Engaging patients in health and health care processes: the role of patient platforms

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Institute of Health Policy Management and Evaluation
University of Toronto

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Abstract

Background: Health-specific social media platforms, referred to as patient platforms (PPs), are now freely available on the Internet to engage users in their health care process; yet, little is known about what they are trying to achieve, for whom they are designed, and how they attempt to achieve their goals.

Methods: Qualitative methods were used to analyze textual and visual data (e.g., platform policies and other relevant webpages) collected from a purposive sample of eleven PPs stratified by various attributes (for-profit/not-for-profit, single/multiple
conditions, different conditions). Data were systematically tracked and rigorously analyzed according to Framework Analysis methodology.

Results: The study identified a framework for mapping tools. It also revealed that PPs connected users in what was referred to as communities, to share information on specific medical conditions. Forums were the main tools connecting users. Some PPs offered simple forums for posting questions and answers whereas others offered forums for ongoing discussions. Besides supporting patients, PPs were also noted as a channel for delivering advertisements and marketing material directly to patients. Lastly, platform tools have the potential to engage and empower patients to take on an expanded role but can also be oriented towards supporting the platforms’ own interests, and the interests of their sponsors.

Discussion: The emergent framework described in this study can be used to support the design of future tools for better engaging patients. Second, users may not be aware of other platform interests without reading or understanding policies to which users are required to consent. Finally, advertisements provided through PPs can
affect the health of patients and the health care system in various ways, both positive and negative. More research is needed in this evolving area to better understand the impacts on the health of patients and the health care system.
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# Table of Contents

Acknowledgments ........................................................................................................ v

Table of Contents........................................................................................................ vii

List of Tables................................................................................................................ x

List of Figures................................................................................................................ xi

List of Appendices.......................................................................................................... xii

Chapter 1 Introduction ................................................................................................... 1
  1.1 Background ............................................................................................................. 2
  1.2 Research questions ............................................................................................... 7

Chapter 2 Review of the literature ................................................................................ 8
  2.1 Background on patient engagement with technology ........................................... 8
  2.2 Concepts informing the analytical framework ....................................................... 14
    2.2.1 US National eHealth Collaborative (NeHC) framework ................................ 14
    2.2.2 Patient role in treatment decisions ................................................................. 16

Chapter 3 Methods ....................................................................................................... 19
  3.1 Platform selection .................................................................................................. 19
  3.2 Data collection ....................................................................................................... 22
  3.3 Data analysis ......................................................................................................... 23
    3.3.1 Analytic framework ....................................................................................... 25
  3.4 Strategies to establish trustworthiness of analysis ............................................... 29
  3.5 Ethical considerations ........................................................................................... 30

Chapter 4 Results .......................................................................................................... 31
  4.1 The tools ............................................................................................................... 32
    4.1.1 One-way tools ............................................................................................... 32
      A) Informing patients with one-way tools .......................................................... 37
      B) Involving patients and empowering patients with one-way tools .................. 38
    4.1.2 Two-way tools .............................................................................................. 45
      A) Involving patients with two-way tools .......................................................... 45
Chapter 5 Discussion ................................................................. 119

5.1  Mapping of tools................................................................. 119

5.2  Direct-to-consumer advertising and marketing: new ways to reach patients .......... 123

5.3  Disruptive technology: changing how patients participate in health care process .......... 129
5.4 Forum as a community and platform as a community ................................................. 133
5.5 User information for generating income and privacy issues ........................................ 136
  A) Collection and use of non-personal information ....................................................... 137
  B) Collection and use of personal information .............................................................. 139
  C) Protecting user information ...................................................................................... 141
5.6 Limitations and future research .............................................................................. 142
5.7 Summary .................................................................................................................. 147

References .................................................................................................................... 151
List of Tables

Table 1: Definition of NeHC patient engagement stages ................................................................. 16
Table 2: Clinical decision-making models .......................................................................................... 18
Table 3: Platform dimensions guiding case selection ......................................................................... 21
Table 4: Data from website home page and other webpages ............................................................... 22
Table 5: Examples of platform policies data collected for study ......................................................... 23
Table 6: Summary of platform tools provided to engage patients ...................................................... 32
Table 7: Examples of one-way tools according to the patient engagement process supported .......... 37
Table 8: Contrasting user requirements to provide information vs information provided by site owners . 44
Table 9: Examples of Platform A2 forums listed under the category “Neurological disorders and injury” . 56
Table 10: Mechanisms connecting the community .............................................................................. 66
Table 11: Collecting data and information from users ........................................................................ 72
Table 12: Partners and sponsors and their relationship with the platform .......................................... 95
Table 13: Mapping of platform tools according to how they engaged users ..................................... 120
List of Figures

Figure 1: NeHC Patient engagement framework ................................................................. 15
Figure 2: Health tools provided by platform A5 ................................................................. 41
Figure 3: Drug and Medication Center page from platform A9 ......................................... 50
Figure 4: Doctor directory link from platform A1 .............................................................. 50
Figure 5: Breast cancer forum from platform A5 ............................................................... 53
Figure 6: Event sharing tool from platform A1 ................................................................. 65
Figure 7: Pop-up screen blocking content on platform A4 ............................................... 83
Figure 8: Tools to find other patients sharing specific characteristics or experiences on platform A8 .......... 92
Figure 9: Tools to find other patients sharing specific characteristics or experiences on platform A1 ............ 93
Figure 10: Channel for sending message from sender to receiver (adapted from Shannon & Weaver, 1949) .... 123
# List of Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix A</td>
<td>NeHC Patient Engagement Framework</td>
<td>170</td>
</tr>
<tr>
<td>Appendix B</td>
<td>Table of Selected Platforms</td>
<td>171</td>
</tr>
<tr>
<td>Appendix C</td>
<td>Chronic Illness Trajectories</td>
<td>173</td>
</tr>
<tr>
<td>Appendix D</td>
<td>Coding scheme</td>
<td>175</td>
</tr>
</tbody>
</table>
Chapter 1
Introduction

It has been estimated that seven in ten Americans now use social media platforms (Duggan & Smith, 2013; IMS Institute for Healthcare Informatics, 2014), and almost four in ten smartphone or tablet owners have used their devices to make a decision about how to treat an illness or condition (Patel & Johnson, 2018). The emergence of social media technologies and increasing Internet accessibility (e.g., WiFi connections, smartphones, or electronic devices with data plans) has enabled patients to connect with others virtually anywhere and anytime, depending on needs and context. A number of health-specific social media platforms (referred to as “patient platforms” hereafter), are now freely available on the Internet to engage patients in their own health care process (e.g., PatientsLikeMe and WebMD).

Although patient platforms share commonalities with other non-specific social media platforms by offering Internet-based channels for users to share content with broad and narrow audiences (such as Facebook and Twitter), patient platforms are health-specific and offer tools for engaging patients in health and health care processes. Specifically, patient platforms are defined as websites that offer tools for engaging patients (and their informal caregivers) in their own health care journey (e.g., self-care tools, symptom tracking tools, discussion forums) with peer networks to support their learning. While patient platforms offer one potential mechanism for engaging patients, little is known about what they are trying to achieve, whom they
are designed to support, and how they attempt to achieve their goals. This doctoral dissertation aims to explore these issues.

### 1.1 Background

The Internet has introduced a communication infrastructure that permits new ways to retrieve health information (Deshpande & Jadad, 2006), as well as post content for widespread dissemination to others through social media platforms such as Facebook, Pinterest, Instagram, LinkedIn, Twitter, Snapchat, YouTube, WhatsApp (Eysenbach, 2008; O’Reilly, 2005; Pew Research Center, 2018). For patients, this means that they can seek information from multiple websites including authoritative ones such as MedlinePlus and Mayo Clinic websites, as well as a vast array of less credible websites to learn from what they might consider to be relevant information. In addition, patient platforms now enable patients to participate in the information exchange process, fostering a collaborative environment for patients to connect with one another to create and share content (Kamel Boulos, Maramba, & Wheeler, 2006; O’Reilly, 2005).

Moreover, patient platforms enable users to access information that would have been difficult to attain otherwise, or would not have been accessible without these technologies. Specifically, patients can now use platform tools to access and interpret medical information, referring to documented (or explicit) science-based information that supports the clinical and professional work of health care
professionals (Hakkarainen, 2009). For example, by using symptom-checking tools on health-related websites (such as, HealthLinkBC, or WebMD), patients can identify “ringing in the ears” as a potential drug-induced side effect from aspirin therapy without the need to consult with a doctor or a pharmacist. These tools can help some patients identify possible causes of their symptoms (e.g., tinnitus), potential factors associated with the problem (e.g., older age, aspirin therapy), and ways to address the issue (e.g. discontinue aspirin therapy). While some patients might use these tools to better prepare for medical appointments (Hu et al., 2012), others might use them as a proxy for self-diagnosis or care instead of visiting their doctor (Veinot, 2010), which may or may not be beneficial to patients (e.g., problems from errors in self-diagnosis). Although individuals from jurisdictions without universal health coverage (such as U.S.) may be more likely to use tools as a proxy for self-diagnosis, the possibility of using tools for self-diagnosis can occur regardless of insurance coverage given the ease of Internet access.

Besides medical information, platforms enable patients to learn from personal experiences shared online by other patients with similar disease (or drug use) experiences, which can be based on implicit knowledge, referring to knowledge not documented elsewhere (Hakkarainen, 2009). While sharing experiences existed before the emergence of social media technologies, social media has facilitated the speed of access to this information, as well as the ability to find others sharing the
same condition(s) for support. In the example of an individual experiencing aspirin-induced tinnitus, one can go to patient platforms to find others who have experience with this problem, which could help some individuals better care for themselves, as well as better cope with their health problem.

Additionally, patient platforms enable users to share personal experiences related to their illness journey, which collectively reflect the experience of many patients. The sharing of patient experiences (relying on the expertise of patients) can support patients in ways which differ from the expertise of health care providers(s) (Hartzler & Pratt, 2011; Veinot, 2010). Patient platforms also enable users to debate experimental therapies and collaborate with each other to co-create knowledge that can extend beyond what might be documented in the literature (Fox & Jones, 2009; Frost & Massagli, 2008; Kamel Boulos et al., 2006; Scardamalia & Bereiter, 2006; Swan et al., 2010). Thus, platforms offer an infrastructure for participation that promotes a sense of community, empowerment and ownership, with “amateur knowledge surpassing professional, when the right kind of systems and tools are available” (Kamel Boulos & Wheeler, 2007, p. 4). For example, by collaborating and sharing personal health information on the experimental use of lithium therapy for amyotrophic lateral sclerosis (ALS), a group of ALS users contributed sufficient clinical data to enable platform users and platform owners to determine the drug’s lack of benefits on this patient population (Frost, Massagli, Wicks and Heywood,
2008; Wicks, Vaughan, Massagli & Heywood, 2011). This negative finding was later confirmed in a worldwide clinical trial (UKMND-LiCALS Study Group, 2013).

Finally, the emergence of patient platforms has brought about a growth in the grassroots movement of ePatients. The term ePatients refers to individuals who are “equipped, enabled, empowered and engaged in their health and health care decisions” (Ferguson, 2007), and become an expert in their own care. ePatients can use patient platforms to better understand, advocate for, and manage their own health care. In contrast to “the ways that clinicians are educated, deployed, rewarded, and updated”, which some consider as “no longer keep[ing] pace with scientific advances” (Institute of Medicine, 2012a), patient platforms enable their users to actively learn about new research findings as quickly, if not quicker, than their healthcare providers. Also, besides helping users learn how to better manage their health issues, platforms also connect users with one another for social companionship and emotional support (Sugimoto, 2013; Veinot, 2010). This self-directed approach to find information and support using platform tools instead of, or in addition to, going to traditional intermediaries (such as health care providers), has been referred to as “apomediation” (Eysenbach, 2007, 2008).

Despite the potential benefits of patient platforms, at least for some patients who might prefer a more autonomous role, they introduce new challenges as they typically operate outside the realm of the traditional health care system but could
influence the health of patients and health care utilization. That is, information sharing on patient platforms can influence how patients manage their health issues and their choice of experts with whom they might consult for health advice (e.g., health care providers, or other patients with related disease or drug use experience). For instance, a survey conducted by an American patient platform reported that one in five users decided to stop a medication, and 6% to 21% changed their physician as a result of using their platform (Swan et al., 2010). These actions could influence how patients manage their health issues in ways that might benefit, or potentially harm them. Furthermore, information sharing on patient platforms can channel users to unconventional therapies with limited evidence, thereby resulting in unnecessary, ineffective and potentially harmful interventions. For example, based on a small preliminary trial by Zamboni et al. (2009a, 2009b), Canadians with multiple sclerosis (MS) have paid up to $10,000 to travel out of the country to treat the so called “chronic cerebrospinal venous insufficiency” (CCSVI) (Andreatta, 2013). Despite insufficient clinical evidence to support the risky surgical intervention (Laupacis et al., 2011; Traboulsee et al., 2013), including reports of severe complications (Burton, Aikham, Goyal, & Costello, 2016; Doležal, Horáková, Gdovinová, & Szilasiová, 2012), information sharing on social media drove research funding to support the controversial CCSVI trials (Chafe, Born, Slutsky & Laupacis, 2011). Moreover, patient platforms can potentially be used to promote ideologies of interest groups with public health impacts such as anti-vaccination groups. For example, decisions to
decline vaccination based on information shared by anti-vaccination groups online, platforms could have possible public health implications (e.g., if they get infection and spread disease to others or lowering herd immunity) and potential implications on the health care system (e.g., if they require medical care). For these reasons, and with a growing number of patients using social media (Eysenbach, 2008; Fox & Jones, 2009), it is important to better understand how patient platforms engage their users, what they are trying to achieve, how they attempt to achieve their goals, and whom they are designed to support.

1.2 Research questions

The purpose of this study is to address the issues discussed above. The specific research questions guiding this effort are:

1. What tools do patient platforms provide to engage users in health and information sharing processes? How do these tools flow information to users, and from users to users?

2. What are patient platforms trying to achieve in terms of patient engagement?

3. What types of data and information are collected by platform tools?

4. Who else, besides patients, do platform tools support (e.g., sponsors or partners)? How do platforms generate income from these tools?
Chapter 2
Review of the literature

As discussed above, platforms offer new ways for patients to use technology in their health care processes. Therefore, this section will begin by reviewing background information on patient engagement with technology to provide additional context to the study. Following this, salient concepts that underlie the research problem and inform the analytic framework will be described including a patient engagement framework and concepts relating to patients’ role in treatment decisions (or clinical decision-making models).

2.1 Background on patient engagement with technology

Engaged and empowered patients are now viewed as an important part of patient care and are considered a pillar of the ideal patient centered care model (Health Council of Canada, 2013b, 2013a; Institute of Medicine, 2012a), with technology promoted as a necessary enabler for patient engagement (Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013). Besides engaging patients to improve health and quality of care, patient engagement has also been associated with reducing costs (Health Council of Canada, 2013a; Institute of Medicine, 2012a). As such, concerns have been raised over the efforts to engage patients to better care for themselves to ease an overburdened health care system (Lorig, 2002). Yet, engaging patients with technology has also been associated with “higher health resource
consumption” instead of reducing overall health care costs (Otte-Trojel, de Bont, Rundall, & van de Klundert, 2014).

Despite the enthusiasm to engage patients in their health care processes, it is not yet clear how best to do so, with varying perspectives on what is meant by patient engagement. For instance, patient engagement has been associated with patient level changes such as health promotion, screening and disease prevention aimed at changing patient behavior (Health Council of Canada, 2011); patient education to “obtain the greatest benefit from the health care services available to them” (Gruman et al., 2010); self-care or self-management for patients to better care for themselves (Institute of Medicine, 2012a); and activation to encourage those who have “the skills and confidence that equip patients to become actively engaged in their health care” (Hibbard & Greene, 2013).

In addition to these patient level changes, patient engagement has also been associated with broader system changes such as increasing health literacy at the population level (Health Council of Canada, 2012b; Koh, Brach, Harris, & Parchman, 2013). Researchers identified that individuals with low health literacy can have poorer health outcomes and less effective use of health services (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Rootman & Gordon-El-Bihbety, 2008). Given that approximately 60% of adult Canadians (ages 16 and older) have been reported as “lacking the capacity to obtain, understand and act upon health information and
services to make appropriate health decision on their own” (Canadian Council on Learning, 2007, p. 5), low health literacy has also been described as a barrier to patient engagement (Goel, Brown, Williams, Cooper, Hasnain-Wynia, & Baker, 2011; Institute of Medicine, 2012b). Finally, patient engagement has been associated with interactions with health care providers relating to shared decision-making processes (Bisognano & Goodman, 2013).

Various jurisdictions have made efforts to engage patients to better manage (or prevent) their own health issues such as self-care or self-management initiatives (Health Council of Canada, 2010; Lorig, 2002). For example, the United Kingdom’s Expert Patients Programme has reported over 70,000 participants who have taken self-management courses to take control of their health and better manage their health condition(s) (Office of the Regulator of Community Interest Companies and Department for Business, 2013). Similarly, the Ontario government launched the “Healthy Ontario” website to help individuals and their families live healthier lifestyles (e.g., “healthy eating” and “active living”) aimed at reducing obesity risk since “obesity can lead to diseases like diabetes, cancer and heart disease, and costs Ontario’s health care system $4.5 billion” (Ministry of Health and Long-Term Care, n.d.).

As part of the effort to support patient engagement, a number of information and communication technologies (ICT) have been introduced including personal health
records, patient accessible electronic health records, and patient portals. A *personal health record* (PHR) refers to a record kept by a patient on his or her own health information over time (Archer, Fevrier-Thomas, & Lokker, 2011; Canada Health Infoway, n.d.). An *electronic health record* (EHR) refers to a record kept by the patient’s health care provider, which can be shared amongst providers within a health care organization, or other providers working at various health care organizations (HealthIT.gov, n.d.). *Patient portals* connect patients to the information system of their health care institution, or government information system (Ammenwerth, Schnell-Inderst, & Hoerbst, 2012), which can encompass both a patient’s PHR and EHR (Emont, 2011). Various jurisdictions and health care organizations have implemented patient portals to engage patients in their health care process. Denmark, for example, has offered a national health portal since 2003, which enable patients to access their electronic health record (Jensen & Thorsent, 2017; Sundhed.dk, n.d.).

In the U.S., as a result of the EHR Incentive Program, commonly referred to as Meaningful Use incentives, an increasing number of health care organizations are implementing portals to provide patients with access to their EHR along with a number of tools (e.g., disease tracking tools, journaling tools) (Blumenthal & Tavenner, 2010; Goldzweig et al., 2014). Stage 1 and Stage 2 of the Meaningful Use program, initially aimed at encouraging the adoption of the new technology (such as
encouraging doctors and hospitals to give patients their electronic health records) (Centers for Medicare & Medicaid Services (CMS), n.d.), includes criteria that promotes patient engagement (Centers for Medicare & Medicaid Services (CMS), 2017a). While patient engagement is further promoted under Stage 3 of the Medicaid EHR objectives and measures (Centers for Medicare & Medicaid Services (CMS), 2017b, 2017c), its full implementation has been pushed back over concerns of “putting too much of a burden on physicians and pulling their time away from caring for patients” (Slavitt & DeSalvo, 2016). With the current approach to “put patients at the center of how we pay for care and support physicians” (Slavitt & DeSalvo, 2016), Meaningful User incentives have transitioned to one of the four components of the new Merit-Based Incentive Payment System (MIPS), which is part of the Medicare Access and CHIP Reauthorization Act (MACRA) (Slavitt & DeSalvo, 2016). Nevertheless, although earlier studies reported low percentages of registered users using patient portals offered by health care organizations (such as Geisinger Health System, Kaiser Permanante, and the U.S. Department of Veterans Affair) (Emont, 2011), the Office of the National Coordinator for Health Information Technology (ONC) reported that as of 2017, 52% of individuals have been offered online access to their medical record and more than half of these individuals viewed their record within the past year (representing 28% of individuals nationwide) (Patel & Johnson, 2018). The ONC was legislatively mandated in the Health Information Technology for Economic and Clinical Health Act (HITECH Act) of 2009, “to ensure
that every American had access to his or her electronic health information and establishing connectivity of health information technology” (DeSalvo, Dinkler, & Stevens, 2015, p. 507).

Recognizing the many different health apps (programs) currently available for storing, using and managing health records, and tracking health parameters (such as Fitbits) using phones, tablets, or computers, the ONC now promotes the use of health apps available from “The Apple App Store” or “Google Play, the Android app store,” (Office of the National Coordinator for Health Information Technology, n.d.). Similar to health apps, a number of patient platforms are now freely available on the Internet to engage patients in their own health care process, which also operate outside the realm of the health care system. As discussed above, patient platforms, which are the object of this study, can further support patient engagement by facilitating information exchange processes. They can influence how patients manage their health issues, and whom they might decide to consult with for health care advice. Patient platforms offer a valuable way to engage patients in their own health care process beyond accessible EHRs and patient portals since they support the sharing of information which would otherwise be difficult to access; and, encourage active learning virtually anywhere, anytime, depending on needs and context. Since platform tools are freely offered on the Internet to engage patients in their own
health care process, research in this evolving area is needed to better understand how platform tools engage patients.

2.2 Concepts informing the analytical framework

Currently, there are no established frameworks or tools to study patient platforms. This study builds on the US National eHealth Collaborative (NeHC) patient engagement framework and concepts relating to patients’ role in treatment decisions, which are described in detail below, to inform the analytical framework. Section 3.1.3 – Data Analysis, explains the application of this framework for data analysis.

2.2.1 US National eHealth Collaborative (NeHC) framework

The NeHC developed a patient engagement framework for health information systems that aligns with various stages of the Meaningful Use incentive program (National eHealth Collaborative, n.d.). Figure 1 describes the following five concepts (or levels) of the NeHC framework: 1) Inform me; 2) Engage me; 3) Empower me; 4) Partner with me; and, 5) Support my eCommunity.
Figure 1: NeHC Patient engagement framework

Taken from the National eHealth Collaborative website (National eHealth Collaborative, n.d.).

Although the NeHC framework is intended to be applied to information systems within health care organizations (e.g., patient portals), it offers five patient engagement categories (or levels) which can be used to explore how patient platforms engage their users. Further details on the various components associated with these five patient engagement categories are provided in Appendix A. Table 1 below provides excerpts from the Patient Engagement Framework describing each of the five patient engagement categories.
Table 1: Definition of NeHC patient engagement stages

<table>
<thead>
<tr>
<th>Patient engagement category</th>
<th>Description and examples</th>
</tr>
</thead>
</table>
| Stage 1 – Inform Me         | Information and Way-Finding  
• Maps and directions  
• Service directory  
• Physician directory |
| Stage 2 – Engage Me         | Information and Way-Finding  
• Mobile  
  o Nearest healthcare services  
  o Symptom checker |
| Stage 3 – Empower Me        | Information, Way-finding and Quality  
• Quality and safety reports on providers and healthcare organizations  
• Patient ratings of providers, hospitals and other health care organizations |
| Stage 4 – Partner With Me   | Information, Way-Finding and Analytics/Quality  
• Patient-specific predictive modeling  
• Patient-specific quality indicators  
• Patient accountability scores |
| Stage 5 – Support My eCommunity | Information, Way-Finding and Analytics/Quality  
• Care comparison for providers, treatments and medications  
  o Costs  
  o Quality  
  o Convenience |

Taken from the National eHealth Collaborative website (National eHealth Collaborative, n.d.).

2.2.2 Patient role in treatment decisions

Given that the NeHC framework does not account for the power differential between health care providers and patients, and the different roles that patients may play in their treatment decisions, concepts from Deber et al. (1996; 2007) and O’Grady & Jadad (2010) were used to supplement the analytical framework. Specifically, Deber et al. (1996, 2007) identified two dimensions involved in making treatment decisions: problem-solving and decision-making. Problem-solving tasks involve only factual knowledge about diagnosis and treatment options and are preference-independent.
Decision-making tasks require knowledge, but also “involve weighing the relative importance of potential outcomes (Deber et al., 2007, p. 249). From these two dimensions, three possible patient preferred roles emerge. Passive patients wish to hand over both problem-solving and decision-making tasks to their health care provider(s). Patients who prefer a shared role wish to be involved in decision-making tasks and may either hand over or share responsibility for problem-solving tasks with their health care provider(s). Finally, autonomous patients wish to keep responsibility for both problem-solving and decision-making tasks (Deber et al., 1996, 2007). Related to the shared role, O’Grady and Jadad (2010) offer an additional collaborative decision-making category, where patients play a proactive role which might involve both clinical and non-clinical issues. While the shared category involves informing patients on clinical issues to come to a shared decision on a medical intervention (e.g., health care provider working with a patient on the decision to start, or not start medication to manage high cholesterol levels), the collaborative category involves working with patients to come to an optimal care plan based on shared learning that can extend beyond clinical issues (e.g., a health care provider working collaboratively with a patient to manage his or her cholesterol with dietary changes that considers the patient’s social and emotional well-being and is manageable for the patient and his or her family). Table 2 describes these four patient roles in treatment decisions, referred to as clinical decision-making models.
Table 2: Clinical decision-making models

<table>
<thead>
<tr>
<th>Patient physician interaction model</th>
<th>Patients’ role</th>
<th>Physicians’ role</th>
<th>Knowledge “flow”</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paternalistic</td>
<td>Passive</td>
<td>Directive</td>
<td>One-way knowledge transfer (physician to patient)</td>
<td>Compliance of patient to physician’s directive</td>
</tr>
<tr>
<td>Autonomous</td>
<td>Directive</td>
<td>Receptive</td>
<td>One-way knowledge transfer (patient to physician)</td>
<td>Compliance of physician to patient’s directive</td>
</tr>
<tr>
<td>Shared decision making</td>
<td>Informative</td>
<td>Informative</td>
<td>Two-way knowledge exchange</td>
<td>Equity in the decision-making process</td>
</tr>
<tr>
<td>Collaborative decision making</td>
<td>Proactive</td>
<td>Supportive</td>
<td>Knowledge building that can go beyond clinical issues (shared learning by exchanging information)</td>
<td>Optimal action plan to improve health</td>
</tr>
</tbody>
</table>

Taken from (O’Grady & Jadad, 2010).

In summary, the NeHC patient engagement framework, as well as concepts from the literature on patient roles in their treatment decisions (Deber et al., 1996, 2007; O’Grady & Jadad, 2010) were used to inform the preliminary analytical framework, which will be described in the next chapter on methods.
Chapter 3
Methods

This dissertation employed qualitative methods to analyze eleven patient platforms using Framework Analysis (Richie & Spencer, 2002). The eleven patient platforms, which included both for-profit and not-for-profit platforms, varied in medical conditions supported. This approach allowed for the discovery of new findings that are grounded in both the literature and data (Morgan, 2007). It was necessary to take this exploratory approach since there are no previous measures, or instruments to build upon (Charmaz, 2006; Miles & Huberman, 1994).

3.1 Platform selection

Eleven patient platforms were selected from published literature and grey literature (e.g. white papers), patient advocacy websites, industry websites, and Internet searches using various search terms such as “social media platforms,” “patient tools,” “online patient communities.” Efforts were made to select information rich cases, as suggested by Denzin (1970, pp. 300–303), which include platforms that support patients who can have high but different health and information needs. Initially, the intention was to continue sampling additional platforms based on theoretical sampling. However, common concepts and repeated patterns were discovered across the different settings based on the data collected and theme. Thus, no additional platforms were selected.
The convenience sample of eleven platforms was initially chosen to partly capture variability across the following attributes: 1) for-profit and not-for-profit platforms; 2) platforms supporting single/multiple conditions; and, 3) platforms supporting different disease dimensions including a rare condition, non-progressive conditions (e.g., mental health conditions) and progressive chronic conditions. (See Appendix B for selection of platforms based on these attributes). Progressive chronic conditions were selected from three distinct types of illness trajectories described by Murray et al. (2005): trajectory 1, which refers to chronic conditions with short period of evident decline (e.g., incurable cancer); trajectory 2, which refers to chronic conditions with long term limitations and intermittent episodes of acute deterioration (e.g., multiple sclerosis (MS)); and trajectory 3, referring to chronic conditions with a prolonged gradual decline (e.g., neurological conditions). (See Appendix C for charts illustrating these three illness trajectories). This platform selection strategy allowed for the discovery of concepts that were common across settings, as well as unique features and contextual factors that may affect platforms. Table 3 below describes the rationale for case selection using these platform dimensions.
Table 3: Platform dimensions guiding case selection

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Platform selection</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of disease groups</td>
<td>• Specific group of patients</td>
<td>Platforms that might achieve higher levels of patient engagement by pooling resources to support a specific group of target users, versus platforms that might have rich resources to target a broader range of users.</td>
</tr>
<tr>
<td></td>
<td>• Multiple patient groups</td>
<td></td>
</tr>
<tr>
<td>Disease related characteristics</td>
<td>• Rare disease (e.g., amyotrophic lateral sclerosis)</td>
<td>Platforms that might achieve higher levels of patient engagement by targeting potential users with high health and information needs.</td>
</tr>
<tr>
<td></td>
<td>• Non-prgressive conditions (e.g., anxiety disorder, physical disability, diabetes)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Progressive conditions (e.g., Trajectory 1: steady progress and usually a clear terminal phase such as cancers; Trajectory 2: long term limitations and gradual decline with intermittent episodes of acute deterioration and some recovery such as, organ failure, or multiple sclerosis (MS); and, Trajectory 3: prolonged gradual decline such as neurological conditions)</td>
<td></td>
</tr>
</tbody>
</table>

Besides selecting platforms based on the different dimensions, efforts were also made to select platforms that would provide rich information (Patton, 2002, pp. 44–45), such as platforms with high utilization, or platforms that have been operating for long periods of time, to explore how they might promote health and encourage information sharing processes. Also, the selected platforms were geared towards supporting patients of all age groups but typically included age restrictions (i.e., children under the age of 13 not allowed to visit or use platform). Although none of the platforms were designed or intended for use by children, some of the platforms allowed minors over the age of 13 to use the platform under the supervision of their
parent(s) or legal guardian(s), or allowed parents (or caregivers) to use the platform for supporting children with health problems.

3.2 Data collection

Textual and visual data in the public domain were collected from the platforms’ interface and other relevant webpages including platform owner websites. Table 4 describes some of the data collected on the patient platforms (e.g., frequently asked questions, about us, description of tools, mission statement, registration form), which offered rich data to study what the platforms were trying to achieve. Table 5 describes some of the policies collected for analysis (e.g., terms of use or privacy policies), which provide details on rules governing the use of the platforms. Platform policies provided a rich data set to study what the platforms say they were trying to achieve, and for whom.

Table 4: Data from website home page and other webpages

<table>
<thead>
<tr>
<th>Data collected</th>
<th>Example of data collected</th>
<th>Volume of data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website home pages</td>
<td>Site purpose; platform characteristics (e.g., target user groups, # of registered users); description of platform tools</td>
<td>12 webpages</td>
</tr>
<tr>
<td>Frequently asked questions</td>
<td>Platform tools, funding sources, rules pertaining to website use</td>
<td>32 webpages/ documents</td>
</tr>
<tr>
<td>About us</td>
<td>About owner, about site, about investors, site mission, patient testimonials, news releases, and other information describing site or site owners</td>
<td>40 webpages/ documents</td>
</tr>
<tr>
<td>Registration process</td>
<td>Registration form</td>
<td>12 webpages</td>
</tr>
<tr>
<td>Sponsors and Partners</td>
<td>Sponsors, Partners, and promotional information for Sponsors and Partners</td>
<td>37 webpages/ documents</td>
</tr>
<tr>
<td>Tools</td>
<td>Tools and description of tools</td>
<td>133 webpages/ documents</td>
</tr>
</tbody>
</table>
Since the websites were dynamic and can change over time, data collected during September 2013 to August 2014 were captured as screenshots, saved, and stored for offline analysis. Textual data were stored as documents to be analyzed using NVivo 11 qualitative data analysis software.

### 3.3 Data analysis

Data collected from patient platforms were systematically tracked and rigorously analyzed using Framework Analysis methodology. This is an analytic approach developed for applied policy research which offers a well-defined, systematic procedure for “sifting, charting and sorting material according to key issues and themes” (Richie et al., 2002, p.311). Framework Analysis was selected for studying patient platforms as it allows for the systematic analysis of platform tools according to a preliminary framework, which was informed by concepts identified from the literature on patient engagement and clinical decision models. At the same time, its flexibility allows for the discovery and addition of emergent concepts to the framework (Richie et al., 2002).
Specifically, Framework Analysis involves various steps, which are not mutually exclusive, including familiarization and identification of a thematic framework, indexing, charting, mapping and interpretation. First, preliminary data were collected from a selection of patient platforms and initially reviewed by the author. Drawing from concepts identified from the literature (as discussed in Section 2.2), key ideas and recurrent themes that emerged from the familiarization stage were used to develop an initial thematic framework (discussed in Section 3.3.1 below) to narrow the analytic field of vision (Richie et al., 2002). Subsequently, the data were systematically and rigorously coded and categorized based on the initial thematic framework. Open coding (Glaser & Strauss, 1967) was also used to identify emerging concepts that were not captured in the initial framework, and data were coded by additional categories as new concepts emerged from the data. This constant comparison process enabled the framework to be expanded upon and further developed as new concepts emerged (Richie et al., 2002). Next, all coded data were reviewed to expand and improve upon the emergent framework (See Appendix D for coding scheme). This iterative process resulted in the development of a thematic framework grounded in both the data and the literature. Finally, recurring and overarching themes, unique themes, relationships between various themes, as well as other contextual factors, were identified to form theoretical propositions.
3.3.1 Analytic framework

The preliminary analysis revealed that platforms provided tools in the public domain (i.e., accessible to site visitors and registered users), as well as tools for registered users only. Site registration was available without charge but required users to provide their personal information and consent to platform policies (such as terms of use, and privacy policies). The author did not register for a site account to collect data for ethical reasons (see Section 3.5); thus, the analysis of tools provided to registered users only relied on descriptions of these tools, which were posted in the public domain to encourage site registration. Regardless, platform tools were classified into the following types:

- One-way tools, which disseminated information from platform to platform users;
- Two-way tools, which provided information based on data and information collected from individual users; and
- Multi-way tools, which posted information shared by many users.

These three types of tools were subsequently coded and categorized as part of the emergent analytical framework to identify data elements with corresponding theoretical concepts. The interpretation of the patient engagement categories used for the coding and categorization of platform tools will be discussed as follows.
The *inform patients* category refers to a patient engagement process whereby information is disseminated from the platform to users, who passively receive information as determined by platform owners. Information coded as *inform patients* was typically featured on the platform homepage or other main web pages to engage patients as content readers without engaging them in making treatment decisions. Examples of tools coded as *inform patients* include:

- One-way tools (e.g., health articles on lifestyle changes to prevent disease, research news or health trends);
- Two-way tools (e.g., excerpts from the most recent user blogs); and
- Multi-way tools (e.g., excerpts from the most recent discussion forum postings).

The *involve patients* category refers to a patient engagement process whereby platform tools can support platform users with decision-making tasks, but do not engage them to take on problem-solving tasks. For instance, a number of one-way tools were coded as *involve patients* where individual users can actively select the information they wished to receive (such as information which could inform them on the risks and benefits of treatment options); however, the information was insufficient for engaging platform users to take on problem-solving tasks on their own. Examples of tools coded as *involve patients* include:
• One-way tools (e.g., patient information on medical conditions or drug therapies);
• Two-way tools (e.g., user journals or diaries for recording their illness journey);
  and
• Multi-way tools (e.g., simple forums for posting brief questions and answers).

The *empower patients* category refers to a patient engagement process whereby platform tools can support users with both decision-making and problem-solving tasks. Platform tools coded as empower patients can engage some users to assess the risks and benefits of their own treatment options, actively track their own symptoms, or maintain their own health record. These tools can empower some patients to gain control over their own health issues without necessarily relying on their health care providers to do so for them. Accordingly, patients can use these tools to make their own treatment decisions before, after, or instead of consulting with their health care providers. Examples of platform tools coded as *empower patients* include:

• One-way tools (e.g., in-depth medical references to look-up how to manage side effects, or symptom checking tools for self-diagnosis of potential causes of symptoms);
• Two-way tools (e.g., self-tracking tools for patients to track their own symptoms, or tools for patients to maintain their own personal health records); and

• Multi-way tools (e.g., forums for discussing possible treatment options to manage their medical condition(s)).

The *support patient eCommunities* category refers to a patient engagement process whereby platform users are connected with one another for information and support. Platform tools coded as *support patient eCommunities* include:

• Two-way tools which posted information shared by individual users (e.g., user profiles, health charts or health records); and

• Multi-way tools which posted information shared by many platform users (e.g., discussion forums for sharing experiences, information and knowledge with other users).

The *partner with patients* category refers to a patient engagement process whereby patients are connected with their health care providers to support shared and collaborative decision-making processes. Only two-way tools were coded for *partner with patients*. Two-way tools used for sharing information collected from individual patients with their health care providers include, for example, personal health records, or health charts. Two-way tools for health care providers to share medical records with their patients include electronic medical records.
Expanding beyond the patient engagement framework, other themes that emerged from the data through open coding included concepts relating to “the community” and “the business model”, which will be discussed in Section 4.2 and Section 4.3 respectively.

3.4 Strategies to establish trustworthiness of analysis

A number of strategies were employed to establish trustworthiness of the analysis. First, all collected data (including screenshots, documents and research notes) were systematically tracked in terms of where and when the data were collected (e.g., website address, date and time collected). This allowed for the research process to be accessible and visible to all members of the research team (thesis supervisor, committee members, other graduate students) for discussion during meetings. Second, each theme (category) was referenced to the original text to facilitate data retrieval. Third, the thesis supervisor was consulted on a regular basis (bi-weekly) to review and discuss the coding of the data and emergent themes to reduce potential bias that comes from a single researcher, and to increase reliability in observations. Lastly, efforts were made to collect data from multiple sources for data triangulation (Denzin, 1970). Thus, data were collected from the platforms’ interface (e.g., web pages), platform policies, platform owner websites, as well as publicly available documents on the platform, where available, to establish trustworthiness of the analysis.
3.5 Ethical considerations

This study collected data at the platform level and was not expected to pose risks to platform users, the research team, or others associated with the research process.

Ethics approval was obtained from the University of Toronto Ethics Review Board. All data were stored on encrypted storage devices, secured institutional network drives, or locked in file cabinets. The research was considered low risk, non-intrusive, with no direct interaction between researcher(s) and individuals through the Internet. Also, the study did not involve any intervention staged by the researcher. Only publicly available information shared on patient platforms, which were freely open to the public for registration, were collected for analysis. Any data that could potentially identify a user was masked, and no specific platform users, platform user groups, or patient communities, were identified in this dissertation. Also, the names of platforms and other parties (e.g., platform owners, medical writers) were masked in the reporting of results, although they may still be identifiable. This masking of names was intended to describe what can happen on patient platforms without singling out individuals or individual platforms.
Chapter 4
Results

This chapter will begin by discussing how platform tools engaged users according to the patient engagement framework, as discussed in Section 3.3.1 – Analytical Framework. The subsequent section will discuss how the platforms supported user communities, followed by a discussion of what else the platforms were doing besides supporting patients, which relates to their business models.

The analysis revealed numerous processes which could be used to engage patients from different points of access, where some tools were provided in the public domain (e.g., to engage visitors and registered users), and other tools required registration or subscriptions (e.g., to engage registered users or subscribers). Table 6 below provides a summary of three types of tools provided by platforms to engage users, which will be discussed subsequently.
Table 6: Summary of platform tools provided to engage patients

<table>
<thead>
<tr>
<th>Information flow</th>
<th>Site visitors or registered users</th>
<th>Information type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>One-way tools</strong></td>
<td>Disseminates information from platform to users</td>
<td>Mainly science based</td>
<td>Health articles, patient information, medical references</td>
</tr>
<tr>
<td></td>
<td>Site visitors can read content posted by the platform in public domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Two-way tools</strong></td>
<td>Provides information collected from individual users</td>
<td>Based on data and information collected from individual users</td>
<td>Journals, personal health records, self-tracking tools</td>
</tr>
<tr>
<td></td>
<td>Site visitors can read content posted by individual users in the public domain but site registration required for using two-way tools</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Multi-way tools</strong></td>
<td>Posts information shared by many users</td>
<td>Can be science-based, based on patient experiences; or co-created by multiple users</td>
<td>Discussion forums</td>
</tr>
<tr>
<td></td>
<td>Most, if not all, content posted by other users in public domain but requires site registration to participate in the exchange process</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.1 The tools

4.1.1 One-way tools

All of the patient platforms, including both for-profit and not-for-profit platforms, provided one-way tools, which disseminated information from platform to users. Information provided by one-way tools was static (or updated infrequently) with limited, or no opportunity for users to add to the site-determined content. One-way tools disseminated science-based information, ranging from very limited information
Platforms produced a variety of health contents (e.g., health information or health articles), as well as provided third-party contents to engage their users (e.g., patient information produced by FDA or CDC, or sponsored tools funded through sponsorships or educational grants). Also, platforms can post links to other content producers or post full-text health articles written by other content producers who shared common patient care goals. This can be mutually beneficial for platform owners who can leverage third-party content to engage their users, and third-party content producers who can benefit from reaching a broader audience with their content. For example, platform A1 posted a video clip on its home page using the following link title:

Learn More About Your [condition]. Brought to you by [site sponsor]. (A1, homepage)

This clip was produced by a third-party organization to inform the public about that medical condition. Similarly, platform A3 provided a collection of information produced by third-party content producers (e.g., patient information from the National Cancer Institute), as described below:
[Platform A3] creates most of our own editorial content, using a team of experienced writers, editors, designers, and web producers. When we do include material from other sources, such as the National Cancer Institute, we clearly identify those original sources of the material used. (A3, Editorial and Advertising Policies)

Regardless of the content producers, one-way tools were typically provided in the public domain aimed at reaching a large number of readers. Also, platforms made efforts to increase their inclusivity to reach a broader range of patients. For instance, three platforms (A1, A3, A9) reached out to patients with language barriers, or other limitations, by providing information in different languages (such as Spanish) or providing tools to translate site content (such as Google translate). In fact, one platform (A3) described a Spanish Advisory Committee for reaching out to Hispanic patients:

The Spanish Advisory Committee is made up of key opinion leaders connected with the Hispanic community who provide advice and guidance regarding breast cancer and breast health. Hispanic women are more likely than non-Hispanic white women to be diagnosed at a later stage of breast cancer, with cancers that are more difficult to treat. One of [Platform A3’s] priorities is expanding our mission to the Spanish-speaking community: to help women and their loved ones make sense of the complex medical and personal information about breast health and breast cancer so they can make the best decisions for their lives. Our advisors help us identify these needs so we can effectively connect and communicate with this community. (A3, About us)
Besides translating site content, tools were provided to enlarge text and most of the platforms posted some information via other media such as podcasts or video, as illustrated in the examples below:

Podcasts: “Listen to our experts discuss current breast cancer research.” (A3, homepage)

Videoclip: "New Cholesterol Drugs: Could They Help You? By xxx, MD | xxx Women's Hospital" (A9, homepage)

Various mechanisms were also used to engage patients outside of the platform. For instance, platform users can download site content or print site material for sharing with others offline, as illustrated below where users were asked to include copyright notices on the printed material:

Unless otherwise prohibited from doing so, you may download and make one (1) copy of the content and other downloadable items displayed on the website for your personal, noncommercial use only, provided that you maintain all copyright and other notices contained in such content. (A10, Terms of Use)

Five platforms (A1, A3, A6, A9, A10) also facilitated the electronic sharing of site content through features such as “email a friend”, or through external social media platforms such as Facebook, Twitter, Goggle+, Instagram, Pinterest, Tumblr, BlogSpot, and YouTube; however, this process can involve additional user consent with third party policies, as illustrated by platforms A3 below:
Social Media Features and Widgets are either hosted by a third party or hosted directly on our Site. Your interactions with these Features are governed by the privacy policy of the company providing it. (A3, Privacy statement)

Finally, two platforms (A3, A9) engaged patients offline by offering eNewsletter subscriptions and/or mobile services, which may also be subject to additional Terms of Use and Privacy Policies. For example:

The new [A9] app for iPhone has been re-imagined with you in mind, offering on-demand healthy living information in addition to physician reviewed health content and interactive tools. (A9, Mobile Apps)

These examples illustrate how platforms tried to attract readers, which in turn can increase site traffic. Table 7 below provides a summary of one-way tools provided by patient platforms according to three patient engagement processes that the tools supported, which will be discussed subsequently.
**Table 7: Examples of one-way tools according to the patient engagement process supported**

<table>
<thead>
<tr>
<th>Information flow</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inform patients</strong>&lt;br&gt;Disseminate information to a large number of patients</td>
<td>Information featured on the platform</td>
<td>Very brief, written in lay language</td>
</tr>
<tr>
<td><strong>Involve patients</strong>&lt;br&gt;Provide information to individual patients which can inform them on risks and benefits of their treatment options but insufficient for engaging patients to take on problem-solving tasks on their own</td>
<td>Individual patients select the information they wished to receive</td>
<td>More detailed, written for patients</td>
</tr>
<tr>
<td><strong>Empower patients</strong>&lt;br&gt;Provide information directly to individual patients which can enable some patients to take on problem-solving tasks traditionally done by health care provider(s) such as assessing risks and benefits of treatment options on their own, which can enable patients to better control their own conditions</td>
<td>Individuals patients interactively look-up the information they required</td>
<td>More comprehensive, some tools written for higher health literacy levels</td>
</tr>
</tbody>
</table>

**A) Informing patients with one-way tools**

Three platforms (A3, A6, A9) produced a number of one-way tools coded as *inform patients* (such as health articles, site blogs, news or research updates, newsletters).

These platforms defined themselves as a source of information and produced science-based information written in lay-language by platform staff or professional
writers. Platform owners determined the information provided to inform their users, which were featured on the platform home page, or other main web pages under various topic headings such as research, trending topics, or news. In general, one-way tools coded as inform patients were provided in the public domain aimed at engaging a large number of platform users as content reader without requiring site registration. The information tended to be static and brief, containing insufficient detail for engaging platform users in making their own treatment decisions.

B) Involving patients and empowering patients with one-way tools

Most platforms provided a wide range of one-way tools coded as involve or empower patients. Platform users typically select the information they required through tabs or links located on the homepage, headers and/or sidebars. Generic search tools were also available for users to retrieve relevant information by entering search terms (e.g., patients can enter conditions, treatments and symptoms). One-way tools coded as involve patients included patient information on conditions or drug therapies, which can help some users decide on whether to start drug therapy as recommended by their health care provider. However, the content did not contain enough details for users to assess the risks and benefits of their treatment on their
own (e.g., insufficient information for checking for drug interactions, or possible causes for their symptoms).

In contrast, one-way tools coded as empower patients, such as in-depth medical references or comprehensive drug information resources, can be used by some platform users to assess the risks and benefits of their treatment options on their own. Thus, these tools can enable some users to better control their own health issues either before, after, or in place of consulting with their health care provider. A variety of different one-way tools coded as *empower patients* will be described below.

Specifically, platforms provided their users with access to in-depth medical references produced to support health care providers with problem-solving tasks. These references might be too costly, or not available for purchase by individuals; however, patient platforms made these references accessible in the public domain, which enable some users to assess the risks and benefits of their treatment options on their own without necessarily first consulting with their health care provider. For example, the following disclaimer illustrates drug information provided by platform A8:
... drug information is an informational resource designed to assist licensed healthcare practitioners in caring for their patients and/or to serve consumers viewing this service as a supplement to, and not a substitute for, the expertise, skill, knowledge and judgment of healthcare practitioners... (A8, drug information tool)

Also, platforms provided a number of one-way tools intended for use by patients, which were coded as *empower patients* such as symptom checkers or calculating tools. These tools enable some platform users to gain control over their own health issues without requiring higher health literacy levels. For instance, users can look-up their own symptoms using self-assessment tools (e.g., symptom checkers, or self-assessment tools) in order to retrieve what the tool determines as potential causes of their symptom(s), such as:

Take the first step and see what could be causing your symptoms. Then learn about possible next steps. Get Started (A9, self-assessment tool)

Multiple Sclerosis Assessment
This content is selected and controlled by [platform A9’s] editorial staff and is brought to you by EMD Serono, Inc. and Pfizer Inc.
How Well Are You Managing MS?
... Answer a few questions, and you’ll get:
Treatment options for your type of MS
Information about the progression of the disease
Tips for dealing with symptoms while still enjoying life
Reviewed by xxx MD on xxx
Sources: This tool does not provide medical advice. See additional information (A9, self-assessment tool)
As well, users can enter their health parameters (e.g., height and weight) on calculator tools in order to receive relevant information (e.g., body-mass-index), which can enable some users to measure (and subsequently keep track of) their health information without relying solely on their health care provider to do so for them. For example, Figure 2 below shows some tools provided by platform A5 which align with the process of empowering patients:

![Health tools](image)

**Figure 2:** Health tools provided by platform A5

Lastly, one-way tools were provided to help users find health care services such as doctor or pharmacy directories, which aligned with the *empower patients* process. These tools were not intended for individual users to manage their own health issues without consulting health care providers; yet, they were coded as *empower patients* because they can enable some users to find medical experts for treating
what the user might determine to be their own health issues, or to find medical experts to consult with for second opinions.

In general, one-way tools coded as *empower patients*, enabled platform users to actively seek the information they require to support them with problem-solving tasks (e.g., tools to identify potential drug related problems, or tools to evaluate potential causes of symptoms). Some users may take this information to *partner with* their health care provider in making collaborative treatment decisions; however, the sharing of this information with health care providers offline was not captured by the data collected in this study. Also, although this study explored a wide variety of one-way tools offered to engage patients in their own health care process, none of the platforms claimed to provide information for health care purposes. Rather, platforms typically included disclaimers which clarifies that platform tools were provided for other purposes, such as “for personal use only,” or “enjoyment only,” as illustrated below:

[The platform] provides this Service to promote a community to connect medical patients, caregivers, and professionals... The Service is for the personal use and enjoyment of individual Members only and may not be used in connection with any commercial endeavors. (A4, Terms of use)
Accordingly, the analysis of platform policies revealed that patient platforms were not as patient-centered as they might appear to be since the platforms do not hold themselves accountable for providing accurate or updated information. This contrasts sharply with how platforms require their users to provide accurate and updated personal information, which the platform can subsequently use for generating income (e.g., sending users customized marketing material for their sponsors, or selling user information to third parties). Examples illustrated on Table 8 illustrate how platforms did not hold themselves to the same level of accountability in their provision of health information but required their users to provide accurate (and updated) personal information:
Table 8: Contrasting user requirements to provide information vs information provided by site owners

<table>
<thead>
<tr>
<th>Requirement for user to provide accurate information (and update information)</th>
<th>Platform not committed to providing accurate, or updated health information</th>
</tr>
</thead>
<tbody>
<tr>
<td>You agree that the registration information you provide is accurate, complete and current, and you further agree to promptly update that information to keep it accurate, complete and current. You acknowledge that the use of false registration information or creating multiple accounts on the [platform A3] site may result in permanent suspension of all associated registrations without notice. (A3, Terms of Use)</td>
<td>You acknowledge that by using this Web Site you may be exposed to information that is inaccurate or unreliable or material you find objectionable, and in this respect your use of the Web Site and your reliance upon any such third party information or material is at your own risk. (A3, Terms of Use)</td>
</tr>
<tr>
<td>You must provide us with current, complete, and accurate information as requested by the registration form. Updating this information is your responsibility. (A4, Terms of Use)</td>
<td>Disclaimer of Warranties. The information and opinions expressed in postings on this Service are not necessarily those of [platform A4 owners] or its content providers, advertisers, business partners, or related entities, or of any health association to which this Service is linked, and [platform A4 owners] is not responsible for any incorrect or inaccurate Content posted on the Service, whether by [platform A4 owners], its business partners, Members, or due to equipment or computer programming associated with this Service. (A4, Terms of Use)</td>
</tr>
</tbody>
</table>

These findings suggest that patient platforms might operate in ways to support their own interests over the interests of platform users; but, this might not be apparent without reading platform policies.
4.1.2 Two-way tools

Most of the platforms offered two-way tools which provided information based on data and information collected from registered users (such as user profiles, user blogs, user journals, self-tracking tools, personal health records). Although registration was free of charge, users were required to provide their personal information (e.g., email address) and accept terms of service and privacy policies. In general, two-way tools were coded for supporting various patient engagement processes depending on how the tools were intended to be used, as described below.

A) Involving patients with two-way tools

A number of two-way tools were coded as involve patients, which were not intended for engaging users to make treatment decisions on their own (e.g., user journals, smoking cessation tools, medication adherence tools). These tools actively engaged registered users to enter their own data, information or experiences but did not engage them to take on problem-solving tasks. For instance, platform A11 provided behavior modification tools for helping users quit smoking, which were coded as involve patients, as described below:
A Self-Guided Behavior Change Program Customized to quitter type, registered program users are presented with a full range of behavior change and motivational exercises. All exercises are presented to the user after registration, and users are encouraged to browse topics that are of particular importance to their quit attempt.

We encourage registered members to complete these exercises, or re-complete specific exercises, at their own pace. (A11, Tool information)

Platform A7 offered tools for helping users adhere to prescribed therapies, referred to as an “oral chemotherapy adherence program,” which were coded as involve patients. These tools did not conflict with the traditional role of health care providers in making treatment decisions on behalf of their patients.

B) Empower, partner with and support eCommunities with two-way tools

Two-way tools coded as empower patients can enable registered users to track their own symptoms, or manage their own health records, without necessarily relying on their health care providers to do so for them, as illustrated in the example below:

Daily Health Tracker information, including self-reported details about your general health and well-being, as well as self-reported disease symptoms and/or side effects of treatment (A7, Tool information)

Self-tracking tools or tools to maintain personal health records were also coded as empower patients since the tools can help some users gain control over their own health issues through the self-knowledge gained by learning from one’s own health
information collected over time. Although none of the tools were described for providing medical advice, or replacing health care providers, the tools can also include components which take on tasks traditionally performed by health care providers (such as notifying patients on potential drug interactions from FirstDataBank, drug alerts from the US Food and Drug Administration, or clinical trial opportunities from platform sponsors) as illustrated below:

[Platform tool] helps you safely take your medicine.

Interactions: Check for interactions between your medications.

FDA Warnings & Alerts: Learn if there are any major FDA warnings or alerts on saved medicines.

Email Alerts: When adding a medicine, sign up for alerts. We’ll email you if any important FDA warnings or alerts are added.

Read reviews: written by users with your condition. (A9, Tool information)

Moreover, one platform (A8) was noted for providing two-way tools which can engage some users to track their use of unproven drug therapies, or therapies outside of what might be considered as safe therapeutic doses. For example, their two-way tools enable users to track the efficacy and safety of medical interventions to treat “brain fog”, a medical condition which has yet to be clearly defined in clinical settings, or medical interventions (e.g., vitamin D) which can exceed the upper limits of what might be considered as safe therapeutic ranges.
Two-way tools can generate information (health charts or personal health records) for sharing with others which align with the *support patient eCommunity* process, as well as sharing with health care providers which align with the *partner with patients* process. The following examples illustrate how information generated from two-way tools can support the process of *partnering with patient*, which enable users to share health information with their health care providers, and for health care providers to share electronic health records with their patients (registered users):

4.1.3 Multi-way tools

All of the patient platforms provided multi-way tools which posted information collectively shared amongst many platform users for engaging content readers, which align with the *support patient eCommunities* process, as well as other patient engagement processes, as discussed below.
A) Engaging patients with sharing tools and aggregating tools

A variety of multi-way tools collected information from many platform users for sharing with others. For instance, four patient platforms (A1, A7, A9, A10) provided multi-way tools for sharing experiences, photos, videos, and resources (such as other websites, references, organizations, financial services, providers or hospitals), which align with the process of *supporting patient eCommunities*.

In addition, four platforms (A1, A5, A8, A9) provided tools which aggregated information collected from many users (such as user recommendations, reviews or ratings on health products, services, or content). These tools also align with the *empower patients* process since they can help platform users learn how to better control their health issues, as noted below:

> Learn from others: Compare treatments, symptoms, and experiences with people like you and take control of your healthcare (A7)

Figure 3 below provides an example of a tool which aggregated drug reviews and ratings collected from many users on the effectiveness of drug therapies, which can be used by platform users to assess the risk and benefits of various treatment options:
The resultant drug reviews and rating tools can empower users to take on problem-solving and decision-making tasks. Similarly, platform A1 offered a directory of recommended doctors which aggregated doctor recommendations collected from many users, as illustrated in Figure 4 below:

The resultant doctor directory can empower some users who might not otherwise know where to locate medical experts with the clinical experience to treat their rare condition or locate specialists to consult with for second opinions. Also, platform A8
offered tools for aggregating health information collected from registered users (e.g., side effects collectively reported by all registered users using specific doses of drugs, or used for specific purposes), along with a list of platform users who reported these effects. Thus, users can learn from the collective information shared amongst many users, as well as potentially connect with users who reported experience with taking the drug(s) for specific purposes, or experienced specific side effects to drug therapies.

Besides tools which posted specific types of information collected from many users, all of the patient platforms facilitated forums which can be used more freely for sharing textual information (e.g., for share experiences, information and knowledge on specific topics of interests), as discussed in the next section.

B) Engaging patients with forums

All of the patient platforms facilitated forums, or bulletin boards, for connecting their users with one another for information and support. As with many of the multi-way tools, forums were typically posted in the public domain for engaging readers without requiring site registration; however, site registration was typically required to participate in the information exchange process (e.g., post or share content on forums). Forums aligned with various patient engagement processes depending on
the content shared. For example, forums engaged users to share experiences which are not related to treatment decisions; to seek advice on whether to start drug therapy as prescribed by their doctor (which might contain insufficient detail for patients to assess risks and benefits of treatment options on their own); to consult with others on possible diagnosis or assess risks of treatment options (which can engage patients to take on problem-solving tasks); and support a community of platform users by connecting them with one another for information and support. In contrast to the tools provided for aggregating information collected from many users (as discussed above), users can create forum postings, as well as determine where and what they might wish to share on forums, as the free text format allows for the sharing of information for various purposes. That said, forums were generally set-up for encouraging different types of information exchanges, which will be discussed below.

a) Simple forums for posting questions and answers

Four platforms (A4, A5, A7, A9) facilitated simple forums organized in a question-answer(s) format to promote quick information exchanges. Register users can post questions and answers on multiple condition-specific forums. (See Figure 5, example of a condition-specific forum)
Site visitors can typically go to multiple condition-specific simple forums to find information shared on specific medical conditions. That being said, simple forums were generally not sorted to facilitate information retrieval, as one might need to scroll through numerous user postings to find relevant content.

b) Discussion forums for sharing experience, information and knowledge
Six platforms (A1, A2, A3, A6, A10, A11), including for-profit and not-for-profit platforms, offered discussion forums sorted by categories and sub-categories, which enable users to better distinguish where they might wish to seek information and support. Registered users can use these forums for sharing of experiences, information and knowledge related to the same medical condition. Besides posting replies to original user postings (as in the question and answer format), this type of forum typically enabled users to post replies to replies in threaded discussions, which can encourage more back-and-forth information exchanges. The following
example illustrates forum categories offered by platform A3, which supports breast cancer patients:

Welcome to [platform A3]
Not Diagnosed but Concerned
Tests, Treatments & Side Effects
Connecting With Others Who Have a Similar Diagnosis
Support & Community Connections
Day-to-Day Matters
Site News and Announcements
Recovery, Renewal, & Hope
Advocacy and Fund-Raising (A3, Forums)

Under the category of “Tests, Treatments & Side Effects”, the following sub-categories were offered by platform A3, which connected smaller groups of users to exchange information on more specific areas of interest:

Surgery - Before, During, and After 5,921 Topics 146,034 Posts
Surgical options and helpful tips for recovery and side effects.
Latest post: xxx by xxx 56 minutes ago

Breast Reconstruction 9,326 Topics 270,786 Posts
Is it right for you? Discuss timing and various procedures and techniques.
Latest post: xxxs by xxx 19 minutes ago

Chemotherapy - Before, During, and After 5,954 Topics 416,422 Posts
Regimens, side effects, and support from others going through chemo.
Latest post: xxx by xxx 12 minutes ago

Radiation Therapy - Before, During and After 2,732 Topics 101,048 Posts
What to expect from treatment and ways to cope with side effects.
Latest post: xxx by xxx 2 hours ago (A3, Forums)
Similarly, under the category of “Connecting with Others Who Have a Similar Diagnosis”, the following sub-categories were offered by platform A3:

DCIS (Ductal Carcinoma In Situ) 3,150 Topics 42,022 Posts
Just diagnosed, in treatment, or finished treatment for DCIS.
Latest post: xxx by xxx 14 minutes ago

Micro-invasive DCIS that is HER2 positive 50 Topics 825 Posts
Meet others with this diagnosis.
Latest post: xxx by xxx [date, time]

Less Common Types of Breast Cancer 76 Topics 2,956 Posts
Meet others with less common forms of breast cancer, such as Medullary carcinoma, Inflammatory breast cancers, Mucinous carcinoma (colloid carcinoma), Paget's disease, Papillary carcinoma, Phyllodes tumor, Tubular carcinomas, Metaplastic tumors, Adenoid cystic carcinomas and Angiosarcoma.
Latest post: xxx by xxx 7 hours ago

Stage III Breast Cancer 3,356 Topics 64,479 Posts
You are not alone. Meet others who have Stage III breast cancer.
Latest post: xxx by xxx 9 hours ago

HER2+ (Positive) Breast Cancer 1,576 Topics 55,265 Posts
Testing, treatment, side effects, and more.
Latest post: xxx by xxx 2 minutes ago

Triple-Negative Breast Cancer 1,855 Topics 57,193 Posts
Share with others who have ER-/PR-/HER2- breast cancer.
Latest post: xxx by xxx 2 hours ago (A3, Forums)

These examples illustrate how such discussion forums can enable breast cancer patients to better locate others whom might have experience with an illness, or drug
therapy. Another example of how platforms connect smaller groups of users who shared related conditions is through sorted forums, as illustrated in Table 9 below.

Table 9: Examples of Platform A2 forums listed under the category “Neurological disorders and injury”

<table>
<thead>
<tr>
<th>Forums</th>
<th>Threads/ posts</th>
<th>Last posting</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Neurology &amp; Rare Disorders</td>
<td>Threads:65 Posts: 184</td>
<td>xxx posted by xxx [date, time]</td>
</tr>
<tr>
<td>If you don't see a forum that matches with your condition and/or symptoms post here.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aneurysm</td>
<td>Threads:92 Posts: 627</td>
<td>xxx posted by xxx [date, time]</td>
</tr>
<tr>
<td>An aneurysm is a weak area in the wall of a blood vessel that causes the blood vessel to bulge or balloon out. There are many different types of aneurysms. A berry aneurysm can vary in size from a few millimeters to over a centimeter. Giant berry aneurysms can reach well over 2 centimeters.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ALS / Lou Gehrig’s disease</td>
<td>Threads: 6 Posts: 13</td>
<td>xxx posted by xxx [date, time]</td>
</tr>
<tr>
<td>In Amyotrophic lateral sclerosis, (ALS), neurons waste away or die, and can no longer send messages to muscles. This eventually leads to muscle weakening, twitching, and an inability to move the arms, legs, and body. The condition slowly gets worse. When the muscles in the chest area stop working, it becomes hard or impossible to breathe on one’s own.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>Threads:18 Posts: 443</td>
<td>xxx posted by xxx [date, time]</td>
</tr>
<tr>
<td>Alzheimer’s disease (AD), is one form of dementia that gradually gets worse over time. It affects memory, thinking, and behavior. There are two types of AD -- early onset and late onset.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Arnold Chiari
A malformation of the brain. It consists of a downward displacement of the cerebellar tonsils through the foramen magnum, sometimes causing non-communicating hydrocephalus as a result of obstruction of cerebrospinal fluid (CSF) outflow. The cerebrospinal fluid outflow is caused by phase difference in outflow and influx of blood in the vasculature of the brain. It can cause headaches, fatigue, muscle weakness in the head and face, difficulty swallowing, dizziness, nausea, impaired coordination, and, in severe cases, paralysis.

Threads: 9 Posts: 10
xxx posted by xxx [date, time]

Again, this example illustrates how discussion forums sorted by categories and sub-categories can enable smaller groups of registered users to discuss relevant areas of interests relating to the same or similar medical conditions.

c) Group forums for connecting smaller groups of users

Five platforms (A1, A4, A6, A7, A9), including both for-profit and not-for-profit platforms, offered group forums for connecting smaller groups of registered users to exchange information related to specific conditions, or topics of interests. While some group forums shared information in the public domain, other group forums can be set-up for sharing information with group members only. Nevertheless, group forums provided an additional mechanism to connect smaller groups of registered users to share information; however, users were typically required to register for a site account and join groups in order to share information within
group forums. Group forums were typically offered in addition to simple or discussion forums; however, one platform (A4) provided group forums only (i.e., all users were required to join group forum in order to post any content on the platform). The following examples illustrate some of the group forums offered by platform A6:

Newly Diagnosed
[Group description:] An online support group for newly-diagnosed individuals, and their families and friends. Join to learn from others – about multiple sclerosis, available resources, and preparing for and overcoming potential challenges. This XXX support group is led by experienced volunteers who are here to help you navigate your new diagnosis.
2006 Members

Healthy Despite MS
[Group description:] For people interested in learning how to be healthy, despite being diagnosed with MS. Discuss diet, lifestyle practices, recipes, exercise, and other healthy living subjects.
1168 Members

Over 40 and living with MS
[Group description:] A group for those over 40 years old.
962 Members

Walk MS
[Group description:] A community for everyone interested in Walk MS – the MS movement’s local rallying point and fundraising event in 600+ communities nationwide that, dollar by dollar, changes lives.
958 Members

(A6, Group forums)
Group forums also connected users for a common purpose, such as groups of users who might volunteer their personal time to support the platform by greeting new users:

...Greeters’ group
8 members
Latest Activity: on Saturday
(A1, Group forums)

Many of the group forums also provided a comprehensive list of group members with whom platform users can contact for information and support.

4.1.4 Summary

In summary, platforms provided a variety of tools to engage their users, which were coded for engaging patients according to five patient engagement processes. First, one-way tools were typically provided by all patient platforms for engaging both visitors and registered users as content readers. One-way tools were coded for supporting various patient engagement processes including inform patients, involve patients and empower patients. Specifically, one-way tools coded as inform patients tended to be very brief (e.g., lifestyle articles, or news on recent research findings), without engaging patients in treatment decisions. Whereas, one-way tools coded as involve patients tended to contain more information which might support treatment
decisions; however, the information contained insufficient detail for supporting patients with problem-solving tasks on their own (e.g., patient information on drug therapies). And, one-way tools coded as *empower patients* can be used by some patients to assess the risks and benefits of their treatment options on their own, either before, after, or instead of consulting their health care providers (e.g., in-depth drug references to look-up drug interactions, or symptom checking tools to assess possible causes of their symptoms).

Two-way tools were typically provided to engage registered users to actively participate in their health care process which entailed submitting their own information on the platform. Two-way tools were coded as aligning with various patient engagement processes depending with whom the collected user information was intended to be shared. Specifically, two-way tools coded as *empower patients* can enable patients to track their own condition and organize, and potentially manage, their own health issues without relying on their health care providers to do so for them (such as personal health records, or self-tracking tools). However, these tools can generate information for sharing with health care providers which align with the *partner with patients* category, or generate information for sharing with other users which aligns with the *support patient eCommunities* category, and
potentially empower many users in their health care process. Two-way tools were the only platform tools coded for partnering with patients.

Third, multi-way tools were offered by all of the platforms, which could support many patient engagement processes depending on how the tool was used. Multi-way tools typically provided information posted by many users in the public domain but use of multi-way tools to participate in the information exchange processes generally required site registration. Although multi-way tools were generally coded as support patient eCommunities, the tools can also align with other patient engagement processes. For instance, discussion forums can engage patients to share personal experiences which do not involve treatment decisions, seek advice for supporting decision-making tasks only, consult with others on both decision-making and problem-solving tasks, or connect patients with one another for information and support. In general, forums were the main type of multi-way tool provided by patient platforms to connect users with one another. Some platforms facilitated simple forums to promote quick information exchanges relating to specific medical conditions (e.g., question and answer(s) format) whereas other platforms facilitated discussion forums sorted by multiple categories and sub-categories which can enable users to better locate where they might wish to participate in information
exchanges. Also, some platforms also offered group forums for registered users to join and participate in information exchange processes with smaller groups of users to share information relating to specific topics of interests.

4.2 The community

As illustrated so far, platforms provided a variety of different tools to engage patients according to five patient engagement categories. Expanding on the category of support patient eCommunity, this section will discuss how platforms promoted a sense of community by connecting users to share information on the same, or related medical conditions, as illustrated in the examples below:

Connect with people like you
Share your experience, give and get support to improve your life and the lives of others (A8)

Be your healthiest
Join the millions of people who use [Platform A5] every day.
Find support, get motivated. Connect with others just like you. Get advice, share your experience. Hundreds of conditions covered. Find your community (A5)

Platform users were encouraged to connect with others like themselves to find information and support, as noted below:

Certainly on the emotional side there's a great deal of connecting with one another, sympathy, empathy, being with other people who know what it's like. (A4)

Find support, get motivated
Connect with others just like you. (A5)
This site is a virtual community intended to be a safe place for patients and family members as young as age 12, to visit for information, discussion, and mutual support. (A1)

[Platform A3] is designed to be a website for a thriving community concerned about breast cancer, and a comfortable place for visitors to find information, emotional support and share experiences. (A3)

Within the communities, users can remain anonymous to the extent that they do not disclose their personal information during use of platform tools (e.g., on their user profile, or through discussions). For example:

Our mission at [Platform A1] is to ensure that patients living with rare diseases or chronic illnesses, as well as their caregivers, family, and friends, have a safe and supportive place to connect with others like them. (A1, homepage)

We all need a safe place to discuss health. We can help each other. Together, we are better. (A4, homepage)

Accordingly, the communities were described as a safe and supportive environment for users to find others who might share common conditions or interests, for example:

Meet others who are discussing the health issues that are important to them... make friends who share your health interests. (A4, homepage)

Find supportive friends who know what it’s like to live with the chronic pain of arthritis – whether it’s in your own life or as a caregiver. (A10, homepage)
Although all of the platforms connected patients sharing the same medical conditions in what was typically referred to as a community, the term community could refer to different groups of patients, as discussed below.

4.2.1 Virtual connections only versus offline connections

All of the platforms facilitated virtual connections, where users participated in information exchange processes using their online identity. Exchanging information with others, the information exchange processes can remain online. That being said, beyond virtual connections, some platforms allowed users’ actual identities to be disclosed, as illustrated in the following example describing how one platform (A7) aimed to connect patients with their family, friends, and caregivers:

Receive Support from Family & Friends
Keeping friends and family up to date should be easy. Update your loved ones with one click so you can receive the care & support you need, or assign a caregiver to update others on your behalf. Use your private profile page to share updates on your progress with a single message. Invite your friends and family and receive notes of encouragement and support. Ask for help and send supporters reminders about tasks delegated to them. (A7, homepage)

Also, three platforms (A1, A3, A6) were operated by patient advocacy groups, which supported an existing community of patients sharing a common condition (e.g., rare disease, breast cancer, multiple sclerosis). Accordingly, this group of platforms
offered offline support (e.g., telephone support, in person peer support groups, or in-person meet-ups), as illustrated in the example from platform A6 below:

Knowledge is truly empowering. The [Platform owner A6] offers an extensive variety of programs, services, resources and connection opportunities for people living with and affected by MS, including family members, caregivers and other members of their support systems. These resources can be accessed in person in your community, online, by phone and by mail. MS can be an isolating disease -- but it doesn’t have to be. Let’s explore the many ways to get connected to information and to others living with the disease...

Also, Figure 6 below illustrates how one platform (A1) actively connected their users offline:

![Figure 6: Event sharing tool from platform A1](image)

4.2.2 Mechanisms connecting the community

Although all of the platforms connected users with one another for sharing information relating to the same (or related) medical conditions, different
mechanisms were used for connecting the community of users, which will be discussed subsequently (see Table 10).

Table 10: Mechanisms connecting the community

<table>
<thead>
<tr>
<th>Mechanism connecting patients to share information on specific medical conditions</th>
<th>Description of what registered users can do</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forums as community&lt;br&gt;Platform facilitates condition-specific forum, referred to as community</td>
<td>Registered users can typically participate on multiple condition-specific forums</td>
<td>Different conditions: A4, A5, A9&lt;br&gt;Related conditions: A7</td>
</tr>
<tr>
<td>Platform as community&lt;br&gt;Platform referred to as community for connecting users to share information relating to the same (or related) condition(s)</td>
<td>Registered users participate on discussion forums to share information on the same (or related) condition(s)</td>
<td>Same condition: A1, A3, A6, A10, A11&lt;br&gt;Related conditions: A2</td>
</tr>
<tr>
<td>Tools connecting users&lt;br&gt;Platform offers tools to find users sharing specific medical conditions, treatments, symptoms or other characteristics.</td>
<td>Registered users provided with condition-specific tools but advanced search tools offered to locate other users with various different conditions</td>
<td>A8</td>
</tr>
</tbody>
</table>

A) Forum as community

Four platforms (A4, A5, A7, A9), which included for-profit platforms only, offered simple forums referred to as communities or community forums. The community forums were condition-specific, set-up for posting questions and answers relating to specific conditions. As discussed in Section 4.1.3, site visitors can go to multiple community forums to find information relating to various medical conditions, which were not sorted for information retrieval. Community forums tended to promote quick information exchanges, where registered users can post questions on multiple
condition-specific forums (e.g., registered users can post questions on breast cancer community or depression community).

In general, community forms tended to include minimal features to distinguish content authors (e.g., users who post content). For example, platform A7 used the same image to represent content authors instead of user photos, screen names and other details. As well, platform users can be restricted from using professional designations (even if they have medical expertise).

Two platforms also offered expert forums for posting questions for reply by site-determined experts (e.g., doctors, or other health care providers), who participated in the information exchanges using their actual identity (e.g., photo, name, medical credentials). Although site-determined experts might appear to provide more trustworthy replies to patient questions, the exchange of information within expert forums tended to be static (or not dynamic), as a delay was often noted in expert postings in response to questions posted by platform users (e.g., medical experts may take days to respond to patient questions). Also, expert responses tended to be very brief, with minimal back and forth exchanges, and many questions may never be answered at all. That being said, almost all of the expert forums studied in this research were no longer accepting new patient questions; thus, expert forums may
in fact be viewed as one-way rather than as an interactive multi-way tool. The platforms did not articulate why expert forums were no longer taking user questions.

B) Platform as community

Six platforms (A1, A2, A3, A6, A10, A11), which included for-profit and not-for-profit platforms, referred to the platform as a community. These platforms were condition-specific, supporting the sharing of information on the same (or related medical conditions). These platforms offered discussion forums sorted by categories and sub-categories for sharing of experiences, information and knowledge relating to the same or related conditions (A1, A2, A3, A6, A10, A11). As discussed in Section 4.1.3, discussion forums sorted by multiple categories and sub-categories, enable users to better distinguish where they might wish to seek information and support, as well as connect groups of users to discuss relevant areas of interests such as for sharing experiences with symptoms, or scientific knowledge relating to treatments and conditions. This group of platforms did not offer expert forums; rather, experts can participate in the same discussion forums to discuss and share knowledge with other users, as illustrated by the quote below:

Established in 1993 and affectionately known as [Platform A2], we are an online support community designed to promote education and awareness of various neurological conditions and general health related concerns. Our goals are to
foster better communications between patients and all of their medical caregivers, as well as inviting friends and family to voice their support, experiences, and questions concerning people living with any medical condition. We also encourage all medical professionals to join our dialog with their knowledge, experience, and insight. (A2)

It was noted that two of these platforms (A1 and A10) (one for-profit platform and one not-for-profit platform) were owned by platform owners who also owned additional platforms for other medical conditions. For example, platform A10 support users for anxiety but the platform owners also operated another platform for diabetes, and another platform for fibromyalgia. Each of these condition-specific platforms operated independently with its own set of tools, registration and login process, and listed its own group of sponsors and partners.

In general, platforms that were referred to as a community, tended to include more author details such as platform titles (e.g., new members, distinguished members, community members, community moderators), history of platform use (e.g., length of membership, number of posts written, join date), and other platform credentials (such as ratings assigned by the website). Platform users typically developed an online identity through participation on the platform over time. Yet, despite the similarities in this group of platforms, differences were noted from the for-profit and not-for-profit platforms, which were referred to as communities. First, all of the not-
for-profit platforms operated as if the platform was a community, which tended to have experienced users whom patients can connect with for information and support. Experienced users were noted for welcoming new members using their online identity; however, two of these not-for-profit platforms (A3, A6) were supported by multiple moderators who participated as a single entity under generic screen names, “moderator” or "navigator." Thus, it was unclear whether these moderators participated as volunteers or were paid for their participation. In contrast, for-profit platforms which referred to itself as a community, were supported by staff moderators who were noted for welcoming new members using their actual identity, and supporting other users seeking information and support.

C) Tools to find community of users

One platform (A8) (which supported users with multiple different conditions), provided tools to find other registered users sharing the same medical conditions or other characteristics (such as location, symptoms, treatments). Registered users were also provided with condition-specific tools (such as tools to track pain). This platform was the only platform that did not rely on the posting of discussion forums in the public domain to engage content readers, and did not rely on forums for connecting their users.
In summary, platforms connected patients in what was typically referred to as communities for sharing information relating to the same, or related medical conditions. However, the different ways in which platforms connected users in communities, illustrate the complexity of how platforms engaged their users in information exchange process, which were supported by different business models as discussed in the next section.

4.3 The business models

Previous sections have analyzed how platform tools were offered to engage users in their own health care process, and how users were connected with one another for sharing information relating to the same (or related) medical conditions. This section will describe business processes supported by these tools. All of the platforms engaged their users without charging registration fees and relied on other income sources for operating the platform. This section will begin by describing how platform tools collected information from their users, which can support the interests of other parties, followed by identifying other parties who have an interest in the information exchange processes. Subsequently, the last section will summarize the various income generating processes.
4.3.1 Collecting user information

Although platform tools engaged patients in their own health care process, the tools also collected different types of information from their users for business purposes. Table 11 below provides a summary of the different types of information collected from platform users which will subsequently be discussed.

Table 11: Collecting data and information from users

<table>
<thead>
<tr>
<th>What information was collected</th>
<th>From whom</th>
<th>How information was collected</th>
<th>Main purposes</th>
<th>Business purposes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-personal information</strong> (e.g., IP address, Internet service provider)</td>
<td>Site visitors and registered users</td>
<td>Automatically collected when users visit the platform using cookies and other tracking mechanisms</td>
<td>Operational and administrative purposes; delivering personalized health information</td>
<td>Provide target advertisements and marketing material based tracking behavior of user</td>
</tr>
<tr>
<td><strong>Personal information</strong> (e.g., email address, mobile number, name)</td>
<td>Site visitors, and registered users</td>
<td>Site registration and other points of access (e.g., subscriptions and registration for tools and services)</td>
<td>Administrative purposes (e.g., contact users); fulfill request for services, tools, products, or rewards</td>
<td>To contact users with promotional information, or provide user information to other parties; To sell user data or information to other parties</td>
</tr>
<tr>
<td><strong>Personal health information</strong> (e.g., diagnosis, symptoms, treatments)</td>
<td>Site visitors, and registered users</td>
<td>Site registration and platform tools</td>
<td>Deliver health information; track medical condition; maintain personal health records</td>
<td></td>
</tr>
<tr>
<td><strong>User profile information</strong> (e.g., user photos, personal stories, peer networks)</td>
<td>Registered users</td>
<td>Site registration and platform tools</td>
<td>User profiles for connecting with others</td>
<td></td>
</tr>
</tbody>
</table>
A) Collecting non-personal information

Platforms automatically collected information from their users, whether registered or not, when the platform is accessed for information (e.g., user visits the website to read site content) such as user IP address. The platforms described this information as non-personal information, referring to information that contains insufficient detail on its own to identify or contact individual users, as described in the example below:

We may collect “Non-Personal Information” – information that cannot be used by us to identify you – via Cookies, Web Beacons, [Platform A9] mobile device applications and from external sources, even if you have not registered with or provided any Personal Information to [Platform A9]. (A9, Privacy Policy) As is true of most web sites, we gather certain information automatically and store it in log files. This information includes Internet protocol (IP) addresses, browser type, Internet service provider (ISP), referring/exit pages, operating system, date/time stamp, and clickstream data. (A3, Privacy Policy)

Non-Personal Information We Collect About You

Even if you do not register with [Platform A5], we collect Non-Personal Information about your use of our Web site, special promotions and newsletters. (A5, Privacy Policy)

Platforms described the automatic collection of different types of information from their users, which included the user IP addresses (e.g., equivalent to the Internet mailing address). Specifically, the IP address refers to a number that can identify the users’ Internet Service Provider and some geographical information (e.g., city and/or
postal code). The IP address alone does not normally provide sufficient information for platform owner(s) to contact individuals, but it can be used to identify and track their users, as described below:

We may use your IP address to administer the Service, to help identify problems with our server, to analyze trends, to track your webpage movements, to help identify you, and to gather broad demographic information for aggregate use. (A4, Privacy Policy)

Platforms also described the automatic collection of user information using cookies and other tracking mechanisms. Cookies refer to small data files that are placed on the computers of platform users to track their information, as described below:

A cookie is a small data file that often includes an anonymous, unique token, which is sent to your browser from a website’s computers and may be stored on your computer’s hard drive. (A8, Privacy Policy)

Other mechanisms were also described for automatically collecting (or tracking) user information such as beacons (clear gifs), tags, scripts, Local Shared Objects (HTML5 or Flash cookies), which are described by platform A10 below:

Click-through URL:

In some of our email messages we use a click-through URL linked to content on our site. When visitors click one of these URLs, they pass through our web server before arriving at the destination web page. We track this click-through data to help us determine interest in particular topics and measure the effectiveness of our
communications. If you prefer to avoid this type of tracking; avoid clicking text or graphic links on the site or in site related emails.

Pixel tags:

Pixel tags are tiny graphic images that tell us what parts of our site visitors have visited. This allows us to measure the effectiveness of searches visitors perform on our site. Pixel tags also enable us to send email messages in a format consumers can read. Pixel tags also allow us to determine whether emails have been opened, thereby ensuring that we’re sending only messages that are of interest to consumers. We may use this information to reduce or eliminate messages sent to consumers.

Web Beacons:

We employ or our third party tracking utility partner employs a software technology called clear gifs (a.k.a. Web Beacons), that help us better manage content on our site by informing us what content is effective. Clear gifs are tiny graphics with a unique identifier, similar in function to cookies, and are used to track the online movements of Web users. In contrast to cookies, which are stored on a user’s computer hard drive, clear gifs are embedded invisibly on Web pages and are about the size of the period at the end of this sentence. We do not tie the information gathered by clear gifs to our customer's personal information. (A10, Privacy Policy)

Regardless of the information automatically collected, this process was described for supporting administrative and operational purposes such as for login functions, to block banned users, evaluate website traffic, or analyze trends, as illustrated here:

We use these logs to help improve our service by evaluating the “traffic” to our site in terms of number of unique visitors, level of demand, most popular page requests, and types of errors. These logs may be kept for an indefinite amount of time, used at any time and in any way necessary to prevent security breaches and to ensure the integrity of the data on our servers. (A2, Privacy Policy)
We use cookies to track aggregate user statistics on the site to help us determine how people move throughout the site, which areas are popular, and which links are unpopular or hard to see. (A3, Privacy Policy)

Besides these purposes, platforms also described the automatic collection of user information for supporting business processes such as for delivering targeted advertisements based on users’ browsing behavior or web content accessed, as explained below:

The information collected by Cookies (i) helps us dynamically generate advertising and content on Web pages or in newsletters, (ii) allows us to statistically monitor how many people are using our Web site and selected sponsors' and advertisers' sites, (iii) how many people open our emails, and (iv) for what purposes these actions are being taken. We may use Cookie information to target certain advertisements to your browser or to determine the popularity of certain content or advertisements. (A5, Privacy Policy)

Behavioral Advertising. We also may use Behavioral Advertising cookies which are a way of providing advertisements on the websites you visit and making them more relevant to your interests. Your web browsing activity is grouped together with your shared interests and advertising is then displayed to you when you visit an Online Platform which matches these interests. Behavioral advertising works based on your web browsing over time. (A6, Privacy Policy)

Moreover, platforms described the sharing of non-personal information with third-party advertisement companies for delivering targeted advertisements on the patient platform, as well as on external websites, as noted below:
To tailor advertising to you both on our site and other sites on the web based on cookie information collected on our site (A10, Privacy Policy)

We may share Non-Personal Information that we have about you, including about your browsing activity on [platform A9], with third party advertising service providers who may use this information, on our behalf, to help [platform A9] deliver advertising on the [platform A9] Web Sites as well as on other sites on the Internet. (A9, Privacy Policy)...it is possible that such advertising company may, through your use of this Site and other Websites, develop its own separate profile of you. Any information collected or stored by the ad-service or the cookies is subject to the terms and policies of that company. (A4, Privacy Policy)

In addition, it was noted that platforms typically allowed sponsors to automatically collect information from their users through third-party cookies placed on user computers when users are inadvertently redirected to other websites by links on advertisements and sponsored content. The collection of user information from third-party websites is not governed by platform policies (e.g., privacy policy). Only one platform (A9) was noted for putting restrictions on how their sponsors collect user information for one of their tools (i.e., requiring sponsors not to automatically collect personal information or combine user information). Instead, other platforms either claimed to have no control over third-party cookies or did not advise their users that they could allow third parties to automatically collect their information by clicking on links on advertisements or sponsored content. In fact, one platform (A1) encouraged users to “Click an Ad. Or Two” to help the platform generate funds but
did not advise users of the risk of inadvertently picking up third-party cookies by doing so.

Also, platforms may acquire information on their users from external sources, which can be combined with the non-personal information automatically collected from all users:

We may combine Personal and Non-Personal Information collected by [Platform A9] about you, and may combine this information with information from external sources. (A9, Privacy Policy)

Information from Other Sources: In order for us to develop a more personalized service offering, we may receive information about you from other sources and add it to our account information. (A7, Privacy Policy)

Information Third Parties May Provide About You. We may, from time to time, supplement the information we collect about you through the Online Platforms or mobile application with information from third parties in order to better to serve you. We may combine such information with information we collect through the Online Platforms. We will apply this Privacy Policy to any Personal Information received, unless we disclose otherwise. (A6, Privacy Policy)

Thus, although non-personal information contains insufficient detail on its own to identify or contact individual patients, by combining the non-personal information and personal information collected, and/or acquired on their users, platform owners could potentially identify and contact the users whom they tracked. Since the automatic collection of user information takes place without the need for platform
users to submit their information, those who access these sites are typically not aware of the information collected from them without reading platform policies. This differs from personal information which users submit to the platform for site registration, as discussed in the next section.

B) Collecting personal information

Platforms collected personal information from their users during site registration, from subscriptions (such as eNewletter subscriptions or mobile services), and at other points of access (such as redemption of rewards, questionnaires and surveys). Personal information refers to “any information of a type that is commonly used, alone or in combination with other information, to identify or purport to identify an individual” (Lacroix & Hamilton, 2017). Platforms typically handle the personal information they collected in a secured manner, not to be shared with others, except as required to do so by law. The following examples illustrate this:

Except for authorized law enforcement investigations or other facially valid legal processes, we will not share any of your personal information that you provide during registration or posting on the forums with any parties outside of [Platform A2]. (A2, Privacy Policy)

We have put in place technical, physical, and administrative safeguards to protect the Personal Information that we collect. (A9, Privacy Policy)
That being said, platforms varied on their stated effort to safeguard personal information. The examples below illustrate how one platform described non-specific security measures (such as “commercially reasonable practices”); whereas, another platform said that they offered higher levels of security (such as “bank-level system security”):

[Platform A4] employs commercially reasonable security measures consistent with standard industry practice, to safeguard personal and other information collected through this Site. We believe these commercially reasonable practices provide adequate security to protect against the loss, misuse, or alteration of the information we collect on our Site. (A4, Privacy Policy)

Account Security [platform A7] is committed to providing our customers and patients with a secure online experience that protects their confidential information. We only deliver encrypted data to your patient portal account. We are committed to the highest standards for business and technical excellence to ensure the security and privacy of your health information. Bank-level System Security [platform A7’s] services are hosted in a private, secure cloud environment that is not shared with anyone else. Our data centers are SOC SSAE 16 Type II compliant and feature biometric security, automatic backups, redundant power supplies, and continuous surveillance systems. (A7, Privacy Policy)

Regardless of the level of security used, platforms described the collection of personal information as being for administrative and operational reasons such as setting-up user accounts or sending out administrative communications.
We may use information we collect about you to: Administer your account; Provide you with access to particular tools and services; Respond to your inquiries and send you administrative communications. (A9, Privacy Policy)

Yet, platforms did not necessarily commit themselves to using the personal information at their disposal to inform users on policy changes. In fact, platforms tended to put the onus on their users to check for changes to platform policies, as illustrated below:

We reserve the right to modify this policy at any time, and without prior notice, by posting an amended Privacy Policy and terms on this website. We encourage Members to review this policy periodically for any updates. (A8, Terms of Use)

You are responsible for regularly reviewing this Terms of Use document. [platform A10] reserves the right, at its sole discretion, to change, modify, add, remove or terminate any portion of this document, in whole or in part, at any time, without prior notice. (A10, Terms of Use)

Modification of these Terms of Use. [Platform A4] may from time to time change the terms and conditions governing this premium service. It is important that you regularly review these terms and conditions to stay informed with regard to any changes in the terms and conditions governing your use of this premium service. Your continued use of this premium service constitutes your agreement to all such terms and conditions. (A4, Terms of Use)

Thus, platforms did not appear to commit themselves to the use of the personal information at their disposal to inform their users of policy changes, even though the platforms claimed to collect the information for administrative purposes. Nevertheless, platforms also disclosed the use of personal information collected
from platform users as being for marketing purposes. Accordingly, the analysis identified issues with the registration process and issues associated with user identity and anonymity, as discussed below.

a) Persuasive text to encourage site registration

The analysis identified a number of persuasive texts used for encouraging visitors to register for a site account, which was the main mechanism for collecting personal information, such as posting patient stories, testimonials, pictures and other persuasive texts on registration forms. For example, platform A1 encouraged users to register for a site account to connect with “more than 7535 [members] for information and support”, along with persuasive text stating “We are [rare condition] survivors, here for your support.” Similarly, platform A8 posted the following testimonial on the registration page where a platform user with epilepsy claimed to “drive again” through use of the patient platform:

Thanks to what I learned on xxx, I got a new epileptologist and now I'm seizure free for the first time in 31 years. I can even drive again! (A8, Registration)

Persuasive texts were also identified on the registration page to persuade users to agree with platform policies, as illustrated in the following example:
We believe that you-the patient-should be at the center of healthcare. Other members and researchers will learn from your real-world health experiences so we call can start living better, together. (Don’t worry, certain account information like your email address will not be shared.)

☐ I agree to the [platform A8] terms & conditions of use and privacy policy (A8, Registration)

Moreover, platforms were noted for persuading patients to register for a site account by posting information which was subsequently blocked with a pop-up notice requesting users to sign-up to see more information, as illustrated in Figure 7 below:

**Sign up and see more**

You're not seeing 3,126,051 posts. Sign up today, for free, and see everything.

- Enter your e-mail address
- Create your password
- Select a screen name

By clicking Sign up, you agree to our terms of use and privacy policy.

Sign up for free

*Figure 7: Pop-up screen blocking content on platform A4*
Also, platform A8 posted many user profiles in the public domain, but users were encouraged to sign-up for a site account to view additional user profiles which were shared only with registered users. The use of persuasive texts or blocking content demonstrates how patient platforms were interested in registering their users without necessarily ensuring that their users understand the terms with which they are required to consent with during the process (e.g. terms of use and privacy policies).

b) Issues with user identity

Users were encouraged to participate anonymously in health and information exchange processes using an online identity, as platforms stated that they could register for an account without disclosing their real name, as noted below:

> How do I choose a nickname? When you register for the site, you will be asked to select a nickname. This is how people will know and address you on the site. While some members use their real name as their nickname, others choose an alias that provides them with anonymity. (A10, Member support)

Although users could potentially remain anonymous with other users to the extent that they do not disclose personally identifiable information during the use of platform tools, their identity could be made known to platform owners in various ways. The possibility of disclosing their actual identity to platform owners was not
clearly articulated to users. For instance, platforms can require users to provide personal information which can reasonably be used to identify them such as name, address, contact information, phone number, credit card number, date of birth:

Personal information including your name, address and contact information. (A7, Privacy Policy)

"Personal information" means information that alone or when in combination with other information may be used to readily identify, contact, or locate an individual, such as: name, address, email address, zip code, credit card number, expiration date & security code and or information regarding your PayPal, Google Wallet or other digital payment accounts, or phone number. Information that has been anonymized so that it does not allow a third party to easily identify a specific individual is not Personal Information. (A6, Privacy Policy)

Thus, it was somewhat confusing for platform A2 to suggest that their users could remain anonymous by not entering their real name for site registration, but then require their users to provide personally identifiable information (such as date-of-birth), as illustrated below:

If you wish to remain ANONYMOUS, please do NOT enter your real name when registering. Also please remember that all posts here are viewable by anyone on the Internet, and posts may be indexed by global Internet search engines (e.g., Google). (A2, Terms of use)

Please Enter Your Date of Birth: The date of birth you enter here is binding and may not be altered at a later date. Make sure you enter it correctly! Month: - Day: - Year (A2, Registration)
Similarly, platform A1 which support patients with a rare condition, stated that users were not required to use their real name, as illustrated in the quote below:

Concerned About Privacy? If you are concerned about privacy, please use your last initial in place of your last name. You are not required to use your real name at all here... (A1, homepage)

In fact, a persuasive statement was posted next to the date-of-birth field reassuring users that their age would not be disclose to others; however, providing the initial of their last name and their date of birth could potentially make their actual identities known to platform owner(s), particularly amongst users with rare conditions (Krishnamurthy & Wills, 2009).

Moreover, while patients might not be required to provide sufficient personal information to disclose their identity during site registration (e.g., only required to submit their email address as contact information), their identity could subsequently be disclosed through information submitted at other points of access (such as user profiles, questionnaires or surveys, subscription, email correspondence, coupons, offers or redemption of rewards), as illustrated in the examples below:

[Platform A3] collects personally identifiable information only from our users who choose to provide it. We do so at several different points on our web site, for example: at the Discussion Boards/Chat Rooms sign up at the Free Booklets By Mail request page at the subscription point for the Breastcancer.org e-mail
Updates at the Tell a Friend email card page at the online credit card acceptance form when you contact [platform A3] by e-mail, either to ask questions or to submit your ideas or suggestions from within our mobile application accessible from your mobile device (A3)

There are several ways you may provide information on the Online Platforms, including completing a survey, contacting us by e-mail, contributing online, participating in an online community, or registering for an event online. The information we collect is used to provide you with information about our programs and services available through the Society. We generally respond to you by postal service mail, e-mail, or telephone - depending on your requests and our resources. (A6, Privacy Policy)

We may collect “Personal Information” about you – such as your name, address, telephone number, email address or health information – in the following ways: When you register for or update an existing profile on our web sites or Apps or register for the [Platform A9 tool]; When you use certain interactive tools and services (e.g., the Ovulation/Pregnancy Calendar, certain of our mobile Apps, or tools in certain Apps such as the Healthy Target Program in the [Platform A9] mobile application, or Symptom Checker); When you sign-up for newsletters or other communications from [Platform A9]; When you use our “Email a Friend” service; When you participate in an online survey; or When you provide personal information in a community area or other public forum. (A9, Privacy Policy)

These other points of access represent the main ways for which platforms collected personal information from site visitors who do not wish to sign-up for an account, as well as from registered users who provided limited information during the registration process (e.g., provided their email address only). Users may or may not be aware that their personal information collected from other points of access can be retained by platform owners, and potentially used for purposes beyond the
reason the information was provided, which will be further described in the next section on income generating processes.

In addition, platforms can collect user information from other social media accounts. For instance, platforms offered the ability for their users to login using other social media account details as a convenience; however, platform policies revealed that this process can subsequently enable platform owners to collect additional information on their users from social media websites, as illustrated in the example below:

Social Connect. When you choose to connect your social media account to your profile in an Online Platform, we collect Personal Information from that social media website. For example, when you connect your Facebook account, we may collect the Personal Information you have made publicly available in Facebook, such as your profile picture, gender, age range, locale, and friend list. We may also obtain other non-public information from the social network website with your permission. (A6, Privacy Policy)

Yet, platform users did not submit their information on external social media websites for patient platforms to collect and use for other purposes.

C) Collecting personal health information

Besides collecting personal health information during site registration, and from other points of access (as describe above relating to the collection of personal information), personal health information was collected through two-way tools such
as self-tracking tools, or tools to manage personal health records. Personal health information refers to “identifying information in oral or recorded form about an individual that relates to the physical or mental health of the individual” (Lacroix & Hamilton, 2017, p. 92). The following examples illustrate various types of personal health information which can be collected by patient platforms:

- Personal information including your name, address and contact information
- Diagnosis
- Treatments including surgeries, radiation treatments, chemotherapy, complementary or alternative medicines
- Prescription medications, dietary supplements, herbal remedies, or other medications
- Care team member’s contact information such as your doctor's name, specialty, address, email and phone numbers
- Care facility information, such as names, addresses and phone numbers
- Daily Health Tracker information, including self-reported details about your general health and well-being, as well as self-reported disease symptoms and/or side effects of treatment
- Medical appointment dates, times and physician information (A7, Terms of use)
- Interact Interactive tools within xxx gather self-reported Personal Health Information. In addition, certain of these tools can store Personal Health Information coming from third party data interchange agreements between your employer, health plan, pharmacy benefits manager and other third parties that provide data interchange services. We maintain and limit the use of that information to the Opt-in permission you have provided at the time you use the tool. (A5, Privacy policy)
Personal health information (such as medical conditions) was collected from all patient platforms as it was used for connecting patients sharing the same medical conditions, for providing condition-specific tools (such as tools to track pain symptoms or blood glucose), and for engaging patients in their health care process. Besides these reasons, personal health information was also used for supporting business interests, which will be discussed in Section 4.3.3 on income generating processes.

D) Collecting user profile information

Platforms collected additional background information from platform users for posting on user profiles. Without non-verbal cues to facilitate in-person conversations, additional background information shared on user profiles can play an important role in facilitating online communication amongst users whom have never met. In contrast to personal information, which was handled in a secured manner (e.g., not to be disclosed to other parties without the user’s consent or unless required to by law), information shared on user profiles was posted for sharing with others. Providing user profile information was not mandatory for site registration, but users were encouraged to provide additional information for better connecting with others, as illustrated below:
After you have registered, you will have the opportunity to provide additional personal information and to create an extended personal profile, including the posting of a photograph. Whether you provide this additional personal information is entirely your option, although it may affect your full enjoyment of the Service. (A4, Terms of use)

You register by clicking on the 'Register' link near the top of the page. You will be asked to choose a user name, password and enter a valid email address. In addition there will be some other fields to which you will be invited to respond. Some will be mandatory while others are optional. Once this is complete you will either be fully registered, or in some cases you may have to click on a link in an 'activation email' sent to your email address. Once you have done this you will be registered. (A2, Terms of Use)

Although additional background information can include personally identifiable information such as their date-of-birth, photo, gender, location, city, interests, and reason for joining site, which could disclose their identity, users typically have the option to choose with whom they wish to share their user profile through privacy settings. For instance, some users might choose to share their profile with family, friends, health care providers only, other platform users, or groups of users. Whereas, some users might choose to share their profile in the public domain.

More importantly, user profile information was used to connect users who share common conditions, characteristics or interests (e.g., personal interests, geographical location, medical treatments, gender, age, disease progression), as described below:
If you or a loved one has been affected by a rare disease, you are not alone. Join a community and connect with others like you. (A1, homepage)

Connect with people like you Share your experience, give and get support to improve your life and the lives of others (A8, homepage)

Two platforms (A1 and A8) provided advanced search tools which rely on additional background information on their users to connect users sharing specific experiences (e.g., condition, drug use, or location), or connect users with others like themselves, as illustrated in Figure 8 and Figure 9 below:

Figure 8: Tools to find other patients sharing specific characteristics or experiences on platform A8
Figure 9: Tools to find other patients sharing specific characteristics or experiences on platform A1

Beyond learning from the information shared on user profiles, other users can typically be contacted for information and support (e.g., user to contact other users who have experience with specific conditions, symptoms or side effects). Thus, sharing information on user profiles can provide invaluable information and support for patients learning to better manage their own illness. However, besides connecting patients, user profile information was noted for supporting various business purposes, which will be discussed later in Section 4.3.3.
4.3.2 Sponsors and partners

Besides supporting patients, the analysis revealed that platform tools can also support other parties with an interest in the health and information sharing exchanges, including patient advocacy organizations, pharmaceutical companies, insurance companies, hospitals and health care providers, employers, health plan administrator, regulators and government, corporations, and foundations and individual donors. Other parties were typically referred to as Sponsors and Partners, where the distinctions were not always clear. First, the term Sponsors can refer to other parties who donated funds to the platform; however, Sponsors can also provide or fund platform tools, or purchase platform services such as advertisement or marketing services. Second, Partners can refer to other parties, such as patient advocacy organizers or researchers, who might collaborate, or use the platform with or without financial arrangements. Partners can also provide platform tools, or purchase platform services such as clinical trial recruitment services or marketing services. Table 12 below provides a list of Partners and Sponsors and their relationships with the platforms:
### Table 12: Partners and sponsors and their relationship with the platform

<table>
<thead>
<tr>
<th>Partners and Sponsors</th>
<th>Relationship with platform</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient advocacy groups</td>
<td>Platform owned by patient advocacy organizations (A3, A6); facilitated forums for patient advocacy groups (A4, A8) and, sold tools to a patient advocacy group for supporting another patient platform (A11)</td>
</tr>
<tr>
<td>Pharmaceutical companies; researchers, and insurance companies</td>
<td>Platforms generated income from pharmaceutical companies through posting advertisements or sponsored content, connecting them with patients for clinical trial recruitment, or distributing drug samples to patients (A3, A4, A6, A7, A9, A10). They also sold tools to a pharmaceutical company for supporting another patient platform (A11), sold patient data to pharmaceutical companies, researchers and insurance companies, and connected users directly with site sponsors on the patient platform (A8).</td>
</tr>
<tr>
<td>Hospitals and health care providers</td>
<td>Hospitals and health care providers were listed as partners and sponsors (A1, A7); hospitals and health care organizations were described as clients (A5, A7, A9).</td>
</tr>
<tr>
<td>Employers, health plan administrators, regulators and governments</td>
<td>Employers, health plan administrators, regulators and “innovative government organizations” were described or listed as partners or sponsors (A5, A7, A9, A11)</td>
</tr>
<tr>
<td>Corporations, foundations and individual donors</td>
<td>Platforms sought donations from corporations, foundations and individual donors (A1, A3, A6)</td>
</tr>
</tbody>
</table>

It was noted that the patient platforms supported their Partners and Sponsors, as discussed in the next section.
4.3.3 Income generating processes

Patient platforms generated income in various ways including A) fundraising, donations, and sponsorships; B) posting advertisements and sponsored content; C) marketing services; D) providing tools to support portals or other patient platforms; and, E) providing research services, as explained below.

A) Fundraising, individual and corporate donations, sponsorships

Three not-for-profit platforms (A1, A3, A6) sought financial support through fundraisers, individual donations, corporate sponsorships and grants. Various fundraising processes were identified such as platform A1 asking users to shop at designated retailers (where the platform receives rewards for purchases made by their users), or platform A3 selling mugs or products (where a portion of the sales are donated to the platform), as illustrated below:

Shop at AmazonSmile and Amazon will make a donation to [Platform A1]:
Get started (A1, homepage)

Welcome to Shop for [Platform A3]. Our partners have selected or created items specifically for the benefit of [Platform A3]. A portion of the sale proceeds from your purchase of these items will be donated to [Platform A3], which enables us to continue to provide our online resource to the millions of people we serve each year. Thank you for your contribution. (A3, Shop webpage)
Platform A3 also facilitated a forum dedicated for engaging their users to share fundraising opportunities, as illustrated below:

Advocacy and Fund-Raising Fundraising Opportunities for [Platform A3]
16 Topics 252 Posts
Help support our organization, [Platform A3]! Please note, this is NOT a forum for fundraising for other organizations. (A3, forum description)

In addition, platforms accepted donations from individual users and corporate sponsors. The following examples illustrate how platform A1 sought donations from individuals and corporations, and how platform A3 facilitated a forum for acknowledging donations made in honor of loved ones:

Thanks To Our Sponsors
Want to sponsor this site? Corporate and individual sponsors welcome.
(A1, homepage)

Help us help... Tens of thousands of lives changed every month. Help us change even more lives by donating spare change.
(A1, homepage)

I've Donated to [Platform A3] in honor of...
64 Topics 1,463 Posts
Thank you for your donation! Here is a forum to share with others who you're honoring with your donation.
(A3, forum)

Platforms also accepted sponsorships or grants which can be used for developing platform tools, as illustrated in the example below:
When confronted by breast cancer, many women feel overwhelmed by vast amounts of information, and terrified by the burden of having to make critical decisions quickly. The terms used by doctors to describe breast cancer diagnosis and treatment can sound like a foreign language. And there just isn't enough time to figure out the meaning and pronunciation, when today's average doctor's visit is less than 10 minutes. Xxx has created an innovative tool to address this problem. This dictionary is a compilation of numerous complex breast cancer terms defined in plain English. This program was developed by [Platform A3], and is sponsored in part by an unrestricted educational grant from Bristol-Myers Squibb Oncology, and launched in partnership with Lifetime Television. (A3, Tool)

Start now: Each module below includes information to help you learn and manage your disease including: Videos, publications, worksheets, links to relevant web pages. Navigate these resources and information at your own pace, choosing the topics most relevant to you in order that works best for you and your situations...Sponsors [Platform A6] gratefully acknowledges these educational grants to support this project. Bayer HealthCare. Biogen, Novartis, Sanofi Genzyme, Teva Neuroscience (A6, Tool)

Platforms typically acknowledged the generous financial contribution made by corporate sponsors, which could potentially encourage some users to act more favorably to platform sponsors in future purchases of their products, or services.

That being said, one platform (A10) was noted for marketing their editorial page for posting sponsor content (or accepting funds to write editorial content for their sponsors), as this platform also marketed the trust of their users to sponsors, as illustrated below:
Sponsorship
Highly marketable full editorial page – your content or ours.
(A10 owner site, Advertising Opportunities)

LEVERAGE OUR BRAND TRUST
Let us introduce you to our users with a custom performance-based campaign.
(A10 owner site, Advertising Opportunities)

Thus, it is not clear to what extent platform sponsors could potentially influence the message delivered to engage patients in their health care process. While this was the only example noted where platform owners marketed their editorial page for supporting platform sponsors in this way, it illustrates the potential for patient platforms to post content for their sponsors without necessarily articulating the potential for bias to their users. The posting of sponsored content or advertisements are further discussed in the next section.

B) Advertisements and sponsored content

Most of the patient platforms, including both for-profit and not-for-profit platforms, generated income by posting advertisements and sponsored content at prominent places on their website such as the platform’s homepage, side bars, and/or title bars. The posting of advertisements was justified as a necessary process for offering tools to the public without charging upfront fees, as illustrated below:
[Platform A4] is a mission-driven company, and we want to ensure that we can provide our community free to individuals and non-profit patient advocacy associations. Our feeling on this topic is best captured by the way Katherine Graham described her responsibility as publisher of The Washington Post: "In order to be a good newspaper, we must also be a good business." (A4, Business model)

Advertisements and sponsored content were typically labelled to inform users of content that was subject to different editorial controls. Various labels were used to identify sponsored content, as illustrated in the example below:

In using our site, you will see that some content, buttons, badges and banners are labeled "Sponsored", "From Our Sponsor" or "Advertisement". This content has not been reviewed by the [Platform A9] Editorial Staff and is not subject to this Editorial Policy. Content, buttons, badges or banners labeled "From Our Sponsor" are subject to the policy governing Our Sponsors. Content, buttons, badges and banners labeled "Advertisement" are subject to our Advertising Policy. (A9, Editorial Policy)

Whenever we create original editorial content at the request of a sponsor and the sponsor has selected the topic of the content/program they are funding, we identify the content as being "brought to you by", or similar designations (labels) noted below during the period that the sponsor funds the content/program. In addition sponsors may request similar attribution on our pre-existing editorial content during the period that they fund a program. (A3, Our Sponsors)

Nevertheless, the various labels might not be understood without reading platform policies. With the labelling of advertisements and sponsored content, platform users were viewed as being able to make an informed decision as to whether or not to
view the content, as pointed out below. Thus, platform tools can still be free of charge to users who choose to ignore advertisements and sponsored content.

Since we launched [platform A9], we have regularly sought sponsorships and advertisements from relevant commercial organizations, manufacturers, and other leaders dedicated to providing health and lifestyle information. These sponsorships, which are a form of advertising, enable us to provide you with our award-winning content at no cost to you. [Platform A9] provides opportunities for sponsors to bring you their marketing message and information about their products and services by publishing their information or links within our site. We take several steps to ensure that you can clearly identify content that is provided by and is under the editorial control of our sponsors before you view it, so you can make an informed decision as to whether or not to view it. For more information, read our Advertising Policy. (A9, Our Sponsors)

Furthermore, there was a tendency for some of the platforms to blur the lines between content intended for the benefit of patients (e.g., evidence-based health information), and content intended to benefit sponsors (e.g., advertisements or sponsored content). For example, the terms of use for platform A7 described “marketing material from pharmaceutical manufacturers and company information and data about cancer care” intended to promote the sale of products or services in the same manner as “articles,” “news reports”, or “calculation tools” intended to educate patients. Thus, the platform might not clearly distinguish information provided for different purposes. Moreover, the delivery of advertisements was often
framed as beneficial for platform users, such as posting advertisements as a “convenience to patients” (A5, Terms of Use), or helping patients “make educated healthcare choices” (A10, Privacy policy); however, advertisements are not oriented towards empowering patients to make educated health care decisions; rather, patients can be influenced to purchase products or services as advertised. The framing of advertisements as empowerment may be misleading, as content provided for marketing purposes tends not to be neutral as users are encouraged to act in ways to benefit the advertiser. Besides posting advertisements, platforms also generated income by connecting patients with their sponsors, which will be described in the next section on marketing services.

C) Marketing services

Seven platforms (A3, A4, A6, A7, A8, A9, A10), which included both for-profit and not-for-profit platforms, generated income through marketing services, as illustrated below:

To provide you additional communications, information, and promotions such as newsletters; To generate internal reports about the use of our site; To inform you of other offers, services, or websites available from [platform A10] or third parties including our advertising partners (A10, Privacy policy)

We use personal information that you provide to us in several ways. First, we use it to confirm your Membership, to understand better who is visiting our Site and
using our Service, and to enable us to present content, including advertising, which might suit your interests. Second, we may use the personal information you give us to send you information about [platform A4] and the Service, as well as material on behalf of some of our third parties with whom we have a business relationship. By third parties, we mean, for example, entities such as health associations and advertisers that link to our Site or that make use of our Service. The information we send you may, on occasion, contain advertising or requests either from us or from a third party on whose behalf we would send the information. For example, we may contact you to see whether you are interested in being considered for an upcoming clinical trial that is being sponsored by a pharmaceutical company. (A4, Terms of Use)

Platforms described the use of the personal information collected from their users for supporting marketing services, which can be associated with financial costs to patients (if they are influenced to purchase products, or services). That being said, marketing services can also be associated with unknown costs (e.g., connecting patients directly with pharmaceutical companies for clinical trial opportunities). For example, platform A4 stated that their business model involved helping their users “find relevant clinical trials by inviting them to connect with researchers seeking qualified participants. Clinical trial sponsors pay [Platform A4] for this service” (A4, Business model). The costs associated with this marketing services is not clear as the process deviates from the traditional process whereby patients go to their health care provider(s) who assesses optimal therapies.
Platforms varied on how they obtained user consent to use personal information for business purposes; for instance, platform A9 enabled patients to opt-in for marketing services during the site registration process. In contrast, platform A10 required users to consent with the use of their personal information for marketing services but suggested that patients could opt-out after site registration (e.g., through “message preferences”); however, their privacy policy contradicts this opt-out process as users were told to deactivate their site account if they did not wish to be contacted with sponsor opportunities, as illustrated below:

We help [platform A4] members find relevant clinical trials by inviting them to connect with researchers seeking qualified participants. Clinical trial sponsors pay [platform A4] for this service. Members may choose, if they wish, to not receive information about clinical trials using their message preferences. For more information please read our policy on clinical trials. (A4, Business model)

We do not disclose individually identifiable information about you to third parties without your prior consent. For example, we might contact you to advise you that a pharmaceutical company is planning a clinical trial and to see if you would be interested in learning more information. If you consent, we would arrange for the company to contact you; however, if you did not consent, we would not provide information about you to that company. If you do not wish us to use or disclose personal information that you provide through this Site as disclosed in this Privacy Statement, you should deactivate your membership by notifying xxx and including "DEACTIVATE" in the subject line. (A4, Privacy Policy)
This illustrates how platforms can be oriented towards their own interest (e.g., to generate income from clinical trial enrolments), as users cannot continue to use the platform without agreeing to receive sponsor opportunities.

Also, implicit consent for the sharing (or selling) of user information can be provided during site registration, or when users sign-up for platform tools, offers or services. For instance, to register for one of the sponsored tools provided by platform A9, users must provide implicit consent for sharing their personal health information with the sponsor of the tool. Similarly, users can be deemed to have provided implicit consent to share their personal information with site sponsors when they join patient communities (or community forums) sponsored by these sponsors, as illustrated below:

When you register to join an [platform A10] community and/or register for offers available through our advertising partners you consent to sharing information about yourself, Personally Identifiable Information, so that we can make our services and the services of our partners available to you. (A10)

A social network, organized by health condition, that connects pharmaceutical companies with patients and caregivers in a safe, permission-based manner. (A4)

Regardless of how user consent was sought to share their personal information, platforms can generate income in various ways such as charging their sponsors a fee
for each user they connect with their sponsors. For example, coupons offered by platform A10 to “help patients save money on their healthcare costs,” were also marketed for expanding the market of products sold by site sponsors (which included pharmaceutical companies or diagnostic products company). Thus, what was described as helping users save money, can be coupons to persuade users to change therapies for blood pressure drugs, diabetes drugs, or diagnostic products, as illustrated below:

CHRONIC CONDITION PRESCRIPTION MEDICATIONS

We make managing chronic health conditions easier. We'll work with your doctor and insurance provider to get your medications delivered right to your door at little or no cost.

Save Money Every Month. What if you could save money every single month on the prescription medications you already need and use? Here are a few of the ways we can help you save money every month: We're going to work closely with your insurance provider to ensure that you’re getting the maximum insurance benefit We're going to get you the tools and social support to help you stay with your individual medication regimen – helping you stay healthy and out of the doctor’s office

Your Prescription Medications, Delivered. We know picking up your medications every month isn't exactly the highlight of your day – most would even call it a hassle. Why not sit back and let us help you? We'll make sure you get the right medications, at just the right time. Hands-off, hassle-free. One less thing to worry about. GET DETAILS No Insurance? No Problem. What if you could save money every single month on the prescription medications you already need and use? What if you could pay less for your prescribed medications, even without
insurance? Believe it or not, such a thing is possible. But don’t take our word for it, get in touch with us and find out for yourself! GET DETAILS

(A10, Health medical supplies)

A blood pressure pharma brand presented a coupon to a narrow, qualified audience using our xxx program. Of more than 28k leads delivered, nearly 10% converted to a prescription, well over target...

A diabetes pharma brand sought to increase awareness and patient enrollment through branded placement within targeted content on [a diabetes patient platform]. Their goal was to recruit patients at a cost of under $100 per patient enrollment. We met volume goals with an effective cost of $45 CPPE, 55% below projected cost to client...

A pharmaceutical diagnostics brand sought qualified leads through our [platform program]. We delivered more than 300k qualified leads and 27k new prescriptions. The cost per new patient was $60 and offered a value of $280 to the brand. They quadrupled their [platform] lead budget the following year.

(A10, Advertising opportunities)

While platform users might appear to save money from the transaction (e.g., when the coupon is applied), it is not clear what impact the new drug therapy might have on longer term health care costs, or whether users might be persuaded to change to drug therapies which might not be the optimal therapy for treating their medical condition(s). Nevertheless, these marketing services generate income from users using their actual identities, as the platform can get a fee for each user connected with site sponsors.
D) Tools for other portals or platforms

Three for-profit platforms (A7, A9, A11) marketed their tools (or services) to support health portals or patient platforms for other organizations. Two platforms (A7, A9) described tools which can support users from other health care organizations or employer health plans. The example below illustrates how platform A7 advised external users (e.g., clinic patients) to sign-up, or login, using the link provided to them from their health care provider:

Important note for clinic patients.

If you have been directed to [Platform A7] by your clinic, do not join here. Instead, use the link that was sent to you via email, or sign up through your clinic's website. (Platform A7, Sign-up)

External users (such as clinic patients from other organizations) might be offered additional tools (such as offline health risk assessments and telephonic health coaching), which were not offered in the publicly available patient platform, as illustrated in the example below:

[Platform A9] provides employers and health plans with private online health portals that enable their employees and plan members to make more informed benefit, treatment and provider decisions.

Through a single, secure gateway, individuals can access their personal health information, which is integrated with medical claims and plan specific data within [Platform A9’s] personal health record. Our platform delivers relevant health
content and targeted messaging based on each individual's profile. Our health management services include online and offline health risk assessments, lifestyle education and telephonic health coaching. (A9, Private portal)

Similarly, another platform (A11) described how their publicly available patient platform offered tools to engage users free of charge for the purpose of beta-testing software (e.g., testing software updates, or new tools), which can later be sold to other organizations (or used to operate external patient platforms), as described below:

This public version of our smoking cessation software platform is designed to: Collect anonymous efficacy and clinical data that is used in validating the effectiveness of our software platforms. Your information will be used to collect anonymous efficacy and clinical data that is used in validating the effectiveness of this software platform. (A11, Privacy policy)

In contrast to the other two platforms noted above, which described the possibility of users on the patient platform from external organizations, platform A11 did not mention external users from other organizations. However, platform A11 listed site clients who also provided tools to help users quit smoking; thus, the platform owner appeared to provide smoking cessation tools for supporting three different patient platforms (1 publicly available platform studied in this research; 1 platform owned by a patient advocacy group; and 1 platform owned by a pharmaceutical company).

Although these platforms can provide the same or similar tools to engage patients,
and can be supported by the same staff moderators, the platforms operated as separate entities (e.g., different user interfaces, login processes and site policies).

E) Supporting research services

Platforms collected information from their users for supporting research services, which can help platform owners generate income. First, platforms collected user information through questionnaires and surveys, which can be used to deliver customized health information (including customized advertisements) or sold to platform sponsors. While platform users were not required to provide their information on surveys or questionnaires, some of them could be encouraged to do so; yet, it is not clear to what extent users might understand how platforms generate income from survey results, or the extent of information that could be sold to site sponsors. For example, the following platform disclosed how survey results can be combined with other information collected from their users and subsequently sold to site partners:

[Platform A8] may also periodically ask Members to complete short surveys about their experiences (including questions about products and services). Survey responses are analyzed, combined with Members’ Shared Data and shared with and/or sold to Partners. Member participation in these surveys is not required, and refusal to do so will not impact a Member’s experience on the Site. (A8, Privacy Policy)
Second, platforms collected user information through two-way tools (e.g., user profiles, self-tracking tools), which can be retained in a larger repository for supporting research purposes. Patients were encouraged to submit their information for their own benefit (e.g., provide more information about themselves on user profiles to better connect with other users online), where the repository of information can subsequently be used to support others, as described by the platforms below:

Track your healthcare
Chart your health over time and contribute to research that can advance medicine for all. (A8, homepage)

How is the optional background information used? The more other users know about the users rating the drugs, the more valuable those ratings become. An 18-year-old college student might have a different experience with a particular medication than a post-menopausal woman of 60 on the same drug. Once we have a good sampling of this data, we’ll begin letting you search the effectiveness of a drug in individuals similar to you. (A9, Frequently Asked Questions)

Accordingly, platform users were encouraged to share their information to support research for the greater social good, such as:

As for sharing health information, we believe the more health information you share, the closer we get to improving our health system and advancing the knowledge of your conditions. So, all we can ask is that you participate as fully as you feel comfortable doing. (A8, Frequently Asked Questions)
Our goal is to provide a platform for patients who want to share their health information to create collective knowledge about disease, health, and treatments. (A8, Privacy policy)

When people share information on our website, they generate data about the real-world nature of disease that helps researchers, pharmaceutical companies, regulators, providers and nonprofits develop more effective products, services and care. (A8, Who we are)

Yet, the analysis revealed that the repository of information can also be used in ways to support the financial interest of platform owners, which may not always support the advancement of knowledge in general. For example, platform A8 was not interested in supporting environmental research, or student research, which might not generate income. Instead, it was noted that the platform was more likely to apply the repository of information collected from their users to support research where income can be generated, as illustrated below:

Have you thought of doing research on the relationship between exposures and disease (e.g. chemical exposure, occupation, infection)?

While this is an interesting research area the reality is that it is very difficult to do well on our platform. We tend to have a highly engaged population with a number of biases such as higher education and socioeconomic status that might mask subtle effects of things like exposure (e.g. it might be unsurprising to find a high instance of engineers with a given disease on our site because measurement and self-tracking may appeal to this group disproportionately). We believe the best exposure studies still come from traditional epidemiology, and while this is on our long-term plan we have no current work in this area. (A8, Frequently Asked Questions)
I’m a student and I’d like to post a link on your site to my survey for a research project, is that OK?

Because we want to minimize response burden to our users and avoid duplication of work we don’t typically allow links to student projects from our site. Please do not post in our forum or contact patients directly without an agreement in place, as this is a violation of our terms of service. If you have a project you want to discuss, reach out to our research team. (A8, Frequently Asked Questions)

I am a clinician / researcher and would like to collaborate with you on a new research project. Who should I contact?

We are proud to collaborate with some of the leading research institutions in the world on useful and interesting academic research. Please write to the research team with your initial research proposal. If we think a research project has the potential to benefit our users we would be happy to assist you in writing a grant proposal and helping to describe what we do for your local Internal Review Board (IRB). The proportion of funding we would receive depends on a number of factors including the contribution of our staff to the design, the difficulty of accessing the specific population of interest, and the source of funding. (A8, Frequently Asked Questions)

The above quote taken from platform A8 reflects the platform's policy to not allow students to post surveys on the platform. It does not apply to research done for this dissertation since this study relied on information posted in the public domain and no survey was posted on any patient platforms to collect user information.

Tensions were also associated with how platform A8 collected user information to share with their sponsors to generate income; yet, users were required to provide implicit consent to the sharing of what was defined as "Shared Data" as part of the
registration process. The “Shared Data” includes all of the personal health information submitted by users through platform tools, such as the user’s health profile, biographical information, condition/disease information, treatment information, symptom information, health scores/charts over time, laboratory results, as well as “connections with other people” on the platform, as illustrated below:

Shared Data

Some of the information that Members provide about themselves may be shared with the xxx community, Partners, and others (“Shared Data”). Examples of Shared Data that Members may submit at the Site, including through their health profile (“My profile”), may include:

Biographical information, e.g. photograph, biography, gender, age, location (city, state and country), general notes;

Condition/disease information, e.g. diagnosis date, first symptom, family history;
Treatment information, e.g. treatment start dates, stop dates, dosages, side effects, treatment evaluations;
Laboratory results and biomarkers, e.g. CD-4 count, viral load, creatinine, voice features, images; Genetic information, e.g. information on individual genes and/or entire genetic scans; Individual and aggregated survey responses;
Information shared via free text fields, e.g. the forum, treatment evaluations, surveys, annotations, journals, feeds, adverse event reports; and
Connections to other people on the Site, e.g. invited care team member, mentors, feeds, subscriptions. (A8, Privacy policy)

In fact, users were advised to expect “almost any piece of information they submitted” to be shared or sold (except restricted data such as their email address,
name and physical address). This included information which may not be accessible to the users themselves (or “not currently displayed”), as noted below:

How your data is used

Members should expect that every piece of information they submit (even if it is not currently displayed), except for Restricted Data, may be shared with the community, other patients, and Partners. Members are encouraged to share health information but should consider that the more information that is entered, the more likely it is that a Member could be located or identified. (A8, Frequently Asked Questions)

Besides selling user information such as biographical information, personal health information, genetic information, and connections to other people on the website, this platform also enabled their sponsors to communicate directly with users on the patient platform, as noted below:

...We also provide a voluntary opt-in service to allow partners to directly communicate with patient members through our system. To learn more, see how we make money or read details on what is shared and sold in our Privacy Policy. (A8, Frequently Asked Questions)

What’s more is that this platform was very transparent in disclosing their intention to sell the information they collected from their users to “companies that are developing or selling products to patients” which included companies that sell “drugs, devices, equipment, insurance, and medical service,” as noted below:
How does [platform A8] make money?

We take the information patients like you share about your experience with the disease and sell it to our partners (i.e., companies that are developing or selling products to patients). These products may include drugs, devices, equipment, insurance, and medical services. Except for the restricted personal information you entered when registering for the site, you should expect that every piece of information you submit (even if it is not currently displayed) may be shared with our partners and any member of [platform A8], including other patients. We do not rent, sell or share personally identifiable information for marketing purposes or without explicit consent. Because we believe in transparency, we tell our members exactly what we do and do not do with their data.

By selling this data and engaging our partners in conversations about patient needs, we’re helping them better understand the real world medical value of their products so they can improve them. We are also helping companies accelerate the development of new solutions for patients.

[Platform A8] is a for-profit company (with a not-just-for-profit attitude). Every partnership we develop must bring us closer to aligning patient and industry interests. Our end goal is improved patient care and quality of life. (A8, Frequently Asked Questions)

Also, users were warned that despite the potential benefit for sharing information about themselves, sharing information can put platform users at risk of being identified and their information potentially used against them, as described below:

Is sharing data on [Platform A8] safe?

When sharing information online about your health or a specific condition, you should know there is always a risk that someone could use this information against you. For example, medical and life insurance companies have clauses that exclude pre-existing conditions or employers may not want to employ someone with a high-cost or high-risk disease. We know these risks are real.
We also believe that openly sharing information (see our Openness Philosophy) is an important way to improve medical care. Ultimately, you decide how to balance these risks. When you provide your name and email upon joining the site, we treat that as “restricted” (or unshared) data (see our Privacy Policy). However, you control what information you enter and, therefore, share everywhere else on the site. The more personal information you share on our site (e.g., photos, location, birthday or other personal information which is optional to add in your profile), the more risk there is that someone can identify you. (A8, Frequently Asked Questions)

Therefore, while the selling of user information was framed as supporting research to find cures, users were required to allow the platform to sell almost all of the information they collected on their users to companies that sold products and services to patients (including insurance companies). Although this platform was the only platform which was transparent in describing how they can sell user information to other parties, including companies that can use the information against patients (e.g., insurance companies can deny insurance coverage for patients), it illustrates how platforms can operate in ways which may not be mutually beneficial to patients.
4.3.4 Summary

Patient platforms generate income in multiple ways, including fundraising, donations, and sponsorships; posting advertisements and sponsored content; providing marketing services, providing portal services; and supporting research services.

Results of the study illustrate how patient platforms provide one-way tools, two-way tools and multi-way tools to engage patients in their health care process, which can also collect user information to support other interests. This included information automatically collected from patients when they visit the website (which can be used to deliver advertisements, or personalized advertisements), personal information (including personal health information) collected during site registration and other points of access (which can be used for marketing services such as contacting patients with offers from site sponsors), and user profile information for sharing with other platform users. It was therefore noted that while patient platforms provided a collection of tools to engage patients in their health care process, the tools can also support various income generating processes. Given that platforms engaged patients in ways that can influence how users manage their health issues, the use of platform tools to engage patients can have a broader impact on the health care system.

Implications from these study findings will be discussed in the next chapter.
Chapter 5
Discussion

This chapter will discuss the implications of the study findings in terms of what the platforms said they were doing, what types of tools were provided, and issues associated with income generating processes (i.e., posting advertisements, marketing services). The income generating processes highlight that while all platforms studied in this research were freely available without upfront charges, other potential costs were associated with using them. The ways that platforms engage their users can have significant implications for the health of patients, and the health care system.

5.1 Mapping of tools

As discussed in Section 4.1, the study identified three types of tools provided by patient platforms to engage their users (i.e., one-way, two-way and multi-way tools). The patient engagement framework, as described in Section 3.3.1, served as a useful way to analyze and categorize platform tools according to how they engaged their users (see Table 13). As can be seen, tools could be mapped to more than one category; however, two-way tools were the only ones identified as aligning with the partner with patients category. The mapping of various tools to patient engagement processes can support health care organizations in designing how to engage patients using ICT. For instance, health care organizations interested in supporting
collaborative decision-making processes might use it to identify tools that support the *partner with patients* process.

**Table 13: Mapping of platform tools according to how they engaged users**

<table>
<thead>
<tr>
<th>Inform patients</th>
<th>Inform patients</th>
<th>Involve patients</th>
<th>Involve patients</th>
<th>Empower patients</th>
<th>Support patient eCommunities</th>
<th>Partner with patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Featured on platform homepages, or other main webpages</td>
<td>Health articles on lifestyle changes to prevent disease; news, trends</td>
<td>Patient information on medical conditions or drug therapies</td>
<td>User journal for recording personal experiences</td>
<td>In-depth medical references; symptom checking tools</td>
<td>Tools to share health charts or health records with other users</td>
<td>Tools to share health charts, or health records with health care providers</td>
</tr>
<tr>
<td><strong>One-way tools</strong></td>
<td><strong>Two-way tools</strong></td>
<td><strong>Multi-way tools</strong></td>
<td><strong>Multi-way tools</strong></td>
<td><strong>Multi-way tools</strong></td>
<td><strong>Multi-way tools</strong></td>
<td><strong>Multi-way tools</strong></td>
</tr>
<tr>
<td>Disseminates information from platform</td>
<td>Provides information collected from individual users</td>
<td>Excerpts from most recent user profiles</td>
<td>Excerpts from most recent discussion postings</td>
<td>Forums for sharing experiences, or posting brief questions and answers (which does not provide sufficient information for supporting problem-solving tasks)</td>
<td>Forums for consulting with others on treatment options or diagnosis</td>
<td>Tools to share health charts, or health records with health care providers</td>
</tr>
</tbody>
</table>
Previous research by Klasnja & Pratt (2012) identified five intervention strategies used in mobile or phone-based interventions which share similarities with the patient engagement framework; namely, 1) track health information, 2) involve the healthcare team, 3) leverage social influence, 4) increase the accessibility of health information, and 5) utilize entertainment. Specifically, the first intervention, track health information, applies to two-way tools, which can support various patient engagement categories. The second intervention, involve the healthcare team, is related to the partner with patients category. The third intervention, leverage social influence, is related to the support patient eCommunity category. The fourth intervention, increase the accessibility of health information, is related to the inform patient category. The patient engagement framework does not include any categories relating to the use of entertainment as a strategy to engage patients. Although some of the patient platforms were described for entertainment purposes, tools provided to entertain users may not necessarily be evidence-based and users may not be aware of this without reading platform policies. A recent scoping review of direct-to-consumer mobile apps for self-diagnosis was inconclusive with respect to safety and effectiveness (Millenson, Baldwin, Zipperer & Singh, 2018).
evidence supporting web-based patient platform tools, which is the scope of this dissertation, remains to be studied.

Nevertheless, the mapping of platform tools according to five patient engagement categories can be used for designing new tools for better connecting patients with their health care providers. Such tools may include, for example, features to enable discussion of information disseminated through one-way tools with health care providers, or multi-way tools to connect users with their team of health care providers, which can promote patient participation in decision-making processes and improve communication amongst the health care team. Nevertheless, besides engaging patients in their health care process, the analysis revealed that both for-profit and not-for-profit platforms provided tools which supported other business interests, such as delivering advertisements and sponsored content, which will be discussed in the subsequent section.
5.2 Direct-to-consumer advertising and marketing: new ways to reach patients

As discussed in Section 4.1.1, patient platforms provided a broad range of one-way tools to disseminate science-based information in the public domain. Applying concepts from the Shannon & Weaver (1949) model of communication, one-way tools act as a channel to send messages from platform owners (as information source) to platform users (as receivers), as illustrated in the figure below:

![Channel for sending message from sender to receiver](adapted from Shannon & Weaver, 1949)

Accordingly, the study revealed that besides delivering health information to engage patients in their health care process, this channel was also used for delivering advertisements and marketing material to users. That is, both for-profit and not-for-profit platforms generated income by posting advertisements and sponsored content at prominent places on their website, such as the platform’s homepage, side bars, and/or title bar, which was accessible to all users without requiring site registration (See Section 4.3.3). Although the posting of advertisements was described as a necessary process for offering tools to the public without charging
upfront fees, studies have shown that advertising directly to patients (referred to as direct-to-consumer advertising) can drive up health care costs since pharmaceutical companies tend to promote more expensive drug therapies (e.g. newer drugs, or newer dosage forms of drugs), and patients can be influenced to go to their doctors to obtain drugs as advertised (Gagnon & Lexchin, 2008; Mackey, Cuomo, & Liang, 2015; Wilkes, Bell, & Kravitz, 2000).

Despite the fact that advertisements and sponsored tools were typically labelled to inform users of potentially biased content, at least one platform marketed their editorial page for posting sponsored content (or accepting funds to write content for their sponsors on their editorial page). As discussed in Section 4.3.3., this illustrates the possibility that sponsors could influence messages delivered to engage platform users. Moreover, there was a tendency for platforms to blur the lines between content intended for the benefit of patients and content intended for the benefit of sponsors such as framing advertisements as empowering patients to make health care choices (Section 4.3.3). Without governing bodies to ensure the accountability of health information over the Internet, patients can be exposed to content which could potentially promote behaviors intended for the best interests of
site sponsors (such as encourage users to purchase of products or services) rather than for the best interests of patients.

Besides advertisements, platforms provided users with sponsored tools produced through various funding arrangements such as educational grants, or sponsorships. This can be viewed as mutually beneficial for users who can access health information without paying upfront fees; however, more research is needed in this evolving area to better understand its impact on the health of patients and health system costs. For instance, the tools could potentially influence some users to act more favorably towards tool sponsors in future purchases of health care products or services. Also, the study identified various types of sponsored tools provided to engage users, such as the multiple sclerosis assessment tool illustrated in Section 4.1.1, which was sponsored by two pharmaceutical companies that sell drugs to treat multiple sclerosis. While self-assessment tools could potentially lead to earlier diagnosis, the impact of providing self-assessment tools with potential treatment options warrants further research, particularly since these tools were provided directly to users (with various health literacy levels), who may, or may not have consulted their health care provider on their symptoms. Also, with the availability of online drug distributors (operating from global jurisdictions) from which platform
users might attempt to obtain medications (Gernburd & Jadad, 2007; Ivanitskaya et al., 2010; Liang & Mackey, 2011), and the ability to order diagnostic tests over the Internet (Rockwell, 2017), sponsored tools can potentially influence some users to order their own diagnostic tests and/or drug therapies, which could have broader health implications (e.g., treat conditions with unauthentic or unnecessary drug therapies).

In addition, patient platforms offer a rich environment for disease awareness efforts (such as educating the public on rare diseases). Researchers have identified concerns over disease awareness campaigns, which have the potential to promote diagnostic testing and drug therapies. For instance, Layton et al. (2017) found that increased television exposure to testosterone advertisements was associated with more testosterone tests ordered and more testosterone prescribed without testing; yet, routine testosterone supplementation may not be beneficial.

Similarly, Mailankody & Prasad (2017) raised concerns over disease awareness campaigns, which can act as a subtle form of advertising. The authors identified a partnership between a pharmaceutical company (Inocyte Corporation) and soap opera producers (i.e., General Hospital television series) to raise awareness about a rare disease (polycytermia verais), which could potentially drive “wasteful diagnostic
testing, overdiagnosis and inappropriate therapy” (Mailankody & Prasad 2017, p. 2480). This is because the disease awareness campaign could potentially increase diagnostic testing for the rare disease, which can subsequently increase the number of patients identified and treated for the rare medical condition; however, the diagnostic criteria for the rare disease have yet to be clearly defined. Also, the television series was noted for promoting the drug to be used outside of FDA approved indications. Since advertising on patient platforms can act in a similar manner as TV advertisements, expanding the use of drug therapies for treating indications beyond those approved by the FDA, can be associated with unknown benefits and risks, as well as escalated costs.

Similarly, concerns have also been raised over disease awareness campaigns, which can potentially influence the choice of therapy and thereby increase drug expenditures (e.g., patients asking physicians to prescribe promoted drugs which may not be the most cost effective therapies) (Mintzes et al., 2003). For instance, Jong et al. (2004) studied the impact of a national campaign in Denmark to raise awareness of onychomycosis (toe nail fungal infection), which was funded by Novartis, the manufacturer of an antifungal medication (terbinafine) for treating onychomycosis. The researchers found that despite the availability of various
antifungal treatment options, the disease awareness campaign was followed by an increase in prescriptions for terbinafine only (the drug sold by the campaign sponsor) and not for competitor products. This example illustrates how sponsored tools can potentially promote products and services sold by the pharmaceutical company sponsoring the educational information.

Finally, one platform was noted for providing coupons directly to users for marketing purposes. As discussed in Section 4.3.3, users were presented with coupons to lower their health care costs, which encouraged them to switch drug therapies from those determined by health care providers without incentives. Research is needed to better understand the impact of such marketing process on the health of patients and the health care system.

In summary, this section has illustrated how patient platforms provide a channel to deliver advertisements, sponsored tools or disease awareness information directly to patients, which can have a broader impact on the health of patients and the health care system (e.g., influence patients to request drugs as advertised, or diagnostic tests). Patient platforms fall outside traditional safeguards that would otherwise monitor the marketing of drugs by pharmaceutical companies, such as the Pharmaceutical Advertising Advisory Board (PAAB) in Canada. Additionally, social
media platforms are not health care entities that would otherwise be governed by privacy legislations such as *Health Insurance Portability and Accountability Act* of 1996 (HIPAA) in the U.S., or *Personal Health Information Protection Act*, 2004 (PHIPA) in Ontario. Although direct-to-consumer advertising and marketing (e.g., television advertising, posters) is prohibited in many countries, including Canada, patient platforms now enable new channels to reach patients with advertisements across geographic boundaries (Mackey et al., 2015; Rozenblum & Bates, 2013). Thus, pharmaceutical companies in countries with less stringent direct-to-consumer advertising policies, such as the United States and New Zealand, can now post advertisements on the Internet to reach patients in other countries such as Canada (Hébert, 2008). Liang and Mackey (2011) argue that changes are needed to regulate how pharmaceutical companies advertise their drugs globally through social media platforms, as these processes can promote drug therapies and drive up drug costs.

### 5.3 Disruptive technology: changing how patients participate in health care process

A wide variety of disruptive technologies are now readily available on the Internet, which have the potential to engage and empower patients to drive better health outcomes. Besides self-diagnosis tools provided differently to patients, as described
by Millenson, et al. (2018), patient platforms also provided a variety of two-way tools to actively engage registered users to submit information (e.g., user profiles, self-tracking tools, personal health records), as described in Section 4.1.2. Applying concepts from the Shannon & Weaver model of communication (1949), two-way tools act a channel for users to send their own information to health care provider(s) (which align with the partner with patients category), or to other users (which align with the support patient eCommunity category). Two-way tools also align with the empower patients category since patients can better control their own health issues through the self-knowledge gained by collecting their own health information over time.

None of the tools were described by the platforms as providing medical advice, or replacing health care providers, but the tools can include components which take on tasks traditionally performed by health care providers (such as notifying patients directly on potential drug interactions, FDA warnings or clinical trial opportunities (Section 4.1.1)). Despite the potential benefits of engaging patients to take on an expanded role in their own care, this may or may not reflect the role that patients truly prefer, as concerns have been raised over use of technology “as a substitute for rather than a complement to conventional health care” (Miller & West, 2009, p. 263).
This is particularly important as recent research by Thakkar (unpublished PhD dissertation) confirms findings from earlier research by Deber and colleagues (1996, 2007) that patients prefer a shared or collaborative role, rather than an autonomous one in their treatment decisions.

In addition, the analysis of platform policies revealed disclaimers which do not hold platform owners accountable for their tools. For example, platforms tended not to hold themselves accountable to the accuracy of their tools, whereas, platform policies can require users to submit accurate and updated information to the platforms (Section 4.3.3). Interestingly, none of the platforms stated that they were intended to be used for health care purposes and, as illustrated in Section 4.1.2, some claimed that their two-way tools (e.g., quit meters) were provided for entertainment purposes. However, users may not be aware that the accuracy of two-way tools might be “undetermined” without reading platform policies. Thus, without governing bodies to ensure the accuracy of platform tools, platforms can potentially provide tools to engage patients in their health care process, which may not be evidence-based. Given that platforms are generally not responsible for how users might decide to use their tools (which platforms clearly stated were not intended for
health care purposes or to replace health care providers or services), patients can be left to address negative consequences should they occur.

Finally, two-way tools have the ability to support health behaviors, which can have broader health care impacts such as testing of unproven drug therapies, or therapies outside of what might be considered as safe therapeutic doses. As discussed in Section 4.1.2, one platform offered two-way tools that can track the efficacy and safety of medical interventions not yet studied in clinical settings. While this type of information might be useful for patients who wish to experiment with medical interventions (e.g., drugs which have not yet been shown to have clinical effects for specific indications, or taking high dose of drugs beyond therapeutic ranges for extended periods of time), as well as for platform sponsors (such as pharmaceutical companies in search for new markets or new indications for established medical interventions), this process can have critical impacts on the health of patients and the health care system if patients are harmed as a result of using these tools. The platform is not accountable for what users decide to do on their own, even if it is done through use of the patient platform. Therefore, findings from this study add to the body of literature that raises concerns over unhealthy behaviors promoted by information shared on the Internet such as information shared by groups promoting
anorexia (Gavin, Rodham, & Poyer, 2008; Juarascio, Shoaib, & Timko, 2010), information promoting unproven treatments such as CCSVI (Chafe, Born, Slutsky, & Laupacis, 2011), and information encouraging people to self-(mis)diagnose (Pulman & Taylor, 2012)).

5.4 Forum as a community and platform as a community

As discussed in Section 4.2, all of the platforms promoted a sense of community by connecting users with one another for sharing information relating to the same or related medical condition(s). However, unlike communities which were historically defined by “close knit groups in a single location” based on factors such as birth and physical location (Wellman, 1982), these communities resembled online communities as described by Preece & Maloney-Krichmar (2005), which focus on “the people who come together for a particular purpose and who are guided by policies (including norms and rules) and supported by software.” That being said, the so-called communities facilitated by the patient platforms in this dissertation do not necessarily meet the criteria of online communities as defined by researchers who study them, which can also be variably defined (Preece, 2000; Preece & Maloney-Krichmar, 2005).
Regardless, forums were generally the main tools used by patient platforms to connect their communities of users. As discussed in Section 4.2, platforms facilitated two types of communities which were supported by different forum information architectures; namely, 1) one group of platforms offered condition-specific forums referred to as communities for posting questions and answers on specific medical conditions; and 2) another group of platforms referred to themselves as communities, which offered discussion forums for sharing information, experiences and knowledge relating to the same condition. Only for-profit platforms were noted for offering conditions-specific community forums, which appeared to supplement other one-way and/or two-way tools. All of the not-for-profit platforms referred to the platform as a community, and relied on content shared on discussion forums for engaging other users. These discussion forums were sorted by categories and subcategories, included more author details (such as user photo, screen name, history of platform use, platform titles), enabled platform users to develop an online identity through participation on the platform over time and support an existing community of patients whom can meet offline. This resembles online communities described by Fayard & DeSanctis (2005), who found that a loose connection of professionals with a common interest can develop into online communities, which
can evolve into an offline group. Conversely, Kavanaugh, Carroll, Rosson, Zin, & Reese (2006) studied how offline communities can meet online, supporting the view of Wenger et al. (2002 as cited by Fayard & DeSanctis, 2005), who highlighted the importance of embodiment for distributed communities of practice (e.g., arranging teleconferences, face-to-face meetings, etc.).

Nevertheless, previous research identified that patients still go to social media platforms to exchange information in jurisdictions such as Denmark and U.K. that have successfully implemented population-wide patient portals (Andersen & Medaglia, 2012; Griffith et al., 2012). This dissertation adds a possible explanation to these findings. That is, it was noted that patient platforms supporting multiple conditions (which referred to their forums as communities), tended to encourage quick information exchanges. Whereas, platforms supporting a single condition (and referred to the platform as a community) tended to encourage discussions of various topics of interests. This latter group of platforms offered features for better connecting users with one another for information and support, such as forums sorted by multiple categories and sub-categories, user postings with more author details, mechanisms for developing an online identity through participation over time, and potentially ways for connect with others offline (see Section 4.2.2). These
findings may support the design of better tools for engaging patients by incorporating some of these features into health care organizations' patient portals, although more research on this topic is needed.

Nevertheless, besides connecting users, some platforms were noted for encouraging their so-called community to act in ways which could also help the platform generate income. Issues associated with how platforms generate income from their community of users, will be discussed in the next section.

5.5 User information for generating income and privacy issues

Platform rules and policies (e.g., terms of use and privacy policies) served as a rich resource for studying what patient platforms were doing, particularly since the policies typically disclosed the different types of information collected from platform users, as well as how the collected information may be used for generating income. While some users might not mind the use of their information in this way, more research is needed to better understand the impact of these income generating processes since all of the platforms collected user information from site visitors and registered users, which can influence how patients manage their health issues.
A) Collection and use of non-personal information

The study revealed that patient platforms automatically collect information from content readers (including both visitors and registered users), whenever the platform was accessed for information such as the IP address. The patient platforms described IP address as “non-personal information”, particularly since all of the platforms collected this information and none of the platforms committed themselves to handling IP addresses in a secured manner. Although some jurisdictions might define IP address as personal health information, such as the US Health Insurance Portability and Accountability Act of 1995 (HIPAA), patient platforms are not considered healthcare entities governed by HIPAA. Thus, by defining IP addresses as non-personal information and allowing themselves the ability to combine non-personal information with personal information collected or acquired on their users, platforms can potentially identify the users whom they track, which can be used at their disposal for various business purposes such as marketing.

As discussed in Section 4.3.1, users do not submit their information during this process. Instead, the platforms automatically collected information from users through cookies and other tracking mechanisms whenever users visit the platform.

While some users might not mind being tracked to receive personalized
advertisements, or might view this form of advertising as a fair exchange for using platform tools without paying direct fees, others may be influenced to purchase products or services as a result of receiving personalized advertisements. Also, the automatic tracking of platform users can be associated with privacy costs which may not be obvious to platform users since platforms can potentially identify users whom they track by combining the non-personal and personal information collected, or acquired, on their users, as discussed in Section 4.3.2. Citing Malin’s (2005) observation that the majority of Americans (87%) can be uniquely identified by linking a birth date, five-digit zip code, and gender, Krishnamurthy & Wills (2009) argued that very few details are needed to identify a person. Users may not be aware of the extent to which they might be tracked, particularly since this process could take place automatically without the need to submit their information and without the ability for users to control what information is collected from or acquired on them from other sources.

In addition, it was noted that platforms typically allowed their sponsors to automatically collect information from users through links on advertisements and sponsored content, and users may not be aware when they are inadvertently redirected to other websites where third-party cookies can be placed on their
computers. The collection of user information from third-party websites is not governed by platform policies (e.g., privacy policy). As discussed in Section 4.3.1, only one platform was noted for putting restrictions on how their sponsors collect user information on one of their tools. Therefore, study findings point to the need for measures to protect users from inadvertently providing information to others without their knowledge, particularly since the tracking of users can potentially include their health information (e.g., tracking rare disease patients where their identity might be revealed). This can pose risks for patients (e.g., individuals with rare diseases who are tracked) such as declined insurance, as well as enable site sponsors (e.g., pharmaceutical companies) to potentially reach them with more opportunities, or marketing material.

B) Collection and use of personal information

As noted in Section 4.3.3, personal information collected from platform users can be used for business purposes such as connecting patients with sponsors for marketing purposes. However, besides promoting the purchase of products and services, the study revealed that platforms can use personal information of their users to notify users on clinical trial opportunities where the costs might not be clear. Connecting patients directly to pharmaceutical manufacturers for clinical trial enrollment
warrants more research because this process deviates from the traditional health care process where patients seek medical interventions (including clinical trial opportunities) from the patient’s health care provider (who determines the optimal drug therapy for their patients).

Furthermore, the study revealed numerous examples where the access to platform tools required users to provide implicit consent for sharing their information with site sponsors. Although platforms can be transparent in disclosing how they intend to sell the information they collect to generate income, tensions were associated with the informed consent process since users can be required to consent with these terms in order to access platform tools. In one particular case, the platform was transparent in disclosing how they sell user information to companies (including insurance companies) which can use the information against platform users (e.g., for insurance policies or claims). Yet, it is not clear to what extent platform users read and understand the terms to which they are required to consent with in order to use platform tools. Previous research has noted that most users do not read platform policies before consenting to the terms of use (Obar & Oeldorf-Hirsch, 2016; Steinfield, 2016). Schaub et al. (2015, p.12) argue that “a privacy policy, which may be necessary for regulatory compliance, is insufficient and often unsuitable for
informing users.” These authors suggest design options for more effective privacy notices (such as using alternative channels to notify users, and providing notices and control options at different times).

Finally, one platform encouraged their community of users to contribute their own personal information for the benefit of the community, or for the greater social good. However, the repository of information can be sold to sponsors to generate income (e.g., selling user information to support pharmaceutical companies looking for new markets for drug therapies) rather than support research with limited or no funding (such as environmental research exploring ways to prevent disease in larger populations or student research), which could benefit patients without necessarily generating profits for companies.

C) Protecting user information

As discussed in Section 4.3.1, all platforms were committed to protecting the personal information they collected from their users; however, platforms varied in their efforts to protect the user information they collected. Platforms who offered portal services for health care organizations tended to describe higher security measures, such as bank-level security. The varying levels of security efforts is consistent with other research, which identified privacy issues from health care
applications (Carrión, Fernández-Alemán & Toval, 2011; Señor, Fernández-Alemán & Toval, 2012), as well as privacy concerns identified from applications certified as clinically safe and trustworthy by health care authorities such as the UK NHS Health Apps Library (Huckvale, Prieto, Tilney, Benghozi & Car, 2015).

In summary, the analysis of platform policies illustrated how platforms can be oriented towards supporting their own interests, and the interests of their sponsors, which may or may not align with the patients’ interests. This dissertation points to the potential for harm and evokes the policy issue of whether (and how) authorities might protect users from processes which may not be in their best interests, particularly since users may not read or understand the policies to which they are required to consent.

5.6 Limitations and future research

Although the collection of publicly available data from patient platforms provided a rich source of data to analyze what platforms were doing, there are some limitations to the study and opportunities for future research, which will be discussed as follows.
First, the platform selection process was designed to capture the variability of platforms across several attributes. This served as a useful way to analyze the selected platforms since patient engagement processes were identified across the different platforms analyzed. However, data collected from eleven patient platforms were not sufficient to produce generalizable findings. Although study findings relate specifically to the selected platforms studied in this research, study results produced transferable insights that can be applied to similar settings such as health portals for health care organizations (or government information systems) to support the design of better tools for supporting patient engagement processes. For instance, the mapping of platform tools provides a listing of various types of tools, which can support the design of health care portals (Section 5.1). Also, future studies can explore the potential for designing one-way or multi-way tools with features to share content with health care providers to better support learning and collaborative decision-making processes.

The research findings reflect processes occurring on the selected platforms during the data collection period only. Since websites are dynamic and subject to changes in design, content and link structures (both from and to the website), data were captured as screenshots, saved and stored for offline analysis (Bar-Ilan & Peritz, ...
2004). While this approach only captures a snapshot of the platforms at the time of data collection, it offers a useful way to analyze what can occur on patient platforms in this emerging area. It was noted that one of the patient platforms subsequently ceased its operations during the study period, and one platform later required platform users to register for a site account in order to view content that was previously posted in the public domain. Nevertheless, the analysis of data collected from selected platforms during a defined period of time, illustrates what can occur on social media platforms and highlight important policy implications, particularly since platforms are not currently governed to ensure the sharing of accurate information, or information which does not do harm.

Moreover, this study discovered how patient platforms can be used for direct-to-consumer advertising and marketing, which have the potential to drive higher health care costs. Given the rapid development of artificial intelligence and the current debates about “fake news”, future research is needed in this evolving area since sharing information (which might not be evidence-based) through patient platforms can have an impact on the health of individual patients and broader impacts on health care systems.
All of the study platforms provided tools to engage and empower patients to gain control over their health care process without necessarily consulting with their health care providers. This disruptive technology can encourage patients to manage their health issues in ways that deviate from traditional processes of consulting with their health care provider(s). Although patient platforms can re-shape the role patients play in their health care process, and perhaps encourage some users to take on a more collaborative role in their treatment decisions, future research is needed to explore what patients think about platform tools and how patients might wish to use tools to support their health care process. Also, the classification of tools reflects what platform tools can do, but did not include direct observation of user behavior. Since platform tools can be used in ways which are not intended by platform owners, future research exploring how people actually use the different types of tools can add to our understanding of how best to engage patients in their own health care process.

Another limitation of the study is that although framework analysis helps to delineate the scope of the analysis aimed at addressing the research problem and questions, it can potentially limit the discovery of issues not identified in the research questions and analytical framework. As such, efforts were made throughout
the study to remain “curious,” “adaptable” and “open to the emergence of unexpected data” (Morgan, 2007), where framework analysis allowed for interpretation and modification of the framework as themes emerge from the data. Accordingly, while the initial framework was based on concepts described in the background section, the framework was revised and improved upon as data emerged. The final framework was grounded in the data as well as the literature and themes revealed in the analysis, which extended beyond patient engagement processes.

Qualitative research can be associated with researcher bias, as it relies on researchers to code data for analysis. Although coding by multiple researchers can help minimize the possibility of coding errors, study data were analyzed only by one researcher to ensure consistency in coding. To mitigate this limitation, the researcher met with her thesis supervisor on a bi-weekly basis to discuss coding and data analysis to increase reliability in observations and interpretation of the data. Furthermore, since the researcher is also a health care provider who has supported patients seeking unconventional therapies to treat critical illnesses, bi-weekly discussions with her thesis supervisor (non-health care provider) also helped to minimize subjective biases that could potentially influence the analysis. To further
promote trustworthiness, efforts were made to collect data from different data sources where available (e.g., data collected from webpages describing offline tools or tools provided to registered users only, data collected from marketing material intended for platform sponsors, and interviews of platform owners), and to support findings with multiple quotes and examples.

Lastly, the study relied on publicly available data, which were taken at face value, and contents not displayed in the public domain were not analyzed. Offline patient engagement processes and tools to support patients in the private domain may be missed in the analysis. Also, patient platforms can have companion mobile applications, or be optimized for mobile devices; however, the mobile interfaces were not studied in this dissertation. Future research to explore mobile interfaces and mobile-based patient platforms, and offline process would be valuable to enhance our understanding of how tools can better engage patients in their health care process.

5.7 Summary

In summary, this dissertation has identified a mapping for categorizing platform tools provided to engage patients in their health care process. By categorizing one-way, two-way and multi-way tools according to five patient engagement processes
(inform patients, involve patients, empower patients, support patient eCommunities and partner with patients), this mapping can support the design of tools for better engaging patients in their health care process.

Also, despite the fact that platform tools were available free of charge to anyone on the Internet, this study revealed numerous ways in which these tools collected data and information from users for business purposes. Specifically, platform tools can be used to deliver advertisements and sponsored content (which can encourage some users to purchase products or services as advertised) and to collect user information (which can be used to more effectively influence users to act in ways that could benefit site sponsors). These issues might not be fully understood without reviewing the fine print on platform policies, or content posted on other websites (such as company information intended to reach investors or content intended for their sponsors). Given the rapid development of artificial intelligence and the current debate about “fake news”, this study highlights opportunities for more research in this evolving area to prevent the sharing of information which may not be evidence-based, and could potentially have impacts on health care expenditures.

Also, all of the patient platforms studied in this dissertation connected their users in what was typically referred to as communities for sharing information on a medical
condition or related condition(s). One group of platforms facilitated condition-specific forums, referred to as communities, for posting questions and answers relating to specific medical conditions. Another group of platforms, referred to the platform as community, offering discussion forums for ongoing discussions. The discussion forums were sorted by categories and sub-categories, which enabled users to better distinguish where they might wish to participate in information exchanges. Also, the discussion forums tended to offer features to identify content authors, as well as features for users to develop an online identity through participation on the platform over time. The latter group of platforms also tended to enabled their users to connect with one another offline. These findings highlight features of multi-way tools that can better connecting users with one another for information and support.

Finally, the study identified tools provided directly to patients, which have the potential to engage and empower patients in their health care process such as providing access to information and knowledge, which can support patients with both decision-making and problem-solving tasks, without necessarily first consulting with their health care provider. Despite the potential benefits of empowering patients with these technologies, the study revealed how platforms might be
oriented towards operating in ways which support their own interests, which may not always be mutually beneficial to patients. Given that these tools can engage their users in ways which can have significant impact on their health and the healthcare system, more research is needed in this evolving area.
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Appendix A – NeHC Patient Engagement Framework

Taken from the National eHealth Collaborative website (National eHealth Collaborative, n.d.).
Appendix B – Table of Selected Platforms

<table>
<thead>
<tr>
<th>Platform</th>
<th>Single or multiple</th>
<th>Disease dimension*</th>
<th>For-profit or not-for-profit</th>
<th>Year started</th>
<th>Volume of data</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
<td>Single condition</td>
<td>Rare condition</td>
<td>Not-for-profit</td>
<td>2006</td>
<td>29 webpages /documents</td>
</tr>
</tbody>
</table>
| A2       | Multiple conditions| Multiple related chronic conditions  
*Trajectory 3: prolonged dwindling | Not-for-profit | 1993 | 15 webpages /documents |
| A3       | Single condition   | Chronic condition  
*Trajectory 1: Short period of evident decline | Not-for-profit | 2000 | 27 webpages /documents |
| A4       | Multiple conditions| Multiple different conditions | For-profit | 2005 | 24 webpages /documents |
| A5       | Multiple conditions| Multiple different conditions | For-profit | 1994 | 21 webpages /documents |
| A6       | Single condition   | Chronic condition  
*Trajectory 2: Long-term limitations with intermittent episodes | Not-for-profit | NA | 24 webpages /documents |
| A7       | Single condition   | Multiple related chronic conditions  
*Trajectory 2: Short period of evident decline | For-profit | 2010 | 17 webpages /documents |
<p>| A8       | Multiple conditions| Multiple different conditions | For-profit | 2004 | 48 webpages /documents |</p>
<table>
<thead>
<tr>
<th>Platform</th>
<th>Single or multiple</th>
<th>Disease dimension*</th>
<th>For-profit or not-for-profit</th>
<th>Year started</th>
<th>Volume of data</th>
</tr>
</thead>
<tbody>
<tr>
<td>A9</td>
<td>Multiple conditions</td>
<td>Multiple different conditions</td>
<td>For-profit</td>
<td>NA</td>
<td>49 webpages /documents</td>
</tr>
<tr>
<td>A10</td>
<td>Single condition</td>
<td>Mental health condition</td>
<td>For-profit</td>
<td>NA</td>
<td>21 webpages /documents</td>
</tr>
<tr>
<td>A11</td>
<td>Single condition</td>
<td>Mental health condition</td>
<td>For-profit</td>
<td>2000</td>
<td>27 webpages /documents</td>
</tr>
</tbody>
</table>

* See Section 3.1 for discussion on platform selection for chronic diseases based on illness trajectories described by Murray (2005).
Appendix C – Chronic Illness Trajectories

Trajectory 1 – Short period of evident decline

![Graph showing Trajectory 1: Short period of evident decline]

* Taken from (Murray et al., 2005) *

Trajectory 2 – Long term limitations with intermittent serious episodes

![Graph showing Trajectory 2: Long term limitations with intermittent serious episodes]

* Taken from (Murray et al., 2005) *
Trajectory 3 – Prolonged dwindling

Taken from (Murray et al., 2005)
## Appendix D – Coding scheme

<table>
<thead>
<tr>
<th>Codes</th>
<th>Sub-Codes</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient engagement</td>
<td>Inform patient</td>
<td>Patient engagement process whereby information is disseminated from the platform to users, who passively receive information as determined by platform owners. Information, which is insufficient to support users with treatment decisions, was typically featured on the platform homepage or other main web pages to engage patients as content readers.</td>
<td>Health articles on lifestyle changes to prevent disease, research news or health trends.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involve patient</td>
<td></td>
<td>Patient engagement process whereby tools can support users with decision-making tasks, but do not engage them to take on problem-solving tasks. Users can actively select the information they wished to receive, which can inform them on the risks and benefits of treatment options (but the information was insufficient for engaging platform users to take on problem-solving tasks on their own).</td>
<td>Patient information on medical conditions or drug therapies</td>
</tr>
<tr>
<td>Empower patient</td>
<td></td>
<td>Patient engagement process whereby tools can support users to take on both decision-making and problem-solving tasks, empowering some patients to gain control over their own health issues without necessarily relying on their health care providers to do so for them. Accordingly, patients can use these tools to make their own treatment decisions before, after, or instead of consulting with their health care providers.</td>
<td>In-depth medical references to look-up how to manage side effects, or symptom checking tools for self-diagnosis of potential causes of symptoms.</td>
</tr>
<tr>
<td>Support patient eCommunity</td>
<td></td>
<td>Patient engagement process whereby tools connect users with one another for information and support.</td>
<td>User profiles, forums</td>
</tr>
<tr>
<td>Partner with patient</td>
<td></td>
<td>Patient engagement process whereby tools connect patients with their health care providers to support shared and collaborative decision-making processes.</td>
<td>Personal health records</td>
</tr>
<tr>
<td>Codes</td>
<td>Sub-Codes</td>
<td>Description</td>
<td>Examples</td>
</tr>
<tr>
<td>--------------</td>
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<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Tools</strong></td>
<td>1-way</td>
<td>Tools which disseminated information from platform to platform users;</td>
<td>Health articles</td>
</tr>
<tr>
<td></td>
<td>2-way</td>
<td>Tools which provided information based on data and information collected from individual users</td>
<td>Self-tracking tools</td>
</tr>
<tr>
<td></td>
<td>Multi-way</td>
<td>Tools which posted information shared by many users.</td>
<td>Forums</td>
</tr>
<tr>
<td></td>
<td>Reaching out</td>
<td>Efforts to reach engage an expanded number of users through enhanced accessibility such as ways to translate site content into different languages or larger text, or providing information as podcasts or videos, or ways to share content outside of platform</td>
<td>Tools to enlarge text, tools to translate site content, podcasts, video clips</td>
</tr>
<tr>
<td><strong>Type of information</strong></td>
<td>Science-based</td>
<td>Content which appeared to be science-based</td>
<td>Patient information on drug therapy</td>
</tr>
<tr>
<td></td>
<td>Based on personal experiences</td>
<td>Content which is based on experiences of users</td>
<td>Health articles on patient experience with illness, user journals for sharing patient experiences</td>
</tr>
<tr>
<td></td>
<td>Co-created</td>
<td>Content which reflect the knowledge shared collaborative from a group of users</td>
<td>Forums for many users to collectively share personal experiences</td>
</tr>
<tr>
<td><strong>Collecting data and information</strong></td>
<td>NPI</td>
<td>Information automatically collected from platforms, which the platforms defined as non-personal information</td>
<td>IP address, cookies and other tracking mechanisms</td>
</tr>
<tr>
<td></td>
<td>PI</td>
<td>Personal information, which can be used to contact or identify platform users</td>
<td>User’s name, address, birthdate, photo, email address</td>
</tr>
<tr>
<td></td>
<td>PHI</td>
<td>Personal health information refers to “identifying information in oral or recorded form about an individual that relates to the physical or mental health of the individual”(Lacroix &amp; Hamilton, 2017, p. 92)</td>
<td>User information disclosing their medical condition, drug therapies</td>
</tr>
<tr>
<td><strong>Sponsors and other parties</strong></td>
<td></td>
<td>Other parties, third parties, who support the platform through funds, or tools.</td>
<td>Pharmaceutical companies which offer educational grants to support</td>
</tr>
<tr>
<td>Codes</td>
<td>Sub-Codes</td>
<td>Description</td>
<td>Examples</td>
</tr>
<tr>
<td>------------</td>
<td>-----------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Registration process</td>
<td>Required information</td>
<td>Information required</td>
<td>Email address, name (or initials), date of birth</td>
</tr>
<tr>
<td>Optional information</td>
<td>Information collected</td>
<td>Persuasive texts and images which might encourage user to act in certain ways (such as provide required information for site registration)</td>
<td>Persuasive texts and images on registration forms.</td>
</tr>
<tr>
<td>Tactics</td>
<td></td>
<td>Other ways of collecting user information besides site registration</td>
<td>Surveys, questionnaires, tools to personalize tools</td>
</tr>
<tr>
<td>Other information collection processes</td>
<td></td>
<td>Promoting sense of community (Ways which platforms connect users with one another)</td>
<td>Community of patients sharing the same medical condition, community of platform users, community as forums users, connecting users with others like themselves.</td>
</tr>
<tr>
<td>Community</td>
<td>Income generating processes</td>
<td>Ways which platform makes money</td>
<td>Posting advertisements, selling products or services</td>
</tr>
<tr>
<td>Generate income</td>
<td>Tensions</td>
<td>Making money in ways which may not be mutually beneficial to patients</td>
<td>Encouraging users to click on advertisement but not disclose the possibility that this process can enable site sponsors to track their users with cookies</td>
</tr>
</tbody>
</table>