

About the Patient and Public Involvement Programme (PPIP)

What does the PPIP do?

The Patient and Public Involvement Programme (PPIP) provides NICE with advice on involving patients, carers and members of the public. It also identifies patient, carer, community and other lay organisations interested in contributing to its work programmes. The PPIP promotes effective patient, carer and public input to NICE's work by providing training and support to these organisations, and to those individual patients, carers and lay people who contribute to NICE's work programmes. NICE is committed to promoting equality and eliminating unlawful discrimination (for further information, please see our [Equality Scheme and Action Plan](#)).

NICE produces guidance in three key areas:

- **Clinical guidelines** – recommendations for the NHS on the care of patients with a particular condition or disorder. They are based on the best available evidence on how well treatments work (clinical effectiveness) and how much value for money they offer (cost-effectiveness). Guidelines help healthcare professionals in their work, but they do not replace their knowledge and skills
- **Healthcare technologies** – recommendations for the NHS on the use of new and existing individual drugs, healthcare devices (for example, hearing aids or inhalers) and surgical and other procedures
- **Public health guidance** – recommendations on the prevention of ill health and the promotion of good health

NICE also supports local and national organisations (such as NHS Trusts and local authorities, as well as patient, community and other lay groups) in helping them implement NICE's guidance.

How does the PPIP support the [selection of topics](#) that NICE works on?

The PPIP works with NICE to:

- Identify appropriate patient/carer/voluntary organisations who may wish to provide views on topic selection issues
 - Provide topic selection panels with patient/carer/voluntary organisations' views on prospective topics
 - Provide support for patient/carer/voluntary organisations who may wish to contribute to the topic selection process
 - Provide support and training for lay members of the topic selection panels
- Read more about [how to submit a topic](#) for consideration.

How does the PPIP support the development of **clinical guidelines**?

The PPIP works with NICE to:

- Advise the NICE guidelines team on patient and carer issues.
 - Identify appropriate patient and carer organisations to register, if they wish, as stakeholders for individual guidelines.
 - Seek out applications from patients and carers to join Guideline Development Groups (the groups that produce clinical guidelines on behalf of NICE).
 - Support the guideline developers, (the **National Collaborating Centres**), and patient and carer members of Guideline Development Groups on involvement issues throughout the development process.
 - Advise on methods for involving patients and carers in the work of the Collaborating Centres and their Guideline Development Groups.
 - Provide formal training and informal support to the Collaborating Centres and to patient and carer members.
 - Comment, from a patient and carer perspective, on all draft documents.
 - Review, from a patient and carer perspective, the NICE guideline process.
 - Help produce the patient version of the guideline.
- Read a **guide for patients, carers and the organisations** that represent their interests, on how they can participate in NICE's clinical guidelines work.

How does the PPIP support the development of **guidance on healthcare technologies**?

NICE's work on healthcare technologies is divided into two:

- **Technology appraisals guidance** – recommendations on the clinical and cost-effectiveness of new and existing drugs and devices
- **Interventional procedures guidance** – recommendations on how well new surgical procedures work, and how safe they are.

The PPIP works with NICE to:

- Advise the NICE technology appraisals and interventional procedures teams on patient and carer issues.
- Identify appropriate patient and carer organisations for consideration as consultees and stakeholders for technology appraisals and interventional procedures topics.
- Develop and support effective patient and carer input to its technology appraisals and interventional procedures work.
- Promote the effectiveness of patient and carer input by providing information, training and support to individual patients and carers and patient and carer organisations.
- Support patient and carer organisations who wish to make written submissions of evidence to individual NICE technology appraisals.
- Support individual lay people who make verbal submissions to the Technology Appraisal Committees.
- Support individual patients who wish to contribute their experiences of individual new surgical procedures to the Interventional Procedures Advisory Committee.

- Read [a guide for patient and carer organisations](#) on how they can participate in NICE's technology appraisals work.

- Read [a guide for patient and carer organisations](#) on how they can participate in NICE's interventional procedures work.

How does the PPIP support the Institute's [public health guidance](#)?

NICE's public health guidance is divided into two:

- [Interventions guidance](#) - recommendations on types of activity (interventions) that helps to reduce people's risk of developing a disease or condition or helps to promote or maintain a healthy lifestyle.
- [Programme guidance](#) - dealing with broader action for the promotion of good health and the prevention of ill-health. This guidance may focus on a topic, such as smoking, or on a particular population, such as young people, or on a particular setting, for example, the workplace.

The PPIP works with NICE to:

- Develop and support effective lay and community input to its public health work
- Advise the public health team on lay and community issues
- Identify appropriate voluntary and community organisations to register, if they wish, as stakeholders for individual pieces of guidance.
- Seek out applications from lay people (including those involved in community groups or voluntary organisations) to join Programme Development Groups (the groups that produce public health programme guidance on behalf of NICE).
- Provide formal training and informal support to the lay people (called "community members") on Programme Development Groups
- Support the lay members of the Public Health Interventions Advisory Committee and other organisations and individuals who share their experience and expertise with this Committee as co-opted lay or community experts.
- Advise on methods for involving lay people in the work of the Centre for Public Health Excellence and their guidance development groups (the Programme Development Groups and the Public Health Interventions Advisory Committee).
- Comment, from a lay perspective, on draft documents produced for public consultation.
- Review, from a lay perspective, the processes that NICE uses to develop its public health guidance.

- Read more about NICE's [Public Health guidance](#) work

How does the PPIP support NICE's independent advisory committees?

The Institute's independent advisory committees include healthcare professionals working in the NHS (and professionals from other sectors as appropriate) and people who are familiar with the issues affecting patients, carers, members of the public or specific population groups. Although these committees seek the views of organisations representing healthcare professionals, patients, carers and communities, and manufacturers and government when developing guidance, their advice is independent of any vested interests.

The PPIP works with NICE to:

- Identify and recruit lay people onto its advisory committees.
- Support lay input by providing information, training and support to lay people on the committees.

How does the PPIP support NICE's guidance implementation work?

The implementation team at NICE provides advice and support to organisations responsible for implementing the guidance. This includes producing practical support tools and developing systems to facilitate implementation.

The PPIP works with NICE to:

- Identify key patient, community and other lay organisations to participate in NICE's implementation planning processes
- Liaise with key patient organisations to include their details in the patient versions of NICE clinical guidance, and to work with them to promote NICE guidance with their membership and local branches
- Encourage groups such as Patient Advice and Liaison Services and Patient and Public Involvement Forums to monitor uptake of NICE guidance in their local areas, and work with local communities to promote NICE's recommendations. From April 2008 the PPIP will also be exploring ways of working with the new Local Involvement Networks (LINKs) in helping support the implementation of our guidance.
- Provide information for patients and the public who feel they should receive a service or treatment recommended by NICE, but are unable to access it.

- Read more about how to [involve patients and the public in NICE's implementation activities](#).

- Read more about what patients and the public have done to [help implement NICE guidance](#).

- Read more about what patients can do if they are not able to [access treatment recommended by NICE](#).

What training and support does the PPIP offer?

All of the lay people who work with us are offered induction training together with specialist training and support while they are on our committees or working groups. The training we offer includes:

- Information about NICE and the different types of guidance it produces
- Introduction to health economics and key statistical terms
- How to appraise a piece of research critically, identifying its strengths and weaknesses
- How to develop recommendations from research evidence
- Peer support from former group members
- Ongoing support from PPIP team members.

- Read more about our [training and support resources – page to be developed](#)

How is the PPIP evaluating patient and carer involvement in guidance development?

The PPIP is evaluating what works well, for NICE, its Collaborating Centres, and for the lay people involved in the work programme. The PPIP's first project to evaluate the experiences of patient and carer members involved in Guideline Development Groups was completed in 2004. Read the [evaluation report](#). The evaluation project will be repeated during 2008 and an updated report should be available towards the end of the year.