Patient and public involvement in living guidelines

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This chapter is the result of a collaboration, and involved staff and patient and public members of guideline development groups from the Australian Living Evidence Collaboration (ALEC) and the National Institute for Health and Care Excellence (NICE).

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Key messages of this chapter

- 'Living guidelines' use a new approach to evidence synthesis that allows the most up-to-date evidence to be quickly integrated into a guideline to ensure recommendations are current, valid and relevant to the healthcare context.
- Because living guidelines use the same guideline development steps as conventional guidelines, patient and public involvement (PPI) remains an essential part of living guidelines.
- Three models for PPI in living guidelines are described: a standalone patient and public panel, patient and public members included as guideline development group members, and a pool of patient and public members matched to tasks and development groups. There are likely to be other suitable approaches and methods for PPI in living guidelines.
- Living guidelines differ from conventional guidelines in that the volume of work varies, and the pace is more unpredictable. ~~m~~Meetings are usually held online; and they may need a longer-term commitment from patient and public members. These differences have implications for how PPI is done.
- Recruitment is similar to that for conventional guidelines, but there are additional considerations, such as needing to quickly recruit patient and panel members.

- Managing, maintaining and retaining the panel over a long period may mean involving more patient and public contributors and ensuring ongoing enthusiasm. But the ongoing and continuous nature of living guidelines activity can help with developing trust, relationship building and co-learning, which supports meaningful and effective PPI.
- Anticipating patient and public members' ongoing training and support needs might include making reasonable adjustments, providing pre- and post-meeting chats, and giving constructive feedback.
- Priority setting can be ongoing in a living guideline, which can be challenging but also offer a meaningful and enhanced role for patient and public members in informing priority areas from a patient perspective.
- Training and co-learning opportunities in living guidelines can be ongoing and help with peer support, in which less experienced patient and public members are supported by more experienced patient and public members.
- Regular feedback and evaluation of PPI in living guidelines from patient and public members, other committee members and guideline developer staff allows ongoing PPI improvement, fosters mutual respect and ensures the PPI process remains effective and meaningful.

Top tips

- Take the differences between living and conventional guidelines (that is, volume and pace of work, online only meetings and longer-term commitment) into account when planning your PPI model.
- Build on established PPI best practices in guideline development (for example, clear expectations, trusting relationships, avoiding medical jargon).
- Consider involving more patient and public members than in conventional guideline development and prioritise including people with a range of perspectives and experience levels.
- Plan strategies to engage, maintain and retain patient and public members over time.
- Anticipate that patient and public members' support needs may be greater than in conventional guideline development and that they can change over time. Work

with these members to ensure their needs are being met, including by making reasonable adjustments.
- View the engagement as living and anticipate that it will grow and improve over time.
- Build in mechanisms that allow patient and public members to provide regular feedback about their experience, which will help improvement to be ongoing.

Aims of this chapter

The concept of living guidelines is a recent change in the field of guideline development and has been quickly adopted since the COVID-19 pandemic (Cheyne et al. 2023). Living guidelines use all the main steps of conventional guideline development, including involving patient and public members. But so far, the experiences of people involved in developing living guidelines suggests they are different enough to experiences with conventional guideline development for them to have implications for PPI.

In this chapter we aim to:

- explain what is meant by living guidelines and when they are used
- describe current models for PPI in developing living guidelines
- explain the differences between developing living guidelines and conventional guidelines, highlighting what these differences mean for PPI
- provide practical examples of recruitment; managing and supporting patient and public panel members over time; setting priorities with patient and panel members; training and co-learning; and feedback, evaluation and improvement.

We have drawn from the limited research literature in this field, and the practical experiences of the author team, which includes patient and public members and guideline developers involved in living guidelines internationally.

What are living guidelines and when are they used?

In recent years, a new approach to evidence synthesis emerged, resulting in what are called ‘living guidelines’ (Cheyne et al. 2023. El Mikati et al. 2022). Living guidelines are the output of ongoing systematic reviews, that allow the most up-to-

date evidence in the field to be quickly integrated into recommendations. They combine the methodological rigour of established best practice in guideline development, with the ability to nimbly respond to changes in the evidence, guideline users' needs, or the broader healthcare context, to ensure recommendations are current, valid and relevant.

In 2017, the Stroke Foundation in Australia started their guidelines on stroke care, the world's first living guidelines (English et al. 2022). The COVID-19 pandemic increased the pace of living guideline development. The Australian Living Evidence Collaboration (ALEC), the National Institute for Health and Care Excellence (NICE) and the World Health Organization (WHO) all chose to implement a living approach to keep up with the rapidly growing body of research and to produce up-to-date recommendations on COVID-19. Guideline developers internationally are now developing living guidelines on many different topics. For example, ALEC is currently developing many more living guidelines, including for topics such as inflammatory arthritis, type 1 diabetes, kidney disease and pregnancy and postnatal care.

Guideline developers can create a living guideline from the beginning (involving first developing a conventional guideline and then making it living), or adapt and change an existing published guideline to a living approach. Either way, guideline developers may select specific questions or recommendations that are appropriate for a living approach, rather than committing to keeping all recommendations up to date (Cheyne et al. 2023). The decisions to use a living guideline approach are based on whether the recommendations are a high priority, if new evidence is likely to change recommendations, and if new evidence is expected (Akl et al. 2017). Living guidelines may consist of a single guideline, or a set of guidelines covering a common area.

Models for involving patients and the public in living guidelines

Few models for PPI involvement have been used, and far fewer evaluated, because living guidelines are a recent concept. Many factors determine how patient and public members are involved in conventional or living guidelines. Such factors include the topic, the stages when input is needed, the backgrounds and preferences

of the patient and public members and guideline developers involved, the kind of patient and public input needed, and resource considerations.

We have practical experience with 3 different models:

- a standalone patient and public panel
- patient and public guideline development group members
- a pool of patient and public members matched to tasks and development groups.

But there are likely to be other suitable approaches and methods for PPI in living guidelines.

Standalone patient and public panel model

ALEC used a standalone patient and public panel, that is, a consumer panel, in its living guidelines on stroke, COVID-19, and pregnancy and postnatal care. In all 3 guidelines, ALEC used an expression of interest process to recruit patient and public members from an existing pool of patient and public members (stroke guidelines), a patient organisation (COVID-19), or an open process carried out mainly through social media (pregnancy and postnatal care).

The consumer panels are composed of at least 8 people with lived experience of the health condition or health state. In all 3 living guidelines, ALEC aimed to recruit a group with geographic and cultural diversity. The consumer panels have an advisory role, but between 1 and 4 patient and public members of the panels are also members of other decision-making or oversight groups, such as the guideline development group or the steering group. These members act as a bridge between the PPI panels and decision-making groups.

The Consumer Panel Model allows patient and public members with a broad range of perspectives, skills and backgrounds to be involved. Other advantages include ensuring consumer input is recognised and prioritised, especially if the consumer panel's input carries the same weight as that of the clinical panel(s).

While developing and maintaining the Australian COVID-19 guidelines, the 8-member panel met every 2 months (every 2 weeks in the first months of the pandemic) by videoconference in 90-minute meetings. The members had an

orientation and GRADE training, together with clinical panel members. Two patient and public member co-chairs, drawn from the group, led the panel. They were also members of the guideline's leadership group (who functioned as a guideline development group). The consumer panel generated new questions, topics, and outcomes, and provided feedback on draft recommendations, with their views considered at guideline development group meetings, and included in the additional information on individual recommendations.

This model was adapted and further developed for the Australian Pregnancy and postnatal care guidelines (Living Evidence for Pregnancy and Postnatal Care [LEAPP]), with the formation of the 16-member LEAPP Consumer Panel who meet every 3 months through a 2-hour videoconference. Four patient and public members of the Consumer Panel are also co-chairs of the 2 clinical panels (2 for each panel), and all 4 are also members of the guideline leadership group. The Consumer Panel reviews recommendations before the clinical panels, and their feedback is incorporated in the draft recommendations before the clinical panel meeting.

For the stroke guidelines, the 28-member consumer panel gets emails with draft summaries of relevant guideline sections (for example, patient values and preferences, practical considerations) that align with their nominated interest areas, together with guidance on how to respond. Panel members email feedback to staff members of the organisation, who review all their feedback. Consumer panel members co-produce lay versions of finalised recommendations through writing groups with clinicians, and meeting by video or phone. Synnot et al. (2023) give more detail on the Consumer Panel Model for living guidelines.

Patient and public guideline development group members' model

NICE's COVID-19 guidelines in the UK and the Australian guidelines on inflammatory arthritis and type1 diabetes are 3 examples of living guidelines in which patient and public members are included in the guideline development group. Patient and public members were recruited either through guideline developer networks (inflammatory arthritis and diabetes) or an open recruitment process, using expressions of interest forms and informal interviews to check suitability of experience relevant to the topic (COVID-19 guidelines). In these guidelines, patient and public members contributed to all aspects of guideline development,

participating in meetings and out-of-session email discussions. Both the type 1 diabetes and inflammatory arthritis guidelines included a patient and public member in the guideline oversight or steering committee.

In the COVID-19 guidelines, the guideline development group scheduled a 2-weekly online meeting, but only met as needed. The PPI guideline development group for the inflammatory arthritis guidelines meets as needed, depending on the recommendation (to date, this has been about once a month). For the type 1 diabetes guidelines, the PPI guideline development group met about once every 2 months but had more meetings at the beginning of the process. Synnot et al. (2023) give more detail on the model of patient and public member involvement in the living guideline development groups.

Patient and public members matched to tasks and development groups model

NICE tested a model of living guidelines to update the breast cancer guidelines, for example the early and locally advanced breast cancer guideline. At the start, they recruited a pool (also known as a 'faculty') of 10 patient and public members, and another pool of clinicians. When topics were scheduled to be updated, a guideline development group was formed from clinicians and patient and public members in the pools. Further detail on the recruitment experience and matching process is given in the section on recruiting patient and public members to a living guideline group. Each guideline development group included at least 2 patient and public members, who had the same membership and voting rights as all the other members of the development group. This model also ensured diversity among the pool regarding different societal characteristics (for example, gender [including one man], age [including younger and older individuals], and LGBTQ+ members)

The guideline development groups were involved in different stages of guideline development, such as:

- prioritisation (a survey and 1 meeting), including helping the guideline developer decide which topics were a priority from a patient perspective
- scoping and protocol development (1 meeting), including identifying the topics, outcomes and preferences that are important for patients and the public

- developing recommendations (1 meeting), including influencing discussions
- post-consultation (1 meeting), including shaping recommendations by incorporating the comments from patient and professional organisations.

Using this model ensured that the pool included people with a broad range of experiences covering different aspects of the recommendations to be updated. For example, individuals were recruited with experience of genetic testing, different treatments (for example, neoadjuvant chemotherapy), different types of breast cancer (such as HER2-positive breast cancer), and other aspects associated with breast cancer (for example, lymphoedema, psychological support).

What is different about PPI for developing living guidelines compared with conventional guidelines?

The paper by some of the authors of this chapter (Synnot et al. 2023) describes guideline developers' and patient and public members' reflections on their experiences of being involved in 5 living guidelines. These living guidelines, discussed in the section on models for PPI in developing living guidelines, were developed in Australia (stroke, COVID-19, inflammatory arthritis and type 1 diabetes) and the UK (COVID-19). They found the fundamental differences between PPI in living guidelines compared with conventional guidelines related to how patient and public members (as well as other guideline contributors) were expected to work on the guideline. The differences for living guidelines were:

- the volume of work fluctuated, and the pace was more unpredictable, sometimes resulting in fewer and shorter meetings, or faster paced work
- meetings were often held online, which could affect relationship building and displace collaborative working with working by emails and digital documents
- the commitment was longer term, which raised different issues about ongoing engagement and management of patient and public members.

These differences have implications for how best to involve patient and public members in living guidelines. The experience at NICE has been that the differences can hamper best practice implementation for PPI, including, practical support (for example, financial reimbursement, making reasonable adjustments), training and co-

learning of patient and public members and staff, and feedback and evaluation of effectiveness. While others in the author group have found that training and co-learning is improved through repetition of tasks involved in living guideline meetings.

Although the guideline development tasks may not differ in the case of living guidelines, patient and public members may be asked to contribute to different tasks at multiple timepoints. For example, although recommendations will be developed or updated at regular meetings, guideline scope and priority questions may be revised or emerge over time. Similarly, publication and dissemination can happen at multiple timepoints, or when a recommendation is made, rather than when the whole guideline is published (Cheyne et al. 2023).

Also, the main differences in developing living guidelines mean that the guideline developers might need to consider adapting involvement methods or tasks. For example, NICE found that the highly clinical nature of some living guideline topics meant that patient and public members were sometimes unsure of when and how to contribute within meetings. One possible solution can be drawn from the Australian COVID-19 guidelines. Guideline developer staff, known to the consumer panel, presented the evidence, and interpreted and explained the evidence together with a clinician, who clarified any clinical issues and questions. Such an approach meant all queries could be addressed during the meeting, allowing patient and public members to focus on providing their comments and feedback on the evidence and recommendations.

The authors of the Synnot et al. (2023) paper found that these differences could present as barriers to overcome as well as opportunities to enhance the experience of PPI for everyone involved. Specific implications, barriers, and possible strategies to overcome them in living guidelines are discussed in detail in this chapter, including:

- recruitment
- managing, maintaining and engaging patient and public members developing a living guideline over a long time
- supporting patient and public members throughout the development of living guidelines, including informal, practical and emotional support

- setting priorities for updating living guidelines
- training and co-learning
- feedback, evaluation and improvement in PPI in living guidelines.

What is same about PPI for developing living guidelines compared with conventional guidelines?

Synnot et al. (2023) found that the experiences of patient and public members and guideline developers involved in living guidelines highlighted that the fundamentals of good practice in PPI (for example, trusted relationships and co-designing the engagement) still apply to a living approach. Guideline developers were asked what worked well and what could have been improved in their living guidelines experience. Many of their reflections were consistent with established good practice in PPI in healthcare more generally, or echoed the experiences of contributors in conventional guidelines, for example, insufficient preparation of patient and public members or unclear expectations (van der Ham et al. 2014).

We suggest that because living guidelines have only recently begun to be developed, as well as the complexity of changing to a living guidelines model, guideline developers should:

- preferably, be experienced in working with patient and public members
- ideally, operate in an organisation with in-house expertise.

Guideline developers should be sufficiently skilled in PPI (either through training or previous experience) and be able to plan and support best practices throughout guideline programme. The GIN Public Toolkit offers considerable guidance about how to engage patient and public members in ways that are meaningful and beneficial for all parties.

Recruiting patient and public members to a living guideline development group

Recruiting patient and public members to a living guideline development group is mostly like recruitment for a conventional guideline. The chapter on recruitment and

support covers many of the recruitment considerations (for example, who to recruit and how to gain a wide range of experiences) and recruitment methods, including open recruitment (that is, the selection process through an advert, application form, and informal interview) and nomination (that is, inviting expressions of interest through patient organisations). But for living guidelines, there are some additional considerations for recruiting at the beginning and also for managing, retaining and renewing membership. Considerations when recruiting a living guideline group at the start include:

- Some living guidelines, particularly those developed for a public health emergency, need patient and public members to be quickly recruited and with short notice. This can make it more difficult to ensure that people with the right experience and capacity are involved at the right time and that they have sufficient experience of the topic area.
- The recommendations that will be updated can reflect the emergence of available evidence and that could mean it is unclear what experience and representation is needed at the start of developing a living guideline.

Case studies of recruiting patient and public members to a living guideline development group

Recruiting a broad pool of patient and public members to be matched to tasks and development groups

NICE's early and locally advanced breast cancer living guideline used the model in which a pool or faculty of patient and public members were matched to tasks and development groups. As described, this allowed patient and public members to be quickly recruited from the pool to a guideline development group. It also ensured recruitment of individuals with diverse characteristics and different breast cancer treatments that aligned with the topics to be updated. This helped to address the issue of pace and

representation of experiences relevant to the emerging evidence. There were 2 stages to recruitment:

- recruiting and developing the patient and public member pool before development work on the guideline started
- selecting and matching process of individuals from the pool to the development groups as work on the guideline began.

Ten patient and public members were recruited to develop the pool at the start. One person was a member of a voluntary and community sector organisation. NICE recruited people using an open recruitment method. Adverts were promoted through social media and voluntary and community sector organisations for breast cancer. In an application form, individuals were asked about their:

- experiences of different treatments and experiences relevant to the topics to be updated
- knowledge of issues facing patients with breast cancer
- experiences of group working
- knowledge of equality, diversity and inclusion related to the topic.

Shortlisted applicants attended an interview in which they were asked about their experiences, knowledge and skills in more detail. They were also given information about the guideline development process.

After the patient and public member pool had been established, NICE guideline developers and the People and Communities team worked with the patient and public member pool to co-create a selection process to help match individuals' experience to topics associated with the early and locally advanced breast cancer and advanced breast cancer living guidelines. Patient and public members completed a survey about their experiences with breast cancer. The information helped the developer team select and invite at least 2 patient and public members to the different update panels, when the development groups started work. This ensured that the

developer teams could quickly convene a guideline development group with relevant experience.

Co-designing and carrying out recruitment for a living guideline

As noted, the LEAPP guideline used a standalone patient and public panel model for PPI. The team partnered with 2 highly experienced patient and public members to co-design the PPI approach for their living guideline. Together, 1 LEAPP team member and the 2 patient and public members designed and carried out the recruitment approach. This included wide promotion through trusted patient organisations and networks, and invitations for written applications in an expression of interest process. They received 101 applications, which included considerable diversity in people's lived experiences of pregnancy and postnatal care, experience as a patient and public representative, and demographic characteristics. Because it was a living guideline, we selected a large panel (16 members), which ensured more diversity in people's pregnancy and postnatal journeys and healthcare experiences. It also helped to recruit a group that was more reflective of the Australian population (including people living in regional and remote areas, Aboriginal and Torres Strait Islander women, recent migrants and refugees). Being a living guideline that was funded for 5 years, the team recruited a large panel because we anticipated member attrition over time. The LEAPP guideline team also used this opportunity to select some people with limited or no experience as a patient or public member (but who brought diversity characteristics, such as experience of being a teenage mother, or living on a low income). The team expected that they would, with support, gain skills and confidence over time and learn from more experienced members.

Managing, maintaining and engaging patient and public members during living guideline development

Because a living guideline programme may continue for some years, guideline developers need to consider retention, renewal and succession planning for patient and public members from the start. The approach needs to be tailored or designed for the type of PPI model being used, for example, a standalone patient and public panel who are regularly consulted, or a pool of patients ready to be called to action for specific tasks or guideline development groups.

Development groups with the same core membership

Feedback from NICE staff and patient and public members involved in developing living guidelines suggested advantages and disadvantages of maintaining a guideline development group with the same core membership over 24 or more months. Maintaining a core membership provided the advantage of consistency that allowed patient and public members to build better relationships and to feel a sense of safety and connection in meetings. This helped them to share sincere and authentic insights that more deeply influenced the development of recommendations. Having a consistent guideline development group also meant that members developed knowledge of the guideline development processes through co-learning, and so needed less training resources for new topics.

In contrast, a disadvantage was that the experience needed could change over the lifecycle of a living guideline. Also, some patient and public members' experience might not be relevant over time. For example, some individuals stated that if they became well a year or two after a diagnosis of long COVID they did not think their experience would still be relevant. One suggested solution was to review membership and experience every 1 to 3 years, depending on the length of the guideline development lifecycle. But it is important to carefully manage turnover so that there is continuity of guideline development experience and knowledge in the group. Training and mentorship of new patient and public members is important to build knowledge and skills for guideline development.

Another disadvantage of retaining a core membership is that patient and public members can become generalists rather than specialists in specific areas over time.

For example, in topics with a broad scope, it is unlikely that all participants will have specific experience of all topic areas. This means that some patient and public members might contribute to discussions more broadly, rather than specifically. To address this, guideline developers can ensure that consultations involve patients and the public with the right experience. Additionally, members with less experience can develop their knowledge of healthcare and guideline development processes throughout the lifecycle of a living guideline, resulting in richer contributions. For example, in the Australian COVID-19 guidelines, the panel provided valuable input about specific paediatric treatment options without having specific lived experience. This included a reminder to clinicians to consider the whole child and family situation when recommending treatments, to include parent and child input when decisions are more complex in children with high medical needs, and to ensure the evidence for treatment is clearly communicated.

It is also important to gain a variety of perspectives, including appropriate representation from a range of community groups. A solution is to ensure that gaps in committee experience are regularly reviewed, and new members are intentionally recruited to provide different perspectives. But diversity and inclusion must not be tokenistic and should be justifiable, for example, recruiting to enrich the guideline development.

Larger, more diverse development groups

Developing living guidelines can involve a workload that is more burdensome and with tighter deadlines compared with conventional guidelines. The process can also move at a much faster pace. The Synnot et al. (2023) authors found that involving a large group of patient and public members (more than 10 people) in a consumer panel allowed:

- a wider range of patient and public members' perspectives
- the formation of writing groups with equal numbers of patient and public members and clinicians
- greater peer support for patient and public members
- upskilling of less experienced development group members
- sufficient flexibility to cover scheduling difficulties.

A large group of patient and public members also allows guideline developers to recruit people with a broader range of experiences and backgrounds. This can include people who might not have been a patient and public member representative before, as well as experienced patient and public members who can mentor others.

Patient and public member renewal

Because a guideline may be living for several years, it is reasonable to expect that patient and public members may prefer to make a limited time commitment or reduce or stop their involvement when their circumstances change. This has resource implications for:

- recurring recruitment activities
- devising new processes
- providing additional induction
- accessibility adjustments
- training and support
- ensuring clear (and ideally mutually agreed) expectations for new and continuing patient and public members.

It also provides an opportunity for succession planning. This is particularly so if there are different tasks or roles (for example, co-chairing meetings) for patient and public members with particular skills or experience.

It is essential to consult with, and involve, patient and public members about how the succession planning is carried out. Expectations and commitments should be made clear to PPI members. It is also important to ensure remuneration increases over time, in line with inflation or the current industry standard for an honorarium.

Maintaining engagement and motivation among a pool of patient and public members

NICE experienced some specific considerations for maintaining patient and public members' motivation for continual engagement when working with a large pool of patient and public members for the breast cancer living guidelines. Staffing and resource limitations meant that not all recommendations could be updated at the same time. This resulted in some individuals being selected to work on guideline

development groups, leaving other members with nothing to do. To address this, active pool members who were not assigned to a group were invited to take part in other involvement activities throughout the organisation (for example, to apply for another committee or take part in any organisational research or evaluation opportunities). When new topics were scheduled to be updated, the guideline developer team ensured that pool members with the relevant experience, who had not yet been selected, were invited to a guideline development group. This ensured fair distribution of opportunities to all members.

Based on feedback, NICE also found that clearly communicating the schedule of planned work, and giving regular updates on the outcomes of work between the guideline developer team and the patient and public member pool were essential for maintaining engagement. It is important for the guideline developer to not ‘become invisible’ to the pool of patient and public members while working in private or between meetings. To prevent this, the project manager emailed updates and schedules at the start of the development phase and before recruitment to the guideline groups. NICE is considering having quarterly newsletters to describe work that is ongoing and out of the public eye. NICE also has a People and Communities Network and shares regular newsletters on involvement opportunities, updates and webinars with all patient and public contributors in the organisation.

Maintaining engagement in a living guideline when there is minimal guideline activity

ALEC has maintained the guideline on type 1 diabetes in living mode since 2020. For much of that time, difficulties in getting ongoing funding and staffing challenges during the pandemic have meant that progress with recommendation development was significantly slower than anticipated. Because of the slower pace of updates, the frequency of communication from the guideline developers also reduced, and some members of the guideline development group (including patient and public members) felt uncertain about the status of the guideline and plans for future updates.

Although the type 1 diabetes guideline group faced unique circumstances, this example highlights issues that could occur in other living guidelines with resource challenges or limited activity because of minimal new evidence. In such

circumstances, guideline developers should maintain regular and transparent communication with all guideline contributors, including the patient and public members. This is to ensure that they are kept up to date on the status of the guideline and plans for ongoing development (for example, through monthly emails).

Case study - Building trusting relationships

LEAPP living guidelines

For the LEAPP Pregnancy and postnatal living guidelines, the 16-member patient and public panel meets the LEAPP programme manager, PPI lead and a clinical panellist every 3 months to discuss the most recent set of draft guideline recommendations. Patient and public members have reported several benefits of these regular meetings, in which similar material (that is, draft recommendations) is covered. Working together allowed confidence and skills to grow, and helped build trusting relationships among all contributors.

Patient and public panel members are the first to review the draft recommendations. Their feedback is incorporated in the recommendations before they are seen by the first clinical panel. This review sequence is intended to make the recommendations more patient centred and relevant. The sequence has continued through subsequent rounds of recommendations, in which the evidence team has learnt from the previous feedback and adopted some of the same language or tone. These iterative changes and improvements have enhanced the patient-centred culture of the guidelines programme.

Supporting patient and public members throughout living guidelines

The methods and strategies to support patient and public members throughout living guidelines are generally the same as for standard or conventional guidelines. The

GIN Toolkit chapter on recruitment and support provides a detailed overview of best practice from research and guideline developers. Types of support can be broadly categorised as informal support (for example, peer-support, a named contact, check-ins, emotional support), and practical support (such as, making reasonable adjustments, financial reimbursement).

Anticipating ongoing training and support needs

The specific challenges of living guidelines (for example, shorter time frames to complete the work, fewer or more meetings for each update) can make it difficult to implement best practice for involving people. Examples from our experience include a lack of time to do a thorough person-centred needs assessment, create plain language evidence summaries of large evidence reviews, or produce detailed glossaries of technical terms. Alternative solutions are needed in these situations, such as:

- avoiding using jargon during meetings
- organising pre-meets and debriefs to adequately address patient and public members' training and support needs
- providing clear timelines of the guideline development lifecycle and involvement points
- managing expectations better, such as by signposting patient and public members to where they can be most effective when commenting on documents between meetings.

Since the COVID-19 pandemic, many living guideline development meetings are now held online. Guideline developers may have to assess patient and public members' digital literacy and technology needs for them to be able to fully participate in meetings (for example, access to a working computer with a microphone and camera). Training on using the meeting platform (such as Zoom) might also be needed. Patient and public members also sometimes report that they miss opportunities to connect informally and would welcome the chance to connect outside of meetings (for example, by using WhatsApp, sharing email addresses, organising meetings). The section on virtual working in guideline development groups in the chapter on recruitment and support gives further information.

Remuneration is particularly important for living guidelines, because of the tight timeframes, changeable meeting times and possible increased workloads between meetings. This can affect work or other commitments (for example, childcare arrangements), or result in financial loss. Remuneration should be current with relevant standards in your region, and be updated each year in line with any changes or inflation.

Case study: Implementing and testing a tailored toolkit of support in NICE's living guidelines

NICE's toolkit

NICE developed a basic 'toolkit' of PPI support strategies designed to overcome some of the barriers preventing the application of best practice in living guidelines (described at the beginning of this section). Figure 1 shows the toolkit of support that was pilot tested for a rapid COVID-19 guideline for systemic anti-cancer treatments and the breast cancer living guidelines. The strategies in the model are described in this section.

An informal person-centred needs assessment was implemented to ensure that individual support, accessibility or training requirements were considered. This was done during the induction or in a one-to-one meeting shortly after recruiting the patient or public member. It ensured that individual needs were identified when timelines were short and could be reviewed after the first meeting.

Newly recruited individuals were also paired with a more experienced patient and public member, who offered peer support. At first, this strategy was implemented to foster relationship building, a sense of community during virtual meetings, and to quickly build confidence to contribute during meetings. This also supported the co-learning process, because the experienced member shared knowledge and tips on how to contribute and make an impact.

Inductions were done at the start of the guideline development phase, either in a group setting or in a one-to-one meeting. The purpose of the induction was to build rapport with a named contact in the public involvement team, provide essential information on the processes and available support (to foster co-learning), and to do an informal needs assessment.

Pre-meets (before a meeting) and debriefs (after a meeting) were set up with technical staff, the chair, and the patient and public members. The primary aim was to focus on co-learning and to ensure that the patient and public members understood the structure of the meeting, and the work to be discussed. Patient and public members could ask questions about the work and the meaning of any technical jargon. Technical staff could propose important areas that the patient and public members could prepare for before the main meeting. For the debrief meetings, patient and public members could ask for feedback on their contributions, which helped them to understand what impact they might have had. Debriefs ensured they could ask any questions about the guideline methodology and clarify anything they were uncertain about.

Feedback about their experience was collected from patient and public members either by email or during the debrief meeting. Technical staff, or the chair, gave feedback on the areas in which they had been effective. Examples of such areas of impact included influencing discussions, informing recommendations, and shaping the guideline scope. Armstrong et al. (2017) provide a framework for areas where patients can have an impact in guideline development, and this can be used to help guideline developers shape feedback responses to patient and public members.

Additional support and techniques were implemented. These included creating and circulating biographies of all committee members to help build a sense of community, ensuring adequate breaks, and adding patient and public items to the agenda. Agenda items were only implemented if patient

and public members felt comfortable with this approach and agreed that it would be useful.

An informal evaluation of the model of support indicated that most techniques were easy to implement, were not too resource intensive, and allowed patient and public members to become more involved in the meetings. Template agendas were found to be useful for guiding the pre-meets and debrief meeting discussions. The strategies helped patient and carer members understand what was needed from them, helped them to prepare for the meeting, and to provide rich discussion during the meeting. Patient and public members reported that they appreciated the feedback from technical staff because it enhanced their confidence, and they felt valued or appreciated. Some patient and carer members found that they required less pre-meets and debriefs as they became familiar with their role after sitting on multiple committees and updates. Over the course of the lifecycle of a living guideline, the toolkit of support should be tailored and adapted based on the needs of the patient and public member, rather than using a fixed or rigid approach.

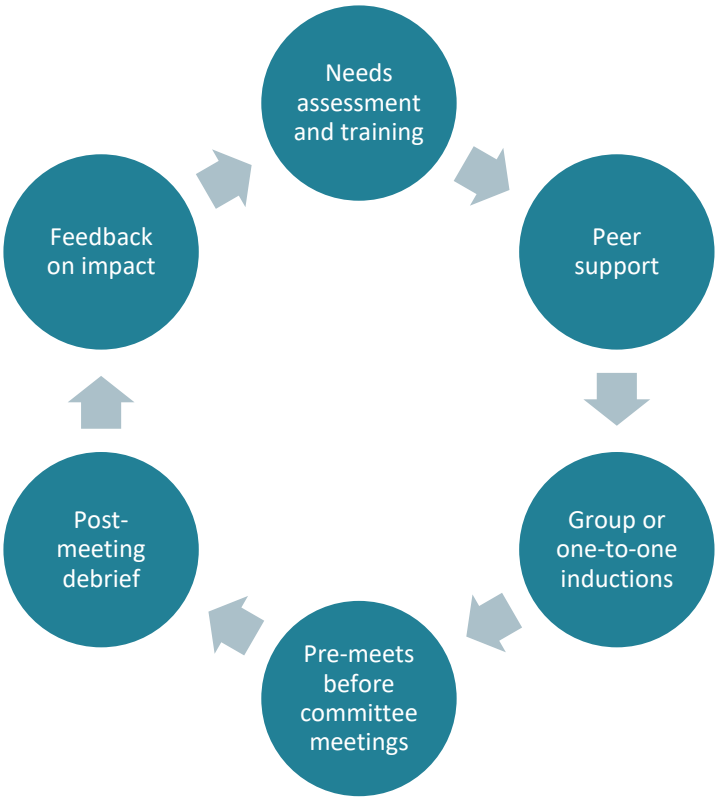

Figure 1 Toolkit of PPI support strategies to overcome barriers to best practice

Setting priorities for updating living guidelines

Adapting the prioritisation stage for patient and public members

Certain tasks in a living guideline, such as identifying important priority areas to be maintained as living, might need to be adapted for patient and public members unlike for clinicians. For example, to identify an essential priority area, group members might need to have knowledge of ongoing clinical trials or those trials for which data are about to be published. Although patient and public members might know about some of these trials, developers cannot expect that all patient and public members will do. Therefore, adapting the task for patient and public members and giving guidance on how they can contribute to a prioritisation exercise can help them to be effective. For example, presenting a summary of the latest developments in the guideline area and then inviting patient and public members to highlight key topics of interest to patients can assist them to prioritise the order for updating recommendations. This can be helpful when there are multiple recommendations to

update (for example, on psychological support, neoadjuvant chemotherapy, breast cancer, menopause) but staff resources are limited.

Setting priorities in real time

Guideline topics and questions would likely be prioritised at the start of developing a living guideline but may be revised at multiple points during its lifecycle. In some ALEC living guidelines (for example, pregnancy and postnatal care), this has meant inviting the patient community to take part in formal priority-setting processes at the beginning. Then later, inviting anyone in the community to submit questions or raising clinical points about which there is some uncertainty, which can be addressed through a recommendation. An online form on the guideline webpage is used to help this engagement.

While developing the Caring for Australians and New ZealandeRs with kidney Impairment (CARI) living guidelines for autosomal dominant polycystic kidney disease, patient and public members were able to raise, and advocate for, timely new guideline questions and topics. This fast feedback on the guidelines improved their relevance for patients and showed the trustworthiness of the process and value of the participation, as described in the case study on the guideline.

Case study: Real-time priority setting with patient and public members in a living kidney disease guideline

CARI living guidelines

The first scope for the autosomal dominant polycystic kidney disease living guidelines was intentionally narrow, focusing on high-need aspects to ensure timely completion. The guideline working group began by basing the scope on 2 topics recently examined in clinical trials: a disease-modifying medication and fluid intake. The guideline development group included 2 patient and public members with lived experience of the disease who had contributed to the guideline organisation over the past 5 years. The trust and reciprocity developed over this period, and being able to discuss the guideline scope at the early meetings, allowed the patient and public members to provide a perspective that the clinical members had not

considered. The patient and public members, through their active engagement with the patient community on social media, recognised the need for guidance on using ketogenic diets in managing the disease.

Ketogenic diets were a topic of active discussion in the community because of the marketing of the diet together with a supplement, which could be bought at a substantial cost. Patient and public members considered that it was a high priority topic that would support patients in their self management, and it would also enhance the community's confidence that the guidelines assessed the highest priority areas in the disease. The living approach to prioritisation allowed a pilot trial to be quickly included during the guideline development, so that its findings were later published and incorporated in the evidence review.

Training and co-learning for patient and public members during living guideline development

Training and co-learning are described in detail in the GIN Public Toolkit chapter on recruitment and support. Briefly, training can be viewed as formal or informal training workshops, seminars or courses that can be delivered as in-person, virtual or hybrid activities. Ideally, training is given by public involvement specialists and experienced patient and public guideline members. Co-learning is considered as ‘on the job learning’, in which presentations on important aspects of the guideline development process are delivered to all guideline development group members. Peer-support and mentoring are forms of co-learning.

In living guideline development, the pace of developing some living guidelines can occasionally prevent adequate opportunities for training or co-learning. For example, when producing living guidelines in an emergency, there might not be time during meetings to give a presentation on guideline development methods, so a co-learning opportunity is lost. This means that guideline developers will need to develop specific training or resources about patient and public involvement in the living guideline development. Patient and public members can use these resources and training

outside of development meetings, in their own time. But, NICE and ALEC found that the living guideline development process can offer some opportunities for ongoing learning and allow new or less experienced patient and public members to be matched with those who are more experienced. This can promote peer-support, co-learning, relationship building and psychological safety, which can speed up the learning process and increase an individual's confidence that they can make meaningful contributions, shape discussions, or influence recommendations.

When specific training resources or courses were not available, NICE found that implementing pre-meets and debrief meetings before and after most meetings, when possible, supported co-learning. This is described in the model of support in the case study on implementing and testing a tailored toolkit of support. Such meetings helped patient and public members to develop in their role, understand when they could contribute the most, ask questions about the guideline development process, or clarify any medical jargon.

Feedback, evaluation and improvement of PPI in living guidelines

Viewing involvement as living can improve PPI processes over time

Although living guideline developers should aim to meet the fundamentals of good practice in PPI from the start, living guidelines offer a chance to continually improve how PPI is done. Clarifying from the beginning that the involvement is living can help all contributors to expect that it will grow over time. ALEC has found that if members view their involvement as living, it allows improvements in the processes while building mutual respect.

Evaluating PPI in living guidelines

Living guidelines provide an excellent opportunity to improve PPI by evaluating how patient and public members (and other guideline contributors) experience the process. Like evaluation in conventional guideline development, this can include seeking feedback informally, inviting patient and public members to share any feedback directly over email or in one-to-one meetings, or anonymously through a

brief online survey. More formal process evaluations can include surveys and interviews with external evaluators.

Creating feedback and evaluation opportunities for both patient and public members and staff can help to develop an understanding of what works or what needs to improve. For example, it can be an opportunity for staff to share examples of what effect patient and public members have had, which can improve confidence and create a sense of feeling valued.

Whatever the methods used, patient and public members should be involved in planning the evaluation, and the guideline development team must commit to addressing the feedback received, using a continuous improvement loop. The case studies from ALEC in the rest of this section highlight some informal and formal evaluation approaches used for living guidelines.

Case study: Informal feedback in 2 living guidelines

LEAPP informal evaluation

For the LEAPP Pregnancy and postnatal care guidelines, 17 patient and public members (16 Consumer Panel members and 1 Steering Group member) are part of the multidisciplinary expert panels. From the beginning, the LEAPP team collected anonymous feedback after every 3-monthly meeting through an online survey. Recently, this changed to 6-monthly feedback through a more formal rolling process evaluation.

The regular request for and response to feedback from the beginning resulted in innovations such as the formation of a WhatsApp group in which patient and public members could get to know each other, and changes to the meeting agenda (to allow more time for relationship building). It also led to the creation of a ‘feedback’ document, which made it clear how the guideline recommendations had changed because of patient and public member input. This feedback document supported patient and public members to feel encouraged and empowered, and to want to continue being involved and the share their vulnerability and stories that were often quite personal. This continuous improvement process has strengthened

relationships and enhanced PPI processes and outputs as the guidelines programme has developed.

In ALEC's COVID-19 living guidelines, the Consumer Panel met every 2 months. Directly after meetings, the guideline team sent panel members an anonymous survey with the following questions:

- What's working well with the Consumer Panel?
- What needs improvement, or could be done differently?
- How could we improve the impact of patient and public member input to the COVID-19 guidelines?
- Is there anything else we should know?

If you would like us to follow up with you directly to discuss your feedback, please enter your name.

Case study: Formal process evaluation in a living guideline

LEAPP formal evaluation

In the LEAPP Pregnancy and postnatal care guidelines programme, the team is carrying out a mixed methods process evaluation to improve LEAPP processes and outputs as the guideline is developed. This process evaluation uses biannual activity audits and progress audits, online surveys of all LEAPP contributors (guideline staff, clinical panellists, and patient and public members), and interviews with purposively selected contributors. The survey for the Consumer Panel members explores:

- their satisfaction with the work of the LEAPP team
- their satisfaction with the level of PPI
- strengths in the process
- challenges or opportunities for improvement
- what they have gained from their involvement and any disadvantages

- their perspectives on the impact that patient and public members are having on the LEAPP guideline.

The survey also evaluates the quality of PPI in the guideline development process using the 6-item Patient Engagement Evaluation Tool (PEET-6; Moore et al. 2022). After each round of evaluation, the findings are fed back to the LEAPP teams and panels to consider what is working well and what challenges need to be addressed. Providing these results as a series of repeated steps allows the LEAPP team to identify and address emerging issues and determine whether issues raised before are being effectively addressed, while the project is ongoing.

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