The Need for Medical Professionals to Join Patients in the Online Health Social Media Discourse

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Abstract: Health social media is frequently used by e-patients for seeking health information online for self-diagnosis, self-treatment, and self-education. Health social media also provides various benefits for patients and layper-sons, such as allowing users to be part of virtual support groups, having quick access to advice, and the convenience of access via the Internet. At the same time, it raises concerns about misinformation being propagated by laypersons without professional medical expertise, especially during pandemics like COVID-19, leading to an infodemic. There are only a handful of health social media websites that allow medical professionals to participate in discussions with patients online. We postulate that the modern face of medicine and healthcare needs medical professionals to be included in the online patient discourse so misinformation can be addressed early on and head on. To this end, we propose a new and free health social network named Cardea that is under development which aims to bring patients, laypersons, and medical professionals together on the world wide web. Users can share experiences, ask questions, and get answers in three streamlined environments: Patient to Patient (P2P), Patient to Medic (P2M), and Medic to Medic (M2M). While there are several forums that cater specifically to patient-patient discussions or medic-medic connections, Cardea's added value is in providing a unified portal for both patients and medics, as well as enabling interactions between patients and medics. Moreover, Cardea applies machine learning, information retrieval, and natural language processing methods to promote credible health information and demote misinformation. At the same time, with enhanced veracity, anonymity, and privacy controls, the vision of Cardea is for e-patients to confidently share experiences and opinions without being stigmatized or compromising their right to privacy. Our hope is to generate discussion and gather insights from other researchers on developing Cardea.

1 INTRODUCTION

The Internet originally allowed a few people to generate content on websites. With the advent of social media, anyone with access to the Internet was able to have their say and generate content. Laypersons and patients have used this opportunity to interact, collaborate, and share their personal health stories, advise, and opinions on Health Social Media (HSM). However, this has led to varying degree of misinformation being propagated online, with severity ranging from acute to chronic, depending on the nature of the topics being discussed (Oliphant, 2009). Early on, there were signs of the severity of this problem when websites that promoted harmful cures for cancer using apricot pits were widely being read, despite being banned by the U.S. Food and Drug Administration (FDA) due to pits containing cyanide that would be harmful when consumed in large doses. Also not too long ago, the impact of health misinformation was felt once more as anti-vaccination campaigns started after viral posts on Facebook linked autism and measles vaccines (Nyhan et al., 2014). We are currently living through the COVID-19 pandemic which has turned into a full-blown infodemic with severe consequences for misinformation being spread online about various facets of the disease including origins, causes, symptoms, prevention, and cures (Ferrara, 2020). In the face of this new reality, laypersons crucially need trusted information in HSM discourse.

Medical professionals have been using HSM as well, albeit to a more limited extent. A few websites enable medical professionals, such as doctors and nurses, to consult with patients via video conferencing or phone call. For instance, My Health Alberta's 811 HealthLink service[1] allows patients

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[1]HealthLink https://myhealth.alberta.ca/811

637

or caregivers to connect with registered nurses via phone call to discuss or ask questions on non-severe health issues (Sharun, 2012). Other paid telemedicine services, such as Dialogue, offer virtual healthcare services through web chat and video conferencing (Shecter, 2017). It has also become common for healthcare organizations to have social media presence for brand recognition. Some websites are dedicated to enabling medical professionals exchange information with each other, such as DocCheck[2]. Other forums like Doctors Lounge[3] enable patients to ask questions of medical professionals.

The challenges of medical professionals dedicating time to HSM are understandable. With limited human resources and busy schedules, it is not always feasible to engage patients online. However, it is equally important to acknowledge that a new type of patients, termed as an *e-patients*, are seeking self-education for self-diagnosis and self-treatment online (Fox, 2008). These e-patients seek information about their health online and feel comfortable interacting with health professionals online as well via telemedicine. Getting involved in the online discourse would be beneficial at multiple levels of public health and medical practice. Patients and laypersons who resort to unproven cures often do so out of desperation and lack of engagement and advise. Medical professionals can remedy this situation by authoritatively clarifying misinformation and also understanding latent needs of patients, essentially giving rise, credence, and popularity to *e-medics*. There is definitely growing awareness on the importance of knowing and being prepared for e-patients as part of medical education (Masters, 2017), but this may fall short of expectations until medical professionals meet e-patients where they are: online on the Internet.

Towards this goal of functional health literacy, the vision of Cardea is to build a free-to-use HSM portal that is suitable and attractive for medical professionals as well as patients and laypersons. At the core of Cardea is the metaphor of the hospital building, represented in the online environment. A hospital has different rooms, some are public and some are private, some are meant for doctors or nurses only, others for patients, and others for interactions between doctors, nurses and patients. Similarly, Cardea provides Patient to Patient (P2P) secure online pages where laypersons can interact exclusively with other patients. Medical professionals can interact with patients in the Patient to Medic (P2M) online web pages, while medical professionals can engage in private discourse on the Medic to Medic (M2M) pages. The in-

teractions follow the traditional HSM format of asynchronous textual conversations. Additionally, patients and medics are able to chat synchronously in real time via online chat on the P2M web pages. All discussions are indexed and grouped by health topics, hence patients can join these virtual support groups to get information by health topic. There are several forums that cater specifically to only patient-patient discussions, such as Patients Like Me, Doctissimo, WebMD, Health Boards, Medical Sciences Stack Exchange, to mention a few. There are also some forums that are meant for medic-medic connections, such as the defunct BMJ's Doc2Doc forums, and the aforementioned DocCheck. Cardea's added value is in providing a unified portal for both patients and medics.

In this paper, we present the functional design of Cardea[4] and showcase how the needs of various health and medical stakeholders can be served with ease. In addition, we discuss how HSM can use machine learning, information retrieval, and natural language processing to support information credibility, right to privacy, and personal information security.

2 BENEFITS AND CAVEATS OF HEALTH SOCIAL MEDIA

2.1 Fighting Misinformation

There are various definitions of trust among users, and it is often used interchangeably with reliability and credibility, but the general consensus is that trust involves a willing interaction between two or more entities. There is an implicit belief that the interaction will at least be self-beneficial in the worst case, and mutually beneficial to all entities involved in the best case (Golbeck, 2005). There is no guarantee that this belief is correct. Nevertheless, some level of trust, however minuscule, is fundamentally essential for interactions to happen, even when given limited or non-existent knowledge about another entity or group of entities. Despite the popularity of HSM and an implicit sense of trustworthiness between users, untested claims for cures, lack of contraindications, and false claims about disease prevention are common features, having life-threatening potential.

Social networks have presented enormous opportunities to connect across the world, but also inadvertently have allowed the rampant propagation of inaccurate information, rumours, propaganda and conspiracy theories. Recently, the term "infodemic" has

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[2]DocCheck https://www.doccheck.com

[3]Doctors Lounge https://www.doctorslounge.com

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[4]Source code https://github.com/hwsamuel/Cardea

gained popular attention as an umbrella term to refer various types of inaccurate information related to COVID-19 (Wang et al., 2019; Zarocostas, 2020). Conjoining "information" and "epidemic", this portmanteau word uses disease or illness as a metaphor and illustrates the pervasiveness of health misinformation. HSM like Cardea can help medical professionals to have a nuanced understanding of the detection and spread of health misinformation and to design effective intervention strategies against them.

Understanding human behaviours is a precursor to design and implement such interventions. HSM like Cardea therefore provide a unique opportunity to closely examine the circumstances of infodemics and to strategically design interventions that can go beyond simply raising awareness. Organic interaction between patients and medical professionals can act as a foundation for a comprehensive understanding of how human behaviours are impacted by the infodemic at a different individual, organizational, and community level. This perspective can also help to explore the different factors associated with a multi-faceted problem like an infodemic.

Moreover, patients interacting with medical professionals provides the laypersons with an authoritative source of knowledge to gravitate towards when dealing with actors who want to spread misinformation. The prevalent strategy in measuring information quality in HSM presently is consensus-based "wisdom of the crowd" methods such as votes and likes. When only patients and laypersons are interacting with each other, these subjective metrics could easily lead to creation of echo chambers. With medical professionals getting involved in appraising online content through interactions on HSM, this also opens up possibilities for objective trust metrics that are based on machine learning models trained on the votes and feedback of medical professionals.

2.2 Preventing Stigmatization

In addition to physical accessibility, there are various cultural, social and psychological barriers to health seeking behaviors (Stangl et al., 2019). Certain health conditions and diseases, particularly related to addiction, mental health, or sexually transmitted infections, have social stigma associated with them. Stigmatization of these health conditions often result in delay in care and over-reliance on treatment based on online research which can ultimately lead to possible harmful consequences, reinforce misinformation, and overall poor health outcome of patients (Hatzenbuehler et al., 2013). Even though there are several health promotion initiatives on raising awareness,

the current healthcare system is primarily based on an intervention-focused model which relies on self-reports and does not account for public perception, social norms, and other individual or social determinants that influence both individual and population health (Stangl et al., 2019).

HSM can mitigate the harmful consequences of health-related stigma on both communicable and non-communicable diseases. Peer networks and online support circles can normalize reaching out for help on health conditions which are perceived negatively in our society. Moreover, such online platforms can enhance the role of physicians and other healthcare professionals as advocates of healthy lifestyles which will facilitate a more prevention-based health measure (Luft, 2017).

At the same time, the personal identity of HSM users usually needs to be hidden to avoid social stigmatization online. Typically, the author of a posting on a social media website is identifiable by their registered user name or full name being displayed next to the post. However, situations can arise in which the user does not want to be identified at all. For instance, if a user were to share a link with their friends about sexual dysfunction or infertility, the user may wish to do so anonymously to avoid any stigmatization resulting from the assumption that sharer suffers from the condition. Despite the potential severity of online social stigma, options and controls to anonymously post content are not well-supported in most social media websites. Users on these websites may hide their real identity by creating a new account with a fake name or pseudonym, thereby duplicating the website's user base. This is not ideal and unnecessarily complicates the process of information sharing. From the list of popular social media websites such as Facebook, Twitter, LinkedIn, YouTube, Stack Exchange and Quora, only the latter allows asking questions anonymously without needing to create a new account. There are also potential drawbacks with the approach to replace the user's real identity with the generic pseudonym "anonymous". Firstly, despite their name being hidden, users still may be inadvertently revealing their identity because of the similarities between the content they have posted in the past. Phrases, wordings, topics and other nuances about the writing style in the user's past postings may constitute a quasi-identifier that can be associated with a specific user. Quasi-identifiers are not unique by themselves but can be correlated with an user's identity due to frequency of occurrence or other patterns (Sweeney, 2000). Secondly, the generic anonymous pseudonym also eliminates the user's associated reputation, motivating the need for trust-preservation
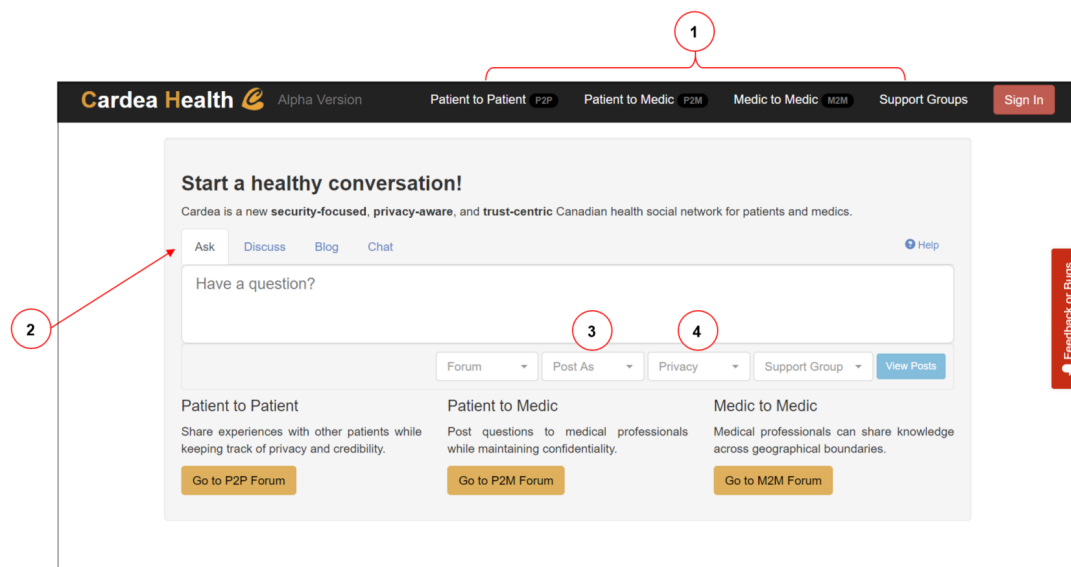
Figure 1: Cardea homepage (screenshot from web application); 1 - Forums and support group folksonomies; 2 - Content types; 3 - Authorship settings; 4 - Privacy controls.

during anonymization. Cardea addresses these issues and enables free online discourse among patients and medical professionals without fear of stigmatization.

2.3 Privacy Preservation

HSM offer insightful behavioural data which can improve overall access to healthcare and can be used for evidence-based policy-making (George et al., 2013). However, for a successful implementation of such networks, there are various factors that need critical considerations, such as ensuring user privacy, ethical use of technology, and understanding challenges and limitations of the network (Grajales III et al., 2014).

Cardea generalizes the various viewpoints of privacy observed in HSM into two broad categories of content visibility and user identity. Users are given full control of who can see the content that is being posted. Moreover, users also have control over their how their identity is associated with the content they post. Identity privacy is often not considered in HSM and can lead to unwanted online social stigmatization.

A third category covers the need for analysis of user-generated content for research purposes. To facilitate this while preserve the user's right to privacy, only aggregated content analysis will be supported after filtering Personally-Identifiable Information (PII). All Cardea users are required to consider the use of HSM in the context of permission, privacy, informed consent, security and the broader social impact. Future extension and application of Cardea can be further aligned with the existing legislation and regulations on personal information protection and the ex-

change of electronic information.

3 FUNCTIONAL DESIGN SPECIFICATIONS OF CARDEA

Cardea aims to address the various challenges outlined with trust, stigmatization, and privacy. From a research perspective, Cardea has been conceptualized as a sandbox for facilitating and understanding HSM interactions. The Cardea homepage[5] is shown in Figure 1 while various other features outlined in this section are summarized in Figure 2.

3.1 User Types

Cardea allows two user roles: *Patient* or *Medic*. The patient is a generic label for anyone who would be seeking health information, while the medic label is for identifying medical professionals. In addition, a select group of users are assigned as *Moderators* for housekeeping and administrative tasks related to the website and content. Medics are manually verified based on their institutional email and correspondence with their organizations to ensure good standing. Unaccredited users are assigned the patient role by default until verified.

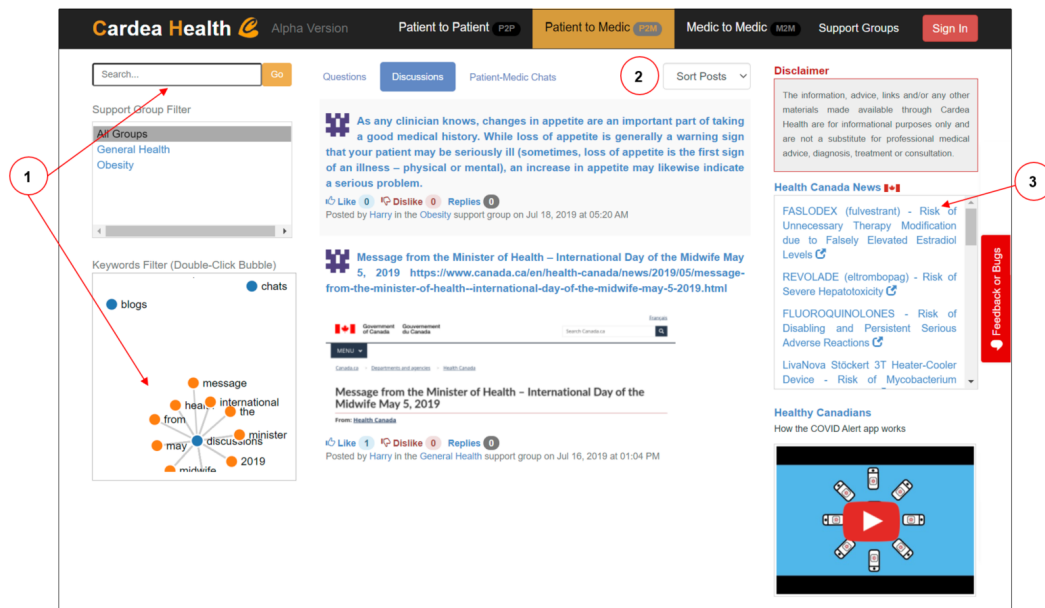[5]Alpha version of Cardea demo website available on https://www.cardeahealth.ca

Figure 2: Cardea features showcase (screenshot from web application); 1 - Search and exploration; 2 - Content sorting (default by trust); 3 - External information integration and recommendation.

3.2 Content Types

Cardea allows registered users to post text or hyperlinks to websites, images, and videos. Content is created within three categories: *Questions*, *Discussions*, and *Blogs*. Questions are focused on getting answers, while discussions are more open-ended conversations. Blogs provide an avenue for users to curate opinion pieces. Additionally, replies allow other users to be able to respond, leading to conversation threads. Replies to discussions and blog posts are referred to as *Comments*, while replies to questions constitute *Answers*. A fourth content category of *Chats* between medics and patients is also provided only within the P2M forum.

3.3 Folksonomies

A folksonomy is a methodology for allowing users to tag items, whereby the tags can be automatically organized as a classification system based on tag frequencies (Morrison, 2007). In Cardea, content is tagged by *Forums* and *Support Groups*. There are 3 forums based the metaphor of a hospital building for specialized and segregated online conversations: Patient to Patient (*P2P*), Patient to Medic (*P2M*), and Medic to Medic (*M2M*). The P2P forum allows only patients to create new content, while the P2M forum allows patients and medics to interact. The M2M forum is meant exclusively for medics only. Depending on the privacy settings, the content itself within the forums

may be visible to other members, but the ability to create new content is restricted based on user types associated with the forums. Support groups constitute specific health-related topics that allow grouping of questions, discussions, and blogs topically.

3.4 Privacy Controls

Users can specify who can view their content using four levels of privacy, from broadest visibility to more limited viewership: *Public*, *Registered*, *Medics / Patients*, and *Connections*. At the first level, content can be shared publicly and viewed by all visitors to the website without needing an account. The next level of privacy restricts content viewing only to users who have registered on the website. Thirdly, the type of user and the forum being browsed dictates viewership, either medic or patient. At the fourth level, users can opt to share the content only with other users that they have explicitly added as connections. Connections are required to accept requests, hence a connection is a two-way virtual relationship between users.

3.5 Authorship Settings

In addition to privacy control for visibility of content, users are also able to determine how their identity is displayed and associated with their own content. Three options are provided to label authorship: *Myself*, *Pseudonym*, or *Anonymous*. For the first option, the user's registered name is shown

for authorship. For the second option, a trust-preserving pseudonym will be automatically assigned to the user. The pseudonym is assigned using a two-stage approach outlined in the Iron Mask algorithm (Samuel and Zaïane, 2017): firstly, the content to be posted is scrutinized to determine the probability of de-anonymization using machine learning and the whiteprint identification approach (Keretna et al., 2013) on the user's prior historical content.

Whiteprint is defined as the unique writing style of an author based on grammatical and lexical patterns (Kayarkar and Ricchariaya, 2014; Masood et al., 2019). This approach enhances anonymity by minimizing the risk of re-identification or de-anonymization. If there is no risk of de-anonymization, then the user's authorship label displayed to the user's connections is "Your Connection". This allows other connections to associate some level of trustworthiness with this user, even though their actual identity is hidden. For all other users, the user's type is displayed, either medic or patient. The last option is to show the generic label "Anonymous" as the author.

3.6 Trust Metrics

The veracity of content is established within Cardea using subjective and objective metrics. Cardea allows users to provide subjective feedback on the quality of content by reacting with *Likes* or *Dislikes*. These specific reactions are limited to questions, discussions, blogs, and comments. Answers to questions can be *Up-Voted* or *Down-Voted* to reflect the extent to which the answer addressed the original question, in addition to quality and correctness.

Objective metrics enable credible content to be surfaced using established medical knowledge. This is achieved by processing content containing medical claims through MedFact (Samuel and Zaiane, 2018), which uses automated information retrieval process with natural language processing and machine learning to compare the claims against known facts extracted from publications in reputed medical journals. At the end, a percentage score is calculated to represent *Agreement* of claims with known medical facts.

In addition, votes and likes by verified medics are given more weight when scoring content quality and ranking search results. Additionally, Cardea's user reputation system keeps track of positive and negative feedback received on users' content. Reputations are displayed to other users, contextualized by topic. For instance, a user may receive good feedback on topics related to pediatrics, but negative feedback on other topics.

3.7 Search and Recommender Results

Cardea provides standard search mechanisms, while also allowing faceted filtering within results by content topic and type. In addition, exploratory search is available whereby new content can be discovered from search results by displaying related concepts to the user's currently viewed content. For exploratory search, Cardea incorporates BubbleNet (Mohajeri et al., 2016), which presents an abstract and high-level representation of major concepts, keywords, and topics discussed in a set of conversation threads. The relationships are visualized in the form of a network, showing the topics as well as their inter-connections. This network is built using an estimation of semantic relationships between topics. The user then can navigate through this network by either refining or expansion. The user can drill down from a given topic to see other related concepts in a lower and more detailed level. The user can also navigate to other related topics and finally find a set of documents talking about their desired topics. This interface is shown in Figure 2 alongside other features.

Cardea facilitates discussions by recommending external content that is relevant to existing conversations, including real-time chats between patients and medics using PubMedReco, a real-time recommender to suggest citations from PubMed (Samuel and Zaïane, 2017). PubMedReco analyzes keywords within synchronous chats to form search queries for retrieving PubMed citations. The same approach is applied to asynchronous conversations for suggesting articles from Health Canada. Users can then directly discuss these news items within Cardea.

4 DISCUSSION

The COVID-19 pandemic has revealed the widening gap between health experts and the general public in terms of following appropriate public health measures. To understand such gaps, it is important to critically examine the communication process itself: how people seek health information, share their concerns with medical professionals, interpret new information or suggestions and follow the medical guidelines. The current literature in public health and behavioral science show how making decisions on personal health is a subjective process embedded into personal experience, prior knowledge, cultural norms, and social and physical environment (Glanz and Bishop, 2010). In the absence of proper communication between e-patients and medical professionals, laypersons can often be persuaded by anecdotal evidence and make cru-

cial decisions based on prior belief or online misinformation (Swire-Thompson and Lazer, 2020).

On the other hand, there are various challenges concerning patient-medic online interactions, such as lack of financial incentives for medics, regulations on patient personal data transmission, and insurance coverage on online telemedicine services. Current literature on health equity has also highlighted the fact that although modern technology has increased the overall accessibility of information, it is still far from ideal and has inadvertently created a digital divide (Mullangi et al., 2019). What is even more concerning is that people's access to information now depends on their online activities.

Search engines and social media influence people's information seeking behaviour and customize results based on their online interaction (Mowshowitz and Kawaguchi, 2002). Such selective exposure to information eventually creates "echo chambers" or disjointed bubbles between experts and the public (Choi et al., 2020). For example, Getman and colleagues studied the network of online discussions on vaccination and empirically proved the limited or rare interactions between the experts and vaccine-hesitant or anti-vaccination groups (Getman et al., 2018). These gaps are further exacerbated by the spread of health misinformation such as conspiracy theories of disease origins, amplified risks and false claims on health benefits. General social media platforms and other pseudo-scientific websites are inadvertently becoming hosts of such inaccurate information posted and propagated by conspiracy theorists, political parties, celebrities or autonomous programs (bots) (Vosoughi et al., 2018). The convoluted online space makes it difficult for the public to track the source of news and evaluate its credibility (Bridgman et al., 2020).

There is a perceived notion that these divides emerge from the lack of education or information (Mackert et al., 2016). While that might be true to some degree, we argue that such divides are rooted in more systemic issues within the practice of science itself. Historically, health research, or the scholarship of science as a whole, has been conducted in isolation with limited engagement between researchers and the public (Eagle et al., 2003). New discoveries are often confined in academic circles or specific interest groups. Timely access to health information based on new discoveries of drugs or treatment is a major challenge for patients, particularly those in rural areas.

5 CONCLUSION

HSM can play a bridging role and address these challenges in various ways, but more specifically, by empowering both medical professionals and patients through inclusive online communication research; addressing health misinformation, creating a safe space to discuss sensitive health issues; and improving the overall access to healthcare. Grounding the health communication process in equity, inclusion and impact, such online networks can also help promote a more user-centred design of technology as well as its effective application to improve overall public health. Additionally, through active participation in HSM, medical professionals can gain valuable insights on patient perspective and perception on emerging diseases. Similarly, patients and caregivers can connect with their peers and engage in knowledge exchange which may lead to an increase in their awareness and adherence to health guidelines. In this position paper, we presented our ongoing development work on the Cardea Health Social Network with various features for trust-enforcement and privacy-preservation. The ultimate goal of Cardea is to create an attractive environment for medical professionals to fully engage with e-patients in online discourse as e-medics. From a research perspective, our hope is to gather feedback and generate discussion for enhancing Cardea.

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