

# When Experts Meet for Better Treatment: Putting the Patient at the Research Table

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**W**ounds Canada's Best Practice Recommendations documents are clear regarding the patient role in the prevention and management of wounds: "Assessments must identify all relevant factors, while interventions must acknowledge and align with a patient's culture and values. This approach, which treats patients as experts in their own lives, assists in developing attainable goals of care and supports self-management once the patient leaves the care setting."<sup>1</sup> As well, "clinicians must let the patient tell their story to help identify what put them at risk for wounds or how their wound developed. Clinicians should always listen to the patient's perception of what is happening and how it is affecting their quality of life."<sup>1</sup> This reality must also be reflected in the field of research.

## Why Patients?

Patients can enhance collective expertise in health care because they are savvy about their own experience and how their condition affects them and their families on both a day-to-day and longer-term basis. Yet the notion of patients being experts might disturb those few who equate expertise with knowledge sanctioned



by advanced education, diplomas and degrees.<sup>2</sup> It is important to note, however, that an expert is defined as a person who has “acquired great ability and knowhow in a profession or a discipline, derived from extensive experience in the field.”<sup>3</sup> So who better than patients to help us understand their perspectives as partners in research in their own “patient discipline”?

Over the last 30 years we have witnessed a strong mobilization of patient associations, as well as a recognition of their expertise, which gives them a legitimate voice in their dealings with governments and health-care professionals.<sup>4,5</sup> This is coupled with the emergence of translational research where patients are the closest collaborators. This type of research was the missing link between discoveries in biomedical research and its impact on patients at the clinical level—in

other words, the transition between the “laboratory” and the “patient’s bedside.”<sup>5,6</sup>

Though it has been a long time coming, it seems obvious now that the beneficiaries of research results should be active partners in the whole research process: orientation, conception, financing and implementation. Despite billions of dollars in research funding and considerable laboratory productivity, only a fraction of promising basic science discoveries result in applied clinical practices and health gains.<sup>7</sup> As a result, large research budgets, a wealth of scientific knowledge and significant public health benefits are lost.<sup>5</sup>

## Finding the Linkages

It is therefore essential to make research results available and useful to the people most concerned, while at the same time getting their perspective on its pertinence. The lifelong experiences of patients with chronic illnesses are but one example. Over and above therapeutic promises, the notions of quality of life must be taken into account. The effects of research must be guided by the global (physical, physiological, social, economical and psychic) nature of the person on the receiving end. Moreover, patients’ views of the ethical aspects of research, which may be different from those of researchers, should be considered.

## Realistic Expectations

Caution must be exercised, however. Though patients may be experiential experts, they do not have the same knowledge base as researchers. The role of the expert patient must be limited to offering untutored competence, in order to question professional practices, to participate in defining the clinical processes in health care.<sup>5,8</sup> That said, it will be important to find ways to recognize and validate the acquisition of patients’ knowledge and competence,<sup>2</sup> such as having them participate in evaluation committees.

Patients should be encouraged to sit at the table and participate in the decision-making process concerning research programs, in the





## Making the Most of the Patient Experience in Framing Research Questions: A Case Study

By combining the voices of patients, clinicians and researchers, a more complete representation of reality can emerge. Let's take the example of a patient with a venous ulcer who has difficulty wearing compression bandages during the summer. The use of compression has been well documented as the cornerstone of effective treatment for this type of wound. Some clinicians might think lack of adherence to the care plan is related to discomfort due to heat or for esthetic reasons.

As a group, however, patients have clearly expressed that the issues relate to more frequent outings in the summer and inadequate access to points of service for the application of their compression. If clinicians don't listen to their patients, they will never know the true reasons for lack of adherence to the care plan.

Once clinicians are aware of their patients' concerns, they can work together on a plan to develop and achieve appropriate goals of care. In this case, the goal would still be compression to heal the ulcer. But knowledge gained from listening to patients might lead to a new research question: How can services be organized to respond to patients whose care settings change in certain contexts, such as summer vacation, to be sure that essential treatment will be maintained?



context of both non-profit organizations and government-funded bodies such as the Canadian Institutes of Health Research (CIHR) or the Natural Sciences and Engineering Research Council of Canada (NSERC).

## The Need for Increased Funding

Research funding is increasingly more difficult to obtain as well as to grant. Chang et al.<sup>9</sup> concluded, in their scoping review of the literature, that more funding, whether government or private, should be made available to ensure that effectiveness is translated to health-care delivery, and delivery translated to population health research.

In addition, the tremendous challenges of driving translational research in older, vulnerable and diverse populations include inadequate financial support, financial disincentives and the intricacies involved in progressing from an acute-care paradigm to a multifaceted, patient-centred and chronic-care model.<sup>10,11,12</sup> According to Kessler and Glasgow,<sup>11</sup> this latter shift would include

greater focus on the needs of practitioners, patients, payers and policymakers and generate more relevant evidence. Funding priorities would change to include increased focus on patients in community settings with complex multi-morbidities, such as chronic wounds.

Changes would be made in grant review criteria, and review sections would require reviewers with new methodological skills and experience in pragmatic studies and contextual factors.<sup>11</sup> But a paradigm change is a long way away ... and each of us, in our fields of expertise, both in research and in clinic, must work to fill the gap for the future.

## Conclusion

Researchers can use a qualitative approach to help apply translational research to action research, participative research and all other kinds. Understanding the patient's view helps researchers to upgrade the interventions or treatment investigated by randomized controlled trials

(RCTs) and to complete the continuum of translational research.<sup>11</sup>

According to Desroche,<sup>13</sup> there are two possible paths for action research: stepping out of action to plan fundamental research, or moving from research to action, which is fundamental to the clinic.<sup>14</sup> In both cases, the patient is involved.

Generally speaking, the researcher's mindset is "knowledge," and the patient's is "well-being." In the end, isn't the best solution to mesh knowledge and well-being to best serve the needs of the patient? 🇩🇪

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