

This compendium aims to provide an overview of service user involvement in health and social care policy and legislation. It functions as a companion piece to the 4Pi Standards for Involvement document and aims to enable readers to use it for reference purposes.

# Service User Involvement in Health and Social Care Policy and Legislation

‘Nothing about us  
without us’

## Service User Involvement in Health and Social Care Policy and Legislation

This compendium aims to provide an overview of service user involvement in health and social care policy and legislation. It charts developments chronologically from the NHS and Community Care Act of 1990 to the present day. The compendium functions as a companion piece to the 4Pi Standards for Involvement document and aims to enable readers to use it for reference purposes. Where possible, specific references and web links to original documents have been included. Whilst aiming to be as comprehensive as possible we recognise that this is an evolving document and that further key reports may come to light. A degree of selection has also been required in order to prevent the document from losing focus and becoming unwieldy.

### 1990 Legislation

#### **NHS and Community Care Act**

The NHS and Community Care Act is widely cited as the first piece of UK legislation to establish a formal requirement for user involvement in service planning. Local authorities were required to prepare Community Care Plans and consult with groups that represented people who used, or were likely to use, services. The act states that local authorities should consult:

*'such voluntary organisations as appear to the authority to represent the interests of persons who use or are likely to use any community care services within the area of the authority or the interests of private carers who, within that area, provide care to persons for whom, in the exercise of their social services functions, the local authority have a power or a duty to provide a service'. Section 46 (2) (D)*

The act enshrined in legislation many of the key objectives set out in the government White Paper Caring for People (1990). It promoted the concept of the state as an enabler rather than a provider of care through the application of market principles and privatisation. It also introduced the idea of user-centred services, stating that individual service users and their carers should be involved throughout the process of their assessment and care management. Consequently, the subsequent NHS and Community Care Act has been viewed as an important shift in government thinking regarding the central importance of the 'consumer' or 'service user'.

<http://www.legislation.gov.uk/ukpga/1990/19/contents>

### 1991 Policy

#### **Patient's Charter (Department of Health)**

The Patient's Charter emphasised the government's intention to provide 'patient-centred' care and ensure that the patient's voice was heard. It also reinforced the concept of consumerism by positioning health care recipients primarily as economic consumers of services (see Beresford, 2002, for a discussion on 'consumerist' and 'democratic' approaches to service user involvement).

### 1992 Policy

#### **The Health of the Nation – A Strategy for England (Department of Health)**

The Health of the Nation strategy, launched in 1992, aimed to improve the physical and mental health of the population in England. Despite the wide remit of the report, 'mental illness' was one of the five priority areas for improvement. The strategy also noted the importance of consulting patients/service users when planning, evaluating service quality, and promoting better health.

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<p><b>1994 Policy</b></p>	<p><b>Working in Partnership: Report of the Review of Mental Health Nursing (Department of Health)</b></p>
	<p>The government review of mental health nursing stated that the role of service users should be developed from having a say in individual care and treatment, to active involvement in curriculum development and teaching. The report also asserted that the work of mental health nurses rested primarily upon the kind relationship they had with service users.</p>
<p><b>1995 Policy</b></p>	<p><b>Building Bridges: A Guide to Arrangements For Inter-agency Working for the Care and Protection of Severely Mentally Ill People (Department of Health)</b></p>
	<p>Together with the Health of the Nation and Working in Partnership, this document was one of the first to stress the importance of service user involvement in the area of mental health.</p>
<p><b>1998 Policy</b></p>	<p><b>Modernising Mental Health Services: Safe, Sound and Supportive (Department of Health)</b></p>
	<p>Following the election of the 'New Labour' government in 1997, Modernising Mental Health Services was one of the key documents (alongside the National Service Framework and the NHS Plan) that set the framework for mental health service delivery over the following decade. Despite the increasing focus on public safety and risk management, it also makes reference to the importance of joint decision-making and contains a short section entitled 'involving patients, service users and carers':</p>
	<p><i>'The Government believes that patients, service user, and their carers, should play an active part in the process of treatment and care. During the past two decades, more than one hundred research reports bear witness to the beneficial impact this can have. For example, the quality of the relationship between patient and professional in psychological therapies can make as much as a 25 per cent difference in outcome. Patients and service users value being involved and informed, and a better standard of day-to-day practice in this area is clearly essential to the delivery of good quality care.'</i> (Section 4.49)</p>
	<p><a href="http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003105">http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003105</a></p>
<p><b>1998 Legislation</b></p>	<p><b>Human Rights Act</b></p>
	<p>The Human Rights Act (1998) incorporated into UK law the European Convention on Human Rights, adopted in 1950. Section 3 requires laws to be interpreted so they are compatible with human rights. If legislation is not deemed to be compatible with the act, the government can amend legislation accordingly. The rights included in the act are:</p>
	<ul style="list-style-type: none"> <li>• The right to life</li> <li>• The prohibition of torture and inhuman or degrading treatment</li> <li>• The right to liberty</li> <li>• The right to a fair trial</li> </ul>

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### 1998 Legislation

- The right to a private and family life
- Freedom of thought, conscience and religion
- Freedom of expression
- The right to marry
- The right not to be discriminated against
- The right to property
- The right to education
- The right to vote

The act does not specifically relate to service user involvement in itself and some researchers have suggested that it does not go far enough with regard to promoting the autonomy of service users (Bindman et al. 2003, cited in Rankin, 2004). However, the act is significant in that it reflects social changes with regard to the development of thinking around human rights and has a broad impact upon the rights of mental health service users in a range of different settings.

<http://www.legislation.gov.uk/ukpga/1998/42/contents>

For further information on aspects of the human rights act in relation to mental health:  
<http://www.mind.org.uk/information-support/legal-rights/human-rights-act/human-rights-relevant-to-mental-health/>

### 1999 Policy

#### **National Service Framework for Mental Health: Modern Standards and Service Models (Department of Health)**

The National Service Framework (NSF) set out a 10 year agenda for improving mental health care in England. The document focuses on seven areas or 'standards':

1. Mental health promotion and discrimination/exclusion
- 2 & 3. Primary care and access to services
- 4 & 5. Services for people with severe mental illness
6. Services for carers
7. Actions necessary to reduce suicides.

The NSF addresses potential conflicts of interest between service users and their carers and states that specific arrangements should be in place to ensure service user and carer involvement:

*'The views, circumstances and needs of service users and carers may be distinct, and can sometimes conflict. Local arrangements should be made to ensure that the user's and carer's plans are considered together'. (p.72)*

Although there are very few other references to service users within the document, it does contain a section entitled 'Engaging service users' (p.59) which includes a case study relating

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<p><b>1999 Policy</b></p>	<p>to the development of a service user involvement initiative in Northumberland.</p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198051/National_Service_Framework_for_Mental_Health.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198051/National_Service_Framework_for_Mental_Health.pdf</a></p>
<p><b>1999 Policy</b></p>	<p><b>Patient and Public Involvement in the New NHS (Department of Health)</b></p> <p>The phrase ‘patient and public involvement’ became one of the central tenets of the Blair government’s NHS modernisation agenda. The document Patient and Public Involvement in the New NHS (1999) introduced the idea of a ‘partnership’ between the NHS, patients and the public. It stated that this partnership should be genuine rather than tokenistic, and that people needed to be fully involved, not only in decisions about their care, but with regard to service provision. The document states that patient and public involvement should be embedded throughout the NHS, including Primary Care Groups, GP Practices, Health Authorities, NHS Trusts and Research and Development teams. The policy also states that appropriate training should be provided for patients who were involved in partnership working.</p> <p>Relevant Quotes:</p> <p><i>‘NHS bodies, staff and health professionals alike, will need to work in partnership with all parts of the local community, not just those groups they have traditionally had links with (important though those are) so that those who have in the past been marginalised or ignored can have a voice’. (p.1)</i></p> <p><i>‘There is growing acceptance that patients and carers are the “experts” in how they feel and what it is like to live with or care for someone with a particular illness or condition’. (p.3)</i></p> <p><i>‘Involving service users and carers is an important part of improving service quality in the NHS. Working with individual users and both local and national user groups can often provide a different view of problems and can lead to imaginative and innovative solutions... such approaches have often helped to make services both more responsive and cost effective’. (p.3)</i></p> <p><a href="http://www.xnn40.dial.pipex.com/Documents/PatientandPublicInvolvement.pdf">http://www.xnn40.dial.pipex.com/Documents/PatientandPublicInvolvement.pdf</a></p>
<p><b>2000 Policy</b></p>	<p><b>NHS Plan (Department of Health)</b></p> <p>The NHS Plan formalised the New Labour government’s user involvement agenda in policy terms. It proposed the development of the Patient Advice and Liaison Service (PALS) and emphasised the concept of a ‘patient-centred’ NHS with users’ needs at the centre of service design and delivery. Section 10.28 – 10.34 also sets out how patients will be represented through the NHS on professional regulatory bodies, the NHS Modernization Board, and Citizens Council (established to advise the National Institute for Clinical Excellence).</p> <p>Relevant Quotes:</p> <p><i>‘The NHS will shape its services around the needs and preferences of individual patients, their families and their carers. The NHS of the 21st century must be responsive to the needs of different groups and individuals within society, and challenge discrimination on the grounds of age, gender, ethnicity, religion, disability and sexuality. The NHS will</i></p>

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<p><b>2000 Policy</b></p>	<p><i>treat patients as individuals, with respect for their dignity. Patients and citizens will have a greater say in the NHS, and the provision of services will be centred on patients' needs'.</i> (p.4)</p> <p><i>'The patient's voice does not sufficiently influence the provision of services. Local communities are poorly represented within NHS decision-making structures. Despite many local and national initiatives to alter the relationship between the NHS and the patient, the whole culture is more of the last century than of this. Giving patients new powers in the NHS is one of the keys to unlocking patient centred services'.</i> (p.30)</p> <p>Full Report: <a href="http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118522.pdf">http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118522.pdf</a></p> <p>Summary Report: <a href="http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118523.pdf">http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_118523.pdf</a></p>
<p><b>2001 Legislation</b></p>	<p><b>Health and Social Care Act</b></p> <p>Section 11 of the Health and Social Care Act required all NHS Trusts, Primary Care Trusts and Strategic Health Authorities to consult with and involve people in service planning and evaluation:</p> <p><i>'It is the duty of every body to which this section applies to make arrangements with a view to securing, as respects health services for which it is responsible, that person to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on-</i></p> <ul style="list-style-type: none"> <li><i>a) the planning of the provision of those services,</i></li> <li><i>b) the development and consideration of proposals for changes in the way those services are provided, and</i></li> <li><i>c) decisions to be made by that body affecting the operation of those services'.</i> Section 11 (1)</li> </ul> <p>The act also provided opportunities for decision-making with regard to treatment. The structural bodies responsible for the implementation of these requirements included the Commission for Patient and Public Involvement in Health (CPPIH), established through the NHS Reform and Health Care Professions Act (2002).</p> <p><a href="http://www.christie.com/en/documents/22.pdf">http://www.christie.com/en/documents/22.pdf</a></p>
<p><b>2001 Policy</b></p>	<p><b>Involving Patients and the Public in Health Care (Department of Health)</b></p> <p>This document developed mechanisms for putting into place the legislation of the Health and Social Care Act. The programme for action included:</p> <ul style="list-style-type: none"> <li>• setting up Patient's Forums made up of local people in every PCT and NHS Trust (see section 5.3 – 5.9)</li> </ul>

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<p><b>2001 Policy</b></p>	<ul style="list-style-type: none"> <li>• setting up the Commission for Patient and Public Involvement in Health to build capacity within local communities and set standards (section 5.25 – 5.29)</li> <li>• introducing a patient survey programme to inform local decision making (Annex A, section 6)</li> <li>• requiring every NHS Trust and PCT to publish an account of how the public had been involved and the effect of that involvement. (Annex A, section 6)</li> </ul> <p><a href="http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_088803.pdf">http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_088803.pdf</a></p>
<p><b>2003 Legislation</b></p>	<p><b>Health and Social Care (Community Health and Standards) Act</b></p> <p>The Health and Social Care (Community Health and Standards) Act of (2003) authorised the first NHS foundation trusts. They were part of the government’s aim to create a ‘patient-led’ NHS by devolving decision-making from central government to local organisations and communities. Foundation Trusts are led by an independent board of directors and are accountable to local communities through a system of local ownership. The public, staff members, service users and their families can join the Foundation Trusts as members and elect governors to represent them. They have the freedom to decide, with their governors and members, their own strategy and the way services are run. All NHS Trusts are required to become Foundation Trusts by 2014.</p> <p><a href="http://www.legislation.gov.uk/ukpga/2003/43/part/1">http://www.legislation.gov.uk/ukpga/2003/43/part/1</a></p>
<p><b>2003 Policy</b></p>	<p><b>Inside Outside: Improving mental health services for Black and Minority Ethnic Communities in England (Department of Health)</b></p> <p>Although there is no specific involvement legislation regarding BME user involvement, discussions around the need to involve BME service users and their families began to take place in policy documents. These discussions often tended to be framed in terms of ‘community engagement’ (please see the Dancing to our own tunes report, 2011, for an extensive assessment and critique of BME user involvement initiatives and policies).</p> <p>For example, the Inside Outside document stated that ‘one of the reasons mental health services in general have not been able to adapt successfully to meet the needs of people from minority ethnic communities is the lack of local community involvement in shaping and delivering services’ (p.20). Consequently, the report asserted that arrangements should be made to encourage BME participation in service planning, commissioning, delivery and evaluation.</p> <p><a href="http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4084558">http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4084558</a></p>



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<p><b>2003 Policy</b></p>	<p><b>Engaging and Changing: Developing effective policy for the care and treatment of Black and minority ethnic detained patients (National Institute for Mental Health England)</b></p> <p>Similarly, this document argued that institutional processes were ignoring the expertise and knowledge existing within BME communities. It proposed a model of 'community engagement' in which knowledge would be shared between service providers and communities. It was anticipated that this in turn would enable services to be developed that were 'sensitive to the cultural and religious needs of Black and minority ethnic detained patients'. (p.71)</p> <p><a href="http://www.ciellp.com/wpress/wp-content/uploads/2013/12/Engagaing-and-changing.pdf">http://www.ciellp.com/wpress/wp-content/uploads/2013/12/Engagaing-and-changing.pdf</a></p>
<p><b>2004 Policy</b></p>	<p><b>Mental Health and Social Exclusion Report (Office of the Deputy Prime Minister)</b></p> <p>This report focused on the links between 'mental health problems' and social exclusion, including stigma, discrimination, and barriers to work. Although the document states that people should have 'genuine choices and a real say about what they do and the support they receive in order to fulfill their potential' (p.6), there are no other references regarding user involvement in service design or delivery.</p> <p><a href="http://www.socialfirmsuk.co.uk/resources/library/mental-health-and-social-exclusion-social-exclusion-unit-report">http://www.socialfirmsuk.co.uk/resources/library/mental-health-and-social-exclusion-social-exclusion-unit-report</a></p>
<p><b>2005 Policy</b></p>	<p><b>Delivering Race Equality in Mental Health Care</b></p> <p>This document combined:</p> <ol style="list-style-type: none"> <li>1) A five-year action plan for reducing inequalities in Black and minority ethnic patients' access to, experience of, and outcomes from mental health services</li> <li>2) The government's response to the recommendations made by the inquiry into the death of David Bennett (a 38-year-old African-Caribbean man who died in 1998 in a medium secure psychiatric unit after being restrained by staff).</li> </ol> <p>The report stated the need for more appropriate and responsive services, improved community engagement, and better information and dissemination of good practice. More specifically, it called for:</p> <ul style="list-style-type: none"> <li>• action to engage communities in planning services, supported by 500 new Community Development Workers (p.62)</li> <li>• more peer support services (p.19)</li> <li>• a more active role for BME communities and BME service users in the training of professionals, the development of mental health policy, and the planning and provision of services. (p.76)</li> </ul> <p><a href="http://www.rbmind.org/content/assets/DRE_summary.pdf">http://www.rbmind.org/content/assets/DRE_summary.pdf</a></p>



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### 2006 Legislation

#### NHS Act

The NHS Act consolidated previous legislation regarding the health service. Section 11 of the Health and Social Care Act (2001), the duty to involve and consult, became section 242 of the new NHS Act (see Health and Social Care Act above). A 'user' was defined as someone who was using services, or someone who may use them. The requirement of 'involvement' could be fulfilled through consultation, the provision of information or in other ways. Section 243 sets out the function of the Commission for Patient and Public Involvement in Health (CPPIH), with regard to overseeing the local structures for patient and public involvement and supporting Patients' Forums.

<http://www.legislation.gov.uk/ukpga/2006/41/contents>

### 2007 Legislation

#### Mental Health Act

The Mental Health Act (2007) amended the Mental Health Act (MHA) of 1983. The main purpose of the legislation is to ensure that 'people with serious mental disorders, which threaten their health or safety or the safety of other people can be treated irrespective of their consent where it is necessary to prevent them from harming themselves or others' (Mental Health Act explanatory notes). The amended act introduced:

- a new broad definition of 'mental disorder' to encompass 'any disorder or disability of the mind'.
- an 'appropriate treatment test', preventing patients from being compulsorily detained unless appropriate medical treatment is available.
- Community Treatment Orders to supervise the treatment of certain patients in the community.
- new safeguards including a provision for Independent Mental Health Advisors to provide information and help people understand and exercise their rights.
- new roles to replace the roles of approved social worker and responsible medical officer.
- provision for powers to reduce the time limits for the automatic referral of some patients to the Mental Health Review Tribunal.

The Mental Health Act 2007 and its subsequent implementation have proved to be controversial. In 2013 the House of Commons Health Committee conducted a post-legislative assessment in order to review the operation of the act. The report stated that:

*'It is now acknowledged that there appears to be an inverse relationship between the number of available beds and rates of detention. The most worrying consequence of this was the suggestion that voluntary admissions to psychiatric wards are now so difficult to access that patients are being sectioned to secure treatment in hospital. The Committee is very concerned that clinicians would resort to a practice which represents a major infringement of a patient's civil liberties. In the Committee's view, the Department of Health should urgently investigate whether patients have been sectioned in order to access psychiatric unites and report to Parliament on the prevalence of this practice'. (p.3)*

*'the Committee also heard reports that patients who manage to access treatment*

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### 2007 Legislation

*voluntarily are subject to 'de facto detention', whereby they are detained under section if they seek to leave hospital. It appears that this practice is not extensive within the mental health system; nonetheless, the Committee regards it as completely unacceptable. We believe that the professional regulators should review their advice to clinicians regarding the use of sectioning powers'. (p.3)*

Consequently, any developments regarding service user involvement in policy and legislation need to be examined within the broader context of the current Mental Health Act.

<http://www.legislation.gov.uk/ukpga/2007/12/contents>

<http://www.mind.org.uk/information-support/legal-rights/mental-health-act-1983-amendments/>

<http://www.publications.parliament.uk/pa/cm201314/cmselect/cmhealth/584/584.pdf>

### 2007 Legislation

#### **Local Government and Public Involvement in Health Act**

The Local Government and Public Involvement in Health Act incorporated the recommendations of A Stronger Local Voice (2006). This government White Paper had set out the government's plans to abolish the Commission for Patient and Public Involvement in Health (CPPIH) and the patient forums that had been established in 2001. Local Involvement Networks (LINKs) were to replace patient forums with the intention of promoting public and community influence in health and social care. The intention was that these arrangements would make NHS organisations more accountable to their local populations and that the patient and service user voice would be strengthened through the creation of these new mechanisms.

With regard to the development of the Local Involvement Networks, the Act states that:

*The activities for a local authority's area are –*

- a) *promoting, and supporting, the involvement of people in the commissioning, provision and scrutiny of local care services;*
- b) *enabling people to monitor for the purposes of their consideration of matters mentioned in subsection (3), and to review for those purposes, the commissioning and provision of local care services;*
- c) *obtaining the views of people about their needs for, and their experiences of, local care services; and*
- d) *making –*
  - i) *views such as are mentioned in paragraph (c) known, and*
  - ii) *reports and recommendations about how local care services could or ought to be improved, to persons responsible for commissioning, providing, managing or scrutinising local care services'. Part 14, section 221 (2)*

<http://www.legislation.gov.uk/ukpga/2007/28/contents>

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<p><b>2007 Policy</b></p>	<p><b>Putting People First – a shared vision and commitment to the transformation of Adult Social Care (Department of Health)</b></p> <hr/> <p>Putting People First focused on the concept of ‘personalisation’ within health and social care. The aim of personalisation is to tailor care and support services to a person’s individual needs rather than delivering services in a ‘one size fits all’ fashion. The document states that:</p> <p><i>‘The time has now come to build on best practice and replace paternalistic, reactive care of variable quality with a mainstream system focused on prevention, early intervention, enablement, and high quality personally tailored services. In the future, we want people to have maximum choice, control and power over the support services they receive’. (p.2)</i></p> <p>Although this document does not discuss service user involvement directly, it marks a further shift towards the increasingly prominent rhetoric of ‘choice’, ‘control’ and ‘empowerment’ of the individual.</p> <p><a href="http://www.cpa.org.uk/cpa/putting_people_first.pdf">http://www.cpa.org.uk/cpa/putting_people_first.pdf</a></p>
<p><b>2007 Policy</b></p>	<p><b>Health and Social Care Act</b></p> <hr/> <p>The Health and Social Care Act (2008) established the Care Quality Commission (CQC) as the regulator of all health and adult social care services. The Act contains a ‘statement on user involvement’ (chapter 1, section 5) requiring the CQC to publish a statement describing how it proposed to:</p> <ol style="list-style-type: none"> <li>a) promote awareness among service users and carers of its functions,</li> <li>b) promote and engage in discussion with service users and carers about the provision of health and social care services and about the way in which the Commission exercises its functions,</li> <li>c) ensure that proper regard is had to the views expressed by service users and carers, and</li> <li>d) arrange for any of its functions to be exercised by, or with the assistance of, service users and carers.</li> </ol> <p><a href="http://www.legislation.gov.uk/ukpga/2008/14/pdfs/ukpga_20080014_en.pdf">http://www.legislation.gov.uk/ukpga/2008/14/pdfs/ukpga_20080014_en.pdf</a></p>
<p><b>2008 Policy</b></p>	<p><b>Real Involvement – Working with People to Improve Health Services (Department of Health)</b></p> <hr/> <p>This document provided guidance and clarification for NHS organisations on several sections of the NHS Act (2006), including section 242(1B) ‘the duty to involve and good involvement practice’. It discussed the meaning of the term ‘involvement’, stating that a number of activities could constitute involvement, including consultation. It also encouraged organisations to consider a variety of appropriate approaches and involvement activities ranging from ‘giving information through to active participation in the planning and provision of services’ (p.16). It also advised developing relationships with communities in a systematic way over a period of time in order to gain ‘a clear and up-to-date understanding of the views, needs and preferences of the people for whom they commission and provide services’ (p.18).</p> <p><a href="http://www.suffolk.nhs.uk/LinkClick.aspx?fileticket=TSZoua8DPIU%3D&amp;tabid=333&amp;mid=856">http://www.suffolk.nhs.uk/LinkClick.aspx?fileticket=TSZoua8DPIU%3D&amp;tabid=333&amp;mid=856</a></p>

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<p><b>2010 Policy</b></p>	<p><b>Essential Standards for Quality and Safety (Care Quality Commission)</b></p> <p>In accordance with the Health and Social Care Act (2008), the CQC provided detailed guidance for a wide range of health care organisations, including hospital services for people with mental health needs. The document prioritises the need to respect and involve people who use services and includes a range of ‘prompts’ to enable providers to achieve this aim. Consequently, the guidance enables service users in hospitals to make or participate in making decisions about their care, treatment and support needs.</p> <p><a href="http://www.cqc.org.uk/sites/default/files/media/documents/gac_-_dec_2011_update.pdf">http://www.cqc.org.uk/sites/default/files/media/documents/gac - dec 2011 update.pdf</a></p>
<p><b>2010 Legislation</b></p>	<p><b>Equality Act</b></p> <p>In 2010, all anti-discrimination laws (Race Relations Acts, 1965, 1968, 1976; Equal Pay Act, 1970; Sex Discrimination Act 1975; Disability Discrimination Act, 1995) were brought together in the Equality Act. The act makes it unlawful to discriminate against someone based on a ‘protected characteristic’ (including disability, age, gender, sexual orientation etc.). Under the Equality Act a person is considered to have a disability if they have an impairment that is either physical or mental; and the impairment has substantial adverse and long-term effects on their ability to carry out normal day-to-day activities (chapter 1, section 6). The government has published guidance with regard to what may or may not be considered a disability under the Equality Act (<a href="http://odi.dwp.gov.uk/docs/law/ea/ea-guide-2.pdf">http://odi.dwp.gov.uk/docs/law/ea/ea-guide-2.pdf</a>). Under section 6(5) of the act, courts and tribunals need to take account of the guidance when deciding whether or not someone has a disability. People who are deemed to have a disability as defined by the act are protected from being discriminated against at work and when using services (eg. housing or education).</p> <p>Mind and Rethink have published extensive guidance relating to the Equality Act and mental health:</p> <p><a href="http://www.mind.org.uk/information-support/legal-rights/disability-discrimination/">http://www.mind.org.uk/information-support/legal-rights/disability-discrimination/</a></p> <p><a href="http://www.rethink.org/living-with-mental-illness/mental-health-laws/discrimination">http://www.rethink.org/living-with-mental-illness/mental-health-laws/discrimination</a></p> <p>Although the act does not address the issue of service user involvement, it is an important legislative landmark within the broader context of service user rights.</p> <p><a href="http://www.legislation.gov.uk/ukpga/2010/15/contents">http://www.legislation.gov.uk/ukpga/2010/15/contents</a></p>
<p><b>2010 Policy</b></p>	<p><b>Equity and Excellence – Liberating the NHS</b></p> <p>The White Paper Equity and Excellence: Liberating the NHS was underpinned by the principle of ‘no decisions about me, without me’. The phrase ‘nothing about us without us’ had been used by disability activists and campaigners for many years prior to this document, so it was therefore a striking development that it should be adopted as a principle by the new coalition government. The document promises an NHS that puts patients at its centre, offers greater choice and control, and provides personalised care that reflects individual needs. It foregrounds the principle of ‘shared-decision making’ under which patients make joint decisions about their care with their clinicians. It also promises that the collective voice of patients and the public will be strengthened by arrangements led by local authorities and at a</p>

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### 2010 Policy

national level through HealthWatch England. However, it is interesting to note that embedded within this discourse of 'choice and control' patients are also required to 'accept responsibility for the choices they make' and comply with 'treatment programmes' (p.16).

Relevant Quotes:

*'compared to other sectors, healthcare systems are in their infancy in putting the experience of the user first, and have barely started to realise the potential of patients as joint providers of their own care and recovery. Progress has been limited in making the NHS truly patient led. We intend to put that right. [2.3] We want the principle of "shared decision-making" to become the norm: no decision about me without me'. (p.13)*

*'In future, patients and carers will have far more clout and choice in the system; and as a result, the NHS will become more responsive to their needs and wishes. People want choice, and evidence at home and abroad shows that it improves quality. We are also clear that increasing patient choice is not a one-way street. In return for greater choice and control, patients should accept responsibility for the choices they make, concordance with treatment programmes and the implications for their lifestyle'. (p.16)*

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213823/dh\\_117794.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf)

### 2011 Policy

#### **No Health Without Mental Health: a cross government mental health outcomes strategy for people of all ages (Department of Health)**

The coalition government's mental health strategy, No Health Without Mental Health aims to a) make mental health as important a priority as physical health, b) promote good mental health through early intervention particularly in childhood and teenage years, and c) reduce the social inequalities that contribute to mental ill health.

In order to achieve these aims it sets out six shared goals:

1. More people will have good mental health.
2. More people with mental health problems will recover.
3. More people with mental health problems will have good physical health.
4. More people will have a positive experience of care and support.
5. Fewer people will suffer avoidable harm.
6. Fewer people will experience stigma and discrimination.

The document reiterates the principle of shared decision-making, 'no decision about me without me' and the need for personalised care, choice and control. It highlights the need for professional staff who put service users,

*'their families and carers at the centre of their care by listening to what they want, giving them information, involving them in planning and decision-making, treating them with dignity and respect, and enabling them to have choice and control over their lives and the services they receive'. (p.18)*

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<p><b>2011 Policy</b></p>	<p>It also states that commissioners and service providers should establish 'mechanisms that allow local user groups to engage with providers and commissioners, and that empower and support them so that they can engage effectively'. (p.62)</p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf</a></p>
<p><b>2012 Legislation</b></p>	<p><b>Health and Social Care Act</b></p> <p>Following the Health and Social Care Act, new organisations were made responsible for making decisions about mental health services. Primary Care Trusts and Strategic Health Authorities have been abolished and funds transferred to new GP-led Clinical Commissioning Groups (CCGs). The CCGs have a legal duty to promote the involvement of service users and their carers or representatives in decisions that relate to, a) the prevention or diagnosis of illness, or b) their care or treatment (section 13H).</p> <p>Within each local authority area, Health and Wellbeing Boards have been established and are responsible for assessing and addressing the current and future health and social care needs of local communities (sections 194 – 199). They are required to carry out assessments known as Joint Strategic Needs Assessments (section 192) and are required to involve the local community in this process. Healthwatch organisations have replaced the Local Involvement Networks (LINKs). They have been created to enable patients and the public to influence and improve their local health and social care services (sections 181 – 189).</p> <p>There has been some uncertainty and confusion with regard to service user involvement in the new structures (Perry et al. 2013). For example, issues have been raised with regard to the demands that are placed on single service user representatives who are representing diverse community views on Health and Wellbeing Boards and other local decision-making bodies. NSUN's Review of values-based commissioning in mental health (2013) recommends that that at all levels of decision-making, boards should comprise at least three people who have lived experience of mental ill health.</p> <p><a href="http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted">http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted</a></p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138257/A1.-Factsheet-Overview-240412.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138257/A1.-Factsheet-Overview-240412.pdf</a></p> <p><a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138262/B3.-Factsheet-Greater-voice-for-patients-300512.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/138262/B3.-Factsheet-Greater-voice-for-patients-300512.pdf</a></p>
<p><b>2013 Inquiry</b></p>	<p><b>The Francis Report</b></p> <p>Following an inquiry report in 2010, a further investigation led by Robert Francis QC, was held into the serious failings of the Mid Staffordshire NHS Foundation Trust between 2005 and 2008. The inquiry heard harrowing evidence relating to standards and mortality rates in the main hospital serving Stafford and the surrounding area. It concluded that 'conditions of appalling care had been able to flourish' (p.7). Numerous warning signs had been ignored throughout the organisation, in part due to a culture that 'focused on doing the system's business – not that of the patients' and which 'ascribed more weight to positive information about the service</p>



## Service User Involvement in Health and Social Care Policy and Legislation

### 2013 Inquiry

than to information capable of implying cause for concern' (p.4).

The report made 290 recommendations. It called for a fundamental culture shift within the NHS and emphasised the need for patient-centred care:

*'...there needs to be a relentless focus on the patient's interests and the obligation to keep patients safe and protected from substandard care. This means that the patient must be first in everything that is done: there must be no tolerance of substandard care; frontline staff must be empowered with responsibility and freedom to act in this way under strong and stable leadership in stable organisations'. (p.66).*

In the light of the findings, the government stated that:

*'The essential diagnosis from the Inquiry is of an NHS that had veered, or was pushed, too far from its core humanitarian values and in too many places had its priorities wrong. Targets and performance management in places overwhelmed quality and compassion. Top down management instructions drowned out patient voices. Pressure to perform and fear of failure led to a controlling and defensive approach from organisations. Regulators, commissioners and others in the system became focused on their own roles and in some cases lost sight of the patients they were there to serve. [6.] The job now is to put the system back on track and to put in place sustainable measures to ensure that it continues to drive improvements. This means restating clearly our common purpose and binding principles – that quality is as important as finance, that patient interest comes before institutional interest, that we all work together in the interests of patients'. (Patients First and Foremost p.21)*

Summary Report:

<http://www.midstaffpublicinquiry.com/sites/default/files/report/Executive%20summary.pdf>

Patients First and Foremost: Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/170701/Patients\\_First\\_and\\_Foremost.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf)

### 2013 Policy

#### **NHS Constitution for England**

The NHS Constitution, first published in 2009, was updated in 2013 in the light of the Health and Social Care Act (2012) and the findings of the Francis Report (2013). The Constitution sets out the principles and values of the NHS in England and details the rights of patients, the public and staff. It also details the pledges and commitments of the NHS and the responsibilities that patients, staff and the public have in order to ensure that it operates effectively. All NHS bodies and private and voluntary health providers are required by law to abide by the Constitution.

The Constitution states:

*'The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will*



## Service User Involvement in Health and Social Care Policy and Legislation

### 2013 Policy

*actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services’.* (section 1(4), p.3)

*‘Patients come first in everything we do. We fully involve patients, staff, families, carers, communities, and professionals inside and outside the NHS. We put the needs of patients and communities before organisational boundaries. We speak up when things go wrong’.* (section 2, p.5)

With regard to involvement in services, it states:

*‘You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services’.* (section 3a, p.9)

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/170656/NHS\\_Constitution.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf)

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/170649/Handbook\\_to\\_the\\_NHS\\_Constitution.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170649/Handbook_to_the_NHS_Constitution.pdf)

The NHS Constitution demonstrates the extent to which ideas of patient-centred services and service user involvement are now central discourses within health care. Policy rhetoric has explicitly shifted towards shared decision-making and the principle of ‘no decision about us without us’ in recent years. But although service user and carer involvement has been legislated for and proposed as ‘best practice’, it appears that there continues to be a culture within the NHS (highlighted in the Francis Report) whereby co-production at service level and individual support level is still not practiced as the norm. Further work needs to take place with regard to how policies that promote involvement are successfully translated into practice. The National Involvement Partnership is taking steps to address this issue through the development and promotion of the 4Pi Involvement Standards Framework.

<http://www.nsun.org.uk/assets/downloadableFiles/4Pi.-ni-standards-for-web.pdf>

### 2014 Legislation

#### **The Care Act**

The Care Act makes major changes to the social care and support system and introduces new responsibilities for local authorities. The Act defines the primary responsibility of local authorities as the promotion of an individual’s wellbeing and this duty will now apply not only to service users but to carers as well. One of the aims of the Act is to put people at the centre of their care and support. Councils will be required to enable users or potential users of care services to access financial advice by arranging for independent advocates to support people to be involved in assessment, planning, appeals or safeguarding (sections 67 and 68). After assessments have been made local authorities will also be required to offer a personal budget and produce care plans which must involve:

- (i) the adult to whom the plan relates,
- (ii) any carer that the adult has, and
- (iii) any person whom the adult asks the authority to involve or, where the adult lacks capacity

## Service User Involvement in Health and Social Care Policy and Legislation

### 2014 Legislation

to ask the authority to do that, any person to appears to the authority to be interested in the adult's welfare.

Part 1, section 27 (b)

Despite the person-centred rhetoric of the Act, Peter Beresford (2014) states, "the guidance does not explain how councils will move from the person's views to their own views other than 'an assessment must be person-centred, involving the individual'. These are concepts that are interpreted at the council's discretion". Given that there are continued funding restrictions across health and social care, he claims that it is difficult to see how service users and carers will be genuinely empowered in this setting and concludes that 'the act looks less like a new beginning than a continuation by other means of social care's marginalisation'.

<http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<http://www.theguardian.com/social-care-network/2014/dec/02/care-act-2015-service-users-power-social>



## References and further reading

Beresford, P. (2002) 'User Involvement in Research and Evaluation: Liberation or Regulation?', *Social Policy and Society*, 1(2): 95–105.

Bindmen, J., S. Maingay and G. Szmukler (2003) 'The Human Rights Act and Mental Health Legislation', *British Journal of Psychiatry* 182: 91–94.

Department of Health (1989) *Caring for People: Community Care in the next Decade and Beyond* (White Paper), London: Department of Health.

Department of Health (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services*, London: Department of Health.

Department of Health (2007) *A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services*, London: Department of Health.

Gould, D. (2012) *Service users' experiences of recovery under the 2008 Care Programme Approach*, London: NSUN.

<http://www.nsun.org.uk/assets/downloadableFiles/service-users-experiences-of-recovery-under-the-2008-care-programme-approach--a-research-study--dorothy-gould-2012.-full-report2.pdf>

Kalathil, J. (2011) *Dancing to our own tunes: reprint of the 2008 report with a review of work undertaken to take the recommendations forward*, London: NSUN.

<http://www.nsun.org.uk/assets/downloadableFiles/dtoots-report---for-website2.pdf>

Norfolk, Suffolk and Cambridgeshire SHA (2003) *Independent Inquiry into the death of David Bennett*, Cambridge: Norfolk, Suffolk and Cambridgeshire Strategic Health Authority.

Perry, E., J. Barber and E. England (2013) *A review of values-based commissioning in mental health*, London: NSUN.

<http://www.nsun.org.uk/assets/downloadableFiles/values-based-commissioning-report--20132.pdf>

Rankin, J. (2004) *Developments and Trends in Mental Health Policy*, London: Institute for Public Policy Research (IPPR).

Tait, L. and H. Lester (2005) 'Encouraging User Involvement in Mental Health Services', *Advances in Psychiatric Treatment*, 11: 168-175.



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The National Involvement Partnership (NIP) project supported this work with a three year grant from the Department of Health's Innovation, Excellence and Strategic Development Fund (IESD).

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‘Nothing about us  
without us’

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Registered Charity  
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Company number  
7166851

First published  
March 2015