

# How to recruit and support patients and the public, and overcome barriers to their involvement in guideline development

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## Key messages

- Guideline developers can experience several barriers to recruiting and engaging patient and public members in guideline development work. These include the lack of a clear cost-effective recruitment strategy, the ability to achieve genuine representation, and members lacking the appropriate skills to conduct the work (for example, good communication or research knowledge).
- The patient and public member's role will influence the tasks, experiences and qualities required to perform in the guideline group. This might influence the number and type of patient and public members, such as patients, carers and advocates from patient organisations. Information outlining the role and person specification should be carefully planned from the outset and openly advertised to reduce barriers to recruitment and engagement.
- There are 2 types of recruitment methods: open recruitment and nomination through patient organisations. But each method has advantages and disadvantages that need to be considered, taking into account the developer's resources and availability of patient organisations for specific conditions. Whichever method is selected, the way it was implemented must be documented and transparent.
- Barriers to effective patient and public member engagement during guideline development can be overcome with careful planning and:
  - delivering practical support (for example, providing easy read versions of documents)
  - informal support (such as providing advice and support)
  - financial compensation for time and travel expenses

- co-learning (during guideline development in the form of presentations or seminars)
- training, performance feedback and managing group dynamics.
- There are occasions when patient and public members cannot be included in guideline groups (for example, children) or it is difficult to recruit seldom heard groups (for example, people in secure settings). Alternative approaches to consider are reference groups, additional sources of data on patient and public views, patient expert testimony, and consultation using research methods.
- Very specific barriers to involvement will need to be considered when engaging seldom heard groups, such as children, people with learning disabilities, and people with severe mental illness. Such barriers include legislation, cognitive capacity, and illness fluctuations. The practical and informal support strategies will need to be very carefully considered, adapted and tailored to each individual.

## **Top tips**

- Plan, develop and advertise a role description and person specification during the planning stage of the guideline. It should outline in advance, the roles, tasks, experiences and qualities, and the type and number of patient and public members to gain a broad representation needed for the guideline.
- Involve patient and public members from the start, and throughout development, to ensure the scope applies to the people who will use the guideline and to encourage ongoing engagement.
- Recruit at least 2 patient or public members, who might be patients, parents, carers or advocates from patient organisations, with a range of perspectives, experiences and characteristics to gain a breadth of representation.
- Recruit people based on their experiences and understanding of the issues that matter to people with the condition.
- Consider the open recruitment method to reach a large pool of people if your organisation has the time and resources to produce recruitment documents and conduct interviews.
- Consider the nomination process if you have less resources to conduct open recruitment and have access to relevant patient organisations for the topic of interest.

- When openly recruiting, advertise opportunities through websites, patient organisations, health professionals and social media, which can help recruit from seldom heard groups.
- Assess practical and informal support needs, including training needs, from the outset and during guideline development in case needs change. Tailor support and training to each individual member.
- Provide initial training and implement co-learning in which the whole guideline group learns and shares knowledge on guideline development and research, using presentations, seminars, and discussions.
- Create and offer opportunities for new members to meet an experienced patient and public member 'buddy' to allow them to discuss their role and any concerns.
- Regularly assess the patient or public member's performance and provide feedback to ensure ongoing learning and to address any issues that arise, such as feeling unable to contribute.
- Manage group dynamics through training for the chair to ensure patient and public members are treated equally and can contribute and feel valued.
- Carefully plan and tailor specific practical and informal support strategies when engaging seldom heard groups, such as children, people with learning disabilities and people with severe mental illness. Take into consideration legislation, cognitive capacity, and illness fluctuations.

## Aims of the chapter

This chapter provides guideline developers with advice on how to identify, recruit and support patients and members of the public as participants in guideline development groups. It will also explore how facilitators can overcome some of the main barriers to recruitment and effective involvement. Published literature has highlighted several barriers for involving patient and public members (Armstrong et al. 2017b; Légaré et al. 2011; Ocloo and Matthews 2016), including:

- the developer being unclear of recruitment strategy, including the number or type of patient or public members to recruit to achieve genuine representation
- the developer, patient or public member being unclear of their role in guideline development
- scheduling and planning issues, or having the resources to adequately engage patient and public members
- lack of relevance of the scope to patient and public members
- difficulties in gaining meaningful involvement or avoiding tokenism
- patient or public member not respected, not seen as equal, or feeling devalued
- achieving a breadth of perspective or adequate representativity of patients and the public
- recruitment difficulties
- lack of methodological expertise, skills or knowledge related to guideline development
- patient and public members feeling isolated or lacking in confidence to speak up in a large group of experts.

The 4 sections of this chapter will address these barriers. The first section focuses on the [role of patient and public members](#), including the qualities, experience, type and number, and skills needed. The second section focuses on the [recruitment process and strategies](#). [Support](#), including practical and informal support, group dynamics, training and co-learning, and re-assessment and feedback procedures, is addressed in the third section. The fourth section focuses specifically on the [barriers and solutions to recruiting people who might face barriers to participating](#), such as children, and outlines a series of alternative approaches. Practical examples will be

provided, based largely on the expertise and best practice of guideline developers from around the world, These include the National Institute for Health and Care Excellence (NICE) in England, Ärztliches Zentrum für Qualität in der Medizin (ÄZQ) in Germany (or the German Agency for Quality in Medicine [AEZQ]), the Registered Nurses' Association of Ontario (RNAO) in Canada, and the Scottish Intercollegiate Guideline Network (SIGN) in Scotland. Reference is made to published research where relevant. The advice in this chapter will help guideline developers avoid tokenism, defined as the 'difference between...the empty ritual of participation and having the real power needed to affect the outcome' (Arnstein 1969).

## **The role of patient and public members**

Research has found that a barrier to involving patients and the public in guideline development can occur when the role and required skills, experience and knowledge have not been clearly outlined (Armstrong et al. 2017b, Carroll et al. 2017). At the planning stage of a new guideline, developers need to have a clear understanding of the role requirements and expectations of the patient and public members. This helps developers carefully plan the offer of support, training and any additional resources needed, and ensures that only suitable members are recruited. The information will also help patient and public members to understand what is required of them, including the time commitment, which enables better engagement because they will be able to plan their work. This section will explore the factors that guideline developers should consider during the planning phase, including:

- the role and tasks of patient and public members
- the type and number of members
- gaining appropriate representation
- the required skills and experience.

## **The role and tasks of patient and public members**

Developers should be clear of the purpose and rationale for patient and public involvement because the role will influence the tasks, skills, and the qualities that developers will need to recruit for. The role is defined as their function in a group, including being an equal partner in decision making during guideline development.

Knaapen and Lehoux (2016) defined 3 models that might be useful to consider when developing roles based on the tasks to be achieved: consumerist, democratic, and expert. A consumerist model emphasises an individual's right to have autonomy in making choices in healthcare decision making and that healthcare improves when tailored to patients' needs and preferences. This model applies if the task is to identify patient preferences and develop decision aids. A democratic model refers to the 'rights of citizens (and taxpayers) to democratic decision making on a policy or collective level' (Knaapen and Lehoux 2016). This model applies if the tasks are to develop policy documents that influence the design or redesign of healthcare services. An expert model emphasises the patient and public's experiences and knowledge of a condition, treatment, and quality-of-life outcomes. So, it offers a different kind of expertise to that of health professionals and is useful when producing guidance.

Although the models might be a useful starting point to consider roles and tasks, they can be contradictory because patient and public members are sometimes required to perform multiple tasks. For example, formulating recommendations, synthesising knowledge, revising drafts and, occasionally, strategic decision making such as deciding committee membership, outlining the scope, and producing decision aids (Légaré et al. 2011). The type and range of tasks will influence the number and type of patient and public members to recruit.

It is also important to ensure that the patient and public members' role, ideally, spans every stage of the development process, including the scoping stage. This can help prevent patient and public members disagreeing with the topic scope and disengaging from the guideline group (van Wersch et al. 2001). When it is not feasible to involve members early on, or at all stages of the development process, an alternative is to invite additional representatives, to attend 1 meeting or contribute to a consultation (see the chapter on how to conduct targeted and public consultation).

### **Role and tasks in practice**

NICE in England involves patient and public members throughout the guideline development process. They have the same role and tasks as health and social care professionals. Tasks include:

- agreeing the review questions and protocol
- assessing and interpreting the evidence
- producing recommendations
- identifying relevant stakeholders for consultation
- contributing to draft documents
- producing information for the public.

The RNAO involves patients and members of the public in similar ways to NICE. For some topics, NICE recruits patients or carers early on to help develop the guideline scope, as part of a smaller scoping group, and possibly also to support the development of patient-decision aids. When patients or public members cannot be involved in all stages of the guideline development, SIGN in Scotland invites additional representatives, living with the condition, to specific meetings. Patient and public members might also be recruited for different types of roles and tasks. NICE in England, ÄZQ in Germany, and RNAO in Canada all involve patients and the public when developing quality standards and indicators, based on guidelines, which includes the rating and assessment process.

## **The type and number of patient or public members**

### **What type of patient or public member should we recruit?**

The guideline topic and role and tasks will influence the type of members to include. The members can include patients, carers, parents or advocates from patient organisations. A carer or parent might be important to include when relatives are affected by the condition, or they have an integral role in caring for the person with the condition (for example, dementia). Parents or carers can be recruited if it is difficult to involve a patient living with the condition, such as young children (for more information, see the section on [overcoming barriers to involving those who are seldom heard](#), in this chapter). Developers may also consider an employee or volunteer from a patient organisation. Even if this person does not have personal experience of the condition, they can provide a broad perspective on the condition and population. It is important to note that a patient, carer or advocate from an organisation will have different perspectives and it can be helpful to include all types of perspectives.

## How many patient or public members should we recruit?

NICE advocates that at least 2 patient or public members should be recruited to any guideline group, who might be patients, parents, carers or advocates from patient organisations. More members could be recruited if the guideline covers multiple issues, a complex condition, or requires multiple roles and tasks. The advantages of this are that it:

- broadens the experiences of the group and ensures different aspects of the guideline are covered from the patient or public member's perspective
- can build confidence, provide social support and empower patients to contribute
- reduces feelings of isolation, which is a known barrier to patient engagement
- provides peers to work with other patient and public members.

Consideration can be given to socio-demographic representation, such as the age range, which is likely to influence how many patients and public members are needed. For example, for the [NICE guideline on babies, children and young people's experience of healthcare](#) that is in development (2020), NICE recruited 6 members (out of 16), including 2 parents and 4 young people aged between 18 and 25, with experience of different aspects of healthcare.

## Representing compared with representative

It is important to recruit patient and public members who represent the condition or issues of those affected by the guideline. A common barrier to effective involvement is the difficulty in recruiting people to the guideline group who can broadly represent the guideline without heavily focusing on their own individual subjective experience or agenda (Carroll et al. 2017, Légaré et al. 2011). The individuals should be able to represent the commonalities and different aspects of the condition in question.

However, patient and public members cannot be representative of everyone or all the socio-demographic characteristics (for example, age, gender, ethnicity) that make up the population of concern. Therefore, developers need to consider multiple patient and public members, who might be patients, parents, carers or members of a patient organisation, to achieve such broad representation. Additional approaches to involvement should be considered to address gaps in representation (see the [section on supporting individual patient and public members](#) in this chapter).

Guideline developers and patient organisations report that a barrier to achieving sufficient representation on guideline groups is the lack of interest from patient and public members to get involved in guideline development. Solutions can be to engage other patient organisations who are associated with the health topic of interest. Alternatively, engage organisations who focus on a different condition that produces similar symptoms or experiences to the condition of interest. For example, if the guideline topic covers blood pressure then consider engaging organisations associated with coronary heart disease.

### **The experience, knowledge and skills required**

After the role, type and number of patient and public members have been defined, developers should consider creating plain language information outlining the role and person specification. An important attribute of patients and public members is their experience of the condition and this should be included in the role specification. Exclude people who do not have experience but have only an intellectual or professional interest in the condition. Outline additional skills required, such as communication and team working skills. Ideally, recruit people who will actively contribute to group discussions and be able to represent the views of a wider patient or public group, which could be gained through membership of a support group or patient organisation. Depending on the roles and tasks of the guideline group, developers might need to recruit for different types of skills or they might need to recruit multiple people to achieve such diversity. The role and person specification should explain such skill requirements, what the work entails, the time commitment, expenses or payment arrangements, and what support or training is available. The [SIGN 100 handbook for patient and carer representatives](#) provides an example of the roles and skills required to be involved in guideline development (2019) and an [example role description from NICE can be found in resource file 1](#).

The role specification should not disqualify people who may be able make a highly valued contribution to the group. For example, asking for academic levels of attainment or research experience can present a barrier to achieving genuine lay representation (Boivin et al. 2009). At RNAO and NICE, persons with lived experience are not required to submit a curriculum vitae when applying but are required to describe their experience relevant to the topic. Developers could consider

that certain knowledge or skills can be gained 'on the job' with adequate co-learning with project teams (for example, research terminology) or through formal training. Some courses exist online, either free or with a small charge (see [resource file 2 for a list of training resources](#)). A greater emphasis should be placed on 'soft' skills, experience or knowledge that cannot be learned in the role, such as having contact with other people living with the relevant condition and being able to reflect on their experiences.

To recruit 2 or more patient or public members with a range of experience, knowledge and skills, the following factors could be considered:

- relevant experience of the condition
- an understanding of the issues that matter to people with that condition
- the ability to reflect and advocate on the experiences of a wide group of people living with the condition gained from contact with people through patient organisations, forums or self-help groups
- the time and commitment to attend the meetings and complete associated work
- good communication and teamworking skills
- a commitment to maintain confidentiality
- declaration of interests, such as receiving funds from pharmaceutical companies.

## **Recruitment of patient and public members**

Successful recruitment strategies are key to recruiting appropriate people with different skills and experiences (Boivin et al. 2010). Research suggests that a barrier to recruitment for clinical guideline developers is not having the resources to implement recruitment strategies (Armstrong and Bloom 2017b). Therefore, this section provides advice on a range of recruitment methods, some of which are cost neutral.

### **Nomination and open recruitment**

There are 2 key methods of recruitment: open recruitment and nomination. In open recruitment, guideline developers advertise the post using the role and person specification. Applications are reviewed against criteria and the developer is responsible for selecting people who meet the criteria. Nomination is used when

developers approach patient organisations to nominate someone who, in their opinion, can reflect and understand patient or public issues relevant to the guideline. With nomination, the patient organisation is responsible for recruiting and the developer should not have any input. It is possible to combine elements of both approaches, but whatever method is selected it should be an accepted, transparent, and justifiable approach that can be documented.

### **Advantages and disadvantages of each method**

Each method has advantages and disadvantages to consider when deciding which to use. These are outlined in table 1. In summary, open recruitment enables a wider range of people to become involved and is transparent. It helps minimise bias by allowing developers to choose between people from different geographical locations, treatment centres, and groups in society. However, it can increase bias if the developer chooses people who appear to be more ‘compatible’ with the interests or culture of the guideline group. To help avoid that bias, involve a suitable person external to the guideline team in the selection and ratification process, such as a patient involvement specialist. Open recruitment can be costly in terms of human resources and time compared with nomination. Timescales should account for developing recruitment criteria, administering the recruitment process, and reviewing applications. Templates of application forms and person specifications can help speed up the process.

Alternatively, nomination is rapid but can narrow the pool of potential candidates. To prevent this, a predefined nomination process should be outlined from the outset and strategies should be implemented to ensure people are nominated from a broad pool of candidates. Sometimes patients and public members recruited from patient organisations can pursue their organisation’s agenda. This should be prevented through induction and training that emphasises that the individual is to represent their experiences and those of others living with the condition.

If developers choose nomination as a method, they need to consider how this might affect the status of the individual within the group if the professional members had to compete to ‘earn’ their place. Conversely, if health professionals are nominated there may be no perceived unfairness. Open recruitment can increase patient and public members’ confidence by knowing that they were selected from a pool of applicants.

Regardless of the method selected, the way in which it was implemented needs to be documented and transparent.

**Table 1 Advantages and disadvantages of open and nomination recruitment methods**

-	Open recruitment	Nomination
<b>Advantages</b>	<ul style="list-style-type: none"> <li>• Attracts a wider range of people</li> <li>• Reduces bias by recruiting people who are unknown to rest of guideline development group, which lowers the chance of people agreeing with group in fear of disagreeing with their own doctor</li> <li>• Phone interviewing shortlisted applicants helps screen out people with narrow perspectives and those who cannot reflect on broader patient issues. Advice from a patient and public involvement specialist can be helpful in eliminating unsuitable applicants</li> <li>• Attracts people with broader perspectives</li> <li>• Transparent - can answer questions about why certain people were recruited and demonstrate where procedures have followed equality legislation</li> </ul>	<ul style="list-style-type: none"> <li>• Less resource demanding</li> <li>• The guideline developer has no influence on the choice of the group members and so no risk of influencing group composition through selective recruitment</li> <li>• Could increase the chance of recruiting individuals who you might not have considered because of the joint expertise of patient organisations and people with specific aspects of a disease</li> <li>• In most cases, patients nominated by a patient organisation are trained in championing patient perspectives</li> <li>• Can be faster than open recruitment although it depends on how long it takes the patient organisation to respond</li> <li>• Can recruit patients with a background in user-led research or known ability to work well in groups</li> <li>• Assures that patient organisations decide themselves who is best to provide their perspective (respects patient autonomy)</li> <li>• May facilitate reaching specific seldom heard groups, especially if there are barriers to patients or public engagement</li> </ul>

-	Open recruitment	Nomination
<b>Disadvantages</b>	<ul style="list-style-type: none"> <li>• Time consuming</li> <li>• Costs of advertising, if paying for advertising to be placed</li> <li>• Costs of preparing and processing paperwork and applications</li> <li>• Risk of biased choice, that is, a risk that the guideline developer actively influences group composition in a way that 'easy to handle' patients are recruited</li> <li>• Needs rigorous and transparent documentation of the selection process to avoid risk of bias or being selective</li> <li>• If relying on patient organisations to circulate the advert, this could be perceived as nomination</li> <li>• Risks of failed recruitment - if the condition is rare or the affected population is less likely to use recruitment channels like the internet</li> <li>• Ethical concerns if organisations persuade a vulnerable person to apply and they are unsuccessful</li> </ul>	<ul style="list-style-type: none"> <li>• Risk of missing people with a very unique expertise and experience</li> <li>• When nominating from patient organisations, there is a risk of recruiting people with biased perspectives, such as those who have only had negative experiences of healthcare systems</li> <li>• Can exclude patients who have not had experience of similar work, but might still be able to make valuable contributions</li> <li>• May introduce bias. In some countries, nominated members from patient organisations could be associated with teaching hospitals, pharmaceutical companies or campaign organisations, and have different experiences from those in rural areas or general clinics</li> <li>• Risk of narrow patient perspectives if patients with a background in lobbying on one aspect of a condition are nominated</li> <li>• For some guideline topics (for example, rare conditions or symptom-based topics) there may not be any relevant patient organisations who can nominate patients</li> <li>• Some patient organisations may not have the capacity to identify appropriate nominees</li> </ul>

## Selection of methods in practice

The method to choose will depend on the developer's requirements and resources.

Local circumstances may dictate which approach would work best. For example, in

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countries with well-resourced or well-developed patient organisations, the nomination process can work well (especially for main condition areas like cancer). Open recruitment works well for well-resourced guideline development agencies with specialist patient or public involvement support (like NICE).

NICE uses open recruitment and has found that it leads to a range of individuals applying for the role, including many who are not associated with patient organisations. NICE advertises positions for patients and public members for 4 weeks thereby allowing patient organisations time to contact their members and for the advertisement to get maximum exposure through websites and other social networks.

The Dutch Institute for Healthcare Improvement (CBO) in the Netherlands, the German ÄZQ and SIGN in Scotland, recruit primarily through umbrella patient organisations, such as The Richmond Group of Charities or National Voices in the UK. The ÄZQ uses a predefined nomination method, which is outlined in detail in their manual (Sänger, 2008). It recruits from 4 umbrella organisations to ensure people are nominated from a broad pool of candidates. ÄZQ asks them to select all the patient organisations they think are appropriate for the condition in question, and then have a discussion with every organisation about the patients they want to nominate. This results in a list of members for the guideline development group for the developer, who then starts training and support for them. During the initial meeting, the guideline group is asked if there any expertise is missing from the group and the developer then seeks to fill any gaps in experience.

## **Advertising the role**

Open recruitment works best when patient organisations, or healthcare professional organisations with public involvement functions, can inform their members of the vacancy by promoting it on their websites, through social media, email distribution or newsletters. Patient organisations can also provide advice on how to recruit people from seldom heard groups.

Healthcare professionals in the development group may also be able to support recruitment, either by advertising the opportunity through their networks or by nominating a patient. However, this can increase the likelihood of recruiting a patient

or public member who is treated by the same health professional on the panel. This should be avoided because it can prevent the patient from speaking freely during discussions.

If using social media to advertise, developers can reach a larger audience who are invested in the guidance topic by 'tagging' relevant patient organisations in any social media posts. Developers can engage seldom heard groups, such as black, Asian, and minority ethnic groups (BAME), on Twitter, Facebook or patient forums. Permission should be obtained before sharing any opportunities. Starting online conversations with public members who express interest in the recruitment opportunity can increase applications by addressing any concerns or queries that arise. This approach is relatively cost effective although time is required to build online relationships with the public. Not everyone has easy access to the internet, so additional methods of publicising the vacancy should still be used to reduce inequalities in the recruitment process. If seldom heard groups are not active on one form of social media (for example, Twitter) then they might be more active on another channel, such as Facebook. If not, it will be difficult to engage them through this means.

When advertising the role, state explicitly the kinds of support that individuals can receive to encourage more people to apply. This should be realistic and deliverable in practice. The [section on supporting individual patient and public members](#) describes the types of support that can be provided.

## **Documents for recruitment**

It is helpful to publish the role and person specification (in both open and nomination recruitment methods), either as a detailed advertisement or as additional information to help applicants decide if they are suitable for the role. The application or nomination form should be well structured, which will make it easier for people to provide the relevant information. NICE also includes an equality monitoring form for applicants in line with the UK's Equality Act (2010). Guidance on this act can be found in the [further reading section](#). The form collects personal information, such as age and gender, and can be used to evaluate and review the diversity of membership. The form is processed separately from the main application form to ensure anonymity.

To enable people with various disabilities to apply (for example, people with sight impairment), developers need to consider the accessibility of their information, such as ensuring documents can be read using a screen reader. Guideline developers should check government or organisation guidelines on accessibility for further information.

## **Interviewing candidates after open recruitment**

Interviewing candidates after open recruitment can help overcome some of the known barriers to effective patient and public involvement. These include concerns over skills, breadth of experience and the ability to reflect on experience, objectively review the evidence, or work critically within a group. People who have had only negative experiences of care, or people who are opposed to the methodology behind evidence-based care, may not be appropriate candidates. Developers should consider how to interview people with specific health conditions or disabilities, or those who work full time. Interviewing over the phone or by video conference (for example, Skype or Zoom) are useful alternatives if some people cannot attend face-to-face interviews. Group interviews might also help assess communication and group working skills.

## **Making the appointment**

Successful candidates should be notified in writing. Consider whether they should complete a declaration of interests form, to identify possible conflicts, and a contract. Some organisations designate alternate members at the interview stage in case the appointed member has a change in circumstance and cannot take up the role. But, in some cases, it may be better to re-advertise or get new nominations.

It is also important to ensure the recruitment process is fair and to document the process, including the reasons for who to recruit, to avoid any potential accusations about discriminatory practices. Unsuccessful candidates can be offered other involvement opportunities, such as being a peer reviewer. Candidates should have a named contact and details, so the developers know who contact for further information or to discuss the outcome of their application or interview.

## Supporting individual patient and public members

Appropriate and adequate support strategies play a large part in overcoming barriers and facilitating effective patient and public engagement during guideline development. According to Armstrong et al (2017a), these include:

- practical support (for example, making reasonable adjustments to support people who are ill or disabled)
- informal support (for example, listening, advice and emotional support)
- financial compensation
- co-learning and training
- managing group dynamics
- enabling re-assessment and feedback on the patient or public member's role.

### Practical support

Qualitative research suggests that practical support can consist of providing multiple shorter meetings instead of full-day meetings, providing the premeeting papers in good time before a meeting, providing physical resources (for example, paper versions of documents), and agreeing mechanisms for soliciting opinions (Armstrong et al. 2017a). However, individuals might have various practical support needs associated with their work and provision should be made for 'reasonable adjustments' to respect those needs. This might include changes to the physical environment for the group's meetings (for example, accessibility of the rooms). How meetings are conducted should be considered (for example, with a hearing loop induction system or chairing techniques in a virtual meeting), and the communication used in the group (for example, avoiding jargon and titles such as doctor, explaining medical and research terms, and agreeing appropriate communication channels, such as email). The length of meetings might need to be altered, and breaks added, if a person's condition affects their level of concentration (such as those with pain or some mental health conditions). Catering requirements should also be considered for those with diabetes or other conditions affected by diet. If conducting virtual meetings by tele- or video-conferencing, provide regular breaks.

## **When to assess support needs**

Patient and public members should have the opportunity to discuss their practical support needs at interview, on appointment, and throughout their role. This is because many physical and mental health conditions fluctuate, and additional needs might arise during guideline development. In some countries, the laws on disability discrimination or equality cover the provision of aspects of practical support. For example, the Accessibility for Ontarians with Disabilities Act (Thompson 2020) in Ontario outlines and enforces accessibility standards that developers would need to follow to remove barriers. This could include providing accessible formats on request.

## **Practical support examples**

There are many examples of practical support for guideline developers to consider and include (but are not limited to):

- Making adjustments for people with sensory impairments, like providing large print documents, microphones in meetings, or a hearing induction loop system. An interpreter could attend guideline meetings to assist members who have hearing loss.
- Offering the chance to participate virtually by video call (for people with high-grade conditions that prevent them from leaving home, like late stage heart failure, or individuals who cannot attend a meeting in person).
- Providing hints and tips on having an effect in virtual meetings, such as keeping oneself on mute when not speaking and methods to get the chair's attention.
- Booking meeting rooms large enough for an electric wheelchair or other medical devices and stair-free access.
- Making adjustments for people who experience fatigue, such as longer breaks or having a room available in which people can rest.
- Adjusting the room lighting or lighting of screens, such as illumination levels, glare and direction.
- Providing chairs that meet the needs of individuals with musculoskeletal conditions.
- Creating a 'break out' room for young people, or anyone, to take a break if they find the meeting too emotional (for example, when discussing sensitive topics).

- Providing documents on coloured paper for people who have an autism spectrum condition or those with dyslexia. Also, providing documents in plain language, or at very low-level language and offering support to explain these for people with low literacy or numeracy.
- Providing a dedicated toilet for people who need one.
- Providing financial support for care for a dependent relative if a carer has been recruited, or for childcare if someone has children.
- Providing financial information to ensure any payments do not adversely affect individual's state benefits.
- Ensuring any food provided meet people's dietary requirements.
- Texting a person with dementia or with memory problems half an hour before a pre-arranged telephone conversation or to remind them that support is available.
- Having a neutral support person (to minimise bias) highlight the most important sections of papers to read or comment on, or ask them specific questions with a patient or public focus.

For some topics, a patient organisation could offer practical support to individuals. For example, for the [NICE guideline on tuberculosis](#) (TB) among under-represented groups (NG33; NICE 2019), members who had experienced TB were involved and received additional practical support from a homeless charity. This included use of a permanent address for communications because they lived in temporary homeless shelters, and access to a computer for communications between meetings.

## **Valuing members**

Patients and public members largely volunteer their time to be involved in guideline development activities so their time, effort and value should be acknowledged. At a G-I-N PUBLIC workshop, patients collectively stated that being welcomed and respected for their dedication was more important than financial compensation for their time. However, taking part in guideline development for some people can mean taking unpaid time off work or can incur costs. The advantages of offering compensation outlined by INVOLVE (2011) include:

- Supporting equity of access, by compensating people for lost income if they must take time off work or arrange childcare, travelling costs, access to journals and technology, access to care or personal assistants and so on.
- Supporting equity of power in groups.
- Acknowledging the professionalism and contributions to public service of group members.

## **Types of compensation**

As a minimum, G-I-N PUBLIC recommends providing expenses, such as travel costs or accommodation, and providing compensation for time and effort. Compensation might also cover carer or childcare responsibilities and should be fair and appropriate for their role. Compensation could be provided in other cases, such as for attending training events or other preparation work. Payment in kind, such as vouchers, can also be offered. This is likely to be governed by local and national policies. Whatever the type of compensation, developers should be transparent during recruitment about any compensation arrangements.

## **Lack of budget**

Some organisations may rely on volunteers to conduct patient involvement. In this case, be clear in recruitment documents that volunteers are needed. A lack of funds to cover payment or reimbursement of expenses may affect the ability to recruit people, especially those from a lower socio-economic background. In rare cases, patient organisations may offer support. There may be policies or laws that govern unpaid work so check the local context.

## **Consideration for those receiving state benefits**

In some cases, receiving a payment will qualify as paid work and could cancel any state benefits (unemployment or disability payments) received. Furthermore, payments may qualify as taxable income, which can affect members who are self-employed. In this case, expenses (for example, train tickets and accommodation) should be booked by the organisation and paid from organisational budgets, which should avoid the individual being taxed. There may be an organisation in your country who can advise on this. If so, get their advice before the recruitment stage so that enquiries from potential applicants can be answered.

## **Compensation in practice**

[NICE's lay member payments and expenses](#) provides an attendance fee for patient and public members that covers either a half-day or full-day rate (2020a). Travel, subsistence expenses, accommodation costs and contributions to carer costs (for example, childcare or carer arrangements) are covered. NICE will book and pay for any such expenses so that the members are not out of pocket while they wait for reimbursement. If the member is an employee from a patient organisation, then it is possible to reimburse or pay the attendance fee to their organisation rather than the individual.

## **Informal support**

Informal support might consist of emotional support and building trust and rapport, which can make someone feel welcome in their role. The amount of informal support someone might need will vary so it will need to be tailored to the individual. Some individuals might have a strong background in patient advocacy, committee work and decision making, whereas other people might find guideline development group work a completely new experience.

## **Methods of informal support**

Examples of informal support include:

- Providing individuals with a key contact person who can help if they need further information or encounter any difficulties, either with practicalities or with the personal effect of working in a group.
- Offering to contact a 'peer group' of other patients who have been involved in previous guideline panels. Additionally, developers can offer contact with a one-to-one 'buddy', who is an experienced patient or public member at your institution. It is usually advisable to have someone who is not another member of the same guideline development group. Another contact could be a guideline project manager.
- Contacting each individual before the group's first meeting. This will provide an opportunity to address any questions about the first meeting and assess any additional practical or informal support needs for the meeting. It is useful for a key

contact person to introduce individuals to both the guideline group and the supporting staff.

- Following up each individual after the group's first meeting and any other key meetings. This will provide an opportunity to receive feedback of their experience and identify if anything can be improved for the next meeting.
- Making additional check-in calls or sending emails can be useful for specific tasks (for example, reviewing materials) to find out if any supports are needed.

### **Managing emotional impact**

Taking part in a guideline development group can have an emotional impact for some individuals. They might become frustrated if they feel their ideas are not fairly considered, or they can become upset when the group discusses sensitive issues, for example. It is important that individuals discuss any difficulty they have early on. Guideline developers should make it clear that these are normal reactions, not unprofessional, and they should identify any support networks and coping strategies if the need arises. If left unresolved, it could lead to patient members stepping down from the guideline group.

### **Informal support in practice**

To provide informal support, NICE in England and the ÄZQ in Germany provide a key contact person for patient and public members, so that they know who to contact for support or to discuss any issues that arise. At NICE, the key person will contact the patient member before the first group meeting and this is an opportunity to confirm any additional support needs. They will also greet the member at the first meeting. After that, the key person makes contact by email after the first and second meeting and then every 3 months (for shorter guidelines) or 6 months by phone or email. NICE also provides the opportunity for new members to meet existing experienced patient and public members, either face-to-face or virtually, to discuss the guideline development process and their role. Individuals are also able to contact their key person at any point. Similarly, SIGN offers a buddy who can provide support on a one-off basis or throughout the guideline development process (SIGN 2019).

Sometimes patient organisations or support groups can provide informal support, particularly for specialist groups. For example, when working with migrant groups, the ÄZQ works with migrant interest groups who could help or give support for certain conditions when possible, such as diabetes.

It is also particularly important to develop trust and rapport with certain groups and this can involve considering specific cultural norms and traditions. In Canada, when working with indigenous populations, RNAOs integrate traditional cultural ceremonies or practices, such as sharing a gift of traditional tobacco or smudging, into guideline development processes. Providing culturally relevant support demonstrates respectful engagement and can establish trust and rapport between the individuals with lived experiences and the developers.

## **Training and co-learning**

A barrier to patient engagement is the concern over whether the patient or public member has the skills and knowledge associated with research and group working to participate effectively in the guideline development process (Armstrong et al. 2017). As previously discussed, it is not necessary or advisable to only recruit individuals who have existing research and technical skills. Furthermore, patient members fear that professional members will dominate the meeting with their knowledge and ideas (Shippee et al. 2015). Training and co-learning are useful strategies to overcome such barriers and can increase patient confidence by encouraging capacity building, which is a fundamental principle of patient and public involvement. However, there are also concerns that too much training may result in ‘professional’ patients who no longer bring their individual experience. Even basic training in evidence-based medicine can automatically exclude people with low numeracy skills. Therefore, training should be tailored to the needs of everyone. An explanation of the difference between training and co-learning follows.

## **Training**

Training should improve members’ confidence about their roles and how to make an impact in the guideline development process. Training is more formal than co-learning and can consist of 1 or more days of structured learning with specific

learning outcomes related to patient and public involvement in guideline development.

Training can include different topics, including:

- guideline development processes
- research methods and terminology
- technical skills
- critical appraisal skills
- specific guideline development knowledge (for example, GRADE)
- strategies for participating effectively in the group (for example, assertiveness)
- building positive working relationships
- managing group dynamics.

There are different formats for delivering training. It can be provided in-house, by an external organisation, patient organisation or international society (for example, the European Lung Foundation), or be self-directed (for example, online training). Large organisations might be better equipped to provide their own training either face-to-face or electronically, which might not be possible in smaller organisations.

Organisations may choose to use external training events or courses covering research and critical appraisal skills. If neither internal nor external organisations can offer training, free online resources to support self-directed learning exist. Several organisations offer free online courses to patients and members of the public, including Cochrane and CUE – Consumer’s United for Evidence-based healthcare. A [list of courses and websites offering free training can be found in resource file 2](#).

## **Co-learning**

One fundamental principle of effective patient and public involvement is co-learning (Nguyen et al. 2020). Co-learning differs from training because it is mainly informal and is an ongoing process that should occur throughout the entire guideline development process. It is the process by which patient and public members, professional members and the guideline developer team teach, learn and share research knowledge and skills together. The process also benefits professional members. There are several ways to encourage co-learning:

- Providing training on guideline methods and processes, research strategies and overviews of the evidence retrieved from a review at the start of a meeting. This could be in the form of a presentation or verbal description by the technical team to the whole group, with an opportunity for the group to discuss their understanding. Presentations or learning resources can also be sent before the meeting when appropriate.
- Providing an online repository for all documents and sections for different working groups, which might include a specific section for patient group members.
- Avoiding jargon, explaining technical terms in the meeting, and having a glossary of medical, or guideline-related definitions and acronyms. Professional members should be aware that it is also their responsibility to explain medical acronyms and terms. Different professional groups may have different terms for the same concept or use the same term, but with a different meaning.
- Providing resources, in the form of toolkits or a 'hints and tips' document that informs the individuals about their role, the processes and resources to support their work.
- Holding lay-friendly seminars on specific topics, such as health economics.
- Offering networking opportunities with other patient and public members, which can be face-to-face or through an online forum.
- Providing free access to online journals.
- Providing regular contact with a key contact person to discuss ideas and any issues.
- Providing feedback on performance to encourage learning and development.

Co-learning is a valuable process to consider, especially if your organisation cannot offer formal training. Networking opportunities can be provided either before the start of a group or during development in the form of a lunch, an event, a workshop or by providing people with contact details for other patient and public members. New members can meet more experienced patient members and discuss the guideline development process or how to contribute effectively. During development, the patient and public members may be willing to support each other by sharing contact details but local data protection rules need to be followed and details should not be shared without permission.

## **Training and co-learning in practice**

NICE provides a formal full-day training event (either face-to-face or virtually through Zoom) for new patient and public members, including presentations and group exercises covering the following: research terminology, the guideline development process, critically appraising scientific research using the GRADE system, group working and skills, producing recommendations, and a chance to learn from experienced patient and public members. Similarly, the ÄZQ initially assesses patient and public member's training needs and provides them with reading materials, such as 'testing treatments' (Evans et al. 2011). If required, ÄZQ offers a full-training day, or shorter units, tailored to their training needs. Digital modules are also provided using software such as Microsoft PowerPoint with audio narrations.

In terms of co-learning, NICE's Public Involvement team delivers a presentation on patient and public involvement at the first group meeting. The developer team provides brief training on the guideline development process, the roles and responsibilities of staff, and health economics. Any learning materials are sent to members before meetings. Technical or research leads are available to answer any questions from all group members. Patient or public members are provided with a paper or digital toolkit of resources and information for working effectively. They are also given the chance to meet an experienced lay member before the start of some guidelines. Their key contact person will also provide knowledge, by telephone or email, on the various stages including consultation, publication, and action to support guideline implementation.

## **Re-assessment and feedback**

Another strategy for enhancing co-development is through re-assessment of the roles and expectations and providing feedback on the patient and public members' performance throughout guideline development (Shippee et al. 2015). This process can identify areas for development, which can be addressed through further training and co-learning. It can also help to address barriers associated with performance, such as not contributing or attending, or advocating their own agenda, which undermines the guideline. The process can also highlight the need for additional practical support strategies and areas where the member is having the most impact.

Providing feedback can ensure continual upskilling of the participants and is important to ensure meaningful and valuable involvement throughout the development process. For those with limited committee experience, it can increase confidence by confirming they are fulfilling the role to an acceptable standard and contributing effectively. Furthermore, it can ensure that the members feel supported and valued, which enhances engagement by empowering the individual. For some guidance programmes at NICE that are longer than 1 year, assessment of the role and feedback is provided every 6 months during telephone check-ins, or yearly for more formal feedback by the group's chair.

## **Managing group dynamics**

There is a large body of psychological and sociological literature on how groups form and behave, including the factors that create productive groups and the effects of power dynamics and status on the productivity of groups (for example, Forsyth, 2019). Power dynamics can occur as a result of age, gender, race, culture and socio-economic status, which largely operate at the unconscious level through stereotypes (for example, as discussed in Guinote and Vescio 2010). There are many useful texts focusing on this topic, which go beyond the scope of this chapter, some of which are listed in the [section on further reading](#).

Understanding group dynamics is important and can help guideline development groups operate effectively and ensure that patient and public members' insight is included. This responsibility largely lies with the chair or moderator of the group and some useful general strategies are:

- Highlight the importance of patient and public involvement: Consider delivering an early presentation to the guideline development group on the importance of patient and public involvement. Stress that these members have equal status with valuable contributions and provide examples of where patient and public members have had an impact on previous guidelines.
- Chair training: Brief the chair to discourage the use of medical and other jargon in meetings, which can exclude patients. Ensure they have the skills for running effective and inclusive meetings and understand the importance of meaningful patient or public involvement (see the chapter on how the chair can facilitate

patient and public involvement). At NICE, chairs are assigned to topics in which they have no professional experience so that they remain objective and limit bias, rather than trying to contribute their own opinions.

- **Management of the meeting:** Patient and public members should not be seated in an isolated area of the meeting and should be able to get the chair's attention. The chair should be briefed to bring the patient and public member into conversations, and some groups find it helpful to have a specific agenda item on patient and public matters associated with the guideline.
- **Relationship building:** Encourage individuals to identify potential allies in the group who can be a source of support for patient and public members during meetings. Alternative methods should be considered if meetings are conducted virtually when individuals need to connect by email, telephone and other digital means of communication.

The upcoming chapter on how the chair can facilitate patient and public involvement has further information on this topic. It is important to reassure patient and public members that their experience may differ from other patients and public members. Confirm that this difference of opinion is encouraged, and they should share this with the guideline group.

## **Overcoming barriers to involving those who are seldom heard**

Throughout this chapter, we have highlighted several generic barriers and facilitators that guideline developers can take into account when recruiting and encouraging meaningful involvement of patient and public members in guideline development. These barriers and facilitators are summarised in table 2. Although these can apply to all patient and public members, including those who are seldom heard, there are specific barriers and facilitators to be considered when guideline developers cannot recruit patient and public members or when specific groups of people might have very specific support needs because of:

- age, such as babies and children
- circumstance, such as those living in prisons and other secure settings, or

- condition, such as people with learning (developmental) disabilities, or severe and complex mental or physical health conditions.

**Table 2 Summary of generic barriers and facilitators for recruiting and promoting effective patient and public involvement in guideline development**

<b>Barrier</b>	<b>Facilitator</b>
Developer unclear of recruitment strategy in terms of the number or type of patient or public members to recruit to achieve genuine representation	<p>Consider open recruitment as opposed to nomination methods, including where to advertise. Recruit through patient organisations and social media (for example, Twitter, Facebook and other online patient or support forums).</p> <p>Recruit at least 2 patient or public members who might be patients, carers, parents or advocates from patient organisations. The organisations should represent a breadth of views and experiences associated with the guideline and other important socio-demographic (for example, age range) factors.</p> <p>Re-advertise the position if there are no suitable applicants. Consider other involvement methods.</p>
Developer or patient or public member unclear of their role in guideline development	<p>Plan the role and associated tasks early in the planning phase.</p> <p>Develop and advertise a role description and person specification. Consider patient demographics and characteristics.</p> <p>Provide induction materials and discuss the role requirements before the first group meeting.</p>
Scheduling and planning, such as meetings clashing with personal commitments	<p>Ensure meeting dates are planned and shared with all guideline group members in advance of the first meeting. This will allow patient and public members to plan and arrange any necessary time off work or childcare arrangement, for example. Any changes to meeting dates must be communicated and agreed with all group members and communicated as soon as possible.</p>
Lack of relevance of the scope to patient and public members	<p>Involve patient or public members early in guideline development and invite them to smaller scoping groups. If this is not feasible, then involve a patient advocate from a patient organisation to represent the views of patient and public members in scoping discussions.</p>
Gaining meaningful involvement or avoiding tokenism	<p>Interview applicants to ensure they have the right skills and experience and recruit early so they can contribute to the topic prioritisation or scope development stage.</p> <p>For meaningful engagement, include members in strategic decision making (for example, in developing the scope), development of decision aids, or implementation strategies.</p>
Patient and public member not respected, not seen as equal, or feeling devalued	<p>Make certain that the group's chair understands group dynamics and ensures equal power balance, including a right to vote to reach consensus and providing feedback on patient contributions. Include a specific slot for patient and public members to provide input during discussions.</p> <p>Encourage relationship building between patient and public members on the same group or with health professionals to build allies.</p>
Achieving a breadth of perspective	<p>Recruit members according to their personal experience of guideline topic, wider understanding of patient issues from patient networks or support groups, and soft skills (for example, communication skills).</p>

<b>Barrier</b>	<b>Facilitator</b>
Recruitment can be resource intensive or costly	Use nomination as a recruitment strategy through patient organisations, if possible. Use social media to advertise.
Lack of methodological expertise, skills or knowledge related to guideline development	Deliver or signpost to relevant training (for example, research methods and critical appraisal skills) and consider ongoing co-learning (for example, presentations in meetings) or regular feedback on performance.
Lack of confidence to speak up in a large group of experts	Consider including hints and tips in induction materials, training, and also in catch-up calls with a patient and public involvement specialist, or key support person. Peer support from other patient and public members from previous or different guideline groups can help.
Supporting people with a range of practical support needs	Assess support needs early in the recruitment phase and continue to re-assess throughout guideline development. Make reasonable adjustments and offer practical and informal support through.  During development, conduct regular check-ins (by email, phone or video call) to identify issues or to assess ongoing support needs.
Lacking peer support	Recruit more than 1 patient and public member.  Offer a 'buddy' or a chance to meet or talk to someone from a previous or different guideline group to discuss the role and any issues at the beginning and throughout guideline development.
Limited funds to reimburse members	Consider vouchers (gift in kind), offer free training to upskill members to improve their curriculum vitae. If possible, pay travel expenses or offer virtual participation in meetings (for example, using video-conferences or tele-conferences).

The remainder of the chapter will discuss alternative approaches to involvement and specific considerations for different groups who are seldom heard, such as children or people with learning disabilities.

## **Alternative approaches**

Specific groups of people might not be able to be full members of the guideline development group (for example, children or people with advanced dementia). In addition to involving parents, carers and advocates, there are alternative approaches to involving people with the condition or from the affected population. These include a reference group, additional sources of data on patient and public views, patient expert testimony, consultation using research methods.

## Reference groups

A reference group in this context, is a group of people who use the relevant services or experience a particular condition. They can help the guideline group identify patients' perspectives and priorities at key stages of guideline development.

Reference groups have the advantage of generating a wider range of patient and carer views by including people with different experiences of the condition, treatment and care, or people from a specific socio-demographic background. For example, for the [NICE guideline on child abuse and neglect](#) (NG76; 2017), the developer commissioned an independent charity to recruit and facilitate a reference group to inform the guideline group's deliberations and development of recommendations (Fielding et al. 2018). If considering involving a reference group, guideline developers should carefully plan the work including:

- the objectives
- involvement methods
- time and costs
- travel arrangements and incentives or reward for participation
- demographics and other characteristics or experiences of the group
- ethical issues, such as safeguarding
- methods for presenting findings to the guideline development group.

The work of the reference group should be facilitated by people with expertise in facilitation and a track record in working with the group of interest.

## Additional sources of data on patient and public views

In addition to using peer-reviewed literature, guideline developers may find relevant information on patient and public views and experiences in surveys conducted by stakeholder organisations. SIGN, in Scotland will contact relevant patient organisations and charities before starting the development of a guideline (SIGN, 2019). They are asked for their views on the important issues that they think the guideline should focus on. Their input on these issues could be based on data gathered through surveys or telephone helpline experience.

Patient and the public views and experiences can also be found on patient forums or patient-focused websites. For example, a UK-based reputable website, [HealthTalk](#),  
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covers many health conditions or groups, such as young people. It is informed by the Health Experiences Research Group at Oxford University's Department of Primary Care. The team uses rigorous qualitative research methods to capture the full range of patients' experiences associated with each health issue, condition, or intervention. Similar websites exist in other countries (for further information, see the section on consulting patient and public members using online engagement methods in the chapter on how to conduct public and targeted consultation).

### **Patient and public expert testimony**

When there are gaps in the patient and public evidence, an alternative option is getting such evidence from the expert testimony of people in the affected population (in person, in writing or by video). Such expert testimony may be sought one or more times during guideline development because the need for expert testimony may only become apparent later in the process. It is important to support the individual providing the testimony. Support should include giving them information about the guideline group and what information is required, and preparing them for questions they may receive. Stakeholder organisations may also be able to support people providing a testimony. At NICE there is no minimum age for people providing expert testimony, but if they are under 16 years, or a vulnerable adult, they must be accompanied by an appropriate adult with responsibility for their welfare. When children or vulnerable adults contribute evidence to meetings, the testimony might need to be given through a video-recording or in a closed, confidential session if meetings are usually held in public.

### **Consultation using research methods**

When important gaps in the evidence are unlikely to be filled through consultation with stakeholder organisations or using any of the above approaches, some guideline developers may consider consulting the affected population using research techniques. This is an exceptional option requiring additional resources. Types of methods and when to use research methods for consultation have been covered in detail in the chapter on how to conduct public and targeted consultation.

## **Involving people who are seldom heard in guideline development**

Developers are likely to produce guidelines for a range of topics where the barriers to involvement can be greater for certain people. This section considers 3 groups of people: children and young people, people with learning disabilities, and people with severe and complex mental health conditions.

### **Children and young people**

The UN Convention on the Rights of the Child (UNICEF 2016) enshrines the rights of children to be involved in decisions that affect their lives and to be heard. In the UK, health researchers, policy makers and services have increasingly engaged children and young people in matters that affect their health and wellbeing. Qualitative research indicates that children can provide their views, including those who are less articulate because of age, ability or culture. It also suggests that most children are acutely aware of the way in which they are treated, and their perceptions do not mirror those of adults (Doorbar et al. 1999). However, guideline developers find involving children and young people difficult and have several questions concerning when and how to involve children and young people (Schalkers et al. 2017). Some strategies for addressing common questions follow.

#### **When should children be included in guideline development?**

There is consensus that developers should seek the views of children and young people when the guideline specifically looks at a condition that affects this group or when the treatment or disease affects children differently compared with adults (Schalkers et al. 2017). It is likely that their views and experiences will differ from adults around symptoms, treatments, side effects, recovery, and care. An addendum to guidance for adults could suffice if the experience of the disease for children does not differ that much from adults.

Developers may need to prioritise involving children and young people in certain guidelines over others. Schalkers et al (2017) list 14 criteria for supporting this decision, with the top 3 criteria being when:

- there is a clear expected health benefit for children
- professionals identify that guidance is needed for children

- there is difference of opinion between professionals around the treatment of children.

The criteria that are least important in deciding whether to involve children are when the disease has high expected healthcare costs, the lack of availability of scientific evidence, and when the focus is on pharmacological treatments.

### **What is the minimum age of children for involvement in guideline development?**

Developers can be concerned about the ability and competence of a child or young person to be able to understand, contribute to and engage in decision making. The UN Convention on the Rights of the Child defines a child as a person under 18 years (UNICEF 2016), as does UK child protection legislation. In the UK, a child is deemed competent to decide about their treatment without parental or guardian consent from 16 years. This is the minimum age for a young person to join a NICE guideline development group without being accompanied by an appropriate adult. However, mental capacity should be considered. Some young people aged 16 and over might have a specific vulnerability, such as a learning (developmental) disability, and would need to be accompanied by an appropriate adult. But a child under 16 years, who does not have a specific vulnerability, might demonstrate sufficient mental capacity, known as Gillick competence, and be able to contribute to decision making.

Qualitative health research has demonstrated that children as young as 6 can share their views and provide useful information (Gibson 2007). However, young children would be unable to participate in a guideline development group and additional approaches to elicit their views would be needed, such as focus groups or reference groups. There may be country-specific age thresholds and so developers should consider local legislation and policies on children and young people, and their mental capacity.

### **Should a parent or primary caregiver provide the views of children?**

One debate that could arise is whether parents or caregivers should provide the views of the child younger than 16 years. At NICE, an appropriate adult would likely need to be involved in a guideline group if the child is under 16 years. Although NICE acknowledges that parents and carers can bring valuable insights, they should not

be regarded as a proxy for children. If guideline developers have the available resources, it is useful to work with a specialist external organisation, or a stakeholder organisation, with expertise and access to appropriate networks to elicit views from children.

### **How do you recruit children and young people?**

Strategies outlined in this chapter also apply here, particularly working with relevant patient organisations, charities or other voluntary and community organisations for children and young people. Advertising on social media can also be useful for parents to identify the involvement opportunity for themselves and their child.

### **How do you involve children and young people and what approaches can be used to elicit their views?**

NICE has developed a systematic approach, outlined in the [NICE manual for developing guidelines](#), to ensuring that the views of children and young people are included in guideline development for relevant topics (NICE 2020b). The approach also includes involving parents or other family members. There is much research in the social sciences on how to elicit the views from people of different age groups, and it highlights the need for age-appropriate techniques (see Gibson 2007). But it is likely that for working with young and very young children, specialist input and training from an external organisation will be needed. Some general strategies to consider when involving children and young people aged 16 to 25 years are:

- Involve children and young people in a meaningful way, setting out clear objectives and working with sensitivity and flexibility, especially if the topic is sensitive.
- Consider measures for protecting the safety and welfare of children, including following local 'safeguarding' policies.
- Make adaptations, such as providing age-appropriate training, ensuring the chair asks specific questions or provides opportunities to contribute during meetings, and allowing regular breaks.

SIGN involved children and young people in the development of its guideline on diagnosis and management of epilepsies in children and young people. Two young people were full members of the guideline development group. Young people,

associated with Epilepsy Scotland, engaged in an interactive session to discuss the issues identified from a patient-focused literature search. They explored what the additional priorities were for them and whether there were any other issues that the guideline group should consider. For further information, the Royal College of Paediatrics and Child Health provides guidance on how to involve children and young people in committees (2018; see the section on further reading).

### **People with learning disabilities**

People with learning disabilities and their carers are increasingly being involved in guideline development groups (Caldwell et al. 2008). Although it is important to follow the guidance in the sections on the [role of patient and public members](#), [their recruitment](#), and [supporting individual patient and public members](#), guideline developers must consider very specific reasonable adjustments to meetings and practical support to encourage meaningful involvement. Table 3 lists several considerations and adjustments that have been documented in the literature and implemented in NICE guidelines on learning disabilities (Caldwell et al. 2008; Karpusheff et al. 2020). There is no exhaustive list of strategies, but they can be categorised into accessibility of meetings, communication adjustments, environmental adjustments, financial support, and transportation.

**Table 3 List of reasonable adjustments for supporting people with learning disabilities**

Category	Adjustment strategy
Meeting accessibility	<ul style="list-style-type: none"> <li>• Provide physically accessible meeting locations</li> <li>• Be aware of the pace of the meeting – not too fast</li> <li>• Provide opportunities for discussions and questions</li> <li>• Ensure members with learning disabilities have had the opportunity to give input by asking them what they think and making them feel comfortable to talk</li> <li>• Provide meeting papers a few days in advance of the meeting</li> <li>• Prepare the individual about the topic of meeting discussions in advance of the meeting</li> </ul>
Communication adjustments	<ul style="list-style-type: none"> <li>• Consider whether sign language interpreters are needed, as well as closed captioning services and amplified hearing devices</li> <li>• Create easy read versions of meeting documents, including large print, or use braille or disk formats. Avoid jargon and use simple language</li> </ul>
Environmental adjustments	<ul style="list-style-type: none"> <li>• Consider scent-free meeting environments or rooms with specific lighting</li> </ul>
Financial support	<ul style="list-style-type: none"> <li>• Consider paying expenses, and accommodation and travel costs upfront because some people with learning disabilities do not have the financial capacity to pay for costs upfront</li> <li>• Offer childcare support or cover costs of a carer, support worker or other advocate</li> <li>• Provide an honorarium or stipend if possible</li> </ul>
Transportation	<ul style="list-style-type: none"> <li>• Offer transportation options, such as a taxi or cab from and to home, train station, airport and bus station</li> </ul>

Support and reasonable adjustments will need to be tailored and continually assessed throughout the guideline process through regular contact and feedback from the individual and the group’s chair. At NICE, a key contact person was beneficial for supporting individuals with learning disabilities to formulate their ideas before and after the meeting.

### **People with severe or complex mental health conditions**

People living with severe or complex mental health conditions (for example, psychosis, alcohol misuse or schizophrenia) still experience barriers to participating in guideline development (van der Ham et al. 2014). There are several specific

barriers and facilitators to consider, which van der Ham et al. (2014 and 2016) have reviewed in detail. In summary, guideline developers could consider the following:

- **Value and contribution:** People living with mental health conditions may be perceived as unable to make valuable contributions or valid statements about different therapeutic treatments (medical or psychological) because of their impaired cognitive state. This can be an inaccurate assumption. A review of mental health guidelines in the Netherlands revealed that the number of patient members with mental health conditions on a guideline group ranged from 2 to 5 per guideline (van der Ham et al. 2014). For Norwegian guidelines on mental health, 5 user representatives had significant influence in scoping the topic and formulating recommendations (Helsedirektoratet [The Norwegian Directorate of Health] 2013).
- **Recruitment and representation:** Gaining sufficient representation across the different classifications of mental health conditions can be difficult if the guideline topic is broad. Recruiting through patient organisations can help but could lead to over-representation of a particular mental health condition, depending on the focus of the organisation. In this instance, multiple recruitments and additional involvement methods will help gain representation, including incorporating existing patient research, panel or dialogue meetings, questionnaires or user focus groups, case studies or personal narratives. However, depending on available funds and resources, guideline developers will need to find a balance between gaining in-depth insight that requires fewer participants (for example, case studies) and methods that give broad perspectives but require large numbers of respondents (for example, questionnaires). If the right level of perspective is not achieved, there is a risk that patient organisations will reject the guideline, which would prevent it from being implemented.
- **Topic of interest and scope:** Members with mental health conditions are likely to be less interested in traditional biomedical approaches and more interested in holistic approaches, social support, quality of life, and non-medical implications, for example, the ability to retain employment (van der Ham et al. 2014). Such factors should be considered in the scope of mental-health related guidelines, and their inclusion is achieved by inviting mental-health related patient organisations to scoping meetings at NICE.

- Dropout and support: Dropout from a guideline group is a risk that developers will need to consider from the outset. Mental health can vary and fluctuate over time leading to patient members either joining the group late or resigning. Additionally, patient members might struggle to read lengthy guideline documentation. Solutions involve recruiting multiple patient members and providing and adapting specific content and process-related support. For example, documents should be summarised or discussed with the patient members before a meeting and a key contact person should have regular contact with the patient member throughout the guideline process. Developers could also consider enabling input for specific parts of the guideline that need the patient's perspective. For the [NICE guideline on violence and aggression in mental health and community settings](#) (NG10; 2015), the developer encouraged peer support by providing a room for 4 patient and public members to meet before and after meetings to support each other. Members often experienced fluctuations in their conditions resulting in non-attendance at meetings. Peer support empowered the members to share experiences, encouraged a healthy critical debate, and ensured opinions were voiced in meetings.

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## Resources

## Resource file 1: Example role description

# What we're looking for and what's involved

## What is a lay member?

We use the phrase 'lay member' to refer to a member of one of our committees who has personal experience of using health or care services. The phrase can also mean someone from a community affected by the committee's topic area or an advocate or unpaid carer.

## What will the committee be doing?

The committee will look at the evidence that is available, and develop NICE guidance on [Thyroid cancer: assessment and management](#). The NICE guidance will be written recommendations about the best types of treatment, support and services.

For more information about our committees and what they do, visit the [committee area](#) of our website.

## What knowledge and experience will I need?

We're looking for people with an understanding of Thyroid cancer: assessment and management and the issues important to patients, people using services, unpaid carers, communities and the public.

As a lay member, you will have this understanding:

- through personal experience you have of treatment and care provided for you by the NHS
- as a relative or unpaid carer of someone who has used relevant health services
- as an advocate, volunteer, or officer of a relevant charity or organisation.

You will also have:

- good communication and team-working skills
- the ability to listen and take part in constructive debate, while being respectful of other people's views

- knowledge of the experiences and needs of lots of people which gives you the ability to champion a range of different perspectives on this topic.

## Who sits on the committee?

NICE committees develop our guidance. As well as [lay members](#), committees are also made up of [professional members](#). This includes people who work in health or social care, as well as a range of other roles.

Lay members have the same status and carry out the same functions as other committee members.

## What does the role involve?

- attending committee meetings (see time commitment below for more information) and taking part in discussions to shape the guidance
- reading committee papers
- commenting on documents between meetings
- keeping the committee's work confidential.

## What am I expected to do?

- Make sure the views, experiences and interests of patients or people who use health and social care services are taken into account by the committee.
- Identify areas of concern to people using NHS, public health or social care services.
- Review topic information and the draft guidance from a patient, service user, carer or community perspective. For instance, does the information address issues important to people affected by the guidance? Does the guidance take their views into account?
- Make sure the guidance considers people from different backgrounds.

## How much time will I need to give and where?

It's important that you are available for the committee's meetings.

- Meetings for this committee will take place from 1 May 2020
- Committee meetings will usually last for 1 day, but sometimes 2 day meetings are held
- The meetings will happen every 4-6 weeks for a period of 18 months
- The meetings will take place in central London
- If you are appointed, you will be invited to a training day in Central London on 12 May 2020

## What's in it for me?

- You will be helping to make national and local health and social care services work better for patients, people who use services, carers or the public.
- Previous lay members have said they found their confidence improved, as well as developing other skills like public speaking and critical thinking.
- Being a member of a NICE committee shows you are an expert by experience. It also shows you are able to work in a team, as an equal contributor to the committee alongside healthcare and other professionals.

## What support will I get?

A named member of the public involvement team will be available throughout your time working with us, to offer help and support.

You will be offered training and guidance to make sure you feel confident on the committee, as well as regular chats with your named contact.

If you have any special requirements, for example access or travel needs, we can discuss this with you and make adjustments where needed.

## What happens after I apply?

The public involvement team passes on applications to the team running this committee. Your application is then shortlisted against the required skills and abilities set out in this document.

If you are shortlisted you will be contacted for a phone interview to talk about the position, your application and what is involved before a formal invitation is offered to sit on the committee. The date for interviews has been set for the 14 and 17 February 2020. They will take place on the phone and will last no more than 30 minutes.

## More information

For more information about becoming a member on this committee, read our [additional information](#).

This gives more information about:

- payment and expenses, including how this could affect any benefits you receive
- how we can help you to apply if you have a disability
- how we monitor equality and diversity in NICE's work
- what we expect from our committee members
- what might prevent you from sitting on a NICE committee
- how we will use the personal information you give us
- what you can do if you're not happy with our recruitment process

# Resource file 2: List of training resources

<b>Title</b>	<b>Description</b>	<b>Website</b>	<b>Cost</b>
Cochrane Evidence Essentials	Modules cover: Evidence-based medicine, randomised controlled trials, introduction to systematic reviews, and understanding and using systematic reviews	<a href="https://training.cochrane.org/essentials">https://training.cochrane.org/essentials</a>	Free, login required
CUE - Consumers United for Evidence-based Healthcare	Multiple educational resources and free courses covering: evidence-based healthcare, FDA and the regulation of healthcare interventions and advisory panel engagement resources. There is a video covering consumer involvement in guideline development.	<a href="http://consumersunited.org/education&amp;training">http://consumersunited.org/education&amp;training</a> <a href="http://consumersunited.org/rrguideline">http://consumersunited.org/rrguideline</a>	Free
EUPATI: Patient engagement through education	Toolkit of resources and a course on patient engagement and medicines research and development	<a href="https://eupati.eu/">https://eupati.eu/</a>	Application process for course. Resources are free.

Title	Description	Website	Cost
Coursera	Coursera is a platform that hosts free and paid courses offered from reputable institutions around the world. There is a range of courses on research methods, statistics, and quantitative and qualitative research methods. Many other courses are offered that might be relevant to specific guideline topics, such as public health courses.	<a href="https://www.coursera.org/">https://www.coursera.org/</a>	Most courses are free, unless you want a certificate. There is a fee for specialisations, which are a series of courses.
Future Learn	Future Learn is similar to Coursera and offers courses from reputable institutions covering many aspects of healthcare and medicine, science, psychology and mental health topics that might be relevant for specific guideline groups.	<a href="https://www.futurelearn.com/">https://www.futurelearn.com/</a>	Courses are free for 6 weeks with the option to pay a fee to upgrade.

<b>Title</b>	<b>Description</b>	<b>Website</b>	<b>Cost</b>
Testing Treatments	A valuable resource on critically appraising treatment claims. The book is available for free in PDF and audiobook formats. The book is available in different languages. The website also includes an interactive toolkit of additional resources.	<a href="https://en.testingtreatments.org/">https://en.testingtreatments.org/</a>	Free
The NICE glossary	NICE provides a glossary and definitions of the terms used in guidance development	<a href="https://www.nice.org.uk/glossary">https://www.nice.org.uk/glossary</a>	Free
Bandolier	The website provides a free resource of journal articles related to evidence-based medicine. There is also a learning zone with free articles related to different aspects of trials, meta-analyses, statistics, guidelines and health economics. A glossary of terms is also provided.	<a href="http://www.bandolier.org.uk/">http://www.bandolier.org.uk/</a> <a href="http://www.bandolier.org.uk/learnzone.html">http://www.bandolier.org.uk/learnzone.html</a> <a href="http://www.bandolier.org.uk/glossary.html">http://www.bandolier.org.uk/glossary.html</a>	Free
HTA Glossary	A free glossary for members working in health technology assessments.	<a href="http://htaglossary.net/HomePage">http://htaglossary.net/HomePage</a>	Free

