TRANSFORMING PARTICIPATION IN HEALTH AND CARE

‘The NHS belongs to us all’
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Who is this guide for?

This guide will help clinical commissioning groups (CCGs) and other commissioners of health and care services to involve Patients and carers in decisions relating to care and treatment.

It will also be of interest to:

- People providing health and care services
- People providing support to commissioners.
- NHS England nationally, regionally and at Area Team level
- Patients and carers
- Voluntary sector groups and organisations with an interest in patient and public participation

The public in commissioning processes and decisions.
The NHS and our vision for participation

‘The NHS belongs to the people. It is there to improve our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill, and when we cannot fully recover, to stay as well as we can to the end of our lives.’

The NHS Constitution

The NHS is a cherished national institution. Its founding principle is to provide healthcare which is free at the point of delivery, to anyone who needs it, regardless of their circumstances. The NHS must be more responsive to the needs and wishes of the public, all of whom will use its services at some point in their lives.

NHS England will ensure that public, patient and carer voices are at the centre of our healthcare services, from planning to delivery. Every level of our commissioning system will be informed by insightful methods of listening to those who use and care about our services.
This guidance supports two new legal duties placed on NHS Commissioners by the Health and Social Care Act 2012, requiring Clinical Commissioning Groups (CCGs) and commissioners in NHS England to enable:

- patients and carers to participate in planning, managing and making decisions about their care and treatment, through the services it commissions;
- the effective participation of the public in the commissioning process itself, so that services provided reflect the needs of local people.

The purpose of this document is to support commissioners to improve individual and public participation and to better understand the needs of the communities they serve. The guidance aims to help commissioners and others understand what individual and public participation mean in practice and to support them in developing the culture, systems and processes which will make participation a reality.

The guidance highlights a range of ways in which NHS commissioners can fulfil their statutory responsibilities and seize the opportunity to deliver personalised and responsive care to all. It applies equally to clinical commissioning groups (CCGs) and to NHS England's own directly commissioned services.

However, participation is not only about legal requirements. It underpins everything that the NHS in England does. The first annual planning document of the NHS Commissioning Board (now NHS England), *Everyone counts: planning for patients 2013/14*, outlines the incentives and levers that will be used to improve services and is accompanied by other documents to help local clinicians deliver more responsive health services, focused on improving outcomes for patients, addressing local priorities and meeting the rights people have under the NHS Constitution.

*Everyone counts* sets out clear expectations of how participation is central to achieving these improvements.

The statutory duties and a downloadable summary of the legal obligations for CCGs can be found on page XX.
The Equality Delivery System (EDS) was developed in 2011 to help the NHS understand how equality can drive improvements and strengthen the accountability of services to patients and the public. Equality must lie at the heart of the NHS – its values, processes and behaviours – if we are to create a service that meets the needs of every patient and benefit from the contribution of all staff. It has been designed as an optional tool to support NHS commissioners and providers to deliver better outcomes for patients and communities and better working environments, which are personalised, fair and diverse.

‘A quality service is one that recognises the needs and circumstances of each patient, carer, community and staff member and ensures that services are accessible, appropriate and effective for all, and that workplaces are free from discrimination where staff can thrive and deliver.’

Good engagement practice for the NHS
An Equality Delivery System for the NHS, 2011
Participation to address inequalities

Health Inequalities

‘The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. The service is designed to diagnose, treat and improve both physical and mental health. It has a duty to each and every individual that it serves and must respect their human rights. At the same time it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.’

The NHS Constitution, 2010

The Marmot Review, Fair Society, Healthy Lives (2010) clearly demonstrated the difference in life expectancy between socio-economic groups. At a local level, Joint Strategic Needs Assessments (JSNAs) tell a similar story. If we are to truly address these inequalities, all our activity should start from the stance of those who experience the greatest inequality, whether in the individual’s own care, or as part of wider public participation in health and care.

To understand what is and is not working for patients and communities, we need to ensure that:

- all participation activity reaches communities and groups with distinct health needs and those who experience poor health outcomes;
- we consider how to reach people that experience difficulties accessing health services or have health problems that are caused or affected by their socio-economic circumstances;
- people who have characteristics that are protected under the Equality Act 2010 are integral to all participation and measures taken to enable patients to participate in their own health are designed in a way which is meets individual needs.
Participation to address inequalities

Working with the voluntary sector

Source:

‘Working with the voluntary and community sector: a guide for health and wellbeing boards’, by kind permission of Regional Voices.

Voluntary and Community Sector (VCS) organisations often work with the most disadvantaged communities - both geographic localities and communities of interest - and are therefore an excellent route to engagement.

Locally, the best source of support for linking with the voluntary sector is frequently the council for voluntary services (CVS), sometimes called a local development and support agency. These organisations can help commissioners reach large numbers of VCS organisations in their area. CVSSs often facilitate a network of organisations working in health and social care, which can be useful for commissioners and policy-makers to work with and are a good starting point in developing engagement mechanisms.

In each of the nine English regions, there is a regional infrastructure organisation which works closely with health and care organisations and networks as well as those operating in areas which are wider determinants of health, such as housing or employment. Working with the VCS at a regional level promotes networking, sharing and learning between localities. The regional networks are a good point of contact for an alternative view on engaging with the VCS in each area.
The Health and Social Care Act 2012 sets out two complementary duties for Clinical Commissioning Groups (CCGs) with respect to patient and public participation. These and related reporting requirements are summarised here. NHS England is bound by the same duties with respect to public participation and is also required to publish an annual report which is laid before Parliament.

Further information about other statutory and regulatory frameworks for patient and public participation will be made available on the NHS England website.

‘Must dos’ for commissioners

NHS commissioners must:

1. Make arrangements for and promote individual participation in care and treatment through commissioning activity.

2. Listen and act upon patient and carer feedback at all stages of the commissioning cycle – from needs assessment to contract management.

3. Engage with patients, carers and the public when redesigning or reconfiguring healthcare services, demonstrating how this has informed decisions.

4. Make arrangements for the public to be directly engaged in governance arrangements.

5. Publish evidence on an annual basis of what ‘patient and public voice’ activity has been conducted and how it has informed decision making.

An overview of the legal duties for NHS commissioners set out in the Health and Social Care Act 2012 can be found here.
Individual Participation

Putting patients in control of their own care
TRANSFORMING PARTICIPATION IN HEALTH AND CARE

INDIVIDUAL PARTICIPATION

WHAT? WHY? HOW? HELP & SUPPORT CASE STUDIES

SARAH CLARK
CCG COMMISSIONING GROUP

Click to Play
What is our vision of individual participation?

‘I want to feel heard and understood. I want to know about my options, and I want to be supported to make a decision based on what matters to me.’

A personal view of shared decision making

‘I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.’

A narrative for person-centred co-ordinated care

People are involved in decisions about their care, when they are managing their own care and when they have choice and control over the NHS services they receive. From booking an appointment, or choosing which hospital to attend, to receiving 24 hour nursing care, the NHS will offer patients as much control over the services they receive as they want.

The amount of control an individual wishes or is able to take may vary according to their background and experience as well as their current circumstances.

For example, someone with a long term condition may work collaboratively with health professionals to develop a care plan which helps them achieve their own goals and self manage their health. Someone with complex needs requiring 24 hour care may want to take full control and employ their own carers using a personal health budget. People who need to make episodic decisions about treatment or care (for example, whether they should have an operation) will be supported to make shared decisions with their health professionals.

View individual participation ‘Must Dos’ here
What is our vision of individual participation?

Requirements of clinical commissioning groups

As stated in the NHS England business plan ‘Putting Patients First’, ‘by 2015 80% of CCGs will be commissioning to support patients’ participation and decisions over their own care. They will have a plan in place to do so by December 2013. This includes information and support for self-management, personalised care planning and shared decision making within normal service planning and commissioning.

In addition, the NHS Mandate sets an objective that ‘everyone with a long-term condition, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions’.

Care plans should be digitally accessible as well as in printed form. Meanwhile, people who could benefit will have the option of a personal health budget by April 2015.

By April 2014, people with NHS continuing care will have the right to ask for a personal health budget, including a direct payment.
People’s lives can be transformed when they have knowledge, skills and confidence to manage their own health, when they are able to shape their care and treatment to fit with what is important to them. When health outcomes and goals are agreed, needs are better met and people are supported to manage their own care. There is now a growing body of literature to show that patient participation:

**Improves outcomes**

We know that when patients are involved in decisions about their own care and treatment and have more knowledge and confidence, they have better outcomes, follow appropriate drug treatments, avoid over-treatment, and are less likely to be hospitalised.

Reviews of evidence around self-management have shown it to be highly effective with the right support, including health coaching, structured education, tele-monitoring and supported patient networks.

For major users of NHS services, the evidence suggests that personalised care planning is highly effective.

**Provides value for money**

Around 15 million patients with long term conditions (LTCs) provide 4,800 hours of self-care for every four hours of NHS care. At the moment, our energies go into making the four hours of NHS care more efficient, rather than seeing the value that patients and carers can bring. A recent study by Nesta estimated £4.4bn could be saved in the NHS through greater participation and self-management of long term conditions.

One US study found that a patient’s skills and confidence to engage in their own health and care could amount to 21% reduction in costs.
Improves quality of life

An extensive trial of Personal Health Budgets has shown improved quality of life and cost-effectiveness of treatment, particularly for people with higher levels of physical or mental health needs. Carers also reported improved quality of life and perceived health.

Shared decision making allows individuals to discuss their options with the health care professional and come to a decision that fits in with their needs, preferences and circumstances, also leading to an improved quality of life and better outcomes.

Research has shown that treatment decisions change when patients are well informed and that there are substantial gaps between the outcomes patients prefer and the outcomes doctors think patients prefer.
Commissioners need to work with providers to bring about a rebalanced, collaborative relationship with patients, and develop the following:

- **Self-care and self-management** to help individuals better manage their health and healthcare.

- **Shared decision-making**, discussing options and the risks and benefits of each with the patient including the use of Patient Decision Aids (PDAs) where appropriate.

- **Collaborative, personal care planning** for people with long term conditions and personal health budgets.

Professionals need to work towards holding a new type of conversation (a more inclusive discussion) to identify each individual’s needs and goals and the ways in which these can be achieved, developing and supporting:

- **Self-management support** such as peer support, personal and telephone coaching, peer support networks - face to face and digital, health literacy programmes, ‘expert patient’ programmes, community health champions, volunteer ‘health trainers’.

- **Training and support in patient-centred approaches** for clinicians/healthcare professionals and patients, focusing on patient participation in decisions about their care. For example, Ask 3 Questions, Co-creating health and personal health budgets and shared decision making such as Patient Decision Aids (PDAs).

- **Information** to ensure that people have access to clinically accurate, understandable information material and practical tools, tailored to their particular conditions and needs such as ‘Information Prescriptions’ or information produced by organisations accredited with the Information Standard. People should have access to their own records and data. Those who need it should have customised support to help them understand their health, the options available to them and to make decisions.

Different systems and pathways which move away from traditional reactive and disease-centred systems and towards proactive and person-centred ones which are outcome focused and build on individual’s goals and preferences in partnership with clinical need. See, for example, the **House of Care**.
Commissioners should use the full range of levers and incentives available to them in order to promote individual participation. These include:

- the service condition clauses on care planning in the NHS Standard Contract;
- local CQUINs;
- enhanced service schemes.

NHS England will continue to support commissioners to use these levers, including signposting and developing robust metrics.
Measuring Progress

All services should be seeking to improve all of the time. Information on the quality of services, including patient feedback, should be used to help:

- services understand where they can improve (insight data);
- services understand how they can improve (improvement data);
- commissioners understand whether services are delivering their overarching aims (outcome data).

A coherent measurement system (otherwise called a measurement hierarchy) can be built by using insight data to feed into an improvement data set that delivers on the overall purpose of the system.

Details of a range of existing measures and tools available to help monitor and evaluate progress in individual participation can be found [here](#).
The ‘House of Care’ is one example of how a proactive, person-centred approach can be achieved. It is made up of four interdependent components:

Commissioning – driving quality improvement.

Engaged, informed individuals and carers – enabling individuals to be involved in all decisions about their care, to self-manage and truly say ‘No decision about me without me’.

Organisational and clinical processes – structured around the needs of patients and carers using the best evidence available.

Health and care professionals working in partnership – listening, supporting, and collaborating for continuity of care. Professionals starting with patients not services.
Personalised care plans

Every person with a long-term condition or disability should have a personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health.

There is no single standard or methodology for producing a care plan. However, there are some common principles which should be applied:

- Plans should be developed in partnership between patients, carers and health professionals.
- Plans should be holistic and consider health, wellbeing and life more widely than the symptoms or condition the person has.
- Plans should be focused on agreed goals and outcomes which are relevant to the person, with an agreed action plan for achieving these and, where relevant, contingency planning for crisis episodes.
- Plans should be agreed by both parties and owned by the patient.
- Plans should be reviewed regularly at intervals which make sense to the individual.
- People should have the right information and support to be able to manage their conditions in ways that work for them, including access to community and wider services.
How?

Continuum of strategies to support shared decision making

Helping people share decision making: a review of evidence considering whether shared (supported) decision making is worthwhile.

A suggested plan of action for commissioners

1. Understand what individual patient participation is and what is already happening locally. What are patients saying about how they are involved in their care? How can individual participation better meet their needs and improve outcomes?

2. Identify the gap. What more is needed locally to ensure that patients and carers are involved in decisions about their healthcare. For example, access to relevant information and informed discussions with clinicians; integrated personal care planning for patients with long term conditions, and, where appropriate, the option of a personal health budget.

3. Identify local champions and resources, linking in with local patient groups, other CCGs, Commissioning Support Units (CSUs), voluntary organisations and other partners.

4. Use the tools and support guides available, many of which are highlighted in this guidance, to develop local implementation plans.

5. Monitor implementation, and measure the impact of patient participation, for example on service improvement and health outcomes.

6. Seek feedback about what is working well and areas for improvement, through commissioner assurance and wider patient engagement.

7. Share learning through local, regional or national networks.
Practical support from NHS England

NHS England will work with partners to:

1. Develop a standard for interactive / digital care plans to support GPs and health professionals by April 2014.

2. Develop training for health professionals and ensure it becomes part of the appraisal process in revalidation from 2015.

3. Develop local support and training for patients and carers so that by 2015 everyone has access to a locally appropriate support service.

4. Launch a new certification process for entrepreneurs to easily offer tools and services that support personalisation.

5. Develop further guidance and support including best practice and other information which will make personalisation a reality.

6. Provide delivery support to aid the introduction of personal health budgets.
Individual participation case studies

View all case studies for download here.

- Personal Health Budgets
  Download

- Shared Decision Making
  Download

- Bolton Staying well
  Download

- Virtucare Phoenix
  Download

- Newcastle FT Magic
  Download

- Birmingham - Living Well
  Download
Public Participation
Communities with influence & control
SARAH CLARK
CCG COMMISSIONING GROUP

Click to Play
What is our vision of public participation?

Every part of our health and care system is shaped and improved by involving those who use and care about our services. Everyone contributes their distinctive perspective, especially those who face the greatest health disadvantage and the poorest health outcomes.

Progressing from listening and understanding to collaboration, we all benefit from a rich understanding of what is needed and how to co-design and deliver services that meet these needs.

People have a voice at different levels throughout our structures, from board level to front-line services.
Evidence suggests that engaging and involving communities in the planning, design and delivery of health and care services can lead to a more joined-up, co-ordinated and efficient services that are more responsive to local community needs. NHS England will work with partners to identify further evidence that involving patients and communities in commissioning decisions improves outcomes and increases efficiency, and to disseminate it widely.

Why?

Improving outcomes

Services are better designed around the needs of patients, service users and carers when they are involved in the commissioning process.

Enabling public participation also provides other specific benefits for those who contribute including:

- improved self confidence;
- better understanding by the public of how the NHS operates;
- more appropriate use of health services;
- shared responsibilities for health care between NHS services and the public.

Building relationships

Continual and open dialogue between commissioners, local leaders, community members and other stakeholders fosters a culture of transparency and trust. Commissioning decisions are better supported when people are involved in identifying problems and designing solutions that work.
From insight to improvement

Insight gathered from the public helps to improve services and outcomes as well as potentially helping to spot failures. Listening to and using the voice of patients and the public were never more forcefully presented than in the Francis report.

The use of patient and staff focus groups in the Keogh review into the quality of care and treatment provided by 14 hospital trusts in England was probably the single most powerful aspect of the review process and ensured that a cultural assessment, not just a technical assessment, could be made.
A suggested plan of action for commissioners

1. Use the tools and support in this guidance.

2. Identify experts within your own organisation and networks, for example Lay Members and Practice Managers with thriving Patient Participation Groups.

3. Build upon existing structures and relationships, use tried and tested methods to involve patients, carers and the public - especially those who represent excluded or marginalised groups.

4. Work with health and wellbeing boards to plan shared approaches with communities.

5. Develop joint approaches with local authorities, local Healthwatch, voluntary groups and other organisations, especially those who have existing relationships with local communities and have successfully worked together with local people in the past.

6. Through your CCG assurance, seek feedback from your partners and communities about what is working well and areas for improvement.

7. Reflect on your participation plans to ensure they reach those who experience the greatest health inequalities.

8. Feed back to communities about the impact of their involvement.
The ‘Ladder of Engagement and Participation’

There are many different ways in which people might participate in health depending upon their personal circumstances and interest. The ‘Ladder of Engagement and Participation’ is a widely recognised model for understanding different forms and degrees of patient and public involvement, based on the work of Sherry Arnstein. Patient and public activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

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<th>Step</th>
<th>Description</th>
<th>Example</th>
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<tr>
<td>Devolving</td>
<td>Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets.</td>
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<td>Collaborating</td>
<td>Working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.</td>
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<td>Involving</td>
<td>Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered. For example, partnership boards, reference groups and service users participating in policy groups.</td>
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<tr>
<td>Consulting</td>
<td>Obtaining community and individual feedback on analysis, alternatives and / or decisions. For example, surveys, door knocking, citizens’ panels and focus groups.</td>
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<tr>
<td>Informing</td>
<td>Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.</td>
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The principles of participation

NHS England has developed some principles of participation based on a review of research, best practice reports and other evidence.

Working with each other

1/ Our relationships will be conducted with equality and respect.
2/ We will listen and truly hear what is being said, proactively seeking participation from communities who experience the greatest health inequalities and poorest health outcomes.
3/ We will use all the strengths and talents that people bring to the table.
4/ We will respect and encourage different beliefs and opinions.
5/ We will recognise, record and reward people's contributions.
6/ We will use plain language, and will openly share information.

Working well together

1/ We will understand what's worked in the past, and consider how to apply it to the present and future.
2/ We will have a shared goal and take joint responsibility for our work.
3/ We will take time to plan well.
4/ We will start involving people as early as possible.
5/ We will give feedback on the results of involvement.
6/ We will provide support, training and the right kind of leadership so that we can work, learn and improve together.
The ‘Engagement Cycle’

The ‘Engagement Cycle’ represented here identifies key points in the commissioning cycle for public participation.

More information can be found here including resources to help develop public and patient engagement strategies and plans, which have been developed with the support of the Department of Health, the NHS institute for Innovation and Improvement and patient groups.
Good practice patient/carer and public engagement is ……

Consistently delivered by all staff, using good practice principles and ensuring that there is always a genuine intention to listen and respond to people.

Coordinated across all aspects of the organisation – with feedback from different sources being looked at together to influence commissioning decisions.

Properly resourced and delivered by people who really want to listen and learn, and who are supported to do so.

Delivered through a range of innovative and effective mechanisms, selecting the most appropriate for the audience targeted.

Delivered in partnership with patients and the public, especially when the most difficult decisions need to be considered and taken.

Going out of our way to ensure that different voices are heard across the communities we serve – often the most vulnerable people are most likely to be affected by any change.

Speaking with people who don’t currently use our services but may in the future or perhaps should be already using them but are not accessing services. We need to understand why this might be the case.

Able to clearly demonstrate the impact – that is, what has changed or been done differently in response to what we have heard.

14 http://www.clch.nhs.uk/media/122733/ppe_engaging_people_strategy_2013/pdf
NHS England will put in place:

1. An online CCG resource library including a library of tools, ‘how to guides’, best practice examples, and case studies highlighting the evidence for change as well as support with building networks for lay members on CCG governing bodies who have a lead role in championing patient and public involvement.

2. A Regional ‘field force’ offering practical support to develop greater participation, providing support to CCGs, CSUs, voluntary sector organisations and insight specialists.

3. A national ‘Excellence in Participation Awards’ scheme that gives status and profile to patient and public participation, promoting best practice. NHS England is working with patients and carers to develop this and expect details to be available soon.

Practical support from NHS England
Practical support from NHS England

NHS England will put in place:

4. An online participation space where anyone will be able to join, contribute or start a conversation about health and care. This will be supported by work with organisations such as Healthwatch England, the voluntary sector strategic partner programme, and the NHS Equality and Diversity Council, to ensure conversations from the online forum reach communities and that communities not able to participate digitally can contribute.

5. A national Citizens’ Assembly, by the end of 2013. This will put a representative citizen voice at the heart of decision making and hold the board of NHS England to account.

6. A ‘People Bank’ where citizens and organisations can register their interest in participation opportunities across NHS England’s activities, and for commissioners to identify interested people to engage with.
Help & support

Practical support from NHS England

NHS England will put in place:

7. A 360 degree feedback process to be used by NHS England and CCGs each year, aiming to achieve at least 80% satisfaction from stakeholders regarding the ways in which they have involved people in planning and commissioning services. The first of these within NHS England will be conducted in Spring 2014 and CCGs will be making their own arrangements.

8. The Building Local Health Partnerships programme to improve health outcomes through the development and national sharing of best practice in partnerships and relationships between CCGs, Health and wellbeing Boards and the VCS. Supported by NHS England, the programme is run by NAVCA and Social Enterprise UK in association with the Institute for Voluntary Action Research (IVAR). The programme leads on from a successful pilot that demonstrated the importance of partnership work in developing effective health care for patients in the emerging health environment.
Public participation case studies

Dorset pain management .......................................................... Download

Vision aims and values Leeds West ........................................... Download

Teenage cancer South West ..................................................... Download

People’s panel Hull ..................................................................... Download

Healthvoice Eastern Cheshire ..................................................... Download

View all case studies for download here.
Insight & Feedback

Understanding people’s experiences
Click to Play

Sarah Clark
CCG Commissioning Group
Our ambition is for the NHS to become a world class customer service, delivering treatment and care that always meet the needs and preferences of patients and service users. This means being flexible, responsive and efficient, but above all else it means always listening to what our patients and service users tell us. By routinely gathering people’s comments, feedback, complaints and suggestions, we can construct a rich database of information and evidence that will enable us to commission the services people want. This is what we mean by insight.

Insight can come in many forms: large scale surveys, focus groups, complaints, conversations with patients and service users, public consultations, comments on social media, personal feedback and patient stories. It can tell us what current and former patients think of our services, and the type of experience they have had. It can also tell us what people who are not yet patients or service users will need when the time comes. We have a lot of insight data already, but it is not always turned into structured or easily usable information; and it can often be quite dated, especially where it is only collected annually or for big research studies. Insight needs to be comprehensive, real-time and detailed, so that NHS commissioners have a strong and compelling evidence base to use in commissioning world class customer services on behalf of the people they serve.
Beyond the right to a good service, there is also evidence which demonstrates a clear link between patient outcomes and patient experience.

We also know that, where staff satisfaction is positive, the patient experience is likely to be better.

Collecting data on how people are experiencing services and how they report their quality of life following an intervention from the NHS allows us to understand where we are making a difference and what we might do to improve. The Patient Reported Outcome Measure (PROM) is an established method for patients to report back to providers and commissioners on the difference made to their quality of life, following diagnosis and treatment.

In addition to these measures the move towards real-time data through programmes such as the Friends and Family Test means that we can adapt and change quickly based on this feedback.
Listening as a driver for change

If we listen we will learn. Hearing first hand from people who use services is a powerful driver for change as this work produced by NHS Kidney Care show.
NHS England will undertake and publish 360 degree feedback from partners and stakeholders and use that to inform future planning, approaches and priorities, alongside CCG 360 degree feedback.

We will roll out the ‘Friends and Family Test’ to cover all NHS services by the end of 2014/15. This is an integral part of ‘Putting Patients First’, NHS England’s Business Plan for 2013/14 – 2015/16.

We will be launching an online health literacy programme with UKOnline to train 100,000 people from disadvantaged communities by April 2014.

All NHS organisations will work with partners and providers to make online feedback and comment the norm in all settings, including NHS Choices.

CCGs will publish feedback they receive from their local Healthwatch about the health and care services in their locality.
In practice, the steps commissioners might want to take include:

**Set aims and objectives**

Be as specific as possible about what you need to know and identify the full range of people who can help you answer your question. This could include both users and non-users of a service.

**What do we know already?**

Knowing what evidence and insight already exist is a sensible starting point. There is a lot of good work readily available which might provide answers to your brief or at least ensure that anything you are designing draws on existing evidence. However, this does not remove the need to build evidence of local need and involve people at a local level.

**Commissioning new work**

Think about the best way of getting the information you want, based on your target population and what you need to know. Do you need qualitative data or quantitative data? What is the most appropriate methodology for gathering this: surveys, focus groups, observational work, interviews? There are many different organisations who work in this area, from academic bodies to market research companies. They will be able to offer help and advice on what will be most appropriate.

**Commission jointly**

Reflect on whether work can be commissioned jointly, including with your local authority partners. There may also be pieces of work where you might want to work with other CCGs, CSUs and other partners within the NHS or other sectors such as the voluntary sector. Sometimes a piece of work might need to be conducted at a very local level but often it can be done more cost-effectively and with a wider scope and pooled resources.

**Share the results**

Think about the best way to convey the findings. People will not always read long reports so how can you communicate quickly, clearly and effectively? A good example is provided here (insert link to CPES).

**So what?**

This is the most important stage. What does it mean? What do we do as a result? Too often research does not move beyond the reporting. Make sure you build in an action planning session with key stakeholders present who will take ownership of the results. Without this stage, the research is just a ‘nice to know’ and not the case for change it should be.
Help & support

NHS England will work with partners to:

1. Run a suite of national surveys and point you in the right direction to understand what you can learn from these. NHS England will review these over time and welcome your feedback on what you find useful, and where you think there are gaps in the data. Information about current surveys can be found here.

2. Offer support and advice to CCG and NHS commissioners on the different forms of insight available through our Insight Strategy to be published later in 2013. This will include a series of case studies and will provide guidance on which methodologies are most suitable for which projects.

3. Roll out the ‘Friends and Family Test’ to cover all NHS services by the end of 2014/15. This is an integral part of ‘Putting Patients First’, NHS England’s Business Plan for 2013/14 – 2015/16.
Develop Patient Centred Outcome Measures (PCOMs), which will be owned and driven by patients themselves. PCOMs move forward into a model that is owned by the individual, who then chooses to share their outcomes with peers and clinicians, in an open source approach. PCOMs will put patients in control of assessing their own health, illness and outcomes. PCOMs and PROMs are genuine methods of involving and understanding a patient’s perspective on the issues impacting their health.

Publish the most useful data and insight through the ‘Patient Insight Dashboard’, in a format that can be used and understood by patients, the public and local Healthwatch. The Patient Insight Dashboard will be available from Autumn 2013. Compile a list of suppliers of insight services. Different organisations will specialise in different types of work; some will be better suited to quantitative work whilst others’ expertise might lie in qualitative or observational work.
Insight & feedback case studies

Hillingdon A&E  Download

View all case studies for download here
<table>
<thead>
<tr>
<th>Glossary Item</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accessible</strong></td>
<td>Information, services or processes which can be used and understood by as many people as possible. In some cases, specific actions will need to be taken to make things accessible for different groups, for example providing information in different languages and formats or offering health services at different times of the day.</td>
</tr>
<tr>
<td><strong>Advocate</strong></td>
<td>Advocacy is a process of supporting and enabling people to express their views and concerns, access information and services, defend and promote their rights and responsibilities, and explore choices and options. An advocate is a trusted individual willing to act on another person’s behalf as well as someone who can work well with different members of the healthcare team such as doctors and nurses.</td>
</tr>
<tr>
<td><strong>Carer</strong></td>
<td>Someone who provides unpaid support to family or friends who cannot manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.</td>
</tr>
<tr>
<td><strong>Continuing Healthcare</strong></td>
<td>NHS continuing healthcare is the name given to a package of care that is arranged and funded solely by the NHS for individuals who are not in hospital but who have complex, ongoing healthcare needs.</td>
</tr>
<tr>
<td><strong>Co-design</strong></td>
<td>A process where commissioners work jointly with patients, service users or carers in the development of services and re-examine a service from the perspective of what service users want, need and find most effective.</td>
</tr>
<tr>
<td><strong>Co-production</strong></td>
<td>Co-production often refers to from the perspective of what service users want, need and find most effective.</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>Group of persons in a specific location (sometimes called a ‘community of place’) or a group of people who have a shared interest or characteristic bringing them together (sometimes called a community of interest).</td>
</tr>
<tr>
<td><strong>Consultation</strong></td>
<td>Asking patients, the public and others about specific proposals often within a set time frame. In a clinical setting, a consultation refers to a one to one medical appointment.</td>
</tr>
<tr>
<td><strong>Direct payments</strong></td>
<td>One way of managing a personal health budget is a direct payment where money is given directly to an individual or their representative for the management of their NHS care. This option became legal on 1 August 2013 and is in addition to the pre-existing legal options for managing a personal health budget - by the NHS, or through a third party.</td>
</tr>
</tbody>
</table>
Engagement  

The process of asking patients and the public (including specific groups) about how services are planned and provided with a view to informing decisions. See also The Ladder of Engagement on p.XX.

Empowerment  

Patients having the power to shape decisions about how services are planned and provided.

Expert Patients Programme  

The Expert Patients Programme (EPP) is a free self-management programme for people who are living with a chronic (long-term) condition. The courses are run by people who have chronic conditions and cover subjects such as pain and fatigue management, relaxation, coping with depression, healthy eating, communicating with family, and planning for the future. For more information, see here.

Health champions or trainers  

Health champions or Health trainers help others to enjoy healthier lives by raising awareness of health and healthy choices, sharing health messages, removing barriers and creating supportive networks and environments. They are two established examples of NHS schemes, often delivered jointly with voluntary or community organisations locally.

Health coaching  

A process that facilitates healthy, sustainable behaviour changes by challenging, supporting and/or mentoring a patient or service user to transform their goals into action(s). Also referred to as ‘wellness coaching’.

Health literacy  

The ability of a person to obtain, process, and understand health information and services needed to make sound health decisions.

Individual participation  

The involvement of individual patients in discussions and decisions about their health and care, and supporting people to have the knowledge, skills and confidence to manage their own health and care. The three main elements of individual participation are: shared decision-making; self-management support; and personalised care planning.

Information Prescription  

A personalised package of information provided by healthcare professionals to help patients and their carers to be better informed and more in control of their health and care. It may include information from the NHS, charities, and local organisations about conditions, treatment options, local services to support individuals to manage their conditions and signposts to holistic services (such as specialized exercise, benefits advice, self-help groups). The Information Prescription Service (IPS) allows users, both professional and public, to create information prescriptions for long-term health needs.
The Information Standard is an independent certification scheme and quality mark for organisations producing health and care information for the public. Any organisation achieving the Information Standard has undergone a rigorous assessment to check that the information they produce is clear, accurate, balanced, evidence-based and up-to-date.

Understanding gained from the evidence from patient experience and engagement in order to make services better and inform decision-making.

People with complex health needs or a combination of health and care needs may require support from a number of different agencies, covering different kinds of services and providers. For health, care and support to be ‘integrated’, there should be seamless transitions between services, and care must be person-centred, coordinated, and tailored to the needs and preferences of the individual, and their carer and family, if applicable.

A member of the public/someone outside the organisation who contributes a non-clinical or other nonprofessional perspective to a group or committee.

Long term or chronic conditions are illnesses that people live with for a long time and that currently cannot be cured, such as diabetes, heart disease, dementia and asthma.

Someone who is receiving medical care or treatment, whether in a health or care setting (such as a hospital or care home) or at home. Sometimes used interchangeably with ‘service user’, which is the generally preferred term in the social care sector.

Patients and the public being part of NHS decision making.

Patient Decision Aids are specially designed information resources or tools that help people to make decisions about difficult healthcare options, such as which treatment they feel will be best suited to their needs and preferences. PDAs enable patients to be more involved in a shared decision making process with their healthcare professional. See also Shared Decision Making below.
Patient Experience
A term used for individual and collective feedback. (1) Individual patient’s feedback about their experiences of care or a service e.g. whether they understood the information they were given, their views on the cleanliness of the hospital where they were treated. (2) A combination of all the intelligence held about what patients experience in services, drawing on a range of sources including complaints, compliments, and reporting of incidents and serious incidents.

Peer support
Peer support is where people with shared experiences come together to offer sympathy, understanding and mutual help. It can range from informal, social support, to more formalised programmes where patients might be referred to a peer support worker who is trained to help patients plan how to manage their health and wellbeing.

Person-centred care
Person-centred care takes patients and their families as the starting point of all decisions. Patients are equal partners with health professionals in planning, developing and assessing care to ensure it is most appropriate to their needs. It involves putting patients and their families at the heart of all decisions and requires a different kind of interaction between patients and healthcare professionals.

Personalisation
Personalisation means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support. The traditional service-led approach has often meant that people have not been able to shape the kind of support they need, or receive the right kind of help. Personalised approaches involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives. (Adapted from Scie Guide 47 Personalisation: a rough guide).

Personal health budgets
A personal health budget is an amount of money to support an individual’s identified healthcare and wellbeing needs, planned and agreed between them, or their representative, and their local NHS team. At the centre of a personal health budget is a care plan. The plan sets out the individual’s health and wellbeing needs, the health outcomes they want to achieve, the amount of money in the budget and how they are going to spend it. Personal health budgets can be used to pay for a wide range of items and services, including therapies, personal care and equipment. This allows individuals to have more choice and control over the health services and care they receive. For more information please visit www.personalhealthbudgets.england.nhs.uk/About/
Personalised care planning

A personalised care plan is an agreement between a patient and their health and care professional(s) which links support for self-management and clinical care to help the person manage their health day-to-day. The process of care planning is based on a collaborative discussion about the goals the patient wants to work towards; the support services the patient wants and needs; who is in charge of providing these services; what the support services have agreed to do and when they will do it. It may also include plans for medication, diet and exercise. These discussions are recorded in a written document and should be regularly reviewed.

Public participation

The public and communities of interest playing an active role in the work and decisions of NHS England and other NHS bodies. Sometimes called ‘engagement’ or ‘patient and public involvement’ (PPI). See also The Ladder of Engagement on p.XX.

Self-care

Self-care encompasses those actions people take for themselves, their children and their families to stay fit and healthy, from knowing how to take medicines and treating minor ailments, to seeking help when it is needed. For people with a long-term condition, self-care is about understanding that condition and how to live with it.

Self-management support

Self-management support enables and encourages patients with long-term conditions to develop the knowledge, skills and confidence to more effectively manage their health and wellbeing. Self-management can include finding out more about your condition; learning new skills and tools to help you manage your health; working in partnership with health care professionals; taking charge of your health care; choosing what is right for you; and getting support from other people in a similar situation.

Service user

Someone who uses health or, more usually, care services. Different people choose to use a range of terms including ‘client’, ‘patient’, ‘consumer’ or ‘customer’.

Shared decision making (SDM)

Shared decision making is the process by which a patient and their healthcare professional reach a decision together about treatment options and next steps. It requires patients and professionals to understand what is important to each other when choosing a treatment, weighing up clinical evidence and patient preferences. Patients will need information and support to understand their options, such as using a Patient Decision Aid. It is appropriate in any healthcare setting in which more than one option is available, including the option to do nothing.
**Structured education**

Programmes that provide patients with the education and support they need to enable them to manage their condition in a structured way, typically including a curriculum or course with trained educators and an agreed quality assurance process. The programmes will help patients learn about making lifestyle changes, managing medication, and monitoring symptoms. This term is particularly used in Diabetes e.g. DAPHNE and DESMOND courses.

**Tele-monitoring**

Where technology is used to monitor patients at a distance from or in a different location from the health care provider. This allows patients to manage their condition in their own home, using monitoring devices that share details such as blood pressure with the health care provider.

**Voluntary and Community Sector (VCS)**

VCS is a common umbrella term for organisations known variously as charities, third sector organisations, not-for-profit organisations, community groups, social enterprises, civil society organisations and non-governmental organisations.
In this chapter, you will find the following downloadable information and resources:

- Legal duties for commissioners;
- Measuring individual participation: measures and tools to help monitor and evaluate progress;
- Surveys for participation: national surveys which gather patient views on different services;
- Communication ‘top tips’;
- Case studies;
- Glossary.

NHS England is developing an online library of material to support commissioners with patient and public participation. The library can be accessed here.

New material will be added to the online library over time. In particular, we are planning resources on the following topics and will work with partners to develop these or use existing ones where available:

- Social value;
- The Compact;
- Working with the voluntary and community sector;
- Using grant funding;
- Working with Healthwatch.

If you would like to suggest additional resources which you would find useful, please contact the NHS England Participation Team:

Telephone 0113 825 0861
Email  england.nhs.participation@nhs.net
Legal duties

Placeholder text to introduce legal duties resource.

Measuring participation

There are a range of existing measures and tools available to help monitor and evaluate progress in individual participation.

<table>
<thead>
<tr>
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Measuring participation

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Download resource 3.0

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Surveys for participation

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</table>
Communication top tips

1. Use plain English, keep your style as simple and direct as possible, and ensure your meaning is clear. This will help people read faster, understand better and remember for longer. Jargon, long sentences and complicated structures can all deter people from getting involved. Avoid using uncommon or surplus words.

2. Be clear about the meaning of the words you use. Using complex or technical language is sometimes necessary, but always consider whether it is possible to use simpler terms. For example ‘use’ instead of ‘utilise’. Use the glossary in this guide, consult a thesaurus, or ask a colleague for suggestions.

3. Spell out acronyms. If you need to use an acronym, make sure that you spell out what the letters stand for as well as the meaning of the acronym. For example, ‘SDM’ stands for ‘Shared decision making’ and is defined in the glossary on p.5 of this guide.

4. Communicate with people as individuals rather than homogenous groups wherever possible. Where you do need to refer to a group and are unsure of the most appropriate terminology, check with someone from that group or someone who works with that group. Try not to generalise unless you are certain it is valid to do so. It is very easy to make assumptions about people without realising and despite the best of intentions.

5. Think about the physical design of your text as well as the words. Consider whether it should be available in alternative format such as ‘easy read’, large print or in different languages.

6. Ask someone else, preferably a lay person, or at least a colleague who isn’t directly involved in what you are doing, to look through any information intended for a non-professional audience in order to check readability.
Case studies

Use the links below to download all or a selection of case studies relating to each of the different participation chapters.

Individual participation case studies
- Personal Health Budgets
- Shared Design making
- Bolton Staying Well
- Virtucare Phoenix
- Newcastle FT Magic
- Birmingham - Living Well

Public participation case studies
- Dorset Pain Management
- Vision aims and values Leeds West
- Teenage cancer South West
- People’s Panel Hull
- Healthvoice Eastern Cheshire

Insight & feedback case studies
- Hillingdon A&E

Download all case studies here
Contact us

Email
Phone
Online
Twitter