Role of the chair

"I have been involved in NICE and its guideline programme in various roles for almost 20 years and have recently chaired three guideline committees. I have seen at first hand what an important contribution patient/public members can make to the discussions and recommendations. But that contribution needs to be nurtured by providing them with adequate support and by the committee Chair encouraging their participation throughout the process. Tokenism is not acceptable – active participation is essential."

Chapter 4 overview:

Authors: Simran Chawla, Sarah Scott, Victoria Thomas and Jane Cowl

Corresponding authors: Simran.chawla@nice.org.uk

Key Messages

- When a guideline agency commits to involving patients and the public in its processes, its committee chairs need to be committed to this principle and to support guideline development committees with patient and public members.

- If the chair of a guideline committee is properly recruited, supported, and trained to be facilitative and inclusive, successful patient and public participation in the guideline's development is more likely. A skilled chair can improve group dynamics by empowering patient/public members, who can then contribute more meaningfully.

- A skilled and well-trained chair will ensure that their guideline committee is an integrated group in which all members are treated equally and can contribute to the best of their ability.

- Good chairing will lead to good group dynamics so that committee members feel able to challenge and discuss the evidence presented to them in a rigorous but respectful way. This will include taking into account the differing dynamics and needs of a

group that is primarily working online vs. one working together in-person.

- All guideline committee chairs, however skilled and experienced, need support, induction and training to ensure they understand the specific requirements of the guideline development agency. All newly recruited chairs should be encouraged to take advantage of any training on offer.

- In recruiting or identifying guideline committee chairs, facilitation skills are more important than topic expertise because others on the committee will have this knowledge.

- All chairs need to commit to developing guidelines within the framework of the guideline agency's established principles of working, methods and processes, and organisational culture. This might include use of language according to the agency's corporate style guide.

Top Tips

- Recruit your chairs openly and transparently or be clear about how your chairs are identified and selected.

- Train and support your chairs, weaving in patient and public involvement rather than having it as a stand-alone training module.

- When inducting your chairs, make sure they have the opportunity to hear from someone who has previously chaired a guideline committee within your agency, which included patient/public members.

- Offer your chairs regular appraisal and feedback on their performance and encourage them to offer something similar to their committee members.

- Offer chairs reimbursement for their time or reimburse their employers for the time they take working on the committee.

- Consider patient/public chairs – they may have valuable expertise your agency could benefit from.

Resources

- General information about the role of chairs in running groups on which patient/public members sit can be found in 2 key additional resources:

- Patient and Public Involvement Toolkit, Chapter 4 Building relationships (Cartwright and Crowe 2011)

- Patient and public involvement in research groups – Guidance for chairs (TwoCan Associates for the UKCRC and NCRI 2010).

- Other useful information to support the chair's role on guideline development groups:

- Supporting effective participation in health guideline development groups: The Guideline Participation Tool (Piggott et al. 2020)

- Checklist for Guideline Panel Chairs (Department of Health Research Methods, Evidence and Impact, McMaster University 2017)

- A guide to small group work in healthcare, management, education and research (Elwyn et al. 2001).

Aims of this chapter

This chapter describes the method for recruiting, selecting and supporting the chairs of guideline committees (GCs), developed for the National Institute for Health and Care Excellence (NICE) in the UK. The model places particular emphasis on involving and engaging with patient/public members (known as 'lay members' at NICE) of GCs as an integral part of the overall responsibilities of chairs.

Interactive discussions throughout an induction session take account of this aspect of the chair's role, alongside other elements that NICE feels are important. The approach described has been developed over time, specifically tailored to the needs of the chairs of NICE GCs. Elements of the model will be generalisable to other organisations, even when the NICE guideline development process and methodology is not being used.

The context for the process described in this chapter is the NICE policy for including patients and/or members of the public on all of its standing and ad hoc advisory committees.

Readers of this chapter should gain an understanding of:

- key issues for inducting and supporting chairs of GCs
- a sample mechanism for recruiting and selecting GC chairs
- the inherent value in providing formal and structured induction for chairs of GCs
- particular issues for chairs of groups with patient/public members
- organisational and resource implications for adequately supporting and inducting GC chairs
- the barriers to effective chairing, and some potential solutions for overcoming them.
-

Chapter topics:

1. **Terminology:**

Guideline committee

NICE uses the term ‘guideline committee’ to refer to the decision-making groups that develop its guidelines. Other agencies may use different terms such as ‘guideline development group’ or ‘guideline panel’.

Patient/public members

For the purposes of this chapter the term ‘patient/public members’ is used throughout to describe the people NICE terms as ‘lay members’. The patient/public members of NICE’s GCs are recruited as individuals with a breadth of knowledge and experience about a particular topic, population, disease, condition or disability. They are not considered ‘representative’ of any particular group, organisation or patient population. We recognise that other terms are in common use but in this context ‘patient/public member’ refers to people with personal experience of a disease, condition or service (patients, consumers, users), their carers or family members, and those representing a collective group of patients, people using services or carers (representatives or advocates).

NICE’s approach to inducting and supporting GC Chairs

Background

“As a lay member on a guideline I really appreciated the Chair treating me as an equal with an equally valid opinion to the professionals on the committee. I felt my lived experience really added to the whole process”.

-Lay member on a NICE Guideline Committee (GC)

A NICE GC is a multidisciplinary group, supported by a technical team (systematic reviewer, information specialist, health economist). It is an advisory group to NICE and sits independently. As a minimum, a GC comprises:

- healthcare professionals, and for relevant topics, public health or social care practitioners (both specialists in the topic and generalists)
- patients, carers or members of the public.

The role of a GC Chair should be rooted in the cultural norms of an organisation in terms of its identity and the methodological approaches it takes to guideline development. The wider legislative and policy framework within which the guideline agency operates is also relevant to the Chair's role. For example, legislative and policy imperatives to promote equality. NICE's GC Chairs are responsible for running independent groups, but knowledge of the methodological and process expectations of NICE is crucial in ensuring the Chairs can run a group effectively.

Chairs must focus on delivering against NICE's strategic objective, which is to produce useful and usable guidance for our end users, that is high-quality and up to date. If a guideline developer has yet to establish explicit methods and processes, the Chair should apply core principles that are recognised as key to good quality guideline development (such as the AGREE II criteria [Brouwers et al. 2010]).

We strongly believe that the underlying philosophy of involving patients and the public in guideline development is important. It may well support guidance development organisations when convening such groups, and in chairing them in a facilitative and inclusive manner.

We elicited feedback from colleagues belonging to member organisations of the GIN Public Working Group, for insights into their training and support for committee Chairs. Their input is woven into the relevant sections of this update.

The importance of the role of a Chair for involving lay members

Reviews carried out by NICE's People and Communities Team (PaCT; formerly the Public Involvement Programme) identified the role of the Chairs of GCs as crucial to the success of the way the GCs function and how well GC lay members feel integrated into the group and its workings.

Generally, GC lay members have variously described characteristics of 'good' Chairs as:

- *'inclusive'*
- *'skilled'*
- *open'*
- *'honest'*
- *'able to influence'*
- *encouraging healthy rivalry'.*

One GC member who was a patient, shared some feedback on the qualities that made their Chair especially effective:

"A NICE guideline Chair needs to be fully conversant in the issues that are likely to arise during the committee decision making process, thus they must not only be well versed in the NICE guideline processes but must also have done extensive background reading on the specifics of the condition their guideline will address. As a patient member of a NICE committee, I liked how our Chair was able to keep a running list of those who had asked to speak, thus I always knew my turn would come around before we moved on. He would also frequently double check with lay members for comments so that we were not forgotten, and particularly encourage quieter folk to add to the discussion. "

Another lay member who was on the committee as an unpaid carer, shared the following, to illustrate the various dynamics that can play out, as well as the skill of the Chair in managing those dynamics:

"As a carer, I had concerns that not only would I need to work extra hard to keep up with and contribute to discussions with professional healthcare colleagues, but that my lay peers with lived experience of the condition would be more knowledgeable, able to contribute better, and be given more airtime. I worried that my contributions might be considered of minimal value. My Chair, from the outset, put those fears to rest. He ensured inclusivity of everyone on the guideline committee. He worked hard to make sure that he (and everyone else) understood points being made, and reasoning. The feeling of being valued and included at all times, even in technical and medical discussions, resulted in a positive and enjoyable experience"

It is also important that Chairs acknowledge the importance of involving lay members.

One experienced Chair has commented: *"Charing a guideline committee is always a fascinating experience but can be tricky at times when balancing competing views and interpretations of the evidence, especially when it is poor or contradictory. Having lay members is essential. They bring a very different perspective grounded in their personal experiences and can sometimes helpfully challenge the settled views of clinical experts. But it is important that they are supported to be genuinely engaged in the process and to really understand the sometimes complex evidence that is presented."*

The overall positive impact on a final guideline of lay members who feel equally included, heard and respected cannot be overstated.

Recruitment of Chairs

In May 2006, the World Health Organization (WHO) conducted a review of NICE's guidelines development programme (de Joncheere et al. 2006) and made several recommendations. One recommendation was that Chairs of GCs should be recruited through a standard process, preferably through open

advertising, and that NICE should develop standardised training for GC Chairs. The first of these recommendations was quickly adopted. NICE also developed an ‘induction’ programme, discussed more fully in the section on NICE’s chairs’ induction programme.

NICE recruits external independent Chairs whereas other agencies may recruit skilled moderators from the agency’s staff or well-known topic experts. This section details NICE’s approach to recruiting Chairs. For many years, NICE has had a policy of **not** recruiting topic experts to chair GCs. Topic expertise is not essential in a Chair as that comes from other members of the GC. In fact, having a Chair with topic expertise may be a risk because they will inevitably have biases and competing interests which may prevent an impartial assessment of the evidence, and given their perceived power and authority, they may be allowed to impose their own views.

To ensure transparency, NICE adopts an open recruitment process, whereby anyone with an interest can apply to chair a group. NICE’s appointments to advisory bodies policy and practice, a corporate recruitment policy, has been developed to support this (2020). Potential chairs must submit an application (as they would for a position of employment), and then a formal process for selection and recruitment follows. Applicants are assessed against criteria in a ‘role description’, and then short-listed. Short-listed candidates are interviewed by a panel comprising senior staff members and a member of the NICE Board. Further information on vacancies for Chairs of NICE groups can be found on NICE’s join a committee webpage. GC Cairs are most often health or social care professionals with extensive commitments, although NICE has experience of recruiting lay people to chair its committees.

This process, although transparent, carries a significant administrative burden, for drafting recruitment paperwork, short-listing the applicants, and the interview process itself. But, because this follows a standardised process, after the template recruitment documents have been developed, they only require minor amendments to tailor them to each new recruitment.

NICE's Chairs' induction programme

Background to the Chairs' induction programme

Because of the WHO report and the subsequent reviews, a programme for inducting GC Chairs was developed jointly by NICE's Centre for Guidelines and the People and Communities Team at NICE. It was specifically tailored to NICE's needs and the context in which it works.

NICE develops and updates its guidance according to methods and processes set out in the publicly-available NICE guidelines manual. A new Chair is recruited for each GC addressing each new guideline topic but some Chairs are recruited to a broad topic area, such as diabetes, obstetrics, weight management. NICE invites both newly recruited GC Chairs and Chairs from these topic areas to attend induction sessions with their peers. The induction process for NICE's GC Chairs is regularly reviewed and refined, reflecting the accumulated experience of GCs, their Chairs and members, and, importantly, changes in the guideline development methods and processes.

The importance of training Chairs in involving lay members

At NICE, the Chair's role in supporting lay members of the GC is part of the overall induction programme, and discussion of this is woven into all the sessions. Evaluations from the People and Communities Team at NICE revealed that lay members felt that the Chairs could either be 'weak' or 'skilled'. This perception depended on how well they managed their guideline group and how well they offered appropriate support to the lay members of the group.

As found in studies of other kinds of small group work (such as in Elwyn et al. 2001), the PaCT's evaluations found a relationship between the skills of the Chair and the success of the group. The Chair is clearly a key element determining how well a GC functions.

Success, or otherwise, of a group, rests on the skills of the chair. Additionally, pre- and post-meeting feedback for lay members, especially from the Chair, is

instrumental in optimising patient and public members' participation, confidence and sense of parity.

This emphasises that lay member involvement is an integral part of the guideline development process and of the work of the GC. If there were a separate section of the induction programme, specifically focusing on patient/public involvement, there is a risk that patient/public involvement might be seen an 'added extra' in the work of the GC and not an integral and essential part of the process.

An overview of the Chairs' induction programme

The day-long face to face programme previously comprised a mix of presentations, discussions and interactive sessions, intended to introduce Chairs to the NICE guideline development methods (NICE 2014). During the COVID-19 pandemic this was reduced to a half-day videoconference session with some of the training material sent out in advance. The virtual session continues to cover practical issues related to running GCs, such as declaring and managing interests (NICE 2021), good facilitation skills, the importance of NICE's duties under equalities legislation (see the NICE equality scheme), and the NICE policy on participation of lay members of GCs.

Presentation slides from the PaCT team are now sent in advance of the online training with a request for new Chairs to review them and bring questions or points for discussion to the half day training. The session has taken on a more flexible structure with more time spent on discussions with at least one experienced, non-specialist Chair- who discusses their experience and offers tips and strategies for effectively chairing a GC in the NICE context. It also includes input from lay members as well as the NICE staff member who leads on the organisation of this training. Lay members are briefed beforehand; they're asked to bring insights and examples reinforcing the importance of an inclusive approach to guideline development and the crucial role of the Chair.

NICE's key staff member who leads on the co-ordination of this induction said, "Our new Chairs' induction sessions are a great opportunity to engage with and support our guideline committee leaders. Having contributions from the PaCT team and a lay member from a past guideline involved in this training enables the Chairs to understand, in a practical sense, the value of this voice in augmenting the published research evidence on a topic. The input from the team and the individuals they identify to attend these sessions is hugely important in providing a depth to our discussions."

Because chairing a NICE guideline requires specific knowledge and skills and may be a new experience even to those used to chairing other work-related committees, all new Chairs are encouraged to attend before they take up the role. Overall objectives of the session – whether face to face or virtual- are to:

- provide a specific opportunity for GC Chairs and NICE staff to meet, share experiences and discuss the work of NICE in context
- provide an overview of key NICE processes and methods
- identify key resources and support.

The format is flexible and interactive, with structured presentations designed both to inform and to act as the basis for discussion. The session gives Chairs the opportunity to work collaboratively with their peers, as well as with the guideline development professionals from NICE.

Feedback about the induction programme

We sought feedback from lay members who participated in this new model of training. One said, "The open conversation with a new Chair, with the opportunity to influence their perspective of lay members, and how to reap the enormous benefit of lived experience, felt constructive, well received, and was an enjoyable task."

However, more than one lay member mentioned that the interaction would have felt richer had it been in-person; while recognising the ways in which

being online is more accessible, especially for those with complex health conditions or mobility issues.

Chairs' Training provided by other guideline developer centres

The Centre in Ireland for Clinical guideline support and Evidence Reviews (CICER) produce evidence reviews and provide methodological support for the development of National Clinical Guidelines in Ireland. They shared the ways in which they especially support lay members through training for staff including Chairs of committees. As part of methodological support, they provide formal training to guideline development groups, as well as informal support to the guideline chair and the guideline project manager.

CICER stated: *"Some of the key PPI related advice we offer to the guideline Chair and project manager at the start of the process includes recruiting two PPI members, as having more than one person responsible for the PPI contribution helps balance the discussion and avoids one individual being solely responsible for this input. We also advise that PPI members are given the opportunity to meet the chair or project manager at the beginning of the process before any initial meetings, to discuss any issues or additional requirements they may have. For example, we have worked with patient representatives in the past that suffered from 'brain fog' where they found it at times difficult to process discussions during the meeting; to facilitate them, the group introduced opportunities to provide feedback after meetings instead."*

SIGN (The Scottish Intercollegiate Guidelines Network) told us they also provide their Chairs with comprehensive guides including practical tips to ensure effective involvement of people with lived experience. This covers every stage of guideline development and pays special attention to group dynamics, clear communication and support mechanisms. All of this ensures decision making that is inclusive and transparent, while being especially mindful of participants who may need additional rest or support. Their post-meeting feedback especially includes positive feedback for valuable contributions; something that lay members at NICE also tell us is vital to their sense of impact and purpose.

Advantages of virtual/online training for Chairs

Since the COVID-19 pandemic, many organisations have incorporated virtual or hybrid meetings into the guideline development process. One universal advantage of moving meetings online has been increased accessibility, especially for those living with health conditions, caring responsibilities or other factors that make physical travel a barrier.

In the context of our Chairs training, it has meant that the additional and invaluable input from lay members has been possible including from those living with debilitating conditions like ME/CFS(Myalgic Encephalomyelitis/Chronic Fatigue Syndrome). It has allowed greater flexibility as all participants are able to fit the training into other commitments by eliminating the need for travel time. However, more than one lay member at Chairs training commented that it would have been a richer experience for all, had the training been in-person, even in its condensed, 2-hour format.

Conclusion

Chairs play an important role in facilitating and involving lay member input during guideline development. However, recruiting and training Chairs in the importance and methods of involving patients and the public is important to ensure impactful involvement. Providing training adds value to committee working and to the experience of the lay member, which undeniably has a positive effect on the final guideline.

Additional resources

General information about the role of Chairs in running groups on which patient/public members sit can be found in 2 key additional resources:

- Patient and Public Involvement Toolkit, Chapter 4 Building relationships (Cartwright and Crowe 2011)
- Patient and public involvement in research groups – Guidance for chairs (TwoCan Associates for the UKCRC and NCRI 2010).

Other useful information to support the chair's role on guideline development groups:

- Supporting effective participation in health guideline development groups: The Guideline Participation Tool (Piggott et al. 2020)
- Checklist for Guideline Panel Chairs (Department of Health Research Methods, Evidence and Impact, McMaster University 2017)
- Groups. A guide to small group work in healthcare, management, education and research (Elwyn et al. 2001).

Resource and planning requirements

Inducting and supporting GC Chairs needs to be planned and sufficient resources allocated. Some of these are financial, but the most significant is the staff time to deliver the induction and provide ongoing support.

Organisation of induction

Given the large number of guidelines that NICE develops at any one time, it can be difficult to identify suitable times and dates for induction sessions. NICE has therefore appointed a dedicated person within the Centre for Guidelines to lead and coordinate the chairs' induction.

Financial commitment

At NICE, either the Chair's employing organisation is re-imbursed or payment is made directly to the Chair for each GC meeting. In addition, travel and subsistence expenses are covered, according to NICE's non-staff reimbursement policy. It is a requirement for all GC Chairs to attend the induction session (see section 3.7 of NICE's guidelines manual 2014). NICE does not provide remuneration for attending the induction, but other agencies might consider it worth doing to encourage attendance.

3. Barriers and strategies to address them

This section outlines some of the key barriers to appropriately supporting and inducting GC chairs, and some proposed solutions, based on the NICE model. The section is presented as a series of questions and answers.

What is the relationship between a GC chair's facilitation skills and their topic expertise? Is there a potential for tension between these 2 functions?

Although there are clear advantages to recruiting GC chairs with highly developed facilitation skills, NICE recognises that these can sometimes go hand in hand with expertise in a particular topic area. However NICE's policy on declaring and managing interests does not generally support the recruitment of topic expert chairs. NICE's current position is that its chairs are recruited for their facilitation skills, and that a 'topic adviser' with expertise in the topic under discussion should be recruited to work alongside the chair. This ensures the chair is more likely to be objective about the evidence the committee considers.

To facilitate inclusive group dynamics and support lay members, there are distinct advantages in having a well-informed chair with highly developed facilitation skills, but one who is not an expert in the guideline topic. These advantages include:

- Being able to ask naive questions of the topic experts and technical staff in order to clarify things for everybody, especially the patient/public members. A topic expert chair will either not realise that there might be a problem understanding something or not be prepared to lose face by asking. These may be genuine questions because the non-expert chair does not understand or might be deliberately asked to help the patient/public members and other committee members.
- Non-expert chairs are less likely to engage in esoteric arguments with specialists about details of the condition or intervention, or the

evidence, and forget their chairing responsibility of engaging everyone in the discussion.

- They are more likely to be seen as impartial and someone to whom the patient/public members can turn for support, advice and comment, either in the meeting or in breaks or other informal settings.

We recognise that other guideline development organisations may wish to recruit chairs with expertise in the topic under discussion. The key to identifying an appropriate approach is to be clear about the role of the chair in running the GC. There will need to be measures in place for managing any conflicts of interest that arise for a 'topic expert' chair, because the goals for facilitating discussion and debate on the evidence within the group may not always coincide with the desire for a particular approach to the guideline topic.

Should induction for GC chairs be compulsory?

Chairs should be encouraged to take advantage of any induction or training on offer. NICE's experience is that GC chairs who have been through the induction are more likely to run functional and successful groups.

The NICE guidelines manual states 'Anyone appointed as a committee chair is required to attend the chairs 'induction session' (NICE 2014, section 3.7). But a strong recommendation from a senior member of the guideline organisation's staff about the value of induction will encourage newly recruited chairs to attend them. It is also important to encourage chairs to attend refresher sessions if they have worked with the guideline agency for many years. This will ensure they are up to date with organisational processes, the policy context, and other relevant changes.

Is there a 'one-size-fits-all' approach to developing and delivering an induction programme for GC chairs from different guidance-producing organisations?

Induction programmes for chairs need to be tailored to the specific context, methods and processes of the guidance-producing organisation. Induction programmes also need to be constantly refined and modified in light of external changes (for example, political priorities and legislation), organisational changes, developments in guideline methods, and in response to feedback from participants. However, there are likely to be common themes that apply across differing processes for guideline development. See, for instance, the generic guidance listed in the Resources section.

How do those offering the induction for GC chairs take account of the differences between guideline topics, between chairs, and between guideline groups?

There are inevitable differences between the topics, chairs and groups, and this variation is entirely appropriate.

The induction sessions include a lot of time for open discussion. This is an opportunity for participants to think about NICE's guideline development methodology, and their particular topic. For instance, in the presentation about NICE guideline methodology, the first section on scoping ends with time for participants to reflect on and discuss themes relevant for their particular guideline topic, using prompts such as those in Box 1:

BOX 1 Chairs' induction – discussion prompts

Each topic has unique characteristics Will there be problems in managing the expectations of GC members about the limitations of s resources? Taking into account patient and public perspectives: • are there some topics specific to this guideline? (information, psychosocial issues, support, a

complementary treatments)
• are there any population sub-groups of patients who might need specific consideration?

In the induction sessions, it is crucial to have input from someone with previous experience as a GC chair for the same guideline development organisation. Their experience of having been through the process enables them to provide practical tips for the newly recruited chairs on how to be an effective chair in this very specific environment. Feedback from GC chairs who have attended the NICE induction session consistently rate the session with an experienced GC chair as the most valuable aspect of the induction session.

Will someone who is a good committee chair automatically be a good GC chair?

Not necessarily – the skills needed to chair a formal committee may not meet the requirements for chairing and facilitating a dynamic, reactive, and discursive GC. A skilled GC chair will be expected to run the practical aspects of the group (for example, keeping to time and process) and also to foster debate and discussion among group members. They will also need to be able to draw together discussions about research evidence into practical recommendations for practice, taking into account all group members' input.

What is the role of the chair in relation to GC processes and methodologies?

The GC chair needs to be familiar with the 'rules' (of methods and process). Induction sessions are an ideal opportunity for these rules and expectations to be clearly outlined. The GC chair needs to fully understand the methodology and the rules, and both champion and follow them during GC meetings. The induction session should be a chance not only to explain them but also to discuss them with methodologists and support staff.

Might the new chairs find the idea of an induction patronising?

This is quite possible and needs to be recognised. But it is very important that a new chair is able to successfully work with a small group that includes patient/public members, while following a specific methodology.

How do you address the fact that the GC chairs may or may not be used to working with patient/public members?

As part of the induction, there needs to be an exploration of the chairs' experience in working with groups, including patient/public members. Their questions and concerns about this can be addressed and shared in a safe environment. At NICE, experience of working with groups, including patient/public members, is now an expectation of a chair's experience and is explored as part of their recruitment.

Providing the chairs with good practice examples (such as those cited in Cartwright and Crowe [2011] and TwoCan Associates [2010]) can give them practical tips to help them support the patient/public members of the GC. It is important for them to understand and recognise that the individual patient/public members of the GC may have quite different knowledge, experience and self-confidence. Some may be very experienced professionals with specialist knowledge of a small topic area, but others may be working on a committee at a national level for the first time.

How do you ensure that the GC chairs get the best possible experience from the induction?

One of the key things that NICE has identified as enriching the induction experience for GC chairs, is to ensure the participation of more than one new chair at the induction session. This allows them to share their concerns and issues, and provides them with a small peer group with whom they can share experiences and discuss problems.

It should be possible for several guideline development organisations to pool resources for chairs' induction sessions, especially with the use of video-

conferencing. But care would be needed to take account of different methodologies if these sessions involved the discussion of anything more than the involvement of patient/public members.

How do you address the issue of scheduling of inductions and the chairs' availability to attend?

The stage of the guideline development process at which the chairs have their induction is crucial. Ideally there needs to be enough time and resources available for chairs to have access to induction before their first GC meeting. But it may be difficult to arrange induction sessions with enough notice for chairs to attend, and also to convince some of the value of attending an additional meeting. Induction should be arranged at regular intervals to enable groups of newly appointed chairs access as early as possible. Details of these scheduled sessions should be included in recruitment materials in order to give a clear message that they are expected to attend and to allow them to plan. Other options are online training resources and induction sessions via videoconference.

Although chairs should ideally attend an induction session before their first GC meeting, it can be helpful to have people at different stages of the development process coming at the same time so that they can describe their different issues and experiences. A newly appointed chair might have chaired a previous GC and feel that an induction session would be a waste of time for them. However, because guidelines methodology and political circumstances are constantly changing, they should still be encouraged to attend.

How do you address the need to provide the chairs with ongoing and additional training opportunities throughout the guideline development process?

NICE offers its GC chairs the opportunity to attend a workshop specifically on the health economics aspects of guideline development. Staff supporting each committee also provide training to GC chairs and other GC members on specific methodological issues (for example, systematic reviewing, meta-analyses) as and when required. GC chairs are also offered the opportunity to

contact NICE's methodological and patient and public involvement specialists, or members of the technical team, if they have specific questions.

4. Appendix 1

Slide 1

Different expertise - equal status

The role of chairs in supporting effective committees

Public Involvement Programme

NICE National Institute for Health and Care Excellence

Slide 2

Aims of this presentation

To introduce the Public Involvement Programme and:

- what we do and why it matters

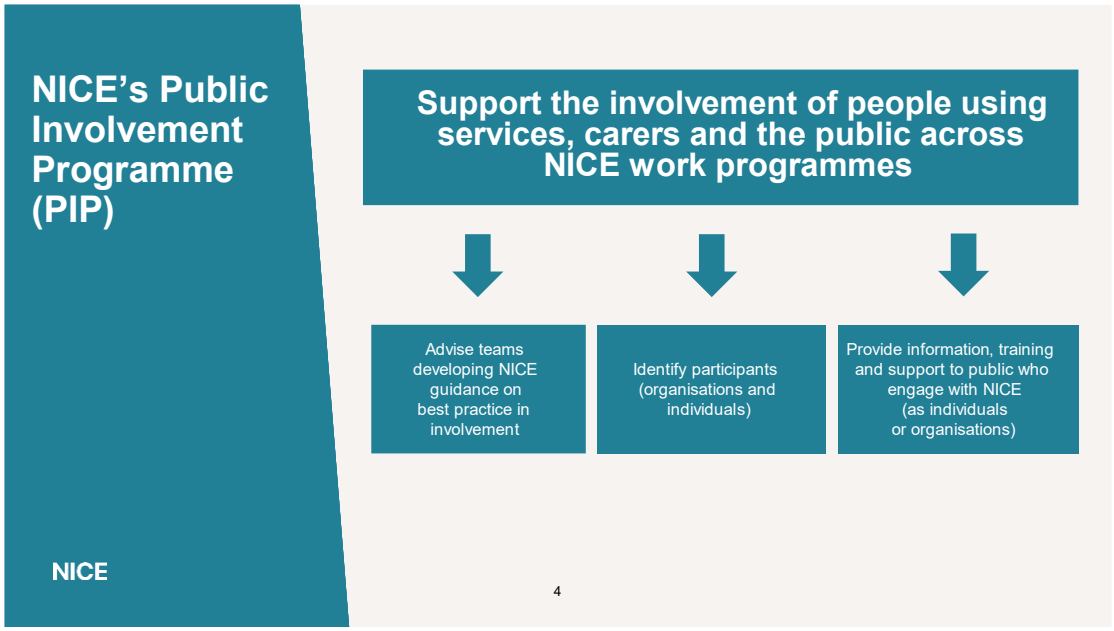
- the role of lay members on our committees
- how we work with Equalities and Health Inequalities
- your crucial role in all of the above

Slide 3

Desired outcomes

- ✓ **Good guideline recommendations**
- produced to time and useful to practitioners and people using services
- ✓ **Effective, amicable group working**
- ‘different expertise – equal status’
- inclusive – avoiding jargon, explaining necessary terms
- responds to evidence, uses collective experience where appropriate and uses consensus
- ✓ **Needs or problems recognised, tackled early, and resolved**
- members feel able to raise issues – inside and/or outside meetings
- known or ‘hidden’ disabilities or desired working arrangements are recognised and catered for

Slide 4



Slide 5

Slide 6

Lay membership of a guideline committee

- Expertise on the lived experience of people affected by the guideline, their families and unpaid carers - different expertise, equal status
- Bring a range of different perspectives to inform committee's work
- Raise issues of importance to people affected by the guideline such as:
  - views on goals and outcomes that matter to people
  - insights on information and support needs
  - highlighting where people's preferences and choices need to be addressed
  - needs of specific groups in line with NICE equality objectives
- Contribute ideas on the guideline's key messages for the public
- Contribute to Patient Decision Aids where relevant

NICE

6

Slide 7

Equality and Equity

NICE

7

This is something to bear in mind both for the guideline as well as the process of developing it. The picture on this slide also demonstrates the difference between Equality and Equity. In the picture on the left, we see three people

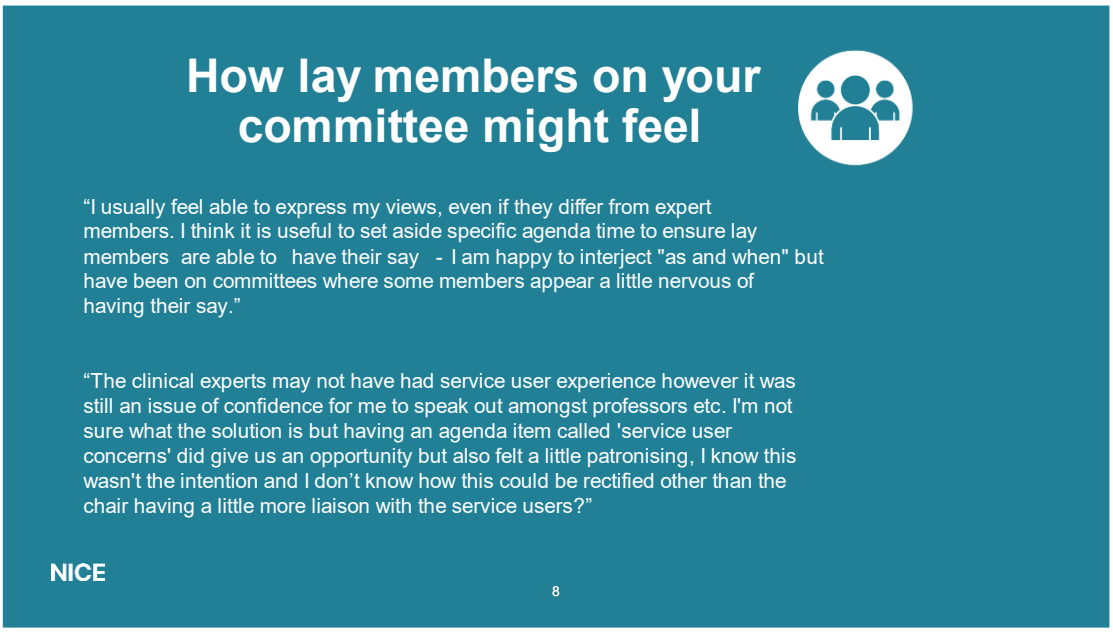
trying to watch a match even though there is a high wall in front of them. Each of them is given a stool that is exactly the same height. The tallest person manages to get a good view; the middle one can barely see what's going on and the stool is absolutely useless to the person in the wheelchair. This is the principle of Equality, where we treat everyone exactly the same. But as is evident, that isn't always effective- or even fair.

In the picture on the right, each person has been given a stool that allows *them* to see comfortably over the wall and enjoy the match. This is Equity and these are useful ways in which to start understanding the principles of Equality.

Therefore promoting Equality effectively, doesn't mean treating everyone exactly the same- we need to take into account individual needs, in order to address indirect discrimination and achieve Equity, as seen in this example.

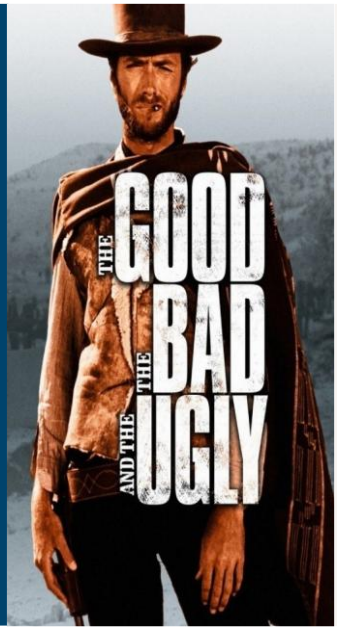
It's important to keep this difference in mind not only from a guideline point of view but also for meetings and every aspect of LM involvement.

Slide 8



Slide 9

Lay members' feedback



How easy did you find it to contribute to the work of your committee?

"The Chair always made me feel my contribution was important."

"I was treated with respect and as an equal member of the group. My views were given equal consideration to others."

"A lot of medical terminology for a lay person to get used to."

"I sometimes felt like the views of the lay members weren't taken seriously or given the same 'weight' as the academic or clinical members. This meant that after a while I was reluctant to contribute unless it was something I felt very strongly about."

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How lay members on your committee might feel

"The guideline I was involved with covered a lot of very technical discussions about drugs, of which I had limited knowledge. I found it difficult to contribute to these discussions. On other points it was easier to contribute."

"As I was just a lay member, I felt very positive about each meeting and made to feel I was valued."

"As a lay member you feel (or at least I do) that you need to have a pretty clear and marshalled argument before you open your mouth. Everyone else in the room has a very clear, gut understanding of diseases and/or how the NHS works - the lay member has neither of these. Consequently, being a lay member requires you to accept that from time to time you may look a fool but that if your point needs to be made that is the risk that you take."

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Working with lay members

- Responding to lay member needs potentially benefits all members
- Being inclusive but not patronising, avoiding tokenism
- Recognising and responding to fears and concerns
  - working around perceived feelings of inadequacy
  - handling lay member input sensitively
  - using NICE public involvement staff as a resource when needed
- Ensuring timely access to papers and admin support
- Ensuring members have adequate technology and know how to participate in virtual meetings
- Maintaining regular breaks in meetings

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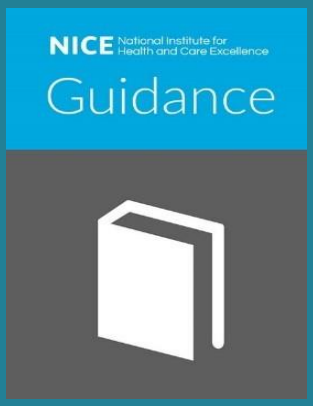

Equalities and NICE guidance

- Our Equality Programme sets out how NICE will meet these duties across our areas of activity.

- Most attention is given to how we ensure rigorous equality analysis when developing the product central to NICE's role – NICE guidance.

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Equalities and Health Inequalities Assessments

- EIAs- as they were in their previous form - were conducted as early as possible, and at significant points throughout the process. Crucially, these have now changed to take account of Health Inequalities and will be Equalities and Health Inequalities Assessments.

- The committee Chair highlights the need to consider equalities at appropriate points in committee meetings.

- Equality analysis happens for every piece of guidance that NICE develops.

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Health Inequalities and why they matter

Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society.

They arise because of the conditions in which we are born, grow, live, work and age.

These conditions influence our opportunities for good health and how we think, feel and act, and this shapes our mental health, physical health and wellbeing.

More information on NHS England's health inequalities definition

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How can NICE reduce health inequalities?

Health inequalities are often caused by the social, economic and environmental conditions in which people are born, grow, live, work and age. It is widely recognised that these “wider determinants” (and subsequent social inequalities) have a greater impact on health than healthcare services

Although the fundamental causes of health inequalities lie beyond healthcare, healthcare organisations such as NICE have a vital role to play in preventing or mitigating the impact of these wider determinants and social inequalities on health.

Preventing Recommendations in social, emotional and mental wellbeing in primary and secondary education (NG223); pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110); and crizanlizumab for preventing sickle cell crises in sickle cell disease (TA743) , and crizanlizumab for preventing sickle cell crises in sickle cell disease (TA743) are examples of how enabling ‘upstream’ structures and services can **prevent** impacts negative health impacts downstream.

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How can NICE reduce health inequalities? (contd.)

Mitigating **Mitigating** is where action is taken to reduce the impact of social inequalities on health outcomes, recognising the barriers to health that may be related to social circumstances. Action can be at the individual, community or system levels. For example, annual health checks in care and support of people growing older with learning disabilities (NH96); shared decision making (NG197) to mitigate the impact of poor health literacy; and promoting health and preventing premature mortality in black, Asian and other minority ethnic groups (QS167)

Undoing requires a reversal in policies, social processes and the wider determinants that result in social inequalities and consequently, health inequalities. NICE’s remit for action here may be limited, however guidance such as workplace health: management practice (NG13) has shown that it is possible to act on wider determinants directly

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How to consider health inequalities

Inequalities between who?

Inequalities of what?

- Health status
- Behavioural risks to health
- Wider determinants of health
- Access to care
- Quality and experience of care

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What is the EHIA?

- The systematic identification, assessment and consideration of equality and health inequalities issues across the guidance development process and identifying areas for action to promote equality and reduce health inequalities

- It is likely that the EHIA will be iterative and continue to evolve to take account of future ways of working, for example Digital Living Guidelines

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Principles of completing the EHIA

- EHIA is used to guide the **identification, recording and communication** of equality and health inequalities issues at any stage of the guidance development process
- Demonstrates that these issues have been given **due consideration** – how they have been explored, what evidence has been reviewed in relation to them, what impact they have had on the guideline recommendations
- Assessment of equality and health inequalities issues should happen at the **earliest opportunity** possible to inform prioritisation and topic selection, and should continue throughout guideline development in an iterative manner

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Resources

- Good practice in chairing guide' – NICE
- 'A guide to maximising lay input on a committee' – NICE
- 'Making an impact at virtual meetings' – NICE lay member guide
- 'Groups: A guide to small group work in healthcare, management, education, and research' – Elwyn, Greenhalgh & Macfarlane, Radcliffe Publishing, 2001
- Approaches to addressing health inequalities
- Mapping NICE guidance to Core20PLUS5

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5. Acknowledgements

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