

# Patient Roles in Engagement-Capable Environments: Multiple Perspectives

## Le rôle du patient dans un milieu propice à l'engagement : perspectives multiples

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### **Abstract**

Engagement-capable environments have well-defined roles for patients. These roles are often described in terms of their functional aspects. In this paper, we provide a complementary way of thinking about patient roles: an interactionist perspective. For interactionists, roles evolve through social interactions and contextual demands that shape how the work is performed. Drawing from a case example at Health Standards Organization (HSO), we demonstrate the need for engagement leaders to attend to functional descriptions of patient roles and their interactive possibilities. Finally, we argue for the connection between multiple patient roles and engagement-capable environments.

### **Résumé**

Le milieu propice à l'engagement du patient lui propose des fonctions bien définies. Ces fonctions sont souvent décrites en termes d'aspects fonctionnels. Dans cet article, nous proposons une manière complémentaire d'envisager le rôle du patient : une perspective interactionniste. Pour les interactionnistes, les fonctions évoluent au fil des interactions sociales et des exigences contextuelles derrière l'organisation du travail. En se fondant sur un exemple de cas de l'organisation de normes en santé (HSO), nous démontrons la nécessité pour les responsables de l'engagement du patient de s'attacher aux descriptions fonctionnelles de son rôle et à ses possibilités interactives. Enfin, nous plaidons en faveur de liens entre les diverses fonctions occupées par le patient et les milieux propices à l'engagement.

## KEY MESSAGES

1. Engagement-capable environments embed meaningful engagement throughout the core work of the organization, providing support to patient roles and ensuring their success.
2. Patient roles are a result of both functional descriptions and emergent interactions. The success of patient roles relies on both functional and interactional aspects, combined with clarity about the purpose of the role.
3. Engagement-capable environments have a range of well-defined patient roles and multiple strategies to ensure access to a variety of voices of patients who might not otherwise participate in engagement activities.

## Introduction

Patient engagement is viewed as an important quality improvement lever with the potential to transform health-care organizations. This emphasis certainly refers to patients engaged in their own care but also includes patients participating in a range of organizational decision-making that will influence the care and work of others. This may mean patients becoming involved in a range of organizational activities, including program planning, evaluation, research, training and recruitment. Organizations that have been recognized as leaders in these kinds of patient engagement practices have been labelled as “engagement-capable environments” (Baker et al. 2016a). Although many organizations may engage patients in various activities, clearly defined and specified roles for patients are a distinguishing feature of engagement-capable environments.

With this increased clarity and specificity on patient roles as part of patient engagement efforts there is an opportunity to meaningfully reflect on these roles. The purpose of this reflection is to take stock of what is being learned about these activities in practice while also benefiting from existing research that could inform ongoing and pressing questions about patient engagement. To this latter point, there is a rich tradition of research on roles in the social sciences. In this tradition, there are two main conceptual camps: (1) those that consider roles as particular kinds of *functions* and (2) those that consider roles in terms of their *interactions* with others. Although these camps are not mutually exclusive, they tend to draw different conclusions about how various roles could be best supported and how their impacts should be evaluated.

In this brief essay, we offer examples of patient roles in terms of their functional features. These examples are drawn from Baker and colleagues’ (2016b) casebook on patient engagement as well as lived examples of patient engagement work at Health Standards Organization (HSO) and its affiliate, Accreditation Canada. To complement this functional perspective, we also draw attention to various reflections on the interactive nature of these roles. These interactive roles are alluded to within the aforementioned casebook, are reflected upon at HSO and are actively explored in the social sciences. Throughout this essay, we are not attempting to create a dichotomy between functional roles and interactive roles. No such dichotomy exists in practice as patients fulfill

both functional and interactive roles in patient engagement initiatives. Instead, we are simply offering additional conceptual tools by which to understand patient roles as part of patient engagement practices. In doing so, we hope to inspire insightful questions about important concepts in patient engagement: how do we define and support purposeful roles for patients and others involved in engagement processes?

## Theory Burst: A Brief Introduction to Social Science Perspectives on Roles

Role theory presents an interesting and long-standing dilemma in the social sciences (Biddle 1986). Although the concept of role features prominently in the study of society, organizations and groups, there tends to be little agreement on the definition of “role.” For the purposes of this essay, we simplify this debate to two perspectives: functional and interactive. Those that take a functional perspective on roles tend to focus on the various norms and expectations that shape the behaviours of individuals in those roles. The emphasis is put on technical role expectations and how these expectations will be governed in an organization. Thus, roles are considered in terms of how people will be recruited, what knowledge and skills they are expected to have and how performance will be managed. In contrast to this functional perspective, those that take an interactionist perspective argue that roles are not entirely described according to their assigned tasks but evolve through social interaction, contextual demands, various negotiations and evolving understandings of the present situation (Goffman 1959). For interactionists, job descriptions and performance management systems are just one resource among many that shape how the role is performed. Taking these ideas to the study of patient engagement practices, we can see much attention to the functional aspects of patient roles. Less discussed are the interactionist perspectives on patient roles. This is far more contested territory and requires some additional consideration.

## Descriptions of Patient Roles: Functional Aspects

Over time, the roles of patients as participants in patient engagement activities have become more clearly defined. In Baker and colleagues’ casebook (2016b), these roles are primarily described functionally. Such roles include: serving as members of various committees, acting as patient and family

advisors, providing direct service as patient and family support coordinators and providing peer support and/or education for other patient and family advisors. In the casebook, these roles are described in terms of the kinds of patient knowledge that the individual brings to the activity at hand. Sometimes this knowledge is described almost entirely in terms of someone's knowledge of his or her illness and associated experiences in healthcare organizations. At other times, patient knowledge also includes insights developed through training and experience as a patient advisor. For example, acting as a peer support for other patient advisors requires not just knowledge of one's illness but also the ability to impart knowledge about the practice of being a patient advisor.

Along with functional roles come clearly defined documents and policies. Thus, some organizations have explicit application processes – including the requirement for a résumé and an interview process – prior to a patient being enrolled into a particular activity. Job descriptions and terms of reference also serve to increase the formality of these roles, providing explicit expectations about how these roles will be enacted with the organization. In one sense, this level of formality signals the organizational importance being placed on these roles. As a necessary corollary, this explicitness also provides an avenue for organizations to potentially exclude patients who cannot (or will not) meet these expectations. Therefore, the emphasis on functional roles may have some unintended consequences, potentially creating a dynamic where patient roles become exclusive, reserved only for those who can demonstrate the required competencies. This is why the focus on engagement-capable environments is so vital. To be a truly engagement-capable environment, an organization must support a full range of engagement, including a myriad of functional roles and a range of ways to access the voices of patients who do not participate in formal or functional roles.

### **Interactionist Perspectives on Patient Roles: Social Science Contributions**

In healthcare, we tend to talk about roles in the functional sense. For example, we talk about teams that involve patients, physicians, nurses, health professionals from other disciplines, quality improvement leaders and administrators. However, each of those role descriptions relies primarily on assumptions about the knowledge base of each person. Patients know about their illness experience, physicians know about medicine and so on. Yet none of those knowledge-based descriptions are explicit about the interactive roles fulfilled by each individual. Such descriptions are usually beyond the scope of how we talk about roles in our organizations. To get a sense of how people interact with one another in these roles, we need to go to the social sciences.

In social science studies of patient engagement, we develop a complex picture of how patient roles play out in organizational contexts. Social scientists have described patients acting as knowledge brokers, connecting and translating knowledge across communities of clinicians and communities of patients (Martin 2008), as symbolic representations of ideals (Rowland et al. 2016), as sources of persuasion for clinicians who require convincing about the need for a change (Armstrong et al. 2013), as informed observers of organizational practices (Rowland et al. 2018) and as mechanisms for challenging dominant perspectives in healthcare (Ocloo 2010). Of course, a discussion of the interactive roles fulfilled by patients would not be complete without acknowledging the critical social sciences. Critical social scientists worry that patients' roles are being used to support managerial intentions, primarily to provide patient endorsement to otherwise unpopular decisions (Carter and Martin 2017; Madden and Speed 2017). In this case, the interactionist role being served is related to managerial interests, where patients bolster the power and credibility of managers through their involvement. Therefore, to take into account the interactionist perspective means to constantly pay attention to how the role is emerging and to anticipate that not all impacts can be predicted.

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### **Case Example: Health Standards Organization**

The previous sections offered two perspectives on patient roles: a functionalist perspective and an interactionist one. However, this is a conceptual divide. In practice, the functional and interactional aspects interact within a single individual. The ways in which they interact are important to consider. To illustrate this point, we draw from an example of a patient role at HSO, highlighting lessons that have been learned over time. HSO is a non-profit organization dedicated to developing standards, assessment programs and other methodologies to enable health and social service providers to advance on their quality journey. Accreditation Canada provides accreditation and assessment programs in Canada and around the world. In our example, we explore the development of a specific functional role: patients as members of an accreditation survey team.

For many years, the on-site portion of the four- to five-year accreditation cycle has been an essential element of Accreditation Canada's assessment process. Traditionally, this on-site assessment has been conducted by "peer surveyors," individuals who are healthcare leaders in organizations other than the organization being assessed. In 2017, Accreditation

Canada started to introduce patients<sup>1</sup> as part of this on-site assessment process. The functional definition of this role meant that patients would be working alongside peer surveyors as part of the on-site assessment. However, much needed to be discovered about how this role would interact with peer surveyors, as well as with the patients, staff and leaders of the healthcare organizations undergoing assessment.

Over a period of 10 months, a group of staff, peer surveyors and patients worked together to define the role of patient surveyors, how these roles were both distinct and complementary to the peer surveyors and what processes needed to be in place to support their unique contribution to the survey team. Collaboratively, the group determined that patient surveyors would have a lead role in assessing criteria related to people-centred care (PCC) processes and structures – specifically, the ways in which organizations espouse “an approach to care that consciously adopts individuals’, carers’, families’ and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people” (World Health Organization 2016). This interactive element eventually became solidified into a functional description, made more visible through the scripting of a PCC “priority process.”<sup>2</sup> This process was developed to ensure that surveyors were at the right place and time to hear from the staff, patients and leaders of organizations being assessed about how they implement PCC in governance, leadership and service excellence. What started as reflective and collaborative observations on interactive processes became organized into functional descriptions of the role. Evaluation of this process of role creation has been an important part of the overall learning.

Although the patient surveyor focuses on PCC priority processes, the assessment tasks of the patient surveyor are not substantively different from those of any other peer surveyor. However, the working assumption is that including a patient in the assessment process will broaden the range of interactive possibilities. Specifically, there is reason to think that patients within the organization under assessment may provide different insights to someone identified as a “patient surveyor.” Thus, the theory of change animating this particular strategy is strongly interactional, based on the proposition that patients will interact differently with patient surveyors than they might with a peer surveyor. It is expected that pairing the patient’s unique lived experience with the expertise of peer surveyors will lead to a deeper and more comprehensive assessment of organizational performance, ensuring a robust and inclusive process.

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We have highlighted the patient surveyor role as an example. However, it is important to note that this role does not exist in isolation at HSO. The work of patient surveyors – indeed, the work of all surveyors – is inherently dependent on the quality of the standards developed, which then serve as the foundation of the assessment process. Without appropriate, meaningful and robust standards, the assessment process would fall short of its desired aims. At HSO, patients are deeply involved in helping to shape these standards. This again points to the importance of an engagement-capable environment that embraces meaningful engagement as embedded throughout the core work of the organization. Individual patient roles – no matter how well planned, supported or implemented – cannot reach their full potential in isolation.

### Implications for the Future of Patient Engagement

With the increasing emphasis on patient engagement and various functional roles available to patients within organizations there is both opportunity and risk. The opportunity is to create mechanisms for more robust conversations that take in the range of human experiences, helping us to collaboratively and collectively make better decisions about healthcare. The risk is that these patient roles may unintentionally become relatively elite, potentially excluding the voices of those who cannot (or will not) participate in such formal ways. To foster the opportunity while remaining sensitive to the risk will require ongoing learning and reflection. Engagement-capable environments of the future may be best described as having multiple patient roles, acting within multiple processes throughout the organization and accompanied by robust strategies for accessing the range of voices not otherwise represented. Furthermore, these roles need to be intentionally shaped – not just by their functional descriptions but also by the interactional possibilities – with great shared clarity as to the purpose of the role.

### Concluding Thoughts

In this paper, we have argued that the functional descriptions of patient roles only tell part of the story of the success of engagement-capable environments. Through these past years of working toward engagement-capable environments, we have learned that the commitment to the work is expansive. As a result, we often find that recruitment is not the most difficult aspect of engagement. The hard part is designing and implementing engagement activities so that they make a meaningful difference to the work at hand. Given the complexities of organizational change, these difficulties are expected. That this is difficult work does not diminish its importance. Instead, it reflects the social complexity of creating new roles within existing organizations, anticipating how these roles will interact with existing structures and where the opportunities

for transformative change will lie. Considering both the functional and interactional aspects of these roles is foundational to their success and the success of engagement-capable environments. **HQ**

## Notes

1. Depending on the health setting or context, patients may be referred to as clients, residents or community members and individuals could include carers and families.
2. HSO defines priority processes as critical areas and systems within an organization that have a significant impact on the quality and safety of the services provided. A priority process is made up of a group of criteria taken from one or more sets of standards and is an efficient way for surveyors to assess compliance with the standards.

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