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Patient and public engagement and the transformation of health systems
La participation du public et des patients et la transformation des systèmes de santé

Présentée par
Susan Usher

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Dedication

This thesis is dedicated to Dr. Bob Usher (1929 - 2006), whose work exemplified so many of the values at the forefront of health care today: physician engagement, team-based care, patient and family engagement, the importance of clinical research, good data and networked systems. And to Anne Usher, still very much with us, whose exceptional skills in community development and strategic social action continue to rally and focus energies at multiple levels.

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And last but not least, I am so grateful to my sisters, Heather and Kathleen, my mother, Anne, and best friend and husband, Robb, and our sons Adam and Cato for being so supportive and providing welcome diversion along the way.

RÉSUMÉ

Problème: La participation du public et des patients contribue à la transformation du système de santé et à la coproduction de soins intégrés centrés sur le patient et fondés sur la valeur. La réalisation de ces attentes est cependant entravée par des ambiguïtés constatées autour du concept même de participation, avec d'une part une attention insuffisante portée à la façon dont les stratégies participatives déployées interagissent entre elles et avec les éléments contextuels, d'autre part une mauvaise compréhension des mécanismes impliqués.
Objectif: Notre objectif est de mobiliser des théories du changement afin d'explorer comment les stratégies de participation adoptées à travers le champ organisationnel contribuent au développement des capacités de coproduction des soins. Les concepts de travail institutionnel, d'acteur-réseau et de gouvernance collaborative sont mobilisés pour comprendre comment les efforts délibérés au sein et en dehors des organisations de santé interagissent avec le contexte du système pour générer des capacités de coproduction.
Méthodologie: Deux études de cas ont été menées dans une juridiction québécoise (Canada) marquée par un contexte de réforme en santé. La première étude explore le travail institutionnel généré par les stratégies de participation aux niveaux central et départemental d'un centre de santé universitaire. La seconde examine les stratégies d'un groupe ad hoc d'acteurs communautaires pour répondre aux préoccupations soulevées par les réformes en termes d'accès aux soins.
Résultats: Au sein de l'organisation étudiée, les stratégies interagissent avec le contexte organisationnel pour générer un travail institutionnel aux effets mitigés sur les capacités de coproduction de soins intégrés. Le travail structurel et conceptuel étend la participation des patients en tant que norme organisationnelle, mais formalise celle-ci dans la sphère administrative aux dépens de la participation dans la gouvernance, les soins cliniques et l'autogestion des soins. Le travail relationnel est d'un côté renforcé par la création de comités projet, mais compromis de l'autre par l'aggravation de la pression du temps ressentie par le personnel dans le contexte de réforme. Malgré la pression accrue pour se départir de services moins spécialisés et accélérer les sorties, les stratégies de participation demeurent déconnectées des forums de participation au-delà de l'hôpital. Dans la seconde étude de cas, des acteurs communautaires développent des capacités de coproduction à travers la création de réseaux et de nouveaux lieux discursifs. L'engagement des acteurs du système de santé dans ces efforts est cependant affaibli par les perturbations et l'insécurité induites par le contexte de réforme.
Conclusion: La présente recherche révèle les processus générés par les stratégies particulières mises en œuvre par des acteurs organisationnels et communautaires pour promouvoir la participation des patients et du public dans les systèmes de santé, la manière dont ceux-ci pourraient contribuer à leur transformation, et l'impact d'un contexte de réforme sur ces évolutions. Les recherches et pratiques futures devraient miser sur la reconnaissance et l'établissement de liens entre les efforts de participation qui soutiendront les capacités de co-production pour la transformation des soins.

ABSTRACT

Problem: Public and patient engagement is expected to contribute to health system transformation towards co-produced patient-centred, value-based, integrated care. Realizing that expectation is hampered by conceptual ambiguities around engagement, insufficient attention to how engagement efforts at different levels interact with each other and with context, and poor understanding of the mechanisms involved.

Objective: To apply theories of change in exploring engagement initiatives at field level and their contribution to the development of co-production capacities. Concepts of institutional work, actor network development and collaborative governance are mobilized to understand how deliberate efforts within and outside healthcare organizations interact with system context to generate capacities for co-production.

Methodology: Two case studies are conducted in one jurisdiction (Québec, Canada) in the context of health system reforms. A first explores the institutional work generated by engagement initiatives across central, department and unit levels of an academic health centre. A second examines the engagement efforts of an ad-hoc group of community actors to address concerns arising through reforms.

Results: Within the organization, engagement strategies interact with system and organizational context to generate institutional work with mitigated effect on co-production capacities. Structural and conceptual work spreads engagement as an organizational norm, but formalizes efforts in the administrative sphere separate from existing governance, clinical care and self-management venues for engagement. Relational work is enhanced by new committees, but jeopardized by staff time pressure exacerbated by reforms. Despite the increased pressure to divest less specialized services and speed discharge, engagement efforts do not reach beyond the hospital to connect with venues in the community. In the second case study, engagement efforts by community actors develop co-production capacities through network-building efforts and the creation of new discursive venues. Commitment to collaboration from health system actors is compromised by the disruption and role insecurity induced by reforms.

Conclusion: Field level study of public and patient engagement based on institutional and network-building theories of change helps to understand processes generated by engagement strategies, how these might contribute to transformation, and the impact of the reform context. Future research and practice should focus on recognizing and establishing links between engagement efforts that will support the co-production of integrated patient-centred care.

Keywords: patient engagement, public engagement, community engagement, institutional work, actor-network theory, Québec, co-production

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LIST OF ACRONYMS

AHC	Academic Health Centre
ANT	Actor-network theory
CE	Community engagement
CEO	Chief Executive Officer
CHC	Community Health Centre (England)
CI(U)SSS	Centre intégré [universitaire] de santé et de services sociaux (Integrated [university] health and social services centre)
CLSC	Centre local de services communautaires (local community services centre)
CSSS	Centre de Santé et de Services sociaux (Health and Social Services Centre)
ENAP	École nationale d'administration publique
FMG	Family Medicine Group (Groupe de médecine familiale or GMF)
GACO	Guichet d'accès aux clientèles orphelins (Central access system for orphan clients)
HSSC	Health and social service centre (Centre de Santé et de Services sociaux - CSSS)
LSC	Large-scale change
MSSS	Ministère de la Santé et des Services sociaux (Ministry of Health and Social Services)
MUHC	McGill University Health Centre
NHS	National Health Service
OECD	Organization for Economic Cooperation and Development
PE	Patient engagement
PLC	People living with and beyond cancer
PPE	Public and patient engagement
PPI	Public and patient involvement
QI	Quality improvement
SNA	Social network analysis
UK	United Kingdom
WG	Working Group
WHO	World Health Organization

PART I: INTRODUCTION

CHAPTER 1: INTRODUCTION

This thesis addresses public and patient engagement and the transformation of health systems. It is presented as a thesis by article in view of obtaining a Doctorate of Philosophy (Ph. D.). It is presented according to the *Guide de présentation des mémoires par article et des thèses par articles pour les étudiants chercheurs de l'ENAP* (ENAP, 2020). Certain sections are adaptations of Susan Usher's thesis proposal (2017): Patient and public engagement and the transformation of health systems.

Chapter I introduces the research program in five sections: the transformative potential of public and patient engagement; conceptual ambiguities in the field and their impact; research objectives and questions; author research affiliations and research ethics certification; and the structure of the thesis by article.

1.1 The transformative potential of public and patient engagement

Public and patient engagement (PPE) is increasingly recognized as essential to achieving value-based, integrated and sustainable health care (WHO Europe 2016; NHS 2014; Lavis and Gauvin 2018). It is also seen as a key driver of health system transformation, infusing new knowledge and energy to assure that care is adapted to changing needs and possibilities (Denis and Forest 2012). Cost pressure, increasing burdens of chronic disease, advances in digital health and care processes simultaneously demand and enable a rebalancing of the respective roles of healthcare providers and users. Millenson (2017) uses the term 'collaborative health' to describe the new desired dynamic.

These imperatives have prompted increasing efforts and investments in engagement initiatives at multiple levels, in the management of disease (Wagner, Austin, and Korff 1996), the quality and safety of care in healthcare organizations (Bate and Robert 2006; Carman et al. 2013; Coulter 2006) and in the co-production of health and care services at field level (Bovaird and Loeffler 2012; Pestoff 2006). These strategies may be used alongside or instead of statutory roles, such as on regional boards or user committees. It has become common for organizations to recruit patients as advisors on improvement teams, coach staff on working with patients, offer leadership support, promote decision aids for shared decision-making, and collect and analyse patient experience surveys (Baker 2014; Bombard et al. 2018; Cené et al. 2016). Strategies beyond organizations can involve efforts to support self-management and navigate services (Coulter and Ellins 2007), and engage patients in consultations and as representatives on planning boards or projects.

There is considerable variation between jurisdictions and over time in the scope and nature of public and patient engagement. In Norway, for example (Torjesen et al. 2017), engagement starts with local and regional health democracy, and involvement through patient organizations. In 2002, it was increased through formal representation on user committees, and with the Ombudsman Act. Patient organizations made coordination a reform priority and play a role in problem definition in primary care. Use of expert patients, especially in chronic illness, is expanding, with learning centres present in hospitals since 2006 training fellow patients and designing programs with professionals. Democratic traditions, policy change, state support and organizational efforts all contribute to shifting care dynamics at individual, organizational and societal level.

1.2 Conceptual ambiguities and their impact on practice and research

Patient engagement has been identified as a promising mechanism to mobilize transformative capacities at the micro level within organizations to improve the provision and design of healthcare services (Denis and Forest 2012). Research provides indications of factors that enable implementation of these strategies (Carman et al. 2013; Boivin et al. 2014; Mockford et al. 2012), however mechanisms that translate engagement into better care are not fully understood (Baker 2014). Engagement suffers from vague conceptualization that offers a fragmented and partial view of the phenomenon (Barello et al. 2014) and a lack of comprehensive theory-driven conceptual models that explain the mediating pathways between engagement initiatives and outcomes (Cené et al. 2016), making it difficult to develop effective policy (Conklin, Morris, and Nolte 2012). There is much attention to levels of engagement along a continuum of democratic participation (Carman et al. 2013), but less evidence on the difference this makes to rebalancing the care dynamics between providers and patients.

In a review of reforms in various countries, Best et al (2012) identified 'involve patients and families' as one of five simple rules for achieving large-scale health system transformation, but regarded the area as "problematic" While it draws on theories of experience-based design (Bate and Robert 2006) and co-production (Ostrom 2014), which consider that service models designed by and with users will be more fit for the purpose and therefore “work better,”, the concept was considered to be badly defined and used “ideologically” in the healthcare context. They found an important gap between principle and practice, with “very few examples of a successful effort to truly engage patients in large-scale transformations” (Best et al. 2012, 441–43). Despite this ambiguity, patient and public engagement is highlighted as a key driver of change in the transformation literature (Saltman and Duran 2015; Baker, Judd, and Maika 2016; Denis and Forest 2012; Greenhalgh et al. 2009; Best et al. 2012), in policy guidance (e.g. MSSS 2015; NHS 2014 “Nothing about me without me”), accreditation standards (e.g. Accreditation Canada 2015) and the mission statements of healthcare organizations.

In practice, we see lukewarm uptake of the evidence that most strongly supports engagement. In Canada, self-management programs are offered in many provinces but funding remains piecemeal and systematic referrals between clinicians and these programs is not yet systematic (Liddy and Mill 2014). Health information technology is still designed mainly for one-way communication from provider to patient (Gammon et al. 2015), and public and patient consultations are not accompanied by an obligation to act on results; in fact, it is not clear who is meant to act following consultations. Two major studies (Greenhalgh et al. 2009; Farmer et al. 2015) found that the "consulted" actors rather than consultation conveners took action to address a health service gap. The ethos of engagement needs to infiltrate the logics of care much more profoundly and spread beyond early 'champions' and engagement professionals in order to bring about the multifold changes needed for collaborative health. Two world-class cardiologists tried and failed to get patient engagement included on the agenda of the 2019 international cardiovascular conference (Swedberg 2019). In Québec, a former health minister stated that participatory democracy in designing social and health policies is still "wishful thinking" (Hébert 2016).

1.3 Research approach, objective and questions

Scholarship on public and patient engagement increasingly highlights the need for a theoretical basis for engagement efforts, consideration for interactions between them, and attention to context and power dynamics (Goodridge et al. 2018; De Weger et al. 2018; Djellouli et al. 2019; Sandvin Olsson et al. 2020). Importantly, the recent attention to public and patient engagement coincides with a period of reforms towards centralized governance in large integrated health systems that have eliminated or eroded the influence of many traditional local venues for citizen and user participation (Alexander, Weiner, and Succi 2000). Means of engagement at multiple levels need to be imagined that can function in new system configurations and contribute to rebalancing roles and responsibilities in the wake of reforms.

In summary, there is an important disconnect between the expectations for public and patient engagement as a contributor to and driver of change, and evidence of that potential in health systems. The lack of "meaningful patient and public engagement" is seen as a key vulnerability in today's health systems (Forest and Martin 2018, ix). It prevents new possibilities and distributions of responsibility from being considered, and options for change within organizations and system remains narrow, contributing to the inertia many have noted in Canadian health systems (Lazar et al. 2013; Tuohy 2018).

The present research aims to develop an operational conceptualization of engagement efforts that recognizes how and in what context particular initiatives contribute to an overall movement toward collaborative health and can inform future practice and research.

Our research is guided by three main questions:

1. What are the transformative expectations associated with public and patient engagement in health care?

2. What characteristics of engagement and context elements are associated with meeting these expectations?

3. What are the mechanisms that enable engagement initiatives to contribute to transformation towards collaborative health?

To answer these questions, we first review recent literature to better understand the ambiguity in the field. Based on this analysis, we look to theories that help explain how change comes about in complex highly institutional domains such as health care. Organizational learning, institutional work and collaborative governance are rallied to empirically explore changes generated by engagement initiatives within a healthcare organization. Actor-network theory informs a second empirical study of efforts beyond the organization to acquire power and legitimacy to participate in collaborative health. By looking at how public and patient engagement manifests at field level, we hope to identify promising targets for investment and policy attention to enable transformation.

To answer our first question, we conducted a meta-narrative review of systematic and scoping reviews of the engagement literature to better understand the expectations and assumptions associated with engagement and arrive at an operational conceptualization to guide empirical study. In empirical work, we undertook parallel case studies to understand the mechanisms and context elements whereby engagement efforts arising within and outside healthcare organizations generate and sustain capacities and conditions for collaborative health.

1.4 Preface: authors, research affiliation and ethics certification

The author of this thesis, Susan Usher, is first author on the three articles integrated herein, and made the major contribution to each, at all stages of research. The co-author on all three articles is Jean-Louis Denis, thesis director, who contributed to the design of the research, validation of the research proposal, facilitation of access to a main research site, guidance on methodological and theoretical approaches, and critical review of each of the three articles at multiple stages of development.

This research project is informed by, though not directly inserted within, the research program of the Canada Research Chair in Health System Design and Transformation held by Jean-Louis Denis. Its main influence was in orienting this research towards consideration of the transformative potential of public and patient engagement at interconnected micro, meso and macro health systems levels.

This research project, in its entirety, was approved by the Research Ethics Committee of the École nationale d'administration publique (CER-ENAP 2018-08) on May 2, 2018. This certification was sufficient for the case study of the community working group. The informed consent form employed in the community case study is presented in Appendix E. Additional ethics certification for the organizational case study was received from the McGill University Health Centre (MUHC) Research Ethics Board (BIAL6000/2019-4960) submitted with a Principal Investigator associated with the Research Institute of the MUHC. The organizational case study was supported by senior administration at the MUHC (Appendix I). The informed consent form employed in the organizational case study is included in Appendix F. Early exploratory observation (January 2017- December 2018) in both case study settings, conducted to inform the study design, was covered by the research ethics certificate of the GETOSS Canada Research Chair held by thesis director Jean-Louis Denis. Additional exploratory research was conducted in the organization in 2016-2017 with a Principal Investigator associated with the Research Institute of the MUHC, for which ethics approval was requested but deemed unnecessary.

1.5 Structure of the thesis

This work constitutes a thesis by article presented according to the ENAP Guide. The three articles are included as Chapters 3, 6 and 7.

Part I introduces the research subject and the structure of the thesis. Part II describes the research approach in three chapters. Chapter 2 presents the definitions of key notions explored in this research and the epistemology that guides the research approach. It looks at ideas of transformation and conceptual and terminological issues around public and patient engagement and related concepts, elucidates the view we adopt of transformation, and describes the realist approach adopted in our explorations. Article 1 is inserted as Chapter 3, and provides a meta-narrative review of systematic and scoping reviews. The review reveals an important gulf between expectations and effects of engagement efforts, along with assumptions that appear to impede the transformative potential of engagement. A first is that engagement in care, organizations and systems can be understood separately; a second is that provider-led initiatives are the way to generate engagement; a third is that the form of engagement is what makes it meaningful. To step away from these assumptions and develop an operational conceptualization of public and patient engagement, we look to theories of change in collaborative governance that suggests the development of capacities and conditions for joint action as a purpose for engagement efforts. Increased capacities that bring greater recognition of interdependencies and motivate collaboration may develop in multiple arenas of the healthcare field, and cross-pollinate and interact over time. This calls for longer studies at field level with attention to the wider system and societal context, and suggests a theoretical foundation for engagement research that may guide efforts more effectively towards something resembling collaborative health. Chapter 4 introduces the concepts of organizational learning, institutional work, collaborative governance and network development that underpin the design of the two case studies, and the methodological approaches employed in the two empirical studies

Part III of the thesis includes the development work of our research in three chapters. Chapter 5 describes the context in which the case studies unfold, that being a period of significant reforms in the province of Québec (Canada). Chapter 6 (Article 2) explores the evolution of engagement strategies within an academic health centre (AHC) in Québec (Canada) to understand the institutional work generated by these efforts to create capacities and conditions for co-production. The case study offers general guidelines for the design and implementation of engagement strategies within organizations that take history and system and organizational context into account. Chapter 7 (Article 3) presents a second case study, this one examining engagement efforts initiated in the extra-organizational space by community actors. Qualitative social network analysis reveals the accrual of social capital through network-building efforts and the creation of new venues for engagement. In a post-reform context, the network opportunities created by community actors for collaborative problematization between providers, patients and publics were especially important in identifying barriers to bringing their contributions together effectively.

Chapter 8 discusses the results of the case studies in relation to existing scholarship and evolving trends, in other comparable jurisdictions and in the Québec health system. While the initial study design sought to map links between organizational and community engagement efforts, these were hardly in evidence. The case studies help understand some of the reasons behind the lack of linking connections, and the risks presented by their absence, especially in the context of vertical integration.

Part IV concludes the work, looking back at the research subject and expectations. It is hoped that energies in the field will evolve to enable the emergence of networks of engagement across the organizational field. In the Québec system at present, we see very little support for the efforts, venues and bridging actors - including frontline providers - that would support these developments. The context of health system reforms, explored with actors still adapting to changes, points to system and process factors that significantly impact on collaborative relationships between formal and community sectors. These offer targets for future work by both organizations and communities.

PART II: RESEARCH APPROACH

CHAPTER 2: RESEARCH APPROACH

Chapter 2 presents the key concepts used in this research, looking first at the multifaceted nature of public and patient engagement and related terms, second at the concept of health system transformation, and third at the realist research approach adopted in exploring the research questions.

2.1. Defining public and patient engagement

Terminology in this domain has proven contentious and has been parsed extensively on three main points. A first is with "engagement" in relation to related concepts around the ability to participate. Table 2.1 presents definitions of the family of concepts that populate this field. Castro (2016) examines literature on patient engagement, patient empowerment and patient-centredness and, while finding that their exact meanings remain unclear, proposes a process model whereby focusing on patient engagement as a strategy facilitates a patient-centred approach which leads to patient empowerment. Graffigna (2015) regards patient engagement rather as an umbrella term that take in related concepts. While recognizing that each of these terms has a particular socio-political history, it may be that, in the health context, they have significantly converged. A second definitional question is between engagement as a process (i.e. an effort to engage) and engagement as an outcome (i.e. engagement as active participation). Many authors adopt the process perspective and discuss engagement as 'efforts' or 'initiatives' to support or enhance engagement. Carman's (2013) framework describes a continuum of engagement from consultation to involvement to partnership and shared leadership, emphasizing the idea that the engagement process itself is an objective or outcome and that there can be more or less meaningful engagement efforts. This question is addressed more extensively in Article 1 (Chapter 3).

The third point is around the use of words such as "patient", "public", "user", and distinctions here appear more consequential, at least in some jurisdictions, as they relate to the legitimacy to participate in health affairs, from regional boards to advisory councils to user committees and improvement work. The definition of “user” eligible to sit on a user committee varies from “current or recent user” in Québec, to also include representatives of patient organizations in France, Italy and The Netherlands (Compagnon and Ghadi 2014; Gagnon et al. 2014; Albertini 2014; Bréchat et al. 2006; Serapioni and Duxbury 2014; van de Bovenkamp, Trappenburg, and Grit 2010). Organizational engagement initiatives have increasingly sought particular characteristics in patient advisors or partners in improvement to infuse the project with lived experience of a care process or situation. This issue arises in the case study presented in Chapter 6. In Canada, Forest and Martin (2018) consider that:

> The health systems of the future – and the changes to get to that future – need to be populated with informed, involved, and active participants engaged not only as patients, family members, and caregivers, but as community members and citizens. Citizens must drive changes, co-design services, and help shape policy to improve quality and experiences (63).

Similarly, in English Vanguard experiments, it was felt important to establish an advisory board that was public rather than patient-focused, reflecting social care, carers and prevention programmes as well as patient care (Naylor and Charles 2018).

Accreditation Canada is changing the language it employs, from "patient-centred" to "people-centred" care. In Sweden, this change was made back in 2011 as the word patient was considered to objectify the person as "a mere recipient of medical services", rather than an active partner in care and treatment (Ekman et al. 2011, 2). Swedberg defines a "person" as having capacities, self-respect and the ability to interact with others (Swedberg 2019).

The present research employs the term “patient and public engagement” to reflect its predominance in recent years and indicate inclusion of people concerned with health services, whether for personal or social reasons.

Table 2.1. Concepts related to public and patient engagement in health care

Patient engagement/participation	opportunities to shape health care services through active involvement in a range of activities (Castro et al 2016).
Patient-centred care	approach to delivering care built on shared knowledge and mutual trust (Castro et al. 2016) personalized, coordinated, enabling care that enhances people’s dignity and offers compassion and respect to patients. (The Health Foundation 2016)
Patient empowerment	ability to exert influence on one's health by expressing needs and taking action to meet needs (Castro et al. 2016).

Health literacy	ability to access and use health care, interact with providers, participate in decision-making, and care for self and others (Batterham et al. 2016)
Organizational health literacy	"establishment of a favorable environment, which stimulates the users to take part in health services' co-production" (Palumbo and Manna 2018, 377) "an organization-wide effort to transform organization and delivery of care and services to make it easier for people to navigate, understand, and use information and services to take care of their health" (Farmanova, Bonneville, and Bouchard 2018, 1)
Shared decision-making	brings together clinical and patient expertise to result in appropriate care. Requires new skills development in clinicians (Légaré et al. 2017)
Patient activation	describes an individual's knowledge, skill, and confidence for managing their health and health care (Hibbard et al. 2004)
Co-production	Interaction between the party providing and the party seeking a service that creates service value (Batalden et al. 2015) "public services, service users and communities making better use of each other's assets and resources to achieve better outcomes or improved efficiency" (Loeffler and Bovaird 2016)

2.2 Health system transformation

Transformation is considered to involve much more than a policy change or reform program. It represents a significant, possibly paradigmatic, change that develops over time. The transformation of healthcare systems is a complex phenomenon involving interrelated changes at the macro level of government policy, the meso level of organizations, and the micro-level of clinical systems (Bohmer 2012; Denis and Forest 2012). Where transformation plays out is among the mix of actors involved in structuring, providing, and seeking care on a day-to-day basis. Change requires that these actors act differently based on a new conception of their roles and the establishment of new relationships. Policies induce transformation only to the extent that they change people, who may then change the structures that frame their actions and set off a positive cycle.

2.3 Realist inquiry

This research is interested in how public and patient engagement contributes to transformation. Prior research has described and categorized engagement strategies (Carman et al. 2013; Boivin et al. 2014; Mockford et al. 2012; Conklin, Morris, and Nolte 2012), however we still know very little about how they activate change. Research is complicated by the circuitous nature of the link between initiative and effect, with perceptions, identities, organizational structures, governance practices, institutional logics, culture.... all coming into play. The question therefore arises as to how research in this area might contribute knowledge to support and guide efforts in highly dynamic and complex situations. The appeal of a realist approach lies in its potential to dig beneath the surface of specific initiatives undertaken in particular situations to arrive at a more solid understanding of some fundamental mechanisms at work to produce change towards transformation. Pioneered (separately) in the 1970s by British philosopher Roy Bhaskar and British sociologist Margaret Archer, each looking at complex questions such as how to explain poverty in the developing world, or the differences between education systems in England and France, critical realism provides a bridge between positivism and constructivism in understanding how change comes about. In realist epistemology, social structures exist and enable or constrain agency, which reproduces or transforms social structure in a process that unfolds over time, revealing emergent properties or powers. Agents have self-determination, but one that is influenced by the range of opportunities in the structural arena.

Making sense of observations requires going beyond identifying correlations to grasp generative mechanisms that are "theoretical motors used to explain change" (Langley 2009, 418). The appeal when looking at public and patient engagement rests in the seeming impossibility of including all potential interacting variables at system, organization and individual level into a controlled experiment. Theory driven research offers the potential to identify mechanisms that activate change, along with context elements that facilitate or impede this activation. The challenge is to inter-connect theoretical and empirical stories and "look for underlying mechanisms that make process sequences more understandable" (Langley 2009, 421) that may not be directly observable but underlie observed phenomena (Tsoukas and Knudsen 2003; Reed et al. 2018). The working assumption is that "a particular intervention triggers particular mechanisms of change. Mechanisms may be more or less effective in producing their intended outcomes, depending on their interaction with various contextual factors" (Best et al. 2012, 421).

In line with this approach, we adopt a meta-narrative review of the literature, focusing on scoping and systematic review to look beyond particular findings of particular studies and make sense of the expectations and assumptions in this literature and understand how the field is evolving. Greenhalgh and colleagues (2005) proposed the meta-narrative approach as a way of tracing scientific paradigms in the literature, offering a means of mapping persistent themes and questions arising from scholarly work in a given area, enabling us to reflect on their meaning for the field.

In empirical study, we are interested in the phenomena of engagement in terms of activity, events and temporal evolution (Langley 2009). Understanding emerges by following the strategies of actors in various roles, along with the development of and shifts over time in networks of actors and the goals they pursue. "Process research addresses dynamic questions about temporally evolving phenomena", looking at patterns in events and activities over time (Langley 2009, 409). Who does what, when and what happens next. "Process knowledge is also relevant to practice" as it helps understand how to move "from A to B" and integrates context into the analysis and recognizes complexity. "Process research that examines how changes in practices are implemented, and how their influence spreads and interacts with existing organizational contexts, offers to move closer towards a dynamic understanding of how to improve them" (Langley 2009, 411). This corresponds with the overall objective of our research: to guide engagement efforts to contribute to transformation.

CHAPTER 3: EXPLORING EXPECTATIONS AND ASSUMPTIONS IN THE PUBLIC AND PATIENT ENGAGEMENT LITERATURE

Preface

ARTICLE 1

Exploring expectations and assumptions in the public and patient engagement literature

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Keywords: patient engagement, public engagement, collaborative health, transformation, co-production, narrative review

Abstract

Public and patient engagement (PPE) is increasingly recognized in policy statements as essential to achieving patient-centred, value-based, integrated care. Despite extensive research over two decades, important gaps and questions remain around how the efforts invested in engaging patients and publics drive the changes needed to meet these objectives. We conducted a meta-narrative review of systematic and scoping reviews to understand persistent difficulties and uncertainties in this research domain. Thirty-six reviews looking at studies of PPE in care, healthcare organizations and systems were appraised. We synthesized the expectations of PPE that prompted each review, the guiding ideas about how PPE comes about, main findings and the questions and gaps they raise. Four storylines are found in reviews: 1. Terminology is inconsistent and concepts are weak; 2. Outcomes of care can be improved 3. Influence on healthcare delivery and design is uncertain; 4. Characteristics of engagement efforts are consequential. We look at three assumptions underlying these storylines that appear as barriers to practice and research and propose alternative approaches based on collaborative governance and theories of change.

3.1 Introduction

Health systems in the 21st century are guided by notions of patient-centred, value-based, sustainable and integrated care that seek to ensure universal access in the context of cost pressures and the growing burden of long-term conditions. "Health systems are at a breaking point and doing business as usual is no longer an option" (WHO 2016). Along with these stresses, medical advances and "digitization" are changing the role doctors play in people's recovery and well-being, and contributing to a shift from paternalism to "collaborative health" (Millenson 2017), a trend that will accelerate alongside advances in artificial intelligence (Petitgrand et al. 2020). These interconnected movements involve a rebalancing of the respective roles of patients and providers. The Institute of Medicine, in its 2001 Crossing the Quality Chasm report, states that "Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs and better health" (Millenson and Berenson 2015, 1). Among system planners, harnessing "the renewable energy represented by patients and communities" is seen as essential to health system sustainability (NHS 2014). Learning health systems rely on patient and public partnership to optimize care pathways towards results that matter to people (Lavis and Gauvin 2018), while integrated care requires engaging and empowering people and communities to take an active role in designing and delivering services (WHO Regional Office for Europe 2019). Quicker discharges, more demanding regimens to manage disease, and the dispersion of care sites create new responsibilities for patients. "Today, sick or well, people will not benefit from their health care unless they bring to bear considerable knowledge, skills and motivation to participate actively in the care that is available to them" (Gruman et al. 2010, 350).

Alongside the greater participation necessary to achieve value-based integrated and sustainable health care, scholars see public and patient engagement as key *drivers* of health system transformation, infusing new knowledge and orienting efforts towards patient centredness and equity (Best et al. 2012; Denis and Forest 2012). Engagement has become ubiquitous in policy and organizational mission statements, and the lack of "meaningful patient and public engagement" is seen as a key vulnerability in today's health systems (Forest and Martin 2018, ix).

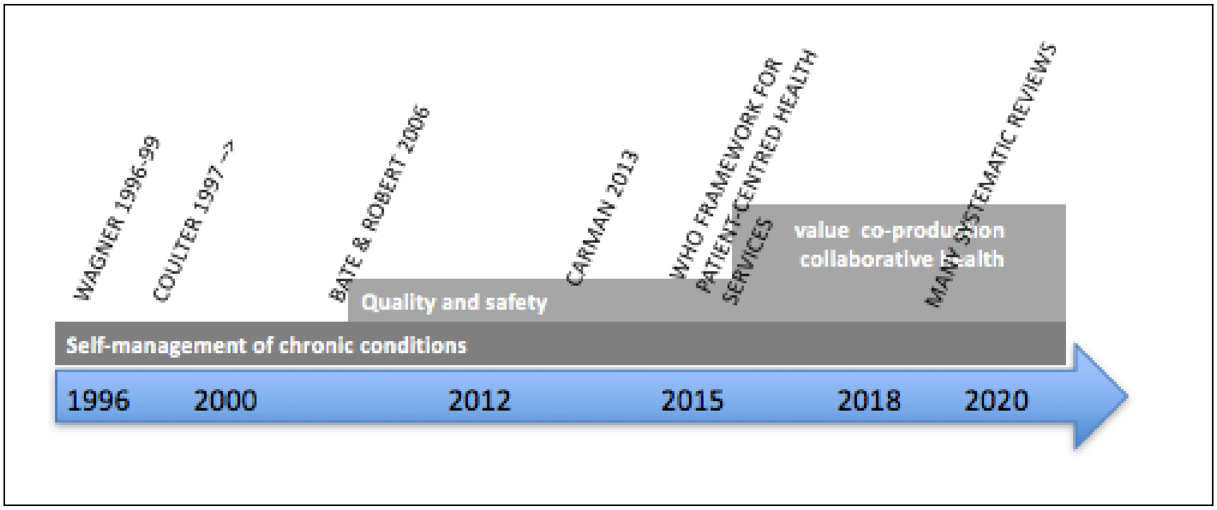
These objectives have spurred a great deal of activity and research around public and patient engagement (PPE), with Google Scholar showing almost six times more studies published after 2000 than in the decade before. However, these efforts do not, as yet, appear to be enabling the anticipated transformation. There are increasing calls for greater clarity around 'engagement' to provide useful direction in the face of uncertain goals, inconsistent terminology and the lack of a convincing theoretical basis. This meta-narrative review of systematic and scoping reviews seeks to understand the difficulties and uncertainties that permeate public and patient engagement research. We look at how scholars have approached this literature, at their expectations and findings, and the questions and knowledge gaps they raise. Holding these up beside the ideas these reviews express about how engagement comes about allows us to identify a number of assumptions that warrant examination to guide the development of theories of change that can help achieve transformation.

3.2 Methodology

3.2.1 Exploring the field

Our research involved an initial exploratory phase to gain a sense of trends in the engagement literature, followed by a meta-narrative review of systematic and scoping reviews of studies of public and patient engagement. In the exploratory phase, we searched various databases for English and French language literature published since 1995, using combinations of the terms patient/public/citizen/community + engagement/involvement/partnership/ participation + health/care/system. The literature is multifaceted and rapidly expanding, with a wide range of terms and focus. We explored 173 papers, which helped to map the main thrusts of research, and pointed to seminal papers/authors (each cited hundreds, if not thousands, of times) that have guided the broader field.

Figure 3.1: Seminal papers and key terms over time



3.2.2 Conceptions of public and patient engagement

As shown in Figure 3.1, we found that the focus of PPE expanded over the past two decades, from engagement in the management of chronic disease, to engagement in quality and safety improvements, to notions of value and co-production. Wagner's Chronic Care Model (1996) emphasized the 'Why' of engagement: productive interactions between an informed, activated patient and a prepared, proactive practice team are seen as key to improving clinical outcomes in chronic conditions. Coulter and colleagues pursued explorations of patient and citizen participation both in their own care, and in service design. Bate and Robert (2006) ventured further into this 'How' of engagement, putting forth the idea of experience-based co-design with patients as a means of improving healthcare services. Carman et al's (2013) framework drew on Sherry Arnstein's (1969) ladder of citizen participation to categorize patient and public engagement efforts with the intent of guiding initiatives in this area. The framework described engagement corresponding to micro (direct care), meso (organizational design), and macro (policymaking) levels along a "depth" continuum from information to consultation to partnership that represents "true engagement" (Carman et al. 2013, 228).

The broad and varied literature produced across this evolution has prompted a growing number of systematic and scoping reviews seeking to elucidate and consolidate the knowledge base available from research on PPE in health care. Instead, reviews often reveal uncertainties and a lack of clarity. This presents significant risk to the 'collaborative health' transformation, which depends on all stakeholders recognizing the need for and value of PPE in health care. The present article explores these reviews to understand the expectations they express for PPE efforts and the reasons these do not seem to become clearer as the body of research expands.

3.2.3 A meta-narrative review

We conducted a meta-narrative review of systematic and scoping reviews in order to understand what public and patient engagement is expected to achieve in contemporary health care and understand the "storylines" (Greenhalgh et al. 2005) of research on engagement as it is approached from different perspectives. Greenhalgh and colleagues proposed the meta-narrative approach as a way of tracing scientific paradigms in the literature. The phases they suggest of planning mapping, appraising, synthesizing and recommendations were followed, with some differences that bear mention. The authors undertook the research without benefit of a multidisciplinary team or patient research partner. However, they brought research experience in health system governance and transformation, along with professional experience in patient and provider education and insights from working with patients, administrators and clinicians at an academic health centre to design conferences on patient engagement over four years with international opinion leaders. This work provided extensive opportunity to hear and discuss the perspectives and efforts infused in this domain and these are brought to bear in the present research. The meta-narrative review was adopted as it offers a means of mapping persistent themes and questions arising from scholarly work in a given area, enabling us to consider underlying assumptions in PPE research, and reflect on their meaning for the field.

3.2.4 Study selection

Searches on databases (Cochrane, EBSCO, JSTOR, Medline, PubMed, Sociological Abstracts) identified 134 articles using the terms 'patient engagement/participation + review' and 75 articles using the terms 'public/community/citizen engagement/participation + health

+ review' in their title. Records were excluded if they 1) were duplicates, 2) were related to engagement in developing countries, 3) addressed engagement in research and technology assessment, or 4) were not related to health; 180 records were eliminated based on these exclusion criteria. The remaining 29 records were retained for analysis and a further nine were added drawing on references from these studies. Figure 3.2 presents the PRISMA flow diagram (Moher et al. 2009), and Table 3.1 presents the journals in which 37 studies were published (one thesis was included). The search was restricted to reviews published since 2000, and 15 of the reviews were published in or after 2018. We included two protocols for reviews (Goodridge et al. 2018; Sagen et al. 2020) for their value in understanding the questions being asked by scholars looking at this literature. The list of publications, with complete authors, title, publication and study design is provided in Appendix B. Tables included in the text will refer to only the first author.

Figure 3.2 PRISMA flow diagram

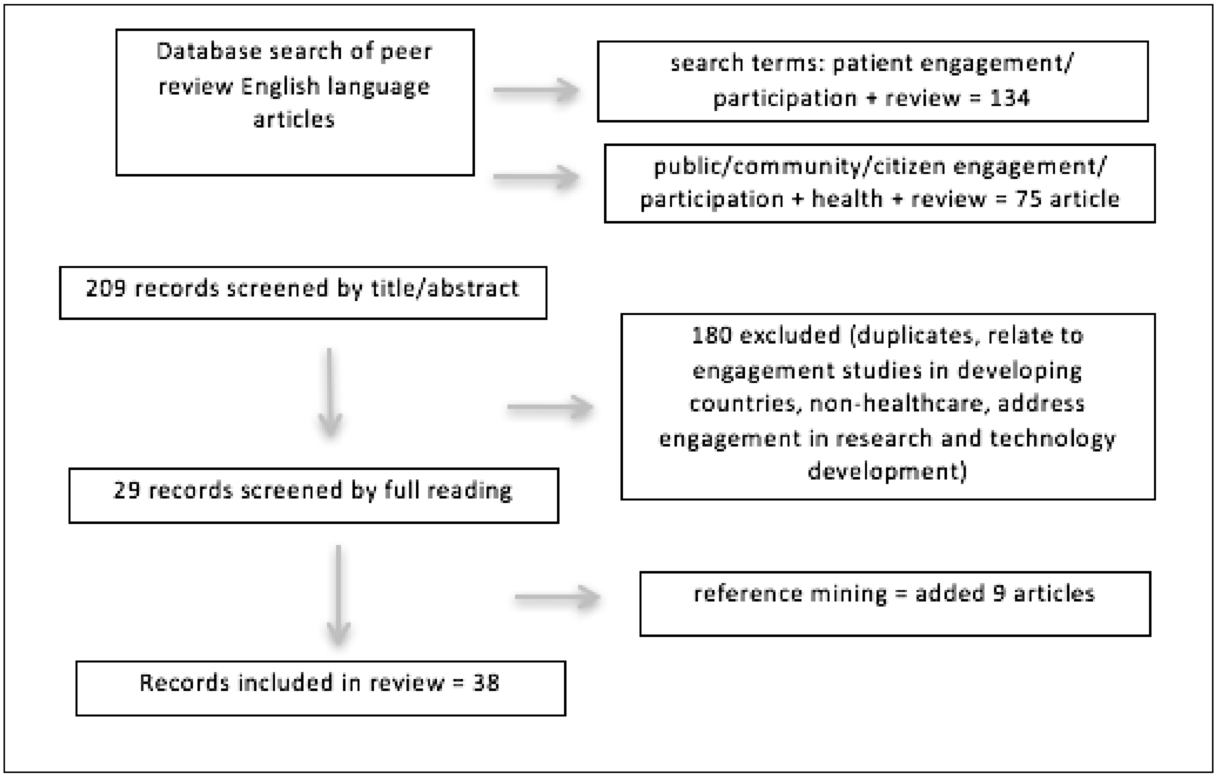


Table 3.1 Journals in which reviews appear

BMC Health Services Research (3)
BMC Medicine (1)
BMJ (4)
BMJ Quality & Safety (2)
CFHI Evidence Boost
Evidence & Policy
Frontiers in Psychology
Genome Medicine
Health Affairs
Health Expectations (2)
Health Policy (2)
Health Research Policy and Systems
Implementation Science
International Journal for Quality in Health Care
International Journal of Health Policy and Management
International Journal of Nursing Studies
International Journal of Public Sector Management
Journal of Advanced Nursing
Journal of Participatory Medicine
Medical Care
Open Science Framework
Patient Education and Counselling (3)
Patient Experience Journal
PLOS ONE
Reviews
Systematic Reviews (2)

Each article was carefully read by the lead author and data were extracted to capture the expectations held out for PPE, the locus of activity, difficulties encountered in reviews, key findings and the authors' conclusions or statements about knowledge gaps and research needs revealed by the review. Table 3.2 summarizes the main questions asked in each review and their key findings. It also describes (where available) how the review authors consider PPE to be produced or enabled, largely expressed in the selection criteria they employed. Table 3.3 presents the gaps and directions for future research identified in the reviews. We look at these data to see what they tell us about how PPE has been explored in research, and find four main storylines, with some reviews informing more than one. The first is a quest to apprehend what is meant by PPE. The second seeks to confirm the effect of engagement efforts on outcomes of care and care encounters. The third questions the influence of PPE on service design and delivery. The fourth is focused on features of the engagement effort itself. Within each of these storylines, we look at the expectations held out for PPE, findings related to these expectations and how this might direct future research in the field.

Table 3.2 Research questions, findings and idea of what enables public/patient engagement (PPE)

First author	Question guiding the review	Key findings	What enables PPE?
Baker (2014)	What can be learned from exemplars about organizational factors that support successful patient engagement?	The mechanisms that translate patient and family engagement into better care and improved outcomes are still not fully understood.	Organizational strategies to recruit and support patients as advisors, coaching for staff to work with patients and leadership strategies
Barello (2014)	What are the main conceptualizations associated with the expression “patient engagement” within the current academic literature?	Conceptualization of PE is vague and has changed over time; it offers a fragmented and partial vision of the phenomenon.	
Barello (2016)	What PE outcomes are considered when describing the effects of e-health interventions?	There is still a passivizing logic implicit in the implementation of e-health interventions due to low engagement of patients in the design of the care process	
Berger (2014)	How have interventions for PE to improve patient safety been implemented?	There is insufficient high-quality evidence informing real-world implementation of PE in safety.	Interventions instituted by the organization
Boivin (2018)	What instruments are available to appraise PPE in decision-making in health systems and research?	Most evaluation tools are designed to improve engagement activities.	Initiatives of engagement practitioners
Bombard (2018)	What are the strategies and contextual factors that enable optimal PE in the design, delivery, and evaluation of health services? What are the outcomes of PE on services?	Identifies facilitators and barriers to engaging patients in improvement efforts and finds that the level of engagement appears to influence the outcomes of service redesign.	Organization techniques to enable and enhance involvement
Castro (2016)	What are the differences and relationship between concepts of patient empowerment, patient participation and patient-centeredness in hospital care?	Their meanings remain unclear; the connecting thread is a balance between the power of professionals and patients.	

Cené (2016)	What is the effect of PFE in direct care and quality improvement?	Evidence of effectiveness is limited, particularly for quality improvement, and few studies assess the effect of PFE on health outcomes.	In care, through involvement in hospital clinical rounds, use of decision aids; in quality, through participating in QI activities, advisory councils, surveys etc.
Conklin (2012)	What are the outcomes of PPE in policy?	Empirical evidence of outcomes of public involvement activities in health care remains underdeveloped.	Multiple types of input from different groups/activities
Coulter (2007)	What is the effectiveness of strategies for informing, educating, and involving patients?	Most studies report improvements and several promising avenues are identified: strengthening health literacy being key.	Various supports to help patients secure appropriate, effective, safe and responsive health care (i.e. health information, decision aids, self-management action plans)
Crawford (2002)	What are the effects of involving patients in the planning and development of health care?	Patient involvement induces some changes to making services more accessible, improving information for patients and changing organizational culture. Evidence not found of effects on use of services, quality of care, satisfaction, or health.	Consultations, patient representation in meetings/planning boards, surveys, community health councils, patient groups/forums, projects in hospitals or in the community
Daykin (2007)	What are the context, mechanisms and outcomes involved in PPI in the UK?	Context factors include community capacity, consumer or activist involvement, and professional culture and resistance. Mechanisms include structures and resources to support user involvement, discursive approach and provider adaptation. Outcomes may be micro service enhancements or containment of user agendas.	Various structures and resources to support user involvement

De Weger (2018)	Why do CE interventions work or not? What are the guiding principles by which CE interventions can be implemented?	Meaningful participation of citizens can only be achieved if organisational processes are adapted to ensure that they are inclusive, accessible and supportive of citizens.	Many efforts that go beyond receiving or providing (consultation) information, including service user networks, healthcare forums, interventions by trained peers, volunteering
Djellouli (2019)	How is public involvement conceptualised in large-scale change (LSC)? How is it carried out? What impact does it have?	The aims of public involvement lack clarity and there is little evidence about which involvement methods are appropriate at different stages of LSC.	Public meetings (town halls); feedback on consultation documents
Dukhanin (2018)	What evaluation tools are available to assess PPE in organizational and system decision-making?	There is no consensus on the objectives of PPE; the ladder of engagement suggests influence over the decision process is the goal. There are no tools to measure scale-up or sustainability.	Interventions instituted by the organization
Gallivan (2012)	What are the definitions of patient engagement?	There is a lack of consistency in terminology and definitions around the concept of patient engagement. Many terms are used interchangeably.	
Goodridge (2018)	What is the nature and outcome of PFE in the hospital setting? - protocol		
Halabi (2020)	What are the dimensions that compose the concept of patient participation at micro, meso and macro levels?	Patient participation is a process, which requires evolution and pre-requisites such as sharing knowledge, power and responsibility. Presents a thematic tree of factors involved in patient participation at multiple levels.	
Hall (2010)	What is the effectiveness of interventions to involve patients in enhancing their safety?	There is limited evidence for the effectiveness of interventions designed to promote patient involvement in safety incidents beyond self-medication.	Information or teaching by provider

Hamilton (2019)	What key elements define the quality of PFPE in decision-making in healthcare systems?	Protocol motivated by little evidence on whether PFPE initiatives improve healthcare systems and a lack of consensus on ideal outcomes of engagement.	Activities to include patient voice, choice and representation in decision-making at individual, health service and system policy level
Kovacs-Burns (2014)	What tools and guides might be used in developing a PE resource kit for patients and providers	Key themes include: definition of PE, roles and expectations, meaningful and appropriate engagement, evaluation and resourcing.	Tools and resources to prepare and support patients and providers; infrastructure to build social capital
Liang (2018)	What are the characteristics of research on PE in hospital health service improvement?	Patient influence on decisions was greater when it provides "unique insight into problems that allowed providers to identify new possibilities for solutions" (p. 6) and when proposed changes were championed by a provider.	Participation in QI projects or committees, working groups, advisory panels
Majid (2019)	What are the barriers and facilitators of PE in planning, service delivery and QI activities in hospitals?	The literature in planning and designing PE has not fully utilized the available theoretical literature. A diversity of terms is employed.	Activities with providers to design, deliver or improve health and care
Manafo (2018)	What are the methods and outcomes of engaging the public and patients in `health ecosystem priority setting?	There is no gold standard of engagement: decision-makers need support of effective techniques and assure patient 'buy-in'; evaluation of engagement initiatives is needed.	Techniques used by decision-makers to engage patient/public
McCarron (2019)	How are health systems investing in the training and skill development of patients and families to participate in healthcare decision-making?	Investments implemented by health systems to build the capacity and ability of individuals to meaningfully participate in health system decision-making have positive outcomes in terms of sustained patient engagement.	Initiatives to harness the skills and build the capabilities of patients to participate in healthcare decision-making (forums, patient instructors, workshops and co-design)

Mitton (2009)	What processes are used in public engagement processes at meso and macro level? With what outcomes?	Deliberative engagement processes were more often on-going than one-off, while non-deliberative processes were more often one-off. Facilitators of include ability and willingness to seek public input in an ongoing way, opportunities for face-to-face interaction among public participants and decision-makers, and use of multiple methods.	Deliberative and non-deliberative processes
Mockford (2012)	What impact has PPI had on the UK NHS?	There are many varied PPE activities in the UK NHS but studies do not provide robust evidence of their impact.	Varied
Ocloo (2021)	What are the theories, barriers and enablers in undertaking PPI in health, social care and patient safety?	Commitment to PPI and partnership working is dependent on taking a whole system approach that considers individual and organisational enablers and constraints and addresses imbalances of power.	Interventions instituted by the organization
Palumbo (2016)	How can co-production of health care be understood? How can patients be engaged and what barriers prevent it?	There is a lack of organizational capabilities to empower patients.	Establishment of co-creating partnerships between providers and patients
Park (2019)	What is the impact of PFE on patient safety?	PFE has some positive effects on patient safety interventions in terms of attitudes and behaviours towards patient safety. Few studies measure outcomes related to adverse events. Barriers include power imbalances and providers need to invest in educating and empowering patients and families during processes like medication administration.	Interventions instituted by the organization
Pinnock (2015)	What is the evidence from implementation studies of self-management support interventions in asthma?	Interventions that explicitly addressed patient, professional and organisational factors showed the most consistent improvement in both process and clinical outcome.	Wide range of interventions

Sagen (2020)	How are patients involved in service development and delivery at meso level? With what results for quality? Protocol	Rationale for review protocol: patient participation is still not always incorporated into work routines in treatment, institutional decisions or at government level.	
Sandvin Olsson (2020)	How is the impact of adult patient participation in health service development described in the literature?	Patient participation in service development in the organization led to improved communication and information to patients and smaller service enhancements, with a few reporting improvements in patient safety.	Working groups, patient councils, steering boards, consultation events in organization
Sharma (2017)	Is patient engagement on advisory councils linked to improvements in quality, safety or satisfaction?	Patient advisors are involved in a wide range of projects toward practice improvement and seem to help healthcare organizations make programs more accessible.	Interventions instituted by the organization
Simmons (2014)	What is the difference in health outcomes between patients who received PE interventions in self-management and those who received usual care?	Results support the link between PE interventions of varying types and delivered in different contexts and improved outcomes. PE should be considered a risk factor given its value in helping individuals effectively manage chronic disease.	Interventions delivered in various contexts that increase a patient's knowledge, skills and confidence to manage a condition
Tobiano (2019)	How do patients feel they are engaged in medication communication at admission and discharge?	Patients generally feel and act on responsibility to communicate with providers about medication and found that families/friends helped them provide, question and absorb information.	Factors that enable patients' medication communication (including provider approach and family accompaniment)
Van Veen (2014)	What key practices are required to develop and sustain patient and family advisory councils in hospitals?	A direct relationship between PFACs and improved outcomes could not be found.	Participation on advisory council of an institution
Zhao (2019)	What is the extent of PE in the development of best practice reports related to transitions from hospital to home?	Only half of best practice reports actively involved patients in report development and few considered marginalised/vulnerable populations.	Interventions instituted by the organization

3.3 Results

3.3.1 Storylines in reviews of the PPE literature

Terminological and conceptual uncertainty: Four reviews specifically address definitions and conceptualizations of PPE. Gallivan (2012) finds a lack of consistency, with many terms used interchangeably. Castro (2016) examines patient engagement, patient empowerment and patient-centredness and, while finding that their exact meanings remain unclear, proposes a process model whereby focusing on patient engagement as a strategy facilitates a patient-centred approach which leads to patient empowerment. Barello et al (2014) conduct a lexicographic literature review of 259 studies and concludes that conceptualization of PPE is vague and offers a fragmented and partial vision of the phenomenon. In line with the evolution of this literature depicted in Figure 3.1, Barello et al note changes over time in how PPE is conceptualized. Halabi et al (2020) consider 'patient participation' to be inclusive of related terms, but see a lack of consensus in the literature on concepts related to the term.

Another definitional question that appears is between PPE as a process (i.e. an effort to engage) and PPE as an outcome (i.e. engagement as active participation), though the vast majority of reviews adopt the process perspective and discuss 'efforts' or 'initiatives' to support or enhance engagement. Several of the other reviews (Barello et al. 2016; Berger et al. 2014) accept Graffigna's (2015, 13) perspective of PPE as an "umbrella term that qualifies the systemic relation that occurs between the “supply” and the “demand” of healthcare" and takes in related concepts of patient activation, health literacy, empowerment, etc.

This first set of reviews tell a story of terminological fuzziness along with an emerging impatience to move away from the dissection of terms and delve into a more general and helpful conceptualization.

Looking for effects of PPE on outcomes of care: Eight reviews focus on efforts to increase patient (and family) engagement in care. They hold out expectations that these initiatives may enable better outcomes (preventing errors, hospitalizations and emergency department use) (Hall et al. 2010; Park and Giap 2019; Pinnock et al. 2015; Simmons et al. 2014; Tobiano et al. 2019), and that PPE interventions can lead to increased patient capabilities for self-management and a rebalancing of care responsibilities (Coulter and Ellins 2007; Pinnock et al. 2015), supported by information and communication technologies (Barello et al. 2016).

These reviews are prompted by questions around the effectiveness of PPE interventions at meeting these expectations. Reviews looking at studies of interventions to develop self-management, confidence and skills in patients with chronic conditions find that they improve outcomes over usual care (Coulter and Ellins 2007; Pinnock et al. 2015; Simmons et al. 2014). In their conception of what enables engagement, these reviews include studies of a broad range of interventions in various contexts, from hospital or internet-based coaching to community-based peer-led interventions.

Three reviews explore the effectiveness of hospital-based interventions in particular to involve patients in preventing safety incidents. One finds limited evidence for their effectiveness (Hall et al. 2010); another that few studies measure outcomes related to adverse events and of those that do, only half reveal significant decreases (Park and Giap 2019). Barriers include power imbalances between patients and providers and attendant patient concerns about jeopardizing their relationship with providers. A third review concludes there is insufficient high-quality evidence on interventions to engage patients in safety to guide real-world implementation (Berger et al. 2014). Tobiano's (2019) review of studies on patient perspectives on their engagement in medication communication identifies family accompaniment and an inclusive provider approach as facilitators.

In this storyline, the plot seems clear: efforts to engage patients in their care are meant to improve health and safety outcomes. The effectiveness of interventions can be assessed by reductions in hospital admissions and emergency department visits, and by improvements in clinical and patient-reported outcomes. Interestingly, in reviews where the story unfolds as planned, a broad range of interventions is considered to contribute to the development of skills such as self-care and communication. Reviews where evidence is less convincing tend to involve only studies of hospital-based interventions.

Uncertain influence, definition and presence of PPE efforts in organizations and systems: In reviews focused on engagement in healthcare organizations, PPE is conceived as a way to improve quality (Bombard et al. 2018; Cené et al. 2016; Ocloo et al. 2021; Sagen et al. 2020; Sharma et al. 2017), enable patient-centred care (Baker 2014; Dukhanin, Topazian, and DeCamp 2018; Kovacs Burns et al. 2014), and induce culture change in providers (Bombard et al. 2018). Some authors find limited evidence of the effectiveness of PPE interventions on quality (Cené et al. 2016; Mockford et al. 2012), while a few note effects in making services more accessible (Sharma et al. 2017), improving communication and information to patients (Sandvin Olsson et al. 2020), patient educational materials, peer support, physical spaces and staff culture (Crawford et al. 2002; Daykin et al. 2007). Many reviews reveal difficulties in evaluating or identifying outcomes (Baker 2014; Cené et al. 2016; Van Veen 2014), or find that evaluation is mostly designed to assess engagement activities (Boivin et al. 2018; Dukhanin, Topazian, and DeCamp 2018; Kovacs Burns et al. 2014) and not outcomes.

Several raise the lack of a theoretical basis for understanding how PPE induces improvement (Baker 2014; Majid and Gagliardi 2019; Manafò et al. 2018) or look at barriers and facilitators. Palumbo (2016) considers that organizations lack capabilities to empower patients. Patient influence on organizational decisions is found to be facilitated when the changes they propose are championed by a provider, and when patients offer "unique insight into problems that allow providers to identify new possibilities for solutions" (Liang et al. 2018, 6). Ocloo (2021, 15) concludes that PPE requires a "whole systems" approach that considers individual and organizational enablers and constraints and addresses imbalances of power. In line with this need for an enlarged perspective, Goodridge's (2018) protocol for a systematic review of PPE in acute care hospitals aims to consider contextual factors and power imbalances.

Reviews addressing PPE efforts at system level express expectations such as improving healthcare services (Berger et al. 2014; Conklin, Morris, and Nolte 2012; Crawford et al. 2002; Daykin et al. 2007), tailoring services to needs (Djellouli et al. 2019; Manafò et al. 2018; Mockford et al. 2012) increasing the legitimacy of decision-making (Djellouli et al. 2019), restructuring healthcare delivery toward patient-centred care (McCarron et al. 2019) and supporting the quadruple aim of improved patient and provider experience, outcomes and cost (Hamilton et al. 2019). These reviews raise similar lack of clarity about objectives (Manafò et al. 2018) and outcomes (Hamilton et al. 2019). Several point to factors that appear important in enabling PPE at system level: inclusive organizational processes (De Weger et al. 2018), infrastructure to build social capital (Kovacs Burns et al. 2014), willingness to seek public input in an ongoing way, and use of multiple methods (Mitton et al. 2009).

A small number of reviews explore whether PPE efforts are actually being made in service design. Zhao (2019), in a review of best practice reports related to the transition from hospital to home, finds that only half involve patients in their development, and only 10% consider marginalised populations. Sagen's (2020) protocol for a scoping review of PPE in service development and delivery is motivated by the fact that patient participation is still not always incorporated into the work routines of providers, institutions and governments. Similarly, Barello (2016, 11) attributes the "passivizing logic" implicit in the implementation of eHealth interventions – often involving one-way communication from provider to patient – to a lack of effort to engage patients in their development.

In this storyline, the plot gets lost in the details of process and the end appears nowhere in sight. Broad expectations for organizational and system improvement through PPE confront findings of changes that are modest and piecemeal when they can be found at all. The most recent and forthcoming work looks to broaden the focus, which may help delve into some of the facilitators and barriers found in reviews. The lack of attention to engagement efforts in actual practice rather than controlled experiments reduces the story's credibility.

Characteristics of engagement efforts: A central preoccupation among researchers looking at PPE has been with characterizing particular engagement initiatives, and many reviews refer to Arnstein's ladder of citizen participation (and Carman's adaptation as a continuum of engagement) in their conceptualization of engagement (Bombard et al. 2018; Castro et al. 2016; Dukhanin, Topazian, and DeCamp 2018; Kovacs Burns et al. 2014; Liang et al. 2018; Majid and Gagliardi 2019; Park and Giap 2019; Zhao et al. 2019). This is especially evident in reviews of PPE studies at organization level. Many focus on strategies to achieve "true engagement" in decision-making, emphasizing two-sided deliberation (Majid and Gagliardi 2019), recruitment strategies, coaching of patient advisors and staff (Baker 2014) and the need for tools to appraise PPE initiatives (Boivin et al. 2018). A commonality in these studies is that PPE is regarded as a phenomenon produced by deliberate initiatives of provider institutions.

Reviews of organization level PPE focus on studies of strategies, initiatives, activities and techniques used by organizations to engage patients, such as advisory councils, surveys, or participation in quality improvement projects. Reviews at system level similarly emphasize opportunities for engagement created by system actors, though some also consider a broader range of community structures and resources outside the provider purview that support PPE (Crawford et al. 2002; Daykin et al. 2007; De Weger et al. 2018; Mockford et al. 2012).

This storyline extracts the protagonists (provider and patient) from their surroundings, and assigns responsibility for drawing the contours of the action to the provider side. That responsibility is enacted through close attention to getting the exercise itself right.

3.3.2 Questions arising from the storylines

The reviews explored here reflect that PPE has been treated in separate streams, with different expectations at the levels of care and organizations and systems. How engagement efforts at different levels interact with each other, within and beyond the care encounter and provider institution, remain less explored, but figure in the questions and knowledge gaps raised by several authors (Table 3.2). Djelouli (2019) calls for greater attention to interaction between invited and uninvited forms of public and patient participation. Halabi et al. (2020) present a thematic tree that assembles factors involved in patient participation at multiple levels. It suggests targets that help create skills, attitudes and conditions required for operationalizing engagement, and these go beyond particular initiatives. De Weger et al (2018, 15) raise the need for studies of engagement efforts to "venture into the power bases and accountability relations that drive action within organizations". These reviews appear to signal a move away from terminological dissection, towards clarifying the conceptualization of PPE and working to understand the mechanisms or mediating pathways that translate PPE into outcomes. This recent work appears as an essential step towards developing a theoretical basis for PPE that can orient efforts more productively to achieve the transformative expectations summed up by 'collaborative health'.

Table 3.2 Gaps and directions for future research identified in reviews

Conceptual work

- A deeper understanding of what PE means is needed to develop knowledge useful for innovation in clinical practice and health policy (Barello, 2014).
- There is a need for common language and a clear view of roles, objectives and responsibilities (Gallivan, 2012).
- There is a lack of clarity on where to focus to assess the impact of PE (Baker, 2014).
- A comprehensive theory-driven conceptual model is needed that explicates the mediating pathways and outcomes of PFE (Cené, 2016).
- The protocol aims to identify key elements for defining the quality of patient and family caregiver engagement in decision-making across engagement domains (Hamilton, 2019).
- Scientific rigour in studies of evaluation tools must be improved (Boivin, 2018).
- The mechanisms linking interventions to outcomes are rarely specified (Daykin, 2007).
- A conceptualization of PPE is needed along with ways to measure its impact (Mockford, 2012).

Understand barriers to engagement

- Look at strategies to overcome patient resistance to actively engage in their care (Berger, 2014).
- What strategies might help patients and families understand that engagement in safety is a responsibility and help providers understand the importance of treating patients and families as partners in safety (Park, 2019).
- Look for strategies to improve health care professionals’ communication skills and empower patients (Tobiano, 2019).
- Research on behavioural interventions to overcome barriers to PE in both patients and providers (Liang, 2018).
- Need to understand how healthcare professionals are being supported to enable patient engagement (McCarron, 2019).

Pay attention to context

- Protocol seeks to consider contextual factors and power imbalances (Goodridge, 2018).
- Need to look at the impact on involvement of discrimination and inequality, the relevance of theories about social context and power, barriers and enablers in involvement processes (Ocloo, 2021).
- Pay attention to power imbalances and appropriate ways to upskill citizens (De Weger, 2018).
- Call to understand the purpose of involving the public and interactions between invited and uninvited forms of involvement (Djellouli, 2019).
- Investigate long-term consequences and context factors that enable identification of complementary systems of patient participation and study participation across levels (Sandvin Olsson, 2020).

3.3.3 Addressing assumptions in the PPE literature

Alvesson and Sandberg (2011, 258) propose that doubts arising in a field of scholarship warrant exploration of assumptions underlying the domain when it appears that "a challenge of the identified assumptions [can] inspire new areas of research". In this next section, we explore three assumptions that appear in the storylines presented above to impede movement towards transformation.

A first assumption is that PPE efforts can be studied in a segregated way in care, organizations and systems. Scholars have very recently acknowledged the need for better connections between levels and a comprehensive vision to orient strategies at different levels in ways that mutually reinforce one another. *The assumption that engagement in care, organizations and systems can be understood separately appears as a first barrier to achieving transformation through engagement.*

A second assumption regards how engagement is thought to come about. At organization and system level, PPE is most often studied as something that provider authorities initiate. Scholars, mainly in the area of integrated care, have found that managerial targets are a primary focus of these initiatives (Wankah et al. 2018) and interventions are designed based on professional knowledge, motivation and perceived benefits (McKillop et al. 2017). This leaves little space for the entry of new ideas and approaches. Certain reviews we explore point to the value of infrastructure to build social capital and recognize that providers are more likely to share decision-making power when patients/public contribute a distinct knowledge base or capacity (Daykin et al. 2007; Kovacs Burns et al. 2014). This suggests that engagement is enhanced by exploratory social spaces (Habermas) that enable knowledge, capacity and skills building *among* patients/publics and *among* providers, along with opportunities to bring them together. *The assumption that provider-led initiatives are the way to generate patient/public engagement can therefore be seen as a second impediment to achieving its transformative potential.*

A third assumption has to do with the value of initiatives. A pervasive tendency in the literature is to see initiatives as increasingly "meaningful" and likely to produce outcomes the farther they are up the ladder of participation (Arnstein, Carman) from information through consultation to partnership. The focus on form in engagement practice and research has been at the expense of function (what is the goal of the effort?) and attention to what parties bring to collaborative dynamics (thus recent calls for attention to power bases). The view of decision-making in this perspective also appears divorced from everyday action in a way that sits uncomfortably with ideas on decision-to-action mechanisms (Chia 1994). *The assumption that the form of engagement determines its impact on change focuses on provider efforts and detracts from the goals of engagement and the power dynamics of decision-making.*

3.4. Discussion

3.4.1 Towards an operational conceptualization of PPE

The assumptions found in this review point to a rebalancing of the relationship between public/patient and provider/system that can be expressed as collaborative governance. The ideas and models put forth in the seminal papers mentioned at the start of this paper (see Figure 1) suggest that engagement entails a new dynamic between providers and patient/public; that 'engagement efforts' are needed to bring about change; and that community, societal, organizational and system factors are consequential. Conceptualizing PPE as a form of collaborative governance or co-production appears to capture the desired dynamic as it sees collaborators driven to bring together different ideas, perspectives and capacities, achieve mutual understanding and undertake joint activity towards a common objective (Emerson and Nabatchi 2015). Collaborative governance scholarship offers a view of the conditions in which contributions of providers and users come together in co-production. Emerson, Nabatchi and Balogh (2012) describe a cyclical process, where threats and opportunities in the system context drive collaboration dynamics and joint action with outcomes that impact both system context (and the next round of drivers) and collaborative dynamics, which improve as capacities and interdependencies are recognized.

The theory of change in collaborative governance suggests the development of new capacities and conditions for joint action as a key objective for public and patient engagement efforts. These reflect the "productive interactions" in Wagner's model, while extending these from the direct care encounter into organizational and system arrangements. An example that has caught the attention of participatory democracy scholars is the Improve Care Now project, where patients and providers participate in a collaborative space as interdependent producers and users of knowledge (Batalden et al. 2015; Fung 2015), with impact on care, organizational processes and policy. The project is driven by acknowledged uncertainties around how to manage a disease (Crohn's/colitis), invests in spaces where patients exchange their own knowledge and strategies, developing and spreading capacities amongst each other independently from providers. Provider interest in this new knowledge base incentivizes collaborative dynamics to integrate new approaches into practice and support them with organizational and system changes. It suggests "collaborative innovation", where innovation is defined as a "step change that problematizes and transforms the way that things are usually imagined and done" (Torfing 2019, 1).

Collaborative governance suggests objectives for engagement efforts that may help assure and assess their contribution to transformative change. A first is the development of public and patient capacities, where policy, investment and research attention need to reach beyond the provider sphere to support public spaces for discussion and development. Venues such as these could provide "a parallel discursive arena" (Barnes et al. 2003, 383) to develop distinct knowledge and resources that contribute to the care and health service equation. A second is recognition of these capacities by providers, which requires increased awareness of external resources and bridges between organizations and communities. A third is the organization of practices, services and systems around a broader set of contributions. The recent focus on learning health systems emphasizes the importance of capturing these contributions to enable a more complete view of activities and conditions impacting on health outcomes (Lavis and Gauvin 2018). Denis and Forest (2012) point to organizational contexts that support learning as key to adapting professional practices and models of care; this appears essential to integrating the contributions and capacities of patients, families and communities. Finally, the drivers of collaboration – uncertainties, opportunities, difficulties – need to be clear to orient joint activity towards outcomes.

Co-production is gaining traction in the healthcare domain. However, recent work reveals risks of definitional muddiness similar to those seen in PPE. Bevir (2019) considers that we are seeing a convergence today of emancipatory, deliberative and New Public Governance trends in a narrative that emphasizes processes for co-production. In effect, a systematic review of studies on co-creation and co-production in public services (one quarter of which were in the healthcare sector) finds that over half mention no objective: co-production, like PPE, appears as a value in itself (Voorberg, Bekkers, and Tummers 2015).

The co-production school represented by Pestoff (2006) and Bovaird (2007) puts forth a clearer objective for co-production in publicly funded health systems as active involvement by users and communities to take on some of the responsibilities borne by the state. This aligns with Alford's (2009) view of collaborative governance, where service users and citizens are "untapped resources" who “can add to the repertoire of institutional arrangements available to public sector organizations in seeking to achieve their purposes” (10). Palumbo describes mobilizing the "dormant resources" of patients and publics (Palumbo 2016, 72) and overcoming the "blind loyalty to the biomedical model" that leads healthcare professionals to overlook patient contributions. Sicilia proposes a 'citizen-capability' approach as "transformative towards a new ethos" (Sicilia et al. 2016, 24).

As with PPE, the challenge in co-production is to move beyond the normative and identify or develop theories of change that serve to operationalize the enhancement and assembly of patient and provider contributions into new and better models. In a bibliometric review of co-production specifically in the healthcare sector, Fusco (2020) finds that "little has been produced on how the organisation of health services should change or adapt in order to consider the patient as a partner in designing, monitoring, delivering and evaluating a work practice" (Fusco, Marsilio, and Guglielmetti 2020, 13). Ferlie et al associate co-production and the creation of public value to 'downward-facing' models of public administration where organizations learn from the environment ... and use all possible resources to solve problems" (Ferlie et al. 2019, 6).

Halabi raises four considerations important to operationalizing PPE: it is a process that requires evolution in power sharing and learning; training is needed for both providers and patients; attention should be paid to factors that influence implementation, and implementation is a systemic process involving micro, meso and macro levels. Similarly among the studies of co-production in Voorberg's (2015) review that mention objectives, the most influential factors in their achievement are, on the one hand, inviting structures and procedures in public organizations and infrastructure to communicate with citizens, and on the other hand, citizen skills, values and social capital.

3.4.2 A lesson on context from the UK

The UK has emerged as world leader in research on PPE over a period of significant and persistent reforms, and certain lessons emerge from that experience that tie into the findings of the present review. The rise of interest in PPE over the past 10 to 20 years parallels significant changes in health system governance that reduced statutory roles for citizens even as their involvement was promoted. Carter and Martin find that despite the fact that "a 'commons' discourse infuses the NHS Constitution" (Carter and Martin 2018, 708), the results are increasing deficits in accountability and instrumental use of public consultation, with 'involvees' divorced from connections to broader communities. The lack of connection prevents development of knowledge bases and capacities that would highlight interdependencies and help to even out power differentials between user and provider spheres. Policies and resource flows will need to shift to support user initiatives and encourage providers to look beyond their organizations.

3.4.3 Future research

The field of PPE appears to be moving beyond terminological dissection and adopting a broader view of what is needed to change the relationship between user and provider. The storylines seen in reviews of the PPE literature reveal assumptions that future research might address. Research approaches are needed to capture developments and initiatives across micro, meso and macro levels to see how they support one another to drive, enable and sustain change among users and providers. This involves looking beyond provider organizations to see where initiatives arise and how they connect, and taking a longer-term view to understand the actions of multiple actors to adapt to and integrate a different distribution of responsibilities.

Empirical research at field level might look at how strategies initiated in various parts of health systems and society produce and sustain capacities to contribute to health care, examine how these strategies cross-pollinate, interact, and evolve over time. Actor-network theory (Callon and Ferrary 2006) appears useful in understanding how different groups in civil society assemble the power needed to be included in collaborative dynamics. Within provider organizations, theories of institutional work and organizational learning appear especially useful to empirically explore how new patient and community capacities are integrated into practices, policies and models. Finally, researchers would do well to focus more on actual practices than experimental initiatives where context variables, including governance reforms, are often neglected.

3.5. Conclusion

Transformation towards collaborative health challenges policy actors to broaden their perspectives, take a greater interest in the capacities of patients and communities to support better health outcomes, and allocate resources for capacity development. Health policy that legitimizes and values these contributions may encourage providers to appreciate patient and community capacities, motivating collaborative work to reshape health care and services.

CHAPTER 4: CONCEPTUAL FRAMEWORK

Chapter 4 looks at how the questions raised by the meta-narrative review inform the conceptual frameworks adopted for the empirical studies of public and patient engagement in organizational and community settings. It then describes the methodological approaches selected as promising ways to explore empirical phenomena based on these frameworks and the theories of change they encompass.

The meta-narrative review in Chapter 3 raises features of scholarship on public and patient engagement that impede progress – or possibly recognition of progress – toward health system transformation. A considerable gap exists between the engagement initiative itself, which receives intense scrutiny, and the desired outcomes, which remains a vague and far distant expectation. We therefore looked to concepts that could help to understand the process of change in health systems, and research methodologies that would enable us to perceive change in the empirical world.

We will first expand on the discussion of co-production and collaborative governance introduced in the previous chapter to situate these concepts within evolving ideas arising in public administration. What becomes clear is that the dynamics proposed require fairly profound changes in healthcare organizations and professions which, as mentioned in the introduction, can be tremendously resistant to change. Organizational learning has emerged as a means of understanding the circuitous route to change in this complex arena that enables profound institutional change in identities, roles and rules that could support new collaborative dynamics.

4.1 Co-production and collaborative governance

Ideas about co-production evolved from the observation (Ostrom 1978) that, unlike goods, the production of a service involves both service provider and service user. That draws attention to what users bring to the table, and to how well provider and user come together to produce value. Loeffler and Bovaird (2016, 1006) define co-production as "public services, service users and communities making better use of each other’s assets and resources to achieve better outcomes or improved efficiency". Co-production can extend, with various suffixes to co-design and co-delivery, though, along with other authors (Bevir, Needham, and Waring 2019; Sicilia et al. 2016), we do not consider these distinctions terribly meaningful. As the division between provider and user becomes less clear in a healthcare context characterised by chronic diseases, resource constraints and new technologies, capacities for co-production gain importance. However organizational routines, professional cultures, policies and incentives are often poorly aligned to support co-production. Organizational health literacy describes an organization's capacity to support and integrate user contributions to the service equation (Farmanova, Bonneville, and Bouchard 2018): along with having "something valuable to contribute", service producers and users need to "experience conditions in which these contributions can be made efficiently and effectively" (Loeffler and Bovaird 2016, 1014).

As seen in the previous chapter, notions of collaborative governance (Emerson, Nabatchi, and Balogh 2012; Emerson and Nabatchi 2015) provide a lens for understanding how capacities for co-production develop, combine and contribute to transformation. The focus on co-production in health care has some unique rationales (Dawson and Morris 2006), but also reflects a general trend in the literature on governance in evolved democracies that recognizes the limitations in government's ability to devise public services to meet complex societal challenges. It reflects new forms of governance that enable collaboration, or the "pooling of appreciations and/or tangible resources... to solve a set of problems which neither can solve individually" (Gray 1985, in Emerson and Nabatchi 2015, 16), and introduce innovative solutions (O'Leary 2015). Similar ideas are expressed in public value governance (Bryson, Crosby, and Bloomberg 2014, 446), where citizens are problem solvers "actively engaged in creating what is valued by the public", and new public service (Denhardt and Denhardt 2007). Democracy scholar Archon Fung describes participatory multisectoral problem solving to "frame the particular problem in more accurate and viable ways than professionals acting alone", adjudicate difficult tradeoffs, "provide information relevant to devising solutions and evaluating implementation" and contribute additional resources through co-production of solutions (Fung 2015, 517).

Collaborative governance is considered to bring increased government accountability, greater civic engagement, and higher levels of process and program success (Fung and Wright 2001; Hicks 2015; Lasker and Weiss 2003; Leach 2006). Governance occurs at multiple levels as formal or informal rule systems or steering mechanisms that exercise a "sphere of authority" to enable movement towards a goal (Bache and Flanders 2005, 39). Collaborative governance therefore plays out at multiple levels in the relationships, processes and structures that engage people and organizations constructively across boundaries (Emerson and Nabatchi 2015). This view finds resonance in ideas around transformation in complex adaptive systems such as health care, where the interaction and alignment among capacities located at various levels in various spheres is considered a key ingredient to change and improvement (Best et al. 2012).

Collaborative governance is seen as a cyclical process where threats and opportunities arising in the health system context motivate actors to invest in collaborative mechanisms across boundaries, work to develop mutual understanding of problems and potential solutions, recognize interdependencies and develop capacities for joint action, which results in new practices, which in turn alters the context. The cycle could continue to benefit from increasing capacities and venues in which to develop mutual understanding to progressively induce transformation. Social network theory underpins the process, stressing the influence of interactions in networks of relationships at motivating collaborative efforts and bringing about recognition of interdependencies (Emerson and Nabatchi 2015).

4.2 Organizational learning

Change and learning are important components of this transformation. Tsoukas and Chia define organizational change as a "becoming" or continuous evolving. It is "a reweaving of actors' webs of beliefs and habits of action to accommodate new experiences obtained through interactions" (Tsoukas and Chia 2002, 567). Organizational change occurs both as a result of the learning of individual actors and through the perpetuation, in structures and policies, of new ways of doing things within the organization (Argyris 2003) and beyond. Learning is seen as a dynamic capability to "integrate, build and reconfigure internal and external competencies to address rapidly changing environments" (Touati et al. 2015, 2). Processes and practices are continually reworked to address new problems and contingencies and integrate new perspectives. Theories around organizational learning support the potential impact of relational work and opportunities for discussion created within healthcare organizations, such as quality improvement projects, that open up “opportunities for creative sense-making” (Cloutier et al. 2015, 17). Patient reported outcome measures and patient experience surveys are now integrated into improvement strategies in some jurisdictions (Greenhalgh et al. 2017; Baker, Judd, and Maika 2016). Chreim, looking at physician role identity change in a Canadian healthcare unit, finds that physicians’ role identity changed, and interactions with patients “transitioned from a transactional mode to a relational mode” as institutional structures that collocated health services and enabled multidisciplinary teams allowed them to appreciate seeing the patient as a “whole” (Chreim, Williams, and Hinings 2007, 1524).

The value of patient and public participation in organizational learning comes in part from expanding the range of options considered in decision-making, providing ideas that are not moulded by the organizational mindset. Contributions provide "unready-at-hand moments of interruption" (Weick 2003, 472), that are recognized as valuable sense-making opportunities for organizational actors (Mintzberg 1979; Weick 2003). They can also enhance intrinsic motivation for improvement (Busuioc and Lodge 2015) and, some feel, help to overcome impediments to change that particularly characterize the healthcare context, such as siloed care specializations, and interprofessional and professional-managerial tensions (Baker, Judd, and Maika 2016). The highly institutionalized nature of health care presents particular challenges to change: "...it seems that the deep-rooted, old organizational structures and professional practices often impede effective patient empowerment and involvement in co-production" (Torjesen et al. 2017, 113).

We look to institutional work as a theory of change that might help understand how public and patient engagement initiatives in an organization activate cycles of learning through collaborative sense-making.

4.3 Institutional work

The dominance of norms, rules and cultures belonging to and perpetuated by the institutional logics of providers (Scott 2000) exert significant influence on the viability of innovative practices, processes and system designs. Institutions have "cultural-cognitive, normative and regulative elements that . . . provide stability and meaning to social life" (Scott 2000, 48) and guide a field (Reay and Hinings 2005). However, institutionalized professions are not stable, but rather "constantly under review and subject to redefinition and defence" (Greenwood, Suddaby, and Hinings 2002, 59). Institutional change occurs through a process of destabilization, the creation of opportunities for innovation, the spread of new standards, and stabilisation as a new system standard becomes taken for granted (Berkhout and Westerhoff 2013). Organizational and field level change occurs through individual and collective actions to create, maintain and disrupt institutions (Lawrence and Suddaby 2006; Greenwood, Suddaby, and Hinings 2002; Maguire et al. 2006).

In our first empirical study presented in Chapter 6, we explore the institutional work generated by engagement efforts within a healthcare organization. Organizations provide a key venue in which professional groups redefine institutional logics that guide their field and reconstruct professional identities (Muzio, Brock, and Suddaby 2013; Chreim, Williams, and Hinings 2007). Healthcare organizations can therefore be important engines for transformation of provider-patient dynamics in health care.

The notion of institutional work developed by Lawrence and Suddaby (2006) provides a helpful means of studying change as it unfolds, by examining the specific and purposive actions taken by individuals and organizations to reproduce, alter and destroy institutions. They identify actions to mobilize support, construct rule structures, (re)construct identities, create connections, and redraw the “cognitive map of the field” (Lawrence and Suddaby 2006, 221) as aspects of creating institutions. Work to maintain institutions involves monitoring and enforcement activities and sustaining myths that support an institution. Institutions are disrupted through actions that disconnect rewards and sanctions from a set of practices, disassociate a practice from its moral foundation, or undermine core assumptions and beliefs.

4.4 The organizational field

Organizational change is necessary but not sufficient for transformation. Health systems, especially in this era of integrated care, are challenged to envelop activities that take place outside organizational boundaries and involve much greater interchange between internal and external actors. Batalden (2015) refers to a 'blurring of boundaries' between care providers and users in modern society. Van Gestel and Hillebrand (2011, 2) define the organizational field as "an established set of organizations engaged in a similar purpose or in related activities which together shape activity and meaning in that field".

The organizational field offers a level of study capable of examining the interplay of multiple actors, structures and strategies. It is suited to conceptions of large-system transformations in health care as "interventions aimed at coordinated, system-wide change affecting multiple organizations and care providers, with the goal of significant improvements in the efficiency of health care delivery, the quality of patient care, and population-level patient outcomes" (Best et al. 2012, 422).

Organizational fields are institutionally defined through increased interaction among organizations, structures of domination and patterns of coalition, and awareness of being engaged in a common enterprise (DiMaggio and Powell 1983). Within organizations, change occurs as groups develop alternate fixes to contradictions and manage to operationalize new ways of acting and new material arrangements (Fairclough 2005; Seo and Creed 2002). At field level, social movements can emerge to challenge field definition, introduce new notions of sense-making and induce collaboration from other actors (Hensmans 2003).

While institutional work is suited to capturing change within the organization that might support new collaborative dynamics, additional means are needed to explore the wider community space involved in the development of user capacities and contributions to collaborative efforts. The meta-narrative review in Chapter 3 suggests that engagement efforts outside of formal healthcare organizations play an important role in developing capacities for collaborative health. As well, significant outcomes of engagement efforts initiated by system actors may actually be produced in the community space. These connections are ill-explored in the literature and ill-developed in practice, but appear vital to realizing the transformative potential of public and patient engagement. We therefore accompany our case study within the healthcare organization by a second case study of how community-based actors within the same contextual space develop capacities and power to participate and be recognized in collaborative arrangements. These two explorations provide a broader perspective on how public and patient engagement might be supported to achieve transformation.

4.5 Networks

Network concepts help to understand how power dynamics can shift to promote collaboration. Networks involve flows of ideas, influence and resources, affect knowledge creation and sharing, and promote recognition of interdependencies and capabilities that can play a key role in institutional change at field level (Weber and Khademian 2010; Argote and Miron-Spektor 2011).

Benson (1975) considers that interactions between organizations must be explained at the level of resource acquisition, with the basic resources being money to mount and sustain programs, and authority, defined as possession of a "domain" in which the organization has "the right and responsibility to carry out programs of a certain kind", with the exclusiveness, autonomy and dominance to define proper practice in this area (Benson 1975, 232). Read from the perspective of health care, this emphasizes the enormous challenge of opening the field to more significant roles of other actors. However, Benson suggests that discursive legitimacy allows some organizations and individuals to speak on behalf of issues because of their ability to mobilize support from groups beyond the immediate set of organizations involved in the collaboration (Benson 1975). This discursive legitimacy resembles the notion of social capital as a means of understanding how changes can come about in the balance of power - the potential to influence - in a field. Pierre Bourdieu describes social capital as "the sum of resources, actual or virtual, that accrues to an individual or group by virtue of possessing a durable network of more or less institutionalized relationships of mutual acquaintance and recognition" (Bourdieu and Wacquant 1992, 119).

Actor-network theory (Akrich, Callon, and Latour 1988) sees power as produced through collective interaction between multiple actors, leading to a focus on how "actor networks grow in size, complexity and influence" (Akrich, Callon, and Latour 1988, 243). The stages through which coalitions of actors develop power to effect change (Denis and Langley 2007) provide useful landmarks in observing the combined effects of various engagement strategies over time. How are issues defined and actors brought together? What encourages actors to continue to devote energies to the effort? How do their interactions highlight or develop capabilities? Do efforts become embedded in roles and routines? Is this done in such a way to facilitate perpetuation and expansion?

4.6 Methodology

These concepts of institutional work and actor-network development inform the methodologies adopted in each of our case studies. These are described in detail in the next two chapters, however we use this section to discuss the rationale behind our methodological choices.

4.6.1 Case study

We mentioned the realist approach earlier to clarify the epistemological basis of our exploration of public and patient engagement in the transformation of health systems. Qualitative case study data from interviews, document analysis, observation etc. is commonly employed to incorporate the subjective understanding actors have of a phenomenon along with more objective data. Critical realism does not require any number or specificity of case studies to produce knowledge, but the process must involve "thoughtful in-depth research with the objective of understanding why things are as they are" (Easton 2010, 119). This is consistent with Yin's view of case study research as being suited to explanatory how and why questions and operational links traced over time (Yin 2003). In a realist research approach, the choice of data can be governed by "what is thought to be required to establish a plausible causal mechanism" within a particular theoretical construct (Easton 2010, 123).

Purposeful sampling was used in both organization and community cases: as our objective was to understand how engagement initiatives contribute to transformation, we deliberately selected cases where efforts were in evidence.

The organization was selected as it was a recognized leader in patient engagement in Québec and Canada. An exploratory research period (2017-2018) helped to identify sub-cases within the organization that would enable a multi-level understanding of engagement efforts. With the approval of senior leadership at the health centre, we observed a number of meetings and obtained documents to understand the organizational objectives around engagement. In parallel, we consulted public-facing documents, annual reports, internal newsletters, media reports, etc. A confidentiality agreement was signed at the outset of this preliminary observation period. Sub-cases at department and unit level were purposefully selected based on indication of their activity around engagement.

Within the healthcare organization, we conducted a single case study with the object of analysis being the institutional work generated organization-wide through engagement initiatives. However, to penetrate the organization deeply enough to grasp the mechanisms of organizational learning involved, we included sub-cases of central, department and unit level engagement initiatives. The study of institutional work in multiple contexts within an organization forms the type of "quintain" Stake refers to, where each case provides slightly different variables and contexts that feed into a better understanding of a phenomenon (Stake 2006, 6).

The naturalistic inquiry undertaken in both cases helps understand the context and situation in which interlevel dynamics unfold. The aim of case study research is not generalizability but to provide enough information that others can determine if their context is similar enough to the study context that results could be transferred (Yin 2003).

The community initiative explored in the second case study (Article 3, Chapter 7) was one of several initiatives we saw emerge in the few years after Québec's health system reforms of 2014-15. During an exploratory period, we attended meetings organized by several neighbourhood resident committees and citizen groups rallied around specific issues (such as hospital closures). The Working Group was selected for longitudinal case study as it brought together, on an ad hoc basis, community residents concerned as users about changes in the health system, and community groups concerned for the impact of change on more vulnerable community residents, and appeared likely to sustain its efforts. The group agreed to allow us to observe their initiative as a non-participant over an open-ended period of time and give us access to their documentation and communications. In this case, as in the organization, we deliberately sought out promising cases in line with our objective to see how engagement initiatives contribute to transformation.

4.6.2 Social network analysis

We combined case study methodology with social network analysis in the second case (Article 3, Chapter 7) as a means of understanding the development of capacities through the accumulation of social capital, or discursive legitimacy, and motivate recognition by and collaboration with health system actors. Network analysis enables the study of relationships between organizations (Provan et al. 2004). "The notion of network enables us to see how a point, which was isolated, becomes a point that controls a large number of other points, becomes a locus of power" (Callon and Ferrary 2006, 37, my translation). Egocentric social network analysis (SNA) is used to trace how the Working Group assembles a network of relations and participates in the exchange of knowledge and resources. SNA has been used to look at how community actors can grow their own networks to gain power within the health system, and become "the indispensable spokespersons" of a neglected group (Brossard and White 2016, 54, my translation).

Our use of SNA in this case study served to see how a small group of engaged community actors assembled legitimacy to both induce system actors to collaborate on understanding problems arising from system reforms and create new venues to further engage community residents in developing capacities to meet their health and care needs. Broader and longer use of SNA could reveal shifts in the set of actors important to addressing a given problem and guide resource allocation. SNA has been used to understand networks important to self-management of chronic diseases (Rogers et al. 2011) and suicide prevention (Menger et al. 2015). Graphic representations of the organizations and actors involved in addressing a complex social challenge can inform ways to improve access and navigation between services, guide public support and give organizations insight into how their services fit within the broader network. Mapping can also identify structural holes between organizations that present opportunities for brokers (Sozen, Basim, and Hazir 2009) who could be supported to establish and maintain connections between them.

These methodologies, underpinned by theories of change, offer a new way of looking at public and patient engagement that may help guide future efforts and research. A global aim of our work is to gain insight into how public and patient engagement initiatives alter the logics that support provider and user identities and transforms the 'référentiel' (as per Muller 2005) that more generally guides social assessment of the value of different activities and the allocation of resources.

PART III

DEVELOPMENT

CHAPTER 5: STUDY CONTEXT[1]

Québec is the second largest province in Canada, with a population of 8.4 million (Institut de la statistique du Québec 2018). Government is responsible for health and social services, with support from transfer payments from the federal government conditional on adherence to the principles of the Canada Health Act: accessibility, comprehensiveness, universality, portability and public administration. Per capita spending on health is lower than many other provinces (Canadian Institute for Health Information 2017). Universal tax-funded health insurance covering hospital and physician services has been in place since 1971, and is accompanied by public provision of many social services and a mandatory public-private universal drug insurance program. At its inception, Québec's health system adopted a broad perspective of health, inspired by the Alma Ata Declaration, and brought together health and social services under a single government Ministry. Looked at very broadly, the Québec system has evolved in two eras: a first based on a highly decentralized, community oriented vision, and a second starting around the turn of the millennium of increasing centralization of governance, and emphasis on performance and integration centred on biomedicine.

This chapter highlights some key elements of history and reforms that appear important to public and patient engagement within this evolution. It starts by taking a moment to look in particular at the history of Local Community Service Centres (CLSCs by their French acronym) for primary care that played a formative role in the institutions and expectations of public and patient engagement in the province. As will be seen in Chapter 7, a number of the actors who came together in a community engagement initiative to address issues arising from reforms were driven by values and expectations formed during this earlier era.

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[1] Sections of this chapter dealing with more recent reforms in the past 20 years are adapted from a chapter in the 2019 edition of l'État québécois, entitled 'Un historique des réformes du système de santé au Québec: les instruments et leur impact', on which I was first author (Usher et al 2019). The chapter was produced as part of the Transformative Capacity of Health Systems research program under Jean-Louis Denis' Canada Research Chair in Health System Design and Adaptation, on which I participated.

When they were instituted by the state in 1972, the mandate of CLSCs was to offer curative and preventive health services, social services, and community action to support the identification and development of solutions to local health and social problems (Ministère des Affaires sociales 1972, in Gaumer and Desrosiers 2004). Early implementation was firmly rooted in the community: a committee made up by citizens interested in questions of health and well-being was accredited, given resources to conduct a needs assessment and put together a programme proposal that was discussed directly with the Ministry and awarded a budget; 65 CLSCs were established in this manner across the province between 1972 and 1974 and new ones continued to open until 1989 (Crémieux et al. 2001). Variation between communities was expected (Gaumer and Desrosiers 2004). Community residents occupied Board positions (Boivin 1988) and contributed to program delivery, largely as volunteers. In the latter 1980s and 1990s, government sought to reduce the variations between services available in different CLSCs and mandated a set of core services (Gaumer 2006), leaving less room for public input and programs geared to specific community needs. The 1990s saw the creation of regional authorities with elected boards that were meant to increase regional autonomy over decisions concerning health and social services (Rochon 1987).

The Clair Commission (2001) marked a turning point in the avenues available for public engagement. Noting that 80% of medical consults still occurred in private practices, and considering this a sign that the "arranged marriage" of health and social services within CLSCs had failed, Clair advocated the creation of family medicine groups (FMG) to provide the entry point into the health system (Gaumer and Desrosiers 2004, 63). In 2002, the "Horizon 2005" government action plan designed by François Legault (now Premier of Québec) committed to implementing 300 FMGs over three years. The Clair Commission also advocated governance changes. Reforms in 2003-2004 replaced regional boards with 15 Health and Social Service Agencies, mandated to organise services and assume responsibility for a territorially defined population with Boards of Directors appointed by the Minister of Health and Social Services. CLSCs were merged with long-term care facilities and community hospitals into 95 Health and Social Service Centres (HSSC) under a unified board of directors. While in 2003 the Québec system included 148 CLSCs and 125 hospitals, by

2004 there were 95 HSSCs and 32 hospitals. The definition of needs moved up to HSSC and Agency level, which became responsible for population health as defined through government priorities. In 2005, Bill 83 mandated the creation of user committees in each healthcare establishment and assured user committee members two seats on each establishment's Board of Directors.

The latest structural reform, Bill 10 (MSSS 2015b) passed in 2015, involved further centralization through the elimination of the Agency level of governance, and the fusion of all establishments in the system to create 22 Integrated Health and Social Service Centres (CISSS by the French acronym) and nine Academic Health Centres (AHCs) or institutes, with Boards of Directors and Directors General appointed by the Minister. This enabled the Minister to assemble 34 CEOs, communicate common priorities and implement common practices, notably around performance monitoring and reporting. In terms of public and patient engagement, while individual facilities within the 34 new establishments (CISSS and AHCs) retained user committees, these lost direct communication and accountability lines with the Boards and Directors: just one user committee representative selected from among all facilities now sits on the CISSS Board of Directors. The 2015 reforms also spelled a net loss in civic capacity to assess system ability to meet needs. The office of the Health and Welfare Commissioner, which conducted independent analyses and reported to both government and the public, was abolished in 2016. Though it was reinstated after an outcry in 2018, a new Commissioner was only appointed in 2020.

In primary care, the 2014-15 reforms sought to increase interdisciplinarity within FMGs by moving health professionals from CLSCs into the FMGs. Once FMGs are accredited – meaning they meet government requirements in terms of patient base and access hours – they can be allocated nurse practitioners, nurses, social workers and other allied health professionals by the CISSS responsible for the territory on which they operate. Job postings for social workers in FMGs stipulate they work under the hierarchical authority of clinical managers within the CISSS, but under the functional authority of the lead physician of the FMG. These professionals then care for patients registered to FMG physicians, not their regular patients in the CLSC territory.

With government heavily invested in the FMG model managed by physicians who remained independent of the system, it exerted control and measured success by the number of people registered with each FMG family physician. A centralized Access System for Orphan Clients (Guichets d'accès aux clientèles orphelins or GACO) was established to facilitate finding a physician and prioritize populations with greater needs (chronic diseases, elderly). Incentives were provided for physicians to accept new patients, though these were less effective than hoped (Pineault et al. 2016), leaving many people without a family physician and, given the transfer of CLSC personnel to FMGs, less access to non-physician services as well. Unlike CSLCs, the FMGs are not territory based and have no mandate to enrol people from a local community.

Objections to the impact of these reforms on public and patient engagement in the health system were voiced, with variable effect. In 2015 reforms, the provincial umbrella group of user committees convinced government to preserve user committees within each facility of the new CISSS rather than instate just a single committee per CISSS. The Health and Welfare Commissioner was reinstated following an outcry from prominent health system actors. In 2017, an alliance of patients, physicians and managers signed a joint declaration proposing remedies to the harms caused by the 2014-15 reforms:

> The latest (reform) centralizes power and confers on just a few people an absolute and uncontestable stronghold over the entire health and social services network. This centralization is undertaken without regard for patients, for local communities or for providers in the network, and deprives them of the means to voice their concerns about decisions made on their behalf (15 Solutions 2017, my translation).

As will be seen in Chapter 6, the de-emphasis on patient and public participation in governance has been accompanied by the promotion of patient engagement in consultations and quality improvement projects, a development supported by a Québec Ministry of Health and Social Services framework (MSSS 2018), by quality and performance departments within the CISSS and AHCs, and through dedicated funding.

CHAPTER 6: GENERATING CO-PRODUCTION CAPACITIES IN HEALTHCARE ORGANIZATIONS (ARTICLE 2)

Preface

Generating co-production capacities in healthcare organizations
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Title: The impact of vertical (dis)integration on the co-productive capacities of hospital providers and patients
Author: Susan Usher
Abstracts from the 2020 conference have not yet been published in IJIC

Early work that informed this chapter was presented as a peer-reviewed oral paper at the Organizational Behaviour in Health Care Conference, May 14-16, 2018, in Montreal
Title: Team-based improvement work, physician engagement and the development of transformative capacities in healthcare organizations
Authors: Susan Usher, Sasha Dubrovsky

A preliminary version of the above work was presented as an oral presentation at the ACFAS conference, May 8, 2017
Title: Comprendre l'impact durable des projets d'équipe en amélioration des services de santé
Authors: Susan Usher, Sasha Dubrovsky

Generating co-production capacities in healthcare organizations (Article 2)

Keywords: co-production, patient engagement, healthcare organization, institutional work

Abstract

Purpose: Despite increasing prevalence of patient engagement initiatives in healthcare organizations, lack of attention to contextual factors and absence of a theoretical basis impede evidence about their effect. This case study, undertaken in an academic health centre in Québec (Canada), looks to institutional work as a plausible mechanism to explain how patient engagement initiatives interact with context to bring about durable change in provider and patient capacities to co-produce care and service improvements. **Methods:** Data collected at central, department and unit level from documents, meeting observation (26 hours) and interviews (n=31) with patients, clinicians and managers informed a process narrative tracing the evolution over 10 years of patient engagement initiatives, context elements, and their meaning to different actors. Thematic analysis identified types of institutional work generated by these efforts. **Findings:** The narrative revealed four key periods, delineated by distinct events. System and organizational context interacted with engagement strategies to generate structural, operational, conceptual and relational work with significant impact on co-production capacities. Notably, structural work to formalize engagement initiatives in the administrative sphere distanced conceptualization of engagement from existing patient roles and local clinician efforts. **Value and practical implications:** Institutional work offers a means of understanding the transformative potential of patient engagement that is applicable across health systems and organizations and can guide patient engagement strategies. Close attention is needed to operational work in maintaining and enhancing opportunities for relational work. Finally, system movement toward vertical integration challenges for developing co-production capacities across care sites.

6.1 Introduction

Healthcare organizations increasingly look to patient engagement strategies to design more responsive practices (Bate and Robert 2006; Berger et al. 2014; Carman et al. 2013; Ziebland and Coulter 2013), generate culture change and provider motivation for patient-centred care (Baker, Judd, and Maika 2016; Bombard et al. 2018; Kovacs Burns et al. 2014). Strategies such as patient experience surveys and patient integration on quality improvement teams have seen rapid expansion in many health systems, alongside or instead of statutory roles, such as on governing boards and patient committees (Pomey et al. 2015; Torjesen et al. 2017; van de Bovenkamp, Trappenburg, and Grit 2010; Ziebland and Coulter 2013) . While recent reviews find some evidence that such efforts can improve service accessibility, communication and information to patients (Park and Giap 2019; Sharma et al. 2017), others find limited effects on outcomes such as quality and safety (Berger et al. 2014; Cené et al. 2016; Hall et al. 2010). A study of 74 European healthcare organizations concluded that patient involvement in quality functions had no impact on the implementation of patient-centred care strategies (Groene et al., 2014). Evidence is lacking around the impact of patient engagement initiatives on organizational policies and procedures and on the sustainability of engagement within organizations (Dukhanin, Topazian, and DeCamp 2018). One reason is that studies are often designed to evaluate the engagement activity rather than its outcomes (Boivin et al. 2018; Cené et al. 2016; Dukhanin, Topazian, and DeCamp 2018; Kovacs Burns et al. 2014; Van Veen 2014), and fail to consider contextual factors, including interactions with existing patient roles (Goodridge et al. 2018; Sandvin Olsson et al. 2020). Most importantly, recent reviews point to the lack of a theoretical basis to explain how patient engagement efforts bring about change (Baker 2014; Majid and Gagliardi 2019; Manafo et al. 2018) and emphasize the need to consider power imbalances, especially in the hospital setting (De Weger et al. 2018; Goodridge et al. 2018; Ocloo et al. 2021).

In this paper, we look to institutional work (Lawrence and Suddaby 2006) as a means of understanding how patient engagement initiatives might bring about substantial and lasting change to the interactions between providers and patients within an organization. Health care is a highly institutionalized field, dominated by provider norms, rules and cultures (Scott

2000), however these are not static, and organizations provide a key venue in which professional groups redefine the institutional logics that guide their field (Chreim, Williams, and Hinings 2007; Muzio, Brock, and Suddaby 2013). Institutional work provides a way to study change as it unfolds by examining actions taken to create, maintain or disrupt the institutions or logics that underpin the way things are done. Patient engagement strategies enacted within an organization thus have the potential to challenge and redraw these logics.

This case study undertaken in an academic health centre (AHC) in Québec (Canada), examines patient engagement initiatives over a 10-year period (2009-2019) following the introduction of the "patient engagement" vocabulary into the organization. AHCs have a tripartite mission of research, teaching and patient care and are motivated to introduce innovations, notably to model leading practices for trainees (Nicklin et al. 2004). We look at how patient engagement initiatives interact with organizational and system context, and the institutional work they effect to bring about change in provider and patient capacities to work collaboratively to improve care. The study offers organizational leaders and patients a new way of thinking about the design and implementation of patient engagement strategies that considers the existing organizational and system landscape.

6.1.1 Conceptual framework

Patient engagement is a slippery term that can refer to a process, tool or outcome, and is invoked in a range of contexts, from care decisions to policy-making (Barello et al. 2014; Carman et al. 2013). Patient engagement in healthcare improvement is a relatively recent phenomenon where initiatives within an organization seek to benefit from patient knowledge and experience to shape more patient-centred processes and practices (Baker, Judd, and Maika 2016). In a lexicographic analysis of terms related to patient engagement, Castro et al (2016) describe a process model that aligns with our study objectives: they consider that patient engagement initiatives encourage providers to adopt patient-centred approaches that empower patients to take on a greater role. This process could play out in a virtuous cycle where increasingly empowered patients come together with providers who are increasingly receptive to patient contributions, progressing towards more valuable co-production (Bovaird and Loeffler 2012) or collaborative health (Millenson 2017). Palumbo and Manna (2018, 379) consider that this progression relies on "a deep redesign of organizational structures and processes".

To understand how patient-engagement initiatives contribute to this "redesign", we turn to theories of organizational and institutional change. In organization theory, change is seen to occur both as a result of the learning of individual actors and through the perpetuation, in structures and policies, of new ways of doing things (Argyris and Schön 1996, in Argyris 2003, 445). Within organizations, professional groups redefine institutional logics and reconstruct professional identities (Muzio, Brock, and Suddaby 2013; Chreim, Williams, and Hinings 2007). These logics exert significant influence on the viability of innovative practices and processes that aim to establish an environment, "which stimulates the users to take part in health services' co-production" (Palumbo and Manna 2018, 377).

Theory of institutional change sees change occur through a process of destabilization, the creation of opportunities for innovation, the spread of new standards, and stabilization when a new system standard becomes taken for granted (Berkhout and Westerhoff, 2013). The notion of institutional work developed by Lawrence and Suddaby (2006) provides a means of studying institutional change as it unfolds by examining the specific purposive actions taken individually and collectively to create, maintain, and disrupt the institutions or logics that govern actions and interactions. Creating institutions includes such actions as advocacy, redefining problems and constructing identities, while maintaining institutions can involve rules, monitoring, routines and myths; disrupting institutions can be done by disconnecting rewards or sanctions from practices or undermining assumptions and beliefs. In this study we rely on Cloutier et al.'s (2015) categorization of four types of institutional work: structural (roles, rules, incentives), conceptual (development of a common vision, discourse), operational (concrete actions to implement a vision) and relational work (promotes interaction and encourages sense-making and learning). Institutional work provides a plausible way of exploring how the patient engagement initiatives of an organization might bring about change and establish conditions amenable to co-production.

In this study, we posit that patient engagement initiatives operate through structural, operational, conceptual and relational institutional work to bring about organizational change and learning with the potential to increasingly (in a virtuous cycle) motivate and enable providers and patients to bring their capacities together to co-produce care and service improvements. Examining these initiatives as they evolve over time allows us to see how they affect and interact with existing organizational realities and changing system context, and helps "move closer towards a dynamic understanding of how to improve them" (Langley 2009, 412). Our main research questions are thus: What is the institutional work generated by patient engagement initiatives in a healthcare organization? How does this work contribute to creating conditions for co-production?

6.1.2 Study context

The study focuses on the development of patient engagement initiatives in an AHC in Québec (Canada). Québec (like other Canadian provinces) has a publicly funded health system governed by a provincial Ministry of Health and Social Services. The system context over the study period is characterized by a progressive centralization of governance, tighter Ministry control, and vertical integration of services aimed at shifting care from hospitals to community-based providers and coordinating care trajectories (Usher et al. 2019). Reforms this direction began in 2004 and accelerated with 2014-15 restructuring that abolished regional agencies and brought, in each of 22 geographic territories, the continuum of services – hospital, post-acute, long-term care, home care and social services, but not primary care – under the governance of Integrated Health and Social Service Centres (CISSS and CIUSSS), with an executive director and board approved by the Minister. AHCs remained separate establishments (with one exception in the province) but were subject to the same governance changes, with the Minister of Health approving the CEO and board. The reform highlighted two forces confronting AHCs across Canada and in other countries: towards hyper-specialization on the one hand, and integration with community and post-acute care on the other (Dzau et al. 2013). Characteristics of the Québec health system and reform effects that more particularly influenced the evolution of patient engagement initiatives are described in the Findings section.

6.2 Methodology

6.2.1 Case selection

The organization was purposefully selected (Guba and Lincoln 2005) based on its innovation mandate as an AHC, its commitment to principles of patient engagement and recognition as an early leader in patient engagement. Empirical study focused on the introduction and implementation of patient engagement initiatives in the organization between 2009 when the term "patient engagement" first entered organizational vocabulary, and 2019. The intent was not to assess the level of activity, but to explore the institutional work generated by patient engagement initiatives over time at multiple levels. We also considered the system context in which the organization functioned (including the reforms mentioned above), and the organizational context that influenced activities in departments and units.

6.2.2 Data collection

On-site data were collected over two years (2018-2019), during a period of high motivation as the organization prepared for an accreditation visit that integrated new standards for patient input and partnership. Accreditation is recognized as a factor that increases the likelihood and rate of change (Pomey et al. 2010). Within the principal unit of analysis (the organization), data collection proceeded in a staged approach from central to department and unit level. The central level is where strategic orientations are set, government and societal priorities interpreted, major resource allocation decisions made, and rule structures for the organization established. Central level interviewees included clinical (n=6) and administrative (n=7) leaders as well as patients active on the organization's central user committee (n=4). Departments constitute an intermediate level, with characteristics that reflect differences in clinical focus, patient population, leadership and history that influence patient engagement strategies. We selected three adult physical health departments based on indications (from central level interviews and documentary data) of patient engagement efforts. Actors interviewed at this level included members (4 patients and 10 clinicians) of various departmental committees and unit level project teams. The study was approved by the Research Ethics Board of the healthcare organization and interview participants signed informed consent forms and agreed to have the interviews audio recorded. Table 1 details sources of data and interviewee characteristics. The interview guide combined questions about participants' experience with patient engagement initiatives, influences on their experience, and changes they observed over time in motivations, processes, challenges and expectations around patient engagement initiatives. Interviews were transcribed and anonymized.

Observation of central and department level committee meetings addressing patient-engagement initiatives and preparations for the accreditation visit allowed us to witness group dynamics and hear the perspectives and concerns of additional provider and patient actors. Consent was obtained from meeting chairs for observation and the researcher was introduced to the group before the meeting began. Notes were taken during meetings and were supplemented immediately afterwards with researcher reflections and observations, notably on how patient engagement initiatives and data on patient experience were received and discussed among participants. Documents, often introduced at these meetings, included department level internal reports, project charters, performance charts and accreditation preparation materials. This material was stored securely in password-protected files. Documents also included publicly available annual reports of the hospital and of different departments and committee within the hospital. Government and other documents referred to in these sources were consulted to better understand context elements.

Table 6.1 Data sources and interviewee characteristics

	Document review	**Meeting observation (26 hours total)**	**Semi-structured interviews (31x 40-80 minutes = 36 hours total)**
Central level	Annual reports: organization, Central user committee, Ombudsman, project reports, Accreditation reports and preparation material, project charters, performance monitoring flow charts	6 (12 hours total)	4 patients 6 clinicians (1 physician, 1 allied health professional, 4 nurses) 7 mngt/admin

Department/unit level	annual reports of user committees and quality committees; special project charters and reports	7 (14 hours total)	4 patients 10 clinicians (5 physicians, 5 nurses), many with some managerial responsibilities
External	Ministry frameworks, reports from affiliated organizations and associations		

Data collection (14 months fieldwork; REB - BIAL6000 / 2019-4960
Gender breakdown: Patients (3 men, 5 women); Clinicians (4 men, 12 women); Mngt/Admin (1 man, 6 women)

Longitudinal study is essential to identify change and drivers of change in the organization (Mullaly 2006). Approximately 80% of interview participants had been at the organization for 10 years or more and could provide first-hand perspectives on past events. Precautions were taken to handle potential hazards of retrospection in interviews, including faulty recall and self-serving representation of past events (Miller, Cardinal, and Glick 1997). This risk was addressed by combining documentary sources and a range of perspectives (patient, clinician and manager/administrator) in interviews to reconstruct a temporal chronology of developments and their meaning (Langley and Tsoukas 2010). Annual reports at hospital, department and committee level provided comparable year-on-year sources of data.

6.2.3 Data analysis

Data analysis was undertaken in three main stages (Miles, Huberman, and Saldana 2019): a first to categorize data into a narrative of the evolution of patient engagement initiatives in context; a second to explore the different types of institutional work this generated; and a third to extract themes around the effect of institutional work on conditions for co-production. We began by constructing, based on documentary sources, a timeline of contextual events within and beyond the hospital over the 10 years. In a first cycle of coding, we extracted key themes around the development of patient engagement initiatives from interview, observation and document data from each of the three departments and the central level. Sense making was facilitated by the contextual timeline. Intra-case analysis was undertaken to gain insight into the different environments in which patient engagement initiatives evolved before aggregating data in cross-case analysis (Stake 2013) for a fuller view of the phenomenon at hospital level. These data were then organized along the timeline to produce a narrative account of the evolutionary process (Langley 1999) of patient engagement initiatives and their perceived meanings and consequences (Riessman 2008). This revealed four distinct periods, which are presented in the first part of the Findings section. Three key informants (patient, clinician and administrator) from the organization reviewed and commented the narrative, confirming the face validity of the story that emerged and the emphasis placed on different developments.

In a second stage of analysis, the narrative, extracts from interview transcripts and meeting observation notes were coded using MaxQDA (Verbi Software 2019) to distinguish categories (Yin 2011) of institutional work generated around patient engagement initiatives in each of the four periods. Coded segments were arranged in Excel files to inductively identify first the structural, conceptual, operational and relational institutional work, and second, the resulting creation, maintenance and disruption of institutions relevant to engagement. This analysis is reflected in the Findings section in Table 6.2.

6.3 Findings

6.3.1 Evolution of patient engagement initiatives in context

The temporal narrative revealed that patient engagement initiatives unfolded in four "temporal brackets" (Langley 1999) delineating periods in which efforts had a degree of internal coherence. At the outset of the study period, the organization offered patients a range of opportunities to contribute to organizational life as public board members, volunteers and on user committees, which, in Québec healthcare organizations, have a statutory mandate to inform patients of their rights, monitor respect of patient rights, represent patients to leadership, and promote improvements (Ministère de la Santé et des Services sociaux 2006). The organization also supported patient education and peer-run self-management support programs; these had been an entry point to broader engagement for a number of patients interviewed.

Period 1. Patient engagement enters the organization's vocabulary: The words "patient engagement" first appeared in organizational documents with the 2010 initiation of a nursing-led project to improve efficiency and patient/staff experience on care units. Unit-level teams integrated patient advisors, mainly user committee members, and conducted local patient experience surveys to monitor improvements achieved through practice and process changes. The initiative was approved by the hospital Board of Directors, received funding from an external foundation for staff release time and project management support, and was recognized as a leading practice by Accreditation Canada. Clinicians and patients involved in the project formed new relationships with outside organizations and presented at national and international conferences. Further external grant funding spread the project model to additional units, notably to improve infection control, a key organizational priority. However, the model was not resourced internally.

Period 2. Formalizing patient engagement strategies in a tumultuous environment: A second period was marked by the provincial reforms described above. Governance changes reduced user committee and public representation on the hospital board. This major upheaval came as the organization was consolidating several hospitals onto a new site, and was accompanied by significant budget cuts that threatened certain services the Ministry felt lay outside the organization's tertiary-quaternary mandate. Public and patient members of the Board resigned in protest when governance reforms giving the Minister the power to appoint boards and name CEOs, and reducing user committee seats on the board, were announced. The user committee tightened links with counterparts in other healthcare establishments to defend common interests and increasingly aired problems, notably around service cuts, in the media; this placed organizational leadership in an uncomfortable position vis-à-vis the Ministry.

During this period, the organization assigned responsibility and resources for patient experience surveys to the quality department, which built capacity to conduct continual surveys of discharged patients and provide departments with results. Department level quality committees with patient advisors were encouraged as venues for exploring this data and developing improvement projects. A patient partnership coordinator position was created within the central quality department, responsible for implementing a process for recruiting, selecting, training and coaching "patient partners" for participation in projects and committees across the organization. This approach drew heavily on a model under development in another local organization. The coordinator was also responsible for presenting patient experience data to department-level quality committees.

Period 3: Tensions and efforts at resolution: This period was marked by preparation for accreditation under new criteria for "patient input" and "patient partnership" on required organizational practices. The quality department coordinator was given an important role in preparing departments for accreditation based on these standards. In encouraging uptake of patient partners, the 'co-creation' role of patient partners on teams and committees was contrasted with the 'advocacy' role of the user committee. Among its members, many of whom had served or were serving on improvement committees and projects, the advocacy/co-creation dichotomy rang false, and tensions marred what had appeared to be a collaborative progression to integrate new patient engagement initiatives within the organization. The need to overcome these tensions led to the creation of a Concertation Table to bring together patient voices within the organization – user committee members and patient partners, volunteers, the quality department coordinator and Ombudsman.

Period 4. Patient engagement efforts focus on the care encounter: In a fourth period, Ministry-imposed performance indicators for patient flow (i.e. faster discharge), monitored in a "control room" at executive level (and later also in departments) in the organization, became a major focus in the organization. As part of final preparation for accreditation, the quality department conducted parallel patient and staff surveys on a number of "engagement-sensitive" indicators that revealed important discrepancies between patient and provider views on performance, notably around communication and discharge planning. The organization also cut funding for the self-management program, which was considered to be outside the hospital mandate. At the end of the study period, accreditors expressed high satisfaction with the organization's patient engagement efforts. At provincial level, a framework for patient partnership (MSSS 2018) emphasized the need for collaboration between user committee and patient partnership programs in Québec establishments. As well, a Ministry grant for patient engagement projects insisted they be endorsed by an organization's user committee.

6.3.2 Institutional work generated by patient engagement initiatives

This next section looks at institutional work accomplished over these four periods, taking an interest in how different types of work interact with each other and with organizational and system context to influence conditions for collaborative work on improvements by providers and patients. Table 6.2 presents an overview of institutional work in each period, and its cumulative influence on co-production capacities across the study period. A major theme to emerge in analysis was the interplay between operational and structural work; we will therefore begin by looking at these two types of institutional work together.

Table 6.2 Institutional work and its influence on capacities for co-production

INSTITUTIONAL WORK	PERIOD 1	PERIOD 2	PERIOD 3	PERIOD 4	OVERALL IMPACT ON CO-PRODUCTION CAPACITIES
STRUCTURAL	*(history of patient and public representation on board, active user committees [UC])*	engagement tied to quality department; input and recruitment formalized Patient/public board participation reduced	new accreditation standards; mandated action plans with patient input	faster discharge as key performance indicator; self-management program cut	**Reduced** patient influence in governance **Change** in patient route to enter organizational roles (from self-management to individual recruitment) **Increased** provider awareness of engagement mandate
OPERATIONAL	nurse-led engagement strategies at unit level with many UC participants;	departments (variably) form quality committees	activity in both quality committees and unit projects (remain disconnected)	unit focus on engagement for communication and discharge planning	**Increased** venues for clinicians and patients to work together on committees **Increase** in unit engagement activity with few resources but increasing motivation

CONCEPTUAL	'patient engagement' enters organizational vocabulary	patient engagement linked to quality department	engagement as organizational priority; distinction between 'advocacy' and 'co-creation roles	engagement as essential to good care and transfers	**Reduced** legitimacy of user committee role in improvement **Spread** of interest in and acceptance of patient input **Emerging** clinical imperative for engagement
RELATIONAL	new venues for unit clinicians and patients to work together	new venues for recruited patients and departments committees to work together; less informal contact around hospital	venue to bring patient voices together (short-lived)	destabilization of clinician confidence in knowing what's best for a patient	**Increased** venues for patient-provider committee work **Reduced** time and place for informal interaction between and among patients and providers
CREATION, MAINTENANCE AND DISRUPTION OF INSTITUTIONS IN EACH PERIOD	**creation**: project teams of unit clinicians and patients **maintenance**: legitimacy of UCs	**creation**: quality department role in engagement **disruption**: patient representation on board	**disruption**: legitimacy of UC members in improvement **maintenance**: quality role in engagement (accreditation)	**creation**: emerging emphasis on clinical responsibility for engagement around discharge **disruption:** self-management as empowerment route into organizational engagement	**The institutions involved in co-production are in flux:** **1. an overall formalization of engagement separate from self-management, governance and clinical care dynamics;** **2. change in hospital role and provider identity with emphasis on speedy discharge to community providers**

Structural, operational work and their interaction: Operational work had a durable effect on creating conditions that motivated and enabled providers and patients to work collaboratively on improvements in the organization, drawing on the early nursing-led initiative that relied on existing actors (unit clinicians and user committees) – street-level expertise, in Cloutier's terms (2015) – supported (and legitimized) by external grant funding and recognition.

> For many of us (patients), (this project) was the first experience of participating with a group of clinicians on improvement. ...We saw a

> sincere desire on the part of the staff to better understand how patients experience care, what they see, how they feel. Participation in making even just improvements to the physical space on units felt productive. (department level patient).

This operational work continued across the study period, with unit clinical staff using localized strategies to gain patient input in addition to or instead of patient experience measures and formal recruitment of patient partners. This work fluctuated over time to contend with a lack of dedicated resources, but appeared to embed patient engagement reflexes in localized unit-level improvement efforts. Initiatives often arose, not from department quality committees, but from conversations among nursing and allied professional staff, or were prompted by "hallway complaints" and clinicians saying: "this is hard on my patients" (unit level clinician). These projects were rarely tracked by department level quality committees or communicated across units and departments.

> These nitty gritty unit-based projects don't necessarily come from or to the quality committee, so there's a bit of a disconnect there (department level clinician).

The structural work in Period 2 to institute patient experience surveys and create a new coordinator role helped establish patient engagement as an organizational norm flowing from the quality department. This was backed in Period 3 by the wider system lever of accreditation as departments and units were required to create action plans with patient input.

> [The coordinator role and accreditation standards] signalled to me that patient engagement had gone from a vague concept to something real that required we put things in place" (central level, clinical director).

Assigning responsibility for patient experience surveys to the quality department in Period 2 built capacity for measurement and analysis. These data were especially appreciated by clinical managers.

> Of all the data produced by the quality department, that's [the patient experience surveys] what I find the most interesting, [with] specific questions about the service we're offering (department level, clinical manager).

However, the department level quality committee structures that explored survey results were not very effective at translating this patient input into operational work. Committees were at different stages of development and were subject to disruptions from fluctuations in department leadership and clinician interest. In quality committee meetings, a frequent request from clinicians and managers presented with patient survey results was: "Can we see this data for individual units?" Based on our interviews, patient experience survey data was not guiding improvement projects in units or organizational decisions at executive level. Neither clinical nor user bodies had responsibility for assuring that the "voices" expressed in surveys brought about change; results were not integrated into clinical evaluations or reviewed by (or even easily accessible to) user committees.

Structural work in Period 4 discontinued organizational funding of patient self-management and support programs. This was mentioned during interviews by patient actors, although not by clinicians or administrators, as an important moment in the evolution of patient engagement within the organization. Also in Period 4, heightened pressure for faster discharge encouraged operational work to improve communication and discharge planning with patients, maintaining practices initiated in Period 1.

> Partnership becomes what tools do we give patients to enable them to navigate their post-hospital course better; give them the information and tools so they can be fully active (central level, clinical director).

Relational work: Operational work in Period 1 prompted new relationships among unit clinicians and between clinicians and patients, including user committees, in improvement projects. External funding afforded staff the time to develop these relationships. In Period 2, structural work created opportunities for relational interaction in the quality committees of clinical departments, playing an important role in spreading the idea of patient engagement as an organizational priority and a new conceptualization of "patient partnership" in improvement. At the same time, the new hospital site layout and increasing time pressures on clinical managers made informal interaction more difficult.

> Doctors are never visible. (department level patient 1) Their offices are behind locked doors (department level patient 2).

> At my level and above, we just get so absorbed in meetings, and your day goes by (department level clinical manager).

Conceptual work: At the start of the study period, operational work instigated by an institutional entrepreneur (Battilana and Lee 2014; Seo and Creed 2002) introduced the concept of 'patient engagement' into the organization in a manner that supported the institutional logics of clinical team responsibility for patient experience and user committees as collaborators. Structural work in Period 2 then introduced a new conceptualization of patient engagement as symbiotically associated with the quality department, as well as the idea of 'appropriate' patients to participate on committees and teams through the enactment of a selection and training process. Across Period 3, discourse that distinguished partner and advocacy roles promoted staff acceptance of patient participation on committees and projects.

> Before... some patients were ill-suited or ill-prepared for that role. This way [with recruitment and training from the coordinator] it's much clearer to everyone, what the purpose of the patient advisor role is (department level clinician).

However, it also challenged the legitimacy of user committee members as collaborators in improvement.

> When a project lead tells the user committee they're going to have a patient partner, sometimes the user committee will ask" what, we're not good enough? (central level patient).

Both patient and provider participants underlined the historical importance of these patient roles in the organization and the Québec system.

> Québec is unique in having a group of user committees. It doesn't exist anywhere else in Canada. This is a reality we need to embrace (central level patient).

> Here, more than in other institutions, it's especially difficult to draw a boundary between the user committee and patient partners because historically the user committee has been very involved in a collaborative way (central level administrator).

Preparation for accreditation in Periods 3 and 4 prompted conceptual work around two questions. A first, saw actors mainly at unit level begin to consider where patient input was in fact most valuable. A second saw a measure of cognitive dissonance arise among clinicians looking at starkly different survey results of staff and patient perceptions of care encounters, especially around discharge planning. This helped move professional logic away from "assuming we know what a patient wants towards asking questions and verifying assumptions with patients" (department level clinical manager). Ministry-imposed patient flow targets heightened staff preoccupation with communication. This conceptual work emphasized patient engagement as necessary to assure safe transitions and timely discharge.

> The organization is challenged to redefine its responsibilities around discharge and how to equip people to manage in the aftermath of an illness in light of new emphasis on specialized short-term stays.... (central level clinical director).

Tension also appeared between the conceptualization of engagement as a performance-oriented administrative requirement embedded in the quality department, and engagement as a clinical responsibility. Over the study period, quality department and clinical efforts in patient engagement appeared disconnected. Training for physicians in communication with patients remained separate from quality department initiatives, organizational assessment processes and the priorities of the Faculty of Medicine associated with the AHC.

> Competence in communication and planning with patients does not figure prominently in clinician performance evaluations (department level clinician).

One project to emerge over the study period - a smart phone application controlled by patients to access their test results and book appointments - provided an outlier example of clinical and patient resources brought together to collaborate on the innovation and its implementation. The department in question had an active user committee, and a culture of patient-centred care and improvement work supported by clinical leadership. This terrain facilitated the emergence of collaboration between a patient highly engaged in her own care with unique expertise and her care providers. As a team, they gained access to external (academic) and internal (foundation and organizational contest funds) resources to pursue their work. Importantly for the present study, they employed established venues to move the project forward: the user committee to gain patient input into the application's design, and Grand Rounds to bring clinicians on board and address their concerns about patients learning about test results outside the clinical encounter.

In summary, the case reveals that structural, operational, conceptual and relational work undertaken over the study period: 1) spread interest in patient input and acceptance of engagement as an organizational norm; 2) created new venues for collaborative work in unit project teams and department quality committees, which nevertheless remained unconnected; 3) reduced patient influence in governance and challenged the legitimacy of user committees in improvement work; 4) altered the route leading patients into engagement roles; and 5) positioned engagement primarily in the administrative rather than the clinical sphere.

6.4 Discussion

Institutional work underpins the change and learning that embeds a vision of care as co-produced by providers and patients. In this study, the structural work to create roles and mandates appears as a mechanism to spread new expectations across the organization. However, it also entails disrupting (and even discrediting) existing venues and channels for collaborative work between patients and providers, and narrows the definition of engagement as it finds its place within the organization. The study reveals interplay between type of institutional work and type of isomorphism (Breton, Lamothe, and Denis 2014; DiMaggio and Powell 1983). While operational work is motivated by normative isomorphism and allows change to be taken up by different actors in their own way, structural work is more clearly mimetic, with roles, processes and discourse transposed from other organizational environments. Bombard et al. (2018) find a temporal trend in studies of patient engagement in quality, with top-down approaches appearing more often in earlier studies and clinician or community-driven initiatives seen more frequently in recent studies. There are signs in the present study that clinician-driven strategies, inspired in part by early operational work, have persisted and are being used to work with patients on emerging challenges.

Operational work represents what is actually done within an organization: findings suggest there are benefits to drawing on existing practices when introducing new engagement-focused structures and practices. In the present organization, the wealth of patient involvement at the outset and staff enthusiasm for unit-driven engagement efforts do not appear to have been adequately considered or supported in later structural work. Operational fixes seen in the persistence of local unit-based solutions to gaining patient involvement and the intermingling of "patient partner" and user committee roles point to potential for adapting structural work along the way.

Looking at hospital implementation of patient-centred care, Bokhour et al. (2018, 6) find that ongoing informal interactions with patients and families are important, and "asking for feedback helps create a relationship”. The smart phone application project in the present case illustrates that open communication during care encounters led to co-production of an innovation that stands to dramatically increase future capacities for patients to participate in their care. However, clinical staff face challenges finding time to interact with patients and with each other. The co-production literature describes collaboration as highly dependent on managerial capacities to "ensure necessary levels of interactivity" and "find ways to engage in the creation of knowledge and quality" with users (Kekez et al. 2018, 5, citing Brandsen and Honingh 2016).

Conceptual work appears especially important and influential when there is ambiguity around a vision. The case study reveals initial uncertainty around the "patient engagement" vocabulary (used in quotation marks in user committee reports at the time) and later tensions around attempts to distinguish patient advocacy and partner roles. Actor-network theory offers a helpful view of how concepts evolve in a translation process where actors mobilize support from others for the redefinition of a technology by making "different meanings mutually compatible" (Denis and Langley 2007, 184). Raynard considers there is benefit to "developing and maintaining productive tensions between logics – specifically in ways that capture the synergistic and value-enhancing potential of compatible logics" (Raynard 2016, 322) and suggests that somewhat aligned logics and blended hybrid structures that "facilitate constructive contestation and problem solving" are conducive to innovation activity (Ibid, 323). The Concertation Table formed in Period 3, bringing together patients engaged in different roles, appears to offer a venue for this type of constructive problem solving. While the Table had not resumed by the end of the study, the Ministry framework that appeared in Period 4 emphasized the value of different patient roles.

More significant logic shifts are produced by contradictions, which appear as driving forces in organizational change (Seo and Creed 2002) and heighten the likelihood of purposeful action to deal with tensions in an existing arrangement. Social constructivists see cognitive dissonance as a stimulus for learning, producing an "uncomfortable tension" that "compels the mind to acquire new thoughts or modify existing beliefs in order to reduce the amount of dissonance (conflict)" (Thomas et al. 2014, 3). The dissonance introduced through discrepancies in comparative survey results encouraged clinicians to view collaboration with patients and development of patient capacities as essential to good care.

Finally, this study links patient engagement with the broader discussion of balancing clinical and administrative influence in the healthcare environment. Dobrow et al. (2008) point to the growing importance of managerial and legal accountability and a less entrenched professional model of clinical accountability in health care. Embedding patient experience and engagement within the administrative rather than clinical sphere is in line with this tendency and risks neglecting the important role clinicians play in bringing about change in an organization (Ferlie and Shortell 2001; Sullivan and Brown 2014). It also distances engagement efforts from the central objective of enabling patients to take on a greater role in their care, which negatively affects clinician interest (Berger 2018; Dukhanin et al. 2018).

The study highlights threats (i.e. accreditation, rapid discharge) and opportunities (i.e. direct patient access to test results) as important drivers of institutional work towards co-production. This is coherent with collaborative governance theory, where threats and opportunities constitute essential motivators for efforts to jointly develop solutions (Emerson and Nabatchi 2015). Spaces for collaboration are then created to enable patients and providers to understand problems and develop and coordinate contributions to solutions. This effort can be seen as opening up the collective sense-making described in the literature on organizational learning (Argote 2011; Argyris and Schon 1978; Touati et al. 2015) to include patients.

System reforms significantly impacted conditions for co-production. Restructuring disrupted accountability mechanisms by breaking connections between user committees, boards and organizational leadership, and dispersing services away from the organizational (and thus user committee and clinician) jurisdiction. The appearance of these jurisdictional gaps points to larger problems with co-production and accountability in vertically integrated systems (see Charles et al. 2018 on English Integrated Care Systems, for example). The vertical disintegration of healthcare processes means that managing interdependencies becomes critical to clinical as well as organizational performance (Osborne 2010; Sorrentino et al. 2017) emphasizing a change in the role of clinicians, "from fixers of problems to facilitators who work alongside their customers to find solutions" (Sorrentino et al. 2017, 1428). The de-stabilization of a logic whereby the provider is responsible for the whole care package - "for seeing patients get better"(central level clinical director) - creates a need for collaborative deliberation to increase the capacities and responsibility of patients to prepare and negotiate next steps in the trajectory. As one informant put it:

> We're moving away from a paternalistic model and are not equipped to do so, on either the provider or receiver side (central level administrator).

6.4.1 Limitations, strengths and future research

As a case study of one organization in a particular context and time period, the specific findings above are unlikely to be replicated elsewhere. The study of engagement in each organization will have a different starting point and trajectory, influenced by its own set of system and organizational variables. The transferability of this study lies in exploring this trajectory through the lens of institutional work, which offers more general and fundamental lessons to guide patient engagement strategies. The approach offers a new way of thinking about how best to encourage and support patient engagement initiatives in a given context.

6.5 Conclusion

The case study presented here is distinguished from much of the patient engagement literature in a number of ways: it explores the evolution of engagement strategies within an organization and their interaction, reaches into multiple organizational levels, and explores patient and provider perspectives with consideration for context. Findings should encourage organizations to carefully inventory and understand available resources and venues when introducing new mandates and initiatives to engage patients. The movement toward integrated systems should also receive much more attention in patient engagement strategies that now need to reach beyond the hospital walls.

Healthcare reforms aim at improving care and services or reducing system dysfunctions and vulnerabilities. Patient-engagement is heavily promoted these days as a way to bring about improvement and adaptation in health systems and organizations. Our study, based on an empirical case in the Québec health system, suggests that obtaining benefits from patient engagement initiatives is complex and will depend, in any system, on careful consideration of context elements and on the institutional work undertaken by key actors.

CHAPTER 7: NETWORK-BUILDING BY COMMUNITY ACTORS

Preface

ARTICLE 3

Network-building by community actors to develop capacities for co-production of health services following reforms: A case study

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Author: Susan Usher

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Author: Susan Usher

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Authors: Susan Usher, Marie-Christine Therrien, Mathilde Jutras

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Authors: Susan Usher, Marie-Christine Therrien

Network-building by community actors to develop capacities for co-production of health services following reforms: A case study

Keywords: Community engagement, co-production, actor-network theory, social capital, networks, health reforms, Québec

Abstract

Introduction: Responsive, integrated and sustainable health systems require that communities take an active role in service design and delivery. Much of the current literature focuses on provider-led initiatives to gain community input, raising concerns about power imbalances inherent in invited forms of participation. This paper provides an alternate view, exploring how, in a period following reforms, community actors forge network alliances to (re)gain legitimacy and capacities to co-produce health services with system providers. **Methods:** A longitudinal case study traced the network-building efforts over three years of a working group formed by citizens and community actors working with seniors, minorities, recent immigrants, youth and people with disabilities. The group came together over concerns about reforms that impacted access to health services and the ability of community groups to mediate access for vulnerable community residents. Data were collected from observation of the group's meetings and activities, documents circulated within and by the group, and semi-directed interviews. A first stage of analysis used social network mapping to reveal the network development achieved by the working group; a second traced network maturation, based on actor-network theory. **Results:** Network mapping revealed how the working group mobilized existing links and created new links with health system actors to explore access issues. Problematization appeared as an especially important stage in network development in the context of reforms that disrupted existing collaborative relationships and introduced new structures and processes. **Conclusion:** Network-building strategies enable community actors to enhance their capacity for co-production. A key contribution lies in the creation of "organizational infrastructure".

7.1 Introduction

Collaborative approaches to public services have been associated with benefits including increased accountability, greater civic engagement, consistent downstream implementation, and higher levels of process and program success (Fung and Wright 2001; Lasker and Weiss 2003; Leach 2006; WHO Regional Office for Europe et al. 2019). In health systems, the capacities of people and communities to co-produce outcomes alongside formal providers now appear key to assuring the sustainability, equity and integration of care (WHO Regional Office for Europe 2019).

Co-production is based on interdependence between the capacities different parties bring to solving an issue, and conditions that enable those capacities to be recognized and made (Loeffler and Bovaird 2016). However, co-production arrangements are not easily achieved nor maintained over time. Imbalances can result when stakeholders lack the "organizational infrastructure to be represented in collaborative governance processes" (Ansell and Gash 2007, 551), or face barriers to participation. A recent realist synthesis of strategies to engage communities in health service decisions identifies power imbalances as a significant constraint (De Weger et al. 2018, 15). The author asks: "why (do) professionals and organizations implement community engagement interventions, but then 'maintain their business as usual' approach?" The question reflects a preponderant focus, in contemporary scholarship, on engagement efforts initiated by provider organizations that retain control over the question at hand, the terms of engagement, and actions taken in response. There is scarce evidence that such initiatives have produced meaningful change in health systems (Djellouli et al. 2019). Reviews of the public and patient engagement literature (Halabi et al. 2020) suggest that initiatives both within and outside the provider sphere, as well as links between the two, are needed to create the collaborative dynamics required for co-production.

This paper is interested in the strategies adopted by service users and their communities to gain the power to influence conditions for co-production of health services with the public sector. It looks to actor-network theory to guide empirical study of the process of creating these conditions. In a longitudinal case study undertaken in an urban neighbourhood in

Québec (Canada), it explores network-building efforts by an ad hoc Working Group (WG) of concerned citizens and community group actors working with seniors, minorities, new immigrants, youth, and people with disabilities. The WG formed through concerns that system reforms were compromising access to health services as well as their own ability to help vulnerable people overcome access barriers. The case study aims to understand how community actors use network strategies to establish (or re-establish) their role as co-producers of health services with the public sector.

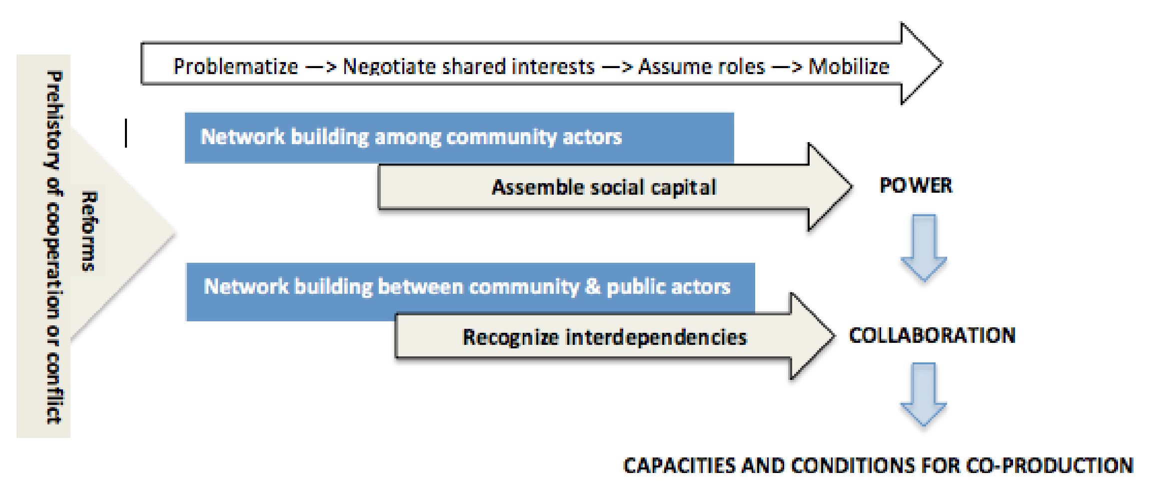
The paper begins with an exploration of power and the role of network relations in enabling less dominant actor groups to achieve influence in a field. It then presents the context for the case study, looking at the 'prehistory' of collaboration between public sector and community actors in Québec, along with key elements of recent reforms: these provide the starting conditions and motivation for the efforts of the WG. The study is based on observation of WG meetings and activities over three years, interviews with WG members and review of WG internal and external communications, which are analysed to trace the evolution of network relations. Findings support network building as a means of developing community capacity, identify venues important to this work, and suggest health system factors that impede or facilitate collaborative dynamics with communities. These insights point to ways in which co-production might be supported in both public sector and community spheres

7.1.1 Collaborative dynamics, power and networks

The collaborative dynamics of co-production are influenced by power differentials that affect the development, recognition and integration of user and community capacities in public services. In their collaborative governance model, Emerson and Nabatchi (2015) stress recurring social interactions as opportunities to highlight and recognize interdependence, facilitating the assumption by community-based actors of a problem-solving role "actively engaged in creating what is valued by the public" (Bryson, Crosby, and Bloomberg 2014, 446). Sociologist Pierre Bourdieu sees power accrue from social capital, defined as "the sum of actual or virtual resources that accrues to an individual or group by virtue of possessing a durable network of more or less institutionalized relationships of mutual acquaintance and recognition" (our translation) (Bourdieu 1980, 2). Social capital provides a means of understanding how power can shift among actors with unequal resources to enable the development of mutual understanding and collaboration. The study of network development through the lens of actor-network theory (Callon and Ferrary 2006) offers a means of exploring how community actors accumulate social capital to create conditions for the co-production of health services.

Networks are seen as “relatively stable and continuous relationships between institutions, individuals, and/or groups that mobilise resources and information to achieve a collective goal” (Bourdieu 1980, 2). Actor-network theory (ANT) (Callon and Ferrary 2006) provides a means of achieving a fine-grained description of the process of building capacity for social action through networks, where actors "converge on common problematizations, negotiate shared interests, engage in new roles and mobilise a critical mass of actors for collective projects.... to build new solutions" (Bilodeau et al. 2019, 166). In ANT, the process of linking entities into these 'sociotechnical networks' is referred to as 'translation'. Callon and Ferrary (2006) describes four stages in translation, starting with *Problematization* where relevant entities are identified and connected, and problems and potential solutions are discussed. *Interessement* (generating actor interest) describes negotiation within the network and integration of new entities, and leads to *Enrolment*, or assumption and alignment of roles within the network. Finally, *Mobilization* is the capacity to act that develops in the network.

Figure 7.1 Conceptual model: Network building to enable co-production



Legend: Figure 1 presents the conceptual model in this study, based on theories about how less dominant actors gain power to be recognized as collaborators with more dominant actors in a field. Network building among community actors assembles social capital that increases legitimacy to represent an issue and gain the attention of public actors. Network building with public actors enables interdependencies to be recognized, making collaboration more likely and enabling new capacities and better conditions for co-production. The arrow at the top of the figure describes the process of network maturation according to Actor-Network Theory (Callon and Ferrary 2006), which passes through four stages, from problematization to mobilization. The triangle on the left side of the figure depicts the starting conditions for network building efforts: both the prehistory of collaborative relations and, in our case, the immediate system reform context.

This study is designed around the conceptual model presented in Figure 7.1. ANT serves as an approach for studying the process of network development *among* community-based actors to assemble power through social capital; and *between* community-based and public sector actors to motivate collaboration (Ansell and Gash 2007) through recognition of interdependencies. Network building therefore acts on the capacities for co-production, and on conditions that enable those capacities to be recognized and brought together to solve problems. The model in Figure 7.1 also includes the prehistory of relationships between community and public sectors, and features of recent reforms. These represent starting conditions for the WG's network building activities and are essential to understanding how interdependencies are perceived at the outset (Johnston et al. 2011, 718).

7.1.2 Study context

This section describes the 'prehistory' of collaboration between public and community actors in the Québec context, and reforms that led to the starting point of the community-driven efforts examined in this case study.

Québec has a long legacy of community participation in health and social services. Local community involvement and citizen participation figured prominently in the early design of the province's health and care system (Bélanger and Lévesque 2016). At the foundation of Medicare in the 1970s, Québec adopted a broad vision of health, combining health and social services in a single ministry and implementing an initial model of primary care that embedded public actors within communities and saw community organizations as partners to meet local needs. Local community health centres (CLSCs) had a mission that included preventive and curative care, social services and community action (Gaumer and Desrosiers 2004) with activities strongly oriented to community-identified needs (Jetté and Dumais 2008). As well, authors (Touzard 2006; White 2009) point to the tradition of "concertation" in Québec as a consensus-building strategy that, without assigning "formal roles or responsibilities for policy development", brings community, public and other actors together to "tackle shared objectives" (White 2009, 4). White describes the 'tables de concertation' as governance networks that provide long-term opportunity to influence policy. However, scholars also note longstanding tensions in Québec between views of community resources as autonomous and arising in a given geographic space or around a given issue, and the perspective that they form a continuum with public services to meet population needs through local and volunteer efforts (Lamoureux and Lesemann 1989). This is pertinent to the idea of co-production as, rather than weaving together distinct contributions, the 'complémentariste' view enlists community-based actors in a mandated policy program.

Reforms beginning in 2003 integrated CLSCs into larger Health and Social Service Centres (CSSS), and mission-based funding of community organizations was replaced by project funding to help with specific program mandates determined by provincial decision-makers (Brossard and White 2016). In this context, public sector community organizers felt "instrumentalized" (Bourque 2009) as they were expected to support community mobilization to achieve targets specified by public authorities and not by communities. Some authors also note a decrease in the policy influence of community actors through the 'tables de concertation', considering that these venues eventually increased the layers separating public services and community actors and made upward communication of community concerns more difficult (Parent et al. 2012). Most recently, major reforms introduced in 2014-15 centralized governance in the health system, consolidated 182 provider establishments into 32 vertically Integrated Health and Social Service Centres (CI[U]SSS) for the province's 8.4 million inhabitants (Bill 10), heavily promoted physician-led Family Medicine Groups (FMG) as the privileged model of primary care (including transferring nurses and other health professionals from public establishments into the FMGs), and established centralized access portals in each CI(U)SSS for health and care services. These structural reforms reduced statutory opportunities for public and local community participation (Lamarche, Hébert, and Béland 2014; 15 Solutions 2017; Regroupement provincial des comités des usagers 2014; Allaire and Nadeau 2017).

These features of the Québec system represent the prehistory of relations and reform context depicted in Figure 7.1 as driving and influencing the efforts of community-based actors in the present case study. The vocabulary of "concertation" and community action persists, but recognition of the distinct contribution of community actors is compromised, and successive waves of reform have eroded opportunities for community and user participation in decision-making. The immediate reform context provides a privileged opportunity to explore co-production dynamics: by disrupting established orders, they generate response and thereby help reveal factors that enable and impede community engagement and collaboration between community and public-sector actors.

7.2 Methods

7.2.1 Case selection

In the years following implementation of the latest reforms in Québec, a number of community-based initiatives emerged to understand the reconfigured system and difficulties experienced by community residents in accessing health and care services. The WG was selected for this case study as an early initiative involving community groups working with vulnerable populations. The lead researcher was invited to attend an early meeting and was introduced to WG members, who agreed to have the researcher study the initiative over an open-ended period of time. The study protocol received ethics approval, and WG members provided informed consent for the researcher to observe meetings and consult materials shared within the group. Informed consent for individual interviews was obtained from the eight original members of the WG.

7.2.2 Case description

Table 7.1 presents characteristics of the eight community actors in an urban neighbourhood who formed the ad-hoc WG in late 2016. The table details the roles they play within the community and the types of activity they undertake to assure that all community residents can obtain the services they need. They were concerned about the opacity of reforms, and the loss of legitimacy and connections with health system actors they needed to play their roles effectively. They held monthly meetings beginning in January 2017. The group's statement of purpose, agreed in June 2017, reads:

> The Working Group on health care is a collaborative effort between residents and community organizations to evaluate the level of need for and access to healthcare services among people living in our neighbourhood. Our mission is to help ensure that everyone living here has the information and resources necessary to access healthcare services, to promote the health and well-being of the neighbourhood, and to seek opportunities for collaboration which lead to improved access for all, with a particular focus on isolated and vulnerable residents.

Between January 2017 and December 2019 (Note: this represents the study period: the WG continued its activities into 2020, though faced disruptions after the Covid-19 pandemic), WG members met monthly at the offices of one of the community groups involved. Members working in community organizations participated as part of their work; community members participated as volunteers. Meeting agendas and minutes were prepared and circulated, with members assuming various research and outreach tasks between meetings. Some 20 invited guests from healthcare establishments participated in WG meetings over the first three years. Members who attended external meetings or events reported relevant information back to the WG. Two additional members joined in the second year: one from a community organization for people with disabilities, one a retired social worker and community resident.

Table 7.1 Characteristics of original Working Group (WG) members

MEMBER CHARACTERISTICS	SOURCES OF KNOWLEDGE
WG member 1 community organization, territory-based to house, coordinate and support community groups and undertake initiatives concerning whole territory population	• local stakeholder meetings to identify community needs • participates in several 'tables de concertation' • regular contact with public sector community organizers • events and consultations organized with community residents, including strategic planning exercise pointing to a need for community action to address changes arising from 2015 health system reforms and improve access, capacity, diversity and quality of public and community services
WG member 2 local resident, retired health professional	• experience of working to obtain CLSC in 1970s + former elected CLSC board member • member and former member/board member of various local organizations and 'tables de concertation'
WG member 3 community group: advocacy and services for minority residents	• provision of direct services to minority residents • hears people's need for cultural safety and trust when seeking help • helps people with problems arising from discomfort in communicating with public service providers • member of various 'tables de concertation' and diversity committees of public organizations • assembles experts from other community and public organizations to try and develop solutions

WG member 4 community group: advocacy and services for seniors	• participates in 'tables de concertation', provincial networks, community organizations • focus on quality of life of low-income seniors • provides direct services for seniors • produced Age-Friendly Cities survey • collaborates with public sector providers to design and obtain funding for projects • works to ensure public sector actors are aware of community services (i.e. transport to medical appointments) and provide their patients that information
WG member 5 community group: outreach and support for vulnerable seniors	• outreach in the community to identify citizens who may need information, help, referrals • intervenes with vulnerable seniors • links people with community and institutional resources • supports people to access services
WG member 6 community group: supports for new arrivals	• provides direct supports to new immigrants • coordinates 'table de concertation' • maintains listing of resources for new arrivals, including refugees • fills requests for translation/interpretation services for public sector health organizations
WG member 7 local resident, prominent figure in local community development, past and present board member/chair of local and national organizations	• issues raised within public, community and national organizations and vast personal network of contacts in health and social services sector and community sector. • personal experience as user and caregiver
WG member 8 local residents, retired nurse, member several community groups, volunteer at healthcare establishment	• Issues raised in various community groups and within the healthcare organization • personal experience of service gaps

This study employs qualitative methods to capture the rich detail of the network-building processes (Langley 2009) undertaken by the WG. Data were collected through observation, document review and interviews between January 2017 and December 2019. Observation notes were kept on monthly meetings of the WG, of member participation in external activities, and of activities organized by the WG. Documents included meeting minutes along with material introduced and shared among members, email communications and material distributed by the WG to the broader community and to public sector actors. Documents helped distinguish between what was discussed internally and how those discussions solidified into more concrete actions or proposals. Interviews were conducted with the eight original members of the WG at staggered time points during 2018. These focussed on members' sources of knowledge about access issues, relationships with other actors related to health and care services (pre-existing and formed through the WG), concerns that prompted them to join the WG, and ways in which the WG helped them address these concerns. Interviews were recorded with participant consent, transcribed verbatim and anonymized. Observation notes, interviews and documents were combined in a single database to triangulate and complement one another (Patton 2015).

7.2.3 Analysis

The first stage of analysis maps the network-building efforts accomplished through the WG. Network analysis provides an empirical entry point to study the dynamics of network formation (Maya-Jariego and Holgado 2015). Interviews with WG members, meeting minutes and observation notes, agendas and email correspondence of group members were mined to trace 1) the network ties related to health and care services each actor had coming into the WG, and 2) the WG's exploitation of these ties and formation of new links over time. These data were analysed using social network analysis software (Gephi) (Bastian, Heymann, and Jacomy 2009) to illustrate the phenomenon of network development. Network mapping helps explore the capacity to develop relationships (Provan, Veazie, and Staten 2005) highlighting bridging actors and events that enable the network to come together and expand (Mills et al. 2014). While often used in quantitative analysis, authors have highlighted its value in qualitative research (Bishop et al. 2012) to trace the relationships developed in a given initiative.

Second, this evolution is explored through the lens of ANT (Callon and Ferrary 2006) to better understand how network building develops capacities for co-production. ANT posits that it is the connections between various entities (social actors, ideas, resources, etc.) that produce an effect on social action (Bilodeau and Potvin 2016). As proposed by Callon and Ferrary (2006), we document the chain of events that produce new connections and the preliminary effects these have on capacities and conditions for co-production. Given that harder outcomes (i.e. better access to health and care services) would emerge only over the long term, the object of observation is the structure and dynamic of relationships (Brossard and White 2016).

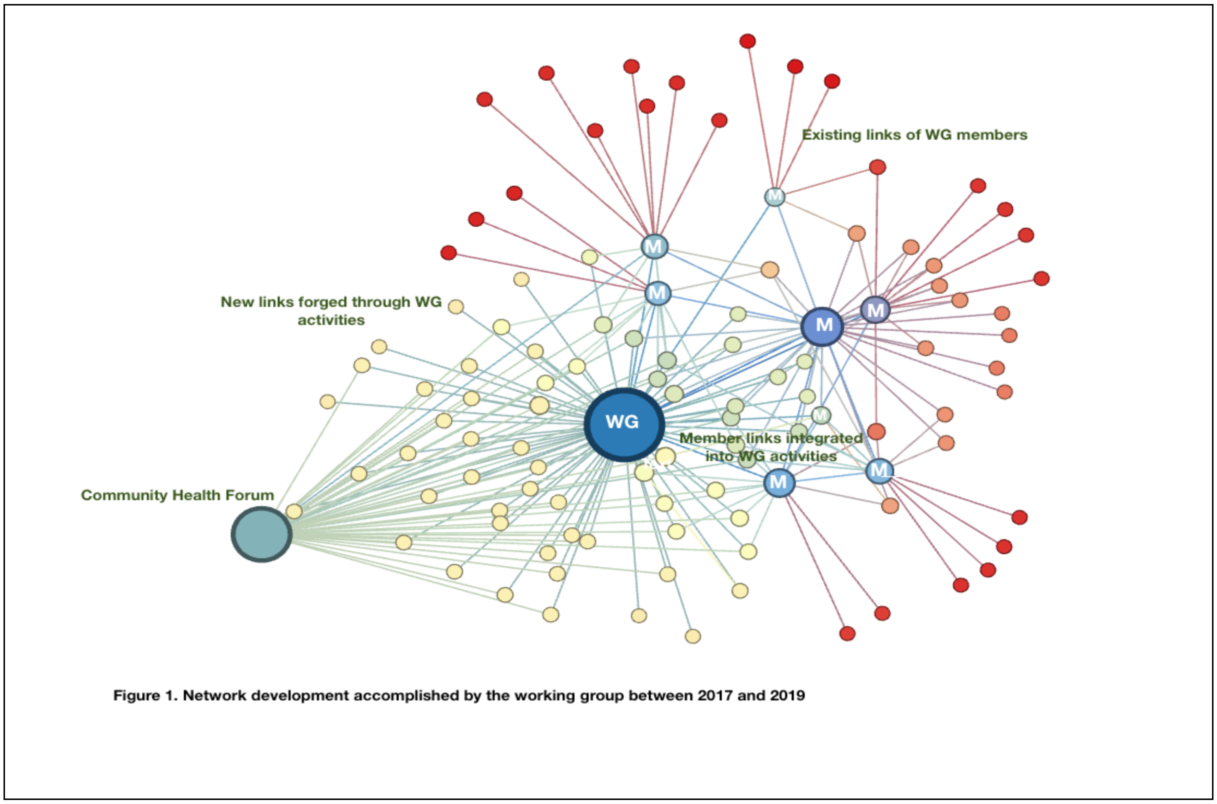
7.3 Results

7.3.1 Network building

Figure 7.2 presents a mapping of the network building achieved by the WG over the study period. It illustrates that creation of the WG brought together community actors with knowledge and insights drawn from the constituencies they worked with, but also from pre-existing links with other community organizations, politicians, researchers, health system providers and managers. Deliberations within the WG (represented by the large blue node in the centre) were therefore, at the outset, informed by this aggregated set of some 70 contacts related to health and care services. Over the study period, a number of these contacts attended WG meetings as guests to explore particular questions: family physicians working in FMGs, front-line professionals, managers and communications officers in the CI(U)SSS, researchers, etc. We further see, in the multiple nodes gravitating around and to the left of the central blue node, that the WG forged a new set of links to explore diverse perspectives on access issues and potential solutions. The organization of a Community Health Forum (the green node at the far left) enabled the WG to bring together health system actors, community actors and neighbourhood residents.

What Figure 7.2 describes is the machine behind the creation of social capital. We now look at how this web was put in action to enable community actors to better understand the post-reform system and effectively act within it to address access issues.

Figure 7.2. Network development accomplished by the WG 2017-2019



Legend: Figure 7.2 graphically depicts a point-in-time view of the network building accomplished by the working group over its first two years. The network mapping is egocentric, meaning it only considers links from the perspective of the working group: the pre-existing contacts of members related to health and care services, and additional links formed through the group's activities. The mapping does not depict relationships between other network actors, though these surely exist. The large blue node in the centre of the figure is the working group. The blue nodes marked "M" are the eight original members of the group, with lines extending to the links they had at the outset that were relevant to health and care services. Some of these links (the red dots) fed into the knowledge and perspectives members brought into the group, while others (the yellow dots) were more directly exploited in working group activities, brought in as "guests" to working group meetings or enlisted to participate in events. The large green node on the left represents a Community Health Forum organized by the WG in its second year of activity.

7.3.2 Actor-network development

ANT considers that power for action accrues as networks mature and develop consensus around paths to action, passing through stages of problematization, development of actor interest, role assumption and broader mobilization towards a consensus mission. This next section explores the work undertaken by the WG along these stages to influence conditions for co-production within the health services field.

Problematizing access issues: Table 7.1 describes the experience and knowledge WG members brought together. In early meetings, they pooled their perspectives to assemble a clearer vision of access difficulties: people's increasing distress and level of deterioration, rigid intake protocols, gaps in post discharge care, difficulties with coordination and access to primary care, long waits, public program cuts, etc. Front-line health services previously available at the local CLSC had been moved outside the neighbourhood, a decision that disregarded recommendations from an earlier community consultation in which several WG members had been involved.

> And we didn't know what was happening in the building that was supposed to be ours. The Agency comes and talks to the community to develop a strategic plan. But then they don't necessarily share their plan, and we might not recognize our input once it's in place. The community input didn't really have any impact, because then the decision was made [for the service governance unit] to become even bigger (WG member 2)

As well, front-line personnel employed by the CI(U)SSS were being moved from CLSCs to FMGs, which are run by physicians and disconnected from local communities.

> A lot of front-line services were moving, and still are, from CLSCs into FMGs, with a whole range of implications for service users, many of which we don't fully understand. These (FMGs) are actors who are not as tied into our community network, and yet they're some of the most important players on our territory and their influence seems to be increasing (WG member 1).

Community actors in the WG found themselves less able to support vulnerable community members. As one WG member said, access to public services depends on "how comfortable the community you serve is in coming to you for that help" (WG member 4) and community groups often play a bridging role. WG members found that longstanding relationships with individual public sector nurses, social workers and community organizers with whom they could troubleshoot access problems were increasingly fragile; these professionals were being moved around, faced new work demands and were less available. This also disrupted connections needed to ensure public sector referrals to community resources: "It takes someone on the inside to put out the memo to all the internal staff" (for example, about the availability of transport to appointments) (WG member 5).

WG deliberations enabled community actors to take stock of these changes, describe their impact, and identify particular system processes that exacerbated difficulties. This problematization stage in network development enabled them to pool and validate their concerns, and translate preoccupations and observations into problem statements to motivate and guide further efforts. As one member stated:

> When a number of groups come together to look at something like access to health and social services, they bring the specificities about local needs (WG member 6).

Generating actor interest: In ANT, a second stage in network development involves generating actor interest. The WG adopted three main strategies. A first was reaching out to contacts from the health and care system who could provide a deeper understanding of the problems identified.

> It was a multipronged approach: Let's really try and link with some of the people who understand the workings of the CI(U)SSS, and let's have some conversations with people who understand these access issues (WG member 6).

"Guests" appeared to welcome the invitation mainly as an opportunity to participate with community actors in problematization: reforms had brought major and rapid changes to working environments, with little opportunity for actors within the system to understand and discuss their impact. These guests were forthcoming with information about the challenges they faced internally, the imperfect rollout of certain plans and their own uncertainties.

A second strategy used by the WG was to participate in public meetings organized by system actors, generating interest in WG issues while also exploring venues available within the system to address their concerns. However, these meetings focused on presenting performance data that did little to clarify how services were being altered or the impact on access. Though a brief question period allowed the expression of concerns, these were not included in the public record for follow-up. CI(U)SSS representatives repeatedly pointed to two venues available within the public system for users to register complaints and participate in decisions: The Ombudsman's office in each establishment, and the User Committees required by law to exist in health and social service establishments. While public actors stressed that complaints to the Ombudsman were needed to prompt action within organizations, WG members (as well as community residents at the Forum) saw this mechanism as ill-suited to vulnerable populations most likely to experience problems.

> If you don't have someone to hold your hand through that Ombudsman process, yes it exists, but it's daunting and our people are not up to that (WG member 5).

The Ombudsman is designed to receive complaints from individuals, with no opportunity for community groups that hear about people's difficulties and have their trust to accompany them or relay their issues to prompt action. WG members were also somewhat ambivalent about the opportunity for participation provided by User Committees. Reforms had inserted greater distance between User Committees and decision-making levels in the CI(U)SSS, dislocating User Committees from local territories while extending the range of services each one represented (from long-term care to ambulatory services). FMGs presented an additional challenge, as they stood outside the purview of user committees, ombudsmen or other communication, participation or accountability mechanisms.

A third strategy used by the WG to generate actor interest was to organize a Community Health Forum, with the objective "to provide (neighbourhood) residents, in particular those living in vulnerable situations, an opportunity to obtain information about health and social services in their community and how to access these services" (WG communiqué). The network mapping in Figure 7.2 reveals how the Forum enabled the WG to expand network links with other community actors and public-sector organizations. This was a free public event with kiosks and workshops that offered community residents and public-sector and community providers a chance to find out about a wide range of services. Presentations by managers, board members and ombudsmen from the CI(U)SSS, as well as FMG physicians, included lengthy Q&A sessions. A second Forum was being planned at the end of the study period. While the WG itself had no funding, some of the groups involved were able to earmark a few thousand dollars to cover expenses (meeting hall, signs, refreshments).

In this second stage of network development, WG members generated interest among system actors to meet with the group and help them understand system changes and processes. They also explored venues within the system where they could pursue further links, and, in the Forum, served as an intermediary to create links between system actors and community members.

By coming together in the WG, and assembling their knowledge and experience to validate concerns and identify priority issues, community actors accumulated the social capital needed to interest public system actors in exploring access issues with them and, at the Forum, with community residents. Exchanges enabled a confrontation of perspectives and clarified some of the changes brought about through reforms.

Enrolment and mobilization: Callon and Ferrary (2006) describe the next stages of network maturation in ANT as the assumption of roles within the network that enable mobilization to pursue a consensus mission. The WG represents the creation of a new role, as a community-based and community-led venue for exploring concerns around access to health and care services that cuts across program areas (seniors, youth, minorities, etc). The WG enabled community actors to undertake joint deliberation and activities towards a consensus mission. Enrolment of public sector actors remained tentative: several stated that opportunities for exchange with community actors in the WG and at the Forum fed directly into their responsibilities. However, they also expressed discomfort about sharing 'insider information' and conflict of interest concerns, which were exacerbated in front-line professionals by the perceived fragility of their positions within the CI(U)SSS. WG members considered that front-line workers saw in the WG a valuable advocacy role that they could not play themselves in the system; "there's some ambiguity there (about how they see their own role)" (WG member 5).

Bilodeau et al use the term "transitional outcomes" to designate, through a modelling based on ANT, events that "mark the progression of the action towards its effects" (Bilodeau et al.

2019, 169). In the present case, we see the creation, consolidation and expansion of network relations among community actors, and looser network ties achieved with public sector actors (as guests to explore particular issues and speakers at the Forum). The first two stages of network building suggested roles community actors could assume to overcome some access difficulties. For example, once provider guests clarified issues with intake processes, community actors recognized how they could increase accompaniment to help people "tell their story" effectively to assure they were assigned the appropriate priority ranking to obtain services. Other roles included helping people register on the waiting list for a family physician, educating people about available services, and working with public institutions to improve their communication tools (i.e. providing feedback on a new website). WG members contemplated moving into roles within the public system (i.e. User Committees), but remained unsure of their suitability for addressing community concerns. Commitment of public sector decision-makers to assume new roles with community actors beyond those of "guest" (at WG meetings) and "speaker" (at the Forum) was not evident as a transitional outcome in the present case.

The network development efforts of the WG conferred on community actors the "discursive legitimacy" (Benson 1975) to speak on behalf of issues as they assembled knowledge of access difficulties faced by community members and understood the system features responsible for these difficulties. During the study period, conditions for co-production were improved insofar as community actors developed capacities to adapt their services to help people negotiate difficulties. The WG received no sign of system changes to facilitate the integration of these capacities. While system actors appreciated the opportunity to problematize alongside community actors, collaborative mobilization was impeded by conditions created by reforms: insecurity and movement of front-line personnel, recourse mechanisms ill-suited to people most likely to have reason to use them, and growing power of physicians over resources without accompanying accountability mechanisms or connection to community actors.

7.4 Discussion

Bovaird defines co-production as "the provision of services through regular, long-term relationships between professionalized service providers and service users or other members of the community, where all parties make substantial contributions" (Bovaird 2007, 847). The present case highlights that reforms can produce challenges to co-production as they disrupt these relationships, and erode the value of existing mechanisms and spaces for sustaining collaborative relationships. The main outcome of WG network building efforts lies in the creation of "alternate venues" (Weber and Khademian 1997) or "organizational infrastructure" (Ansell and Gash 2007) that enables community-based actors to understand system changes and develop capacities to help people overcome access difficulties in the new context.

We will focus discussion on three central findings. A first concerns the particular role of community-driven engagement in creating conditions for co-production. A second regards the territorial dimensions of co-production that are revealed in this case. A third relates to the impact of reforms on the co-production capacities of public sector actors.

7.4.1 Community-driven engagement

De Weger suggests that organizations can create points of connection between communities and local services through forums where citizens and professionals feel comfortable enough to put ideas forward (De Weger et al. 2018). The results of this study question whether public sector organizations are best placed to perform this role. In contrast to the public meetings of provider organizations, the Community Health Forum provided actionable information (to residents, community groups and public-sector actors), revealed and explored gaps and, by presenting a vision of health that included a broad range of providers, had the potential to generate solutions outside the public sector to meet needs as well as suggest improvements to public services. Co-production requires different actors to develop contributions that will be valuable in a given system context. Looking at collaborative strategies in community health, Lasker and Weiss (2003) find that combining the knowledge, skills, and resources of a group of diverse participants can lead to "breakthroughs in thinking and action" to strengthen community capacity to solve problems. They recognize the need for "'neutral' or 'safe' spaces in civic society to support broad-based collaborative problem solving" (Lasker and Weiss 2003, 41) and view problem-solving processes in civil society as complementary to government's role. "Ultimately, it appears that two complementary forms of collaboration are required to strengthen the ability of communities to solve complex problems: one in which the community participates in the work of government and another in which government participates in community-driven processes in civil society" (Lasker and Weiss 2003, 41). Farmanova et al (2019), looking at interfaces between healthcare (medical) and non-healthcare (or non-medical/community) services in nine OECD countries, conclude that capacity building is needed in both community and healthcare systems, along with greater attention to building and using social capital.

Distinguishing between the two can be complicated by the "pre-history" of a given system. The Québec context includes venues such as the "tables de concertation" and user committees that were designed as opportunities for community participation. Scholars looking at the history of Québec's system note a tendency towards a "complémentariste" view that valued community resources not for their autonomous contributions or insight, but for helping to meet Ministry-determined program objectives. The 'tables de concertation' (in which many WG members participated) were insufficient to address increasing community concerns. Alongside this trend, structural reforms to vertically integrate health and care services into very large organizations divorced health and care services from local communities, weakening mechanisms for user and community representation in decision-making.

7.4.2 Territorial dimensions of co-production

Territory is underexplored as a factor in co-production. In England, the involvement of county councils in Sustainability and Transformation Plans (and the Integrated Care Systems now being developed from these), are rooted in local communities with involvement of local elected representatives, providing a defined population at territorial level (Ham 2018). Their challenge has been to align National Health Service (NHS) and local governance in coordinating and funding services. In Québec, vertical integration coupled with the FMG model of primary care preclude accountability to local communities. Farmanova et al find that in integrated models "the population served needs to be defined and perhaps limited in size to enable effective use of resources and to facilitate networking among providers who develop local solutions to issues" (Farmanova, Baker, and Cohen 2019, 20). In Québec, notions of territory in the CIUSSS and from a community development perspective are quite different (IPCDC, Tremblay, and Boucher 2015). Brossard and White (2016) point to the durability of the old CLSC territories as spaces in which community action continues to emerge, despite over a decade of reconfigurations (CSSS then CI(U)SSS) and attribute it to the dynamism of networks developed at that time. It should be remembered that in the 1970s and 1980s, the Ministry required neighbourhoods to present a convincing plan based on community consultation and needs assessment before it would authorize the creation of a CLSC, meaning that neighbourhood cohesiveness and activism predated CLSC structures and defined their location (i.e. the definition of "local" territorial boundaries).

7.4.3 Impact of reforms on the co-production capacities of public sector actors

This case study shows that major barriers to the contributions of community actors lie in the fragility and interruption of their links with public sector actors and the lack of clarity about system changes. Québec's system includes front-line actors with nominal responsibility to support community action and link with community resources – a number participated as guests in the WG. Their hesitancy about the legitimacy of participating points to a disempowerment of these actors through reforms that disrupted their networks within public establishments, as well as their ties to community actors. These findings are in line with Audy and Couturier's observation that structural and personnel changes in 2015 reforms pose an important threat to the efficacy of networked action (Audy et al. 2017). Internal disruption also impedes channels that would allow information drawn from the community to filter into organizational decision-making. In the context of reforms, the problematization stage of network development appears especially important in understanding barriers to bringing contributions together to effectively use and provide services.

The inadequacy of communication from the public system around changes and access mechanisms during recent reforms in Québec could be attributed to the speed with which reforms were introduced, but contributes to the disempowerment of service users. What appears in the case study in Québec is that obfuscating public sector capacity problems behind new unwieldy access processes and poor communication impedes public sector and community capacities to develop solutions to help fill the gaps. From a political philosophy perspective, Badano recognizes that the emphasis on co-production in England to "harness the renewable energy represented by patients and communities" (NHS 2014) and encourage people to "feel both free and powerful enough to help themselves and their own communities" may be a cover for public sector cuts. However, she considers that even if co-production is pursued with an expressly cost-control mandate, it might end up being "the least possible evil" (Badano 2018, 20).

Finally, reforms in Québec give physicians – who remain independent contractors in Canadian systems – greater control over other professionals and public resources, raising new challenges for co-production that the WG found difficult to address. FMGs are not territory-based and have no mechanisms for communication with or accountability to communities. Pescheny (2018), looking at facilitators and barriers to social prescribing in the UK, concluded that “third sector services (community, voluntary, social enterprise) remain underused due to weak links between primary care and third sector.” The lack of routes into the FMG model available to community actors represents a break with historical primary care models embedded within communities (though these had progressively weakened prior to the 2014-15 reforms).

7.4.4 Study limitations

The present study explores network development over almost three years, however given the slow pace of progress and the recent nature of reforms, a longer period might reveal more significant role development and greater collaboration between community and public-sector actors. As well, the study was not designed to capture discussions and actions taken by public sector actors as a result of interaction with the WG network. Research is needed to understand what drives or impedes healthcare providers to establish collaborative relationships with community organizations. The issue of territory as a factor in co-production also warrants greater attention. Finally, other community- driven initiatives occurred in the years after reforms, which adopted different approaches to that seen with the WG; comparison might have provided additional insight into community strategies for gaining legitimacy and power in a given reform context.

7.5 Conclusion: network dynamics, power and co-production

This study provides a better understanding of the specificities and contribution of community-driven engagement efforts in developing conditions for co-production, reveals how network creation enables capacity development and points to venues important in fostering collaborative dynamics between community and system actors. The reform context and attention to history reveal system features that impede co-production and anticipate challenges associated with moving towards vertically integrated care systems. ANT offers a way to analyse network development towards action through the accumulation of social capital. In particular, this study highlights the significance of network activity in problematization to understand changes brought by reforms as a first step to adapting roles and relationships and (re)creating conditions for co-production.

CHAPTER 8: DISCUSSION

In this chapter, our discussion aims not to repeat what has been said in the discussion within each article, but rather focus on a few points that arise as we look at the two cases together and see what experience in other jurisdictions can contribute to the evolving engagement efforts in Québec.

This thesis sought to move away from an atomized examination of engagement initiatives to better understand how the engagement efforts of various actors in various settings build capacities for transformation towards something resembling collaborative health. The two case studies reveal a critical lack of connection between engagement efforts across the organizational field. Factors related to organizational engagement strategies and to health system reforms in Québec appear to contribute to this disconnect.

The organizational strategies to recruit individual patients valued lived experience and a partnership approach, and devalued connections to other patients or communities, which was termed 'advocacy' and seen as compromising potential partnership. As well, the AHC's increasingly superspecialized mandate decreased contact between user committee members and external communities, including the user committees of establishments that now fell under CISSS governance. Reforms to vertically integrate services across the continuum did not include consideration for linking patient engagement venues across the continuum. Neither had clinicians established the links with community-based colleagues to facilitate bridging. Clinician preoccupations with improving discharge planning and communication, seen towards the end of our study, provide an opportunity for engagement efforts that reach outside the organizational walls. However, both cases reveal that reforms disrupted relationships among providers and between providers and communities, increased time pressures on both managers and clinicians, and rendered front-line health professionals insecure in their roles and divorced from their territorial client bases and community collaborators.

Problematization appears as a significant enterprise in public and patient engagement, which represents a novel finding in this research. Reforms bring about effects that are not always visible in the immediate, nor always intentional or anticipated by reformers. The discourse used to 'sell' reforms can obscure changes and impede the development of collaborative efforts to create fixes and palliate gaps. The case study reveals community engagement efforts as important venues for taking on this work, invite providers in to problematize with them and clarify co-production capacities that need to be developed among patients and communities.

The impact of reforms on public and patient engagement has been studied in various jurisdictions, with a wealth of insight available from scholarship from England. Carter and Martin find that despite the fact that "a 'commons' discourse infuses the NHS Constitution", the results are increasing deficits in accountability and instrumental use of public consultation, with 'involvees' divorced from connections to broader communities (Carter and Martin 2018, 708). Though the language embraces principles of patient-centred care and patient participation, reforms are considered to have eroded patient and public voice in health care. Some notable reforms in this regard were the abolition of locally embedded Community Health Centres (CHC) that participated in service design, monitored system operation and had direct links to government decision-makers to report concerns. These were replaced by participation structures called HealthWatch, where citizens have official positions on the Health and Wellbeing boards that commission services, but are discouraged (the law's original wording was "prohibited") from advocating in opposition to policy adopted by government at any level (Tritter and Koivusalo 2013, 118). HealthWatch participants were selected through national recruitment, had no public space for deliberation, and could only communicate concerns to government officials through the provider organization (Tritter and Koivusalo 2013; Carlyle 2013; Parkinson 2004). Duties to consult with communities were imposed on primary care and hospital providers as part of reforms, however these organizations had difficulty identifying community voices and had no obligation to implement or address recommendations arising from consultations (Lewis and Hinton 2008;

Pickard, Sheaff, and Dowling 2006; Farmer et al. 2015). These analyses hold lessons for actors in Québec.

In Australia and Wales, community councils supported by state funding continue to contribute in various ways to healthcare decision-making and are valued by providers as recognizable and approachable sources of information about community needs and views (Hughes, Mullen, and Vincent-Jones 2009; Nathan, Johnston, and Braithwaite 2011). In New Zealand, elected district boards gained clout and credibility through a national organization of district health boards, which provided a forum for deliberation of common issues, and a channel through which to increase the voice of board members in national government decision-making (Barnett et al. 2009, 125; Ashton et al. 2008).

Investment in a broad range of statutory, advisory and voluntary engagement venues builds capacities that can spread across systems. While in Québec and Canada there are a number of promising initiatives, they remain vulnerable to reforms, partly because they are not connected across systems. The province of British Columbia has taken the most significant steps along this path. Government has invested in developing and spreading self-management programs to equip patients with new tools and confidence to manage their own conditions. These increased capacities have been found to encourage patients to assume new roles, both in supporting the self-management skills of others, and in participating as advisors in organizational and system change. The province also supports mechanisms to transfer this new expertise into other forums through the Patients as Partners Network to advise on healthcare policy and care processes (McGowan 2016). Provincial advocates are well resourced and powerful voices to bring attention to public and patient concerns.

Despite Québec's history of local involvement, public investments and energies are currently geared to provider-initiated engagement efforts, with less attention to other venues for capacity development among patients and communities or bridging actors. A community of practice in patient partnership, now in its third year, provides an opportunity for managers - generally in quality departments of healthcare organizations - and the patient advisors working with them to share expertise and experience around patient partnership in improvement efforts. This work is supported by a 2018 government framework for patient partnership, the creation of funded positions in healthcare establishment for patient partnership coordinators, and Ministry funding of specific projects. Additional incentives come through new accreditation standards stipulating requirements for partnership with and input from patients on 'engagement-sensitive' key performance indicators.

At an international Summit on patient partnership held in 2019, Speakers from Québec acknowledged that it was difficult to create real partnership when "institutions are trying to engage patients from their home into our institutions where we're in charge" and considered that community engagement levels the balance of power a little more "because we're working with community organizations and patient organizations as equitable partners to the healthcare institutions" (Boivin 2019). However, there is little evidence that resources are shifting to independent venues for community and patient engagement. Neither does the bridging role of front-line providers appear to be sufficiently supported. Connections with local communities have been steadily deprioritized since the 2003 reforms. A statement issued in 2008 and signed by a number of esteemed Québec academics strongly criticized a CSSS decision to replace community organiser positions by new planning and programme officer positions (agent de planification et de programmation). The signatories described the community organizer positions as keys to the bottom-up dynamic that rendered CLSCs responsive. They created "privileged channels through which demands and needs were expressed by the people and communities targeted by programs and services," and "put in place the conditions of real partnership activity that proved to be a true fount of social innovation in Québec" (Jetté and Dumais 2008, 27, our translation).

The Québec Cancer Network has emphasized patient-centred care and the participation in governance committees at national and local level of people living with and beyond cancer (PLC). A study of the integration of PLC into collaborative governance processes (Tremblay et al. 2021) finds that the creation of a national forum, or community of practice, where PLC can pool experience and ideas and develop a strong common voice, increases their capacities to participate in governance, as well as their legitimacy, in the eyes of providers beside them on governance committees. The National Voices experience in the UK supports this mechanism for increasing power through discursive legitimacy, as does an earlier national association of CHCs in England, which provided a forum at which to exchange strategies and form a unified voice on significant concerns (Hogg 2007).

In Québec today, and in some but not all other jurisdictions with universal tax-funded health systems, centralization and integration have been accompanied by a loss of public and patient engagement. Evidence-based practice and indicator-based performance standards leave less room for variation. The complexity of integrated systems makes it difficult to assure engagement mechanisms that follow patient trajectories across a continuum of care. The professionalization of an increasing number of care domains squeezes out community and volunteer contributions. In universal tax-funded systems, there may also be an inherent tension between public and patient engagement and notions of equity and population health. In Québec, differences between regions, between CLSCs, and between hospitals have been used to justify increasing centralization. Energies for engagement may become difficult to muster when difference is discouraged.

Sustainability threats to publicly funded health systems provoke efforts to exert greater control, often through centralization and standardization of the service offering accompanied by reduced statutory patient and public roles in governance. In this context, the focus on engagement efforts can be seen as a camouflage for disempowerment (Carter and Martin 2018) through rational and technical reforms, or as a transfer of state responsibility to individuals and communities (Bovaird and Loeffler 2012) to reduce the size of the state. While sustainability creates an imperative for change, it should be recognized that greater user responsibility requires an increase, not decrease, in their power and knowledge. The case studies presented here reveal a lack of clarity and openness about the way the post-reform system operates that impedes individuals, communities and system actors from assuming new roles and responsibilities.

PART IV: CONCLUSION

The research undertaken in this thesis seeks to better understand how public and patient engagement efforts contribute to transformation and movement towards "collaborative health" in contemporary publicly funded systems. There is increasing scholarly and practice attention to engagement initiatives as a means of better adapting health services to people's needs to achieve patient-centered care, and enabling users and communities to assume a greater role in care to enhance sustainability. Expectations are high, but the pathways from initiatives to transformation remain poorly understood. The meta-narrative review presented in Chapter 3 reveals assumptions in recent literature that impede movement towards transformation: that engagement in care and in organizational and system decision-making can be understood and studied separately; that provider-led engagement initiatives are the way to generate co-production; and that the form of engagement initiatives (based on ideas of democratic participation) determines their impact. Recent systematic reviews express a need to move beyond these assumptions, calling for both attention to theories of change, and for a systematic approach involving micro, meso and macro levels with attention to context. The two case studies reported in Chapters 6 and 7 seek to respond to these calls, exploring efforts arising in different corners of an organizational field to see how they work to change the 'référentiel' (Muller 2005) that guides societal decisions and action.

The present research calls for a reconfiguration of engagement efforts to recognize where capacities emerge: patient capacities for self-care, community capacity for support, organizational processes that structure provider interactions with patients and communities, and policies that define rules and distribute resources. The case studies suggest that public and patient engagement towards co-production is a long-term project to transform actor configurations and relations. In moving towards co-production within organizations, findings highlight the importance of engagement efforts that build on existing resources, routines and relationships to effect institutional change. Erecting parallel structures risks undermining roles and capacities within the organization. The case also emphasizes that movement towards vertically integrated health systems involves a phase of disintegration, where problems can no longer be addressed internally, and requires close attention to the formation of new relationships and bridges along the continuum, including between venues for patient and public engagement. The community case study reveals the importance of bridging system actors who have links to an identifiable community and influence within their organization. It also suggests that greater support for community efforts to understand the difficulties encountered by system users, explore problematic processes with system actors, adapt community services to fill gaps and support users, and create venues for open exchange, could contribute significantly to developing capacities for co-production among all actors.

By looking at processes of organizational change and power relations between healthcare institutions and communities, I try to understand the characteristics of engagement efforts and context elements that might contribute to collaborative health. Institutional work, collaborative governance and actor-network theory prove helpful in apprehending contributors to change. the mechanisms involved in collaborative governance open the way (if somewhat idealistically) to the emergence of virtuous cycles of engagement that might reconfigure the capacities and contributions of providers and users to improving health care policies, processes and outcomes. Ferlie (2019) sees in collaborative governance and sibling movements such as New Public Governance (Osborne 2010), New Public Service (Denhardt and Denhardt 2007) and New Public Value (Bryson et al., 2014) a trend toward "downward facing" models of public administration that are in a period of expansion. The European Union Horizon COGOV 2020 project aims to "explore and assess the strategic leadership efforts of local governments and other public agencies to transform themselves from ‘bureaucratic authorities’ - treating citizens as legal subjects - and ‘service providers’ - treating citizens as customers - into ‘arenas for co-creation’" (Ferlie 2019, 5).

In line with the COGOV project and recent reviews explored in Chapter 3, this thesis proposes that future research on engagement and co-production focus on natural rather than experimental settings and pay attention to context. It also stresses the need to consider how multiple engagement strategies interact to enhance the capacities of providers and users and the recognition of interdependencies between them that will promote collaboration. Such studies will improve our understanding of the collaborative health ecosystem and efforts that could be targeted for investment and policy attention.

Limitations and future research

The research questions explored in this thesis are rooted in the field of public administration. They do not address the political processes involved in health care in Canada. It would, however, be interesting for future research to explore how the institutional dynamics around engagement initiatives are affected by the positioning of health care in political systems. In Canada, health care is regarded as the Third Rail, making politicians wary of promoting changes: health reforms are rarely pronounced or debated explicitly in election campaigns. As well, the distance between provincial governments and health care makes electoral democracy less powerful in orienting system change. Comparative study between jurisdictions could help to understand how opportunities for engagement in democratic processes and engagement in healthcare establishments and communities combine to contribute to co-production and transformation. Even within Canada, variations in opportunities for participation in regional and community health boards and hospitals could provide informative comparisons.

To conclude, this thesis identifies mechanisms that promote co-production and finds that many of these interact across levels of engagement. Institutional work within organizations brings about changes in the logics of healthcare providers. Network development provides extra-organizational public and patient actors legitimacy as interlocutors, and increases their capacities to co-produce health and care services. The impact of engagement efforts is currently compromised by a fragmentation that mirrors the health system in its present form. Progress toward integrated patient-centred care will need to be accompanied by a reconfiguration of engagement efforts to recognize the interdependence between patient capacities for self-care, community capacity for support, organizational processes that structure provider interaction with patients and communities, and policies that define rules and distribute resources.

APPENDICES

APPENDIX A: RESEARCH TIMELINE

<table>
<tr><td>Exploratory observation AHC (first approached August 2015)</td><td>Exploratory observation AHC
Public document review</td><td>Internal document review
Interview AHC actors (n=31)</td><td>Key informant (3) feedback on case narrative</td><td></td></tr>
<tr><td></td><td colspan="2">Non-participant meeting observation AHC across levels</td><td></td><td></td></tr>
<tr><td>Contact made with community working group (WG); exploratory observation</td><td>Interviews WG members (n=8)</td><td>Document analysis working group materials and communications</td><td></td><td></td></tr>
<tr><td></td><td colspan="2">Non-participant observation community WG meetings; accompany to external events; attend WG events</td><td></td><td></td></tr>
<tr><td>Thesis proposal, December 2017</td><td>Ethics approval, ENAP (May 2018)
Ethics approval, AHC (December 2018)</td><td></td><td></td><td></td></tr>
<tr><th>2017</th><th>2018</th><th>2019</th><th>2020</th><th>2021</th></tr>
<tr><td>Case selection</td><td>Data collection</td><td>Data collection
Iterative analysis of triangulated data</td><td>Iterative analysis of triangulated data</td><td></td></tr>
<tr><td></td><td></td><td></td><td>Submission Article 2 November</td><td>Revision Article 2
Submission Articles 1 and 3</td></tr>
<tr><td colspan="4">Literature review: international statutory participation venues; ongoing public/patient engagement study search; initial systematic review; meta-narrative review</td><td></td></tr>
<tr><td colspan="3">Background observation: RPCU, Community of practice in patient partnership, CI(U)SSS annual public meetings, various user committee meetings, various community/citizen initiatives; AHC quality improvement teams and training</td><td></td><td></td></tr>
</table>

APPENDIX B: DESCRIPTION OF SYSTEMATIC AND SCOPING REVIEWS

Authors	Year	Title	Journal	Study design
Baker, GR	2014	Evidence boost: A review of research highlighting how patient engagement contributes to improved care	CFHI Evidence Boost	summary of case studies in four countries.
Barello S, Graffigna G, Vegni E, et al.	2014	The challenges of conceptualizing patient engagement in health care: A lexicographic literature review	Reviews	thematic analysis - 259 studies
Barello S, Triberti S, Graffigna G, et al.	2016	eHealth for patient engagement: A systematic review	Frontiers in Psychology	systematic review - 11 studies
Berger Z, Flickinger TE, Pfoh E, et al.	2014	Promoting engagement by patients and families to reduce adverse events in acute care settings: A systematic review	BMJ Quality & Safety	systematic review - 6 articles
Boivin A, L'Espérance A, Gauvin F-P, et al.	2018	Patient and public engagement in research and health system decision making: A systematic review of evaluation tools	Health Expectations	systematic review - 27 studies
Bombard Y, Baker GR, Orlando E, et al.	2018	Engaging patients to improve quality of care: a systematic review	Implementation Science	systematic review - 48 studies
Castro EM, Van Regenmortel T, Vanhaecht K, et al.	2016	Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review	Patient Education and Counseling	concept analysis - 103 papers
Cené CW, Johnson BH, Wells N, et al.	2016	A narrative review of patient and family engagement: The "foundation"of the Medical Home	Medical Care	narrative literature review - 14 systematic reviews and primary publications
Conklin A, Morris Z and Nolte E	2012	What is the evidence base for public involvement in health-care policy? Results of a systematic scoping review	Health Expectations	systematic scoping review - 19 studies
Coulter A and Ellins J	2007	Effectiveness of strategies for informing, educating, and involving patients	Health Affairs	literature review
Crawford MJ, Rutter D, Manley C, et al.	2002	Systematic review of involving patients in the planning and development of health care	BMJ	systematic review of 42 papers (1966 to 2000)

Daykin N, Evans D, Petsoulas C, et al.	2007	Evaluating the impact of patient and public involvement initiatives on UK health services: a systematic review	Evidence & Policy	literature review of PPI and systematic review of 8 outcomes studies of PPI in the UK
De Weger E, Van Vooren N, Luijkx KG, et al.	2018	Achieving successful community engagement: A rapid realist review	BMC Health Services Research	rapid realist review - 20 papers
Djellouli N, Jones L, Barratt H, et al.	2019	Involving the public in decision-making about large-scale changes to health services: A scoping review	Health Policy	scoping review - 34 studies
Dukhanin V, Topazian R and DeCamp M	2018	Metrics and evaluation tools for patient engagement in healthcare organization- and system-level decisionmaking: A systematic review	International Journal of Health Policy and Management	systematic review - 199 publications
Gallivan J, Kovacs Burns KA, Bellows M, et al.	2012	The many faces of patient engagement	Journal of Participatory Medicine	literature review - 23 studies
Goodridge D, Henry C, Watson E, et al.	2018	Structured approaches to promote patient and family engagement in treatment in acute care hospital settings: protocol for a systematic scoping review	Systematic Reviews	protocol for a systematic scoping review
Halabi IO, Scholtes B, Voz B, et al.	2020	“Patient participation” and related concepts: A scoping review on their dimensional composition	Patient Education and Counseling	scoping review - 39 studies
Hall J, Peat M, Birks Y, et al.	2010	Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review	BMJ Quality & Safety	systematic review - 14 studies
Hamilton C, Snow ME, Clark N, et al.	2019	Quality of patient, family, caregiver, and public engagement in decision-making in healthcare systems: a systematic review protocol	BMJ Open	scoping review protocol
Kovacs Burns K, Bellows M, Eigenseher C, et al.	2014	Practical resources to support patient and family engagement in healthcare decisions: a scoping review	BMC Health Services Research	scoping review of peer review (76) and grey literature (193)

Liang L, Cako A, Urquhart R, et al.	2018	Patient engagement in hospital health service planning and improvement: a scoping review	BMJ Open	scoping review - 10 studies
Majid U and Gagliardi A	2019	Conceptual frameworks and degrees of patient engagement in the planning and designing of health services: A scoping review of qualitative studies	Patient Experience Journal	scoping review - 18 qualitative studies
Manafò E, Petermann L, Vandall-Walker V, et al.	2018	Patient and public engagement in priority setting: A systematic rapid review of the literature	PLOS ONE	systematic review – 70 studies
McCarron TL, Moffat K, Wilkinson G, et al.	2019	Understanding patient engagement in health system decision-making: a co-designed scoping review	Systematic Reviews	scoping review - 15 studies
Mitton C, Smith N, Peacock S, et al.	2009	Public participation in health care priority setting: a scoping review	Health Policy	scoping review - 175 studies
Mockford C, Staniszewska S, Griffiths F, et al.	2012	The impact of patient and public involvement on UK NHS health care: a systematic review	International Journal for Quality in Health Care	systematic review - 42 papers on 28 studies
Ocloo J, Garfield S, Franklin BD, et al.	2021	Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews	Health Research Policy and Systems	overview of 42 systematic reviews
Palumbo R	2016	Contextualizing co-production of health care: A systematic literature review	International Journal of Public Sector Management	systematic review 65 papers
Park M and Giap T	2019	Patient and family engagement as a potential approach for improving patient safety: A systematic review	Journal of Advanced Nursing	systematic review - 42 studies
Pinnock H, Epiphaniou E, Pearce G, et al.	2015	Implementing supported self-management for asthma: a systematic review and suggested hierarchy of evidence of implementation studies	BMC Medicine	systematic review - 18 controlled trials

Sagen J, Smedslund G, Kjeken I, et al.	2020	Patient participation in the development and delivery of health care services, and implications for quality: Protocol for a scoping review.	Open Science Framework (protocol)	scoping review protocol
Sandvin Olsson AB, Strøm A, Haaland-Øverby M, et al.	2020	How can we describe impact of adult patient participation in health-service development? A scoping review	Patient Education and Counselling	scoping review - 34 studies
Sharma AE, Knox M, Mleczko VL, et al.	2017	The impact of patient advisors on healthcare outcomes: A systematic review	BMC Health Services Research	systematic review - 32 articles
Simmons L, Wolever RQ, Bechard EM, et al.	2014	Patient engagement as a risk factor in personalized health care: A systematic review of the literature on chronic disease	Genome Medicine	systematic review - 10 prospective clinical trials
Tobiano G, Chaboyer W, Teasdale T, et al.	2019	Patient engagement in admission and discharge medication communication: A systematic mixed studies review	International Journal of Nursing Studies	systematic review - 15 studies
Van Veen B	2014	Patient and family advisory councils: engaging patients in how care is designed, delivered and experienced: A literature review	Thesis	literature review - 8 articles/reports
Zhao G, Kennedy C, Mabaya G, et al.	2019	Patient engagement in the development of best practices for transitions from hospital to home: A scoping review	BMJ Open	scoping review - 23 best practice reports

APPENDIX C: ARTICLE 2 MEETING OBSERVATION AUTHORIZATION AND GRID

Meeting observation guide 2019

Dear__
I am requesting authorization to observe the meeting _____ as it concerns the development and/or implementation of patient and public engagement (PPE) initiatives at the MUHC.

My research seeks to understand how and in what context patient engagement strategies in an organization produce changes in structures, policies and social relations that facilitate the emergence of co-production at decision-making, organizational process and care levels.

Observation grid: meetings

- General purpose of meeting
- How patient engagement is defined and its purpose
- Type of information exchanged
- Organizational patient engagement actors and initiatives mentioned
- External actors and initiatives mentioned
- Mechanisms for patient engagement employed/foreseen
- Barriers to/facilitators of patient engagement

I will take notes during the meeting and consult the meeting agenda and minutes (where available) to complete the observation grid. Only information necessary for the study will be collected. Observation notes will remain confidential and no individual present at the meeting will be identifiable in research products.

If you have questions or if you have a problem you think may be related to your participation in this research study, you may communicate with the researcher at the following number: Susan Usher, [redacted].

For any question concerning your rights as a research participant taking part in this study, or if you have comments, or wish to file a complaint, you may communicate with: MUHC Office of the Ombudsman at 514-934-1934 ext 48306

Thank you very much for your collaboration,
Susan Usher
Doctoral candidate, École nationale d'administration publique

Research title: Patient and public engagement and the transformation of health systems
RI-MUHC Research Ethics Board authorization: Dec. 17, 2018 (BIAL6000/2019-4960)
RI-MUHC Principal investigator: Dr. Alain Biron

APPENDIX D: ARTICLE 2 INTERVIEW GUIDES

Article 2 Interview guide

Central level administrative actors

1. How do you define patient and public engagement (PPE)?
2. What have been the main sources of your ideas about PPE (i.e. organizations, individuals within and outside the organization, publications, directives...)?
3. Who are the people within and outside the organization you deal with on PPE?
4. Why and how has PPE emerged as a priority in the organization? (external directives, internal discussion….)
5. Can you describe the strategies you've employed to institute or encourage PPE?
6. What changes have these produced within the organization?
7. What challenges do they present?
8. How do you find out about patient perspectives on various issues/concerns? (what sources of information are available; how are these shared?)
9. In what ways has patient/public participation influenced priorities, problem definition and solutions?
10. What feedback have you received from different groups (professional groups, clinical Missions, care sites, units) within the organization about the focus on PPE?
11. What feedback have you received from groups (i.e. government, other HCOs, other organizations, community) outside the organization about your work in this area?
12. Can you identify Missions (departments) you consider to be most advanced in their patient participation efforts? Least advanced? Explain.
13. How do you deal with variations between Missions in PPE efforts?
14. How has PPE changed the way you approach your work? Your interaction with other individuals/groups?
15. How do you see PPE evolving within the organization in the next 5 years?
16. What developments (internal and/or external to the organization) could do most to accelerate or impede progress in PPE?

Alternate questions for Central level User Committee actors

5. Can you describe the strategies the organization employs to advance patient engagement?

6. Can you describe the strategies the User Committee employs to advance patient participation and increase its impact within and outside the organization?

Interview guide - Department (Mission) level actors

1. How do you define patient and public engagement (PPE)?
2. What have been the main sources of your ideas about PPE (i.e. organizations, individuals within and outside the organization, publications, directives...)?
3. Who are the people within and outside the organization you deal with on PPE?
4. How would you describe the current state of PPE within your clinical Mission?
5. Can you identify key moments in the development of PPE within your Mission?
6. How does the development of PPE within your Mission relate to PPE efforts at the organizational level?
7. In what ways does PPE manifest within the Mission?
8. Can you describe the strategies employed within the Mission to assure/encourage PPE?
9. In what ways do patient partners influence priorities, problem definition, solutions?
10. How would you describe the involvement of (physicians, nurses, staff, others) in PPE strategies?
11. How do you deal with variations among professionals and staff in PPE efforts?
12. What do you feel are the prospects and challenges for PPE in the next 5 years?
13. Is there a particularly promising project underway at the moment I might be able to study?

Interview guide - Unit project team actors

1. How do you define patient and public engagement (PPE)?
2. What have been the main sources of your ideas about PPE (i.e. organizations, individuals within and outside the organization, publications, directives...)?
3. Who are the people within and outside the organization you deal with on PPE?
4. How would you describe the current state of PPE within your clinical Mission?
5. Can you identify key moments in the development of PPE within your Mission?
6. Can you describe the project you are working on at the moment? How and why did it start? What are your main objectives?
7. Can you describe the process of PPE used in your project?
8. What support do you receive from central administration? from your department?
9. In what ways do patients influence priorities, problem definition, solutions in your project?
10. What do you feel are the prospects and challenges for PPE in the next 5 years?

APPENDIX E: ARTICLE 3 CONSENT AND INTERVIEW GUIDE

INFORMATION AND CONSENT FORM

Research Study Title:	**Patient and public engagement and the transformation of health systems**
Researcher responsible for the study:	**Susan Usher, PhD(c), ENAP; Tel: 514-241-3663/ usher@healthinnovationforum.org**
Research supervisor:	**Professor Jean-Louis Denis, Canada Research Chair, Health System Design and Adaptation; Senior Scientist, Centre de Recherche du CHUM**

1. Introduction

We are inviting you to take part in this research study because of your participation in the NDG Community Working Group on Health over the year 2017. The present research seeks to understand how public engagement develops and contributes to the transformative capacity of health systems.
However, before you accept to take part in this study and sign this information and consent form, please take the time to read, understand and carefully examine the following information.

2. Overview and purpose of the study

This section provides a brief description of the research to put the particular component involving the case study of the Working Group on Health in context.

Public and patient engagement (PPE) is considered a key contributor to achieving transformation of health systems, however there is a great deal of ambiguity around what this entails and how it is brought about. The continuum of engagement (in health and democratic literatures) proceeds from involvement to consultation to something resembling co-production, which involves a pooling of resources and appreciations to solve a set of problems.

Our review of the literature on PPE in care, organizational practice and healthcare policy finds little evidence that involvement and consultation bring about significant change. Engagement at the co-production end of the continuum appears essential to fulfil expectations of PPE as a driver of healthcare transformation: outcomes improve and costs decrease as patients and families develop new capabilities for self-care; quality and accountability improve as they provide a 360 view of care processes and disrupt hierarchical barriers to improvement and collaboration; systems evolve as patients and public infuse the policy process with knowledge the state lacks about changing needs and possibilities.

We further identify a set of ingredients that are associated in the literature with the emergence of co-production. These include community resources to support patient activation, links between formal and community settings, new provider practices, fit-for-purpose patient experience input, dialogue forums and interprofessional teamwork, opportunities for participation in decision-making and access to decision-makers, the ability to obtain and exchange information, and a distinct knowledge base acquired from embeddedness in a constituency of one form or another.

Importantly, these ingredients reveal an interdependence between PPE in care, organizational practice and policy. Community resources support self-care as well as assemble knowledge on local needs to introduce into policy debate. Dialogue forums in quality improvement enable providers to contemplate new practices while also giving patient and public actors access to information about provider organizations. Links between providers and communities enable referrals for self-care support as well as information exchange to better understand and respond to local needs. Our hypothesis is that PPE strategies at each level (care, organizations, policy) contribute to developing ingredients of co-production that support movement towards co-production at other levels.

3. Study procedures (general)

Our empirical research therefore focuses on the organizational field and aims to achieve a better understanding of how strategies undertaken by various actors within the field emerge, cross-pollinate and contribute to movement towards the co-production of care, organizational practice and system design. Within a healthcare organization, we will undertake a case study to explore mechanisms and context elements that enable PPE strategies at central, department and unit level to move towards co-production, and explore the flow of ideas, influence and resources in the network of relationships between PPE actors. This data will contribute to a "relationship tree" based on social network analysis to trace the growth of the network arising from the group's work. It will further be analysed to understand how it contributes to the creation/assembly of ingredients involved in the co-production of care, organizational practice and policy.

4. Study procedures (specific to the Working Group on Health and your involvement)

We will follow the emergence of a PPE strategy in the community surrounding the organization to understand the actor-networks brought together, the nature of their engagement, and the contribution to change at field level. Data collection for this case study involves:

1) Attendance at meetings and consultation of meeting minutes and circulated documents
2) Observation of the Community Health Forum organized by the group
3) Interviews with each of the group members to find out:
    a. The role they play in the community
    b. Their constituency and issues that led to participation in the group
    c. Contacts, relationships, discussions, opportunities etc. arising through work on the group
    d. Factors that have (so far) enabled/impeded the group to form/function/work towards goals
    e. Effects (noted and anticipated) of the group's work
4) Access to communications between group members and system/community actors pursued in the context of the group's work.

5. Your responsibilities as a participant

a. Sign a consent form to enable the researcher to consult the materials mentioned in Section 4.
b. Provide an interview by telephone or in person lasting about 60 minutes on the 5 questions in 4.3.

6. Confidentiality

Audio recordings will be transcribed and audio files will be destroyed. The confidentiality of individuals and their particular organizations will be maintained in the final research publication. It is possible that direct quotes of what you said will be presented in publications and/or conferences. However, precautions will be taken to ensure that it will not be possible to identify you. The data collected will only be used for the research purposes described in this consent form.

7. Conflict of interest

The researcher has received no funding to conduct this study and has no conflict of interest to declare

8. Review of ethical aspects of the study

The research is covered by the researcher’s supervisor’s ethics certificate.

9. Purpose of study

Findings of this research will provide organizational, community and system leaders a framework to position localized PPE strategies within a broader movement toward co-production and transformation of health care. Social network analysis to identify hubs and relationships that play a central role in developing, orienting and connecting PPE efforts may point to system actors/groups that could be better supported and recognized to accelerate progress. More generally, this research will contribute to theory development around co-production and collaborative governance in highly institutional fields.

10. SIGNATURES

Signature of the participant

1) I have reviewed the information and consent form. Both the study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. I was given a copy of the information sheet and consent form for my personal records. After reflection, I consent to participate in this study in accordance with the conditions stated above.

2) I accept to arrange an interview with the researcher that will be audio recorded
   Yes ☐ No ☐

   If yes, please provide contact information: ________________________

3) I accept to share my communications related to the Working Group on Health with the researcher.

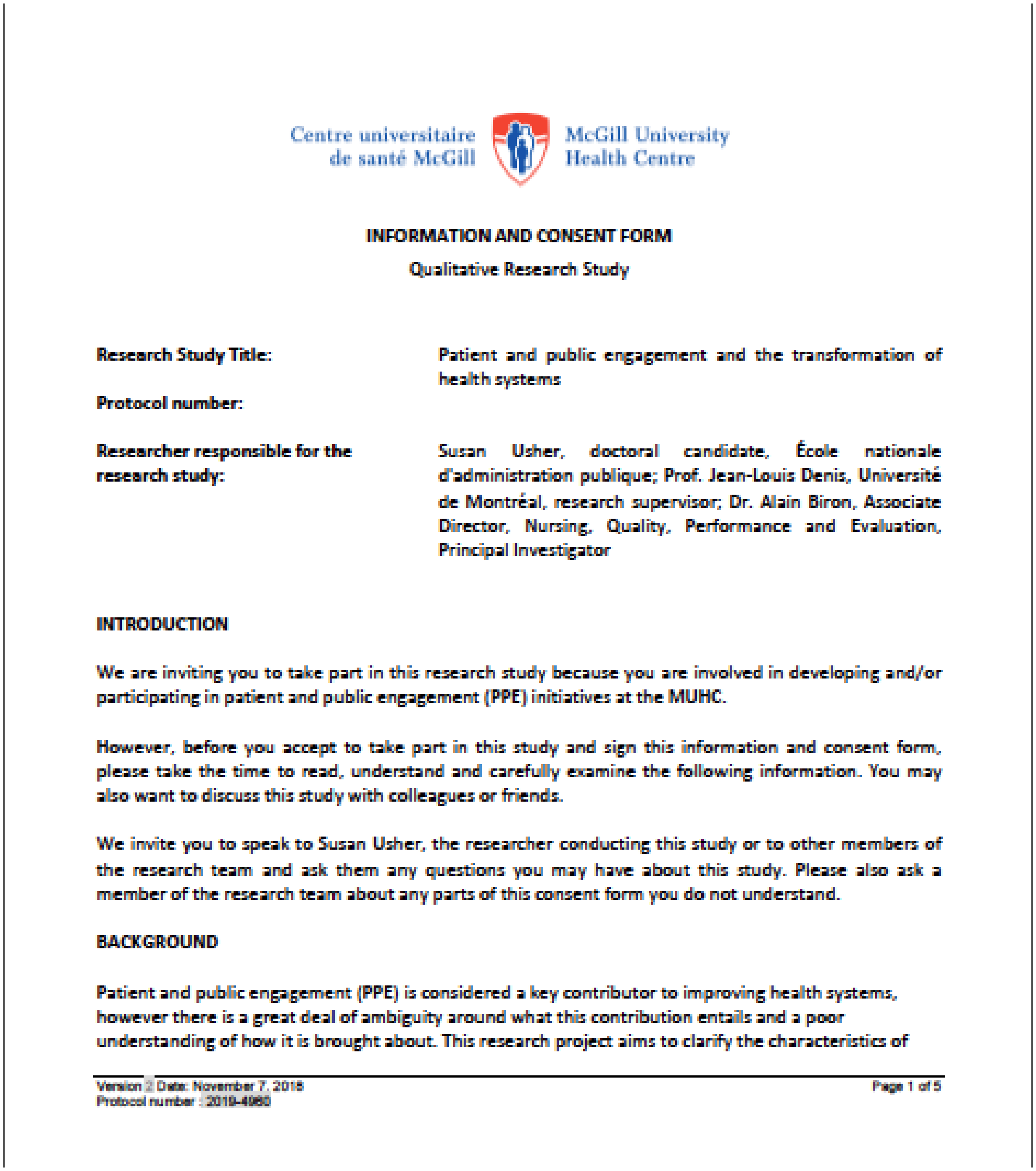
   Yes ☐ No ☐

4) I wish to receive a copy of the study results by email.

Yes ☐ No ☐ If yes, please provide contact information: ______________________

Name of participant Signature Date

APPENDIX F: ARTICLE 2 INFORMATION AND CONSENT



Centre universitaire de santé McGill
McGill University Health Centre

INFORMATION AND CONSENT FORM

Qualitative Research Study

Research Study Title:	Patient and public engagement and the transformation of health systems
Protocol number:	
Researcher responsible for the research study:	Susan Usher, doctoral candidate, École nationale d'administration publique; Prof. Jean-Louis Denis, Université de Montréal, research supervisor; Dr. Alain Biron, Associate Director, Nursing, Quality, Performance and Evaluation, Principal Investigator

INTRODUCTION

We are inviting you to take part in this research study because you are involved in developing and/or participating in patient and public engagement (PPE) initiatives at the MUHC.

However, before you accept to take part in this study and sign this information and consent form, please take the time to read, understand and carefully examine the following information. You may also want to discuss this study with colleagues or friends.

We invite you to speak to Susan Usher, the researcher conducting this study or to other members of the research team and ask them any questions you may have about this study. Please also ask a member of the research team about any parts of this consent form you do not understand.

BACKGROUND

Patient and public engagement (PPE) is considered a key contributor to improving health systems, however there is a great deal of ambiguity around what this contribution entails and a poor understanding of how it is brought about. This research project aims to clarify the characteristics of

PPE associated with meeting expectations that it can serve as a lever of transformation, and identify mechanisms that enable these characteristics to emerge in the health centre context.

PURPOSE OF THE RESEARCH STUDY

This research is being conducted as part of the researcher's doctoral studies in public administration at the École nationale d'administration publique in Montreal. The purpose of this study is to better understand how public and patient engagement strategies are developed and implemented within a health centre and how they might serve as levers of transformation in health systems. The research will explore the evolution of engagement strategies at various levels and from various perspectives within the MUHC.

For this research study, we will recruit approximately 30 clinicians, managers and patient/family advisors working at central, departmental and unit level on PPE initiatives. These participants will be interviewed to find out how they have seen PPE strategies develop and evolve at the MUHC over the past several years.

DESCRIPTION OF THE RESEARCH PROCEDURES

This research study will take at the MUHC.

1. Duration and number of visits

Your participation in this research study will consist of a 60-minute interview, conducted outside of working hours at a time of your convenience, in person or by telephone, in English or in French.

2. Overview of study participation

Your participation will involve a 60-minute interview during which I will ask about how you define PPE and about ideas and example that influence your vision of PPE; how you have seen PPE evolve over the past several years within the MUHC; what impact you consider PPE strategies to have had; and what, to your mind, facilitates or impedes PPE. I will also ask you to identify promising PPE projects and efforts underway in various departments and units across the MUHC.

PARTICIPANT'S RESPONSIBILITIES

- Participant interviews are meant to elicit your views on the evolution of PPE based on your knowledge and experience. No special preparation or materials are required.
- Participants may decline to answer any specific questions.

BENEFITS ASSOCIATED WITH THE RESEARCH STUDY

There is no direct benefit to you for participating in this research. However, as someone who has direct experience in designing, spreading and enacting engagement strategies, your participation will greatly help to identify promising approaches to PPE and strategies for supporting and enacting PPE that can improve future efforts by healthcare establishments. Study results hope to provide useful guidance to design PPE initiatives able to drive meaningful improvement in health centres and systems.

RISKS ASSOCIATED WITH THE RESEARCH STUDY

There are no risks associated with your participation in this study.
Should any problem arise, we will follow rules of the RI-MUHC ethics recommendations of the Research Ethics Board.

VOLUNTARY PARTICIPATION AND THE RIGHT TO WITHDRAW

Your participation in this study is voluntary. Therefore, you may refuse to participate. You may also withdraw from the *ongoing* project at any time, without giving any reason, by informing a member of the study team.

If you withdraw from the study, you may also request, at a time that is reasonable within the timeline of the research, that the data already collected about you be removed from the study. If you request that your data be removed, the information already collected about you that can be identified as yours will be destroyed.

CONFIDENTIALITY

During your participation in this study, the researcher will collect and record information that you provide. You have the right to refuse to be recorded. Only information necessary for the study will be collected.

All the information collected during the research project will remain confidential. The recording and your interview transcript will only be identified by a code number. The key to the code linking your name to your study participant number will be kept by the researcher.

All audio-recordings will be transcribed (your words will be written down) in a de-identified fashion (i.e. your name will not appear in the transcripts) by the researcher. The audio-recordings will be destroyed following the analysis stage of the research. It is possible that direct quotes of what you said will be presented in publications and/or conferences. There will be no way to link you with publicly reported statements. You may request that the researcher send you any quotes from your interview that will be included in publications to verify that your anonymity is not compromised and make any changes you wish.

The study data (de-identified transcripts) will be stored for 7 years by the researcher responsible for the study.

The data may be published or shared during scientific meetings. There will be no way to link you with any particular statement.

FUNDING OF THE RESEARCH PROJECT

The researcher and the institution have not received any funding to conduct this research project.

CONFLICT OF INTERESTS

The researcher, doctoral candidate Susan Usher, doctoral research supervisor, Professor Jean-Louis Denis, Université de Montréal, and Principal Investigator at the Research Institute of the RI-MUHC, Dr. Alain Biron, have no conflict of interest to declare.

COMPENSATION

You will not receive financial compensation for participating in this research study.

SHARING STUDY RESULTS

Results from this study will be presented at conferences and published in journals.

SHOULD YOU SUFFER ANY HARM

There is no foreseeable risk in participating in this research. By agreeing to participate in this research project, you are not waiving any of your legal rights nor discharging the researcher or the institution, of their civil and professional responsibilities.

CONTACT INFORMATION

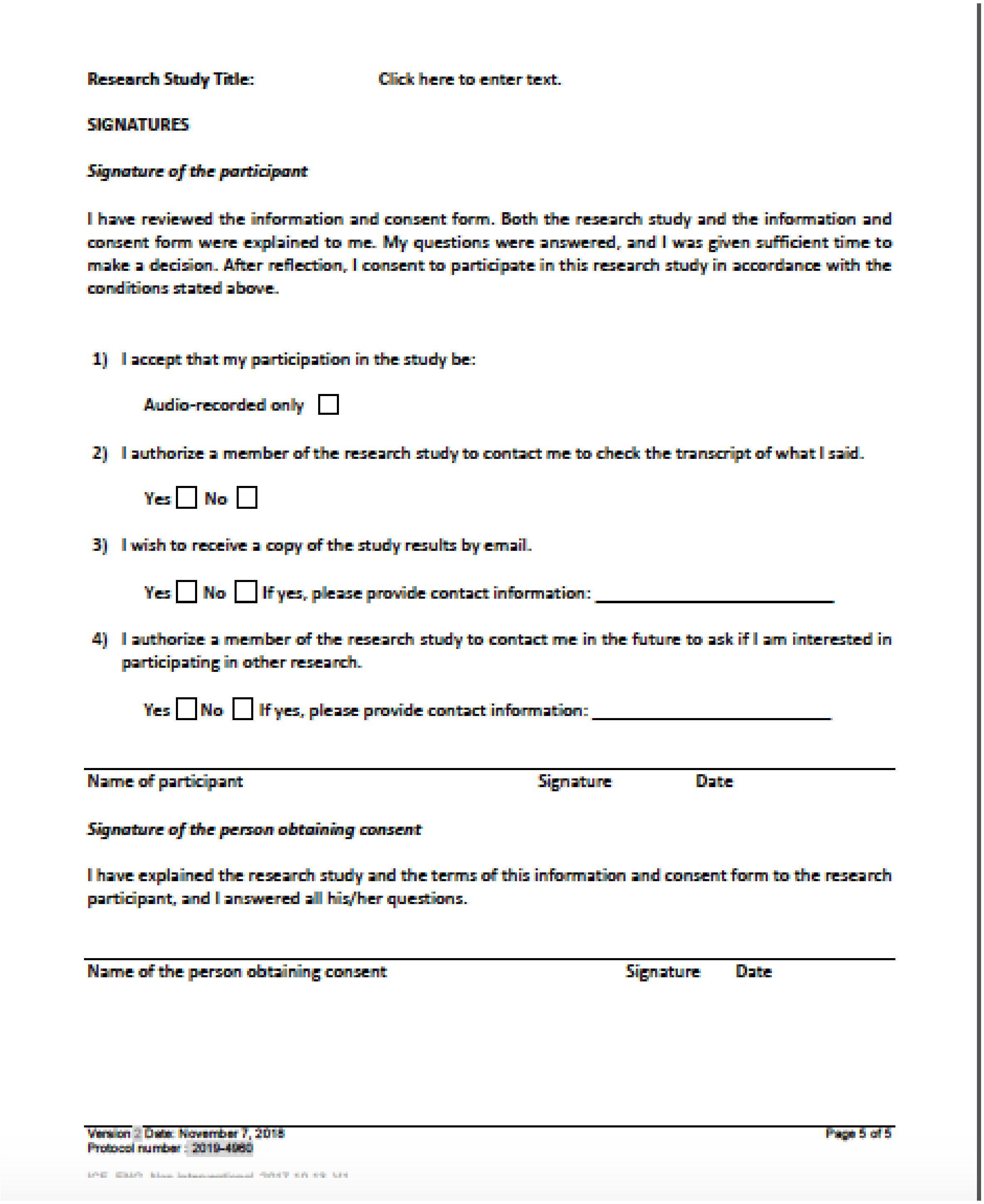
If you have questions or if you have a problem you think may be related to your participation in this research study, or if you would like to withdraw, you may communicate with the researcher or with someone on the research team at the following number: Susan Usher, Tel: 514-241-3663

For any question concerning your rights as a research participant taking part in this study, or if you have comments, or wish to file a complaint, you may communicate with:

MUHC Office of the Ombudsman at 514-934-1934 ext 48306

OVERVIEW OF ETHICAL ASPECTS OF THE RESEARCH

The McGill University Health Centre Research Ethics Board reviewed this research and is responsible for monitoring the study.



Research Study Title: Click here to enter text.

SIGNATURES

Signature of the participant

I have reviewed the information and consent form. Both the research study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. After reflection, I consent to participate in this research study in accordance with the conditions stated above.

1) I accept that my participation in the study be:

   Audio-recorded only ☐

2) I authorize a member of the research study to contact me to check the transcript of what I said.

   Yes ☐ No ☐

3) I wish to receive a copy of the study results by email.

   Yes ☐ No ☐ If yes, please provide contact information: __________________________

4) I authorize a member of the research study to contact me in the future to ask if I am interested in participating in other research.

   Yes ☐ No ☐ If yes, please provide contact information: __________________________

____

Name of participant Signature Date

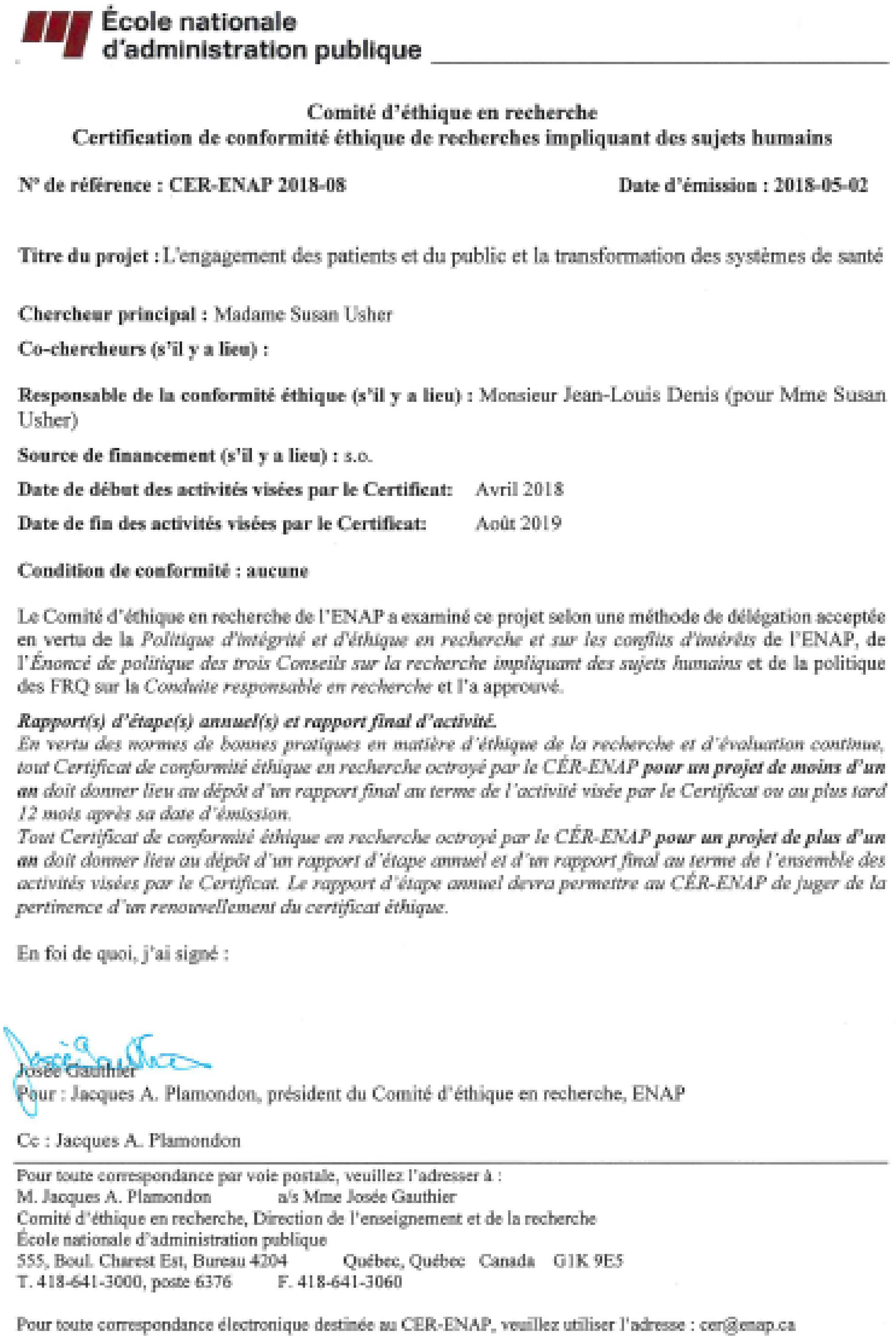
Signature of the person obtaining consent

I have explained the research study and the terms of this information and consent form to the research participant, and I answered all his/her questions.

____

Name of the person obtaining consent Signature Date

APPENDIX G: ETHICS CERTIFICATION CER-ENAP



École nationale
d'administration publique

Comité d'éthique en recherche
Certification de conformité éthique de recherches impliquant des sujets humains

N° de référence : CER-ENAP 2018-08 **Date d'émission : 2018-05-02**

Titre du projet : L'engagement des patients et du public et la transformation des systèmes de santé

Chercheur principal : Madame Susan Usher

Co-chercheurs (s'il y a lieu) :

Responsable de la conformité éthique (s'il y a lieu) : Monsieur Jean-Louis Denis (pour Mme Susan Usher)

Source de financement (s'il y a lieu) : s.o.

Date de début des activités visées par le Certificat: Avril 2018

Date de fin des activités visées par le Certificat: Août 2019

Condition de conformité : aucune

Le Comité d'éthique en recherche de l'ENAP a examiné ce projet selon une méthode de délégation acceptée en vertu de la *Politique d'intégrité et d'éthique en recherche et sur les conflits d'intérêts* de l'ENAP, de l'*Énoncé de politique des trois Conseils sur la recherche impliquant des sujets humains* et de la politique des FRQ sur la *Conduite responsable en recherche* et l'a approuvé.

Rapport(s) d'étape(s) annuel(s) et rapport final d'activité.
En vertu des normes de bonnes pratiques en matière d'éthique de la recherche et d'évaluation continue, tout Certificat de conformité éthique en recherche octroyé par le CÉR-ENAP ***pour un projet de moins d'un an*** *doit donner lieu au dépôt d'un rapport final au terme de l'activité visée par le Certificat ou au plus tard 12 mois après sa date d'émission.*
Tout Certificat de conformité éthique en recherche octroyé par le CÉR-ENAP ***pour un projet de plus d'un an*** *doit donner lieu au dépôt d'un rapport d'étape annuel et d'un rapport final au terme de l'ensemble des activités visées par le Certificat. Le rapport d'étape annuel devra permettre au CÉR-ENAP de juger de la pertinence d'un renouvellement du certificat éthique.*

En foi de quoi, j'ai signé :

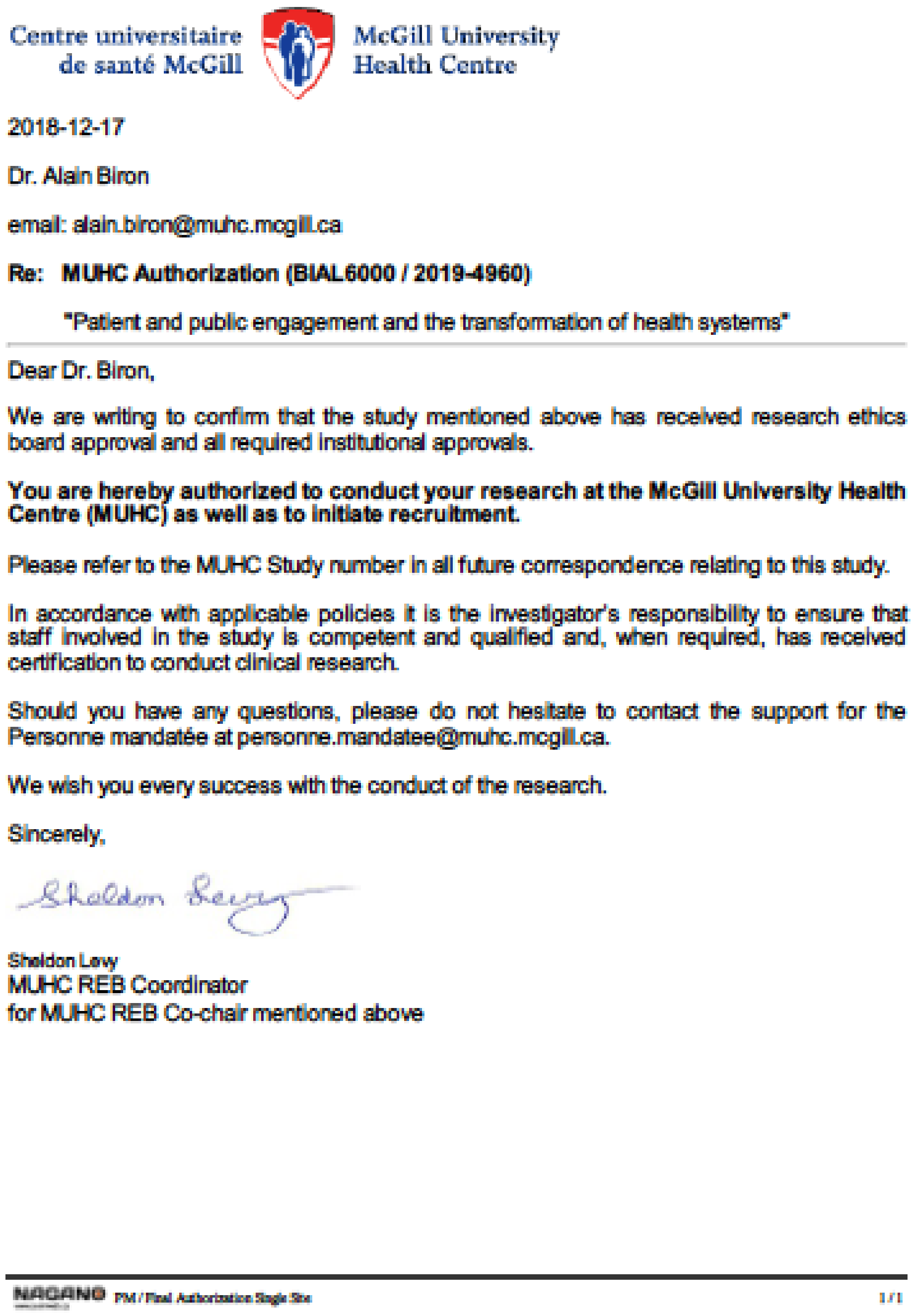
Josée Gauthier
Pour : Jacques A. Plamondon, président du Comité d'éthique en recherche, ENAP

Cc : Jacques A. Plamondon

Pour toute correspondance par voie postale, veuillez l'adresser à :
M. Jacques A. Plamondon a/s Mme Josée Gauthier
Comité d'éthique en recherche, Direction de l'enseignement et de la recherche
École nationale d'administration publique
555, Boul. Charest Est, Bureau 4204 Québec, Québec Canada G1K 9E5
T. 418-641-3000, poste 6376 F. 418-641-3060

Pour toute correspondance électronique destinée au CER-ENAP, veuillez utiliser l'adresse : cer@enap.ca

APPENDIX H: ARTICLE 2 ETHICS CERTIFICATION



Centre universitaire
de santé McGill

McGill University
Health Centre

2018-12-17

Dr. Alain Biron

email: alain.biron@muhc.mcgill.ca

Re: MUHC Authorization (BIAL6000 / 2019-4960)

"Patient and public engagement and the transformation of health systems"

Dear Dr. Biron,

We are writing to confirm that the study mentioned above has received research ethics board approval and all required institutional approvals.

You are hereby authorized to conduct your research at the McGill University Health Centre (MUHC) as well as to initiate recruitment.

Please refer to the MUHC Study number in all future correspondence relating to this study.

In accordance with applicable policies it is the investigator's responsibility to ensure that staff involved in the study is competent and qualified and, when required, has received certification to conduct clinical research.

Should you have any questions, please do not hesitate to contact the support for the Personne mandatée at personne.mandatee@muhc.mcgill.ca.

We wish you every success with the conduct of the research.

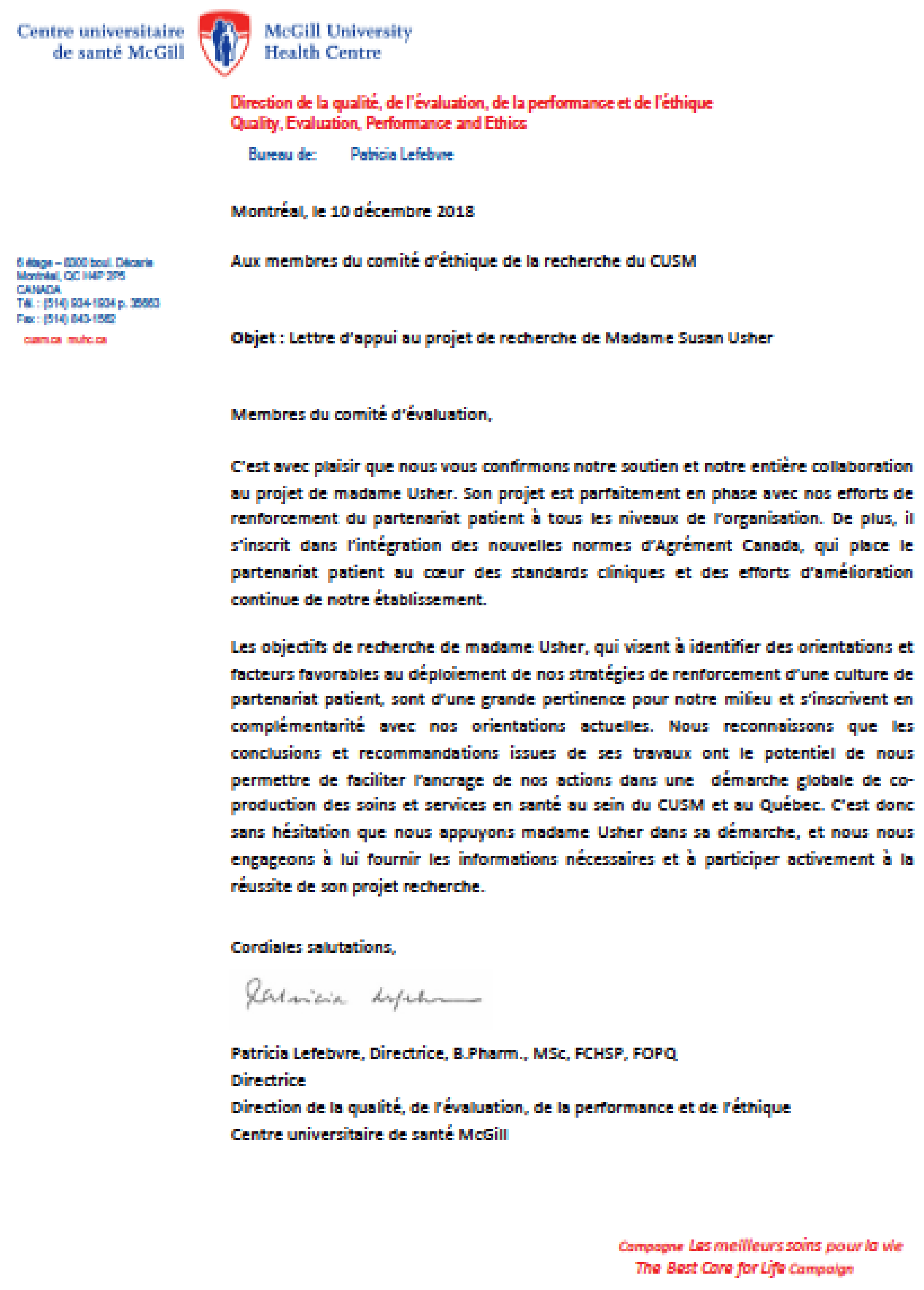
Sincerely,

Sheldon Levy

Sheldon Levy
MUHC REB Coordinator
for MUHC REB Co-chair mentioned above

NAGANO PM / Final Authorization Single Site 1 / 1

APPENDIX I: ARTICLE 2 LETTER OF SUPPORT



Centre universitaire
de santé McGill
McGill University
Health Centre

Direction de la qualité, de l'évaluation, de la performance et de l'éthique
Quality, Evaluation, Performance and Ethics

Bureau de: Patricia Lefebvre

6 étage – 5100 boul. Décarie
Montréal, QC H4P 2P5
CANADA
Tél. : (514) 934-1934 p. 35663
Fax : (514) 843-1582
cusm.ca muhc.ca

Montréal, le 10 décembre 2018

Aux membres du comité d'éthique de la recherche du CUSM

Objet : Lettre d'appui au projet de recherche de Madame Susan Usher

Membres du comité d'évaluation,

C'est avec plaisir que nous vous confirmons notre soutien et notre entière collaboration au projet de madame Usher. Son projet est parfaitement en phase avec nos efforts de renforcement du partenariat patient à tous les niveaux de l'organisation. De plus, il s'inscrit dans l'intégration des nouvelles normes d'Agrément Canada, qui place le partenariat patient au cœur des standards cliniques et des efforts d'amélioration continue de notre établissement.

Les objectifs de recherche de madame Usher, qui visent à identifier des orientations et facteurs favorables au déploiement de nos stratégies de renforcement d'une culture de partenariat patient, sont d'une grande pertinence pour notre milieu et s'inscrivent en complémentarité avec nos orientations actuelles. Nous reconnaissons que les conclusions et recommandations issues de ses travaux ont le potentiel de nous permettre de faciliter l'ancrage de nos actions dans une démarche globale de co-production des soins et services en santé au sein du CUSM et au Québec. C'est donc sans hésitation que nous appuyons madame Usher dans sa démarche, et nous nous engageons à lui fournir les informations nécessaires et à participer activement à la réussite de son projet recherche.

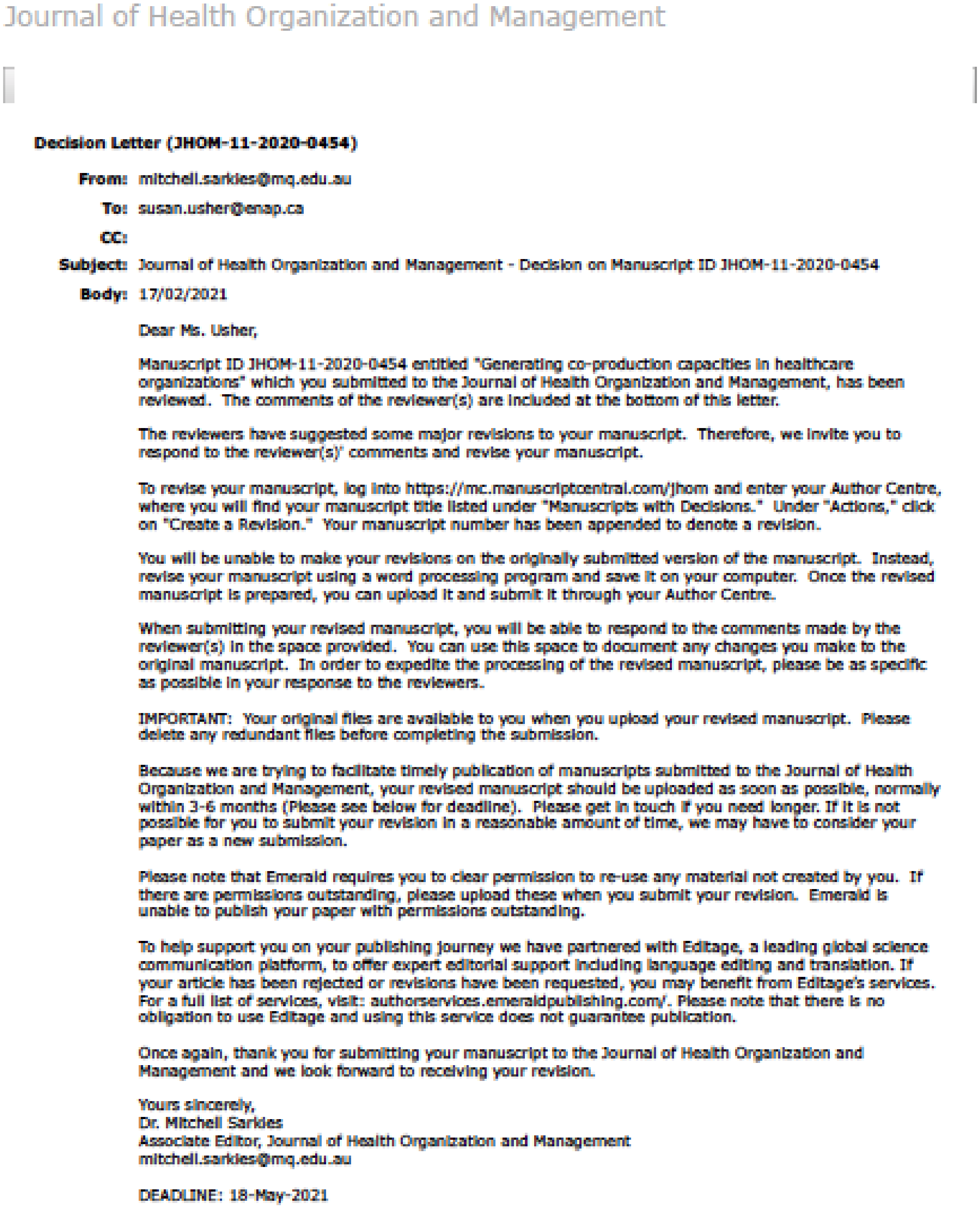
Cordiales salutations,

Patricia Lefebvre

Patricia Lefebvre, Directrice, B.Pharm., MSc, FCHSP, FOPQ
Directrice
Direction de la qualité, de l'évaluation, de la performance et de l'éthique
Centre universitaire de santé McGill

Campagne *Les meilleurs soins pour la vie*
The Best Care for Life Campaign

APPENDIX J: ARTICLE 2 JHOM DECISION 2021-02-17



Journal of Health Organization and Management

Decision Letter (JHOM-11-2020-0454)

From: mitchell.sarkies@mq.edu.au

To: susan.usher@enap.ca

CC:

Subject: Journal of Health Organization and Management - Decision on Manuscript ID JHOM-11-2020-0454

Body: 17/02/2021

Dear Ms. Usher,

Manuscript ID JHOM-11-2020-0454 entitled "Generating co-production capacities in healthcare organizations" which you submitted to the Journal of Health Organization and Management, has been reviewed. The comments of the reviewer(s) are included at the bottom of this letter.

The reviewers have suggested some major revisions to your manuscript. Therefore, we invite you to respond to the reviewer(s)' comments and revise your manuscript.

To revise your manuscript, log into https://mc.manuscriptcentral.com/jhom and enter your Author Centre, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

You will be unable to make your revisions on the originally submitted version of the manuscript. Instead, revise your manuscript using a word processing program and save it on your computer. Once the revised manuscript is prepared, you can upload it and submit it through your Author Centre.

When submitting your revised manuscript, you will be able to respond to the comments made by the reviewer(s) in the space provided. You can use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the reviewers.

IMPORTANT: Your original files are available to you when you upload your revised manuscript. Please delete any redundant files before completing the submission.

Because we are trying to facilitate timely publication of manuscripts submitted to the Journal of Health Organization and Management, your revised manuscript should be uploaded as soon as possible, normally within 3-6 months (Please see below for deadline). Please get in touch if you need longer. If it is not possible for you to submit your revision in a reasonable amount of time, we may have to consider your paper as a new submission.

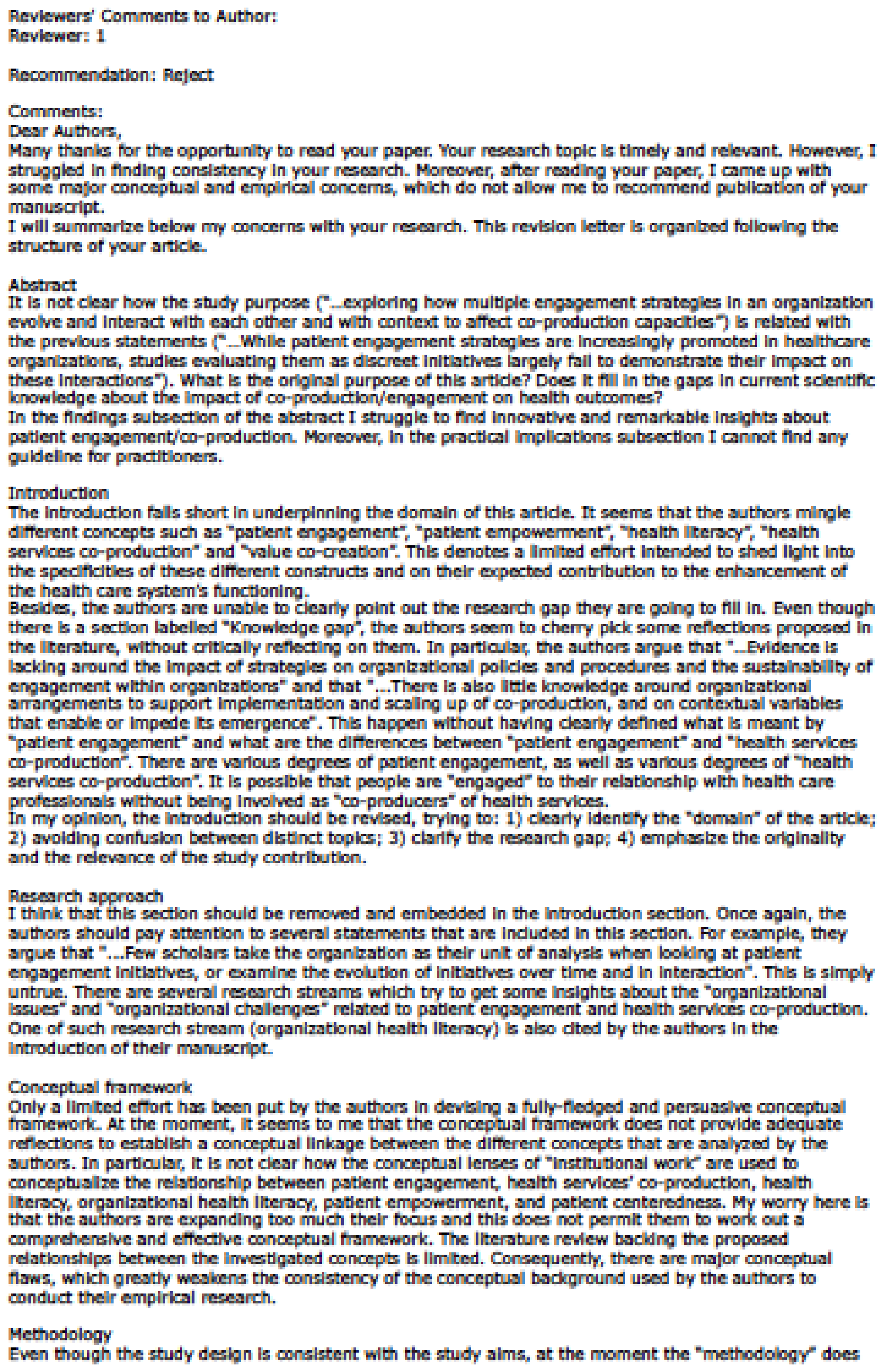
Please note that Emerald requires you to clear permission to re-use any material not created by you. If there are permissions outstanding, please upload these when you submit your revision. Emerald is unable to publish your paper with permissions outstanding.

To help support you on your publishing journey we have partnered with Editage, a leading global science communication platform, to offer expert editorial support including language editing and translation. If your article has been rejected or revisions have been requested, you may benefit from Editage's services. For a full list of services, visit: authorservices.emeraldpublishing.com/. Please note that there is no obligation to use Editage and using this service does not guarantee publication.

Once again, thank you for submitting your manuscript to the Journal of Health Organization and Management and we look forward to receiving your revision.

Yours sincerely,
Dr. Mitchell Sarkies
Associate Editor, Journal of Health Organization and Management
mitchell.sarkies@mq.edu.au

DEADLINE: 18-May-2021



Reviewers' Comments to Author:
Reviewer: 1

Recommendation: Reject

Comments:
Dear Authors,
Many thanks for the opportunity to read your paper. Your research topic is timely and relevant. However, I struggled in finding consistency in your research. Moreover, after reading your paper, I came up with some major conceptual and empirical concerns, which do not allow me to recommend publication of your manuscript.
I will summarize below my concerns with your research. This revision letter is organized following the structure of your article.

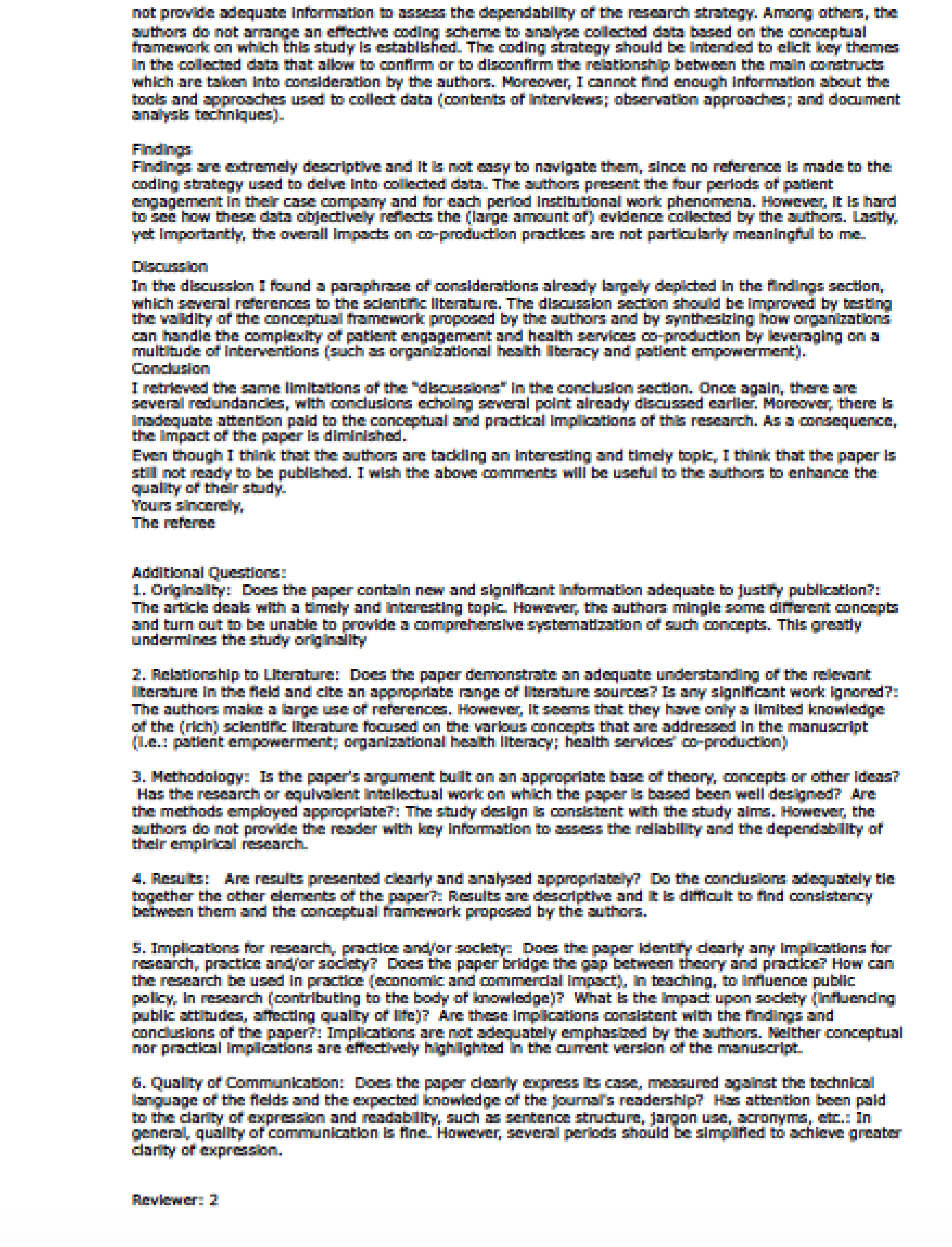
Abstract
It is not clear how the study purpose ("...exploring how multiple engagement strategies in an organization evolve and interact with each other and with context to affect co-production capacities") is related with the previous statements ("...While patient engagement strategies are increasingly promoted in healthcare organizations, studies evaluating them as discreet initiatives largely fail to demonstrate their impact on these interactions"). What is the original purpose of this article? Does it fill in the gaps in current scientific knowledge about the impact of co-production/engagement on health outcomes?
In the findings subsection of the abstract I struggle to find innovative and remarkable insights about patient engagement/co-production. Moreover, in the practical implications subsection I cannot find any guideline for practitioners.

Introduction
The introduction falls short in underpinning the domain of this article. It seems that the authors mingle different concepts such as "patient engagement", "patient empowerment", "health literacy", "health services co-production" and "value co-creation". This denotes a limited effort intended to shed light into the specificities of these different constructs and on their expected contribution to the enhancement of the health care system's functioning.
Besides, the authors are unable to clearly point out the research gap they are going to fill in. Even though there is a section labelled "Knowledge gap", the authors seem to cherry pick some reflections proposed in the literature, without critically reflecting on them. In particular, the authors argue that "...Evidence is lacking around the impact of strategies on organizational policies and procedures and the sustainability of engagement within organizations" and that "....There is also little knowledge around organizational arrangements to support implementation and scaling up of co-production, and on contextual variables that enable or impede its emergence". This happen without having clearly defined what is meant by "patient engagement" and what are the differences between "patient engagement" and "health services co-production". There are various degrees of patient engagement, as well as various degrees of "health services co-production". It is possible that people are "engaged" to their relationship with health care professionals without being involved as "co-producers" of health services.
In my opinion, the introduction should be revised, trying to: 1) clearly identify the "domain" of the article; 2) avoiding confusion between distinct topics; 3) clarify the research gap; 4) emphasize the originality and the relevance of the study contribution.

Research approach
I think that this section should be removed and embedded in the introduction section. Once again, the authors should pay attention to several statements that are included in this section. For example, they argue that "....Few scholars take the organization as their unit of analysis when looking at patient engagement initiatives, or examine the evolution of initiatives over time and in interaction". This is simply untrue. There are several research streams which try to get some insights about the "organizational issues" and "organizational challenges" related to patient engagement and health services co-production. One of such research stream (organizational health literacy) is also cited by the authors in the introduction of their manuscript.

Conceptual framework
Only a limited effort has been put by the authors in devising a fully-fledged and persuasive conceptual framework. At the moment, it seems to me that the conceptual framework does not provide adequate reflections to establish a conceptual linkage between the different concepts that are analyzed by the authors. In particular, it is not clear how the conceptual lenses of "institutional work" are used to conceptualize the relationship between patient engagement, health services' co-production, health literacy, organizational health literacy, patient empowerment, and patient centeredness. My worry here is that the authors are expanding too much their focus and this does not permit them to work out a comprehensive and effective conceptual framework. The literature review backing the proposed relationships between the investigated concepts is limited. Consequently, there are major conceptual flaws, which greatly weakens the consistency of the conceptual background used by the authors to conduct their empirical research.

Methodology
Even though the study design is consistent with the study aims, at the moment the "methodology" does



not provide adequate information to assess the dependability of the research strategy. Among others, the authors do not arrange an effective coding scheme to analyse collected data based on the conceptual framework on which this study is established. The coding strategy should be intended to elicit key themes in the collected data that allow to confirm or to disconfirm the relationship between the main constructs which are taken into consideration by the authors. Moreover, I cannot find enough information about the tools and approaches used to collect data (contents of interviews; observation approaches; and document analysis techniques).

Findings

Findings are extremely descriptive and it is not easy to navigate them, since no reference is made to the coding strategy used to delve into collected data. The authors present the four periods of patient engagement in their case company and for each period institutional work phenomena. However, it is hard to see how these data objectively reflects the (large amount of) evidence collected by the authors. Lastly, yet importantly, the overall impacts on co-production practices are not particularly meaningful to me.

Discussion

In the discussion I found a paraphrase of considerations already largely depicted in the findings section, which several references to the scientific literature. The discussion section should be improved by testing the validity of the conceptual framework proposed by the authors and by synthesizing how organizations can handle the complexity of patient engagement and health services co-production by leveraging on a multitude of interventions (such as organizational health literacy and patient empowerment).

Conclusion

I retrieved the same limitations of the "discussions" in the conclusion section. Once again, there are several redundancies, with conclusions echoing several point already discussed earlier. Moreover, there is inadequate attention paid to the conceptual and practical implications of this research. As a consequence, the impact of the paper is diminished.

Even though I think that the authors are tackling an interesting and timely topic, I think that the paper is still not ready to be published. I wish the above comments will be useful to the authors to enhance the quality of their study.

Yours sincerely,
The referee

Additional Questions:

1. Originality: Does the paper contain new and significant information adequate to justify publication?: The article deals with a timely and interesting topic. However, the authors mingle some different concepts and turn out to be unable to provide a comprehensive systematization of such concepts. This greatly undermines the study originality

2. Relationship to Literature: Does the paper demonstrate an adequate understanding of the relevant literature in the field and cite an appropriate range of literature sources? Is any significant work ignored?: The authors make a large use of references. However, it seems that they have only a limited knowledge of the (rich) scientific literature focused on the various concepts that are addressed in the manuscript (i.e.: patient empowerment; organizational health literacy; health services' co-production)

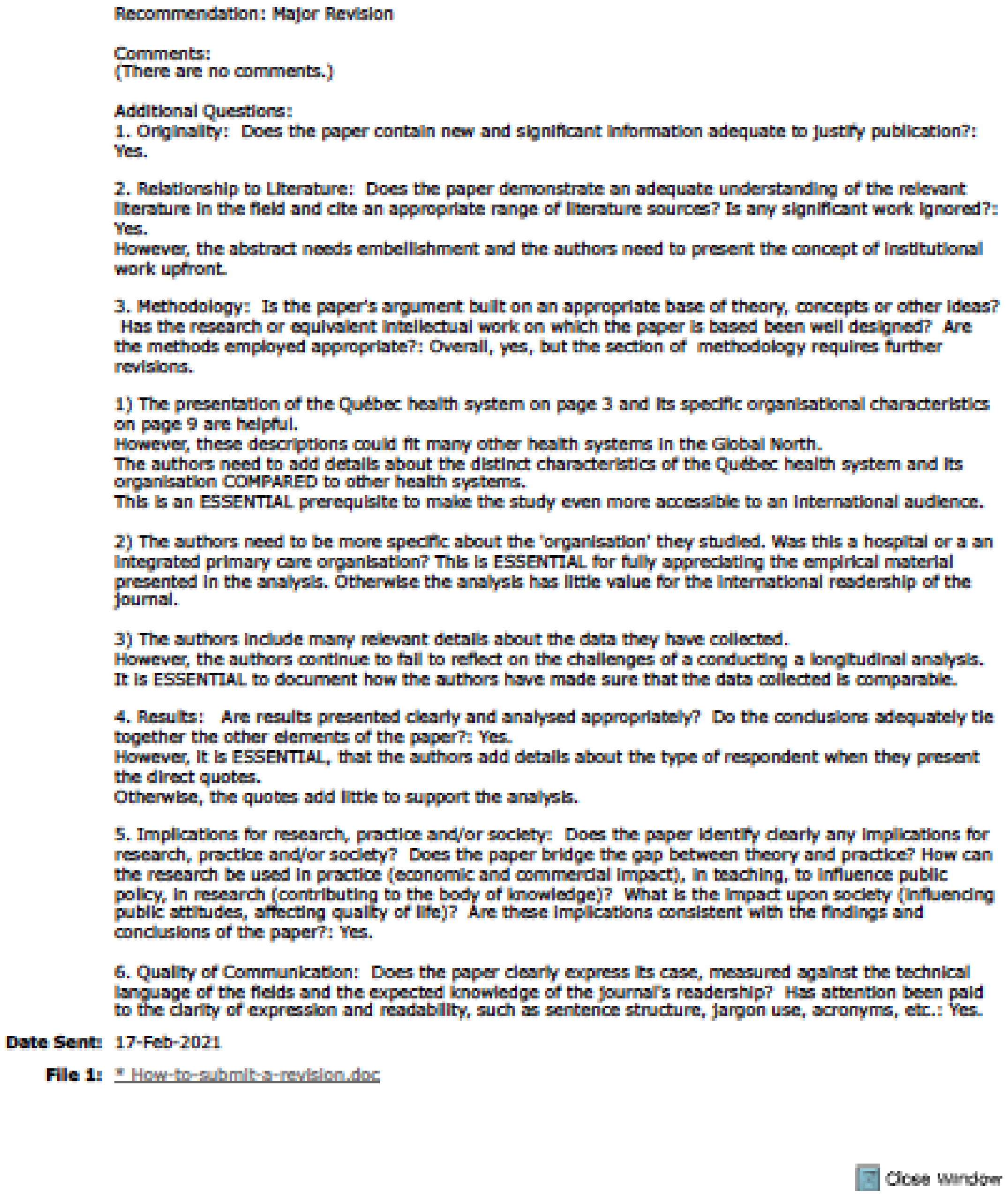
3. Methodology: Is the paper's argument built on an appropriate base of theory, concepts or other ideas? Has the research or equivalent intellectual work on which the paper is based been well designed? Are the methods employed appropriate?: The study design is consistent with the study aims. However, the authors do not provide the reader with key information to assess the reliability and the dependability of their empirical research.

4. Results: Are results presented clearly and analysed appropriately? Do the conclusions adequately tie together the other elements of the paper?: Results are descriptive and it is difficult to find consistency between them and the conceptual framework proposed by the authors.

5. Implications for research, practice and/or society: Does the paper identify clearly any implications for research, practice and/or society? Does the paper bridge the gap between theory and practice? How can the research be used in practice (economic and commercial impact), in teaching, to influence public policy, in research (contributing to the body of knowledge)? What is the impact upon society (influencing public attitudes, affecting quality of life)? Are these implications consistent with the findings and conclusions of the paper?: Implications are not adequately emphasized by the authors. Neither conceptual nor practical implications are effectively highlighted in the current version of the manuscript.

6. Quality of Communication: Does the paper clearly express its case, measured against the technical language of the fields and the expected knowledge of the journal's readership? Has attention been paid to the clarity of expression and readability, such as sentence structure, jargon use, acronyms, etc.: In general, quality of communication is fine. However, several periods should be simplified to achieve greater clarity of expression.

Reviewer: 2



Recommendation: Major Revision

Comments:
(There are no comments.)

Additional Questions:
1. Originality: Does the paper contain new and significant information adequate to justify publication?: Yes.

2. Relationship to Literature: Does the paper demonstrate an adequate understanding of the relevant literature in the field and cite an appropriate range of literature sources? Is any significant work ignored?: Yes.
However, the abstract needs embellishment and the authors need to present the concept of institutional work upfront.

3. Methodology: Is the paper's argument built on an appropriate base of theory, concepts or other ideas? Has the research or equivalent intellectual work on which the paper is based been well designed? Are the methods employed appropriate?: Overall, yes, but the section of methodology requires further revisions.

1) The presentation of the Québec health system on page 3 and its specific organisational characteristics on page 9 are helpful.
However, these descriptions could fit many other health systems in the Global North.
The authors need to add details about the distinct characteristics of the Québec health system and its organisation COMPARED to other health systems.
This is an ESSENTIAL prerequisite to make the study even more accessible to an international audience.

2) The authors need to be more specific about the 'organisation' they studied. Was this a hospital or a an integrated primary care organisation? This is ESSENTIAL for fully appreciating the empirical material presented in the analysis. Otherwise the analysis has little value for the international readership of the journal.

3) The authors include many relevant details about the data they have collected.
However, the authors continue to fail to reflect on the challenges of a conducting a longitudinal analysis.
It is ESSENTIAL to document how the authors have made sure that the data collected is comparable.

4. Results: Are results presented clearly and analysed appropriately? Do the conclusions adequately tie together the other elements of the paper?: Yes.
However, it is ESSENTIAL, that the authors add details about the type of respondent when they present the direct quotes.
Otherwise, the quotes add little to support the analysis.

5. Implications for research, practice and/or society: Does the paper identify clearly any implications for research, practice and/or society? Does the paper bridge the gap between theory and practice? How can the research be used in practice (economic and commercial impact), in teaching, to influence public policy, in research (contributing to the body of knowledge)? What is the impact upon society (influencing public attitudes, affecting quality of life)? Are these implications consistent with the findings and conclusions of the paper?: Yes.

6. Quality of Communication: Does the paper clearly express its case, measured against the technical language of the fields and the expected knowledge of the journal's readership? Has attention been paid to the clarity of expression and readability, such as sentence structure, jargon use, acronyms, etc.: Yes.

Date Sent: 17-Feb-2021

File 1: * How-to-submit-a-revision.doc

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