A need for avoiding an extreme is acknowledged.