

Strengthening Patient and Public Participation in the work of NHS England

Overview

NHS England's ambition is for patients and the public to be at the heart of everything we do, in line with the values of the NHS Constitution. This work is underpinned by our Patient and Public Participation Policy and Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning.

The documents set out our commitment to participation and outline how we will work with patients and the public to enable them to influence the health services they use. We would like to know more about how the documents are being used in practice and give you the opportunity to share your experiences of how well they are working.

Related Documents

[Patient and Public Participation Policy](#)

[Patient and Public Participation Policy - easy read](#)

[Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning](#)

Your response

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From your experience, how do you think the new policy and arrangements are working in practice?

The Royal College of Physicians of Edinburgh (“the College”) has sought views from our Lay Advisory Committee to inform the response to this consultation. Our Lay Advisors are based across the UK and their experience of NHS England has been sought in this regard.

The principles behind the new policy and arrangements are welcomed by the College. However some concerns have been raised about how these actually work in practice. For example, for patient and public voice (PPV) representatives, meetings or training are occasionally cancelled at short notice and the time restrictions faced by representatives due to work or caring commitments is not always recognised and taken into account. It is also important to make the most of the skills and experience of PPV representatives in practice to ensure they can make a full and worthwhile contribution.

In addition to the existing resources available on our website (and intranet pages – for staff), we are developing further information, training and networking support, and taking other action to implement the policy and arrangements. Bearing in mind resource constraints, what more could be done? To avoid misinterpretation, please be as clear and specific as possible in your response.

The information generally appears comprehensive as presented in the Statement of Arrangements also the Patient and Public Participation Policy. It may be useful to have online training or resources available for representatives and nominated link contacts from within the NHS that representatives can contact with questions outside of formal meetings etc.

Do you have any specific suggestions for changes to (a) the policy; (b) the statement of arrangements? If so, please identify the page number and section/paragraph number and provide your suggested new wording or indicate what should be deleted. Please provide evidence to support your suggestion, where appropriate and available.

SECTION 3 3-1: There is limited discussion or identification of hard to reach marginalised population such as homeless people; individuals affected by substance misuse; individuals in the criminal justice system; war veterans – their voices are rarely ever heard in such consultations. It should be ensured that these groups are consulted in relation to their health needs and how services respond to their needs.

It would be helpful if there was more emphasis on ensuring that organisations utilise the patient and public views they collect in a meaningful way. This is perhaps more straightforward if it relates to public/lay participation in, for example trust boards, but information and feedback collected via social media or wide scale public consultations is much more difficult. NHS organisations should not be over burdened with data they don't

know what to do with or can't process effectively and so there should be clarity around these issues.

Please identify any additional documents or links to further useful resources which you think should be referenced in (a) the policy; (b) the statement of arrangements.

None noted.

Do you have any further comments?

One of the key aims of this workstream should be to aim to use language which is inclusive not exclusive – this would hopefully lead to less jargon being used in clinical settings.

Overall, NHS England is to be commended for its commitment to strengthening patient and public participation. Although it makes reference to local authorities and voluntary sector organisations, the policy still has a very strong focus on healthcare and it would be useful to see more about PPP in health and social care commissioning and provision of services.

It may be helpful for information on a human rights approach be added to the resources section: in disability rights, there is a growing realisation that the development of human rights and the rights for persons with disability is indivisible and a human rights approach is the best driver for positive change. This is the approach advocated by the UN and WHO for persons with disability. A starting point for this would be the commonly used, in Human Rights issues, PANEL approach.

There are some underlying principles which are of fundamental importance in applying a human rights based approach in practice. These are: Participation; Accountability; Non-discrimination and equality; Empowerment and Legality.

Participation

Everyone has the right to participate in decisions which affect their health. Participation must be active, free, and meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood. In relation to NHS England service users, this means that individuals should participate in all decisions about the care and support they are receiving. This could range from participation in policy, commissioning and procurement to participating in daily decisions about the care and support being provided.

Accountability

Accountability requires effective monitoring of human rights standards as well as effective remedies for human rights breaches. For accountability to be effective there must be appropriate laws, policies, institutions, administrative procedures and mechanisms of redress in order to secure human rights. NHS England is accountable to a range of bodies which promote accountability for respecting, protecting and fulfilling human rights. These

stretch from parliament to commissioners of services, care provider organisations, patient organisations, charities and inspection and regulatory bodies.

Non-discrimination and equality

A human rights based approach means that all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most marginalised situations who face the biggest barriers to realising their rights. NHS England service users include some of the most vulnerable and marginalised people in our society – taking a human rights based approach means paying particular attention to the protection and realisation of their rights. This is well noted in section 5.2.

Empowerment of rights holders

A human rights based approach means that individuals and communities should know their rights. It also means that they should be fully supported to participate in the development of policy and practices which affect their lives and to claim rights where necessary. This means that everyone should be helped to understand what their rights are and how they can claim these rights. Achieving this may require the provision of appropriate advocacy support. Again it is a positive feature to note that this is acknowledged in section 5.2. In section 1.4, NHS England show a positive attitude to supporting involvement and education.

Legality of rights

A human rights based approach requires the recognition of rights as legally enforceable entitlements and is linked in to national and international human rights law. NHS England should note that it strives to ensure that its practices and procedures are grounded in human rights law.

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