Patient-oriented pharmacy practice research: Why should we care?

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PHARMACISTS DEAL WITH MULTIPLE COMPETING PRIORITIES when practising to their full scope. Deciding on what services to implement, how best to implement them and whether care processes are effective are key questions requiring evidence to inform decisions. The routine involvement of patients and pharmacy practice researchers can help improve how the profession of pharmacy asks and answers these questions.

What is patient-oriented research and why is it important?

The concept of patient-oriented research

Patient-oriented research (POR) is defined as “a continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve health care systems and practices.”¹ This definition has 3 main components:

1. Meaningfully engages patients as partners: This means that patients should actively participate in 1 or more stages of the spectrum of patient and researcher engagement in health research (Figure 1).²
2. Focuses on patient-identified priorities derived using the following:
 - Processes such as the James Lind Alliance Association or similar methods to identify the top 10 uncertainties or unanswered questions about a condition (priorities set by patients and other stakeholders)
 - In-person or online priority-setting activities (e.g., focus groups with patients and other stakeholders)

- Core outcome sets (the minimum data that should be measured and reported in all clinical trials of a specific condition) that have been developed with patient and other stakeholder involvement
3. Has the potential to improve patient outcomes. This may include (but is not limited to) the following:
 - Patient-reported outcome measures (PROMs) such as quality of life, symptoms and functional measures
 - Patient-reported experience measures (PREMs), such as patient access to, or satisfaction with, care
 - Clinical improvements measured by objective laboratory or diagnostic tests
 - Health care service utilization, including emergency room visits, hospitalizations

The importance of POR

POR is a vital component of evidence-informed health care.³ It aims to improve the reach of novel/new therapeutic and diagnostic techniques to patients and assists in delivering high-quality cost-effective care.³ It contributes to improving health outcomes by making sure that the right intervention is delivered to the right patient at the right time.³ Patients are taxpayers who should have a say in the way public funds are used. Ethically (and scientifically), interventions should be designed with and for those who carry the burden of the disease.⁴ This has prompted many organizations, institutions and governments to call for moving towards POR where patients are actively involved through collaboration and partnership.^{1,5,6} Today, patients and the public are actively involved in setting health care priorities through citizen councils and advisory boards, informing management activities within hospital boards and taking an active role in managing their own health care.⁷

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FIGURE 1 Spectrum of patient and researcher engagement in health research²

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Why should we care about POR for pharmacy practice research?

The research we do today influences the care we deliver tomorrow.

—Hallie Brodie⁸

Pharmacy practice research helps inform the profession of pharmacy and other stakeholders about optimal evidence-based patient care. Indeed, Bosworth and colleagues⁹ reported improved adherence rates and clinical outcomes when patients (and their carers) were actively involved in their care.⁹ Patients recognize pharmacists as one of the most trusted health care professionals. They also consider pharmacists to be one of the top sources of information and are highly satisfied with the services and compassion they receive.¹⁰ Such trust, recognition and satisfaction should drive the push towards full-scope pharmacy services,¹¹ since those services improve patient outcomes and patients are asking for them.¹²

Stated another way, involvement of patients in pharmacy practice research will help pharmacy practice evolve because patients will demand a full scope of pharmacist services.

Several benefits for researchers, patients and the research project may emerge when patients are involved early (e.g., the planning stage) in the research process.^{7,13} Not only do patients make the research process more accountable and transparent,

but they also bring their invaluable expertise through their experiences as patients or as carers. Patient involvement can improve the methodology and outcomes of the research and the delivery of care,¹⁴ improve patient enrolment and reduce patient attrition.¹⁵ Meaningful involvement can also result in greater credibility through challenging research assumptions and aligning the goals of the project with patient needs.^{15,16} It can also assist in determining the most appropriate outcome measures—ones that really matter to patients. In addition, it can improve the translation of results to community members.^{14,15} Patients benefit from involvement in the research process through gaining increased confidence and skills, accessing user-friendly information and feeling a sense of accomplishment through their involvement.¹⁷

Some real examples

The level of patient involvement is increasing in pharmacy practice research. For example, the Ontario Pharmacy Evidence Network (OPEN) (www.open-pharmacy-research.ca) is involving patients through citizen panels, focus groups, surveys and interviews. In addition, Alberta Strategy for Patient-Oriented Research Support (ABSPORU, absporu.ca) is supporting pharmacy practice research by encouraging patient involvement across all the stages of health research.

Challenges for pharmacy practice research

The lack of a consensus for common language, definitions and goals represents the major challenge when setting on a course to involve patients and the public in health care decisions.¹⁸ Patients may be frustrated with the lack of role clarity and the length of the research process (i.e., training, meetings, etc.). Tokenism (asking a patient to be involved, but not meaningfully) must be avoided. Researchers may not be sure who to involve and how to effectively engage them. They also may be concerned about the additional time and funds needed for patient involvement and the potential for expanding the scope of their project. Early conversations to define the roles and the expectations of everyone are highly recommended to avoid such frustrations, concerns¹⁹ and tokenism.¹⁵ The lack of formal evaluation of patient involvement initiatives represents another challenge.²⁰ Evaluation ensures that researchers are meeting the goals of the initiatives and areas for improvement are being identified and addressed. This will result in the optimal implementation of the involvement strategy. (Readers who need further information on how to engage patients in health research are encouraged to refer to the how-to guide for researchers published by Alberta SPOR Support Unit.²¹)

The current opportunity

Pharmacists are frontline primary care providers who see patients frequently.²² Patients indicate that they appreciate the care and compassion they receive from their pharmacist.¹² Indeed, they report a high level of satisfaction with a full scope

What can we do?

Pharmacists

- Collaborate with patients to make better and more informed decisions.
- Connect patients who express interest in participating in research with researchers.
- Make sure that the patients' voices are heard.
- Advertise and take part in patient-oriented pharmacy practice research.
- Provide input when required.

Researchers

- Keep open communication channels with practising pharmacists, patients (and carers) and patient groups.
- Seek contribution and input about the research projects.
- Involve practising pharmacists, patients (and carers) and patient groups in all the aspects of the research.

of pharmacy services and highlight that they would reach out to their pharmacist with questions about their condition or treatment regimen.¹² As such, pharmacists are in a prime position to practise to their full scope¹¹ and contribute to the paradigm shift towards POR by collaborating with patients to make better and more informed decisions,^{23,24} which will in turn improve their health outcomes.¹⁴ ■

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