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CITIZENS Collaborating for Health

Are patient-centred care and integration achievable goals?

A discussion paper on

Unleashing Healthcare Innovation:

Excellent Healthcare for Canada

Report of the Advisory Panel on Healthcare Innovation

Sponsored by:

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Introduction

The Institute for Healthcare Improvement (IHI) is a leading think tank based in the United States whose mission is to 'Improve health and health care worldwide'. IHI's Triple Aim framework challenges healthcare systems to redesign their delivery of care to simultaneously achieve: 1) improved health outcomes for the population; 2) reduced health spending per capita; and 3) improved patient experience. (1) The Advisory Panel on Healthcare Innovation (APHI) highlighted some fundamental realities facing the Canadian healthcare system, and by extension each of the thirteen provincial / territorial healthcare systems in the report that they released in July, 2015. (2) At best Canada ranks middle of the pack or worse for most of the measureable health outcomes reported by OECD countries (The Organisation for Economic Co-operation and Development). (3) At the same time, Canada is one of the top healthcare spending countries (in particular physician services and drug prices). (4) The Health Quality Council of Alberta has been tracking Albertan's experience with their healthcare system for over a decade – the grades are average at best and remain largely unchanged (5) despite ever increasing spending by the provincial government. The inescapable conclusion is that Canada's healthcare systems underperform relative to the investments that have been made.

> As one example of poor integration physicians and hospitals are funded through separate budgets in Canadian healthcare systems. This makes little sense for the majority of specialists, given the substantial influence they have over hospital expenditures. Indeed, under the current fee for- service payment system, most of these superbly-trained professionals have no specific financial rewards for quality of care or responsible stewardship of scarce healthcare resources (APHI Report) (2, p4)

"Every system is perfectly designed to get the results that it gets"*. The report from the APHI panel identifies flaws with the way that Canadian healthcare is designed and structured. Patients experience these poorly integrated systems as a lack of continuity of their care. These experiences at best are exceedingly frustrating and at worst result in serious morbidity and in some cases, mortality. In this discussion paper we highlight three areas of focus for the redesign of healthcare in Canada: 1) Governance and Accountability for Community-based Care (starting with Primary Care); 2) Patient / Citizen Engagement & Empowerment (or Co-production); and 3) Continuity of Care. If these issues are addressed by each province and the federal government our healthcare systems will be in a much stronger position to achieve the IHI's Triple Aim, Canada quite likely would become an OECD high performer on return for healthcare dollar invested, and the answer posed to us for this discussion paper would be a simple 'yes'. The real question is "what will it take to make meaningful progress on these three issues and whose job is it to lead this?" Clearly the federal government has a role to play and the APHI recommendations speak to that. However, real change has to come from the provinces, which hold the balance of power in the design and delivery of healthcare to Canadians. It is the responsibility of provincial / territorial health ministers and their ministries to develop the vision and take concrete steps to make progress. But these governments need willing dance partners. As the APHI report highlights - historically Medicare created two streams of funding – hospital services and medical services. This

* Quote is often attributed to Paul Batalden, MD Dartmouth College, Hanover, NH. (6)

established physicians' independence from other insured healthcare services delivered in hospitals, and a weak accountability model for delivering population-level results. It also set up a focus on hospital, aka, acute-care, specialist-based services. The split between primary care and secondary / tertiary level care has only increased in the past two decades as most family physicians have given up their hospital privileges. Primary care has never enjoyed the focus or the investment that it deserves as the pillar of a strong Canadian healthcare system. If real reform is going to take place in provincial healthcare systems it means that because of the independence granted physicians through the historical development of Medicare, physicians must come to the planning table prepared to imagine a new reality as equal, willing partners. In a recent letter to Alberta's physicians, outgoing Alberta Medical Association President Richard Johnston said:

"The confluence of increasing demand for services, the development of ever more expensive treatments and the decreasing ability of government to find the way to pay are now reaching a crescendo.

We cannot begin to manage these problems unless we rapidly enter into new styles of practice and management."

"I do think that we are at a crossroads today. We cannot continue to avoid uncomfortable changes that will eventually provide us with accurate and accessible information in real time. We need that to assess our care and the way we provide that care. We must find a way to create a care model for complex patients that is satisfactory to them and affordable for society. This means we must be open to different funding models, care patterns, and new and different roles for doctors – and I mean all doctors, specialists and primary care doctors." (7)

It is just as critical that independent patient / citizen groups and other healthcare professionals are at the same table – everyone is in this together; we can and we must do better. Some of the keys to improving Canada's current situation lie in the APHI recommendations. However, because the APHI was appointed by the Federal Minister of Health, its recommendations are necessarily directed at the federal government.† But innovative change in healthcare delivery must come primarily from provincial governments because of their responsibility. Therefore, we have developed recommendations for the Government of Alberta to address additional issues discussed in this paper, because we are most familiar with our own environment. But we believe these recommendations would be relevant in most other jurisdictions.

† We have not specifically reacted to the recommendations regarding First Nations and Inuit Health, as we do not have enough knowledge to do so.

Governance and Accountability for Community-based Care

> "This continued weak integration of budgets and accountability may well be 'the fatal flaw' in Canadian healthcare. (APHI Report) (2, p62)

High performing healthcare systems, like successful businesses and well functioning public institutions have strong governance. According to the Institute on Governance, an independent, Canada-based, not-for-profit public interest institution there are three dimensions of good governance: authority, decision-making and accountability - governance determines 'who has power, who makes decisions, how other players make their voice heard and how account is rendered.' (8)

The Institute quotes the United Nations Development Program's five principles of good governance: 1) legitimacy and participation; 2) direction (strategic vision); 3) performance; 4) accountability; and 5) fairness.

In addition to following these principles a high performing healthcare system would align incentives with strategic priorities (including prioritizing opportunities for improvement), be able to measure outcomes (and the processes that influence them) and have clear accountabilities for performance.

The Panel spent time understanding key success elements of several high performing healthcare systems – one of them was Kaiser Permanente, the largest managed care organization in the United States. A key success factor for Kaiser's has been their integration, through partnerships, between physicians and administrators (APHI report) (2, p 59) and accountability across all components of the healthcare system.

In Alberta, like in other provinces, Boards were originally established for hospitals and then for health authorities when they were created. These Boards have been responsible for most of the acute care and specialized healthcare services provided in the province. However, Alberta Health Services (AHS) has not had a Board for over two years. Because the majority of physicians in Alberta (like in other provinces) are paid on a fee for service (FFS) basis from a budget separate from that established for AHS, there is limited system-level accountability for services provided by physicians. Physicians are accountable to the College of Physicians and Surgeons of Alberta for the care they provide to their individual patients, although some would argue that when a patient requires care from more than one provider, longitudinal accountability for care quickly becomes blurred.

Setting and delivering on strategic priorities is a daunting challenge for any healthcare organization when it has incomplete authority over the physicians who provide care. It is even more challenging if not impossible for Alberta's healthcare system to innovate and make changes for improvement in community-based care which is outside the jurisdiction of AHS and for which there is only a weak governance structure. Over the past decade Alberta has created Primary Care Networks (PCNs) which have a degree of accountability for ensuring that people within its geographic boundaries have access to a primary care physician. But because PCNs have no control over the FFS budget, they do not have authority to change patterns or models of practice. A major portion of provincial healthcare expenditures fund care for patients with chronic illness. The prevalence of the diseases creating chronic illness is so

high that any reasonable model of care has to have primary care at its centre, utilizing specialized care as required. The failure by provincial governments to adhere to the basic principles for good community-based care governance ensures at best average, but more likely, less than average performance. Although the APHI recommended "adapting, scaling up and spreading partial integration models, e.g. primary care commissioning, portfolio funding for disease management, and assorted bundled payment strategies' (APHI report) (2, p 67) it did not call for improving the governance models in Canadian healthcare – we believe this is a critical first step.

> High-performing healthcare systems generate large volumes of data and turn those data into useful information for payers, providers, patients, and industry partners. Canada still lags in this regard. (APHI Report) (2, p 18)
>
> Kaiser's rich databanks are used to support quality improvement efforts, evaluate innovations in the delivery of care, find new efficiency opportunities, and facilitate academic health services research. (APHI Report) (2, p 60)

Even if a different funding and governance model was available there is currently no systematic approach that has been designed to capture information from community-based electronic medical records (EMRs) that would allow for accountability at the level of a frontline provider (or team), a clinic, a PCN, a Zone, or the province.‡ Generally you can't improve what you don't measure; in our current system lots of data is collected but little systematic measurement for improvement takes place. Despite the fact that Alberta has led the country in adopting EMRs there has been little integration of them within or between PCNs – there are hundreds of EMRs with no single source of truth for population level data. Alberta's electronic health record Netcare is a comprehensive source of laboratory and diagnostic imaging data but by itself cannot be used to proactively manage performance or improvement.

The first step for systematically creating a performance measurement system is linking each patient to a responsible physician, and by extension to a clinic, and to a PCN. 'Attaching' patients to a primary care practice is called patient paneling. This has proven to be a huge challenge in Alberta for multiple reasons. We suspect it is no different in any other province. High performing healthcare systems figured out this elementary step years ago. Once paneling is accomplished a standard data set from each healthcare encounter can be defined and captured electronically. Using this data 'secondarily' to understand population-level results for the healthcare delivery system provides a platform for improvement. Once reliable data repositories are in place that make possible the reporting of key results across the system (but also down to the individual primary care team level) it becomes possible for informed decisions to be made about priorities. Providing incentives based on strategic quality care goals that are established by the system's governance structure becomes possible. In Canada these very basic building blocks are not in place.

‡ There is evidence from Alberta research that quality improvement efforts, at least in nursing homes, needs to be focused and assessed at the unit level of service delivery. Assessing outcomes only at the facility level sometimes masks important differences at the front lines. (9)

Without strong governance there is little or no hope of assigning accountability, information from healthcare encounters that can be used to understand performance are not collected / reported / used, reimbursement rewards service volume rather than service quality, and there is little or no opportunity for planned continuous improvement / innovation.

An example of where governance deficiencies in Alberta's healthcare system have created a barrier for innovative changes is the recent consideration in Alberta of adopting an approach called the Canterbury Initiative. Canterbury, New Zealand's largest health district, over the past decade has redesigned their healthcare system around primary care and patients. Among many initiatives, the redesign has involved developing hundreds of clinical pathways that standardize care for patients and help primary care teams and patients navigate the complex interface with specialized healthcare. They have also invested heavily in EMRs and an electronic referral system. Results have been impressive – reduced demand on acute care services, increased numbers of scheduled surgeries, and reduced demand on residential (long-term) care for seniors to name a few. (10) There is reason to believe that adopting this approach in Alberta would help the province transform healthcare here as well and set it in on a course to achieve IHI's Triple Aim. Canterbuy has offered to work with Alberta to guide it on this transformational change. However, neither PCNs or AHS have the authority to oversee this transformation – it would require multilevel partnership agreements that while possible would still leave basic questions about governance - who has power, who makes decisions, how other stakeholders (especially citizen-patients) will be able to make their voices heard and who will be accountable for delivering the badly needed reforms. If a 'Canterbury-like' initiative was undertaken in Alberta the other usual barriers in Canadian healthcare would still require attention – poor availability of secondary data for improvement, isolated EMRs, lack of electronic referral, and a FFS reimbursement scheme that cannot incent much needed multidisciplinary care.

As promising as the Canterbury Initiative sounds it appears to still suffer from the almost universal phenomenon of healthcare paternalism – the redesign was done for patients, but not in partnership with, citizen-patients. Engaging patients in discussion and asking for advice about system redesign is a first step but by itself is inadequate. The APHI report appropriately drew attention to concepts like patient-centred care and patient engagement. However, we believe that there is a more innovative way to conceptualize the role of citizen-patients in their healthcare systems.

Coproduction (Citizen-patient Engagement & empowerment)

> "Patients expressed a desire for: better access to collaborative, integrated care where their needs are respected; improved communications with providers, including two-way information sharing that would permit them to better manage their own health; and engagement as partners in all decision-making processes related to their healthcare." (APHI Report) (2, p49)

The panel identified five critical areas for healthcare innovation; with the first being Patient engagement and empowerment. They noted that *"Canada lags on a range of measures related to patient experience, including patient-centred care (8th out of 11 countries), timeliness of care (11th out of 11), coordinated care (8th out of 11) and safe care (10th out of 11)."* (2, p49), and suggested that engaging patients in their own

care, and in both service and system design, as a key strategy for improving Canada's patient experience performance.

In the report, patient engagement is described as involving collaboration and partnership with health professionals, and encompassing the "the important role of the patient as end-user"(2, p48) (i.e., recognizing that patient experience is a valuable kind of expertise). The panel states that involving patients in the design of the healthcare system changes the conversation, and that their participation *"can be a disruptive innovation that accelerates healthcare system reform."* (2, p52)

> "At the system level, policymakers and leaders can involve patients in designing services that go beyond institutional walls and span the continuum of care. This also means engaging patient advocates – and the broader public – in a dialogue about the types of care we need now and into the future." (APHI Report) (2, p49)

This recognition of the importance of patient engagement to healthcare innovation is a critically important step, and we applaud it. However, we believe there are more progressive ways to conceptualize these concepts. The APHI report, in places, lapses into a traditional perspective of patient engagement; for example: *"Canadian healthcare leaders and professionals are clearly taking steps to reorient the system around patients' priorities." (2, p49)*; or, *"This requires firm leadership, engagement of staff through coaching and training, and enlisting and preparing patients to act as advisors."* (2, p50). Such statements imply that designing healthcare services and systems is best left to health professionals, with patients acting at most as 'advisors'. This does not reflect citizen-patients working in partnership with health care professionals or playing any kind of leadership role in health services and system design.

> "Patient-centred care has been defined as care that is respectful of and responsive to individual patient, preferences, and needs and values." (APHI Report) (2, p48)

One reason why this traditional perspective of patient engagement is woven through the report may be that the definition of patient-centred care provided in the report stops somewhat short. What is stated in the above quote from the Panel's report is a critically important part of the definition. Another key dimension of patient-centred care is partnership with patients and their families, as this definition of patient and family centred care from the Institute of Patient and Family Centred Care indicates: *"Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.* (11)

Healthcare organizations and systems can only be responsive if they work closely with citizen-patients, and have them actively identify the approaches that might work for them. Health professionals cannot simply do surveys or focus groups, or listen to patient 'stories', and say they understand patient needs and then come up with service improvements or new design ideas unilaterally. Partnership then is central to patient and family centred care. The Dana Farber Cancer Institute (DFCI) has long been considered a leader in patient and family centred care. In his January, 2015 presentation in Calgary at the Imagine Forum, former chief operating officer Jim Conway recalled a comment from Martha Hayward, a

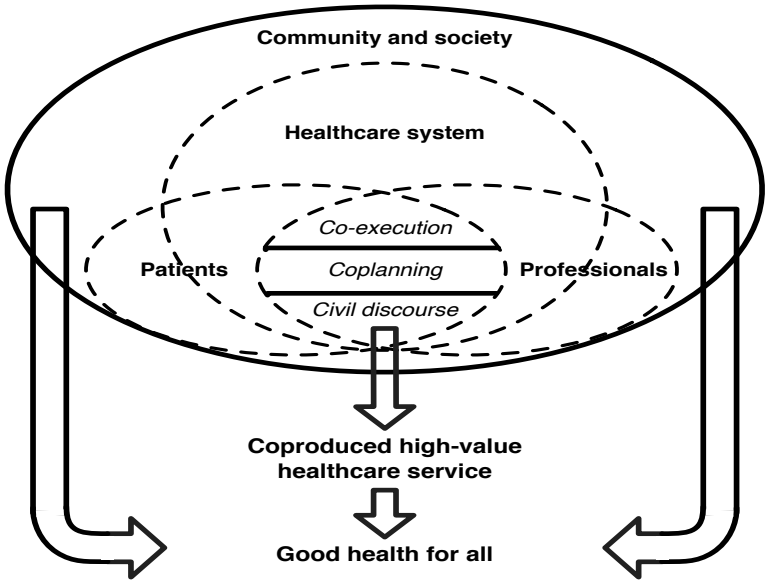
cancer survivor and former member of the DFCI's Patient and Family Advisory Council. She said: *"Jim, you used to do it to me, then you did it for me, now you do it with me... I like where we are today.*"§

Other than the title of the chapter, the APHI's report does not speak directly to patient empowerment, and specifically how it relates to developing the capacity for citizen-patient leadership. Rather than simply wondering how health systems 'engage' citizens-patients the question needs to include how citizens and patients engage health organizations in working with them to re-design OUR healthcare services and systems. This more holistic approach to 'patient engagement' that is increasingly gaining traction across the western world is referred to as co-production.

Co-production refers to a full partnership between professionals and the beneficiaries of public services in coproducing these services. (12) The New Economics Foundation (NEF), describes co-production in this way: *"This is not about consultation or participation – except in the broadest sense. The point is not to consult more, or involve people more in decisions; it is to encourage them to use the human skills and experience they have to help [design and/or] deliver public or voluntary services*."(13) Co-production as an important concept in healthcare has gained increasing traction in the UK over the last several years. Many reports and discussion papers use the tag line "People Powered Health". (14-18)

Batalden et al., argue that advancing a more explicit commitment to facilitating effective co-production in healthcare services is a strategy for improving healthcare services and that this improvement would happen through: "employing the expertise of service users and their networks; enabling more differentiated services and more choice for service users; increasing responsiveness to dynamic user need; and, reducing waste and cost." [11] They state that the recognition that healthcare services are coproduced by patients and health professionals invites four clusters of opportunity for action: education of professionals and public; healthcare system redesign; redesign outside and at the edge of the healthcare system; and, measurement of good healthcare services (Figure 1). (12)

Figure 1: Conceptual Model of Healthcare Service Co-Production *(reproduced from Batalden et al (12))*



§ Quoted with permission from J. Conway and M. Hayward October 16, 2015

The concept of co-production has been spreading. Recently, the IHI's Leadership Alliance developed some guiding principles for health care transformation that are called the "10 New Rules for Radical Redesign in Healthcare". The first of these is: *"Change the balance of power: Co-produce health and wellbeing in partnership with patients, families, and communities."* (18) The IHI's Vice-President Derek Felley, in a blog post describes this particular rule as one that he feels particularly passionate about. He goes on to share an example of co-production which he feels helps illustrate what changing the balance of power can accomplish:

> *"Instead of having a government agency develop an initiative to support patients with chronic conditions (such as diabetes and arthritis), we gave a modest grant to the Long-Term Conditions Alliance Scotland. Using what they had learned from the lived experience of their members, they created a self-management strategy for chronic conditions in Scotland called "Gaun Yersel" (or "Go On Yourself," for those of you unfamiliar with the Scottish vernacular, which is a phrase used to cheer on a person embarking upon a challenge). It's unlikely that the government would ever have given a nationwide initiative such a colloquial name, but we also wouldn't have seen such progress without giving control to those who live with long-term conditions every day."* (19)

Inherent in the concept of co-production is the idea that citizens have both the right and the responsibility to be involved in designing a healthcare system that works for people, if they are to fulfill their duty as citizens. A recent literature review on citizenship commissioned by the NHS notes that: "citizenship as a concept appears to be moving towards defining a reciprocal relationship between the individual and the state". They go on to define three components of active citizenship: responsibility, participation and choice. (20)

The term citizen-patient rather than simply patient, when talking about partnering with patients and families in the design of healthcare services and systems, better encompasses this idea that citizens have both a right and responsibility to be involved. So given that, citizen-patients have a major role to play in determining how they want their healthcare system to function. What do citizen-patients feel is important – what do they value? A recent discussion paper developed by Nesta in the UK entitled: "How we should think about value in health and care challenges conventional thinking about how healthcare adds value, and whether or not it aligns with society's values. They argue that what people using health services value most has not been adequately considered or captured, in part because our healthcare system was designed to deliver acute care and not chronic disease care. Some important points they make include:

- Changing social attitudes have led to notions of wellbeing, quality of life and happiness re-emerging in political conversation as values that society aspires to for its citizens.
- The growing number of people living with long-term conditions is making it clear that patients are increasingly producers of their own health care. This challenges the assumption of the traditional medical model that healthcare organizations produce value and patients consume it.

- The prevailing understanding of health is re-orienting itself from the question 'what's the matter with you?' to the broader question 'what matters to you?' This begs the question of how the value that health services create sits alongside other forms of value.
- The long journey of health and social care towards personalization has pointed the way to a values-based approach which prioritizes improved wellbeing, independence, social connectedness, choice and control; one in which people feel supported to manage their own care as part of their life. (21)

If its accepted that citizen-patients should be working in partnership with health organizations to design healthcare services and systems in a co-production model, then mechanisms that support citizen-patient led groups and organizations to work in partnership with health organizations need to be implemented.

Canadian healthcare systems need to move past the notion that citizen-patients are advisors, and nice to engage, and begin to realize that the thinking they bring is critical to the health care services and system redesign efforts; that they are true partners in these efforts. The phrase *"nothing about me without me",* which has become a tag line for patient-centred care, needs to transcend involving patients in their own care and underpin all the work on healthcare innovation. The challenge is how properly constituted citizen-patient groups are organized and funded so they can be true partners at the table. If funding for such groups comes from healthcare organizations or provincial governments the groups are at risk of unintentionally becoming 'co-opted' by the system they are trying to partner with. The federal government, through the Healthcare Innovation Fund proposed by the APHI, could assume an important role in fostering and funding provincial citizen-patient groups to coproduce innovative healthcare delivery systems with provincial healthcare systems. We address this further in the recommendations section.

The APHI highlight three levels at which patient engagement needs to take place: 1) the individual level where patients are more engaged in their own healthcare; 2) at an organizational level where patients would have a say in improving the local organization of care; and 3) at the system level where policy makers and leaders can involve patients in designing care that goes beyond institutional walls and span the continuum of care. (2, p49) Although the concept of co-production most often is considered to involve the organizational and system levels, it is also being extended to the individual care giving level; that is, patients should also be involved in co-producing their own care plans and their own health.

There are many important innovations that need to be coproduced in Alberta and Canada – none is more important than designing care continuity for patients.

Continuity of Care (Achieving integration) – seamless care for patients across the continuum

Integration (or continuity of care as we prefer to think of it) and patient centred care are inextricably coupled. Without having the impact on patient defined outcomes top of mind, integration as discussed in the Report has no relevance. Any health care system that claims to be 'patient' centred', has to provide integrated care. Integration is defined in the APHI report as 'inter-professional teams of providers who collaborate to provide a coordinated continuum of services to individual patients, supported by

information systems that link providers and settings.' (2, p 58) As discussions of integration often focus on the provider side of the relationship (as it does in the APHI) we suggest increasing the profile of the term 'continuity of care' in the dialogue. A commonly accepted definition of 'continuity of care' is: the degree to which a series of discrete healthcare events is experienced as coherent, connected, and consistent with a patient's healthcare needs and personal context. (22) Three types of continuity are acknowledged in published literature as being important to patients across healthcare settings: relationship, information, and coordination/management continuity[**]; the latter being particularly critical when patients require some of their care to be provided by specialists.

Relationship continuity is of critical importance; the principle is embraced in the initiative promoted by the College of Family Practice (among many others, including Alberta's PCNs) of the 'Medical Home' which is described as the place patients feel most at home to present and discuss their personal family health concerns. It is the central hub for the timely provision and coordination of a comprehensive menu of health and medical services patients need and it involves a multidisciplinary team of caregivers. (23) It is also described as a foundation for patient and family centred care.

Aspiring to provide quality care along a continuum is often a feature of 'integrated care' models and in our view is critical. Indeed, comprehensive services across the continuum of care was the first of ten principles typical of successful health system integration in a report mentioned several times by the Panel (Patient focus was the second). (24)

While there is much to be learned from the massive innovations now taking place in the US under their new legislation the *Affordable Care Act*, the Report leaves the reader wanting lessons learned from other countries that perform much better than the US (and Canada) on many of the quality indicators (e.g. access, coordination of care, patient-centred care) highlighted in the APHI Report (2, p15 Figure 2.6). While it is generally acknowledged that there is no 'silver bullet' with respect to what works, it is clear from the report that there is a wealth of experience in many countries (and in specific instances in Canada) of innovations that have been evaluated and strategic directions proposed. The APHI report quotes evidence from the Rand Health Insurance Experiment dating back 40 years showing that care continuity improves patient experience, reduces healthcare expenditures and improves health outcomes. (25) There is more recent evidence (26, 27) supporting this notion. It would be difficult to describe a 40 year-old concept as 'innovative'; however if Alberta were able to achieve this it would be innovative here. So what has prevented this from happening? The APHI report speaks to many of these barriers and to some of the solutions; others have been mentioned in the previous section on Governance and Accountability.

"We need to shift from an emphasis on acute hospital care to community-based care based on inter-professional teams of healthcare providers working with other community social services in collaboration with specialists and hospitals - and also with municipalities, school boards, police and the business community to address the underlying causes of illness." *Public submission* (APHI Report) (2, p 61)

[**] The authors gratefully acknowledge information and references on continuity of care from a report under preparation for the Health Quality Council of Alberta by J. Jackson.

The APHI mention: 1) realigning incentives and physician payment systems; 2) reimagining the healthcare workforce (optimizing healthcare professional scopes of practice); 3) integrated incentives and shared care; and 4) integrated healthcare for vulnerable populations: the care of First Nations. (2, p 62-65) To that we add the necessity to focus on specific needs of citizen-patients if they are to be full partners in the concept of shared care. In the literature this concept is often referred to as 'shared decision-making' (SDM). (28) SDM has been referred to as a 'meeting of experts' – the physician as an expert in medicine and the patient as an expert in his or her own life, values and circumstances. (29) As this statement illustrates SDM is aligned with the concept of co-production at the individual care level.

Implicit in SDM is the notion of informed decision making. Patients need to be informed about their own healthcare conditions by having easy access to their medical records. Organizations like Kaiser have done this by creating highly functional patient portals.

> In 2005 Kaiser created a comprehensive personal health record called MyChart, which patients can access through a secure patient portal called My Health Manager. Fully integrated with existing information technologies, the portal permits secure messaging between patients and providers, e-scheduling and e-renewal of prescriptions. Since the implementation of the system, the number of digital encounters has risen from five percent to 67 percent, with 50 percent of all interactions between Kaiser patients and physicians occurring via secure messaging. Overall, the number of physical visits (i.e., clinic visits, emergency department visits and hospital admissions) has dropped significantly. (APHI Report) (2, p59-60)

To be effective partners, patients require access to up-to-date clinical information that is relevant to their health condition(s). Knowledge (information) is power. While the internet has been a source of disruptive innovation in many respects and access to 'health information' is relatively easy through 'Dr. Google' there is no authoritative source of information that patients can access to help them participate in shared decision-making with other members of their healthcare team. The playing field needs to be leveled. One way to do this would be for the newly envisioned Health Innovation Fund to create evidence-based sources of data so that patients can obtain answers to key questions about their health in ways that they can understand. The Fund could also be used to generate answers to clinically relevant questions about treatment which patients identify as important for their decision-making. Patients, not surprisingly, have different priorities than healthcare providers (physicians and nurses). (30-32)

The APHI report considers several key aspects of an integrated system as noted above. There are others, however, which we believe are relevant to the Canadian situation. These include comprehensive[††] services across the continuum of care, standardized care delivery through inter-professional teams, governance (including performance management and accountability, inclusion of physician leadership), and perhaps most importantly organizational culture and leadership. (24) We would argue that another key aspect of an integrated system is recognition of patients and their families as integral members of the inter-professional team and the inclusion of patient-citizen leadership.

Organizational culture is often mentioned in conversations relating to change. While acknowledging it is

[††] Comprehensive includes along the lifelong health continuum and between health and social services.

notoriously hard to change, avoiding the discussion will guarantee it continues to be a barrier to progress. Culture is 'the way we do things'. Organizational culture is defined as the way in which members of an organization relate - to each other, to their work and to the outside world. (33) An organization's culture distinguishes it from other organizations. For example, we educate all health professionals in silos for the most part; we have separate medical, nursing and pharmacy faculties; we focus our attention on acute disease and acute care systems (e.g. the large investment in reducing wait times in Canada (34); we reward (or not) front line caregivers and managers for novel innovations that improve defined outcomes; we provide frameworks within which patients can provide input to health care planning (rather than asking citizens what they want to have professionals and administrators hear); we share (or don't) all key results with the community and invite them to help us improve lagging indicators).

"Implementation and operation of an integrated health system requires leadership with vision as well as organizational culture that is congruent with that vision. Clashing cultures . . . is one of the reasons named for failed integration efforts." (APHI Report) (2, p64)

Recommendations

We set out to answer the questions "What will it take to make meaningful progress on these three issues" (Governance and Accountability, Coproduction, Continuity of Care) and "whose job is it to lead this?" In this section we propose some recommendations that we feel may help make substantive progress towards that end. We believe the APHI recommendations[‡‡], although targeted at the federal government who commissioned the report should be heeded by provincial and territorial governments, because the locus of control for action rests at that level. Our reflections on recommendations are based on several important premises:

- The principles of patient centredness and co-production (including patient voice, participation and leadership) must guide all discussions relating to planning and assessing care delivery across the continuum of care.
- Where possible, build on past successes and take advantage of positive momentum and good will.
- It is critical to know the key elements of a desired destination. If we are not clear where we are headed, we will not know if we are making progress toward the desired end. We strongly believe that this 'desired end' needs to be defined in collaboration with citizens and patients.
- In addition to the levers identified in the Report (financing mechanisms, information systems, interprofessional teams) aspects of governance and organizational culture and leadership are key.
- Patients participate in healthcare encounters to the degree they desire, so they obtain the right care working with the right provider at the right time; healthcare encounters are perceived as seamless by patients.

Given that provinces are the primary jurisdiction responsible for delivering health services and our knowledge of one province, we offer recommendations that are made with the Alberta situation in mind, but we believe they are relevant to other provinces. We flag recommendations as being directed at the Alberta government or the Federal government. We acknowledge recommendations that were made by the APHI as part of the accompanying table.

[‡‡] The recommendations from the APHI report, Chapters 5 and 6 are included in the Appendix. We have also included a relevant recommendation from Chapter 7.

Table. Recommendations for achieving patient-centred and integrated care

Recommendation	APHI Report	Alberta Govt	Federal Govt
Enhance governance and operations to create a high-performing healthcare system			
• Implement a governance model and structured accountability for Community- based care beginning with Primary Care		◉	
• Panel patients so every Albertan has a clearly accountable primary care team		◉	
• Develop alternate payment schemes for multidisciplinary primary care teams to incent activities that align with strategic priorities	✓✓	◉	
• Develop a process to define strategic priorities that are 'coproduced' with citizen-patients and align incentives accordingly		◉	
• Develop well-defined processes and accountability for using secondary data from EMRs for continuous improvement and accountability (performance measurement)		◉	
Promote Co-production with citizen-patients			
• Fund an independent provincial Citizen-Patient group that can participate in coproduction and define priorities for investment and disinvestment in Alberta's healthcare system	✓		◉
Promote and Incent Continuity of Care			
• Redesign Alberta's healthcare system on a foundation of a strong 'Primary-Care – Citizen-Patient partnership that 'coproduces' healthcare for Albertans		◉	
• Promote the adoption of the 'Medical Home' that incorporates multidisciplinary teams and builds upon existing Primary Care Network infrastructure		◉	◎
• Promote continuity of care by creating clinical pathways for managing the interface between a patient's Medical Home and Specialized Healthcare services (the approach could be fashioned after the Canterbury Initiative)		◉	
• Produce accessible patient-oriented information that supports 'shared decision making'	✓		◉
• Create a single, system-wide electronic medical record that allows for comprehensive patient care but can also contribute data to drive system-level improvements	✓	◉	◎
• Develop state-of-art patient portals that would allow patients to contribute information to their medical record and also provide patients easy access to their own health data making it possible for them to be full partners in healthcare decision-making	✓✓	◉	◎
• Support the continued development of a single, comprehensive *e*Referral system that assists patients and their primary care providers to navigate 'specialized healthcare'		◉	◎

✓ A recommendation partially covered or alluded to in the APHI Report

✓✓ A recommendation found in the APHI Report

◉ Primary responsibility for the recommendation

◎ Supportive responsibility for the recommendation

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Appendix – APHI Report Recommendations

5.1 Through the new Healthcare Innovation Agency of Canada, with federal investments from the Healthcare Innovation Fund, pursue the following priorities:

- Develop and implement a strategy to promote patient and family-centred care in partnership with governments, patients, providers and others. Elements of this strategy would include:
    - Developing and implementing information tools that patients need;
    - Creating incentives for greater patient engagement at the organizational and system level, with the goal of improving models of care and system design;
    - Sourcing and supporting mobile and digital health solutions that meet needed common standards and interoperability requirements; and
    - Adopting and deploying best practices in the development and use of patient portals, including best practices internationally.
- Support the development of policy and legislative tools to enable patient access to, and co-ownership of, their own personal health records.
- As discussed in Chapter 6, support provinces, territories, and regional health authorities in undertaking large-scale projects that implement highly integrated delivery systems that test new forms of payment, where care is organized and financed around the needs of the patient.

5.2 Through Health Canada, take the lead in consultation and consensus building across provinces and territories on emerging ethical and legal issues arising from technological and social innovation in healthcare, and bring forward needed legislative changes in a timely fashion.

5.3 Through Health Canada, request the federal Privacy Commissioner to work with provincial and territorial privacy commissioners to develop a common understanding on how to protect privacy while enabling innovation (e.g. in precision medicine and genomics, mHealth, and various forms of digitized health records) across Canada.

6.1 Through the new Healthcare Innovation Agency of Canada, alongside federal investments from the Healthcare Innovation Fund, promote integrated delivery systems across Canada.

Relevant themes follow:

- Support provinces, territories, and regional health authorities in undertaking large-scale projects that implement highly integrated delivery systems that test new forms of payment where care is organized and financed around the needs of the patient. (Also in rec 5.1)
- Review and identify the best practices in interprofessional shared care, with specific reference to leading integrated delivery models. Promote adaptation, scaling-up and spreading of similar practices in Canadian jurisdictions.

- Develop, implement, and evaluate strategies for ensuring that integrated delivery arrangements in Canada address social needs and determinants of health, protect and promote health, and prevent disease.
- Support provinces, territories, and regional health authorities in adapting, scaling up and spreading partial integration models, e.g. primary care commissioning, portfolio funding for disease management, and assorted bundled payment strategies. Where possible, introduce elements of competition through tendering or bidding for care contracts.
- Support pan-Canadian multi-sectoral collaboration to implement the recommendations of the Canadian Academy of Health Sciences 2014 report Optimizing Scopes of Practice.
- Collaborate with provinces and territories, professional associations and others on a pan-Canadian pay commission to examine the relative value of healthcare services in terms of cost, provider activity and patient outcomes, thereby helping decision-makers evaluate professional roles, payments and prices.

6.2 Through the Canadian Institute for Health Information, in collaboration with interested provinces and territories, and with supplemental support from the Healthcare Innovation Fund as needed, pursue the following priorities:

- Expedite work to develop methodologies adaptable for use in physician capitation payment and in designing integrative or bundled payments based around common episodes of care.
- Accelerate work in the area of patient reported outcome measures (PROMs) and patient costing data, including case costing data, to create national risk-adjusted patient grouping methodologies and other tools.

6.3 Through Health Canada, and its First Nations and Inuit Health Branch, pursue the following priorities.

- Co-create a First Nations Health Quality Council, in partnership with First Nations representatives and patients, and with provincial and territorial governments. This Council would report on the quality and safety of care for First Nations across all sectors and regions. A priority for the First Nations Health Quality Council should be collaboration with CIHI for data development and collection relevant to First Nations (see Recommendation 7.6).
- Co-create a tripartite liaison committee with Inuit representatives and patients, and with the relevant provincial and territorial governments. The mission of this committee would parallel that of the First Nations Health Quality Council.
- Support First Nations leaders, together with willing provinces or territories and other partners, not least the Federal Government to initiate, evaluate and scale up new models of co-governed integrated care in varied locations across Canada. Managed by First Nations, these holistic entities should be modeled on international best practices, such as the Alaska Native Tribal Health Consortium or the Nuka System of Care.
- Facilitate the transfer of federal healthcare delivery programs to interested First Nations communities, working in partnership with First Nations leadership in those communities and the relevant province or territory, while ensuring that service transfers are accompanied by commensurate resources.

- Continuously monitor existing initiatives that transfer responsibility for services, such as the BC First Nations Health Authority, to ensure that devolution strategies are effective, efficient, and equitable.
- Improve the health infrastructure and health human resource capacity on reserve to meet patients' needs.
- Work with First Nations, Inuit, and other stakeholders to improve the management and responsiveness of the Non-Insured Health Benefits (NIHB) program to enhance access to care through digital technologies and ensure that it provides coverage comparable to other public and private plans.
    - To this end, the federal government should provide quasi-statutory authorities to Health Canada to adjust or expand health benefits offered through NIHB within an overall financial framework set by Parliament.
    - Through the combined resources of the Healthcare Innovation Fund, the Healthcare Innovation Agency of Canada, Health Canada, relevant provincial and territorial partners, First Nations and Inuit communities and others, develop new models of virtual and physical care to mitigate the hardships incurred by patients and families when First Nations and Inuit peoples travel to receive healthcare.

7.5 Through Infoway initially and then through the Healthcare Innovation Agency of Canada, accelerate the deployment of interoperable electronic health records across points of care, including efforts to assist providers and payers in meaningful use and prioritizing the creation of online portals where patients have mobile access to their own records.

- Ensure future investments in health information technologies are standardized, interoperable, linked across multiple sites, and available to third parties for assessment of performance.