

THE NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

PATIENT AND PUBLIC INVOLVEMENT POLICY

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Key Principles

1. NICE's approach to patient and public involvement is based on two key principles:
 - that lay people, and organisations representing their interests, have opportunities to contribute to developing NICE guidance, advice and quality standards, and support their implementation, and
 - that, because of this contribution, our guidance and other products have a greater focus and relevance for the people most directly affected by our recommendations.

Introduction

2. Since 1999 NICE has involved patients, service users, carers and the public, including voluntary, charitable and community organisations in its work. In April 2013 NICE's remit expanded to include producing guidance and quality standards on social care topics. To support this work we are building on existing relationships with organisations who work in social care and fostering new relationships with organisations with whom we have not worked previously.
3. Our guidance aims to address issues relevant to patients, service users, carers and the public, reflect their views, and meet their health and social care needs. Involving patients, service users, carers and the public adds value to the discussions of the independent committees and working groups that develop NICE guidance. Members of these groups have commented on the importance of this involvement:

'Involvement of patients focused on the humanity of the topic and an orientation to patient experiences', *Chair of NICE guideline development group*

*'We were the group's conscience', Lay Guideline Development
Group member, 2008*

4. The value of this patient, service user, carer and public involvement has been shown many times in the guidance NICE has produced. NICE is committed to continuing and developing its patient and public involvement work, a commitment underpinned by this policy.
5. This policy:
 - sets out NICE's commitment and approaches to patient and public involvement
 - outlines the underlying principles of NICE's approach to involving lay people
 - explains the support available to lay people and organisations involved with NICE's work.

Background

6. NICE develops national guidance, advice and standards on promoting good health, preventing and treating ill health and on the care people should receive from social care. NICE guidance covers a range of areas including health technologies, clinical practice, public health and social care. NICE guidance aims to improve quality by providing health and social care professionals, and patients and the public, with the information they need to make decisions about treatment and care.
7. All NICE recommendations are based on the best available evidence. We develop all our guidance by considering the research on different types of treatment, interventions and care and how well they work, and in many cases, how much value they provide compared to their cost.
8. NICE Evidence Services is a service provided by NICE which enables people across the NHS and the wider public health and social care

sectors to access clinical and non-clinical evidence and information of the highest quality. NICE has a formal accreditation programme to recognise guidance producers that reach the highest standards – successful organisations are awarded an accreditation mark. This ensures that people can readily identify the most trusted sources of evidence, and promotes the quality of guidance production.

9. Patients, service users, carers and the public can be involved directly in producing or promoting our guidance, quality standards¹ and other products as formal members of our committees and working groups. They can also be involved in the NICE's work by commenting, through their organisations, on draft versions of our guidance scopes and draft recommendations, and by submitting evidence.

NICE commitment to patient, service user, carer and public involvement

10. NICE will:
 - produce clinical guidance for the NHS that focuses on the patient, service user and carer
 - produce public health guidance that focuses on the public's needs or the needs of specific groups or communities
 - produce social care guidance and quality standards which focus on the needs of service users, their carers and families
 - ensure other activities, such as quality standards and the Quality and Outcomes Framework, involve and focus on patients, service users, carers and the public
 - ensure that all NICE advisory committees and working groups have at least **two lay members** (patients, service users, carers or members of the public)

¹ NICE quality standards are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions

- provide opportunities for patients, service users, carers and the public to give evidence and testimony that can inform the development of our guidance and quality standards
- involve lay people in its corporate decisions
- offer support and training to lay people who contribute to NICE's work
- [offer payment](#) to lay members of NICE advisory committees and working groups in recognition of their contribution
- make its guidance available in language and formats suitable for patients, service users, carers and the public
- work with patients, service users, carers, communities, voluntary and charitable organisations to promote our guidance and to help people access the services, care and treatment NICE has recommended
- engage with groups protected by equality legislation to ensure their views are heard, and that issues of equality are considered in developing its guidance
- review the processes and methods used to involve lay people in its work.

Principles of patient, service user, carer and public involvement

11. NICE's approach to patient and public involvement is based on two key principles:
 - that lay people, and organisations representing their interests, have opportunities to contribute to developing NICE guidance, advice and quality standards, and support their implementation, and
 - that, because of this contribution, our guidance and other products have a greater focus and relevance for the people most directly affected by our recommendations.

12. Involving lay people is integral to NICE's approach to developing guidance, quality standards and other products. Our methods and processes for involving lay people are based on the best available evidence, and on extensive practical experience. We have adopted a flexible model of involvement that allows us to develop different approaches for new areas of NICE work. This flexibility allows for the most effective patient and public input.
13. Our approach reflects policy initiatives to involve patients, service users, carers and the public across the NHS and social care. These initiatives include:
 - [Health and Social Care Act](#) (Department of Health, 2012)
 - [NHS Constitution](#) (Department of Health, 2012)
 - ['Putting people at the heart of care'](#) (Department of Health, 2009)
 - ['Essential Standards of Quality and Safety'](#) (Care Quality Commission, 2010b)

Principles for involving children and young people

14. NICE acknowledges that our mechanisms for involvement do not necessarily allow for all voices to be heard. As a consequence we have developed some principles for working with children and young people.
15. To put the above principles into practice on matters that affect children and young people's health and wellbeing, NICE has adopted the following overarching aim:
 - To involve children and young people, (and the organisations that represent their interests), on matters pertinent to NICE's work and that affect children and young people's health and wellbeing.
16. In pursuit of this aim, NICE is committed to:

- ensuring that the perspectives of children and young people - including those who share the protected characteristics of the Equality Act 2010² or live in disadvantaged circumstances - are taken into account in relevant areas of NICE's work
- producing guidance and standards on topics covering children and young people's health and wellbeing, which have been informed and influenced by their views and experiences
- ensuring that the views and experiences of parents and carers are taken into account in our guidance and standards on children's topics, on the understanding that their views are important but not proxies for children's views
- offering tailored support to young people³ who contribute to our work as members of NICE advisory committees and working groups, or as experts providing testimony
- where appropriate, providing opportunities for children and young people to give evidence and testimony within an age-appropriate and ethical framework
- involving children and young people, and those who speak for them, in NICE's consideration of social values relevant to people younger than 18
- making its guidance and standards on topics covering young people's health and wellbeing, accessible for this audience
- working with children and young people's organisations, and where possible, with young people themselves, to promote our guidance

² The Equality Act 2010 applies to children, except that they are not protected against age discrimination while they are under the age of 18. NICE's equality programme goes beyond legal requirements in covering socio-economic status and vulnerable groups such as looked after children, refugees, asylum seekers and people who are homeless.

³ The minimum age for membership of multidisciplinary NICE advisory bodies is 16; there is no minimum age for young people providing expert testimony

and to help children, young people, parents and carers access the services, care and treatment NICE has recommended.

Further information about safeguarding can be found in Appendix 1.

Opportunities for patient, carer and public involvement

17. There are many opportunities for lay people, and the organisations that represent them, to be involved with NICE's work. There are opportunities across all of NICE's work programmes and associated advisory committees and working groups.

NICE is committed to openness and transparency in its work. To ensure this, each NICE work programme has published process and methods guides that detail how NICE goes about its work. These documents, and more information about each of the programmes, can be found using the links below:

NICE guidance:

- [Clinical guidelines](#)
- [Diagnostics guidance](#)
- [Highly specialised technologies guidance](#)
- [Interventional procedures guidance](#)
- [Medical technologies guidance](#)
- [Medicines practice guidelines](#)
- [Public health guidelines](#)
- [Quality standards](#)
- [Safe staffing guidelines](#)
- [Social care guidelines](#)
- [Technology appraisals guidance](#)

Other activities:

- [Citizens Council](#)

- [Clinical Commissioning Group Outcomes Indicator Set](#)
 - [Putting guidance into practice](#)
 - [NICE Evidence Services](#)
 - [Quality and Outcomes Framework](#)
 - [Research and development](#)
18. To support the involvement of patients, service users, carers and other lay people, NICE has developed a series of guides that explain how individuals and organisations can help us develop guidance. These are available on the website [here](#).
19. When developing guidance, NICE includes national⁴ charitable and not-for-profit (third sector) organisations as stakeholders in its work. As a registered stakeholder, an organisation can:
- comment on draft guidance recommendations and quality standards during development
 - contribute to new and revised methods and process guides across NICE's work programmes, and the accompanying lay factsheets
 - contribute evidence, experience or commentary, from a lay perspective, to inform the scope and development of the guidance
 - help develop and refine NICE's Equality Scheme
 - help identify people who could contribute directly to developing the guidance.
20. We advertise openly for individual lay people to join our independent committees and working groups. Each group is expected to have at least two members who can provide a lay point of view. Some committees and groups also invite individual lay people to attend a meeting as an expert on a particular treatment, intervention, health issue, condition or disability.

⁴ Local and regional organisations can register as stakeholders in the absence of a relevant national organisation

21. The [Citizens Council](#)⁵ has 30 members recruited to reflect the diversity of the adult population in the UK. Members are asked for their views on specific moral or ethical questions important to NICE. These considerations form the 'social values' that underpin NICE's work but do not constitute guidance to the NHS and our other audiences.

Support for patient, service user, carer and public involvement

22. NICE recognises the need to support patient, carer and public involvement. This section describes features of the support infrastructure.

Support for lay people (organisations and individuals)

23. The Public Involvement Programme (PIP) is a team at NICE that develops and supports patient, service user, carer and public involvement. The PIP:
- develops, implements and reviews methodologies to identify opportunities for lay involvement in NICE's work
 - provides guidance and support on approaches to lay involvement for NICE's Board, its internal teams, and the external groups NICE commissions to develop its guidance
 - works with organisations that represent lay people's interests to support their involvement in developing and implementing specific guidance or quality standard topics
 - provides information, training and support to individual lay people who are interested in or contribute directly to NICE's work
 - contributes to the development of the lay versions of NICE guidance

⁵ <http://www.nice.org.uk/Get-Involved/Citizens-Council>

- offers advice to guidance developers on patient, service user, carer and public issues relevant to the scoping and development of NICE guidance
 - evaluates patient, carer and public involvement in NICE activities.
24. Support from the PIP ranges from informal telephone and email advice to training workshops. The PIP supports individual patients, service users, carers and lay members as well as voluntary, charitable and community organisations involved with NICE's work.
25. In addition, an independent group, [Patients Involved in NICE](#) (PIN), exists to provide patient organisations who engage with NICE with a system of mutual support and information sharing, and to act as a 'critical friend' to NICE. PIN also acts to raise the profile of third sector organisations in their interactions with NICE.

Support for the Citizens Council

26. The Citizens Council project is managed by the NICE [Research and Development programme](#). The Citizens Council Committee, on behalf of the NICE Board, sets the question that the Council discusses and decides how the Council's advice should be used.

Payments for lay involvement

27. All lay members of NICE's committees and working groups are offered an attendance payment for each meeting they come to, as well as their travel and subsistence expenses, and a contribution to childcare or other carer costs, where applicable⁶. NICE has produced a set of [policy principles](#) and a '[frequently asked questions](#)' document which explain our approach to attendance payments in more detail.

⁶ Attendance payments and reimbursable expenses are subject to the usual tax and benefit rules that apply to earned income.

Evaluation and development

28. NICE recognises that patient, service user, carer and public involvement can always be improved. We aim to develop new, expanded and improved opportunities, processes and methods for involving patients, service users, carers and the public in the following ways:

- to ensure that new programmes of work and new products (such as social care) integrate opportunities for lay involvement and lay people's views and experiences in new methodologies and processes
- to take account of the views of diverse populations by reflecting their needs and points of view in guidance and standards.
- to use clear methodologies to collect information on lay people's views and experiences
- to support opportunities for involving patients, service users, carers and the public in promoting NICE guidance and other products
- to strengthen the relationship with voluntary, charitable and other third sector organisations, and with the Patients Involved in NICE (PIN) group
- to share lessons learned from involving patients, service users, carers and the public across different NICE's work programmes
- to embed the concept of shared decision-making in NICE's approach, and to explore decision support tools as a way to engage more lay people with our guidance.
- to review the format, content and communication of our written information so it better meets the needs of patients, service users, carers and the public.
- to continue to collect evidence of the impact of lay involvement in developing NICE guidance, quality standards and other products.
- to further develop a web presence specifically for patients, service users, carers and members of the public.

- to consider how to engage with groups of people that cannot take part directly in our committees and working groups, such as people with communication difficulties.
- to continue to develop processes and methods to evaluate the successes and limitations of patient, service user, carer and public involvement work at NICE.

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Appendix 1

Children, young people and safeguarding

1. 'Safeguarding' children involves promoting their welfare and protecting them from harm. For the purposes of child protection legislation (the Children Act 1989 and 2004) and related measures such as criminal record checks, the term "child" refers to anyone under the age of 18. However, 16 and 17 year olds are not considered vulnerable if they are in volunteering or employment situations. The requirement for criminal record checks applies to any position which involves regularly⁷ caring for, training, supervising or being solely in charge of children.⁸
2. It is envisaged that the majority of work NICE will do to engage with children and young people will be indirect in that external agencies (such as third sector organisations, local young people's networks etc.) with experience of working with children and young people would be commissioned to act on NICE's behalf.
3. There are no implications for NICE with regard to safeguarding or Disclosure and Barring Service⁹ (DBS) checks (formerly CRB checks) where a third party is engaged to work with children and young people on NICE's behalf. However NICE would need to satisfy itself that the agency conducting the work has the appropriate expertise, policies and procedures for ensuring the safety and welfare of the children and young people taking part.
4. There are likely to be infrequent occasions where an individual child or young person under 18 attends a NICE meeting. In these circumstances they would need to be accompanied by an appropriate

⁷ Regular means carried out by the same person frequently (once a week or more) or on four or more days in a 30-day period (or in some cases overnight)

⁸ See [DBS checks: eligibility guidance](#)

⁹ The Disclosure and Barring Service (DBS) has replaced the Criminal Records Bureau (CRB) and Independent Safeguarding Authority (ISA).

adult (such as a parent or carer). NICE staff do not need to have DBS checks just by virtue of having contact with a child in a NICE meeting or on NICE premises. Consent would need to be sought from both the child and their appropriate adult and the safeguarding responsibility lies with the appropriate adult. Adaptations may be needed to make the meetings accessible for children – in terms of timing, pace, agenda, language, etc. For children contributing evidence to NICE committee meetings, special measures may be needed, such as giving testimony via video recording, or in private session if the committee meets in public

5. Where a young person aged 16 or 17 attends a NICE meeting, they can give their own consent to attend and do not need to be accompanied by an appropriate adult. This is because attending a meeting is considered equivalent to the young person volunteering or undertaking paid employment and they are therefore not considered 'vulnerable'. If however 16 and 17 year olds have a specific vulnerability, such as a learning disability, then the need for an appropriate adult would apply (as for those aged under 16).
6. Again there are no implications for NICE staff with regard to DBS checks just by virtue of having contact with a young person in a NICE meeting or on NICE premises. Consent would need to be sought from both the 16 or 17 year old themselves and, where necessary (e.g. if they have a learning disability), their appropriate adult.