Patient engagement in pharmacy practice research

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FOR DECADES, PHARMACISTS HAVE UNDERSTOOD the importance of interacting with patients in meaningful ways to improve care. Patient engagement is not an entirely new concept in health care, but it has recently received much attention in the research domain as a strategy to increase the relevance, transparency and acceptance of research findings.^{1,2} For many people, engaging patients in research implies a drastic shift from the traditional role of patients as research subjects to an active role as partners and a transfer of power from researchers to patients.³ This change is happening globally, with many countries advocating for the meaningful incorporation of patients' voices throughout the stages of research, including choosing the research questions and conducting and using the research.^{4,5} In Canada, the move to patient engagement in research is being led by Canada's Strategy for Patient-Oriented Research (SPOR).⁶ In the United States, the Patient-Centered Outcomes Research Institute has the mandate for patient engagement in comparative effectiveness research, aimed to help patients and the public make informed health care decisions.⁷

As with other research areas, patient engagement comes with its own jargon.⁸ The Canadian Institutes for Health Research broadly defines the term *patient* as "individuals with personal experience of a health issue and/or informal caregivers, including family and friends."⁸ *Patient engagement* refers to patients actively and meaningfully collaborating with researchers, health care providers and decision makers in the research process.⁸ It involves genuinely working with patients to understand the value patients bring to research and researching what they consider important to improve care.

Systematic scoping review of patient engagement in pharmacy

While patient engagement in health services research has been studied,⁹⁻¹² we were not aware of similar reviews in pharmacy practice research (i.e., "component of health services research that focuses on the assessment and evaluation of pharmacy practice"¹³). Hence, we carried out a scoping review to characterize the nature and extent of the literature on patient engagement in pharmacy practice research. Our systematic scoping review was based on a recognized methodology.¹⁴ Inclusion criteria were empirical studies in pharmacy practice in which patients had been engaged in the research process. We developed our search terms from a previous systematic review¹¹ and added pharmacy-specific terms. Our database search in OVID MEDLINE yielded 937 results, which underwent independent screening by the authors. First, we screened articles for relevant titles and abstracts. Second, we examined full-text articles for eligibility and discussed discrepancies to reach a consensus. Upon final screening and discussion, only 2 articles met the inclusion criteria.^{15,16} Table 1 summarizes key findings on stakeholders involved, methods of engagement, research stages at which engagement occurred and the levels and impact of engagement.

Our findings show that patients, service users and the public were engaged in both studies. The type of stakeholders may have been influenced by the study objectives. For example, a wider range of stakeholders, including pharmacists and policy makers, was involved in the Krska and Mackridge study¹⁵ than in the Alzubaidy and Marriott study,¹⁶ which focused on diabetes patients and key community stakeholders. Although the strategies for determining the numbers of stakeholders

TABLE 1 Research on patient engagement in pharmacy practice research

Author, year, and country	Study objectives	Stakeholders	Stage of engagement	Methods of engagement	Level of engagement	Impact
Krska and Mackridge, 2014, ¹⁵ United Kingdom	To design and evaluate a pharmacy-based alcohol-screening and advice service from the views of relevant stakeholders	General public, service users, pharmacists, pharmacy staff, primary care trust commissioners, alcohol treatment service staff	Questionnaire design Service design Service evaluation	Stakeholder interviews Street survey Working groups Pilot service delivery	Involvement/collaboration	Commissioning of alcohol-screening service Implementation of methods in future studies Promotional strategies User feedback on service delivery
Alzubaidy and Marriott, 2014, ¹⁶ Australia	To investigate Arabic-speaking immigrants' views and beliefs about diabetes, use of medicines, health-seeking behaviours, learning needs and preferences	Diabetes patients, community social workers, community group leader	Recruitment strategies Study design Data collection protocol	Committee meetings Interviews	Involvement/collaboration	Increased participation rates Rich patient data

targeted were not mentioned, the methods commonly employed were interviews, working groups and committees, all of which demonstrate that collaborative working may have occurred. Patients were engaged in the stages of recruitment and data collection, but involvement in data synthesis, interpretation and dissemination activities was lacking. With regard to the impact of engagement, the authors reported that the engagement process was meaningful and facilitated the achievement of the research objectives, although these studies were not designed to quantify the impact on research or patient outcomes.

While patient engagement is recognized to be of importance in research, our review of the literature found only 2 studies that engaged patients in the research process. Reporting on patient engagement in research is inconsistent in the literature, which may have contributed to only 2 studies being identified through systematic searching. To improve the quality of reporting, Concannon et al.¹⁰ developed a 7-item questionnaire that suggests outlining the type and number of stakeholders, recruitment strategies, methods to balance power and engage stakeholders, study phase in which engagement occurred and the impact of engaging stakeholders on the research process and outcomes. The 2 studies that reported some of these elements are

outlined in Table 1. We recommend that future studies provide information on these 7 key areas to enable researchers to learn about the engagement process and adopt good practices.

Given the scant literature identified in our scoping review, there are numerous opportunities for pharmacy practice researchers to develop specific patient engagement plans for research studies and to publish their experiences of engaging patients at relevant stages of the research process. Ongoing research projects, like one focused on how community pharmacists can improve medication adherence for individuals with major depressive disorder, point to the feasibility of engaging patients and stakeholders in pharmacy practice research (see www.absporu.ca).¹⁷ Pharmacy practice researchers may consider the following questions as they contemplate the role of patient engagement in research.

What are the benefits and drawbacks of research engagement?

Patient engagement in research has had a positive impact on patients, researchers and the research project itself.¹⁸ It has increased study enrollment, contextual knowledge, research dissemination, credibility and ability to secure funding.^{18,19} A major pitfall of patient engagement is tokenism—in which patients are involved but are not making valuable contributions to the research or, when

FIGURE 1 Spectrum of patient engagement in health research

Adapted from the IAP2 Spectrum 2007 by Vandall-Walker, 2016 [Mason-Lai P, Vandall-Walker V. *Patient researcher engagement in health research: Competencies, strengths, readiness tools, and suggested course content*. Edmonton, AB: Athabasca University and Alberta Innovates; 2016.]

they do so, their opinions are ignored.²⁰ Tokenism can be avoided by mutually agreeing on the role of patient partners and researchers early on in the research, then managing and renegotiating expectations as the research evolves.²⁰ Other challenges associated with patient engagement in health research are time and funding constraints.²¹ These barriers must be acknowledged but should not deter those who are interested in patient-engaged research.

How can I meaningfully engage patients?

Patient engagement in health research has taken many forms and is largely context driven. Involvement varies by the engagement methods, stages of research, level of engagement and experiences possessed by patients and other stakeholders.²¹ For example, methods such as interviews, focus groups, surveys and advisory boards or steering committees have been used to achieve dialogue and collaboration among patients and researchers.^{11,12} Patients have more commonly participated in setting research priorities and reviewing funding proposals but less frequently in implementing and dissemination activities.¹⁰ Some tactics to increase engagement include engaging multiple patients, involving patient partners in research team meetings and training patients to understand their role and maintain an authentic patient voice throughout the research process.^{12,21}

Researchers interested in venturing into patient-engaged research are encouraged to access the support services and training available through the provincial SPOR SUPPORT (Support for People and Patient-Oriented Research and Trials) units across Canada.²² For example, the Alberta SUPPORT Unit has 7 platforms providing ongoing support on patient engagement, methods, data, knowledge translation, pragmatic trials, career development, consultation and research services related to patient-oriented research. Each province has a model designed for its unique context.

A further tool for researchers is the Spectrum of Patient Engagement in Health Research (Figure 1). Conceptualizing patient engagement in this way may guide pharmacy practice researchers to reflect on the role of patients and key stakeholders. Engagement lies along a continuum ranging from patients informally providing suggestions to the highest order with patients leading the research. Overall, researchers and patient partners could obtain the competency and readiness assessment tools developed by the Alberta SPOR Patient Engagement platform to understand the competencies that will be required for each level of engagement, gauge how prepared they are to engage and identify relevant education and training.²³

The need for patients to be engaged in pharmacy practice research is rising in parallel with the interest in patient-centred care. Effective

approaches to engage patients need to be clearly defined in the context of pharmacy practice literature. It is often said that pharmacists see

patients 5 times more often than other health care professionals do. Perhaps one day, this may be said of pharmacy practice researchers, too. ■

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References

- Entwistle VA, Renfrew MJ, Yearley S, et al. Lay perspectives: advantages for health research. *BMJ* 1998;316(7129):463-6.
- Stewart R, Liabo K. Involvement in research without compromising research quality. *J Health Serv Res Policy* 2012;17(4):248-51.
- Chalmers I. What do I want from health research and researchers when I am a patient? *BMJ* 1995;310(6990):1315.
- Selby JV. The Patient-Centered Outcomes Research Institute: a 2013 agenda for "research done differently." *Popul Health Manag* 2013;16(2):69-70.
- National Institute for Health Research. *INVOLVE*. Available: www.invo.org.uk/ (accessed May 22, 2016).
- Canadian Institutes of Health Research. *Strategy for patient-oriented research: patient engagement framework*. 2014. Available: www.cihr-irsc.gc.ca/e/48413.html#a7 (accessed May 22, 2016).
- Patient-Centered Outcomes Research Institute. *What we mean by engagement*. 2015. Available: www.pcori.org/funding-opportunities/what-we-mean-engagement (accessed Sep. 20, 2016).
- Canadian Institutes for Health Research. *CIHR jargon buster*. Available: www.cihr-irsc.gc.ca/e/48952.html (accessed May 22, 2016).
- Brett J, Staniszewska S, Mockford C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect* 2014;17(5):637-50.
- Concannon TW, Fuster M, Saunders T, et al. A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research. *J Gen Intern Med* 2014;29(12):1692-701.
- Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89.
- Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect* 2015;18(5):1151-66.
- Canadian Pharmacists Association. *Pharmacy practice research*. Available: www.pharmacists.ca/education-practice-resources/pharmacy-practice-research/ (accessed May 27, 2016).
- Peters MD, Godfrey CM, Khalil H, et al. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13(3):141-6.
- Krska J, Mackridge AJ. Involving the public and other stakeholders in development and evaluation of a community pharmacy alcohol screening and brief advice service. *Public Health* 2014;128(4):309-16.
- Alzubaidy H, Marriott J. Patient involvement in social pharmacy research: methodological insights from a project with Arabic-speaking immigrants. *Res Soc Admin Pharm* 2014;10(6):924-5.
- Patient-Centered Outcomes Research Institute. *Tailoring patient options for medication adherence action plans in community pharmacies*. 2015. Available: www.pcori.org/research-results/2015/tailoring-patient-options-medication-adherence-action-plans-community (accessed Sep. 20, 2016).
- Hewlett S, Wit MD, Richards P, et al. Patients and professionals as research partners: challenges, practicalities, and benefits. *Arthritis Care Res* 2006;55(4):676-80.
- Lindenmeyer A, Hearnshaw H, Sturt J, et al. Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: a qualitative case study. *Health Expect* 2007;10(3):268-77.
- Supple D, Roberts A, Hudson V, et al. From tokenism to meaningful engagement: best practices in patient involvement in an EU project. *Res Involve Engage* 2015;1(1):1-9.
- Forsythe LP, Ellis LE, Edmundson L, et al. Patient and stakeholder engagement in the PCORI pilot projects: description and lessons learned. *J Gen Intern Med* 2016;31(1):13-21.
- Canadian Institutes for Health Research. *SPOR SUPPORT units*. 2016. Available: www.cihr-irsc.gc.ca/e/45859.html (accessed Jun. 14, 2016).
- Alberta SPOR SUPPORT Unit. *Patient engagement platform: resources and services*. 2016. Available: www.aihealthsolutions.ca/initiatives-partnerships/spor/patient-engagement-platform/ (accessed Sep. 20, 2016).