Partnering with patients in the production of evidence

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Introduction

Partnership with patients and carers in the production and implementation of evidence-based medicine (EBM) has long been highlighted as important and necessary.[1] As outlined by David Sackett, the practice of EBM calls for the integration of external evidence and clinical expertise with the 'patient's clinical state, predicament and preferences' to determine if and whether it should be applied.[2] This has led to the development of guidelines and principles around involving patients in the conduct, delivery, implementation and dissemination of evidence in healthcare.[3 4]

The past decade has witnessed a rapid increase in patient partnership in healthcare delivery.[5] The 2017 EBM Manifesto identified patient partnership in the production of evidence as one of the key ways to develop more trustworthy evidence.[6] Patients and carers are increasingly highlighted as having a key role in ensuring that new healthcare research is relevant, accessible and applicable to end users.[7] Despite this increased awareness, there are still several challenges to support both researchers and patients to partner in the development of EBM. The EBMLive conferences (https://ebmlive.org/) have provided one platform to discuss some of these issues by bringing patients, researchers and clinicians together to tackle some of the uncertainty around how, when and where to involve patients in EBM. In this article, we describe some of the perceived challenges within patient and researcher partnerships in the production and implementation of evidence and highlight areas where future EBMLive conferences will explore. We also outline strategies on how researchers can better partner with, and support, patients to be involved in EBM.

Why partner with patients?

Patient partnership is morally necessary as patients are the individuals who are the most directly affected by the evidence generated. The 'Nothing about us without us' phrase is used by many patient groups calling for involvement in healthcare decisions. This highlights that all stakeholders who may be affected by a decision should be involved in decision-making, which is particularly important in EBM.

There are also a number of benefits to partnering with patients in research, including ensuring the research questions are relevant and important,[6] and preventing research waste, including time and money.[8] It can also ensure that research is appropriate to the end users and that the quality of outputs and outcomes are increased.[8] Engaging with patients in research also improves research study design and delivery.[9 10] A systematic review exploring the effectiveness of patient engagement in research identified that engaging patients assisted in protocol design and outcome selection, led to increased study enrolment rates which also helped researchers obtain funding.[11] A Cochrane systematic review further reported that patient involvement can ensure communication of research findings are understandable to patients,[12] helping to facilitate the use of evidence for decision-making.

What are some perceived challenges to patient involvement in research?

Despite the increased importance of patient involvement, challenges arise in its implementation for both researchers and patients. These concerns often relate to which patients are involved, how they are involved and the impact that they have on decision-making in healthcare. There are also a number of elements in patient involvement which should be considered to ensure that patients can actively contribute to EBM. We highlight some of the main perceived barriers to involving patients in the production of evidence and summarise these challenges and potential strategies in table 1.

Identifying patients and carers

The initial challenge that emerges is identifying the 'right' patient.[13 14] Common barriers include knowing where to find interested patients who want to be involved. Unlike academia, where channels exist to identify people with necessary skills (eg, statistics) or expertise (eg, paediatrics), identifying patients is often opportunistic or random. While many large institutions, hospitals and research institutes have created patient advisory panels to draw on, researchers in small communities, with limited expertise, and those early-career are at a disadvantage.[13] The want to find the 'typical patient' is often highlighted as a concern of researchers who want to involve patients in research.[9] Some are concerned that patients may not have the 'necessary skills' to be involved or may not be 'representative' of the patient group. It is therefore important to identify and address any specific challenges that the desired patients or groups may face, such as having meetings outside normal working hours, childcare support to attend meetings or being able to provide input online/over the phone if face-to-face meetings are difficult for patients to attend.

Table 1 Common questions about patient involvement and suggested strategies

Question	Suggested strategies
How do I identify patients to partner with?	▶ Create description of patient partner role, outlining the specific roles and responsibilities, time commitment and skill set ▶ Contact local university, hospital or research foundation about formal channels to identify patient partners (eg, Hospital Patient Family Advisory Council) ▶ Contact relevant charity or national patient foundation, if relevant (eg, Asthma Canada) ▶ Publicise description of patient partner role on social media ▶ Contact a patient advocate and ask them to share within their networks
Do patients need training to be involved in research?	▶ Most patient partners do not require specific training, but should be supported ▶ Based on the role of the patient partner, additional training may be beneficial ▶ Refer to local resources for patient training courses (eg, Patient and Community Engagement Research Unit[19])
How do I engage with vulnerable populations?	▶ Identify researchers and colleagues who have conducted similar studies, contact them and ask them how they identified partners ▶ Work with known patient partners ▶ Obtain additional training on working with vulnerable populations (eg, Patient-Oriented Research Curriculum in Child Health[20])
How do I involve patients in grant writing?	▶ Contact local agencies involved in patient-oriented research for support and guidance (eg, NIHR INVOLVE, Ontario SPOR Support Unit) ▶ Include patient compensation budget in proposed grant ▶ Ensure open communication with patient partners regarding their role, along with grant timelines and budget, prior to agreement to assist
Do I have to pay patients involved in research?	▶ Patients should be compensated for their contribution, which can include monetary compensation, honorarium, in-kind gifts or vouchers ▶ Patients may decline payment, but it should still be offered ▶ Patients should be reimbursed for any expenses incurred (eg, transportation, parking) ▶ Refer to funding organisation guidelines for appropriate details on payment (eg, CIHR SPOR, NIHR INVOLVE)

Engaging vulnerable populations

One of the more ethically fraught aspects of patient involvement relates to individuals who lack capacity for decision-making, such as infants, children[15] and adults with cognitive impairment (eg, dementia). It is critically important to involve these individuals in health research which directly impacts them. Yet, children and youth perspectives may differ from family members and/or caregivers and it is important to ensure that both can contribute their experiences. For example, adolescents living with type 1 diabetes may have different priorities relating to outcomes of importance (eg, independence, least number of glucose checks) compared with their caregivers (eg, reducing long-term complications, adherence to therapy). Both perspectives are important, yet tensions emerge when they conflict. On a more practical level, identifying children and youth to involve in research is an even greater challenge given that children are in school, families have busy schedules and consent is needed from caregivers.

Despite these challenges there are a number of examples where children and young people have been involved in the development of research and evidence. One of these is the BeGOOD Early Intervention Ethics (EIE) Young People's Advisory Group (YPAG) (https://begoodeie.com/ypag/) where young people meet with researchers to collaborate and advise on research projects around mental health and ethics. Another example is the Cochrane Common Mental Disorders Children and Young People Satellite (https://cmd.cochrane.org/news/new-children-and-young-people-satellite) who have conducted a large priority setting project using online surveys and face-to-face meetings with young people.

Health literacy may play a major role, and additional time is needed to ensure that documentation is appropriate for different age groups. It is also important to consider the involvement of other vulnerable populations, including Indigenous peoples, ethnic minorities, non-native English speakers, low socioeconomic status groups and high social risk groups. Researchers should consider the challenges each group may face in partnering and explore how these can be minimised, such as having someone within the community help to identify individuals.

Table 2 Domains of patient involvement in the production of research evidence

Domain	Examples
Research question prioritisation and study design	▶ Inform research question and appropriate study design ▶ Identify areas which are most important or challenging for them within their health condition or care
Identifying and selecting study outcomes	▶ Provide feedback on study outcomes to ensure they are patient-oriented, patient informed and relevant ▶ Comment on feasibility of outcome measures (eg, likely response rates for questionnaires) ▶ Identify any additional outcomes important to them
Design of study materials	▶ Assist in designing consent forms and study information sheets ▶ Ensure language is at appropriate health literacy level ▶ Ensure that all relevant information is included and clear
Recruitment methods and study participation guidance	▶ Inform recruitment strategy ▶ Identify patient groups or organisations who can support with recruitment ▶ Advise on the acceptability of study participation requirements (eg, is the length of participation suitable for patient group?)
Knowledge translation and dissemination of research findings/use of evidence	▶ Draft communication strategy ▶ Identify channels and assist in the disseminating research findings to patients ▶ Help to integrate research findings into shared decision-making tools ▶ Write lay summaries, blogs, tweets and so on, to share research findings

Box 1 Useful links and resources for patient involvement in research

Funding bodies and organisational websites

- International Alliance of Patients' Organizations (IAPO) (https://www.iapo.org.uk/)
- National Institute for Health Research (NIHR) INVOLVE in the UK (https://www.invo.org.uk/)
- Canadian Institute of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) in Canada (https://cihr-irsc.gc.ca/e/41204.html)
- Patient-Centered Outcomes Research Institute (PCORI) in the USA (https://www.pcori.org/)
- European Patients' Academy (https://www.eupati.eu/)
- Consumer and Community Health Research Network in Australia (https://www.involvingpeopleinresearch.org.au/)
- Health Consumers Alliance of Southern Australia (HCA) in Australia (https://www.hcasa.asn.au/)
- Ontario SPOR Support Unit (https://ossu.ca/)
- Centre of Excellence on Partnership with Patients and the Public (CEPPP) (https://ceppp.ca/en/)
- Canadian Foundation for Healthcare Improvement (CFHI) Patient Engagement Resource Hub (https://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx)
- International Alliance of Patients' Organizations – Africa (https://www.iapo.org.uk/africa)
- International Alliance of Patients' Organizations – Latin America (https://www.iapo.org.uk/latin-america)
- International Alliance of Patients' Organizations – Western Pacific (https://www.iapo.org.uk/western-pacific)
- Taiwan Alliance of Patients' Organizations (TAPO) in Taiwan (https://tapo.org.tw/)
- BMJ Patient and Public Partnership (https://www.bmj.com/campaign/patient-partnership)
- Patients Canada (https://patientscanada.ca/)

Education

- Partners in Research (PIR), Knowledge Translation Program at St Michael's Hospital (Canada), (https://knowledgetranslation.net/education-training/partners-in-research/)
- Patient and Community Engagement Research (PaCER) unit at the O'Brien Institute for Public Health (Canada) (https://pacerinnovates.ca/)
- European Patients' Academy Toolbox (https://www.eupati.eu/what-is-the-toolbox/)
- Involving members of vulnerable populations in the development of patient decision aids (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5244537/)
- Patient-Centered Outcomes Research Institute (PCORI) Patient Engagement Toolkit (USA) (https://www.pcori.org/engagement/engagement-resources/Engagement-Tool-Resource-Repository/patient-engagement-toolkit)
- Public reviewing with the NIHR (UK) (https://www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/)
- Training for Consumers and Researchers, Consumer and Community Health Research Network (Australia) (https://www.involvingpeopleinresearch.org.au/researchers/#researcher-training)
- International Alliance of Patients' Organizations (IAPO) Resources (https://www.iapo.org.uk/resources)

Engaging patients in research methodology

Concern around patients' knowledge of research methods is another perceived barrier. Although patients will bring unique knowledge to the team, they may lack the technical expertise in understanding research methods and study design. There is some debate around whether patients should have, or require, any training in methodology to allow them to contribute to study designs in a meaningful way.[16] Although training and support for patients involved in research is recommended,[17] this can also pose challenges in terms of costs and resources in delivering training.

Engaging patients in grant writing

Guidelines around patient involvement recommend reimbursing and compensating patients for time and contribution.[4 18] While these standards are now routinely incorporated in research grants, they are less helpful during the grant writing stage. Grant writing is analogous to research question formulation, a key step in avoiding research waste. Yet, at this stage, research teams do not have funds to compensate patients. From a practical standpoint, it can be challenging to identify patients, particularly given the narrow timelines that grant deadlines follow. Certain grant agencies also require that patients create cumbersome curriculum vitaes, further creating barriers. After grant submission, 6 months may pass before the grant undergoes peer review where in all likelihood, given low current funding rates, the grant will not be funded. It is difficult to justify asking patients to volunteer given such unfavourable funding rates.

How to improve evidence by partnering with patients?

There are many ways to partner with patients and/or carers in the creation, implementation and dissemination of evidence. Table 2 outlines the key domains in patient partnership and describes practical examples. Patient partnership in these areas will ensure that the most important issues for patients are addressed and that key patient-oriented outcomes are included (eg, patient harms). Patients can also provide invaluable insight into how to communicate findings to end users who bear the ultimate burden of healthcare decisions. Box 1 outlines several useful resources to guide researchers.

From the patient perspective, one of the key ways to ensure effective engagement is a strong relationship between the patients and the researchers. An effective strategy is to have one named member of the research team who is a central point of contact for patients, which allows patients to build trust in the research group. It is also important to ensure patients are clear on how research groups will ensure their voices are heard (eg, allowing patients to provide input or feedback first at meetings), how their contributions will be considered and implemented and how they will be informed of the ways in which their contributions have impacted the research. The

named contact discusses these issues with patients at the beginning, and during, the project, and would ideally be able to support patients in understanding the research methods, questions and constraints. They would also have skills in facilitating meeting and workshops, to ensure the patient voice is central within discussions and meetings. Having an additional member of the research team take on this role can have cost implications, however, partnering with a patient and public involvement (PPI) expert within a research group or institution can help support more effective patient involvement within many research projects.

While the COVID-19 pandemic has introduced many challenges to conducting research and particularly partnering with patients; we believe, however, that the previously mentioned strategies can, and should, still be implemented. The increased use of technology can help minimise barriers for patient involvement both during the pandemic and beyond. Some research organisations have published strategies to help ensure patient engagement during the pandemic, such as the NIHR Research Design Service South Central (https://www.rds-sc.nihr.ac.uk/ppiinformation-resources/ppi-covid19/).

Where do we go from here?

Since the EBM manifesto highlighted involving patients as a core element of improving evidence, a central theme of the EBMLive conference is patient involvement in the production and dissemination of research. The EBMLive conferences have included patient keynotes and workshops to help attendees learn how to conduct research with patients as partners. The aim of these are to open up engagement and debate on how to best involve patients in research in light of the challenges highlighted here.

The EBMLive conferences provide an opportunity to embrace the challenges and develop strategies for successful patient partnership in evidence-based medicine by bringing together healthcare professionals, researchers, policymakers and patients. As part of this commitment, EBMLive reserves delegate spots for patients to attend the conference and be involved in the discussions and workshops. In striving to improve evidence, it is crucial that all perspectives are considered and that patients are given the support and opportunities to be part of this movement forward.

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