A Cross Country Health System Study to Understand the Role of Patient Engagement in Quality of Care

By

Vandana Rathore

Dissertation submitted for the partial fulfillment of the

MBA Hospital and Health Management

Academic year, 2015-2017

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INSTITUTE OF HEALTH MANAGEMENT RESEARCH
(WHO Collaborating Centre for District Health System Based on Primary Health Care)

IIHMR UNIVERSITY

TO WHOMSOEVER MAY CONCERN

This is to certify that Vandana Rathore student of MBA Hospital and Health Management from The IIHMR University, Jaipur has undergone internship training at International Health Unit, University of Montreal from 15 Apr 17 to 15 Jul 17.

The Candidate has successfully carried out the study designated to her during internship training and his approach to the study has been sincere, scientific and analytical.
The Internship is in fulfillment of the course requirements.

I wish her all success in all his future endeavors.

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and has successfully completed her Project on

A cross country health system study to understand the role of patient engagment in quality of care

April –August 2017

International Health Unit, University of Montreal

She comes across as a committed, sincere & diligent person who has a strong drive and zeal for learning

We wish her all the best for future endeavors

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This is to certify that the dissertation titled **A cross country health system study to understand the role of patient engagment in quality of care** and submitted by Vandana Rathore Enrollment No.IIHMR-U/01/2015-17/0362 under the supervision of **Dr. S. D. Gupta** for award of MBA in Hospital and Health Management of the University carried out during the period from 15 Apr 17 to 15 Jul 17 embodies my original work and has not formed the basis for the award of any degree, diploma associate ship, fellowship, titles in this or any other institute or other similar institution of higher learning.

Vandana

Signature

THE IIHMR UNIVERSITY, JAIPUR

CERTIFICATE BY SCHOLAR

This is to certify that all ethical issues have been considered while collecting data for my dissertation titled A cross country health system study to understand the role of patient engagement in quality of care.

Vandana

Signature

ABSTRACT

Title: A cross-country health system study to understand the role of patient engagment in quality of care

Author: Vandana Rathore

Background:

Paternalistic healthcare approaches have gradually given way to patient-oriented approaches that take into account patients' differences, values, and experiences. Healthcare organizations, institutions, and universities around the world are increasing their efforts to involve patients and make their participation active using different forms of engagement. With the emphasis on patient centred care and improvement of quality of care in the, potential of patient engagement as a means to improve quality of care is a major area of interest for policy makers in India.

Objectives

- To understand the role of patient engagement in quality of care and how it affects health outcomes in Canadian healthcare system.
- To understand how patient engagement can be adapted to Indian healthcare system.

Methodology

This qualitative case study was conducted across healthcare organizations in Canada at the federal, provincial (Quebec) and other province of Canada level during April'-July'17. An exploratory review of existing guidelines, norms and policies related to patient engagement in Canadian healthcare system was undertaken to understand the process at a policy level. Following purposive sampling, in-depth interviews of eleven stakeholders in patient engagement process were conducted to understand the various models of patient engagement and describe the process as well as the contribution of patient engagement in quality of care. A qualitative analysis of the comments and

knowledge built from the interviews was undertaken to summarize steps that can be taken to adapt patient engagement as a practice to India.

Results and Conclusions

Patient engagement has been a significant contributor to enhancing the quality of care and patient safety practices in Canadian healthcare system. Bringing similar models to Indian healthcare system comes with challenges but adapting to the local environment and constructing models and frameworks that succeed in pilot projects could potentially lead to improvement in quality of care, patient safety and ultimately the health outcomes.

Keywords

Patient engagement, patient partnership, patient partner, Canada, healthcare

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LIST OF ABBREVIATIONS

B.C.	British Columbia
CFHI	Canadian Foundation for Healthcare Improvement
CPSI	Canadian Patient Safety Institute
HealthCare CAN	Health Care Canada
IAP	International Association for Public Participation
ISMP	Institute for Safe Medication Practices
IT	Information technology
NCD	Non communicable diseases
NHP	National Health Policy
PA	Patient advisors
PaCERs	Patient and community engagement researchers
PCP	Partnership in care program
PP	Patient partnership
PPI	Patient and public involvement
SPOR	Strategy for patient oriented research
UM	University of Montreal
UK	United Kingdom
US	United States of America
WHO	World health organisation

A cross country health system study to understand the role of patient engagment in quality of care

Introduction

Paternalistic healthcare approaches have gradually given way to patient-oriented approaches that take into account patients' differences, values, and experiences. Healthcare organizations, institutions, and universities around the world are increasing their efforts to involve patients and make their participation active using different forms of engagement and various means of motivation. However, recent initiatives such as shared decision-making and some therapeutic education approaches, maintain the healthcare provider's monopoly on determining the course and outcomes of treatment**.** (1)

As patients have to live with the illness the rest of their lives, their experience becomes a rich source of knowledge essential for decision-making(1). Patient participation, or engagement, is only recently receiving greater attention as it becomes increasingly evident that it can be an innovative and viable approach to ensuring appropriate care in the current environment strained by limited resources. Around the world, health organizations, care delivery institutions, and universities are striving to expand patient engagement beyond a token level of involvement.(2)

Citizens worldwide are increasingly called upon to participate in healthcare quality improvement. Yet how involvement should be facilitated is often unclear.(3) The recent focus on patient engagement acknowledges that patients have an important role to play in their own health care. This includes reading, understanding and acting on health information (health literacy), working together with clinicians to select appropriate treatments or management options (shared decision making), and providing feedback on health care processes and outcomes (quality improvement)(4). In the United Kingdom, patient and public involvement (PPI) has become a policy requirement and a key official strategy to put patients at the centre of quality care (3). Policy and academic discussions of public involvement frequently refer to the need for patients and professionals to collaborate in improvement, and the 'empowerment' that this may require(3). Advocacy for patient engagement in the US, UK, mainland Europe, and well beyond is driven largely by the belief, backed by some evidence, that engaging patients

will reduce healthcare costs through the avoidance of unnecessary investigation and treatment. Patient engagement is seen as a way to help health systems become sustainable. Some have argued that it is the "blockbuster drug of the century" and will deliver equivalent dividends (5)

Review of Literature

Bringing together patients and professionals into real collaborative relationships is challenging (Martin and Finn 2011; Rutter et al. 2004). Consultative rather than partnership approaches are common (Rutter et al. 2004), replaying divisions and asymmetries between healthcare professionals and patients (Martin 2008b). Findings suggest that organizations that have succeeded in fostering patient-centered care have gone beyond mainstream frameworks for quality improvement based on clinical measurement and audit and have adopted a strategic organizational approach to patient focus(6)

Providing patient and family-centered care and improving patients' experiences with their care are important health system goals. Engaging patients is key to improvements in these goals at clinician, microsystem and organizational levels. Such engagement may help accelerate efforts to improve the delivery of care using quality improvement methods. Patient engagement may be an important catalyst for improving patient outcomes and organizational performance, but the mechanisms that translate patient engagement into better care and improved outcomes are still not fully understood (7)

In Canada, the Canadian Foundation for Healthcare Improvement (CFHI) has brought together health systems across the country to improve patient and family involvement in care (re-) design and measure its impact and has supported organizations that are involving patients and families in the design, delivery and evaluation of healthcare services (7)

Current state of patient engagement across Canada

Across Canada, governments and healthcare organizations are advancing patient and family-centered care, with patients and families taking on more active, informed, and influential roles. Some provinces have introduced legislation that requires organizations to engage patients in health system planning. (8)

For many years, patient groups, often organized around a common disease or health condition, have actively advocated to partner in their own care, in decisions about setting health service and research priorities, and in care-design and delivery. Since 2004, formal and informal patient groups have emerged and continue to emerge across Canada, indicating a strong desire to contribute to safe and quality care.(8)

At the national level, patient groups like Patients for Patient Safety Canada and Canadian Family Advisor Network have worked collaboratively with many leaders, providers, and policy makers to include the patient's perspective in service design and policy making. Their intent is to build a safer, more sustainable healthcare system that is responsive to patient needs. Patients shape tools, resources, guidelines, standards, and learning programs to help other patients, patient partners, providers, and leaders. (8)

At provincial and local levels, patient groups like Patient Voices Network in B.C., and Health Quality Ontario Patient, Family and Public Advisors Council shape provincial and local policies, frameworks, performance measures, and point-of-care interactions.
Informal patient groups and networks are also increasing in number. Patients are connecting, supporting each other, advocating for change, and collaborating with providers, administrators, and policy makers to make positive changes in the healthcare system. (8) Emerging efforts focus on building connections among different patient groups in a "network of networks," primarily by the Canadian Patient Safety Institute (CPSI). Through meetings and building relationships, CPSI helps reduce duplication, transfer knowledge, and align efforts to achieve a common goal: safer care through patient engagement. Early efforts in patient engagement for patient safety and quality grew out of the grassroots work of patients, clinicians, and leading healthcare organizations in-patient and family-centred care. (8)

- The Canadian Foundation for Healthcare Improvement (CFHI) supports organizations to pilot and test projects related to patient engagement. This helped seed a nationwide patient and provider learning community to build evidence for the positive impact of engaging patients. (8)
- CPSI's National Patient Safety Consortium identified patient engagement as a key focus area in the collective effort of key patient safety and quality organizations. CPSI has been modelling patient engagement in patient safety for more than a decade by ensuring that 100% of programs are developed and delivered in partnership with patients. They also develop specific resources for patients and the public, and they support Patients for Patient Safety Canada. (8)
- HealthCareCAN helps train healthcare professionals and organizations through a comprehensive and practical online learning program focused on patient-centred experience and design. (8)
- Accreditation Canada introduced client and family-centred care standards to support organizations increase patient engagement and to advance quality and safety in healthcare organizations across the country. (8)
- The Canadian Institute of Health Research is advancing its own organizational strategy for citizen engagement. Patient engagement is a pillar of its Strategy for Patient-Oriented Research, with provincial and national capacity-building initiatives underway. (8)

At the provincial or territorial levels, jurisdictions launched structures and strategies to progress safe and quality care through patient engagement and patient and family-centered care:

- Saskatchewan's 2009 Patient First review included patient and caregiver opinions in setting priorities for provincial health system reform. These priorities continue to shape progressive change that embeds "Patient First" as a core value and focuses on improving the patient experience. Saskatchewan Health Quality Council's number one priority is to integrate patients and families as partners in all aspects of healthcare. (8)
- British Columbia's Patient Voices Network recruits, trains, and supports patients to partner in change processes that improve care and service design. Health authorities and other stakeholders collaborate to identify opportunities for engagement. (8)

- Health Quality Ontario's patient engagement framework guides a provincial strategy to build capacity for patient engagement across the provincial health system and in its own organization. (8)

Many more health authorities and healthcare organizations are taking steps to integrate patient engagement into their work:

- Kingston General Hospital in Ontario introduced the first organization-wide patient engagement policy. Patient partners are now on all major committees and are involved with hiring decisions, staff orientation, and healthcare provider education. (8)
- Capital Health Authority in Nova Scotia (now the Nova Scotia Health Authority) introduced a policy36 that embraces patient and citizen engagement as a core value and business process, offering tools and consultation support to build engagement capacity. (8)
- The Centre intégré universitaire de santé et de services sociaux de la Mauricie-et-du-Centre-du-Québec, has developed an integrated strategy based on three principles:
  (a) Shared leadership between a patient and a manager to build the strategy; (b) A clear process for recruiting, training, and coaching patient advisors (PA) so that they can participate in decision-making at the various levels of governance of the establishment
  (c) A feedback process for improving the strategy over time (8)

Gaps in current practice (8)

Despite progress, a national consultation in 2015 found that more needs to be done to increase patient engagement in organizations and the healthcare system (8). Providers and administrators in Canada's healthcare system acknowledge that patients and their perspectives and experiences should be the guiding factor in clinical care. However, the degree of patient engagement in care varies. Also, while most healthcare organizations collect patient feedback using surveys and most providers share information with patients about their diagnosis and journey of care, many patients said they expect better communication to help them manage their own health, and greater involvement and more collaborative, integrated care that respects their needs. While partnering with

patients is a recognized strategy to improve safety and quality of care, more work needs to be done to:

- Create a culture that supports partnership and collaboration
- Provide supporting structures and policies, information and tools
- Ensure the purpose of the patient participation fits the needs, preference and capacity of those engaged (8)

Partnership in Care Program (PCP)

The notion of " patients as partners" has gained popularity over the past four years, particularly at the Faculty of Medicine of the University of Montreal (UM) (9).The model of care partnership developed at the University of Montreal goes a step further by considering the patient as a full member of the care team, whose status is based on care expertise. (1). The faculty currently has a group of patient trainers who take part in the education of students in the health sciences (more than 6,000 so far), ensuring that they are introduced early on to the concept of patient partnership (PP). This program holds considerable promise for sustaining and improving healthcare services for patients with chronic illness. The literature points to the necessity of soliciting and harnessing patient engagement to maintain and enhance the quality of health care delivery in the future. However, clearer conceptual models remain to be developed.(9)

The patient partnership is based on patients' experiential knowledge, which is defined as "the knowledge a patient develops from the experience of health and psychosocial problems, from the trajectory of care and services, and the impact of these problems on his personal life and that of his relatives". (1)

With regard to Indian healthcare system, patient engagement is still a fledgling concept and with no studies on the subject. India's epidemiological transition is characterized by dual burden of diseases. The burden of NCD's has been increasing in old age without replacing the burden of communicable diseases.(10) This makes an understanding of patient engagment as a practise even more pertinent for future interventions to improve management of care.

Practised forms include health literacy through advocay groups & internet; patient feedback forms largely restricted to out patient services in the corporate hospitals and

few patient engagement solution IT applications used be some hospitals. The National Health Policy 2017 has recently commited as a policy principle to have focus on patient centred and quality of care clearly stating the need to evolve and disseminate standards and guidelines for all levels of facilities and a system to ensure that quality of healthcare is not compromised (NHP 2017).

Patient involvement in quality of care is complex. A recent study in Canada shows that a change in the philosophy of patient–professional relationship beyond patient centered-care to engagement or even partnership in healthcare services, recognizing the patients' experiential knowledge and their role as full members of the team, becomes a powerful lever for service quality improvement. It also shows that the contribution of patients to this approach depends on selecting patients well and training the whole team. It can be a source of inspiration for healthcare organizations wishing to change their philosophy of care and willing to benefit from their patients' experience to improve their processes and results.(1) From the perspective of patient-as- partner, decision-making and quality care actions are based on both professionals' scientific and experiential knowledge and on patients' experiential knowledge of living with the disease. (1)

Patient engagment as a means to improve quality of care has been backed by multiple studies all over the world. However, in a healthcare system like India, which is intricate and complex with regard to delivery of services; adaptation of the patient engagement processes at a local level is crucial.

Rationale

With the emphasis on patient centred care and improvement of quality of care in the National Health Policy, potential of patient engagement as a means to improve quality of care is a major area of interest for policy makers in India. There has been no cross country study yet with two diverse health systems like Canada and India to understand the role of patient engagement in improvement of quality of care. This study aims to understand how patient engagment has contributed to improve the quality of care in Canadian healthcare system and build on that knowledge to propose a local adaptation of the same in context of Indian healthcare system.

Research Questions

- How does patient engagement contribute to quality of care and affect health outcomes Vis a Vis Canadian healthcare system?
- How can it be adapted to Indian healthcare system?

General Objectives

- To understand the role of patient engagement in quality of care and how it affects health outcomes in Canadian healthcare system.
- To understand how patient engagement can be adapted to Indian healthcare system.

Specific objectives

1. To review the policies, norms and guidelines related to patient engagement in Canadian healthcare system.
2. To describe different models of patient engagement on various levels (clinical and organizational and political if relevant).
3. To describe the contribution of patient engagement in quality of care and patient safety.
4. To analyze how Canadian experience can be a source of inspiration in context of Indian healthcare system.

Methodology

Study design: Case study design

Study Setting: The study was conducted across healthcare organizations at three levels:

- Federal Healthcare Organizations
- Healthcare Organizations from province of Quebec (Montreal is a part of Quebec)
- Healthcare Organizations from other provinces of Canada

Duration of study: The study was conducted over a period of three months starting 15 April'2017.

Sampling Method: Purposive sampling was done to identify organizations to conduct the study and stakeholders (managers, researchers, patients, clinicians) for in depth interviews. A list of 17 people was made. Out of them, four people contacted did not respond and one person dropped out of participating upon contact.

Sample size: 11 stakeholders in patient engagement across healthcare organizations in Canada were interviewed in-depth for the study

Study method:

Objective 1

An exploratory review of existing guidelines, norms and policies related to patient engagement in Canadian healthcare system was undertaken to understand the process at a policy level.

Objective 2, 3

Qualitative method of data collection in a case study was used i.e. in-depth interviews of major stakeholders in patient engagement process to understand the various models of patient engagement and describe the process as well as the contribution of patient engagement in quality of care. In depth interviews were recorded by means of writing, audio clips and were supported by papers provided by the interviewees to supplement the interview.

Objective 4

A qualitative analysis of the comments and knowledge built from the interviews was undertaken to summarize steps that can be taken to adapt patient engagement as a practice to India.

Ethical Consideration

An informed verbal consent was taken on record for each participant after explanation of the project and potential use of data. It was ensured that the participation was

voluntary. The data was coded and names of participants and their organizations were given pseudonyms for confidentiality.

Data analysis of in depth interviews

Grounded theory approach for data analysis was used. Like most qualitative analysis methods, grounded theory is based on the concept of emergent themes. These themes are used not only to explore an issue, but also to construct a cohesive idea or theory about an investigated phenomenon as it emerges from the collected data.(9) Audio transcripts were imported into MAXQDA12 for Mac for transcribing and coding of data. To comply with methodological rigor in qualitative data analysis, primary open coding of data was done followed by more thematic coding leading to parent codes and sub-codes. After the first few interviews, concepts and categories were applied to all interview transcripts. Coding categories were then filled up with relevant quotes to ensure grounding of the data, thereby providing an integrated account of how the participants understood and viewed patient engagement and related themes that were explored.

Observations and results

Name of Code	**Frequency of code/sub-code in data**	**Stakeholder Type with higher frequency**
Patient engagement meaning (PC)	13	All stakeholders
How in patient engagement? (SC)	4	Patient advocate
Policy on Patient engagement (PC)	4	Managers
Institutional (SC)	1	Manager
PE Policy: provincial (SC)	12	All stakeholders
PE Policy: Canada (SC)	5	Researchers
Models of Patient Engagement (PC)	12	All stakeholders
Institutional (SC)	3	Researcher
Medical Faculties Involved (SC)	2	Manager
Case study/leading	20	All stakeholders

practice (SC)		
Model involved in (SC)	6	Researchers and managers
Patient engagement and quality of care (PC)	9	All stakeholders
Patient engagement in patient safety (PC)	9	Patient advocates and researchers
Patient engagement and health outcomes (PC)	3	Managers and researchers
Challenges to Patient engagement (PC)	8	All stakeholders
Barriers (SC)	11	All stakeholders
Enablers (SC)	9	Patient advocates and managers
Adaptation to India (PC)	16	Patient advocates and researchers
Patient engagement in community (SC)	7	Patient advocates
SUM	154	

Table 1: Frequency of codes in data

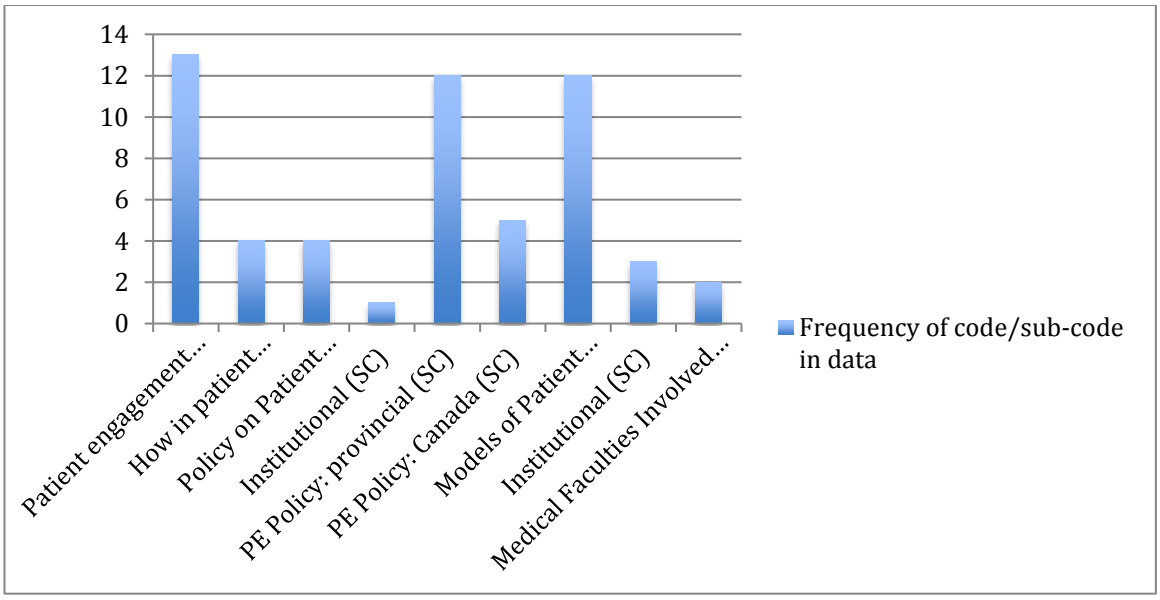


Fig. 1 Frequency of code and sub-codes (SC) in the data

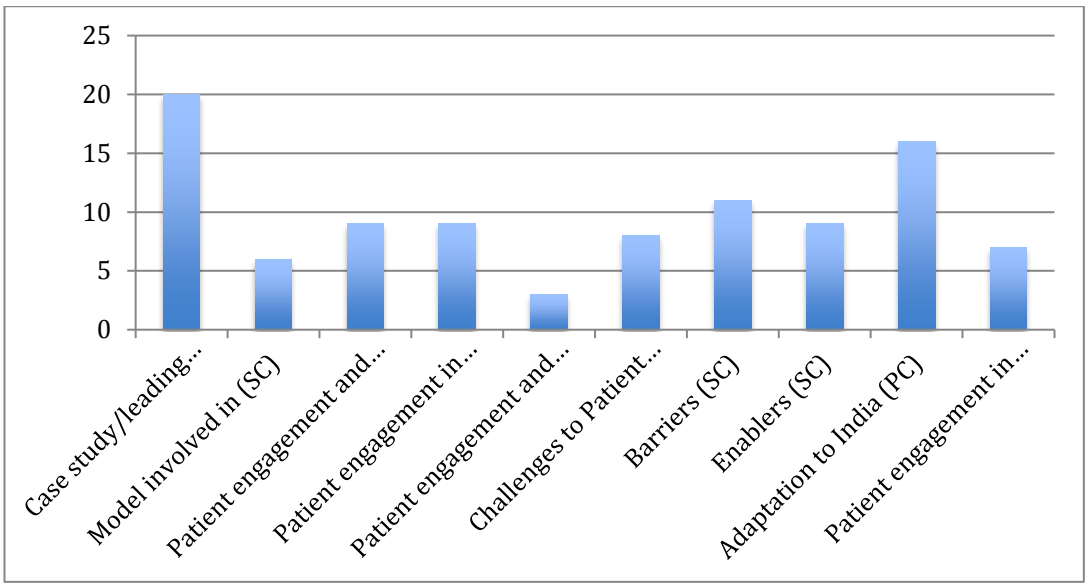


Fig. 2 Frequency of code and sub-codes (SC) in the data (continued)

Word Cloud:

These are some of the words that were frequently mentioned during the analysis of transcribed and coded audios and provide a general essence of the data by highlighting the common themes that were addressed in the data.

Patient, Partnership, engagement, patient expertise, information, consultation, levels of engagement, research, governance, policy, evidence, quality of care, patient safety, lived experience of patients, meaningfully involved, voice of patient, physicians, leadership support, organizational support, culture change, pedagogic barrier, resource intensive, time intensive, stakeholders, local influencers, community, collaborate, track data, training, models, patient pathway.

Discussion of Results (Quotations)

Based on interviews, the results are reported as quotations under the following broad heads

1. Meaning of patient engagement
2. Models of patient engagement
3. Patient engagement and quality of care & patient safety
4. Challenges to patient engagement (barriers and enablers)

5. Adaptation to India

1. Meaning of patient engagement

" It is the direct engagement and involvement of patients in projects, research, evaluation, system design by working directly with them as partner; valuing their expertise and their experience and having real time dialogue about using their perspectives to improve health and health care. "

" It's a broad concept that could apply to all domains of healthcare; governance, care provision, how you organize different services in order to patient patients needs, to assess their experience with healthcare and also in research domains. The three pillars of patient engagement are governance, care and research. "

"Partnering with people who are experts through their lived experience and who have the perspective of beneficiaries of healthcare systems. "

"Working with patients and families in any work related to patient safety, quality improvement and healthcare system. "

"There are three levels to patient participation; information, consultation and partnership at the level of direct care or organizational level. Integrated view on how all of them can be used to improve quality of care. "

"Patients taking part in their own care. Patients really need to direct the process. They are the ones benefitting and at risk from the healthcare system. They need tools to make decisions in an informed way. The old attitude of the benevolent educated caregiver versus uneducated patient who just follows directions is not really a safe model. It's safer to move to a model where the patient is at center of care, and patient and family are actively involved in care and information and knowledge of their care. "

"Patient is meaningfully involved in conceptualization, design, execution, dissemination and knowledge translation of particular task/policy/research/project. The key is to meaningfully involve the patient from first idea of what should be done (identifying area

of study) to what kind of policies are to be issued to all the way through to resolving the problem, in making recommendations and implementing anything that would come forth as a consequence. "

"From a research perspective, it means trying to understand how we can meaningfully engage patients in out research and how we can define our work processes, technology and environment so that they are easier and safer to use. Its about involving them throughout different phases of research project in a meaningful way. "

" A process by which patients are participating in various levels of healthcare. It can range from decision about care an individual patient receives for himself/herself to work around thinking about design/re-design of care for patients similar to ones being involved on a group level or a program level. At an organizational and strategic level, patients become more involved in helping make decisions on policies, program and broader strategic issues about what care is being provided to what groups. "

" Anyway that the healthcare system would involve the patients in either the design or delivery of healthcare services and programs. "

" So, I don't like patient engagement word; because you can be engaged in many ways. What we are doing is partnership; highest level of engagement. Engagement could mean informing, consultation. Partnership is a relationship about co-building, recognition of interdependency and complementarity of expertise/ roles. "

"It's about making sure that the voice of the patient is fully recognized as something necessary. Patients are not just end users but a part of the production chain in healthcare. Health care systems have been involved in delivery of care not partnering with the client/users who are a part of the care. "

2. Models of Patient Engagement

Experience based co-design

" *It's an extremely powerful model. We work with patients to identify their experiences with care service. Patients and families identify their experience and interviews are recorded on videos to produce short films of patient experience. The films are then showed to the patients for their feedback. Healthcare providers are interviewed too on audio. After that we bring them together for co-design meeting where patients and professional work together to identify priorities for change. "*

This model has been used in geriatric in patient department, general medicine, maternity unit, psychiatry and cancer care.

SPOR (Strategy for patient oriented research)

"Its not as much a model, as it is a strategy. "

In this strategy, there is a continuum of research that engages patients as partners, focuses on patient identified priorities and improves patient outcomes.

"There is a strategic unit/methodological unit at the provincial level e.g. Support Unit in Quebec province provides support and training for researchers doing patient engagement in research more specifically in primary care research. "

" They are strategic clinical networks in Alberta charged with the mandate of how to make healthcare services more effective and efficient "

The objective of SPOR is to foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care, so as to ensure greater quality, accountability, and accessibility of care.

SPOR is a coalition of federal, provincial and territorial partners – all dedicated to the integration of research into care:

- patients and caregivers
- researchers
- health practitioners
- policy makers
- provincial/territorial health authorities
- academic institutions
- charities
- private sector

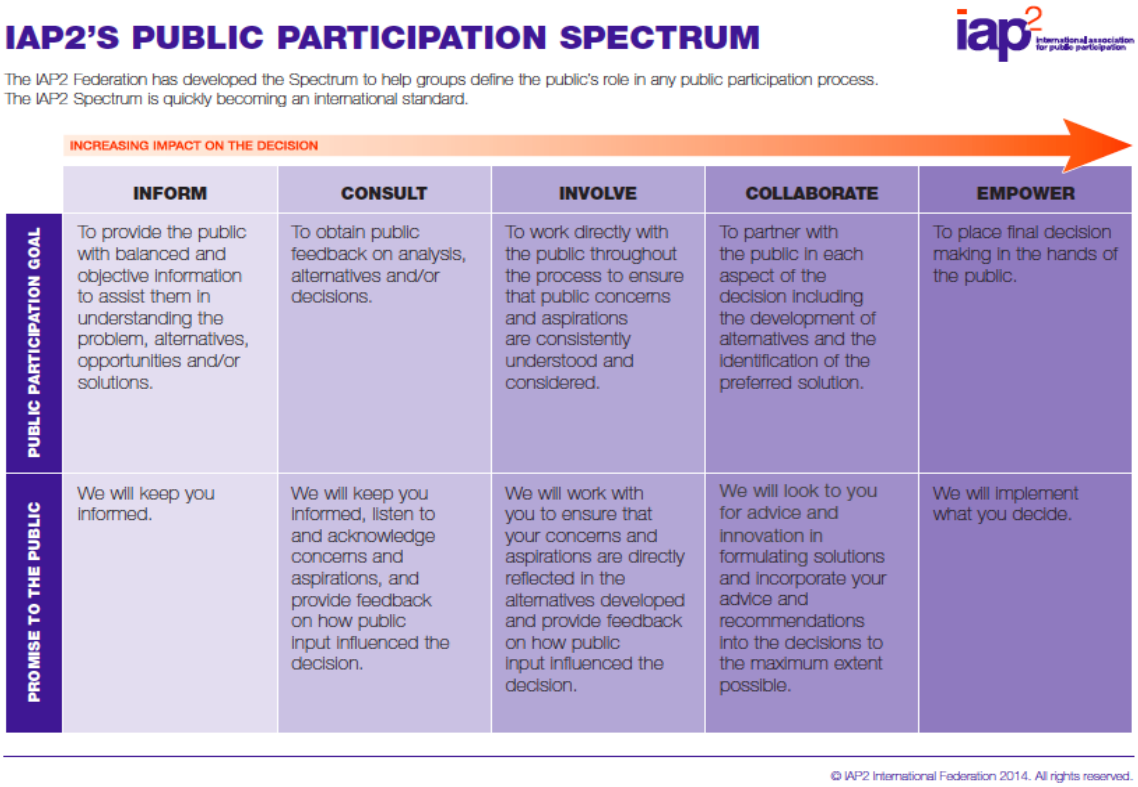
SPOR adheres to the following principles:

- Patients need to be involved in all aspects of the research to ensure questions and results are relevant;
- Decision-makers and clinicians need to be involved throughout the entire research process to ensure integration into policy and practice;
- Funding under SPOR is based on a 1:1 matching formula with non-federal government partners to ensure relevance and applicability;
- Effective patient-oriented research requires a multi-disciplinary approach; and
- SPOR is outcome driven and incorporates performance measurement and evaluation as integral components of the initiative

Spectrum of engagement (IAP 2: International Association for public participation)

" It helps us decide on specific questions/purpose of research "

" We can choose what is appropriate patient engagement to consult, involve, collaborate or delegate to the patient. "



IAP2'S PUBLIC PARTICIPATION SPECTRUM

The IAP2 Federation has developed the Spectrum to help groups define the public's role in any public participation process. The IAP2 Spectrum is quickly becoming an international standard.

INCREASING IMPACT ON THE DECISION

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

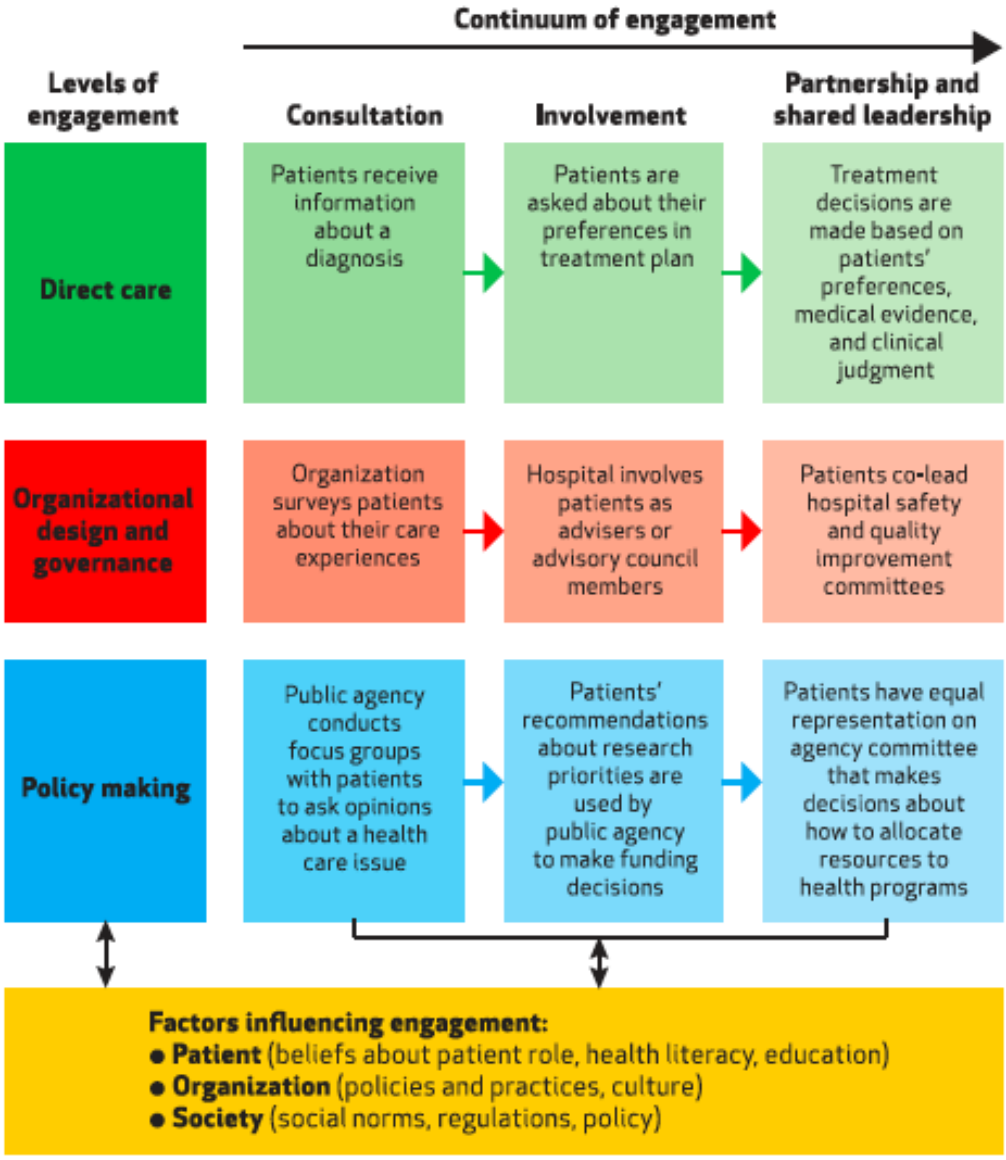
Fig.3 Public participation spectrum (IAP)

" An organization must adapt and create a framework, it's important to have a framework and follow a structure "

Carman Model (from literature)

EXHIBIT 1

A Multidimensional Framework For Patient And Family Engagement In Health And Health Care



SOURCE Authors' analysis. **NOTE** Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

Fig. 4 Carman's Model of Patient engagement (Literature)

Patient centered care model

"Putting patient at the center of care"

"At an organizational level:

- *In quality department : advisory role in quality committee*
- *A structured recruitment process to include patient as a part of the quality committee.*
- *Integrated approach to patient partner and quality*
- *Asking quality teams to have patients in them (at least 2) and involve them in projects "*

PaCERs (Patient and Community Engagement Researchers) Model (11)

Training citizens living with various health conditions to design and conduct health research, using adapted methods of qualitative inquiry, paves the way for new approaches. Patient and Community Engagement Researchers (PaCERs) collaborate with health professionals, policy makers and engage other patients in all phases of research from setting study questions, agendas, implementation, through to the uptake of results.

The PaCER method of data collection and analysis engages patients in focus groups to define the scope and research questions (Set), followed by various data collection activities such as focus groups, questionnaires, observation, narrative interviewing (Collect), and a final (Reflect) focus group. Research protocols are negotiated in collaboration with academic researchers, ethics panels, funders and PaCER teams.(11)

PaCERs have enhanced the research community in tangible ways. Individuals involved in the experience have developed both the self-confidence and competence to be more meaningfully engaged in research outcomes which impact care protocols and the negotiation of healthcare policy. Healthcare professionals have new tools to obtain credible data that are relevant to patients. Based on examples from several recent PaCER studies, its seen that patients often reveal formerly unknown commentary on how they experience current best practices and entirely refreshing views of optimal treatment, care and outcomes from the patient as consumer perspective.(11)

The patient engagement research approach has potential to improve the results of patient experience and outcome analysis, in any clinical research area. Adding the

active voice, and research minds of patients can enrich the patient engagement process in outcome research.(11)

Montreal Model of Patient engagement

" *This model involves engaging patient in quality improvement"*

"The Montreal model is driving projects on three sides:

- *Patient engagement in education*
  - *Patients in medical education*
  - *Simulation activities involving patients/actors as trainers to train students in communication, collaboration as competencies and ethics*
- *Patient engagement in care*
  - *Deployed Quality improvement committees in 16 hospitals to engage patients in the committee. Now 30 hospitals are doing that (province wide)*
- *Patient engagement in research*
  - *Supporting Canadian research network to engage patients in governance committees in research networks*
  - *Involving patients in research projects*
  - *Patient engagement in knowledge translation*

    In a recent initiative, patients are involved in co-building and defining the quality policy"

" We try to multiply the way we engage patients in the specific context of engaging patients to understand how it works and what are the barriers in partnerships. "

3. Patient engagement and quality of care & patient safety

" The link between improved quality of care and providing better information to people is in high demand. The contribution of patient engagement is that patients feel better equipped; asking for more information; quality of care aspect around communication of health care team, perception of responsiveness of team; families manage medication better; patient feels supported. Physicians have said in quality assessments that they feel much better informed and there is better communication in team leading to better quality of care. "

" Ways of contribution to quality of care are:

- *Improved effectiveness*
- *Improved efficiency of care*
- *Better responsiveness*
- *Equity in care*
- *Application of diversity of experience "*

" Patient engagement has an effect on the quality of care, though evidence out there is not so clear because, it is very hard to have two identical projects with patients and control and then compare and evaluate them. "

"Yes, I think its clear that there is an impact. Putting patient partnership department in the quality office makes sense. Just to be able to have patient involved makes a difference. "

" Patient engagement has a strong potential for influencing quality if care and patient safety through several mechanisms:

- *Increased sources of information and inputs for decisions to be made; so that decisions about design of care and strategies of care increases the likelihood that they will influence outcomes*
- *Patients help to change the dynamics of decision-making. With multiple patients in room, it is difficult to revert to traditional style of decision-making, because patients don't understand the prevailing healthcare culture so it becomes a more equitable decision-making environment that respects the sobriety of decisions.*

For reasons of process as well as substance, putting patients in the room changes the way we see and act upon information we have. "

" The contribution of patient engagement to quality of care is huge. In quality improvement, usually you have only healthcare people thinking about improvement and what you have are very complicated solutions to simpler issues with smaller effect. When you bring patients to board; we saw that in experiments that its small improvements with huge impact and this impact are usually systemic. That's what patient and families are bringing to quality of care. "

" The contribution of patient engagement to quality is huge due to following reasons:

- *Patients and families are the only ones who have a systemic view of the care*
- *Before having them engaged; it was almost impossible to have something else than hospital centric view of quality improvement*
- *Now, we have a systemic view and it has shifted to 'patient pathway'*
- *The continuum of healthcare is in a mess. Health system is functioning well in silos but not in terms of patients view. "*

" The very fact that you have a patient engagement project in hospital raises the profile of paying attention to the patients. "

" For patient safety, most striking examples are making patient aware of safety problems that can arise and become your ambassadors. When you see research on hand cleaning, that demonstrate really good impact on making patients participate in project; reminding healthcare workers 'have you washed your hands?' and in medical surveillance as well. "

"The patients are aware of the idea of optimal care they should receive and if they can assess the care they should receive and if they can assess the care they receive is line with what they should receive or best practices. If the patient is engaged, he can discuss with healthcare providers and this is known as shared decision-making where a patient is presented with all options and there is a discussion about their values and preferences and this improves the overall quality of care. "

" Yes, everybody believes that patient engagement has an effect on the quality of care and patient safety, but you need studies to prove that. "

" The insight and knowledge of patient and family members who are informal/unpaid care givers is essential for safety and quality. You can't do without them. Patient safety has been traditionally an examination of what the system defines as unsafe but if you pay attention to the WHO definition of patient safety then it depends on the patient harm i.e. experience of patients and families on harm. If you don't talk to patients and families on what is harmful; what's the experience of harm then you really haven't got a grasp of what is unsafe and managing risk is at the heart of patient safety and quality practices. Patient safety is managing risk and lessening risk of harm by embracing the

notion that there are unpredictable events that will happen and we want to minimize potential of damage to patients, healthcare staff. Patient partnership can be very supportive and encouraging for people in healthcare who go in wanting to heal and provide hope to patient and the family. "

" Yes, patient engagement has an effect in patient safety. For example, the push about medication safety ISMP came out with is just a poster that asks 5 questions about medication. Creating a poster like that with patient engagement not only informs patients about what they should know about medication but also reminds providers that patients and families should have this information. It really helps dialogue in communication. Patient and the family are the first line of defense, first to see any adverse reaction or when something goes wrong. So, a provider sitting in an office waiting for a patient to make a call is certainly not as safe having a patient/family member proactively involved in the care. They are not the medical professionals but they are the eyes and ears on the ground looking for anything wrong so that they can alert the professionals. "

" Yes, patient engagement affects patient safety in many ways. When an organization has initiatives in place where the patients can report incidents. That information can then be fed back to the hospital; just the same way a clinician can report; because patients have a unique view that we don't. It involves giving them a voice, they aren't used to having and making information not easily accessible to patients more readily available. By having a regular feedback system; we can understand the challenges and design solutions. "

4. Challenges to patient engagement (barriers and enablers)

" The challenge is to find a way for patients and physicians to come together; the system is for them. Not everyone gets exactly what they want, but to reach the sweet spot of negotiation between patients lobby and professional "

" There is reluctance to culture change. "

"There is a lot of friction and it is easy to blame the doctors. Work on patient safety is system failure not people failure. It is because the healthcare system is so complex that we set people up to fail. "

" You cannot force patient engagement. It has to be mutually agreed. "

"People who are doing it now are the people already convinced that it's a good idea and that is not a large portion of healthcare system. So, we need to support others who are reluctant to do this in a meaningful way and share experiences of what has already been achieved in terms of what successes are possible if patient engagement is done in a meaningful way. "

" There is a whole list of challenges. Doing it in a way it has meaningful influence on decision- making requires considerable investment in terms of supporting patients to be part of decision- making processes. It required that there is equal investment in helping staff to understand on why this is so important and why not done just a token activity.
So, patient engagement is not free but something that requires investment in resources, time, energy from staff, patients and leaders especially in an environment, which is low on resources. "

" The first challenge is resources; it is a resource intense process. It requires specialized people. It requires leadership support. "

"Physicians are the first challenge. If you do not change physicians nothing changes. They are the first leaders of the system. That is why Montreal Model is a success. It is the first project in world that is written in faculty of medicine. Physicians are hard to convince but once you have them on board; it's done; they are the best leaders. "

"Recognizing that cultures within healthcare has traditionally not accepted patient voice. So, accepting that the cultural change is challenging and can be very disruptive to an organization. Requires senior leadership at the point of delivery because that is where the change happens. Innovators who take on new ideas of patient partnership need support from leadership. "

"Terrific patient partnerships are very much moulded to specific type of environment. Not one size fits all. So culture and setting that healthcare takes place is in important. "
"What enabled patient engagement in Canada was the fact that how welcoming Canadians were to the idea. There were organizations that were ready, willing and embracing patients as partners. "

" The first challenge is that everyone is busy! Both patients and providers. "

" The challenge is to show people what we mean by patient engagement. Some people already feel that they are doing it and don't get the extra step they need to do. You really have to have a communication strategy to create awareness, to showcase examples instead of staying at the level of principle. "

" The biggest challenge is there are cultural challenges we are trying to implement. It is convincing those old school people that patient engagement is cost effective and time effective and safer. "

" The challenge is to define roles that patients being engaged understand the role and clinicians, managers, researchers also understand the role of patients. "

" How to compensate somebody for their time? "

" Main barrier is to define them, patients. Having access to patients is a barrier. "

" A main challenge is the cultural shift for the trained practitioners, a pedagogic barrier. "

A few enablers:

" Patients that themselves are passionate and dedicate hours to volunteer for others benefit. "

"Leadership support / organizational support. "

“ Administrative support and secretarial support to patients to take care of everything else so they are just concerned with bringing in the patient voice. “

“ WHO recognition/ cooperation with the program makes a lot of impact. The patients feel that I belong to WHO community of patients and I am a patient champion. This gave a lot of credibility to our patient champions. “

“ We need a few success stories, build a small project, to promote and communicate and people will see what you can do with patient engagement and inquire more about it “

“ Time investment in patient engagement reaps the benefit of having a sustainable product. “

“ Potential evidence about the impact of patient engagement; there is growing literature that which suggests patient engagement makes a difference. “

“ Having additional resources to support patient engagement. “

5. Adaptation to India

“ We need to find a common ground that meets people on a ground they are on. People with lived experience are the ones needed. Participatory video is a brilliant idea for leveling the plane and the equalizing power dimensions. You need to find right people asking questions and make sure both sides have benefits of information of what is expected out of them. “

“ Define problem, explore options; what might be acceptable, what can be adapted; keep it narrow and feasible in beginning for an impact on policy level. “

“ You need humble people to work in this arena. “

“Pick a place, time, people open to the idea. “

"What you need is both bottoms up and top down mechanism to be really effective. Top down, an idea of a national, regional or even institutional policy to promote this kind of a thing with some real incentives is great. There needs to be an institutional or government policy to set expectation even if its just a guideline or providing a set of examples of where to start. "

" From bottom, finding pragmatic ways of engaging patients at the level of individual care and program/service level. Micro level activities include training for positions about communication eg. patient coordinator and providing better information to the patients. Meso-level activities include providing simple tools like videos example for orientation of patients. At macro level, it requires changing culture within institutions and finding champions. "

" Be clear about which level do you want to implement patient engagement. For each domain, there are specific frameworks and some can be used across domains. Focus on one place, which is more ready, where idea will find less resistance. Assess the barrier and facilitators. Bring all the stakeholders to discuss, followed by planning, implementation and evaluation. "

" First step is to do a survey study of readiness of different stakeholders for patient engagement importance. Take input of stakeholders. Present a model/framework and study examples from UK, Canada and Australia. "

" Start small scale with an innovative partner. For example: with a university hospital because university brings methodological rigor and is more open to innovation and more likely to work not for profit. "

"The words/quote from a patient/ family member can bring out the humanity in your management, leaders, doctors and help them see a bigger picture because that's what patients do; help us see the people behind statistics and numbers. "

" Keep a track of what people say an do, all data. The attitude of people, conversational changes, perspectives of persons who care about health care. Collect everything you can because not everything can be measured. "

“ Recruiting a group of patients and having an organization willing to work with them. Patients need to be coached well. We look for patients who have been harmed by the health care system and they are healed and ready to be productive. “

“ Measure what you are doing and keep a track of everything for evidence. “

“ Traditional medicine whose main tenet is thinking of person as a whole can be a good starting point. “

“You really have to have a communication strategy to create awareness, to showcase examples instead of staying at the level of principle. “

“ Make sure everybody understands the purpose of patient engagement. There is a need to have infrastructure support to provide training support. It requires long-term investment. “

“ Bring a collaborator, body of knowledge together so by creating a multidisciplinary group of researchers, clinicians, patients, policy makers. You need people that are in a position of power to make changes happen. There should be a structure in place for understanding how to engage patients. “

“ Find local influences; people who have status in district and work with them directly on how to test this out. Having continuing dialogue with key players in new environment including professional staff, leaders, patients and families on what would work. I think we can learn from others; but we have to adapt to local environment so how an idea is introduced, supported and developed will be different in India than Canada. “

“ In every society, there are cultural biases about the best way to achieve results so it’s important not to assume that something worked in Canada is going to work in same way in other settings. “

“ It is very tricky to move models from one healthcare system to another because of strong cultural norms developed within healthcare systems. So, looking at the models from North America and Europe is interesting and valuable; but then you need to have

focus groups and discussions with staff and leaders to understand what would make a difference in that setting. "

" Look at what other countries are doing by an environmental scan. A strong leadership support is crucial. "

" At a community level; if you are engaged you have opportunity to hear from patients what their concerns might be and to help feedback into system about what priorities they might focus on. "

" Structure must be there to identify who is to be engaged under community leaders for patient engagement. "

" We built community based medicine; which you don't have to do, I think. So build on that and make the movement emerge from the basis you have already. Strengthen on what you have already and maybe work more on individual basis. Community engagement is patient engagement. "

Leading Practices/Case studies of Patient engagement

<u>CODE Help (Early partnership on patient safety involving patients and families)</u>

In a Vancouver hospital, the leadership wanted to demonstrate that hospital care could be very sensitive to the needs of patients and families. Three patient partners were a part of the committee for the project to develop a rapid response system for patients and families; if they felt that they were at risk or imminent damage, so that they should be able to help. The system was thus made with the insight of patients, nurses and infectious diseases specialists.

The family member or patient could call a phone number and within a targeted time frame of 15 min, a critical care nurse would attend to the call. This became a part of the orientation programme when a patient arrived on the floor where patients and family were told that they are a part of the care team and if they felt a serious issue being overlooked or not getting enough attention or healthcare workers were too busy, they could get attention by calling the number.

The nurses involved in the implementation were trained. It was observed that most patient calls were related to "communication failures " with patients seeking information due to unclear patient provider communication. This highlighted specific challenges.

The practice has been incorporated as a leading practice in Accreditation Canada's book of leading practices.

"*The result has been that people now sleep better and understand information better, both patients and families and have a higher confidence in care givers* "

Patient engagement guide (CPSI)

A consortium of organizations identified a need for the patient engagement for patient safety guideline. An action group consisting of 20 organizations came together to build the guide. From the beginning of the process, the patients were a part of the following:

- Consortium of organizations for need identification
- Building of the guide; sitting at the table side by side
- Focus group consultations along project phases consultations

Quality Improvement project with multiple sclerosis

To begin with, there was a team that was willing to improve care. Before, anything started with the project; patient partners were recruited and involved in an interdisciplinary team that consisted of patient partners, 2 nurses, physician and manager. Patients were involved in "priority of action". The interesting aspect was that, the team minus patients had though that time spent in waiting area was the main concern of the patients, however patients brought in the insight that wait time was not as much of an area of concern as was the phone access to the care team between visits. With this problem area identified, lean approach was used to create a helpline where a patient could call from 9am-1pm and would surely find a nurse dedicated to attending their calls. This also took load off the nursing staff, for calls. Patients were a full member of team at every step of the project right from the problem identification to implementation, evaluation and communication of the project results.

Steps that can be taken to adapt patient engagement as a practice to India

- Environmental scan of various countries and models of patient engagement in their healthcare system to understand frameworks of implementation and challenges.

- An internal/external environmental scan (example SWOT) of the Indian healthcare system with respect to patient engagement.

- Stakeholder analysis and survey of readiness of stakeholders towards the introduction and implementation of the concept.

- Finding local influencers, leadership support, willing organizations and relevant people to form a multidisciplinary knowledge group.

- Recruitment of patient champions (affiliation with WHO community of patients)

- Collaborating with innovative partners like University medical colleges to start small-scale projects demonstrating effect of patient engagement in different levels like governance, care or research.

- Patient engagement in community setting must be explored.

- Tracking all data and gathering evidence.

- Advocacy for policy on national/regional/institutional level on patient engagement.

Discussion

Patient engagement has been defined by the participants as a practice of partnering with people who are experts through their lived experience and meaningfully involving the patients at three levels i.e. governance, care and research right from the first idea to all the way through to resolving a problem and evaluation and knowledge sharing. Canadian healthcare system has some interesting and successful models of patient engagement like experience based co-design and SPOR, which engage patients meaningfully as partners to identify priorities for change. The Carman's model from literature defines three levels of patient engagement i.e. direct, organizational and policy level where patients could be engaged through consultation, involving and partnership The Montreal Model which is by far one of the most successful in terms of partnering with the patient is the first model that was co-built with the faculty of medicine and goes an extra step by having patient as a partner at the level of education, care and research and is increasingly looked upon as a model worthy of replication in terms of success and innovation. PaCER's is model of engaging patients into research by training citizens with health conditions to design and conduct research.

All the participants agreed upon the contribution of patient engagement as a practice to quality of care and patient safety as immense. There are many ways in which it is being done. Patient engagement makes the patients better informed and equipped to seek the right information and report adverse events. There is an improved efficiency and effectiveness to care; better responsiveness. The patients when brought as partners also make the decision making process more equitable. The physicians report better communication with the team and patients. Being a part of the quality committees, patients bring the unique insight of how care processes are viewed by them leading to more efficient identification of problems and designing better solutions in conjunction with the professionals; ultimately adding up to improve the quality of care. In terms of patient safety, patients and families being the first line of defense can alert the professionals and help in managing risk of adverse events better, preventing potential damage to patients and healthcare staff as well.

However, the participants identified challenges to implementation of patient engagement as well as enablers. One of the main challenges is shifting culture for both patients and physicians. The physicians face a pedagogic barrier. Another main

challenge is resources as patient engagement is a resource intensive activity and requires considerable investment of time as well as money. Other barriers according to the participants were defining roles and generating evidence for patient engagement, which is still not enough. Some enablers are committed leadership support, WHO recognition for motivating the patient champions and enhance credibility and additional resources.

All the participants were asked on how patient engagement, as a practice could be adapted to a country and healthcare system like India. In their view, it is important to first find local influencers and do s survey to assess stakeholders' readiness of the system to adapt and according mould a program adapted to the environment. Most of the participants were of the view that starting with a small project with an organization or an innovator who is willing to work and documentation of such success could be very useful in beginning a policy level dialogue about patient engagement. A strong communication strategy to create awareness and explain what patient engagement actually means is also pivotal. Another theme that was brought out was the use of strong community based system of Indian medicine and healthcare system as the starting point because community engagement is essentially patient engagement. The need for gathering and recording data of any and every project to strengthen the evidence base was emphasized upon by almost all the participants. Above all, what is really needed are a dedicated pool of patients, professionals and organizations willing to do the work.

Conclusion

Canadian healthcare system is at the forefront of practicing patient engagement at the level of direct care and progressing steadily towards more at the levels of governance and policy as well. Patient engagement has been a significant contributor to enhancing the quality of care and patient safety practices in Canadian healthcare system; although there are challenges in implementation but the potential benefits are immense. Bringing similar models to Indian healthcare system comes with challenges but adapting to the local environment and constructing models and frameworks that succeed in pilot projects could potentially lead to improvement in quality of care, patient safety and ultimately the health outcomes.

Bibliography

1. Pomey M-P, Hihat H, Khalifa M, Lebel P. Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. Patient Exp J. 2015;2(1):29–42.
2. Karazivan P, Dumez V, Flora L, Pomey M-P, Del Grande C, Ghadiri DP, et al. The Patient-as-Partner Approach in Health Care. Acad Med. 2015;90(4):437–41.
3. Renedo A, Marston CA, Spyridonidis D, Barlow J. Patient and Public Involvement in Healthcare Quality Improvement: How organizations can help patients and professionals to collaborate. Public Manag Rev [Internet]. 2015;17(1):17–34. Available from: http://www.tandfonline.com/doi/abs/10.1080/14719037.2014.881535
4. Coulter A. Patient Engagement—What Works? J Ambul Care Manage [Internet]. 2012;35(2):80–9. Available from: http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00004479-201204000-00003
5. Richards T, Montori VM, Godlee F, Lapsley P, Paul D. Let the patient revolution begin. BMJ [Internet]. 2013;346(2):f2614. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23674136
6. Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: A qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. Int J Qual Heal Care [Internet]. 2011;23(5):510–5. Available from: http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L362553241%5Cnhttp://dx.doi.org/10.1093/intqhc/mzr024%5Cnhttp://limo.libis.be/resolver?&sid=EMBASE&issn=13534505&id=doi:10.1093/intqhc/mzr024&atitle=Promoting+patient-centered+care:+
7. Baker GR. Evidence Boost : A Review of Research Highlighting How Patient Engagement Contributes to Improved Care Strategies to Improve Patient Experiences of Care Barriers to Improving Patient and Family-. 2014;(August):8. Available from: http://www.cfhi-fcass.ca/sf-docs/default-source/reports/evidenceboost-rossbaker-peimprovedcare-e.pdf?sfvrsn=8
8. Engagement P, Team A. Patient Engagement Action Team - May 2017. 2017;(May).
9. Pomey M-P, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study of patients' engagement in their health care. PLoS One [Internet]. 2015;10(4):19. Available from: http://dx.doi.org/10.1371/journal.pone.0122499
10. Yadav S, Arokiasamy P. Understanding epidemiological transition in India. Glob Health Action. 2014;7(SUPP.1):1–14.
11. Hylton C. Patient engagement – the PaCER model. Trials [Internet]. 2015;16(S3):O2. Available from: http://trialsjournal.biomedcentral.com/articles/10.1186/1745-6215-16-S3-O2

Verbal consent script

Hi! I am Vandana Rathore, an MBA (Healthcare) student from India and I am doing a project under the Queen Elizabeth Scholarships to understand how patient engagement works in the Canadian healthcare system and how it can be adapted to Indian healthcare system. For that purpose I am interviewing stakeholders in the process. Your views and perspective on the subject shall be a very valuable input for my project. The data collected is purely for academic purposes and shall remain with the University of Montreal and IIIHMR (subject to what Udem wants to share). All data shall be confidential. Participation is voluntary and you are free to withdraw at any point without any explanations. I would be happy to share my project with you.

Would you like to participate in my project?
Yes/No

If yes, may I please record the interview?
Yes/No

Interview guide

Topic guide:

- Patient engagement
- Policies for patient engagement
- Models of patient engagement
- Patient engagement and quality of care
- Patient engagement and patient safety
- Adaptation of patient engagement for India

Sample questions

1. What do you understand by patient engagement?
2. Do you know of any policies for patient engagement in Canada?
    - In Canada
    - In province
3. For how long have you been engaged in patient engagement?
4. What models of patient engagement are in practice? Can you describe them?
5. In which models have you been involved?
6. Can you state an example/case study illustrating patient engagement?
7. Do you think patient engagement affects the quality of care and patient safety? If yes, how?
8. Do you think patient engagement affects the health outcomes? If yes, how?
9. What are the challenges you face in implementing patient engagement? Enablers and barriers?
10. Finally, what would be your advise on adapting patient engagement as a practice for a country like India

Annexure III

Table 2. Parent and Sub codes

Parent Code	Sub code
Patient engagement	• Meaning • Journey
Policy	• Legislation • Guideline/framework • Institutional • Federal • Provincial
Models	• Model names • Institutional models • Example/leading practice
Patient engagement and quality of care	No sub-code
Patient engagement and patient safety	No sub-code
Patient engagement and health outcomes	No sub-code
Challenges	• Barriers • Enablers
Adaptation to India	• Patient engagement in community

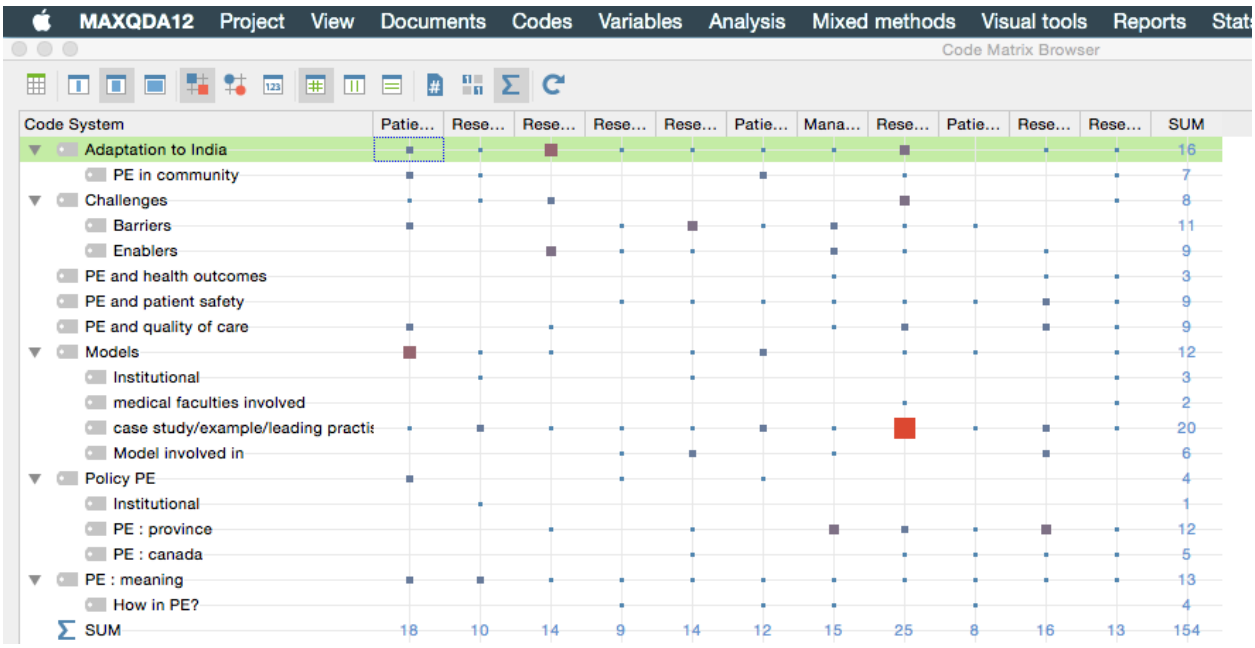


Fig. 5: Code Matrix (Visual)