Exploring Ethical Issues Related to Patient Engagement in Healthcare: Patient, Clinician and Researcher's Perspectives

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Marjorie Montreuil · Joé T. Martineau · Eric Racine

Abstract Patient engagement in healthcare is increasingly discussed in the literature, and initiatives engaging patients in quality improvement activities, organizational design, governance, and research are becoming more and more common and have even become mandatory for certain health institutions. Here we discuss a number of ethical challenges raised by this engagement from patients from the perspectives of research, organizational/ quality improvement practices, and patient experiences, while offering preliminary recommendations as to how to address them. We identified three broad categories of ethical issues that intersect between the different types of patient engagement: (1) establishing a shared vision about goals of patient engagement and respective roles; (2) the process and method of engaging with patients; and (3) practical aspects of patient engagement. To explain these issues, we build from our personal, professional, and academic experiences, as well as traditions such as pragmatism and hermeneutics that stress the importance of participation, empowerment, and engagement. Patient engagement can be highly valuable at numerous levels, but particular attention should be paid to the process of engaging with patients and related ethical issues. Some lessons from the literature on the ethics of participatory research can be translated to organizational and quality improvement practices.

Keywords Patient engagement · Ethics · Institutional practices · Participatory research

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Background

In the healthcare literature, patient engagement has been defined as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—clinical care, organizational design and governance, and policy making—to improve health and health care" (Carman et al. 2013, 224). Patient engagement can therefore occur in different aspects of healthcare, which also includes patient engagement in healthcare education and research (Higgins, Larson, and Schnall 2017, Pomey, Flora, et al. 2015). In research, patient engagement has different labels such as participatory research, community-based participatory research, action research, patient-oriented research, research in partnership, or patient and community engagement research (Cargo and Mercer 2008; Marlett et al. 2015). In all of these approaches, patients are involved in different steps of the research process to contribute to decision-making,

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with various levels of involvement (Wallerstein and Duran 2017). Similarly, the Canadian Institutes of Health Resarch, in their strategy for patient-oriented research (SPOR), define patient engagement as "meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation" (Canadian Institutes of Health Research 2014, 5). Patient engagement thus refers to patients being involved in the research *process* and not only as research *subjects*, as patients become partners to the project (Doria et al. 2018). There are many benefits of engaging with patients for health research, including addressing objectives that are relevant to stakeholders, being more attuned to the local culture in which the research is operationalized, better quality of research results, facilitating recruitment, and enhanced sustainability of project goals (Jagosh et al. 2012). There is also increasing recognition of the benefits of patient engagement in clinical practice, organizational design, governance and policymaking in healthcare, and most notably in enhancing the quality of health services (Bush et al. 2017; Barello, Graffigna, and Vegni 2012; Johnson et al. 2016; Määttä, Lützén, and Öresland 2017; Pomey, Flora, et al. 2015; Pomey, Ghadiri, et al. 2015). However, in contrast to the literature on patient engagement in research, little has been published about the ethical issues of patient engagement in quality improvement initiatives, organizational design, and governance bodies.

Ethical Issues Related to Patient Engagement

In this article, our aim is to share our perspectives and experiences as patient-partner, clinician, ethicists, and researchers (see Table 1) on some of the ethical issues related to patient engagement that cut across organizational design/governance, healthcare quality improvement, and research. We consider that patient engagement can be highly valuable at numerous levels, but particular attention should be paid to the process of engaging with patients and the ethical issues this process entails. Moreover, we believe lessons can be learned from the literature on the ethics of patient engagement in research and also translated to organizational practices and governance. Within the literature, ethical issues related to patient engagement in different aspects of healthcare are typically discussed in isolation even though they share various similarities since they are all

Table 1 Authors' experiences with patient engagement

Marjorie Montreuil
- Trained in nursing, international law, mental health, health ethics, and neuroethics
- Experience as a nurse and clinical nurse specialist in a mental health institute (for six years)
- Has been involved in direct care, quality improvement and research partnering with patients, as a clinician and researcher
- Has conducted projects in partnership with children, youth, and adult patients
- Has developed a methodological framework to engage school-aged children, parents, and healthcare professionals in the research process to address ethical concerns present in clinical practice
- Currently leading participatory research projects and developing further participatory research approaches with children

Joé T. Martineau
- Trained in management, political science, business ethics, and neuroethics
- Active in teaching and research in business ethics and management since 2004
- Experience of cancer in 2011, with two young children under five years old at home
- Has been involved (as patient and as researcher) in numerous quality improvement projects, research projects, and governance bodies since 2011
- Completed a research/action project, accompanying and supporting healthcare institutions in implementing patient-partnership structure/programme/initiatives
- Is now leading research on the ethical issues associated with partnering with patients in research

Eric Racine
- Trained in philosophy, political science, applied human sciences, bioethics, and neuroethics
- Exposed from early on as a research coordinator to new pressures for collaborative and partnered research
- Has led different projects involving patients as co-authors, stakeholder research, deliberative task forces, and participatory research over the last fifteen years
- Actively pursues a bioethics research programme inspired by philosophical pragmatism where the experience of stakeholders, their participation, and real-world outcomes are crucial

concerned with patient engagement. For example, within the context of research, issues related to power differentials between researcher and patients (Carroll et al. 2017; Wilson, Kenny, and Dickson-Swift 2018), tokenism—i.e. with only the appearance of patient participation but no real engagement offered to patients to influence research (or clinical/organizational project) processes and outcomes (Hahn et al. 2017)—the patient's

ideal role in research, and meaningful representation of patient groups have been raised (Carroll et al. 2017; Ives, Damery, and Redwod 2013; Maguire and Britten 2017). Furthermore, in studies in which there are partnerships with communities to respect their autonomy, the challenges related to evaluating impacts of research on entire communities and difficulties of facilitating democratic participation have been articulated, among others (Banks et al. 2013; Buchanan, Miller, and Wallerstein 2007; Mikesell, Bromley, and Khodyakov 2013; Minkler 2016). We will discuss the ethical challenges we consider intersect across different spheres of patient engagement.

Discussion of Ethical Issues Related to Patient Engagement in Healthcare

Building from our personal and professional experiences, as well as traditions such as pragmatism and hermeneutics that criticize the "spectator theory of knowledge" and stress the importance of participation, empowerment, and engagement (Taylor 1971, 2004; Gouinlock 1978, 2002; Widdershoven, Abma, and Molewijk 2009), we engaged in an open discussion about the ethical aspects of patient engagement. We identified areas of ethical concerns that intersect across different areas of patient engagement in healthcare, as well as issues specific to certain levels of involvement. These concerns will be addressed as part of three broad non-mutually exclusive (overlapping) categories, highlighting the similarities and differences across them (see Fig 1). We also offer recommendations for each category of ethical issues we have identified, based on our own experiential knowledge and informed by the literature on patient engagement.
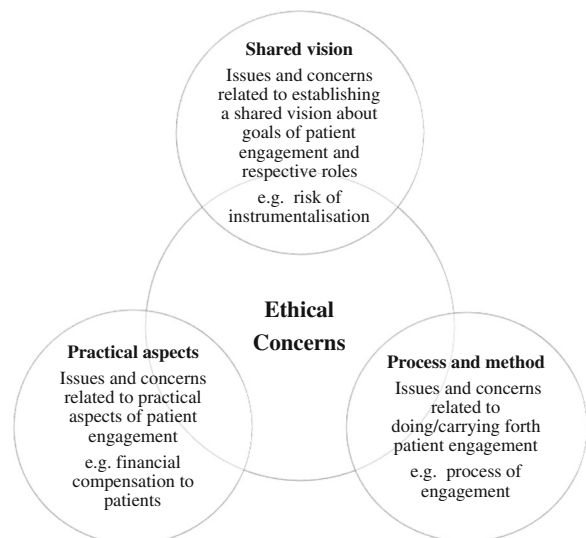
Issues Related to Establishing a Shared Vision About Goals of Patient Engagement and Respective Roles

The issues presented here concern the question of why to engage/partner with patients in healthcare, as well as what are the perceived outcomes of engaging with partners. When starting a research, quality improvement, or other organizational initiative, the pertinence and benefits of involving patients in the committee/initiative/care/programme should be asked. Patient engagement

needs to rely on clear rationales and goals. Making explicit the reasons to partner with patients helps to define the scope of patient engagement for a specific project and clarify roles. It can also prompt those involved to reflect on their perspectives and assumptions related to patient-partners and clarify expectations. In a research project one of us led, there were two distinct perspectives on the expected role of patient-partners: patients as members of the research team versus patients as occasional consultants. By having a discussion early on in the project, these contrasting perspectives were discussed and an agreement was made as to the extent of patient-partners' involvement in the project. However, in our experience with other projects and initiatives, this discussion does not always take place, which can lead to confusion for all team members, including patient-partners, as to their expected role and contribution.

Importance of a Meaningful Patient Engagement

The rationale to engage patients can be based on different perspectives, for example on team members' shared belief that patient engagement is beneficial. This belief may be rooted in philosophical, practical, evidence-informed, or more opportunistic reasons (e.g. for a funding opportunity or as an institutional/organizational directive) (Jagosh et al. 2012, Green 2008, Renedo and Marston 2011). In the absence of a clear vision of the

Fig. 1 Categories of overlapping ethical concerns and issues related to patient engagement in healthcare

rationale for patient engagement, patient engagement can lead to tokenism, i.e. the instrumentalization of patients where there is no substantive contribution from patients to the project or initiative. One of the authors has been involved as a health professional in a quality improvement initiative that claimed to follow a patient engagement model. During the meetings, there were more than twenty professionals sitting around the table with only one patient representative. The patient was very rarely invited to speak, and the language used by the professionals was not adapted to foster the engagement of the patient representative. In the reports from this quality improvement initiative, it was claimed that decisions were made in collaboration with patients. This example reflects the appearance of patient engagement rather than meaningful engagement. As shown in this case, patients can be instrumentalized in different aspects of partnered projects such that they become only a symbol of representation. It is therefore important to come to a shared vision and to foster meaningful engagement from all parties (Minkler et al. 2002; Cargo and Mercer 2008; Kelly et al. 2017).

The legitimacy of patients engaged in different healthcare initiatives relies on their experience as patients. As patients, they bring a unique perspective that is distinct from that of other team members, which can contribute to project goals, an implementation process, and results that are more attuned to patients' experiences. However, patients engaged in a project also have other roles apart from being patients: patients can also be workers, professionals, parents, managers, retired professionals, etc. Each patient's role in a specific project should therefore be clarified from the start to address the expected level of involvement and recognize the richness of their expertise and experiences. For example, in an oncology care quality improvement committee one of the authors participated in, a cancer-survivor patient was integrated as a regular committee member. The committee chose to focus on improving the quality and quantity of information for cancer patients by creating documents and organizing an annual patient-doctor information seminar, among other activities. It so happened that the patient involved in the committee was also a public relations and communications expert, working for a firm in the field. On top of her pertinent experience as a cancer survivor, the patient voluntarily and enthusiastically gave professional advice that helped the committee improve their outreach efforts. If the committee had ignored the professional

background of the patient, and limited her to the patient role, valuable expertise would have been lost. It is therefore important to be flexible in how patient-partners are involved in each project and to work with the strengths of all the people engaged in the initiative. However, patients should have the option to participate to the extent that they wish to prevent possible over-involvement that goes beyond their comfort level. Patients should not be pressured to assume roles they do not wish to undertake, and open discussion and clear communication related to the clarification of roles would contribute to this aim. Moreover, means should be put in place for patients to contribute to the extent that they wish, whatever their level of expertise. For example, in research workshop discussions involving non-experts (including patients), one of us has organized deliberative, collaborative writing processes in which non-experts who had little exposure to academic writing could participate. Initial instructions were circulated and agreed upon to establish a writing process following the face-to-face workshop. Then, the roles and obligations of co-authors were clearly identified and different rounds of comments on the manuscript were structured as group consultations. The lead authors took the responsibility for leading and coordinating this process, thus making it possible for non-experts to share their insights without having to assume a huge burden (Racine et al., 2017). More recently, we have also ensured the possibility of specific accommodations (e.g. accessible rooms for people with disabilities and adapted workshop materials) when engaging a diversified group of stakeholders on research ethics (Cascio and Racine 2018).

Patients can therefore be included in different steps of the project's process, including both adults and children. In a research project conducted by one of the authors in a child mental health setting, children were consulted to offer their input on the research questions, best means of data collection to address these questions, the interpretation of data, and to whom to disseminate the research results (Montreuil and Carnevale, 2018; Montreuil, Thibeault et al. 2018). When seeking input from children, meetings occurred in an environment in which children could move and play as the meeting unfolded, and questions related to the project were specific (e.g. who do you think I should talk to learn more about this problem?). This facilitated children's active engagement in the discussion to share their perspective. In this specific project, children were not trained to become co-

researchers, which can be done successfully in certain projects (Bradbury-Jones and Taylor 2015) but means were used to facilitate children's involvement so they could shape the research project.

Instrumentalization of Research and Organizational Initiatives

In the context of a push for partnered research, there is also a risk of instrumentalization of research. It can be challenging to respect the nature of scientific inquiries within partnered research. For example, there can be expectations from partners that research is not going fast enough and not delivering results. In countries such as Canada—where the authors' work is situated and funded, partnered-research is encouraged by funding agencies. Researchers have faced, as a result, increasing pressures for result commercialization and valorization with the emergence of impact-focused (i.e. focused on real-world outcomes) large-scale initiatives such as Genome Canada, the Networks of National Centers of Excellence (NCE), and the Canadian Institutes of Health Research's Strategy for Patient-Oriented Research (CIHR SPOR). These multi-million dollar initiatives have transformed the landscape of health research in Canada. In some, but not all, of these initiatives patient outcomes and patient partnership have become focal points. However, researchers are generally poorly supported to readily accommodate for this transformation and now face the pressure of not only securing research funds but also increasingly delivering results with real-world benefits. This is a laudable goal in itself, but it means that researchers must now defend the standards of research in the face of pressures to offer tangible goods out of research such as partnership impact and political visibility. This is the experience of one of the co-authors who was part of a large interdisciplinary research network focused on economic deliverables and patient engagement. In the end, the purpose of research became a means to other goals with limited appreciation for genuine patient engagement unless it generated short-term impact, mostly defined as economic impact. Based on these kinds of experience, we find there is a lingering need for partners and funding bodies to understand the nature of scientific research and adequately support researchers who wish to engage in partnered research and respect the nature of academic research. Otherwise, there is a risk of instrumentalization of research toward unrelated aims that do not meet academic standards and in the end also have little to do with patient engagement.

Similarly, this instrumentalization can also happen in organizational projects or governance processes in healthcare. For example, there might be pressure from governmental agencies to rapidly deliver outcomes, and the partnered initiative becomes a means to achieve political aims with little consideration for the process and quality of the work being conducted. It is also possible that patients engaged in a project have goals that differ from the stated goals of the project or the committee they are engaged in. Instead of working in a partnership, the work might instead be directed to promote a personal agenda like patient activism. Some of us have experienced such situations, notably because delving into ethical issues can be instrumentalized to support a particular political position. The instrumentalization of organizational projects and governance bodies in healthcare is therefore a very real possibility.

Recommendations

To render a shared vision about the goals of patient engagement and respective roles, we consider it important to first reflect on the intentions behind patient engagement. The benefits and challenges of partnering with patients should be discussed at the beginning of the project, and the decision should be well thought out. Indeed, it would be unethical (i.e. disingenuous, and an abuse of trust and loyalty) to involve patients if their participation is only tokenistic. One strategy to avoid the unethical involvement of patients is to identify the rationale underlying patient engagement, making it explicit and ensuring it is understood by all parties. (Parry, Salsberg, and Macaulay 2009). The rationale can, for instance, take the form of a specific question or end goal towards which everyone is working. This conversation should take place as early as possible in the project development process to construct a shared vision of the project. It is also important to clarify the limits of the benefits the project could bring to patients (Wilson, Kenny, and Dickson-Swift 2018); unrealistic goals could prompt patients to engage in the project but this would be a deceptive practice and therefore unethical behaviour from the part of the professionals or researchers. As Ives et al. posit, researchers have the ultimate responsibility to make the research topic relatable to the partners and to "be explicit about the input they require" (Ives, Damery, and Redwod 2013, 184).

Within partnered research, training of researchers and partners has been recommended as a strategy to prevent tokenistic participation from patients (Smith et al. 2008). However, the role of patients is not to become experts in research—this is the role of researchers. The main role of patients is typically to share their own experience with researchers to contribute to decisions related to the research process (Ives, Damery, and Redwod 2013). When conceptualizing the roles of researchers and patients as experts in different fields, it helps to set clearer expectations of each person's role and visualize the engagement with patients as a *partnership* in which each partner brings a complementary and mutually beneficial expertise (Määttä, Lützén, and Öresland 2017). When applying this view from research to organizational engagement, it can also clarify the expectations of patients: they bring valuable perspectives based on their experience but should not be expected to be skilled and trained in health services administration or clinical management (even though it might be the case for some patients, in which case this experience should be considered). The value of the unique knowledge that patients bring has to be recognized to be considered in an authentic and meaningful way. Training should therefore target the process of patient engagement and be offered to patients as well as clinicians, managers, and researchers involved in partnered projects. For example, training on the context of the healthcare system, of the institution, of the committee, its mission and vision, as well as language (jargon) could alleviate information asymmetry between patients, professionals, and administrators. We believe all involved actors can benefit from training on how to work in interdisciplinary teams, how to value different types of experience, and how to help all parties contribute to a project. In our experience, training on co-construction, teamwork, and patient-partnership or participatory approaches appeared to foster meaningful engagement from all parties. We also consider that it is important to be aware of the power positions of the healthcare professionals and researchers in the partnership. As mentioned by Määttä et al., healthcare professionals should recognize "partners as both the same and different" from professionals to help prevent inequities (Määttä, Lützén, and Öresland 2017, 5).

The nature of partnered projects calls for a deliberate change with respect to the role and recognition of patients as full partners. The same is true for researchers or professionals who can take on the role of advocates and even entrepreneurs whose role is to defend the interests of patients in healthcare systems, for example, or to pursue the full valorization or commercialization of project results from which patients can benefit. A reflection on the roles each partner plays and clarification of each person's expected role would diminish the risks of the instrumentalization of patients and projects. Putting substantial efforts in communication and information sharing could avoid such issues.

Issues Related to the Process and Method of Engaging With Patients

Once the decision has been made to engage with patients in a specific project and the expected roles have been clarified, questions pertaining to the recruitment of partners, how to select them, how to genuinely partner with them, and when to engage them in the process become important. We will address these issues here, including recommendations for each sub-section as to how to manage these issues in practice drawing from our experience and the literature.

Who to Engage With?

From our experience, the process used to choose partners in a particular project is rarely mentioned in final reports or articles. This is concerning considering the multiple issues related to the selection and potential vulnerability of patient-partners. Information related to the specific criteria to select potential partners would be helpful to clarify the process of patient engagement. For instance, partners could be selected based on opportunistic reasons: because they are familiar, easily accessible, they agree with professionals' or researchers' viewpoints, or they had an excellent patient experience and will more likely support decisions. These opportunistic reasons might not lead to meaningful engagement with patients. Careful consideration should thus be given to the criteria to select the patient-partners, and these should be transparent. For instance, in participatory research, it has been suggested to involve people who have good knowledge of the context of the project and varied experiences, in order to be able to work together to shape the project and its outcomes (Parry, Salsberg, and Macaulay 2009). The same could apply to organizational and governance projects. In a recent

participatory research project on research ethics in autism, we attempted to recruit patient and advocate co-researchers from various regions of Canada in order to engage with experiences from different settings (e.g. urban, rural) and with whom we did not have any pre-existing relationships. Furthermore, in cases in which projects are initiated and co-constructed with patient-partners, reflections around the involvement, selection and representativeness of additional partners could be performed in a participatory manner. In organizational quality improvement initiatives or in governance bodies, the professional and administrative committee members who are to work with patients should also be chosen carefully. In order to facilitate the contribution of patients and other partners, all committee members should share an understanding of the concept and benefit of patient partnership and of the value of a plurality of experiences.

In relation to the potential vulnerable status of patient-partners, issues can arise when patient-partners are working with health professionals who are simultaneously involved in research or organizational projects and providing care to them, which is highlighted as an important issue in Canada's Tri-Council Policy Statement on the Ethical Conduct for Research (2014). Considering the power differential in place, patients might be less inclined to share negative experiences so as to preserve the caring relationship with the health professional. On the other hand, some patients can also expect to receive preferential treatment if they agree to become project partners, as they have direct access to healthcare professionals. For patients, the stakes can be high if they do not receive the care and services required by their health condition; therefore, the fear not to hinder the caring relationship or the will to have preferential treatment might affect their involvement. In the selection of patient-partners, we consider that researchers and healthcare professionals should pay attention to the power differentials in place and reflect on them. While concerns have been raised in the research literature on power relationships in participatory research (Minkler 2016; Wilson, Kenny, and Dickson-Swift 2018), patient-partnerships in organizational initiatives bring additional issues related to the proximity of the patients and institutional representatives to the fore. These issues could also be present in partnered research projects conducted in healthcare settings where the researcher also works as a clinician. A way to address this concern could be to avoid such conflicted situations altogether. If

not feasible, then explaining clearly to all the parties that the patient's participation will not affect their care in any way is paramount although perhaps idealistic. Emphasizing the project's goal and reason for patient involvement could clarify the expectations. Means could also be put in place for people involved in the project to share their perspective in writing, confidentially, if possible (e.g. if there are multiple partners involved). If a group of patients is involved in a specific project, it could be possible to offer some time to discuss in sub-groups, as a way for patients to share their perspective more freely. The latter two recommendations would contribute to addressing power differentials.

The issue of representativeness has also been raised in the literature, as discussed briefly above (Johnson et al. 2016; Maguire and Britten 2017). When patients become partners in a project, there can be an expectation that they will represent other patients. If this is expected from researchers or health professionals, consideration should be given to who is chosen to represent which group of patients. For example, if different groups of patients are expected to be represented (e.g. patients with different diagnoses, from different age groups, with contrasting experiences), mechanisms should be put in place to select partners who will reflect these characteristics. One strategy we have deployed is to engage with the broader community via a discussion forum to allow those patients who are not co-researchers to inform the research process (Cascio and Racine 2018). Likewise, in some of our research projects on transition care, we are planning to consult the broader community of patients via consultative surveys at different moments of the project to ensure greater representativeness. We suggest discussing representativeness openly with potential patient-partners before they engage in the project, so as to clarify expectations early on and help communicate limitations in reports, recommendations, and other publications. Discussing ways to enhance representativeness with engaged partners, including which mechanisms to put in place, could also be helpful. In our experience in organizational design and governance, we have found that systematically integrating at least two patient-partners, with complementary experience, in committees, initiatives, or projects helps in this matter.

How to Engage with Patient-Partners?

When a partnered project begins, many questions can be raised in relation to the process of engagement. One of

them relates to the level of patient engagement throughout the project. When patients are engaged in a tokenistic manner, it is unlikely that their contribution will be valued and facilitated. Sometimes, the motivation for engaging with patients is sincere, but the way this engagement takes shape can be detrimental. In practice, patient participation can be under-recognized and undervalued because of a lack of truthful engagement with the patient-as-partner approach but also, and more commonly, because of a lack of mechanisms, tools, and know-how to ensure a meaningful contribution. During meetings, to meaningfully engage patients in the decisional/deliberative process, mechanisms should be put in place to facilitate participation from all parties (Parry, Salsberg, and Macaulay 2009). This could include "round-tables" to ask every person to share their perspective or an offer to anonymously write comments with one person reading them out loud to then discuss. Ground rules should also be established to foster respect for people and ideas and to reduce potential hierarchical imbalances. Fostering the development of a space where people can share their thoughts openly is key to genuine and meaningful participation from all parties. Strategies employed in workshop facilitation could be useful to reach these ends (Stolper, Molewijk, and Widdershoven 2015; Kaner 2014). For example, in the deliberative workshops we have organized, we typically start with a statement about the ethics of discussion and discuss with the group what ground rules they consider important to foster engagement. Also, as stated before, all participants (patients as well as professionals and managers) should be trained in the patient-as-partner approach.

When to Engage Patient-Partners?

Questions can also emerge related to when to engage patient-partners in the project. In the literature, some authors recommend involving patients as early as possible in the process, even before the project starts (Pomey, Flora, et al. 2015; Parry, Salsberg, and Macaulay 2009). Following some proposals, ideas for a project can come from patients themselves, professionals, researchers, or be co-constructed. Co-constructing the project can reduce the power imbalance and foster an active engagement from patients (Dunston et al. 2009). Patient-partners can also be engaged in disseminating the results from a study (Hagan et al. 2017; Green 2008) or an organizational initiative. Ives

et al. argue that patient-partners should be involved in certain steps of the project in which their expertise as patients is recognized and valued (e.g. during funding applications, review, prioritization of research agenda, dissemination stages, and interpretation of the results) (Ives, Damery, and Redwod 2013). In participatory research, four key stages have been identified in which partners should be engaged for a project to be labelled "participatory": (1) defining or refining the research question; (2) deciding the means for data collection; (3) interpreting the results; and (4) disseminating the results (Parry, Salsberg, and Macaulay 2009; Jagosh et al. 2012; Green, Royal Soceity of Canada, and BC Consortium for Health Promotion Research 1995). A similar framework could be applied to organizational and clinical projects, which could serve as a guide to fostering ongoing involvement from patient-partners throughout the project. Again, we should however warn against tokenistic engagement of patients in dissemination activities, such as academic conferences, when this engagement is not meaningful but more opportunistic.

Issues Related to Practical Aspects of Patient Engagement

During the process of partnered projects, various practical aspects should be considered to foster ethical engagement from patients.

Compensation of Patient-Partners

An important issue is the compensated or voluntary nature of the work from patient-partners. One of the authors experienced a situation in which the involvement from a patient became extensive, without any financial compensation. When all parties but patients are remunerated for their work on a committee or project, it furthers power imbalances and feelings of injustice and frustration. An underlying double standard can be assumed from this practice. Indeed, patient engagement tends to be perceived as a voluntary contribution, but if patients are to be specifically selected, recruited, trained, and there are clear expectations on the quality of their contribution, then the voluntary nature of their participation is to be questioned. Also, not all patients can afford to participate in these activities without being at least compensated for their travel and time, leading to inequalities in access to being a patient-partner. When

patients participate in a project, there are numerous fees such as parking or transport fees, and expenditures related to childcare for the duration of the meeting or lost work time. In a review of the literature on patient engagement in quality improvements for ambulatory care, Johnson et al. mentioned that out of the twenty-six initiatives studied, no patients received honoraria for their involvement as advisers, with an average involvement of a one to two hour meeting per month (Johnson et al. 2016). Considering that all of the other participants in meetings are remunerated as part of their work, we question whether patients are treated fairly by not being remunerated for their participation.

In some of our recent efforts and new grant applications, we have offered compensation on a needs-basis. This allows offsetting costs of participation for those who are otherwise not remunerated and promotes equality of conditions. However, in our experience in quality improvement and governance initiatives, most patients are only occasionally offered parking compensation. Within Canada's Strategy for Patient-Oriented Research (Canadian Institutes of Health Research 2014), offering financial compensation to patients is mentioned, but it remains unclear what just compensation would be. We believe health organizations and funding agencies should reflect on this issue of patient compensation—in collaboration with patient-partners—to foster a meaningful engagement and just compensation.

Scheduling and Time Management

An additional practical issue concerns time management. When scheduling meetings or setting deadlines, patients' schedules and particular needs should be taken into account and respected. For example, some of the authors have experienced situations in which meetings were held during patients' working hours, with no consideration for their schedules or planned at the last minute, leading to limited presence from the patient-partners. One of the authors also experienced a situation in which patients with chronic health conditions who had retired from their work were asked to meet at 8 a.m. Other examples include long three-hour meetings conducted without refreshments. Another team required patients to be present for numerous short, unplanned meetings (e.g. thirty minutes). These patients were volunteering to be part of the project but were asked to attend these short meetings in which no clear agenda or

plan was set and no decisions were made. For professionals and administrative workers who are already on site, this may not pose a problem, but for volunteer patients who have to travel to get to the meeting site to attend short unplanned meetings, this can be a cause of frustration and demotivation. In a study of the experiences of patient-partners in quality improvement projects, scheduling has been identified as the main barrier to patient participation (Pomey, Hihat, et al. 2015). Considering that patients engage voluntarily in these projects, it would be important to ensure meetings are well planned and the objectives are clearly set, so the engagement from partners can be more meaningful. For example, in a workshop project on brain-computer interfaces, we are offering patient-partners with serious health conditions to adjust their participation based on their physical ability.

Expected Outcomes

Another issue relates to outcome expectations. When patients engage in a project or are part of a committee (organizational, governance, or research), there can be an expectation that it will quickly lead to concrete changes, which is not always the case. In a study by Pomey and colleagues, partners mentioned challenges related to the slow implementation of projects in the healthcare setting (Pomey, Ghadiri, et al. 2015). This latter issue could be partially addressed if the project's goals and scope are agreed upon at the beginning of the project (as discussed above) and if issues related to the feasibility of the project and potential ethical issues are also discussed up front, including projected timelines. There should also be a follow up with partners to inform them of the outcomes of the project. In spite of best intentions, one of the co-authors has experienced the challenge of securing funding to pursue collaborative research on numerous occasions. Very often, the ability to develop more practical research is impeded by available funding and some promising ideas are not pursued because funding organizations change ideas or highly qualified research personnel and trainees working on these projects move on. Learning from experience, some of these circumstances could be foreseen while some are rather unpredictable. Once a researcher or organizational committee commits to an area, it is important to not abandon promising ideas and be wary of the temptation to move on to other projects which can be easier to fund or initiate.

Research Ethics and Confidentiality

Research ethics sets a peculiar operational framework. Although we could debate on its value and applicability to participatory and partnered research (Banks et al. 2013), it is important to keep in mind its roles (to protect and inform research participants) and also that many of its goals pertain to partnered research (Tri-Council Policy Statement 2, 2014). For example, issues related to confidentiality and privacy can be important to explain (to those unfamiliar with the standards of research ethics), both as part of research projects and organizational initiatives. For research projects specifically, training on research ethics should be provided to partners to ensure compliance with regulatory norms for research. We consider however that in all projects, training on principles of confidentiality and privacy should be provided: the training does not need to be extensive depending on the nature of the project, but if personal or confidential information is shared during meetings, this information should not be shared outside of the meeting. When patients are engaged in a project, it is not always clear if formal consent is required to use the information shared by partners or if asking for permission is enough. For example, if healthcare professionals or researchers plan to cite or refer to a testimonial from a patient in their reports, can they do so without formal written consent from the patient? Within research, consent is required for data that is collected, but the information shared by patient-partners is not data per se, since it is information to help design and conduct a study. For example, within a partnered project, participants could be sharing information about their healthcare institution, their employers, or their advocacy groups, but this information should remain confidential and never be used against those who share it. It is crucial that a climate of trust prevail such that both patients and others who share sensitive information are not being reported. The same applies to organizational projects in which no research data is collected. We agree that this issue should be openly discussed with patients before they engage in a project, and they should be asked for their preference. Also, before sharing information that could be sensitive with third parties, patients could be asked again if they agree that this specific information be disclosed.

The process of obtaining research ethics approval for a specific project in which patient-partners are involved, can raise particular challenges. For example, one of us experienced a situation in which members of a research ethics board were not familiar with this type of research and requested that meetings with patient-partners began after ethics approval had been obtained. After meeting with members of the board and having an open discussion on what patient engagement in research entails, they agreed that patients could be involved at the different stages of the project (including before obtaining ethics approval) and that patient-partners are not the same as patient participants. In another project, early engagement with the research ethics board allowed us to clarify whether broad patient engagement about the study represented a research activity or not and what kind of information and consent process was required. There is increasing research being conducted involving patient-partners, but not all the members of research ethics boards know the difference between a patient-partner and a research "subject" and clarifying roles helps to foster a shared understanding (Doria et al. 2018).

Authorship

The last practical issue we address here relates to authorship: within partnered research, what counts as a significant contribution for a patient in an academic publication or communication? If we consider the guidelines from the International Committee of Medical Journal Editors, to be considered an author, a person needs to be involved in the "conception or design of the work," "drafting the work or revising it critically for important intellectual content," approving the final version, and agreeing to be "accountable for all aspects of the work" (International Committee of Medical Journal Editors 2016, 2). Depending on the type of publication, it might be challenging for patient-partners to meet all of these criteria for authorship (e.g. scientific publication). We wonder if standards should be different for partners as compared to researchers to recognize their involvement or if an acknowledgment of patient-partners is sufficient (if they wish to be named). These issues should be discussed with patient-partners at the beginning of a project to clarify expectations and discuss different possibilities. In our experience, we have promoted inclusive authorship practices based on the recognition of experiential knowledge and the active role of partners in content creation but different scenarios are possible. They range from the simple acknowledgement of patient-partners, their inclusion as full authors, or the creation of a group authorship where members of a

committee, task force or other group are recognized for being part of the study.

Implications and Conclusion

Patient engagement in healthcare, health research, and health policy has been advocated for decades (Veatch 1988). Increasingly, the value of this visionary idea is being recognized and implemented in practical settings. However, the specific kinds of ethical questions that patient-partners, researchers, and clinicians face merits broader attention. In this article, based on our experiences and the literature, we shared and discussed some of the ethical issues related to patient engagement in different spheres of patient engagement including organizational/quality improvement practices, governance, and research. The initial recommendations we provide in each section come largely from our own experiences and some are also supported by the literature. Further exploring connections between these different areas of patient engagement would be a worthwhile goal and lead to more meaningful engagements from patients in practice. Significant resources are invested in partnered projects. The goals sought vary, ranging from increasing the relevance of projects for patients, to empowering patients in healthcare environments, to the promotion of patient-oriented goals for research and quality improvement projects. However, it is important that the efficacy and relevance of different strategies be assessed as early as possible since both patients and researchers/professionals will gain from knowing which strategies can be futile and which are productive and actually lead to the intended goals. Eventually, training and support should be developed and offered to researchers, professionals, and patients alike to be better skilled in such processes.

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