



G-I-N Public Toolkit

Chapter 2

Recruitment and support of patients and the public in guideline development

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Purpose of chapter

- Advice on identifying and recruiting patient and public members and ensuring they have the status and support to be effective
- Largely based on experience of NICE in UK
- Covers:
 - role of patient and public members of guideline development groups
 - recruitment strategies and methods
 - support and training

Role of patient and public members

- Need for clarity on role and expectations
- Full members of the group or brought in for specific tasks?
- Our chapter focuses on full membership
- Patient and public members involved in same work as other group members
- Equal status for all members of a guideline group
- Representing a patient perspective, not being a representative

What experience, knowledge and skills are needed?

- What are necessary requirements and what can be learned on the job?
- Necessary requirements for NICE include:
 - relevant experience of the condition and issues that matter to people with the condition – as a patient, carer, or employee of a patient organisation
 - ability to provide a balanced view on patient issues
 - good communication and team working skills
 - time and commitment to attend meetings, do background reading and comment on draft documents





Nomination or open recruitment?

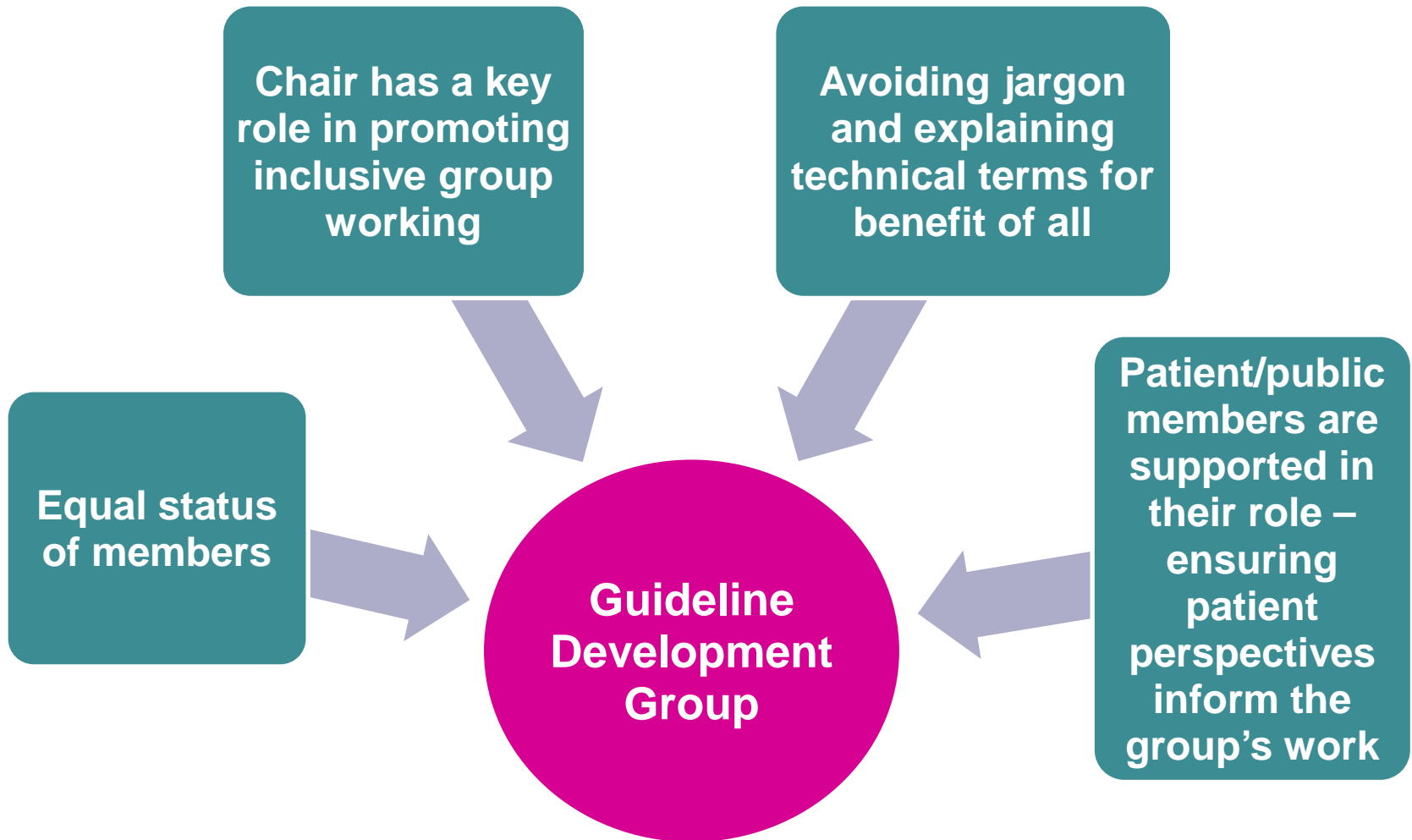
- Advantages and disadvantages of both methods – lack of research on which produces the best result
- Method of selection should be clear and accepted as legitimate
- NICE uses open recruitment and formal application process:
 - advert on NICE website, patient group websites and newsletters, clinical networks, Twitter etc
 - role description and person specification
 - applications assessed against these criteria
 - telephone interviews with shortlisted people



Support and training for patient and public members

- Practical support and physical adjustments for people with specific requirements due to a disability or illness
- Financial compensation
- Informal support tailored to individual needs
- Training
 - tailored in-house programme
 - external training course
 - online learning e.g. Cochrane Collaboration's consumer learning on evidence-based healthcare
 - <http://training.cochrane.org/consumers>

Inclusive group working



Keys to success

- clarity on what is expected of patient and public members
- effective recruitment processes
- equality of status on guideline groups and good chairing
- induction, training, support and financial compensation
- evaluation and refinement of processes

Final thoughts

- *“Those of us with the condition are the REAL experts on how it feels. Others, no matter how brilliant, cannot have that insight”* **(Patient member, guideline group)**
- *“I am even more convinced that development of guidelines must involve the people that the care, treatment or system is for”* **(Chair, guideline group)**

