



## **Applied Health Services Research as a Framework for Patient-Oriented Research:**

### **A Suggested Framework for Health Care Researchers**

By:

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### **Abstract**

Engaging the general population in the research process provides new visions that may lead to innovations and research that are relevant to patients. Many developed countries like Canada are working toward engaging the population in healthcare research to achieve outcomes pertaining to enhanced accountability, transparency, and population empowerment in research. For example, Canada created Canada's Strategy for Patient-Oriented Research (SPOR) (Canadian Institute of Health Research [CIHR], 2011) to empower the patient's role in health research and the healthcare system. However, there appears to be a gap in the literature because few studies or reports could be found on how applied health services research might be used as a framework for patient-oriented research. The aims of these authors in this paper are to (1) discuss how the applied health services research (AHSR) can be used as a framework for patient-oriented research (POR); and (2) describe salient challenges and potential outcomes that may result from implementing applied health research as a framework for patient-oriented research. This is a multidimensional framework for patient engagement using AHSR as a framework for POR as they have shared crossover research aspects between them. Conducting POR at different levels of AHSR reduces the gap between health research and practice, and empower patients to be responsible for their own health and health services (Gooberman-Hill et al., 2013). The multidisciplinary nature of AHSR and POR may face challenges related to research interests, patients, patient involvement, environmental/ organizational regulations and policies, and research culture.

**Keywords:** Applied Health Services Research; Framework for Patient-Orientated Research; Framework for Health Care Researchers

Canada's health care system is evolving from a principle of paternalism to a principle of patient autonomy, wherein patients take an active role in making their own decisions about their health care (Sacristán, 2013). Many developed countries like Canada are working toward engaging the population in healthcare research in order to achieve outcomes pertaining to enhanced accountability, transparency, and population empowerment in research (Boote, Telford, & Cooper, 2002). For example, in 2011 the Canadian government created *Canada's Strategy for Patient-Oriented Research (SPOR)* to empower the patient's role in health research and the healthcare system (CIHR, 2011). Moreover, engaging the population in the research process provides new visions that may lead to innovations and research that are relevant to quality patient care. *Patient-Oriented Research (POR)* covers clinical research, health services research, and the process of integrating clients into the health care system (CIHR, 2011). By contrast, *Applied Health Services Research (AHSR)*, which includes health services at the clinical, institutional, systematic, and environmental levels, focuses on cost-effectiveness at the primary and secondary care levels (Bowling, 2014; Institute of Medicine, U.S. Division of Health Care Services, 1979). In this paper, patient(s), the client(s), community, public, and the population will be used interchangeably to indicate individuals, families, and communities in illness and wellness contexts.

An apparent literature gap indicates a possible disconnect between applied health services research and its use as a framework for patient-oriented research. To our knowledge, this paper is one of few papers to discuss illustrative strategies for using applied health services research as a framework for patient-oriented research. The authors' aim of this paper is two-fold: (1) to discuss how the Applied Health Services Research (AHSR) might be used as a framework for patient-oriented research (POR), and (2) to describe salient challenges and potential outcomes that may result from implementing applied health research as a framework for patient-oriented research. The following topics are discussed: Applied Health Services Research (AHSR), Patient-Oriented Research (POR), AHSR as a framework for POR, challenges, and outcomes in using AHSR as a framework for POR, and recommendations for future research.

### **Applied Health Services Research**

Applied Health Services Research (AHSR) is defined as "a multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of healthcare, and ultimately our health and well-being" (Lohr & Steinwachs, 2002, p.16). It appears that AHSR may have a significant influence on healthcare and health services that are provided for individuals, families, organizations, institutions, communities, and population.

AHSR can be categorized into four primary levels: clinical, institutional, systemic, and environmental. Figure 1 indicates these levels in order of increasing generality, proceeding from the core studies of clinical practice to the broader environmental level. The

characteristics of health services in the broader social, political, and economic environment affect the inner three interrelated levels. Environmental health research typically deals with issues that are somewhat remote to clinically oriented research. However, in AHSR, environmental level research depends ultimately upon its inter-relationship with other studies at the systemic, institutional, and clinical levels (Institute of Medicine (U.S.). Division of Health Care Services, 1979).

### **Patient-Oriented Research**

Patient-Oriented Research (POR) is defined as direct interaction research with human subjects or materials of human origin (tissue, specimen) in either an outpatient or inpatient setting (Sontheimer & Werth, 1998). Given the recent emphasis on patient engagement in health research, the scope of POR has broadened in its effort to improve health and healthcare outcomes for individuals, families, communities, and population. Consequently, POR is now redefined as a research approach that requires direct interaction with patients as research partners at various levels across the healthcare system (clinical care, organizational and governance, and policy-making) to improve the health outcomes for patients and healthcare system (Carman et al., 2013; CIHR, 2011). POR is a multidisciplinary research approach that includes the development of new technologies, understanding mechanisms of human disease, therapeutic interventions, and clinical trials (Rubio et al., 2010; Strom, Norman, & Margolis, 2002). POR has four essential premises (Rosenthal et al., 2009; Shaywitz, Martin, & Ausiello, 2000): (1) the patient is the focus, and the patient must be involved in all aspects of the research process; (2) patients and researchers are equal partners in sharing research responsibility; (3) researchers and patients have to share the skills, knowledge of conducting research, and publishing the research results; (4) research results have to be used to inform and direct change policies and health practice.

There is an agreement in the literature that patient involvement can make a difference in health research (Gooberman-Hill et al., 2013). However, there is a debate about the level of patient engagement in such research (Boote et al., 2002). In general, there are three levels of patient involvement: (1) consultation, (2) collaboration, and (3) patient control. The consultation level entails minimal patient involvement and refers to situations in which researchers solicit patients' perspectives, experiences, and preferences. The collaboration level, which is considered to be the most effective level of patient involvement, refers to situations in which an on-going partnership between researchers and patients occurs throughout the research process. The patient control level has the highest degree of participation where patients initiate, design, and undertake the research process, while professional researchers are involved in inviting patients/public to be part of the research (Boote et al., 2002; Oliver et al., 2008).

### **AHSR as a framework for POR**

AHSR and POR have five common crossover characteristics, both: (1) address multidisciplinary fields, and are conducted by a multidisciplinary research team; (2) focus on individuals, family, communities, and population; (3) aim to improve the health of individuals and society, health services, and cost-effectiveness of the health care system; (4) use a particularly different set of research methods, theories, concepts, statistics, and devices and instruments derived from various disciplines; and (5) can be carried out at different levels of the healthcare system. In conclusion, these five similarities between the two approaches are a promising base to use AHSR as a framework for POR.

Domecq et al. (2014) conducted a systematic review of POR and found that patient engagement is feasible in different health research and at all research levels. Therefore, it is possible to engage POR with AHSR and at any research level. For example, in 1996, the British Institution for Health Research created a project called INVOLVE to engage patients and community stakeholders in health services and research (NIHR, n.d). For more elaboration, Carman et al. (2013) developed and suggested a multidimensional framework for patient and family engagement in health research. Their suggested framework has three levels of POR; direct care, organizational, and policy-making with continuum patient engagement in the research process. From the perspective of authors of this paper, this framework can be adopted and improved in AHSR to engage patients with all AHSR levels (clinical, institutional, systemic, and environmental).

Based on the literature, the authors of this paper proposed a multidimensional framework to engage POR in all AHSR levels (Figure 2). It has been found that the combination of consultation and collaboration of public engagement is the most effective method in large-scale projects (Oliver et al., 2008). Therefore, we assumed a continuum combining consultative and collaborative patient engagement during the research process. At all AHSR levels, patients and their representatives collaborate with community leaders, policymakers, stakeholders, healthcare providers, and professional researchers to set health services priorities, make policies and decisions to improve healthcare outcomes. Since all AHSR levels are in interrelationship, we expect that the outcomes of POR engaged in AHSR are going to be interdependent. For example, a decision that is made at the environmental level will influence health services at the systemic, institutional, and clinical levels.

At the clinical level, patient engagement can integrate patient's view and experiences of the relationship between the healthcare provider and patient and combine resources that affect the processes and outcomes of healthcare. At the institutional level, patient engagement integrates the patient's view, experiences, perspective and expectation of the organization's administrative features in a setting in which services are delivered to improve healthcare outcomes. At the systemic level, patient engagement can integrate the patient's view, experiences, and perspective of the health services system characteristics and governance that affect the inter-relationships among healthcare institutions and the population demand on

health services. At the environmental level, patient engagement focuses on the conditions and actions in the broader social, political, and economic contexts that shape health services system and define its social functions, such as evaluating health policies and programs.

### **Challenges and Outcomes of Using AHSR as a Framework for POR**

Patient engagement in AHSR can be considered in the form of a matrix in which topics such as healthcare financing, health human-resources, policies, and governance overlap to achieve the best healthcare system. In this section, the challenges and outcomes of using AHSR as a framework for POR will be discussed.

#### **Challenges**

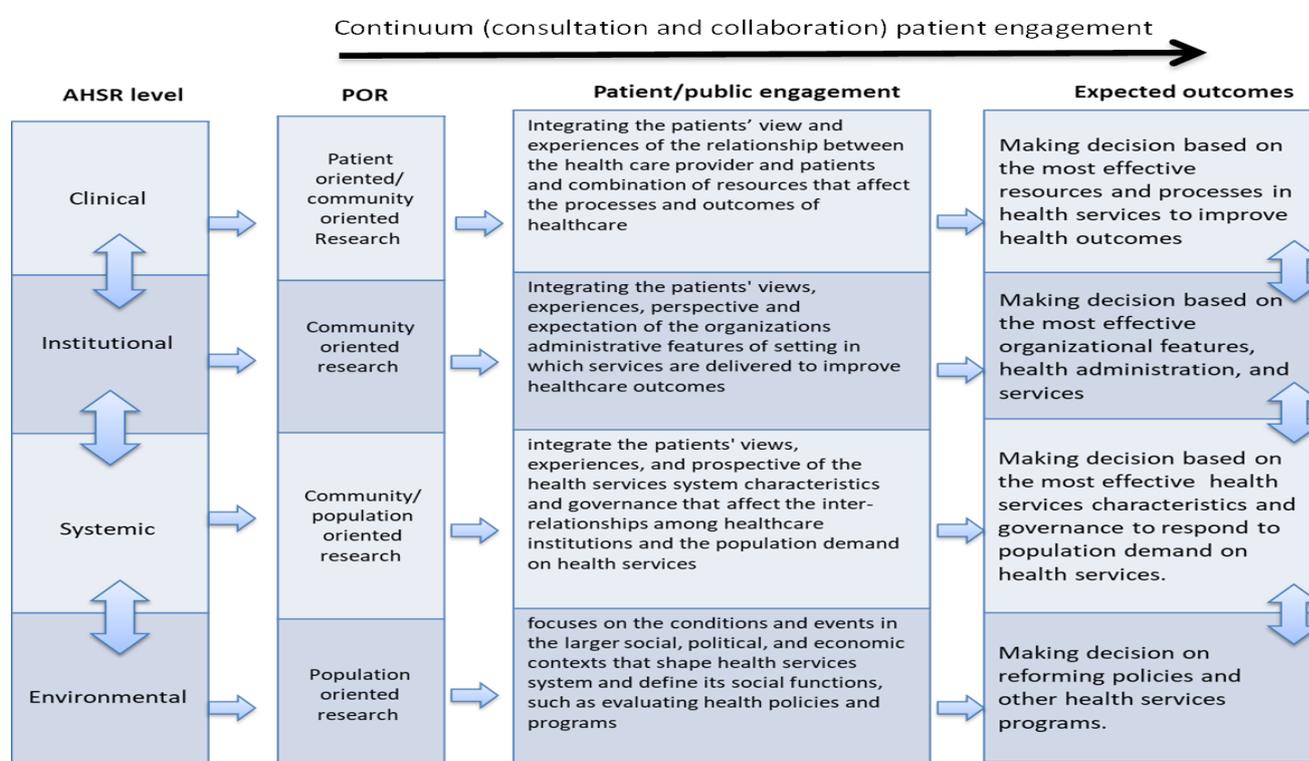
**Research interests.** Researchers may choose a research topic in AHSR based on health services priorities. For example, the health services research priorities in New Brunswick (NB) are the impact of demographic changes on health services; health human resources; and alternative primary care delivery models (Health Services Research Priorities for New Brunswick, n.d). However, the research may include irrelevant community concerns and issues, which may make the study unfeasible. Therefore, some professional researchers and community leaders prefer to consult the public about their concerns with health services and then translate these interests and perspectives into research questions (Domecq et al., 2014).

**Patients and Patients' Engagement.** Current patients or health services users (public) can be invited to participate in the research project. Targeted patient/public participants will be chosen based on the AHSR topic and level. The most challenging part of engaging patients in research is the patients' willingness and ability to engage in the research, knowledge, attitude, beliefs, experience with the healthcare system, health and health research literacy, health status, functioning, patients' age, and vulnerability (Carman et al., 2013; Nass, Levine, & Yancy, 2012).

Oliver et al. (2008) found that the degree of patient involvement in the research has a significant effect on the research outcomes and decision-making. However, there are two common concerns about patient engagement, when the engagement is particularly minimal. First, patient engagement becomes tokenistic (a false appearance of inclusiveness), leading to devaluation of patients' input. Second, organizational and environmental culture, policies, regulations, and practice may limit the degree of patient engagement in the research process (Carman et al., 2013). In conclusion, these barriers may need to be facilitated or removed, and research culture prepared very well before engaging patients in any research project as partners.

**Research culture.** The research culture is defined as “a set of values, beliefs, assumptions, and behaviors related to the implementation of research owned by the organization collectively” (Hajir, 2013, p. 123). It is vital to define the roles and responsibilities of patients in the research process to allow them to develop their skills as needed (Armstrong, Herbert, Aveling, Dixon-Woods, & Martin, 2013). The research planner should discuss with engaged patients the intervention methods, available fund, research timeframe, and research culture. For example, it has been reported that patients involved in POR get frustrated with the length of the process that requires transportation to the training centers for research training, research training process, attendance, etc.(Domecq et al., 2014).

*Figure 2: The multidimensional framework to engage patient/public in all levels of AHSR, assuming continuum combined of consultation and collaboration of patient engagement in the research process.*



Therefore, clarifying the research culture for patients enhances respect between patient and professional researchers and reduces patients' frustration.

### Potential Outcomes

Using AHSR as a framework for POR has a potential to close the gap between HSR and routine healthcare practice due to the interdependence of AHSR levels. It may open doors for a variety of research ideas due to the multidisciplinary nature of both AHSR and POR. It will also empower the public to be more responsible for improving health services and

policies. It will probably enhance the value and outcomes of AHSR as they reflect patients' concerns, views, and experiences.

## Conclusion and Recommendation

The authors discussed the feasibility of using AHSR as a framework for POR where authors shared various intersecting research aspects. However, the multidisciplinary nature of AHSR and POR may face challenges related to research interests, patients and patients' involvement, environmental/organizational regulations and policies, and research culture. Conducting POR at different levels of AHSR may help close the gap between health research and practice and empower patients to be more responsible for their own health and health services. The authors suggested a multidimensional framework for patient engagement at different levels of AHSR. However, more research and scholarly papers are required to find the most effective methods to create opportunities for engaging patients and find out if this continuum of engagement is valid at all AHSR levels.

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