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The tensions between healthcare providers and patient and family advisory committees (PFACs): A comparative health system analysis between England and Ontario

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Abstract

There has been a proliferation of patient engagement (PE) in healthcare activities. However, the concept of "engagement" has existed for decades; the first Patient and Family Advisory Committees (PFACs) in North America were formed in the 1970s. These committees are an important mechanism for involving patients and family and have proliferated across the healthcare sector. However, it is unclear how or why PFACs became the predominant mechanism for PE. The objective of this comparative analysis is to review the historical context and legislative imperatives that have contributed to the proliferation of PFACs in Ontario, Canada and England, United Kingdom.

Keywords

Introduction

Description of Policy

In the last decade, health systems around the world have experienced the proliferation of patient engagement (PE) in multiple forms and healthcare activities.[1] Systems are increasingly integrating the principles of user involvement and consumer engagement into the design, delivery, and improvement of health services. Today, PE is widespread in activities such as health technology assessment, clinical guideline development, research, and quality improvement.[2-5]

Despite its recent proliferation, PE has existed in certain areas of health for decades. The first *Patient and Family Advisory Committees (PFACs)* in North America were formed in pediatric hospitals and mental health service facilities in the 1970s.[6] These PFACs involved children, youth, and parents in clinical care decisions, the design of health services, and quality improvement initiatives. Since the establishment of these pioneering PFACs, this mechanism has become widespread at multiple levels of the health system, especially in general hospitals and health service facilities. For example, a recent survey found that of 110 hospitals in the State of New York, 59% reported having a PFAC and 12% were developing one.[7] Members of these PFACs influence operations, leadership decisions, and strategies, provide training and orientation on PE to non-members, integrate the objectives and principles of PE in other hospital committees, and conduct ongoing evaluations of their work.[7] Similarly, in a survey of 102 hospitals in the province of Ontario, Canada, 66.7% and 57.8% reported at least one PFAC for clinical and corporate activities, respectively.[8]

PFACs are a PE mechanism that allow for greater and more meaningful participation of patients, family, and care representatives in healthcare activities within institutions and organizations. In some jurisdictions, such as Ontario, PFACs are supported by legislative imperatives that narrow the gap between healthcare planning and service users. PFACs do not operate only within the hospital sector; they also exist in regional health authorities, communities, agencies, and subnational and national governments. There are three types of PFACs: general (focused on organizational issues), population-focused (serve specific communities), and condition-focused (serve specific medical conditions).[9]

Goals of Policy

PFACs serve a variety of purposes with regards to healthcare planning. In some jurisdictions, PFACs seek to accommodate a growing desire to bring healthcare decision-making closer to service users and improve health system sustainability by increasing the responsiveness of health services.[9] These goals seem to have been prompted by growing citizen interest in greater transparency and accountability in healthcare; a desire that reflects the advent of consumer-driven industries during the late 20th and early 21st centuries.[10] These goals were also bolstered by regionalization of healthcare. In Ontario, for example, the *Canada Health Act (1984)* set the precedent for provinces to plan and operate their own healthcare plan to better reflect the unique needs and priorities of its population.[11] This Act enabled Ontario and other

provinces to decentralize healthcare decision-making by creating regional health authorities. The structure of these authorities rendered opportunities for greater and more meaningful participation of service users in healthcare activities.

The *Triple Aim* of healthcare advocated for improving patient health outcomes while maintaining healthcare spending and enhancing the patient experience.[12] A desire by healthcare professionals and decision-makers to improve patient experience also contributed to the creation of PFACs. Institutional pressures to improve patients' experiences, patient-centered care, and PE strengthened the position of PFACs in healthcare. In these circumstances, PFACs may have been perceived by healthcare professionals and hospital decision-makers as a mechanism to achieve patient experience objectives by transforming the design and delivery of health services to be more inclusive and meaningful to patients, family, and care representatives. The spread of PFACs across the hospital sector may also reflect shifting policy imperatives that respond to calls by the public, including patients and family, for health policy-makers and professionals to exemplify higher accountability in healthcare decision-making.[13-15] These pressures have been reinforced by a strong need for transparency, dialogue, and partnership in healthcare activities, which provide strong policy and ethical imperatives for the meaningful involvement of patients. PFACs may also serve as a policy lever to advocate for greater collaboration with patients in designing health services to be more relevant, appropriate, and useful to them, which creates health services that are of higher quality, more sustainable, acceptable to end-users, and cost-efficient for health systems.[16-17]

An assumption in these efforts has been that by engaging patients, family, and care representatives in discussions on emergent health care issues, the responsiveness of health services will improve, and accordingly, health services will become more sustainable. This understanding stems from the belief that diverse stakeholder input improves the sustainability and quality of services that also improves their legitimacy, uptake, and sustainment.[18] However, it appears that governments and health service organizations may have used PFACs tokenistically in some instances to achieve symbolic goals of perceived transparency and accountability without the necessary legwork to involve patients and family in ways that truly transform the design and delivery of health services. Moreover, some healthcare professionals may employ PFACs to support existing ways of practice and legitimize existing interventions and innovations. As this paper will demonstrate, this observation is perhaps reflected in the tension between localism (i.e., responsiveness and alignment of health services to users) as represented by patients, family, citizens, and communities, and standardization (i.e.,

consistency in quality and processes of health services) by decision-makers and healthcare professionals.

Materials and Methods

This analysis will examine the historical contexts and legislative imperatives that have contributed to the proliferation of PFACs. This objective will serve as the foundation for analyzing the tensions that may exist between patients and healthcare professionals, most notably, physician groups, and whether these tensions are represented in broader policy statements, documents, and communications. This comparative policy analysis will occur between the province of Ontario, Canada, and England, United Kingdom (UK). These two jurisdictions were chosen because they possess several structural similarities and relevant dissimilarities that may be meaningful to determine the factors that have contributed to the proliferation of PFACs. Canada is a federalism with a highly decentralized health system within each of the provinces. The federal government holds an oversight role that provides cash transfers to provinces predicated on the five principles of the Canada Health Act (public administration, comprehensiveness, universality, accessibility, and portability).[19] Ontario's system is administered at the provincial level through the Ministry of Health and Long-Term Care (MOHLTC), which is managed by the Minster of Health. The system was previously divided into 14 regional health authorities referred to *Local Health Integration Networks (LHINs)*.[20] LHINs were developed to ensure that health services are integrated at the local level and responsive to the needs and preferences of patients. With the exception of physician services, LHINs are responsible for the administration of hospitals, long-term care homes, home and community care, community support service agencies, mental health and addiction agencies, and community health centres.[20] More recently, Ontario went through a regional restructuring that created Ontario Health Teams to replace the LHIN structure. For the purposes of this paper, I will focus on the previous LHIN structure.

Health care in England is more centralized than Ontario because it is stewarded at the federal level by The Department of Health and administered by the *National Health Service (NHS)*. The NHS sets priorities and provides an overall direction to improve healthcare outcomes of citizens.[21] Before the 20th century, the UK was a centralized unitary state. However, due to shifts in political structures and institutions, UK has become a *quasi-federation*; containing elements of decentralization but important elements of centralization have been maintained. For example, the internal market reforms in the 1990s allowed hospitals and physicians to become private providers of health services.[22] As such, physicians' autonomy and decision-making capacity increased dramatically. Further, the organization and processes of

the NHS differs between subnational governments in the UK.[23] For the context of this paper, I will focus on NHS England where relevant data is available but will substitute my discussion with broader trends in the NHS across subnational governments when data is unavailable.

Clinical commissioning groups (CCGs) are clinical bodies under the NHS responsible for healthcare planning and delivery of health services for designated communities.[25] Whereas NHS is responsible for primary care services, CCGs are groups of clinicians responsible for secondary level care such as planned hospital care, rehabilitative care, urgent and emergency care, community health services, and mental health services.[25] For most of the 20th century, the NHS has been divided into regional health authorities, which have decreased in number overtime and were eliminated under the *Health and Social Care Act (2012)*.[26] Today, the NHS is managed by multiple *trusts*, legal entities independent from the government and accountable to service users that manage different areas of the system such as NHS hospitals.[25]

This analysis was informed by policy documents, statements, and briefs from comparator jurisdictions relevant to PE and PFACs, which was found through a grey literature search. Relevant parliamentary and legislative materials (bills, acts, debates, and briefings) specific to Ontario were searched through the Legislative Assembly of Ontario, e-Laws, and CanLII databases accessed from the University of Toronto Library. European materials were found through the same process but through the European-specific function, and specifically England. This latter search was augmented with another search on relevant legislative databases in the UK. A previous comprehensive literature search on PE was utilized to retrieve studies that focus on the politics and/or policy of PFACs in comparator jurisdictions. This analysis does not only focus on hospital PFACs, but also the administration of committee-like PE mechanisms in healthcare. Moreover, there is muddling between patient engagement and patient and public involvement (PPI) as the latter appears to be the predominant term used in the UK. This analysis will focus exclusively on PE because public involvement is a distinct phenomenon with different historical and scholarly literature grounded in citizen empowerment that warrants a separate investigation. Tritter (2009) described PPI as the "ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organization and delivery of health services".[26] This definition differentiates between PE and public involvement and will guide the distinction between these two concepts wherever possible. However, it is anticipated that PPI may not be delineated in English policy documents. In such cases, this analysis will describe them together while noting that they are different mechanisms for participation. Moreover, "physicians" in

this paper refer to professional self-regulated entities and their members.

Two frameworks will be used to analyze and answer the research questions. First, interests from the *3I framework* (ideas, interests, and institutions) will be used to examine the relationships between patients and other health system actors, most notably physicians.[27] This analysis will be augmented by a second framework, *Kingdon's Organized Anarchy Model* of public policy making.[28] This model describes three streams (problem, political, and policy), which when congruent, present a window for making policy decisions. This model will be used to demonstrate the factors that stimulated the need to develop PFAC-like mechanisms in comparator jurisdictions, or alternatively, remove these mechanisms. By tracing different periods of time where PFACs were powerful in both jurisdictions, this model will demonstrate how the three streams can elucidate the symbolic, relational, and legislative enablers or barriers of PE. Two related concepts will be used to augment this analysis: *path dependency* (i.e., a situation where previously ratified policies become self-reinforcing in future policy formulations)[29] and *policy layering* (i.e., adding new elements of a policy onto a stabilized institutional framework).[30] This discussion will revolve around the *decision-making capacity* of patients and physicians. Decision-making capacity may represent the veto points and power available to different groups in a complex system. This analysis adopts a technocratic perspective of power in healthcare – there is a limited pool of decision-making capacity available to healthcare interests, most of which will be given to healthcare providers by legislation. This characteristic introduces elements of tension between PFACs and physician groups that permeate in organizational planning and policy activities. As such, since this analysis focuses on PFACs, the most relevant levels of PE are meso- and macro-levels. PE at the micro-level (i.e., direct clinical care) is beyond the scope of this analysis.

Results

Factors the Influenced How and Why the PE Came onto Agendas
<u>England</u>
Historical archives describe provisions for PPI in England before the inception of NHS. A widely adopted mechanism during this time was *friendly societies* introduced in 1911 to oversee and manage primary care services.[31] Friendly societies were comprised of patients and citizens who would contract primary care physicians to practice within their community.[32] At the same time, hospitals were governed by *hospital management committees*, which composed of local citizens including patients and religious activists. These committees were responsible for appointing physicians, controlling patient admissions, managing income and expenditure of hospitals, and overseeing medical care.[31] Although these committees were initially

dominated by wealthy philanthropists, after 1914, service user representation exceeded other groups because their charitable donations to hospitals became the highest.

Since these pioneering PPI mechanisms in healthcare, there has been ebb and flow with regards to patients' decision-making capacity. Progressive reforms have contributed to these fluctuations, which for the most part of England's history, have been in favor of greater physician autonomy and decision-making capacity. A historical analysis found that the British Medical Association (BMA) and its member primary care physicians disliked their relationship with friendly societies that stemmed from an employee-employer relationship characterized by employees' belief that they were elite professionals serving non-elite citizens.[31] There were regular conflicts between friendly societies and the BMA, which largely focused on remuneration and privileging the expertise of physicians over others. Some believe that these conflicts were bolstered by higher perceived social status presumed by physicians.[31]

These disputes gradually led to structural reforms in favor of physician groups, such as the rebranding of friendly societies into *approved societies* that had control over insurance schemes but could no longer oversee the delivery of primary health care.[31] As a part of this structural reform, the predominant funding model also changed from an annual, renewable contract controlled and monitored by friendly societies to a per capita payment controlled by insurance committees that comprised of elite professionals. As such, physician accountability shifted from citizens to industrial and professional elites of society.

The introduction of NHS England and a universal health coverage scheme was a critical juncture that exemplified ongoing tensions between patients and physicians. The advent of universal health coverage appeared to have temporarily reduced the tensions between physicians and patients that had cumulated by the disputes between physician groups and friendly societies. At this time, it was assumed that patient interests were best represented by the medical profession.[33] On the one hand, the previous unitary state had strong legislative provisions in place for PPI through friendly societies, although this decreased over time in favor of physician interests. The NHS Acts of 1946 and 1947, however, removed all PPI mechanisms in healthcare.[31] Due to conflicts between physicians and friendly societies, this negotiation may have been made to bring physician interests to the table of universal health coverage by removing PPI, so opposition to their autonomy and decision-making capacity could be minimized.[31]

Interestingly, there is no record of public backlash after the removal of PPI from legislation.[32] A historical analysis

conjectured that due to high public satisfaction with regards to universal health coverage, mechanisms for PPI were underprioritized by citizens or they viewed that their interests could be advanced by the medical profession.[33] The introduction of NHS was a moment of temporary reconciliation. Institutionalizing health services that were free at the point of delivery reframed the way in which accountability and transparency were achieved in healthcare.[26] Eventually, the need for PPI mechanisms started to rise with the inception of consumer movements in the 1960s and 1970s.[10] Patient interest groups proliferated during this time, but these groups did not hold the same decision-making power as before the NHS.[34] Nonetheless, the reintroduction of patient interest groups ushered a new era of PPI. Disease-specific groups continued to proliferate in the 1980s.[35] However, the NHS did not have the legislation or infrastructure to accommodate this emerging movement within the existing healthcare milieu, which created tensions between PPI and other groups.

In 1974, patient associations attempted to introduce a *Patients Rights Bill* that would allow patients to refuse treatment. Patient associations were particularly concerned with using patients for medical education without their consent.[35] However, the Bill was not successful due to the language and strong interests that opposed patient movements at the time.[35] In the same year, the government introduced *Community Health Councils (CHCs)* as an attempt to accommodate service user interests in healthcare.[36-38] This dramatic reorganization of health services was prompted by the emerging concern that patients were being used as subjects in clinical trials without their consent.[39] The development of CHCs were championed by consumer interests and represented another critical juncture where for the first time since the NHS a mechanism was introduced that appeared to have strong legislative authority over the design and delivery of health services. CHCs oversaw services, assessed local needs, supported patients, advised on complaints, and participated in health planning.[39-40] CHCs also conducted evaluations of existing services to reveal areas for improvement. For example, the Central Birmingham CHC recommended hiring interpreters at health service organizations to support staff to communicate with Asian patients.[41] However, there was lack of detail on how CHCs would integrate into the existing healthcare system and how they would be evaluated.[31] These characteristics would later contribute to their delicate position within NHS policy.

In 1982, Margaret Thatcher considered disbanding CHCs, but this decision was not carried out due to fear of defensive outcry by the public.[31] Public outcry was an important concern during this time because of consumer movements that were growing in multiple industries. However, certain policy decisions were made that

undermined the decision-making authority of CHCs. Multiple reports indicated that CHCs were regularly dismissed or not included in planning meetings with regional health authorities and trusts.[31] Moreover, before the next election, the Labour government advocated for the broader role of CHCs in healthcare. However, in *NHS Plan 2000*, the Labour government eliminated CHCs, perhaps to appease physician interests.[42] Despite this setback, there appears to have been a widening of discussion after this time surrounding PPI and its role in the NHS.[43-49]

CHCs were replaced by *Public and Patient Involvement Forums* in 2003 that worked with NHS trusts to establish a system for PPI. However, an internal evaluation reported that these forums did not adequately reflect the voices they were meant to represent.[50-51] Furthermore, due to budgetary cutbacks and opposition from physicians, these were eventually replaced by *Local Involvement Networks (LINks)* under the *Local Government and Public Involvement in Health Act (2007)*.[52] LINks had more decision-making authority than the forums, but less than CHCs.[26,31] Their mandate was to use patient feedback and experiences to *recommend* changes to local health services, particularly commissioning local services and priority-setting, which partially resembled friendly societies in the pre-NHS era.[26] Around the same time, the newly elected Labour government in 2009 introduced the *NHS Constitution for England*, which included 25 patient rights.[39] However, in 2010, a white paper released by the government called *Liberating the NHS* proposed the abolition of LINks and introduction of *Healthwatch England* under the *Health and Social Care Act (2012)*.[24] The explicit objective of this policy was to strengthen PPI within healthcare. The mandate for Healthwatch was similar to CHCs and LINks but the organization reported directly to the Department of Health and could only *recommend* changes without any legislative power for enforcement.[53-54] Healthwatch also did not have power over incentive mechanisms, remuneration schemes, and physician delivery practices whereas previous PPI mechanisms had some advisory power over these aspects.[31] Moreover, Healthwatch has experienced gradual reductions in funding, with approximately 25% of their funding reported to have disappeared in 2014.[55]

In comparison to previous PPI mechanisms, it appears that Healthwatch England was another attempt to reduce decision-making capacity of patients and citizens in favor of physician interests. There is an ebb and flow between the decision-making capacity of both parties. Even though physicians will continue to have greater leverage over structural reforms and policy directions, patient interest groups are stronger than before and increasing in strength. New reforms will promote the mobilization of patient groups; for example, some legislators are seeking to replace Healthwatch England with the old CHC model.[31]

Ontario

Compared to England, the history of PE in Ontario is less profound, which could reflect the lack of historical records on the topic that may have allowed a nuanced analysis. Some factors that bolstered PPI in England also occurred in Ontario, but their effects on healthcare were different due structural differences in the health system. Unlike England, there is no data available on whether there were provisions for PE in healthcare before the inception of the *Hospital Insurance Act (1947)* and the *Medical Care Insurance Act (1962)* in Ontario that provided universal health coverage for hospital and physician services, respectively.

In an evaluation of PFACs in Ontario, *The Change Foundation (TCF)* – an independent health policy think-tank – found that some specialized hospitals (i.e., mental health and pediatric health institutions) were among the first to pioneer PFACs.[9] However, there is limited data on which facilities formed these PFACs, when they formed them, and whether they exist today. Early PFACs were most often established because of adverse patient events and comprised of mostly patients and community members.[9] These pioneering PFACs, advanced greater and more meaningful involvement of service users, family, and care representatives in healthcare. General hospitals were much slower to adopt PFACs, which had not occurred until early 21st century.[8]

PFACs in hospitals and communities were supported by legislative imperatives of the *Canada Health Act (1984)*. These imperatives may have been an outcome of the burgeoning consumer-driven movements during the 1970s and 1980s. In Ontario, these consumer movements may have contributed to one of the principles of the Canada Health Act – known as *Public Administration* – that confers regulatory authority to provinces to design and deliver health services.[11] This principle provided provinces the legislative authority to plan, deliver, and operate a healthcare plan with funding from federal cash transfers.[11] This structural characteristic is also known as *decentralization*; subnational governments have greater autonomy and decision-making power over social services and public policy.[56] One of the aims of decentralization is to narrow the gap between healthcare decision-making and service users and citizens.[57] Therefore, the principle of public administration under the Canada Health Act (1984) as well as the burgeoning consumer-driven movements at the same time may have created a policy window for provinces to adopt mechanisms through which the needs and preferences of services users can be integrated into healthcare planning and delivery.[26] In 2002, the Romanow Commission recommended developing mechanisms for citizen involvement in health policy processes to strengthen accountability and narrow the gap between taxpayers and decision-makers.[58] This recommendation represented the first formal and explicit record of

involving non-professionals in healthcare activities as a solution to emerging problems.

Some provinces have taken steps to further decentralize healthcare by forming regional health authorities. For example, the *Local Health System Integration Act (2006)* divided Ontario into 14 LHINs, allowing regions to determine allocation imperatives and cooperation between neighboring healthcare institutions. One of the explicit goals of this act was to achieve a more connected and integrated health system.[20] As a result of further decentralization, this Act may have encouraged stronger legislative imperatives to pursue PFAC mechanisms that bring decision-making closer to service users.

The *Excellence Care for All Act (2010)* was another legislative agenda that reinforced the need to place patient needs at the centre of health system planning.[59] Due to bipartisan support, this Act contributed to greater participation of patients in healthcare activities. Ontario hospitals were required to obtain patient experience data, develop a declaration of patient and public values that would guide health service design, and create mechanisms for a patient relation process to solicit and improve patients' experiences. Moreover, hospitals were required to involve patients and family in the development of annual quality improvement plans, as well as provide a description of their PE activities.[60] This Act provided an imperative to create PFACs for hospitals who had not already created one. Moreover, for hospitals with existing PFACs, this imperative opened a window for increased funding to expand its operations. Even more important, this Act may have set the precedent for the *Patients First Act (2016)* with a provision for each LHIN to establish a PFAC that would discuss regional allocation imperatives, cooperation, and health system improvement.[61] With both Acts, there were strong legislative imperatives in place to establish and sustain PFACs at multiple levels of health care decision-making.

In spite of these legislative imperatives, there were emerging tensions between localism championed by service users and subnational standardization of health services advanced by other stakeholders, specifically physician groups. In particular, the *Patients First Act (2016)* was opposed by the Ontario Medical Association (OMA). The OMA did not support the formation of committees to monitor the quality of health services, especially physician services[62-63] because they believed it would undermine their role in delivering patient-centered care. It may be the case, however, that the OMA used "patient-centered care" as an idea to maintain their decision-making capacity in healthcare.

Evaluation
There has been little research on the evaluation of PFACs in communities or health service organizations. The research that has been conducted was commissioned by

non-government agencies or think tanks. In Ontario, TCF conducted a qualitative investigation of hospital PFACs in 2014.[9] They conducted in-depth interviews with 64 staff, patients, and family members across 29 hospitals with PFACs. As a part of this study, TCF also conducted a literature review of Ontario hospital PFACs to determine whether it was an effective mechanism for PE. They found that a minority of hospital PFACs conducted evaluations. The PFACs that performed evaluation kept track of participant meeting attendance, provided annual updates of achievements, conducted annual and monthly self-evaluations, created annual performance review documents, facilitated impact surveys of member participation, and designed and implemented a preliminary evaluation framework.[9] However, TCF underscored these findings by stating that there is a general lack of information on the effectiveness of PFACs within hospitals and at other levels of government.

There has also been no research evaluating the impact of PFACs in government agencies. At the time of writing this paper, there was an internal evaluation being conducted for LHIN PFACs in Ontario. However, Ontario is undergoing a regional restructuring that is replacing the previous LHIN with Ontario Health Teams. There are several PE evaluation tools available in the public domain. In a recent systematic review, 27 unique PE evaluation tools were found.[64] Evaluation of PE occurs in many hospitals, including University Health Network in Toronto, Ontario.

Strengths, Weaknesses, Opportunities and Threats (SWOT)
Based on the analysis presented in this paper, a SWOT exercise was conducted to determine the strengths, weaknesses, opportunities, and threats that PFACs and related PE mechanisms face in 21st century healthcare. Table 1 presented the findings of this exercise. These findings are discussed in more detail in the following sections.

Comparative Analysis and Discussion

This paper reveals multiple lessons for PE in jurisdictions around the world. The implicit message has been that there is a constant, tacit tension between patient and other interests, most notably physicians with regards to decision-making capacity in healthcare. For some part of England's history, this tension exemplified the conflict between localism championed by patients and citizens and standardization bolstered by physicians and other interests. The analysis of Ontario and England shows that this tension is tacit within the negotiations made by

Table 1. Results from SWOT Analysis

Strengths	Weaknesses
• Improves responsiveness and alignment of health services with patient/family needs and preferences • Narrows the gap between healthcare decision-making and service users • Improves perceived transparency and accountability of health services • Increases legislative, political, ethical, social, and organizational imperatives for patient engagement	• Early legislation formed a stable institutional framework for future changes to patient engagement through path dependency and policy layering • Big bang elimination of PE mechanisms may result in a gap in infrastructure with regards to localism in healthcare • Strong interests in healthcare may perceive localism as a threat to their professional interests
Opportunities	**Threats**
• Expanding the legislative imperatives of patient engagement to reflect a balance between localism and standardization • Incremental introduction to patient engagement mechanisms is possible due to strong external and internal pressures • Formation of alliances between patient groups and other interests in healthcare (e.g., administrations, physicians, decision-makers) can create strong precedents for patient engagement in healthcare practice	• Patient engagement used to legitimize existing ways of practice and interventions at institutions • Patient groups overpower physicians and other healthcare professionals in some areas of health service organizations • Continued risk of big bang elimination of patient engagement mechanisms in favor of physician interests for achieving broader policy goals • Arguments against localism that weakens the strength of patient engagement mechanisms, and may contribute to big bang elimination in health system structure

governments for new health legislation. In England, for example, provider interests did not support PPI because of a belief that it opposed national standards, optimal resource allocation imperatives, the value of expert medical judgement, and autonomous decision-making. This conflict likely prompted ongoing dispute between friendly societies and physician groups in the pre-NHS era, which cumulated overtime and may have contributed to the gradual reduction of localism in favor of physician interests.

The persistence of these tensions ultimately led to ebb and flow between greater decision-making capacity between localism and standardization. Pre-NHS, England had strong mechanisms for PPI in the form of friendly societies in communities and voluntary committees in hospitals. With the introduction of the NHS, however, PPI had minimal legislative support. It was not until the consumer-driven movements of the 1970s that reinvigorated the need for localism.[10] As a result of these movements, there has been a back and forth with regards to the power devolved to PPI mechanisms, which led to the formation of CHCs, then the forums, then LINks, and now Healthwatch England. Similarly, in Ontario, mechanisms for PE have been minimal, but since the consumer-driven movements, they have gradually increased overtime through several legislative imperatives.

However, it remains to be seen whether the negotiations that occurred in England to reduce PPI mechanisms in favor of physician interests has occurred in the past or will occur in Ontario in the future. Nonetheless, practitioners and policy-makers in this area can appreciate the back and forth that exists between localism and standardization and some of the policy instruments and ideas they can employ to achieve their goals. This comparative analysis explains the possible factors that can contribute to tensions between interests and the ebb and flow of decision-making capacity in healthcare.

Centralized Authority
Boothe (2012) hypothesized that the distribution of decision-making authority in a nation determines the policy-making approaches.[65] A more centralized nation, such as England, may be more likely to pursue big bang transformations, whereas a more decentralization state, such as Ontario, may take a more incremental approach because of the compendium of interests involved in policy formulation and implementation.[65] Since there are more actors within decentralized nations, there are more opportunities to oppose big bang transformations that may support broader goals of increased PE. Moreover, incremental change allows multiple interests to bargain and negotiate. An incremental approach to health policy in

such cases may be the only suitable way to pursuing change.

The analysis of Ontario may indicate that new legislation that supports PE and policy layering that bolsters PE can broaden the decision-making capacity of PFACs. These approaches can build a strong foundation for increasing the extent to which service users can participate in healthcare decision-making at different levels. However, big bang changes that broaden PE goals may have been attempted but not successful in both comparator jurisdictions due to a belief by physician interests that patient decision-making capacity may conflict with their own desire for autonomy. On the other hand, big bang transformations that seek to eliminate PE from healthcare may also be difficult to achieve. The one exception to this was demonstrated by the English case where the removal of PPI mechanisms may have been compensated by the introduction of universal health coverage. This policy decision was also made before the consumer-driven movements when patient groups were weaker interests, which made it an opportune time to use PPI as a bargaining chip to bring strong physician interests to the table of broader healthcare equity goals. However, with the proliferation of consumer-driven industries, localism re-emerged as a strong force that reignited the discussions surrounding the role of patients in healthcare. This example shows that physician interests in some cases, may not support localism and patient interests if they have framed the conflict as impinging on their decision-making authority.

On the flip side, it is also possible that patient interests and localism can be used by physicians as a political lever to advance their own decision-making goals, which was demonstrated by OMA's responses to "patient-centered" legislation. Mold (2011) hypothesized that the lack of clarity in the "patient rights" movements allowed healthcare interests to coopt the language and narrative of PE to achieve their own goals.[36] Therefore, it may be conjectured that in a more centralized state, healthcare professionals have less power that may prompt stronger opposition to any changes from the government that may affect their decision-making capacity. In a more decentralized state, on the other hand, professionals may hold more power and as such, may instead coopt PE to achieve their professional goals in negotiations with governments. Similarly, it may also be the case that PE has been used to align the political stream with the problem and policy streams to render windows of opportunities for transforming the extent to which patients engage in healthcare activities.

From these two cases, it appears that building the infrastructure for PE tends to be incremental (i.e., *incremental introduction*) and removing provisions for it can be achieved through big bang transformations (i.e., *big bang*

elimination) if there are mechanisms to compensate for losses. This parallel between promoting and removing PE mechanisms is a natural conclusion of the compendium of interests that characterize healthcare and often tend to maintain the status quo. This parallel between incremental introduction and big bang elimination is made possible due to the unequal distribution of power in healthcare in favor of provider interests. The power imbalance between patients and providers is longstanding in the history of medicine, and although it is less explicit today, this imbalance continues to permeate in broader legislative and policy activities as demonstrated through this analysis.

There is a nuance to this contrast that is not captured in Boothe's hypothesis of centralized authority and policy change. Overtime, strong consumer-driven movements in England led to the reintroduction of PPI mechanisms in legislation. However, this reintroduction was incremental in nature, possibly due to the diversity of and resistance by strong interests. It is possible, therefore, that an incremental approach to policy change may still be used in centralized states when there are *diverse* interests that oppose policy change. The important factor to policy change is how these interests are structured within the nation, and the veto points they hold to support or oppose proposed policy transformations.

Path Dependency and Policy Layering

An implication of the contrast between incremental introduction and big bang elimination relates to the tendency for path dependency in policy processes. Boothe (2012) asserted that if initial approaches and conditions to health policy development are limiting in a nation, then they become limiting overtime.[65] This observation was seen in the introduction of NHS that removed legislative imperatives for PPI. This removal set the precedent for gradual reduction in decision-making authority of patients in favor of physician interests. Using path dependency as a framework for future policy formulations may have been supported by legislators' need to negotiate with strong physician interests to achieve broader healthcare goals. In such instances, PE may serve as a policy instrument for legislators to sacrifice if physicians perceived it as an opposition to their professional interests. This finding is similar to Tritter (2009) who argued that the degree of PE has been a strongly influenced by law and policy developed in the 19th century – something that characterizes the effects of path dependency on PE legislation. Path dependency that resulted from removing strong legislative imperatives for PPI, as in the case of NHS England, made it difficult to introduce effective mechanisms for PPI thereafter (i.e., CHCs, forums, LINks, Healthwatch England). For example, Sustainability and Transformation Partnerships (STP) were introduced in 2016 to address the emerging problems of English healthcare.[66] However, research has found that they lack adequate accountability to citizens and may represent yet another trend in the ebb

and flow of PPI in England that undermines the decision-making capacity of patients.[67]

The case of Ontario is characterized by ongoing policy layering with gradual introduction of legislation that cumulatively broadened the role of patients in healthcare. It may be hypothesized that policy layering may ultimately lead to a point where patients become more powerful than physician interests in healthcare. This outcome is similar to the function of friendly societies that existed before the NHS who were comprised of patients and citizens that determined the planning and delivery of health services within their communities. A PE mechanism like friendly societies has the potential for multiple, beneficial outcomes, for example professional accountability. However, PE must address important conceptual arguments, for example, that it opposes national standardization of health services, allocation imperatives, and medical judgement. Mechanisms for PE can be developed that balance the benefits of both localism and national standardization in a way that is negotiated between various healthcare interests. Another approach can be to reframe the meaning of localism and standardization whereby health outcomes, quality, and cost-effectiveness also result from localism, but require different infrastructure and legislative imperatives.

Strengths and Limitations of this Analysis

The comparison between England and Ontario presented interesting contrasts with regards to the factors that have contributed to the formation of PFACs and related mechanisms. On the one hand, England has had a profound history of PPI that allows tensions between different interests to be mapped and compared and elucidate how legislative factors have contributed to the ebb and flow of PPI. On the other hand, PE in Ontario is nascent, and it remains to be seen what tensions emerge as it is increasingly integrated in the milieu of healthcare. Lessons from England provide essential information about the strengths, weaknesses, opportunities, and threats that Ontario may face as the desire for their involvement in healthcare activities increases. This information is vital for decision-makers and academics who contribute to a patient-centered legislative agenda.

Despite the strengths, this analysis has two notable limitations. It may be the case that Ontario has had remanence of PFACs and related mechanisms throughout its history, possibly before the inception of Medicare. However, there are no historical records with this information. If such mechanisms have existed in Ontario, it would augment the current analysis, and possibly offer additional, insightful parallels with English PPI movements.

This paper also assumed that legislators are "unbiased intermediaries" between patients and physicians. However, legislators and decision-makers have strong interests within healthcare as well. However, since the focus of this paper was to elucidate tensions between healthcare providers and patients, it was assumed for simplicity that other interests were neutral, stable, and constant. This position comes from the technocratic perspective that added a "critical" lens to this analysis. This perspective allowed problematizing the relationships and interactions between strong healthcare interests.

Conclusion/Policy Recommendations

This comparative analysis reviewed the historical contexts and legislative imperatives that have contributed to the proliferation of PFACs in England, United Kingdom and Ontario, Canada. This analysis found a persistent tension between patients and PFACs, and other healthcare interests. The persistence of these tensions emphasizes the ebb and flow of decision-making capacity between localism and standardization with regards to health service planning and decision-making. This analysis also found that building the infrastructure for PE has been incremental in both jurisdictions and current trends show that it will continue along this path, especially since jurisdictions adopt path dependency and policy layering as principles for policies that support PE. However, removing the infrastructure can be drastic if it is compensated by publicly driven priorities such as universal health coverage. This relationship between PE and broader health system objectives are exemplified in the relationships that exist between healthcare interests. It may be conjectured that a more centralized state, whereby healthcare professionals have lower autonomy compared to a more decentralized state, may prompt stronger opposition to any changes from the government that may affect their decision-making capacity, in this case, making provisions to improve the autonomy of patient groups. On the other hand, since professionals in a more decentralized state have more veto points may instead coopt the PE to achieve their professional goals in negotiations with governments and other interests. Practitioners and policy-makers can appreciate the back and forth that may exist between localism and standardization. This comparative analysis explains the possible factors that can contribute to the tensions between interests and the ebb and flow of decision-making capacity in healthcare. This analysis also offers important insight to patients, decision-makers, and healthcare professionals on the factors that may support or oppose PE and the policy instruments and ideas that they can use to achieve their objectives.

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