



If you become involved in a guideline development group, it is essential that you make sure patients' views and experiences influence the guideline development group's work. Each stage of the process is shown below to help you to understand what this may include.

At the start of the process

- Making sure that the main questions guiding how evidence is collected are informed by issues that are important to patients and carers, such as considering quality of life factors.
- Helping to identify issues that are relevant to patients and carers (for example, by helping to prepare discussion points for focus groups to use with other patients or support groups).
- Helping to get other voluntary organisations involved.
- Helping to arrange meetings to consult patients, carers and members of the public (for example, through support groups).

When developing recommendations

- Considering how the recommendations reflect patients' and carers' concerns and feeding this back to the group.
- Reading research papers from a patient's or carer's perspective. For example, do the papers consider the issues that patients and carers think are important? Did the researchers consider patients' and carers' views when drawing their conclusions?
- Making sure that the guideline development group considers patients and carers when drafting their recommendations.
- Making sure that the guideline is sensitively worded (for example, treating patients as people and not as objects of tests or treatments).

At the end of the process

- Raising awareness of the guideline (for example, support groups and voluntary organisations, social media networks).
- Taking part in the launch of the guideline.
- Helping produce versions of the guidelines for patients.

Further training is often available from the organisations producing the guideline to help patient representatives get involved more deeply in the process.