



THE SCHOOL OF PUBLIC POLICY

Master of Public Policy

Capstone Project

Are Alberta's General Practitioner (GP) to Specialist Referral Pathways Aligned with Existing Principles and Best Practices for Patient Empowerment (PE)?

Submitted by:

Sylvia Wong

Approved by Supervisor:

Dr. Myles Leslie

Submitted in fulfillment of the requirements of PPOL 623 and completion of the requirements for the Master of Public Policy degree



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Capstone Approval Page

The undersigned, being the Capstone Project Supervisor, declares that

Sylvia Wong

has successfully completed the Capstone Project within the
Capstone Course PPOL 623 A&B

Dr. Myles Leslie

(Name of supervisor)

A handwritten signature in black ink, appearing to read "Myles Leslie", written inside a rectangular box.

(Supervisor's signature)

25AUG2022

Date



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Dedication

This capstone is dedicated to my family, my dear friends, and my partner Matthew who has always supported me no matter what.

Acknowledgement

I would like to thank Dr. Leslie Myles and Dr. Travis Carpenter for their valuable guidance and advice. They relayed their expert advice and knowledge to help me refine my topic and draw out the most important questions to ask surrounding patient-centered care. I appreciate your willingness to answer my questions in detail and your support as I completed the interview process; your reassurance certainly made the recruitment process less stressful. I especially would like to thank the Carpenter Medical Corporation (CMC) for their financial support.

I would also like to thank Ash Seth, who provided invaluable guidance for my ethics application. Having to do qualitative research for the very first time is challenging, time consuming, and complex, but your advice made the process more enjoyable.

Thank you to all my interview participants, who work tirelessly in their roles to advocate for patients, whether they are advocates, healthcare workers, or public servants. I appreciate you taking the time to answer my questions with enthusiasm and passion. While any healthcare issue is itself a “wicked problem,” Alberta patients are lucky to have you all supporting them, whether on the front lines or behind the scenes. I hope this capstone accurately reflects your valuable perspectives on the subject.

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List of Abbreviations

AHS = Alberta Health Services

GP = General Practitioner

G2S = General Practitioner to Specialist

HCP = Healthcare Professionals

EHR = Electronic Health Records

PE = Patient Empowerment

Executive Summary

Long wait times, inefficient care coordination, and patient disengagement have been identified as significant issues in Canadian specialist care (Liddy et al. 2018). This lack of patient engagement could be attributed to the common belief that patients do not have the right expertise (Baker et al. 2016; Brekke, Nuscheler, and Straume 2007, 18), which seems to be enshrined in the gatekeeping role that Canadian general practitioners (GPs) routinely play when referring patients to specialists (Forrest 2003). Whatever the origins and intents of deploying GPs to control access to specialists, poor performance in the GP to specialist (G2S) pathway not only delays treatment and care (Liddy et al. 2018), but it can also cause unnecessary harms (i.e., pain, stress) to patients (McCarron et al. 2019; Manafo et al. 2018). Indeed, poor transitions between GPs and specialists can lead to negative health outcomes (Yiu et al. 2015, 24), especially when patients face repeated, but necessary, transitions between HCPs throughout their care.

At the same time that GP gatekeeping on G2S pathways has become an object of policy attention, the province of Alberta has taken steps to enact policies to enhance engagement by empowering patients. Most notably, Alberta Health Services' (AHS) *Patient First Strategy* from 2015 aims to “advance healthcare in Alberta by empowering and enabling Albertans to be at the centre of their health care team and improve their own health and wellness” (Alberta Health Services 2015, 5). However, there is little evaluation done on the PE improvements and harm reduction benefits that policies like

this might have had. Moreover, there has been no indication this strategy has been updated since 2015; this calls into question its relevance and its abilities to reflect the new realities of “post-pandemic” healthcare. In other words, PE as it has been implemented in G2S pathways remain poorly understood. We are left with the questions: how, and with what effects on care quality, is PE being put into action as GPs refer patients to specialists, and how might PE policies be in alignment or competition with the principles of gatekeeping?

This capstone uses G2S pathways to analyze how Alberta’s policy aspirations to improve PE are playing out. Using qualitative interviews with specialists, patient advocates, and policymakers, this study seeks to identify both alignments and misalignments between PE best practices and current G2S pathways as these exist in the province’s particular approach to gatekeeping. It begins with a systematic review of PE characteristics, which are then compared with the lived experiences of the interviewees to draw out policy options for improving PE. Physicians in the specialities of dermatology and cardiology were purposely recruited, as their speciality is more community-based and they interact with less acute-care patients than other specialities such as surgery.¹ This study reveals that the gatekeeping role are not at

¹ One participant who identifies as an HCP specialized in vascular surgery rather than dermatology or cardiology. This was due to the limited responses received during the interview recruitment process for the two specialities.

cross purposes with PE; rather, they play an essential part in the facilitation of unfragmented care for patients. The final stage of this capstone proposes recommendations on how to enhance PE as part of long-term decision making, and how this practice can better integrate into the province's current G2S pathways.

Background

Gatekeeping and G2S Pathways in Alberta

Healthcare in Canada can be conceptualized as composed of primary and secondary care. Primary care refers to common healthcare problems and care provided by GPs, while secondary care requires specialized care from hospitals or medical specialists (Toth 2020, 164). Primary and secondary care in Canada are essentially separate, with the two elements acting as “largely disjointed spheres of activity” and integration differing across provinces (Toth 2020, 165).

According to Alberta's Quality Referral Evolution (QuRE), referrals to specialists in the province are made in two main ways: GPs communicate with a specialist on a patient's behalf, or patients can simply put in a request for a consultation or advice (Alberta Health Services n.d.). While not considered mandatory, this first option – one in which GPs ‘gatekeep’ access to specialist care – is an accepted norm in

Canada (Toth 2020, 166). However, existing gatekeeping arrangements across the country have been critiqued for lacking collaborative relationships between primary and secondary Healthcare Providers (HCPs) (Sripa et al. 2019, e302). Gatekeeping has been said to affect patient choice; relationships between HCPs and patients; demand for specialists; and the integration of the two elements of healthcare (Toth 2020, 165). On the one hand, deploying GPs as gatekeepers means, “patients do not have direct access to secondary care” (Brekke, Nuscheler, and Straume 2007, 1) and risk a “poor match” with their care facility (Yiu et al. 2015, 24), but there are also benefits to the arrangement. The following paragraphs examine some of those benefits, along with critiques, related to gatekeeping as an approach to G2S referrals.

GPs acting as gatekeepers have been described as guardians of patients and health systems. In these roles they: proactively and preventively ensure patients get attention from appropriate specialists (Sripa et al. 2019, e301); ensure lower income patients maintain access to care and are able to navigate the health system (González 2009; Greenfield, Foley, and Majeed 2016, 2); advocate against unnecessary medical procedures; and safeguard finite healthcare resources (Breivold, Rø, and Hjörleifsson 2021; Forrest 2003). From a system oversight and professional identity perspectives, gatekeeping has been described as providing a standardized (and in some ways uniquely patient-centred) system for supervising primary and secondary care (Loudon 2008, 129)

. Without it, one of the primary responsibilities of GPs would be removed (Wammes et al. 2014; Anderson and Funnell 2005).

If these are the benefits, GP gatekeeping in the G2S space has also been identified as having disadvantages. It has been linked to poor or delayed diagnosis for some illnesses (Greenfield, Foley, and Majeed 2016, 1) and decreased patient satisfaction and health outcomes (Greenfield, Foley, and Majeed 2016, 2). This is especially true when primary care support and resources are in many cases overburdened or even non-existent.

Ideally, GP gatekeeping on the G2S pathway should be transactional, dynamic, and democratic (Acuña Mora et al. 2019, 17), bringing both advantages and disadvantages (Rotar et al. 2018, 2) that potentially protect patients and the system while also introducing risks. In seeking to understand how the gatekeeper role is playing out in a province committed to PE, this study sheds light on how HCPs from the two elements of the healthcare system are presently balancing the advantages and disadvantages described above.

What is Patient Empowerment?

Conceptually, patient empowerment (PE) assumes that patient involvement in healthcare decisions leads to positive health outcomes and improved quality of care (Baker et al. 2016; Mork, Laxdal, and Wilkinson 2019; Weisbeck, Lind, and Ginn 2019; Ammenwerth et al. 2019; Bravo et al. 2015; Fumagalli et al. 2015; Funnell et al. 1991; Halvorsen et al. 2020; Kambhampati et al. 2016; McCarley 2009; Náfrádi, Nakamoto, and Schulz 2017; Acuña Mora et al. 2019; Funnell 2016). Furthermore, specific definitions of “empowerment” within this broad agreement about PE’s benefits vary considerably (Weisbeck, Lind, and Ginn 2019; Bodolica and Spraggon 2019; Audrain-Pontevia and Menvielle 2018; Bravo et al. 2015; Castro et al. 2016; Fumagalli et al. 2015; Umar and Mundy 2015).

This capstone and its analysis rely on one of the most cited definitions, originally provided by Funnell et. al (1991) and as referenced by Bravo (2015). In this definition, PE is defined as a process through which a patient discovers and develops their:

“inherent capacity to be responsible for [their] own life. People are empowered when they have sufficient knowledge to make rational decisions, sufficient control, and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of their decisions. Empowerment is more than an intervention or strategy to help people make behavior changes to adhere to a treatment plan. Fundamentally, patient empowerment is an outcome. Patients are more empowered when they have knowledge,

skills, attitudes, and self-awareness necessary to influence their own behavior and that of others to improve the quality of their lives.”

Approaching PE as the outcome of a process brings benefits that include: self-efficacy; being informed about care; improved relationships with HCPs; motivation to achieve quality healthcare; self-management; and control (Yeh, Wu, and Tung 2018, 11; Cerezo, Juvé-Udina, and Delgado-Hito 2016, 666).

However, the key challenges associated with defining PE as a patient outcome that seeks to ensure sufficient knowledge, control, and experience is one related to perspectives. From whose perspective is this sufficiency being evaluated? With PE understood from and filtered through both the perspectives of HCPs and patients (Náfrádi et al. 2018, 511), misalignments between GP's training and professional commitments on one hand and patients' cultural expectations about control and self-determination on the other will shape what PE looks like (Weisbeck, Lind, and Ginn 2019). Moreover, HCPs may find it difficult to set aside traditional training and professional approaches to expertise in order to support all aspects of PE (Kambhampati et al. 2016, 48). When this happens, GPs may find themselves dictating what patients ought to do, instead of patients exercising their self-capacity (Weisbeck, Lind, and Ginn 2019, 6) like PE encourages. Indeed, it can be difficult for HCPs to feel empowered enough to then empower their patients (Yiu et al. 2015, 20). Nevertheless,

behavioural changes are needed from both patients and HCPs to successfully enact PE; patients need to “internalize the need for change” as well (McCarley 2009, 413). This capstone will analyze these clashing perspectives on the sufficiency of PE in greater detail.

Literature Review

Castro et. al (2016) identified effective communication between patient and physician, patient-centered approach, strengthened health literacy, and active participation as the four antecedents for PE. However, a full picture of PE reaches far beyond these simple factors. More accurately, there is no conclusive list of characteristics that define PE as it is experienced differently by every patient. The achievement of a single attribute of PE is also not sufficient enough to claim PE has been achieved (Fumagalli et al. 2015).

Acknowledging this, the purpose of the literature review below is to gauge existing publications and explore the indicators of PE to reveal prominent themes. These indicators can be defined as the behaviours that define PE (Bravo et al. 2015, 6). This forms an important baseline understanding of PE that will help guide qualitative questions and be compared with study results to determine any (mis)alignments with

current G2S pathways. This comparison will not only inform policy recommendations but will also assess how well various PE attributes are currently implemented within Alberta's healthcare systems, and the challenges and tensions inherent in current approaches to the concepts of gatekeeping and PE. The description of PE is expected to change to reflect current practices and interpretations of the practice if this comparative study is to be replicated.

Characteristics of PE

The three major themes below summarize the characteristics that define the PE found through the literature review. A more substantive summary of findings from the literature review can be found in [Appendix B](#).²

Theme 1: Patient-sourced expertise

This school of thinking about PE relies on patients contributing to decisions about their own health through self-advocacy. It involves patients playing an active role and showing the will to decide treatment options (Jørgensen et al. 2018; Fumagalli et al. 2015). Many attributes of PE stem from the “self,” including self-advocacy (Bravo et

² The literature review revealed a total of 8 themes relating to PE. However, these thematic elements were further consolidated into three major groups in this section for readability purposes. The summary findings in Appendix B retains descriptions for the original themes.

al. 2015), self-determination (Halvorsen et al. 2020; Castro et al. 2016), and self-management (Akeel and Mundy 2019). Patients can gain self-advocacy skills through their dependence and support from fellow patients as well, which can encourage practices outside of conventional care delivery to improve patient outcomes. This can be done through peer support (Agner and Braun 2018) or learning from the experiences of others (Jørgensen et al. 2018). Computer-mediated social support (CMSS) on online health communities (OHC) also correlate with better health outcomes when patients are able to share information (Audrain-Pontevia and Menvielle 2018).

From this literature review, self-advocacy seems to be the epitome of PE, as it allows patients to exercise control over their own care through means such as self-referrals. However, this bypasses the traditional gatekeeper roles of primary physicians that are currently in place. Rejecting the idea of gatekeeping being eliminated, discussions with participants reveal the belief that overreliance on patient-sourced expertise could lead to unexpected consequences and additional pressures on HCPs, particularly when patients overuse the system. That said, there is the belief that HCPs should still play essential roles in guarding finite healthcare resources within PE policies and, even at the expense of some patient liberties gained through PE.

Theme 2: Relationships with and between HCPs

Just as important as self-advocacy is the quality of relationship between patients and their care team, and between HCPs and their colleagues. In addition to a delicate weighing of different attributes (i.e., health literacy, communication, self-management, etc.), clear definitions of the roles of patient and HCPs is essential. Patients should feel respected (Jørgensen et al. 2018; Halvorsen et al. 2020); be taken seriously by HCPs (Agner and Braun 2018); and partake in shared decision-making (Bravo et al. 2015). This largely depends on the HCPs' acceptance of a patient's control over their own health (Kambhampati et al. 2016) and acknowledgment of patient accountability (Acuña Mora et al. 2019, 81; Kambhampati et al. 2016, 48). HCPs are also obligated to maintain communication between other HCPs (Lenaghan 2019, 152).

PE is not a zero-sum game in which power from one side (HCP or patient) transfers to another (Grünloh et al. 2018, 12). HCPs are important facilitators for PE and achieving it is a joint venture alongside patients (Náfrádi, Nakamoto, and Schulz 2017). HCPs advocate for patients (Royal College of Physicians and Surgeons of Canada, n.d.) as part of their professional obligations. But in their gatekeeping roles, HCPs are required to adhere to certain procedures and standards while catering to the needs of individual patients (Audrain-Pontevia and Menvielle 2018, 160), and this can be a difficult balance. PE believes patient advocacy by HCPs to be an inherent quality to healthcare delivery, but traditional training can dissociate specialists from primary care, resulting in gaps in coordination (i.e., lost referrals) and siloed healthcare delivery.

Other barriers to forming meaningful relationships between HCPs and patients include time constraints, lack of training, uneasiness when handling emotions and behaviours, and the unawareness of paternalistic behaviors (Funnell 2016, 1921; Fenton 2012, 409; Halvorsen et al. 2020, 1269). Not to mention, immense burnout and harsh working conditions can dampen the capabilities of HCPs to supporting patients fully. This reveals a disadvantage of gatekeeping, where characteristics of the current model of healthcare delivery limits the capacity of HCPs to fulfill their obligation to advocate for patients.

Theme 3: Effective Communication and Knowledge Transfer

Building on the need for a shared decision-making between HCPs and patients, this approach of thinking about PE emphasizes the role of information. How informed the patient feels can directly affect their abilities to self-advocate (Agner and Braun 2018). Patients need a certain set of knowledge in order to “make informed-decisions, [and] define strategies to achieve change and solve problems” (Acuña Mora et al. 2019, 21). The level of knowledge transfer and literacy is dependent on the quality of communication between HCPs and patients. This includes positive communication (Jørgensen et al. 2018) or personalized communication (Kambhampati et al. 2016). Alberta’s implementation of Connect Care attempts to achieve this, and has broader

aims to enhance communication between HCPs by providing “a central access point” for patient information (Alberta Health Services n.d.). As part of Connect Care, a patient portal (MyAHS Connect) will allow patients to view messages from their healthcare team, ask for medical advice, and view letters from HCPs (Alberta Health Services 2022).

Given the description above, technology such as Connect Care, telehealth, EMR, eReferral services, and centralized booking services can be significant facilitators of PE. These online patient networks and technology play an informational role providing patients with the basic abilities to participate in their own care (Lenaghan 2019; Lamas et al. 2017). It can also help enhance transparency of the care journey (Yiu et al. 2015) and be a “facilitator of learning” for PE (Akeel and Mundy 2019, 1281).

However, there is tension between what proponents of PE think should be accessible to patients, and the patient’s ability to understand complex medical data according to HCPs. While it is empowering for patients to have access to their own information, the current G2S pathways sees it as a risky endeavor that could result in additional pressure on an already overloaded healthcare system, especially when health information is misinterpreted by patients (Grünloh et al. 2018). Factors like age and education can affect patient abilities to understand illnesses and therefore their engagement with their own care (Bernabeo and Holmboe 2013, 251). Receiving

seemingly abnormal test results can also cause negative emotions among patients and needless pressure on HCPs (Pillemer et al. 2016; Giardina et al. 2018).

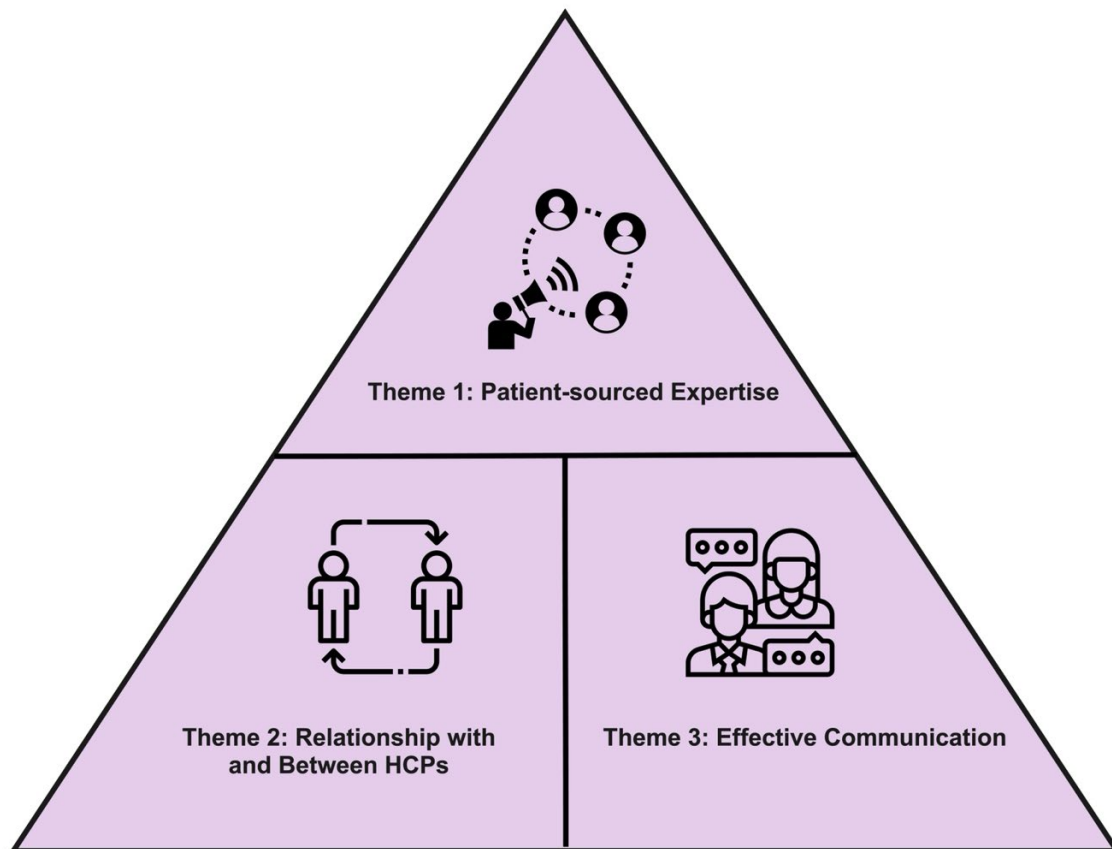


Figure 1- Major themes that form the baseline understanding of PE for this capstone

Methodology

To bring to light both the existing alignments and misalignments that exist between the G2S pathways in Alberta and existing literature on the best practices for PE, qualitative interviews were conducted.

Ethics Approval

The University of Calgary's Conjoint Health Research Ethics Board approved this research by reviewing this study's (REB22-0256) research objectives, methods, and recruitment process thoroughly.

Interview Recruitment

A list of potential interview candidates was consolidated through searches on public directories associated with university medical schools, the provincial government, and patient advocacy groups³. Participants working in health were recruited based on a mix of purposive and snowball sampling. Some individuals were recruited based on existing relationships with the co-investigators in this study established through professional networks. Individuals were chosen based on the relevance of their occupation and their expertise and their knowledge on concepts such as patient health outcomes and PE. These factors determined their abilities to

³ Employees and policymakers of AHS were not recruited as the required ethics process is beyond the abilities of this capstone.

contribute to the core topic. Involving individuals from three different occupation groups provided a holistic view of PE.

Interview Participants

Below is an overview of the roles and jurisdiction of 12 interview participants.

Table 1. Overview of Interview Participants

Participant	Occupation Group	Additional Identifier	Jurisdiction
1	Patient Advocate	Organization 1	Calgary
2	Patient Advocate	Organization 1	Calgary
3	Patient Advocate	Organization 1	Calgary
4	Patient Advocate	Organization 2	Edmonton
5	Patient Advocate	Organization 2	Edmonton
6	Patient Advocate	Organization 2	Edmonton
7	Patient Advocate	Organization 2	Edmonton
9	Healthcare Professional	Specialist	Edmonton
10	Healthcare Professional	Specialist	Calgary
11	Healthcare Professional	Specialist	Calgary
12	Healthcare Professional	Specialist	Calgary
13	Policymaker	Organization 3	Edmonton

Interview Structure

A total number of 7 interviews (with a total of 13 participants) were conducted in a semi-structured format with guidance from thematic categories ([Table 2](#)) identified in the literature review. The format of the interviews allowed for additional perspectives to be recorded via probing questions. Participants were also asked interview questions

about their understanding of PE and the understanding of G2S referral pathways in the province. The full interview guide can be found in [Appendix A](#).

Table 2. Interview Guide Themes⁴

Thematic Category	Rationale for Inclusion
Theme 1: Understanding the Major Attributes of Patient Empowerment (PE)	
Adopting new technology	<p><u>Main question:</u> How can technology (i.e., advanced patient portals, centralized booking services, eConsult, Connect Care), help us achieve PE?</p> <p>The literature review suggests that technology plays a big part in increasing PE. It would be useful to understand barriers to implementing technological developments in the province. With Connect Care finishing its final implementation stage in 2022, it would be informative to know whether interview participants think it will enhance PE.</p>
Role of patients and HCPs	<p><u>Main question:</u> How are the roles and responsibilities of patients and HCPs perceived by stakeholders in the healthcare system? How should the role of patients be defined so that health outcomes are evaluated based on quality (i.e., satisfaction) and not quantity (i.e., consumption)?</p> <p>Achieving PE requires a delicate weighing of different attributes (i.e., health literacy, communication, self-management, etc.), as well as clear definition and acknowledgement of the roles of patient and HCPs. If there is no common</p>

⁴ Not all these themes were discussed in the results section of this study. Only the most relevant insights that illustrated the current challenges and tensions inherent in current approaches to gatekeeping and PE were included.

	<p>understanding on what these roles or responsibilities are, it could impede PE.</p>
Health literacy	<p><u>Main question:</u> What level of knowledge do Albertans currently possess about Alberta’s healthcare processes, and more specifically, G2S referral pathways?</p> <p>The literature review revealed that qualities of PE need to be combined with adequate levels of health literacy to be effective. It would be useful to learn current health literacy levels of Albertans on the current referral process and what could be done to enhance this trait as literacy correlates with the ability of patients to become stewards of their own health.</p>
Theme 2: Understanding GP to Specialist Referral Pathways	
COVID-19 and future of patient centered care in Alberta	<p><u>Main question:</u> How has the pandemic affected HCP and patient relationships as well as the trajectory of PE in the province?</p> <p>It would be important to understand how COVID-19 has changed PE given that some priorities (i.e., surgeries, cancer treatment) took a backseat as resources were all re-directed. It would be important to know what considerations should be kept top of mind as we navigate “post-pandemic” healthcare.</p>
Transitions in care	<p><u>Main questions:</u> What does the current G2S referral pathway look like? What is currently being done to improve transitions in care to ensure continuity?</p> <p>As this capstone will make policy recommendations on how to improve PE</p>

	<p>in the G2S referral pathway, it is essential to decipher existing shortfalls in current processes. It will be important to learn about past, current, or future initiatives aiming to improve transitions, as well as any lessons learned.</p>
Evaluation measures for patient-centered care	<p><u>Main question:</u> How should PE be evaluated to ensure its success? What criterion should be used?</p> <p>PE is complex and multi-faceted, and evaluation metrics could be complicated. Understanding the criterion needed to evaluate it can be valuable for enforcing policy recommendations.</p>
Governance and funding of current healthcare system	<p><u>Main question:</u> How does governance or funding affect the implementation of patient-centered care?</p> <p>How our healthcare system operates affects the feasibility of certain interventions. It is essential to understand whether existing factors related to governance is creating barriers to PE and how might they be mitigated.</p>

Analysis

The data set (transcripts) was analyzed based on Braun and Clarke's 6 phase guide (2006). These steps include reading and re-reading data set for familiarity while identifying initial ideas; creating initial codes based on unique features of data; grouping codes into themes; create thematic maps; creating specific and clear definitions for each theme; and then producing an analysis (87). A thematic analysis, which is defined as "a

method for identifying, analyzing, and reporting patterns (themes) within data” (79), was conducted.

Braun and Clarke suggested a thorough and rich description of the dataset if the views of the participants are unknown (83). This was determined to be an appropriate approach as in-depth analysis of PE in Alberta’s context is scarce. Furthermore, the data set is analyzed using an inductive approach, which is a “process of coding the data without trying to fit it into a pre-existing coding frame” (83). This was essential for unearthing new findings and themes that were unique to the literature review.

In the first stage, the entirety of the data set was analyzed through “repeated reading” (87) to identify initial patterns. The transcripts were analyzed alongside the audio recording to ensure the transcription is true to the interviewee’s original meaning. The second stage involved the initial coding stage, where extractions of the data is coded based on any features that stood out (88). As per the advice of the authors, as many patterns were coded as possible, keeping in mind that a certain segment or extract of the transcript would be left uncoded, coded once, or coded multiple times (89). An example segment of the initial coding done at this stage can be found in [Appendix C](#). The third stage of the coding process involves grouping the codes developed in stage two into thematic groups with the help of a visual representation (i.e., mind map), which

can be found in [Appendix D](#). In the next stage, the overarching themes are refined further and named to capture the quintessence of each theme (92).

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Figure 2 – Phases of thematic analysis from Braun et. Clarke (2008)

Results

The section below presents a set of qualitative data gathered from the study's participants that highlight the central tensions this capstone is attempting to capture: the different perspectives HCPs and patients have about PE (those that align and misalign) and how they are faring in the current G2S pathway.

Insight #1: The literatures overestimates patients' capacity to self-advocate

Participants, in alignment with the broad principals of PE, recognized patients as the focal point of care decisions. However, they felt PE approaches overestimated the

patients' capacities to self-determine their own care. They pointed to a subset of their clinical populations who might be indifferent towards health literacy or self-advocacy. In calling out this sub-population, participants engaged issues of perspective about the knowledge, control, and experience that are sufficient for achieving PE.

On one hand, the literature says HCPs should not play a paternalistic role by giving the patient “permission” to decide their own health, and that the care provided should be holistic, accessible, and fitting for the patient. For examples, patients should be given the capabilities to self-refer to specialists. However, on the other hand, participants from the interviews believe that not all patients have the same competencies to self-advocate and treating it as an inherent ability that patients develop on their own downplays the influence of socio-economic statuses as a determinant for self-advocacy.

“I think people that are engaged in patient empowerment probably have the basic skill set, number one, and social determinants of health in place. So, I do think that makes a difference when you’re constantly struggling to find a place to live, or meet your basic needs, or access medical care, it’s very hard to have these kinds of conversations you and I are having, be able to do something about when you’re not empowered.”

The literature review used the term gatekeeping extensively, but interview participants noted the negative connotation associated with the word as it portrays GPs

as a barrier in the G2S pathway. Participants view healthcare as a finite resource, and while patients should be given the abilities to dictate some aspects of their own health, HCPs remain “captain of the ship” to determine the right allocation of health resources. As captains, HCPs advise patients on the feasibility and plan of action for their goal, which contrasts with the literature’s portrayal of the patient as leaders of their own care.

“I disagree with [the term gatekeeping]. Not that people say that, but with that looking at it as a negative element. Because you need someone who at least has the fundamentals to figure out where to go. And as much as specialists might like to derive general practitioners in terms of not making the best referrals sometimes, I think that if it was coming directly from patients, it would be exponentially worse.”

Finally, the literature views it as logical for patients to have access to their own health information (such as through MyHealth Alberta) or even give advice on how much information they want, but participants saw access to health data as a double-edged sword. Access to sensitive information (i.e., mental health conditions) could lead to inappropriate decision making. Deciding who gets access or what information can be accessible can also be highly contentious, especially if patients abuse the system and become over-users of health resources. Anecdotally, this was described by participants as the 5% of the population that 80% of the health resources. Overall, the literature and results are at odds with self-advocacy as described in the PE literature.

Insight #2: Working conditions within G2S pathways prevent the facilitation of meaningful relationships between patients and HCPs

Participants and the literature align in their views on the relationship between HCPs and patients, in that patient should feel respected and acknowledged in their interactions with HCPs. However, a lack of training and tendency of HCPs to not account for patient emotions, behaviors, and preferences (mostly due to limited clinic time) are barriers for its realization. Within the G2S pathways, HCPs require more training on how to respond to patient perspectives and decisions for care that differ from their own. Not to mention, the additional clinical time or post-care follow-up that is needed to facilitate these discussions.

“I think we need to have more training ...with our residents. They’re taught to ask the patients, I’m not sure they’re taught how to support a patient who chooses to make a decision that goes against what you’ve been taught of what’s best for this problem.”

This deficiency can be exacerbated under the stressful working conditions of healthcare. When there are alarming levels of stress and burnout, it is hard to prioritize encouraging empowerment amongst patients. Patient advocacy is an integral part of the core responsibilities of HCPs (Royal College of Physicians and Surgeons of

Canada, n.d.), but it is often unrewarded or unremunerated, and HCPs' advocacy work is usually done "out of the goodness of their hearts". One participant recalled:

"Thank goodness I've got cancer. I can step away from this with an excuse. That's pretty bad burnout I'd say. And I'm not the only one. I have a friend who was a GP, same thing, major stress. So, I think burnout is affecting health resources. And what decisions are made on the basis of this has to take into consideration the viability and recognizing the value of the personnel that are working."

In other words, HCPs face moral injury, which is defined as the inability of HCPs to put the needs of patients first due to external stressors or demands (Dean, Talbot, and Dean 2019). Paradoxically, PE may involve empowering HCPs by providing enough time and resource for them to focus more on patient advocacy, as well as allowing them to continue their role. Overall, the tension that exists regarding the relationship between the literature and respondents is not due to a clash in perspectives, but rather the inability of the current G2S pathway to facilitate meaningful relationship and best practices.

Insight #3: G2S pathways do not reflect the communication practices of PE

Moving on to discussions about the role of information, the literature says direct communication between HCPs is one of the most effective ways of patient advocacy, but the current set-up of the G2S unintentionally facilitates siloed and disconnected relationships between GPs and specialists. There is a sense of hesitation from GPs to independently manage particular clinical issues once a specialist is involved. This may be a reflection of the impression that specialists' opinions are valued more; that their the advancement is shared responsibility (which can be impeded by inadequate integration of care); or reflective of the perceived lack of exposure to the necessary fields during medical training. As one participant said:

“So, the further we specialize as a society in let’s say healthcare... the more likely we are to forget about the other pieces of the system. We, being the system, so well, in fact, I think it’s done so well at times that there’s so many, let’s say policies, procedures built up within a certain area, that what’s forgotten is that communication to cross over with the next area.”

The literature views health literacy as being directly tied to the quality of communication amongst HCPs and between HCPs and patients, and deficiencies cause important context to be lost in translation during patient transitions. When GPs

seldom or never relay clinical information to specialists where completing a referral (Timmins et al. 2022, 344), this is not reflection of a best practice for PE.

Insight #4: Technology remains a double-edged sword

Moving on to the topic of technology, both the perspectives of the literature review and participants lauded technology as a powerful tool to enhance engagement with patients. According to the literature, technology should ideally help manage timing of care and expectations and allow for transparency of the processes (Forrest 2003). When used properly, these electronic health technologies can also enhance patient participation. However, participants say that technology remains unstandardized and underutilized, and not as easily accepted as the literature would suggest. Not only do some HCPs refuse to adopt the newest technology for personal reasons (i.e., pending retirement), a participant anecdotally claimed that some only use 10 percent of what available technologies have to offer. This forfeits the opportunity to further connect patients with technology, a best practice of PE, particularly if HCPs are unaware of its existence.

“Patients aren't aware that those tools even exist. Because I have this theory that if patients were aware that those things were happening, and if they put a little bit more pressure on their family physicians that they want to see those tools, physicians would be

more likely, and more inclined to say yes to those things. Because oftentimes, it ends up becoming more of a business decision than a patient support, empowerment decision for clinics to decide whether they will engage in a particular technology or not.”

However, participants think tensions remain even if patients do gain access to technology. Patients still can lack the proper structures (i.e., broadband) or personal skills like digital literacy to use the technology available for them, and they may still lack expert context to apply meaning to the health data they see. As one participant illustrated with the currently available MyHealth Records: “everything’s sitting there, but there’s really no education behind it.”

Discussion

The capstone highlights the central tensions inherent between PE and gatekeeping within G2S pathways. This study can conclude that while both concepts can be well-defined, there remains a challenge in determining how it is manifested and evaluated. As the results reveal, whether you are looking at the concepts as a patient or HCPs affects your perception on its sufficiency. Both are areas of tension inherent in current approaches to the concepts of gatekeeping and PE. While literature on PE highly values the patient choice, the lived experiences of participants say that HCPs

play a more essential role in helping to facilitate PE amongst patients than the literature describes.

Interview participants largely viewed the HCPs playing an irreplaceable role in the healthcare system, apportioning scarce resources and most importantly, a facilitation role that involves delivering individualized, but unfragmented care through their interactions with specialists. PE and gatekeeping are not mutually exclusive as the literature suggests, as one informs the other. Although, significant improvements are needed in the execution of G2S pathways and broader healthcare system for the PE and gatekeeping to co-exist better.

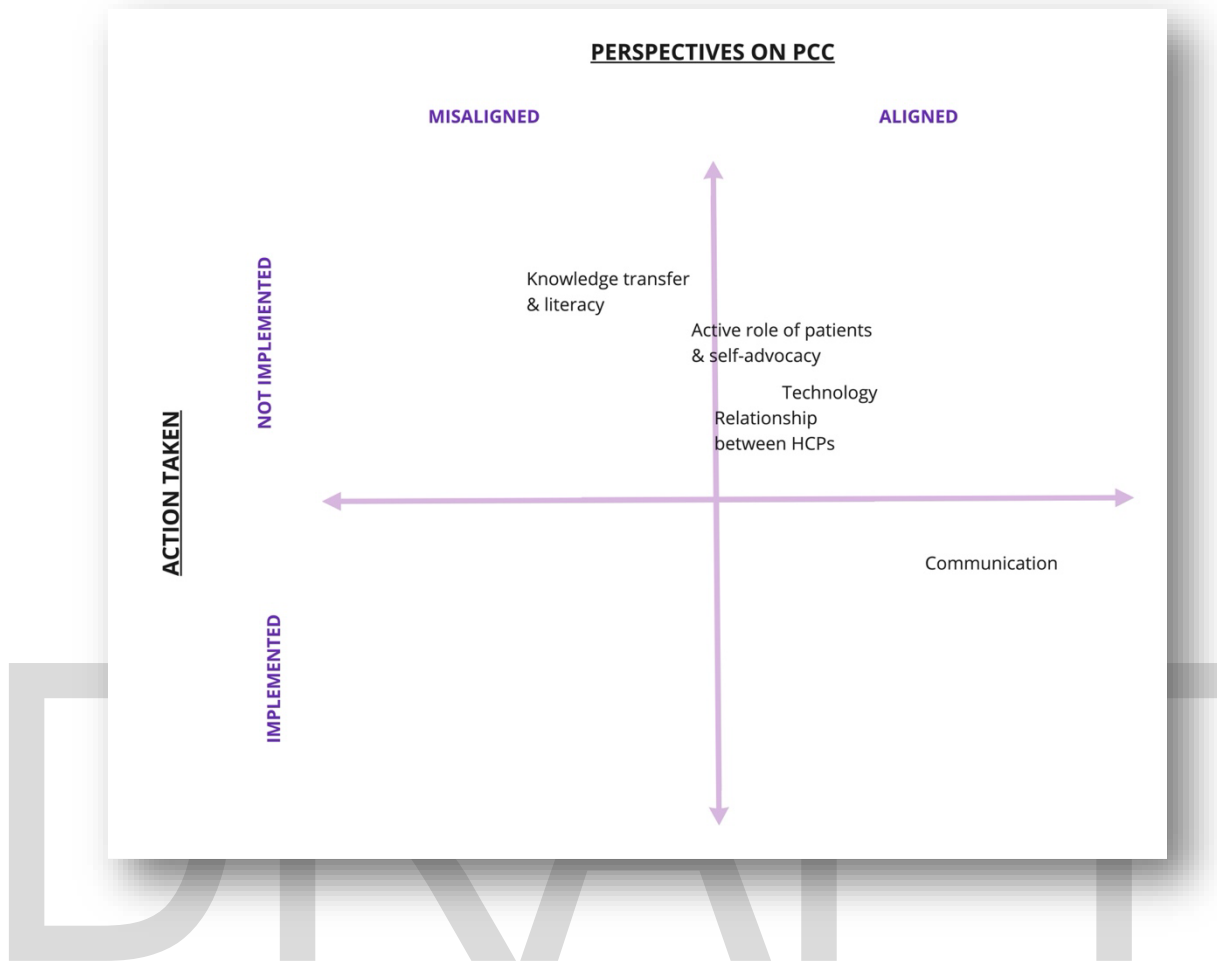


Figure 3 - Compass visualizing the mis(alignment)s of results of this capstone and detailed literature review findings in [Appendix B](#). The top spectrum evaluates how well the current G2S pathways (as described by the findings) aligns with the literature’s interpretation of PE. The side spectrum assesses how well interventions under these themes are currently implemented. While some themes might be well-understood by stakeholders in the healthcare system, corresponding interventions might not be well implemented to bring best practices into reality.

Recommendations

While recognizing the existing debates between the literature and lived experience of the interviewees, below are policy recommendations for each ethos (i.e., patient, HCP) to help reconcile some these different perspectives. The

recommendations include specific suggestions proposed by interview participants. However, the following empowering interventions, which are actions taken to support PE (Bravo et al. 2015, 6), not meant to be carved in stone. As reflected in the literature and interviews, empowerment can and will look different for each patient based on their circumstances. It is a highly iterative process that needs to adapt to changing conditions and experiences (Akeel and Mundy 2019, 1286). Different patients will bring about different choices, and the level of importance they attach to certain characteristics of the HCP they encounter (Victoor et al. 2012, 1). The setting in which patients interact with healthcare workers and the stage of their healthcare journey are also factors that affect one's perception of their relative empowerment ((Jørgensen et al. 2018, 293). Ironically, forcing all patients to adhere to the best practices of PE could be considered paternalistic (Garattini and Padula 2018).

Patient Level

PE is reached once patients acquire the skills vital to gaining capacity to make their own decisions and increase quality of life (Garattini and Padula 2018). However, reviewing Funnell's definition of PE provided [earlier](#), it is rather idealistic in their assumption that PE can be achieved by a patient through their “inherent” capabilities. Realistically, patients facing barriers require a support network to help them feel empowered. PE needs to be supported by interventions and structures that allow for

continuous monitoring for widening inequities and gaps in healthcare access. Overall, the results agreed with patients playing a more active role in their care, but in shared decision-making sense rather than a highly active role that spans to total self-management and self-referral. Patients remain the experts of “the personal,” but HCPs retain expertise of “the medical.” The recommendations below allow for patients to continue to have access to information pertinent to their knowledge and rights as patients, but still with watchful guidance of HCPs.

Table 3 - Policy recommendations for patient level ethos

POLICY RECOMMENDATIONS	DIRECTIONS
1	Create transparent resources to transfer knowledge on patient rights, roles, and responsibilities and to help patients build healthier expectations for the healthcare system. This needs to be translated to layperson language and may require the solicitation of support from patient advocacy groups. Consideration should be given to including patient education into school curriculums (i.e., CALM course).
2	Continue to improve patient portals via Connect Care (i.e., MyAHS Connect) and MyHealth Records to expand communication channels with care team, rather than access to raw health data. New applications should be co-developed or user-tested by patients. Overall patient-orientated health data within these applications should be separated from technical medical record keeping, for medico-legal reasons. MyAHS Connect’s innovative functions such as downloading visit summaries, messaging channel with healthcare team, and access to personal and family medical history (Alberta Health Services 2022) align with best practices relating to health literacy and self-advocacy and should be prioritized. To allow for transparency and

	accountability, patients should also be given the ability to track the status of referrals through a centralized service.
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Healthcare Provider Level

One of the major themes the results uncovered was the reality of HCPs working in silos with a lack of direct communication, which degrades at continuity of care. HCPs need to proactively engage clear advice channels with specialists and share best practices to treat a patient holistically. Such channels should be designed to facilitate frequent and longitudinal contact between GPs and specialists, minimizing the burdens of incomplete information, time commitments, and unnecessary administrative activities wherever possible. Additionally, even though there is currently a good understanding of what PE is, both primary and specialized HCPs still require more training in primary care regarding how to contend with patients who disagree with them. Their training should focus more on human emotions rather than technical aspects, in contrast to the traditional discouragement of such practices in healthcare to limit burnout. The following recommendations encourages the empowerment of HCPs by providing additional time and resources so their roles can focus more on patient advocacy.

Table 4 - Policy recommendations for HCPs

POLICY RECOMMENDATIONS	DIRECTIONS
3	<p>It is difficult for PE to be realized as patient time with their HCPs is very limited (Joseph-Williams, Elwyn, and Edwards 2014, 42). They also lack time to respond to patient's expectations and concerns (Bernabeo and Holmboe 2013). Implementing post-appointment or post-care follow-ups in clinic or hospital settings, or virtually, to ensure patients understand next steps. If this cannot be done by the GP or specialist, other providers like nurses or patient navigators should provide support. In Tang et. al's study (Tang et al. 2021), the authors found 58 patient navigation programs across Alberta that help advance continuity of care, and these programs can be leveraged to realize this recommendation. However, some gaps the study recognized include a lack of awareness and access. Existing structures and resources of these navigation programs should be more widely promoted to increase the awareness of both patients and HCPs.</p>
4	<p>HCPs should familiarize themselves with resources dedicated to supporting patients (i.e., hospital ombudsman) so they can relay relevant information to patients. These topics could be added to curriculums for medical students during their residencies. In addition, medical residents should receive training to shed light on the emotional, social, and behavioural aspects of PE to equip them with handling situations when patient's perspectives for care misaligns with theirs. Medical students looking to pursue careers in specialties should be given opportunities to familiarize themselves with the operations of primary care practice and vice versa.</p>
5	<p>GPs and specialists should overcome the disengagement and siloing between them and start forming more coordinated communication channels to share advice and best practices. This could support the continuity of care for patients. SpecialistLink and Alberta Referral Directory (ARD) already provide detailed pathways and resources GPs can consult to bridge the gap between primary and</p>

	specialty care. These health structures should continue to be further prioritized and funded. Mechanisms that support this bridging should be added to MyAHS Connect (patient portal of Connect Care), where all HCPs part of a care team could share messages and advice between each other easily.
6	Encourage HCPs from both primary and specialist care to adopt technology (i.e., Connect Care) to provide a sense of standardization in the system, with sufficient training. Mechanisms within these infrastructures that are designed for patient use and involvement should be promoted and disseminated to patients.
7	Conduct systematic review of technological structures for managerial purposes to ensure IT and administrative processes are coherent over time. This can streamline administrative procedures and eliminate cumbersome barriers. This involves consultations alongside users of newly developed tools and the inclusion of any relevant training to ensure the tool is being used to its full potential. Special consideration should be given to those less adept to technology or have limited access (i.e., broadband).

Future Considerations and Limitations

Qualitative discussions revealed further considerations that warrant a more in-depth analysis in the following themes that reaches beyond the scope of this capstone: the lack of access to GPs, the need for reforms to physician billing, and burnout amongst HCPs. Research in these areas can provide important insights on how deficiencies in different areas of health can affect PE. The range of this capstone limits its abilities to provide adequate recommendations to address these issues, but

any further studies on this will in no doubt be an advantage in furthering understanding PE.

Future studies on PE could consider a case study on related interventions instigated by the UK's National Health Service (NHS). Several participants noted best practices from the UK related to more patient choice in healthcare providers or centralized information systems. Furthermore, Connect Care is still being implemented outside of AHS at the time of writing this capstone, and future studies can benefit from analyzing how PE is being supported post-expansion. Finally, future research will benefit from the inclusion of a larger sample of interviewees, such as perspectives from primary care physicians or representatives from AHS.

Conclusion

PE is a concept that is gaining traction in healthcare, with organizations like the World Health Organization and the NHS listing it as a priority. Alberta has done the same with the *Patient First Strategy*, but it has since fallen out of priority with little analysis done to determine the impact of the strategy on patient outcomes. PE as it exists in G2S pathways remains an implementation mystery to key stakeholders. Traditionally, family physicians act as gatekeepers, and this is often accepted as a by-product of free,

universal public healthcare. However, the understanding of this role seems to be at cross purposes with PE, as these physicians prevent patients from exercising choices or preferences when it comes to their own care. Furthermore, any roadblocks that incur along this pathway can potentially cause unnecessary harm for patients.

This capstone aimed to evaluate current G2S referral pathways to determine how and what effect on care quality is PE being implemented; what debates exist between the literature on PE and current G2S pathways; and how stakeholders are currently balancing competing perspectives on PE. With the help of qualitative interviews, the importance of the gatekeeper in achieving PE was revealed, albeit needing improvements at both the patient and HCP level to streamline implementation. HCPs playing the role of gatekeepers are not at cross purposes with PE; rather, they play an essential part in the facilitation of unfragmented care. As a result, this study drew out policy recommendations that sensibly enhance information access for patients and empowers HCPs to be able to redirect efforts to patient advocacy in order to reconcile tensions between gatekeeping and PE within the Alberta's G2S pathways.

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Appendix A – Interview Guide

General questions

1. Can you describe your experience working and/or advocating for patients in Alberta's healthcare system?
 - a. How do you define patient-centered care, and within that, patient empowerment?
2. Is your organization/community/workplace currently working to advance patient centered care generally, and empower patients specifically? What barriers, if any, have you faced?
3. **Additional questions only for HCPs working in medical specialties (dermatology and cardiology): Can you describe the current referral pathway for patients seeking your expertise?**
 - a. Do you see any room for improvement in GP to referral specialist pathways that can empower both the HCPs and patients? Please explain.

- b. Is there anything in the referral process that, when it comes to patient empowerment, we are doing well? Please explain.
- c. Some barriers that might exist to achieving patient empowerment involve communication and issues of mutual respect. Do you see any of this, or any other type of barrier, to improving the communication and partnership that are at the heart of empowerment?

Attributes of Patient Empowerment (PE)

Adopting new technology

- 4. The literature suggests that technology is an important lever for achieving patient empowerment. What is your perspective on, or experience of how the province, or your clinic, deploys technology to further PE? Are there any barriers to a more effective implementation of technology?
 - a. *Probe:* What technologies do you think would be most useful and beneficial for patient-centered care?
 - b. *Probe:* Do you existing technologies like Connect Care, given its anticipated increase in use over the years, is sufficient for achieving adequate levels of patient-centered care? Please explain.
 - c. *Probe:* Because technology (e.g., transition passport) may have a larger part in patient-centred care, how do you think patients who might not be as adept to technology will be accommodated?

Role of patients and HCPs

- 5. How do you perceive the respective roles and responsibilities of HCPs and patients in achieving patient empowerment?
 - a. *Probe:* What characteristics or behaviors do HCPs and patients need to exhibit to enhance PE within patient-centered care?
- 6. What roles do HCPs and patients play in influencing key provincial strategies or policies that prescribe what patient-centered care should look like?

Health information and literacy

7. In your opinion, how ‘health literate’ are Albertans about the operations of Alberta’s healthcare system generally, and more specifically, the GP-to-specialist referral pathway?
- a. **If respondents answer negatively (i.e., literacy levels are not high)** – do you think this is an important deficit to close? Why, or why not? What could be done to enhance health literacy in this domain?
 - b. Patients with greater health literacy and “knowledge of the system” are likely to have higher socio-economic statuses. Can facilitating patient empowerment wide that gap? What interventions may need to be considered?
8. HCPs, whilst adhering to established policies and standards when providing care, also act as stewards of the public’s health resources. This seems like a point where empowerment might occur. Do you see patients having the same roles and responsibilities? Should they be empowered in this domain?
- a. What, if any, role does health literacy have in allowing patients to develop this capability?

Understanding GP to specialist referral pathways

Transitions in Care

9. How does the traditional role of GPs as “gatekeepers” affect the GP to specialist referral pathway, and how will this change after the implementation of Connect Care is complete?
- a. *Probe:* The province’s Patient First Strategy mentions the development of something like a “transition passport,” which will include important information such as patient’s care history, medications, etc. Can you explain whether you think Connect Care has achieved this goal? Why or why not?

COVID-19

10. How has COVID-19 impacted the roles and responsibilities patients and HCPs?

- a. *Probe:* How do you think the pandemic has changed the trajectory of patient-centered care for the province?

Governance and funding healthcare system

11. Does the governance and funding of our current healthcare system affect the implementation of patient-centered care and the interactions between HCPs and patients? Please explain.
12. Are current provincial policies or initiatives suitable (e.g., Alberta Patient First Strategy) suitable for enhancing GP to specialist referral pathways?
- a. *Probe:* To your knowledge, are there certain roles in our healthcare system that are dedicated to the implementation of patient centered care (e.g., such as roles dedicated to helping with patient navigation and education) or do we need to create them?

Evaluation measures

13. How are GP to specialist pathways currently evaluated to ensure they are effective and functional for HCPs and patients alike?
- a. *Probe:* Are these metrics adequate? If not, what other evaluation measures should be used? Is there a way to measure empowerment in these pathways? Would that be appropriate?

Final question

14. Is there anything you would like to share about the previous questions or anything else that we have not discussed in this interview?

Appendix B – Literature Review: Major Attributes of Patient Empowerment

Theme	Attributes or Indicators of PE	Authors

Active role of patients / self-advocacy	<ul style="list-style-type: none"> ● Active role in deciding treatment options ● A patient's active role depends on how informed they feel ● Active participation ● Patients "willing and able" to play an active role in their own care ● Maintaining roles/engagement in meaningful activity outside of illness ● Self-management ● Self-efficacy ● Self-care, self-help, self-development, self-belief, self-trust, self-leadership, self-determination ● Self-management education and problem solving ● Personal control, where patients have the capabilities to manage disease outside of the clinic. This involves "strategies to stay in control and be able to communicate" ● Articulate health problems, feelings, beliefs, and expectations in a systematic manner ● Access and evaluate information ● Negotiate decisions with the physicians, give feedback, resolve conflict, and agree on care plan ● Patients are not just recipients of information, but also partners that generate and process information ● Patients are proactive in terms of health awareness and will adhere to treatment ● Greater sense of self-management and ownership in patients 	Jørgensen et. al (2018), Agner and Braun (2018), Yeh et. al (2018), Fumagalli et. al, (2014), Akeel and Mundy (2018), Bravo et. al (2015), Castro et. al (2016), Halvorsen (2020), Kambhampati et. al (2016), Mora (2021), Bernabeo (2013), Umar and Mundy (2015)
Information / Knowledge	<ul style="list-style-type: none"> ● Access to information through various channels ● Asking patient's advice on how much information they want and teaching them how to access it 	Jørgensen et. al (2018), Agner and Braun (2018), Akeel and Mundy (2018), Bravo et. al

	<ul style="list-style-type: none"> ● Information Access, knowledge development ● Patient education, awareness of disease ● Health literacy ● Focus on information/education for individual patients ● Education and access to healthcare ● Health literacy correlates with the frequency in which electronic health records (EHR) are accessed ● Disease-related knowledge that patients must feel in control ● Increase access to information related to risks and benefits of procedures, as well as adding professional staff dedicated to helping patients achieve self-management and health literacy ● Information sharing and access to healthcare system and all health resources 	<p>(2015), Yeh et. al (2018), Garattini and Padula (2018), Jensen et. al (2020), Kambhampati et. al (2016), Nafradi et. al (2018), Mora (2021), Bernabeo (2013), Umar and Mundy (2015)</p>
<p>Relationship with HCP</p> <p>Shared decision-making</p>	<ul style="list-style-type: none"> ● Feeling respected and valued ● Taken seriously by HCP ● Minority groups should be listened to ● Perceived personal control ● Shared decision-making ● HCP should encourage patients towards PE, provide information, discuss, offer suggestions, and inquire about patients' feelings ● Mutual partnership, reciprocity, trust, and respect ● HCP recognizing that patients should be in control of their own health ● Individualized transitional care ● Shared decision making with healthcare providers ● HCPs relinquish control and accept individual responsibility and accountability of patients for their own health 	<p>Jørgensen et. al (2018), Agner and Braun (2018), Bravo et. al (2015), Yeh et. al (2018), Halvorsen et. al (2020), Kambhampati et. al (2016), Lenaghan (2019), Acuna Mora (2021), Bernabeo (2013), Akeel and Mundy (2018), Umar and Mundy (2015), Thompson (2007)</p>

	<ul style="list-style-type: none"> ● Physicians and patients make decisions collaboratively, based on evidence, patient values, beliefs, and preferences ● Physicians should review patient's preferred role in decision making and respond to patient's ideas, concerns, and expectations. This includes exploring alternatives with patient according to their values and lifestyles to agree on a care plan ● Non-paternalistic approach to healthcare services ● HCPs should encourage patients to be involved in healthcare and treatment, this could promote empowerment as well as enhance self-management ● Reciprocal relationships of dialogue and shared decision-making 	
Communication	<ul style="list-style-type: none"> ● Positive communication ● Personalized communication ● Professionals should engage in two-way communication 	Jørgensen et. al (2018), Kambhampati et. al (2016), Thompson (2007)
Learning/depending on others from others	<ul style="list-style-type: none"> ● Peer support ● Learning from the experience of others ● Enable others by sharing individual experience/coping strategies and motivating others in the same situation ● Use of forums, blogs, and social networks for online support 	Agner and Braun (2018), Jørgensen et. al (2018), Mora (2021), Akeel and Mundy (2019)

Technology	<ul style="list-style-type: none"> ● Electronic medical records with referral guidelines integrated within, like timing, expectations ● Patients and front-line providers should be able to influence design, implementation, and evaluation strategies of eConsult and eReferral services ● Centralized booking services, technology that allows transparency of care processes, and Telehealth technology ● Patient empowerment frameworks developed, designed, and implemented through technology ● Electronic health record (EHR) via patient health portal ● Computer-mediated social support (CMSS) on Online Health Communities (OHC), which allows patients to share information with other patients, has been shown to lead to positive health outcomes ● Online resources (i.e., support from peers, guidance on treatment) are complementary to traditional healthcare and supported PE ● Technological advancements (i.e., patient portals) and better patient access to these resources ● Digital networks (i.e., online patient networks, participants led research, lay crowd sourced expertise) can mean new possibilities for PE ● Telephone or telehealth video technology has abilities to enhance PE by connecting patients with someone who helps encourage self-advocacy ● Inconclusive results on whether patient portals help increase PE ● Adopting information systems to link patients with resources and decision aids 	<p>Forrest (2003), Keely and Liddy (2019), Yiu et. al (2015), Akeel and Mundy (2018), Ammenwerth (2019), Audrain-Pontevia and Menvielle (2018), Johansson et. al (2021), Kambhampati et. al (2016), Lamas et. al (2017), Lenaghan (2019), Bernabeo (2013), Umar and Mundy (2015), Grunloh (2018)</p>
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	<ul style="list-style-type: none"> ● Technology supports many different areas of PE ● Electronic health technologies have the potential to promote patient participation and improve health outcomes 	
More market/demand driven healthcare that allows more patient choice	<ul style="list-style-type: none"> ● Websites comparing healthcare providers 	Potappel et. al (2019)
Organizational structure/governance	<ul style="list-style-type: none"> ● Robust, influential organizational structures and dedicated PE roles are essential to integrate PE 	Boudioni et. al (2018)

Appendix C – Codebook for Qualitative Analysis

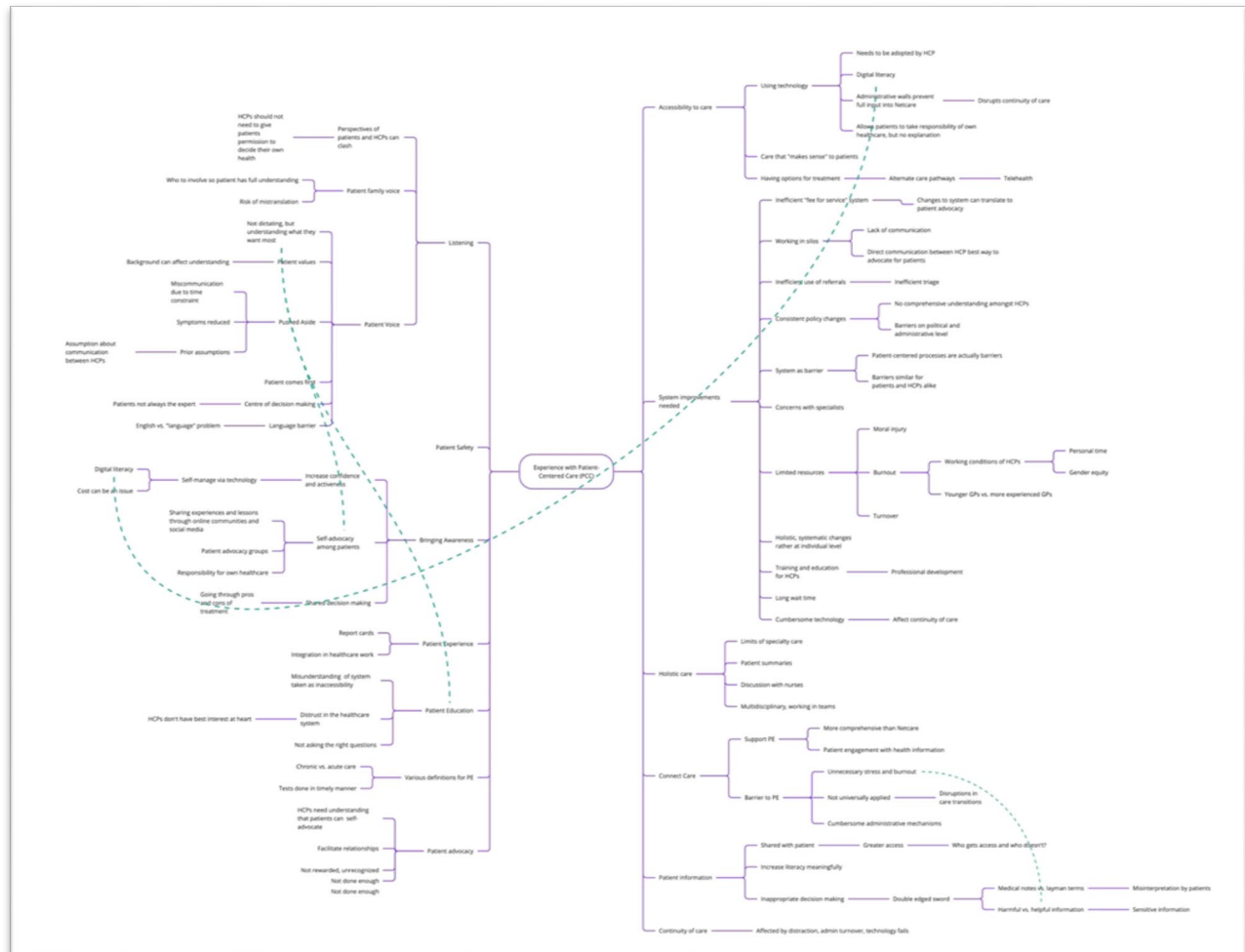
Below is an example of an excerpt (initial coding – phase 1) that shows how certain part of the interviewed were extracted and their corresponding codes.

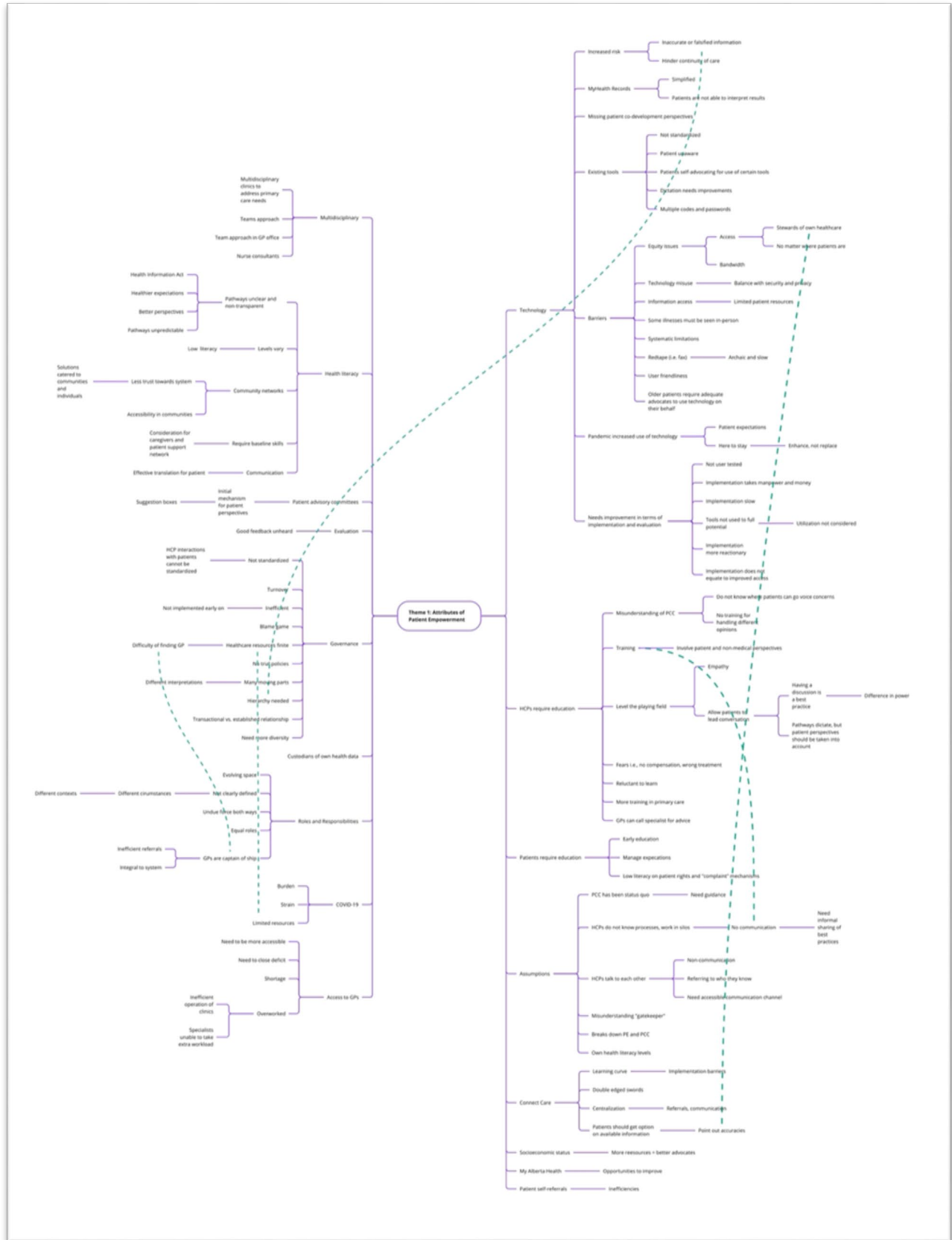
Extracted Data	Coded for
And people had really talked about on the healthcare provider side, there needs to be education on that side, teaching providers how to, well, helping to create, contributing to an interaction in a way that allows them to understand what's important to their patients. That was one barriers that there's all these other improvements that need to happen.	1. Care providers need training and education so they can decipher what is important for their patients
There was something else. Accessibility was something that came up a lot. That there isn't family doctors that are, you have a limited amount of time, and sometimes it's hard to even find a family doctor in the first place. And then, if you have one, you have limited time with them. Maybe there isn't enough time for people to have these types of conversations where they talk about, they bring to the forefront what their preferences are, what their beliefs are, or what's important to them.	1. Limited resources hinder the ability of GPs to interact meaningfully with patients
I also think just in general, just especially for there might be also misconception of what they have as far as health. And so sometimes, people can dismiss the need to empower themselves just because of they might reduce what they have to something that doesn't need a doctor's visit, if that makes sense. I would say just overall, education might just be also another barrier. And maybe also, just a general distrust of doctors in general might also be a barrier. Maybe they've undergone some level of medical trauma in the past that would prevent them from actually engaging in their health a little more in that way.	1. Having symptoms reduced to something that does not need medical attention 2. Education as a barrier 3. Distrust in the healthcare system - preventing engagement

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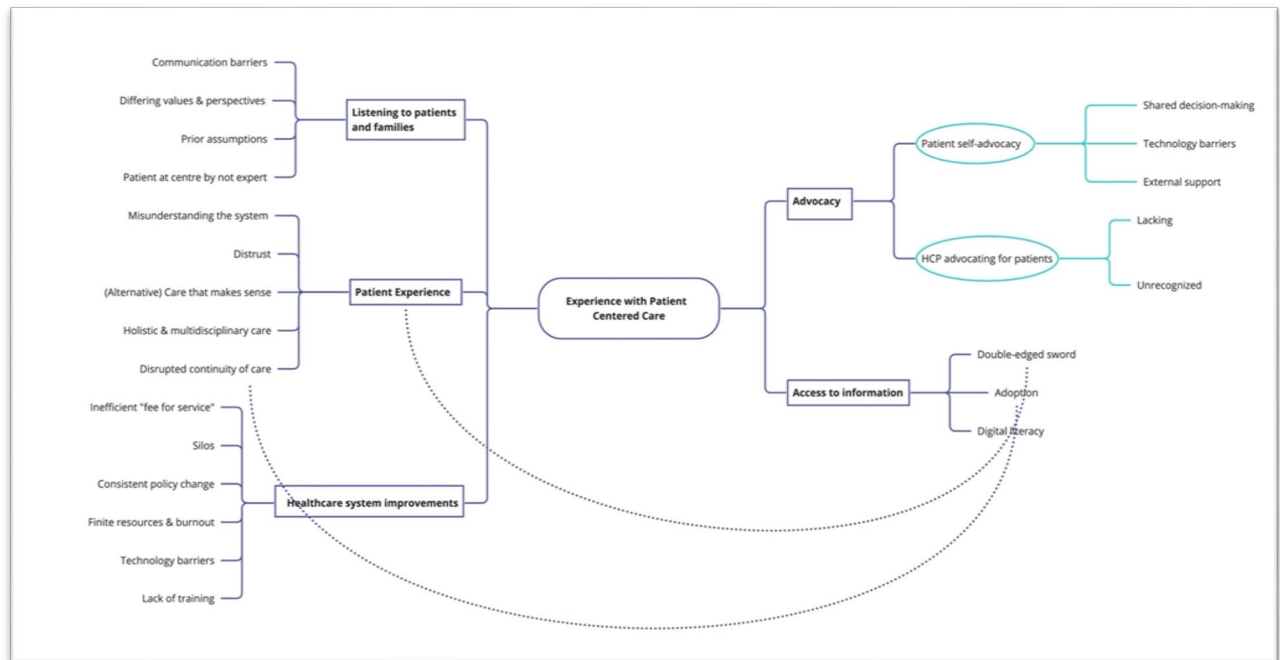
Appendix D – Mind Maps for Qualitative Analysis

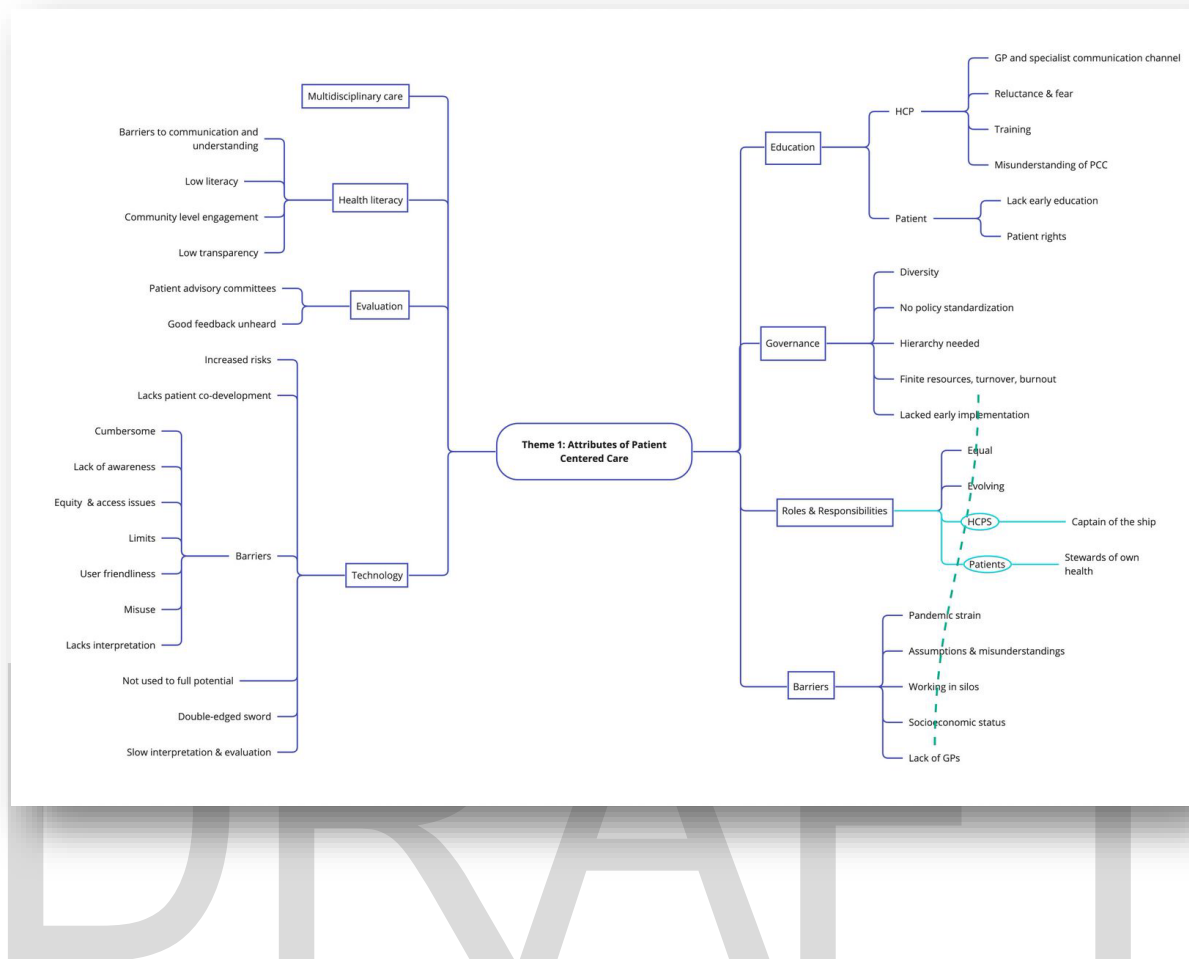
Initial Thematic Maps – Phase 2 & 3

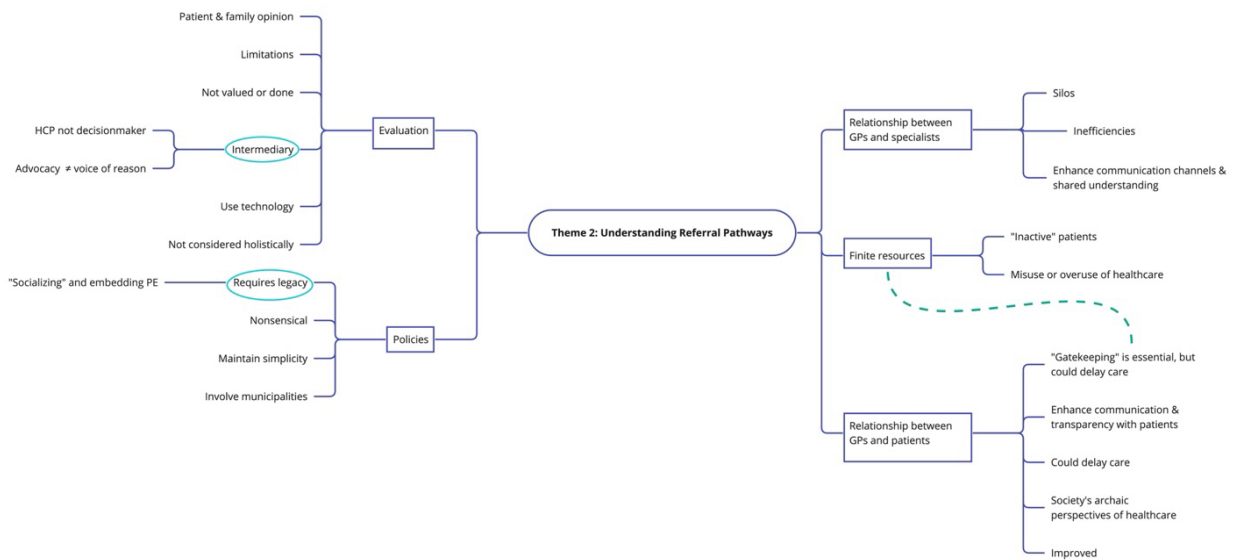




Final Thematic Maps – Phase 4







DRAFT