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# Healthcare in an Era of Patient Engagement: Language for Ongoing Dialogue

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In the last century, we have observed a dramatic paradigm shift in the structure and function of society. Systems and political processes around the world have faced increasing demand by citizens to become active participants in public policy. Decisions made by the professional elite and the scientific truths that were unchallenged before, have become amenable to pressure and interrogation by citizens. This observation has transformed the healthcare system to involve patients, family, and care representatives as active participants in healthcare activities. Today, *patient engagement* (PE) occurs in an array of activities such as drug development, health system restructuring, hospital strategic planning, health technology assessment, and research. For example, hospitals have formed Patient and Family Advisory Committees that discuss organizational issues and quality improvement.

The practice of PE has, however, "jumped the gun" of its language and theory. There is a strong need for common language for discussing the methods and processes of PE. This article summarizes some definitions, goals, benefits, mechanisms, and levels of PE. The information presented in this article provides a language for ongoing dialogue about the optimal approach and value of PE in healthcare.

## WHAT IS PATIENT ENGAGEMENT?

PE has many conceptualizations. PE comes from the literature on patient-centred care (PCC), a term that is in the healthcare vernacular today. PCC advances the notion that medical care and research evidence ought to be guided by patient preferences, perspectives, experiences, and needs [1]. However, PE is a broader concept than PCC; it refers to the mechanisms through which "patients can draw on their experience... and apply their priorities to the evaluation, development, organization and delivery of health services" [2]. There are two dimensions of PE: activities to improve their own care and the care of other patients. For example, patients can engage in their clinical care by using a tool to decide a treatment option that is aligned with their values, beliefs, and life plans. Patients can also engage in the

planning of strategic hospital priorities, designing of care pathways, and patient safety initiatives that affect the care of other patients.

## ETHICAL IMPERATIVES AND SOCIAL AND ORGANIZATIONAL BENEFITS

PE is bolstered by ethical imperatives and social and organizational benefits. Ethical imperatives emerge from rights-based and consumerist modes of participation that empower "lay" people to engage into complex public policy processes. The effects of these imperatives are seen directly in the fields of social sciences and business. In healthcare, these imperatives have transformed the relationships between patients and professionals.

Benefits can be divided into those for patients and groups (e.g., interprofessional healthcare teams), and those for health service organizations. Examples of benefits include higher patient self-esteem [3], improved relationships between patients and healthcare providers [3], improved information for patients [4], the simplification of care processes and administrative structures of hospitals [4], and reduced hospital admissions [5]. The effects of not engaging patients in healthcare activities, however, has been less investigated than the benefits to engagement due to literature's infancy. One study found that not engaging patients may lead to adverse outcomes such as the widening of existing health disparities, the inefficient use of limited healthcare resources, and suboptimal health outcomes [6]. This area of the literature is promising for future research because it may help to anticipate the potential adverse consequences to patients and the healthcare system.

## ACTIVITIES

Patients engage in three categories of activities summarized in Table 1: clinical care, research, and organizational activities (e.g., designing, quality improvement). It should also be noted that there is an overlap between these activities. For example, patient safety initiatives that aim

Table 1: Categories of patient engagement activities in health care.

Activity	Description
Clinical Care	Engaging patients in their own care either by themselves or with the support and guidance from a licensed healthcare provider
Research	The design and conduct of research
Priority-Setting	Determining priorities for research, policy, or health care agendas
Organizational Activities	Planning, designing, delivery, evaluation

to reduce the transmission of in-hospital infections may be categorized under planning and designing, research, and evaluation.

## LEVELS

Patients can also engage at different levels. The *International Association of Public Participation* (IAP2) spectrum comprises of five levels: inform, consult, involve, collaborate, and partner [7]. This framework is based on “ladders of participation,” which indicate a tacit hierarchy between levels of engagement; in other words, partner is the “best” level of engagement. However, as other researchers have noted, ladders or hierarchies of engagement do not reflect PE practice, and may represent healthcare professionals’ views of what engagement should look like [8]. Instead, different levels of engagement may be appropriate for distinct activities determined through communication with patients. Attempting to address this gap, *Ontario’s Patient Engagement Framework* by Health Quality Ontario identifies four levels of PE: share, consult, deliberate, and collaborate [9]. Both of these frameworks are shown in Table 2 for comparison. Using these frameworks elucidates the role, purpose, and objectives of PE in a variety of contexts.

PE has become the expectation around the world in a variety of healthcare activities. The future of health systems will experience a greater integration of patients as decision-makers and partners in interprofessional healthcare teams. This article briefly summarized the strong ethical imperatives and social and organizational benefits of PE and potential negative outcomes of not engaging patients. The information presented in this article provides a language for ongoing dialogue surrounding the optimal approach and value of PE in healthcare.

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Table 2: A comparison of patient engagement frameworks by HQO and IAP2

HQO	IAP2
<b>Share:</b> Provide easy-to-understand health information	<b>Inform:</b> Provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities, and/or solutions
<b>Consult:</b> Get feedback on a health issue	<b>Consult:</b> Obtain public feedback on analysis, alternatives and/or decisions
<b>Deliberate:</b> Discuss an issue and explore solutions	<b>Involve:</b> Work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered
<b>Collaborate:</b> Partner to address an issue and apply solutions	<b>Collaborate:</b> Partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution <b>Partner:</b> Place final decision making in the hands of the public



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