Patient-Centered Care:
An Introduction to What It Is and How to Achieve It

A Discussion Paper for the
Saskatchewan Ministry of Health

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Table of Contents

What Does Patient-Centered Care Mean?

There have been many attempts to define the attributes of patient-centered care (PCC)[1]. However, there are gray areas even in the most comprehensive of definitions. The following is from NRC Picker, the company specializing in tracking patient experiences:

1. Respect for patient's values, preferences and expressed needs. This dimension is best expressed through the phrase, "Through the Patient's Eyes" and the book of the same title, and leads to shared responsibility and decision-making.
2. Coordination and integration of care. This dimension addresses team medicine and giving patients support as they move through different care settings for prevention as well as treatment.
3. Information, communication and education. This includes advances in information and social technologies that support patients and providers, as well as the cultural shifts needed for healthy relationships.
4. Physical comfort. This dimension addresses individual, institutional and system design (i.e. pain management, hospital design, and type and accessibility of services).
5. Emotional support. Empathy and emotional well-being are as important as evidence-based medicine in a holistic approach.
6. Involvement of family and friends. Care giving includes more than patients and health professionals so that the larger community of caregivers are considered.
7. Transition and continuity. Delivery systems provide for caring hand-offs between different providers and phases of care.[2]

All of this seems praiseworthy, but what does it mean in practice? How would you know if the care you received was truly patient-centered? How would providers know if they were delivering patient-centered care? How would system managers know? What indicators best reflect patient-centeredness? PCC is in some ways in the eye of the beholder. Providers might think they are delivering PCC but their patients might disagree. Different aspects of PCC will be more relevant to some patients than others.

The purpose of this paper is to explore PCC in practical terms and propose some possible indicators and measures that would support transparent performance reporting on its achievement. The aim is to make PCC more concrete, so that it is a living concept

[1] Sidani S. Effects of patient-centered care on patient outcomes: an evaluation. *Research and Theory for Nursing Practice* 2008;22(1):24-37 reviews the literature defining the concept and also extracts the main features.

[2] Institute for Alternative Futures on behalf of the Picker Institute. Patient-Centered Care 2015: Scenarios, Vision, Goals, and Next Steps. Alexandria VA, 2004, http://www.altfutures.com/pubs/Picker%20Final%20Report%20May%2014%202004.pdf

meaningful to those who receive, deliver, and organize care, and who make policy. Ultimately, PCC is as much about the culture of the system as specific approaches and behaviours. The challenge is translating it into understandable, consistent and valid terms and indicators.

A. The Fundamentals of PCC

A basic foundation of PCC is the notion of service. Many think of contemporary health care as a combination of science and technology deployed by professionals to address health problems. This is of course true, but PCC is based on a simpler premise: health care is a *service* industry. This may sound like mere common sense, but if truly embraced and built into the health care system, it is a transformative idea. In important ways health care is unlike commercial services like hair salons and hardware stores. Sick people are not shoppers and their relationship with providers is qualitatively different from their relationship with sales clerks. But one concept fundamental to the commercial world is relevant to health care: the customer is always right.

Technically, of course, the customer is not always right – customers are just as fallible as businesses. But a dissatisfied customer is a customer whose needs have not been met, and the essential insight is to recognize this as a failure. Successful businesses view an unsatisfied customer as evidence of their own failures. That ethos lies behind no-questions-asked return policies, ironclad warranties, and personal communication to resolve problems.

Businesses adopt this attitude because it is a key ingredient to their survival and success. Publicly funded health care does not face the grim prospect of collapse due to the loss of customers. It can, and does keep the customers it fails because there is no other place to go. Most of the failures are not catastrophic (although many are and the death and morbidity tolls are high). They are rather the failures of disrespect, inconvenience, poor communication, and fragmentation. Put most simply, the system has been designed for the providers more than for the users of services, and it shows.

It is important to distinguish PCC from consumer-driven health care. The latter uses the language of the market and increased patient control as a purchaser of services, and more informed choice about where to receive care. PCC experts emphasize that while the two concepts may overlap, PCC begins with the premise that people vary in their capacity and inclination to engage in their own decision-making. Some are confident and able to direct their own care, while others are less so. PCC makes no assumptions

about either the suitability of the market mechanism or the consumer orientation of patients[3].

B. What Patients Want

The Change Foundation in Ontario has done a lot of work on PCC. A major literature review confirmed that there is very little research that examines health care integration from the patient perspective[4]. The Foundation conducted a series of focus groups to get a better understanding of the patient experience[5]. Many implicit definitions of the elements of PCC emerged, among which were:

1. Comprehensive care – all of their needs, not just some, should be addressed
2. Coordination of care – someone is in charge, there is someone to go to who knows you and will help you navigate the system
3. Timeliness – they should get care when they need it and where a sequence of services is required, the intervals should be short
4. Functioning e-health – provide information once, ensure that it is accessible to those who need it, give patients access to the records and the opportunity to add
5. Clear and reliable communication – listen, explain, clarify, ensure that the provider team members are on the same page, consistency of messages, access to phone or internet consultations
6. Convenience – minimize the need to go to different physical locations for services; open access, same day scheduling; no unnecessary barriers or steps to getting to the right provider
7. Respect – for their time, intelligence; for the validity of their stories; for their feedback about quality and effectiveness; for their environment and family caregiving partners

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[3] Silow-Carroll S, Alteras T, Stepnick L. Patient-centered care for underserved populations: definition and best practices. Economic and Social Research Institute, January 2006. Prepared for the WK Kellogg Foundation. http://www.esresearch.org/documents_06/Overview.pdf

[4] Spragins WA, Lorenzetti DL. Public Expectation and Patient Experience of Integration of Health Care: A Literature Review. Toronto: The Change Foundation, 2008. http://www.changefoundation.ca/litreviews.html

[5] Who Is The Puzzle Maker? Patient/Caregiver Perspectives on Navigating Health Services in Ontario. Toronto: The Change Foundation, 2008. http://www.changefoundation.ca/docs/ChgFdn_Puzzle_Web.pdf

8. Empathy and understanding – for their circumstances, fears, hopes, psychological state
9. Time – to express needs and be heard effectively
10. Continuity and stability – to know and be known, minimize the number of different care providers
11. Fairness – amount and timeliness of service commensurate with need.

Different initiatives and attributes are required to meet all of these needs. Some are structural: how well the system is integrated, where services are located, the nature and use of an EHR. Some are organizational: how are appointments made, how are staff deployed, are there processes for pro-active rather than reactive communication. And many are attitudinal and behavioural: whose needs come first, do providers listen, do they treat patients as equals and partners, do they welcome feedback.

C. Provider Attributes That Promote PCC

Achieving genuine PCC requires a cultural adjustment. Provider attitudes and behaviours can accelerate or thwart PCC. Among the provider attributes essential to transformation are:

1. Recognition that health care is an integrated service industry designed to respond to people's needs
2. A commitment to organizational effectiveness and collective responsibility for the processes and outcomes of care, with special focus on handoffs, communications, and follow-up
3. Willingness to participate in non-hierarchical teams to ensure that patients get comprehensive, well-integrated care from the most appropriate caregiver
4. Willingness to adopt an incentive structure that encourages spending adequate time with patients with complex needs
5. Trust in and encouragement of those patients who want to be actively engaged in the management of their own health
6. Commitment to organizing the system to provide timely care and adoption of tools and techniques that prioritize patient access over provider convenience
7. Willingness to own the failures on any of the main PCC indicators and dimensions and vigorously pursue remedies
8. Embrace of e-health and other technologies that expedite communication, flow, and efficiency.

All of these attributes come down to attitude and primarily deal with the non-technical aspects of their work. Many of the problems PCC aims to address involve fragmentation – the parts of the system don't work together. Some fragmentation arises because for over a century, professionals have put clinical autonomy at the centre of professional identity. While the exercise of clinical judgment is fundamental to quality, absolute clinical autonomy is anathema to an integrated system that delivers PCC. Because health care is not a market good, there are no "natural" market forces to drive PCC, quality and efficiency. Many values compete for priority status in any health care organization: PCC, clinical autonomy, organizational loyalty, or any number of others. The core value cannot be all of these, and if PCC is to be paramount, the others have to be modified accordingly. Either the sun revolves around the earth, or the earth revolves around the sun. Patients can orbit their providers, or providers can orbit their patients.

D. Governance and Management for PCC

Managers and governors are not directly involved in care but their mandates, values, and policies create a framework that influences the relationship between patients and providers. Managers deal more directly with providers while governors – especially government – are responsible mainly to the public (who are all, at times, patients). And while they may not exercise it fully, governments and managers have the power to stand the system on its head if they are committed to it.

Both governors (including boards) and managers have to make PCC the top priority if it is to be realized. They have two main roles: making policies, and holding the system accountable. The policies have to support PCC, while accountability requires the measurement of relevant aspects of the patient experience and a support system that improves performance. This requires a focus on:

1. Indicators that capture patient-centeredness accurately and comprehensively
2. Health science education programs that build PCC into the core of their curricula and the formative apprenticeship experiences
3. Explicit goals and targets for achieving various elements of PCC
4. Regular patient surveys to monitor the evolution of PCC and identify strengths and weaknesses
5. Regular provider surveys to monitor their attitudes, expectations, behaviours
6. Organizational changes that promote systems thinking, collective accountability, and team-based care

7. E-health and other technologies that facilitate communication, efficiency, and convenience
8. Investments in system re-engineering that advance PCC
9. Progressively more robust policies to spread PCC successes, e.g., mandatory open access scheduling, patient-driven e-health initiatives, transparent reporting of PCC performance, etc.
10. A culture of PCC that refuses to tolerate behaviours that do not put patients first
11. Incorporating important PCC criteria and measures into accreditation and regulatory agency standards and processes.

These boil down to three main functions: defining the desired culture and expectations; investing in the enabling change strategies; and mechanisms to ensure accountability.

E. Potential Policy Measures to Advance PCC

If it is true that policies are designed to achieve the outcomes we observe, then current policies implicitly or explicitly entrench a provider-centered system and the absence of innovative policies impedes the development of PCC. Based on the preceding analyses, the following are examples of policies that could be pursued to promote PCC:

1. Make PCC performance a cornerstone of public reporting and accountability and a major driver of incentive and innovation plans
2. Eliminate all financial incentives (elements of the fee-for-service agreement, etc.) that act as barriers to using multiple methods to communicate with patients (e.g., telephone and e-mail communications, contact with various members of the health care team)
3. Adopt primary health care funding mechanisms that encourage all providers to focus their individual and collective efforts on high-needs populations and complex problems
4. Eliminate all practices and collective agreement provisions that work against developing stable and ongoing patient-caregiver relationships in community and long term residential care – i.e., get rid of the revolving door syndrome
5. Set a timetable for the mandatory implementation of open access scheduling and/or the achievement of same-day primary health care appointments
6. Accelerate the implementation of a patient-accessible, patient-friendly EHR as the cornerstone of the health information system

7. Eliminate all financial incentives that impede the development of team-based care and an optimized division of labour that uses all of the knowledge and skills of the workforce
8. Eliminate all financial disincentives to achieving greater degrees of self-management among patients and their families and more active engagement in their own health maintenance plans
9. Develop, publicize, and disseminate checklists and other tools for patients to use in clinical encounters to ensure that their needs are being met
10. Work with educational institutions, accreditation bodies, regulatory agencies, employers, and unions to incorporate PCC concepts and behaviours into standards and expectations at all levels
11. Develop a legal and operational framework for partnerships between the formal system and family and other caregivers, particularly in community and long-term residential care
12. Audit PCC processes and outcomes to enhance the evidence base for refining policies, practices, and incentives.

F. Potential PCC Indicators

The following indicators are illustrative; to capture experiences in all sectors the questions would have to be tailored accordingly.

1. Time to 3rd next available appointment to see:
    a. A primary care provider
    b. A specialist
2. % of patients with access to an on-line EHR
    a. By region
    b. By practice
    c. That allows them to enter and amend information
3. % of patients who can get all diagnostic work ordered by their primary care doctor done the same day in the same location (excluding certain high-technology procedures such as CT and MRI)
4. Periodic patient surveys that measure their experiences and perceptions of:
    a. Respectfulness of communications

    b. Clarity of communications
    c. Satisfaction with duration of appointments
    d. Continuity of care
    e. Convenience of services
    f. Empathy and understanding
    g. Responsiveness to desire to self-manage and otherwise be a partner in care
    h. Encouragement of independence and ownership of own health
    i. Experiences in obtaining services from multiple providers and navigating the components of the system
5. Periodic provider surveys to measure:
    a. Attitudes towards patients as engaged partners in their own health
    b. Extent of e-health adoption and uses
    c. Participation in teams
    d. Participation in system organization and planning
    e. Mechanisms by which they obtain patient feedback
    f. Impact of funding and other incentives on behaviours, perceived ability to deliver PCC, etc.
    g. Organization of practice to provide after-hours service
6. Surveys or audits of boards and/or their organizations to track:
    a. Policies in place that promote or deter PCC
    b. Nature of information received on measures of PCC
    c. Perceived barriers to higher PCC performance
    d. Plans for enhancing PCC performance
7. Surveys or audits of health science education organizations to track:
    a. How PCC is incorporated into the formal curriculum
    b. How PCC is incorporated into the practicum experience
    c. How PCC capacity is assessed in progress towards degrees/diplomas

G. Examples of PCC in Action

No jurisdiction can claim to have perfected PCC, but some have done some remarkable things. We in Saskatchewan are increasingly familiar with two systems with a notable PCC focus: Jonkoping County in Sweden and the South-Central Foundation in Alaska. The latter in particular is instructive because the challenges were so formidable and the transformation so all-encompassing. One of the more compelling stories from Alaska was the conversation between the leadership and physicians who worked hard, were well-liked by their patients, and who provided high levels of service. The response to them was: you're missing the point. It's not about working endless hours and perpetuating life-long dependence on repeated services. The goal is to wean the patients from system dependency and increase their capacity to self-manage and otherwise participate in their health. This focus on PCC achieved a decline not only in the use of specialists and acute care; it also reduced by 20% the number of primary care visits.

Some components of PCC are in place in other countries. Some examples include:

1. Virtually same-day access to primary health care in England, and performance indicators (publicly available) that in large measure reflect PCC concepts;
2. Web-based patient access to their EHRs in Denmark, with the capacity to add or amend information and an audit trail of providers who have looked at the record;
3. High patient satisfaction scores on areas such as respect and communication at a number of sites in the Commonwealth Fund's patient centered care projects[6].

There is a growing body of evaluative research on the impact of PCC. Just to cite findings from the hospital sector, a PCC approach reduces length of stay; reduces costs; increases patient and provider satisfaction; facilitates teamwork that changes the division of labour; improves safety; reduces malpractice claims; increases employee retention rates; and promotes self-care[7] [8].

There is now a Canada-Europe collaboration to report on the consumer-centeredness of various national health care systems. The most recent report – Euro-Canada Consumer Health Index 2009 (available here) is an interesting exercise in evaluation. One

[6] The Commonwealth Fund. Innovations: patient-centered care. There are write-ups of case studies that describe performance, and summarize interviews with key participants. http://www.commonwealthfund.org/Innovations/View-All.aspx?topic=Patient+Centered+Care

[7] Charmel PA, Frampton S. Building the business case for patient-centered care: patient-centered care has the potential to reduce adverse events, malpractice claims, and operating costs while improving market share. Healthcare Financial Management 2008 (March), online at http://findarticles.com/p/articles/mi_m3257/is_3_62/ai_n24942366/?tag=content;col1

[8] Sidani, op. cit.

can quibble with the indicators and the methods (often the rating score is based on the formal existence of legislation or policy rather than empirical performance data), but the report is quite candid about its limitations. While a consumer orientation is not identical to PCC, many elements overlap and a number of the indicators are identical to those proposed above. Canada does very poorly overall (notably, the report ranks us last of 32 countries on value for money).

This may seem jarring to Canadian sensibilities, and conflicts to some extent with satisfaction surveys that generally give high marks to components of health care. But this should not lead to complacency or denial; it is quite possible that we are acculturated to bad service, have low expectations, and are pleased when they have been met or exceeded. The first requirement for improvement is insight into the status quo; the second is commitment to change.

H. PCC and Primary Health Care

Just as patient-centered care is fundamental to health system transformation, primary care is the fundamental site where it must succeed. The concept of the Patient-Centered Medical Home (PCMH) is at the core of an envisioned transformation of primary care in the US. An evaluation of a multi-practice, national two-year demonstration project has revealed some early lessons about the nature of change. Some of these lessons challenge some of the theory and practice of quality improvement. It is worth quoting the observations on the nature of change at some length:

> Change is hard enough; transformation to a PCMH requires epic whole-practice reimagination and redesign. It is much more than a series of incremental changes. Since the early 1990s, theories of quality improvement emphasizing sequential plan-do-study-act cycles have dominated change efforts within primary care practices. Many N[ational] D[emonstration] P[roject] practices initially chose to take this incremental approach—literally checking off each model component as completed. They were soon overwhelmed with complications. Whereas the traditional quality improvement model works for clearly bounded clinical process changes, the NDP experience suggests that transformation to a PCMH requires a continuous, unrelenting process of change. It represents a fundamental reimagination and redesign of practice, replacing old patterns and processes with new ones. Transformation includes new scheduling and access arrangements, new coordination arrangements with other parts of the health care system, group visits, new ways of bringing evidence to the point of care, quality improvement activities, institution of more point-of-care services, development of team-based care, changes in practice management, new

> strategies for patient engagement, and multiple new uses of information systems and technology.[9]

Change is more than a series of tools and techniques; "Such a fundamental shift nearly always challenges doctors to reexamine their identity as a physician.[10]" This is difficult terrain and among other things depends on the "adaptive reserve" of a practice, mechanisms to assist doctors to rethink their identities and practices, and above all, time to plan, reflect, and experiment. This is a cultural shift that should not be reduced to or presented in purely mechanical terms:

> We should be wary of industrial-like schemes and excessive use of the language of productivity and efficiency. Primary care, like healthy food, works best at a local and personal level. What is waste on an assembly line is not necessarily waste in a healing relationship; allow for appropriate variability. Stewarding patients toward healthier lives is a deliberate process—stewarding practices toward health and toward becoming a PCMH is also.[11]

I. Getting to PCC

The transitional journey to a PCC system will be different for different parts of the system. One research synthesis identified the following as important ingredients in the change process:

- Feedback and measurement
- Patient/family involvement
- Workforce development
- Leadership
- Involvement in collaboratives, pilots.[12]

The report also highlights the importance of policy in promoting PCC. The cited attributes apply to (typically large) organizations; it is different in primary care. Incentives at all levels have to align with the goals.

Researchers emphasize that there is no one proven strategy for implementing PCC. Some organizations, like Group Health Cooperative in Washington and Idaho and the South-Central Foundation in Alaska, are governed by the people who get the service. All the literature suggests that providers need to have the time and support to shift from a paternalistic and dependency-inducing mindset to a more open, participatory, and engaging model of joint decision-making and shared responsibility.

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[9] Nutting PA et al. Initial Lessons From the First National Demonstration Project on Practice Transformation to a Patient-Centered Medical Home. Ann Fam Med 2009;7:254-260, at 255. http://www.annfammed.org/cgi/reprint/7/3/254

[10] Ibid, p. 256.

[11] Ibid., p. 259.

[12] Silow-Carroll S, Alteras T, Stepnick L., op. cit. http://www.esresearch.org/documents_06/Overview.pdf

In Saskatchewan, based on quality improvement experiences to date and the overall health system context, one might reasonably infer that we share a number of the barriers cited in the literature, as well as conditions that support innovation. The following steps would appear to be essential to making progress on the journey:

1. Focus on primary health care. PCC is not just process; it also prioritizes prevention, self-care, and taking control of one's health. Primary health care is the nucleus for these developments. Patients are on a more equal footing than when they are acutely ill or in need of residential care. They can learn to engage and assume control when they are not old and sick and carry this learning forward for the rest of their lives.
2. Develop PCC indicators that reflect the basic elements of PCC: access and convenience; navigating the parts of the system; and the quality of interactions with providers. These not only facilitate the tracking of progress; they also signal to the entire system and the public that PCC is fundamentally different from conventional approaches and the metrics of success are likewise different.
3. Recognize that PCC is essentially a cultural shift supported by tools and techniques – not the other way around. Some of the essential cultural changes are deep-rooted and require a combination of individual and group reflection. They challenge long-standing practices and assumptions. Providers in particular need time and support to begin this journey.
4. Use policy levers to support the transition. Government pays for health care; it has many options for how to pay, what to reward, what to discourage, etc. The literature is unanimous in its assessment that incentives matter. An important initial step might be to do an analysis of how existing financial incentives align with the early versions of PCC goals and indicators. This analysis could be the start of fruitful discussions with boards, managers, professional associations, and unions.
5. Get the public and patients involved early and often. They are the ones who experience PCC or its absence, and their needs and preferences are supposed to drive change. The transition will in many ways be no easier for them than for providers, but in that sense the playing field is level. Identifying articulate and confident citizens and patients should be a high priority. PCC is all about ceding control and listening; so, too is the journey towards successful implementation.
6. Develop a strategy for communicating the concepts and the advantages to the public. One of the dilemmas is that a public long accustomed to a non-PCC system may be a victim of low expectations. Ideally, public pressure should drive transformation. But the public has to have a vision and expectation of a different health care world. Somehow the public has to learn that PCC is possible, and that it looks vastly different from what most of them experience. In a sense their satisfaction with and acceptance of the status quo has to be broken down if they are to be change agents. This is a delicate balance but without a shift in public attitudes and a strengthening of resolve, the barriers to change may prove formidable.

7. Capitalize on opportunities presented by the e-health revolution. The design of the EHR and its use are vital to PCC success. An open, engaged model creates common ground for providers and patients. Having access to and some control over one's own health information can build confidence and create a sense of shared responsibility.
8. Use the main concepts and language of PCC in important speeches, documents, and memoranda of understanding. A serious and sustained effort requires reinforcement, repetition, and constant symbolic affirmation.