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NHS
England

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

‘The NHS belongs to us all’

SEPTEMBER 2013

Patients and Information Directorate, NHS England
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This is an interactive PDF. To navigate, use the arrow buttons on either side of each page or locate a specific section using the tool bars within the document.

What's in this guide?

Executive summary

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.

The public in commissioning processes and decisions.

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;
- Health and wellbeing boards.

Foreword: Viewpoints

Tim Kelsey

National Director of Patients
and Information, NHS England

Sir David Nicholson

Chief Executive, NHS England

Lynne Craven

Expert Patient

Executive summary

Download the glossary **here**

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.

Our approach will focus on the assets in communities working in co-production with patients, families and carers and collaborating to improve outcomes.

Executive summary

What this means for commissioners

The Act sets out two duties for NHS commissioners with respect to patient and public participation. These and related reporting requirements are summarised here.

NHS commissioners should:

- Make arrangements for and promote individual participation in care and treatment through commissioning activity.
- Listen and act upon patient and carer feedback at all stages of the commissioning cycle – from needs assessment to contract management.
- Engage with patients, carers and the public when redesigning or reconfiguring healthcare services, demonstrating how this has informed decisions.
- Make arrangements for the public to be engaged in governance arrangements by ensuring that the CCG governing body includes at least two lay people.
- Publish evidence of what 'patient and public voice' activity has been conducted, its impact and the difference it has made.
- CCGs will publish the feedback they receive from local Healthwatch about health and care services in their locality.

An overview of the legal duties for NHS commissioners can be found here.

An overview of related policy frameworks can be found here.

Executive summary

Download a printable Executive Summary Overview **here**

Transforming participation in health and care: overview

To help NHS England and clinical commissioning group commissioners fulfil their statutory duties and involve patients and the public effectively and systematically, NHS England will work with partners to:

Chapter 1: Individual Participation

1| Ensure that every person with a long-term condition or disability has a personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health. NHS England will develop and implement a best practice standard that defines what good, personalised, digital care plans and planning processes look like, in order to support GPs and health professionals during 2014.

2| Launch a new certification process for entrepreneurs to easily offer on-line tools and services that support personalisation, to help commissioners to identify high quality suppliers.

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Chapter 1: Individual Participation

3 | Build a field force of practical support and help for commissioners, through the Patient and Public Voice Commissioning Support Programme, to introduce and roll out personal health budgets and approaches to personalisation so that anyone who can benefit will be able to have a personal health budget and care plan by April 2015.

4 | Launch an online health literacy programme with **The Tinder Foundation** to train 100,000 people from disadvantaged communities by April 2014.

5 | Launch ‘Patients in control’, a comprehensive programme including practical training, support and tools to support local communities to deliver Shared Decision Making, Personalised Care Planning and better self-management of their health.

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Chapter 2: Public Participation

1| Establish a national Citizens Assembly that will put a citizen voice at the heart of decision-making and hold the board of NHS England to account. We will also work with the British Youth Council and other children and young people's groups to establish a Children and Young People's Forum for NHS England.

2| Launch 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.

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Chapter 2: Public Participation

3 | Set up a Participation Academy, a programme of learning and development for people who want to explore roles as patient and community leaders in health and care. Working with partners, including local Healthwatch and health and wellbeing boards, we will work with local communities to identify routes to reach a diverse range of people who can champion the health needs and interests of local communities and citizens.

4 | Create a 'People Bank' where citizens and organisations can register their interest in participation opportunities across NHS England's activities and/or commissioners can identify interested people to engage with.

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Transforming participation in health and care: overview

To help NHS England and clinical commissioning group commissioners fulfil their statutory duties and involve patients and the public effectively and systematically, NHS England will work with partners to:

Chapter 3: Insight & Feedback

1| Roll out the Friends and Family Test to cover all NHS services by the end of 2014/2015.

2| Publish the most useful data and insight through the **Patient Insight Dashboard** in a format that can be understood by patients, the public and local Healthwatch, by Autumn 2013.

3| Develop Patient Centred Outcome Measures to gather genuine insight from patients about the outcomes that matter most to them across a range of specialised conditions.

Executive summary

Download the glossary **here**

Purpose of this guide

The Health and Social Care Act 2012 introduced significant amendments to the NHS Act 2006. This guidance supports two legal duties, 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 they commission;
- 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 and respond to 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 and to NHS England's own directly commissioned services.

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.

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Children and young people have a right to have their views taken into account on all issues that affect them yet often services are comissioned without effectively engaging with children, young people and their families. The same applies for other groups in the population, and the participation activities must take into account barriers associated with language, age, access to information, disability etc. Great participation reaches people who find it more difficult to get their views heard.

The statutory duties and a downloadable summary of the relevant legal obligations for CCGs and NHS England can be found here.

Executive summary

Participation to address inequalities

> '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

The Equality Delivery System

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.

Executive summary

Participation to address 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*

Health inequalities

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. We should take an asset based approach to working with and empowering communities.

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.
- 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 meets individual needs.
- 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 lack capacity are protected and empowered and that the provisions of the Mental Capacity Act (2005) are met.

Executive summary

Participation to address inequalities

Source:

'Working with the voluntary and community sector: a guide for health and wellbeing boards',

by kind permission of Regional Voices.

Working with the voluntary sector

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. CVSs 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.

A database of local support and development organisations is available from NAVCA the national voice of local support and development organisations.

Individual Participation

Patients in control of their own care

George Fielding Chair of Whizz Kidz, Kidz Board

What is our vision of individual participation?

Download the glossary **here**

'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

Patients and carers are involved in managing their own health, care and treatment. This means being involved in decisions about their care and having 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.

Requirements of clinical commissioning groups

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.

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. The Business Plan states that 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 there is a commitment that, by April 2014, people with NHS continuing care will have the right to ask for a personal health budget, including a direct payment. Meanwhile, people who could benefit will have the option of a personal health budget by April 2015.

Why?

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[1], avoid over-treatment[2], and are less likely to be hospitalised[3].

Reviews of evidence around self-management[4] have shown it to be highly effective with the right support, including health coaching, structured education, tele-monitoring[5] 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 a 21% reduction in costs[6].

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.

How?

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

Self-management to help individuals better manage their health and healthcare, such as:

- Group education, The Expert Patients Programme;
- Patient Activation;
- Peer support;
- Patient leaders;
- Patient online: the road map;
- Health literacy;
- Health Champions.

Shared decision-making

Shared decision-making, discussing options and the risks and benefits of each with the patient, such as:

- Patient Decision Aids (PDAs);
- Training professionals in shared decision-making (SDM);
- Information on options;
- Patient-held records;
- Prompts for professionals.

Personal care planning

Collaborative, personal care planning for people with long-term conditions and personal health budgets, such as:

- Peronalised outcome focused goal setting;
- Electronic care plans;
- Collaborative GP consultations;
- Information, support and advocacy e.g. Age UK;
- Social prescribing;
- Personal Health Budgets.

How?

'The House of Care'

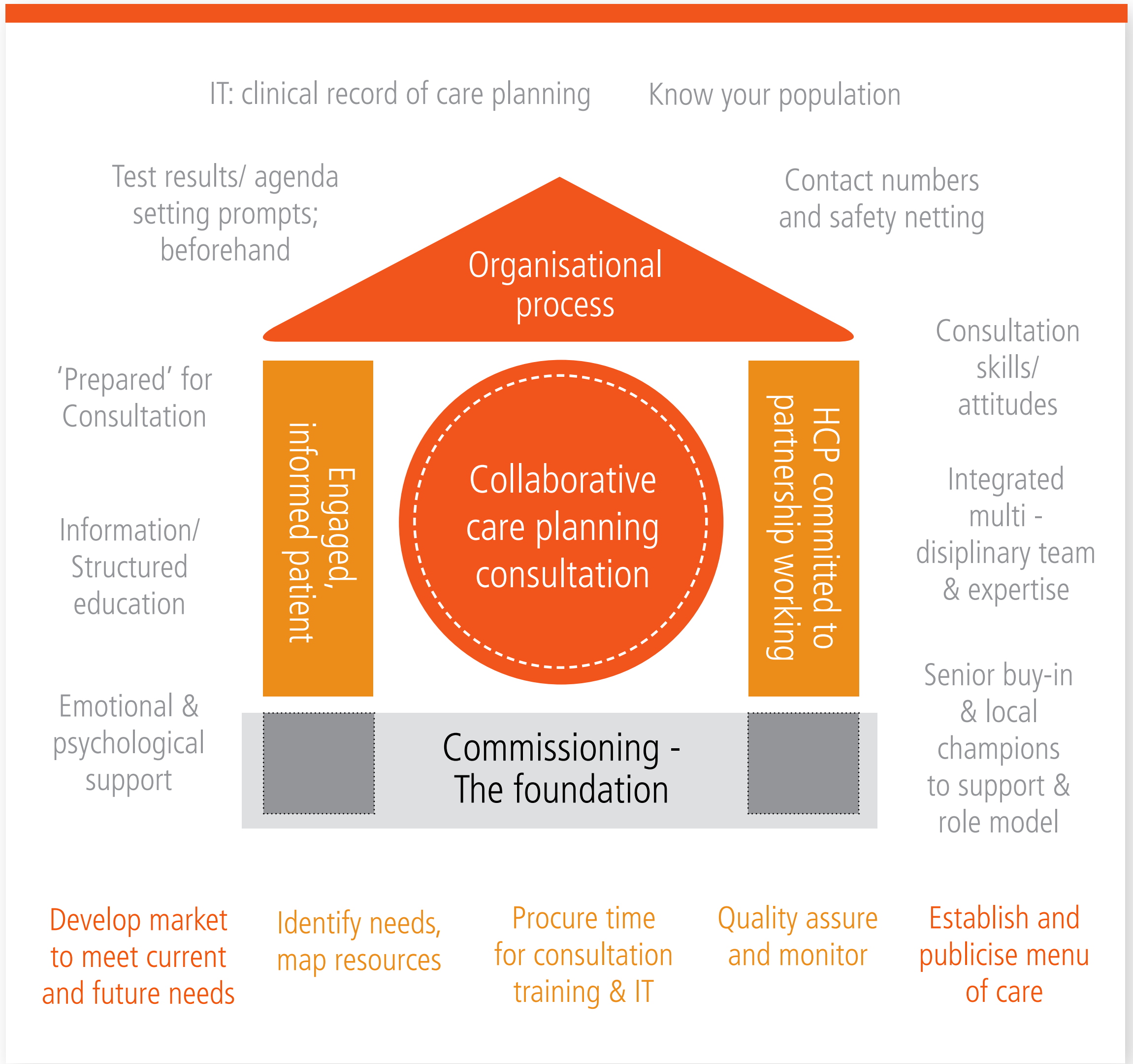
The 'House of Care' is one example of how a proactive, person-centred approach can be achieved. It is made up of four inter-dependent components:

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.



www.selfmanagmentsupport.health.org.uk

How?

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 process or methodology for developing a care plan. However, there are some common principles which are being developed by National Voices. The principles below are based on these:

- Plans should be developed in partnership between patients, carers and health professionals. Planning processes should pay due regard to the Mental Capacity Act (2005).
- 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.
- 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.
- 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.

How?

Levers and incentives

There are levers and incentives available to commissioners 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.

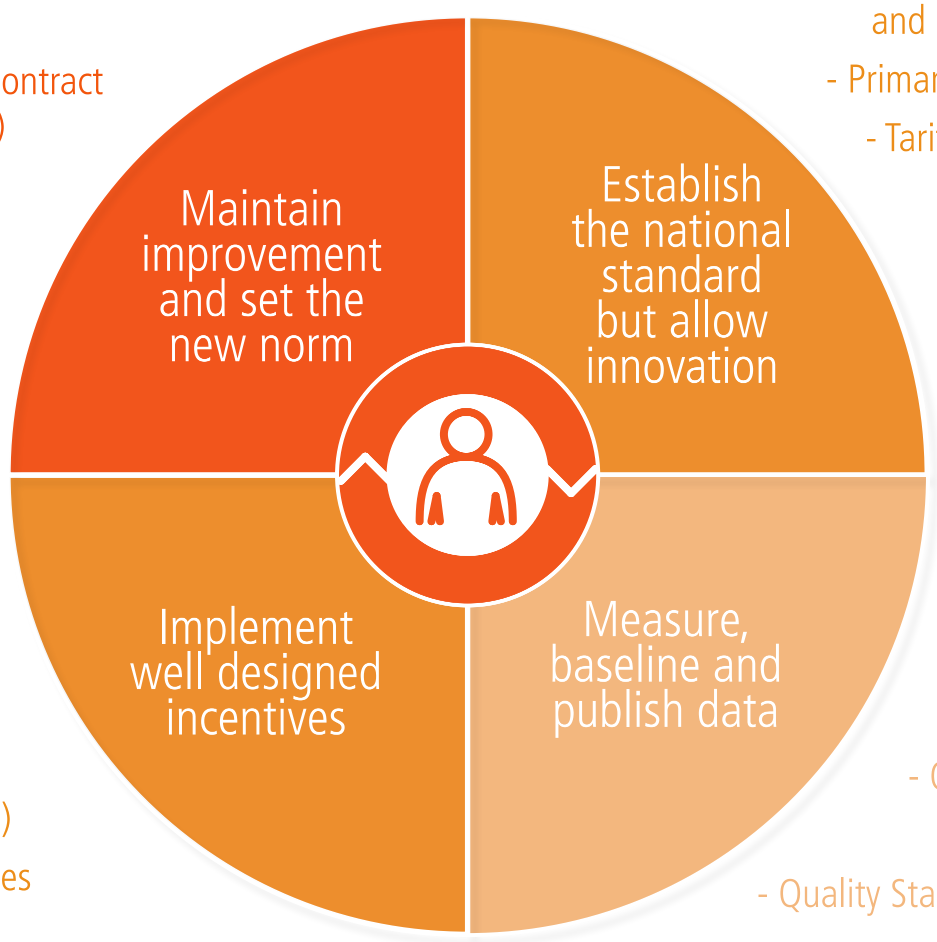
Commissioners should consider the full range of contractual options available to them when designing services to ensure patients receive seamless and personalised care.

4|

- NHS Standard Contract (National sanctions)
- NHS Standard Contract (Local sanctions)
- Primary care contracts
- National and local sanctions

1|

- NHS Standard Contract (particulars and general clauses)
- Primary care contracts
- Tariff business rules
- NICE Quality Standards



Maintain improvement and set the new norm

Establish the national standard but allow innovation

Implement well designed incentives

Measure, baseline and publish data

3|

- CQUIN
- NHS Standard Contract (Local incentives)
- Enhanced Services

2|

- Quality Accounts
- Care.Data
- Quality Standard Indicators

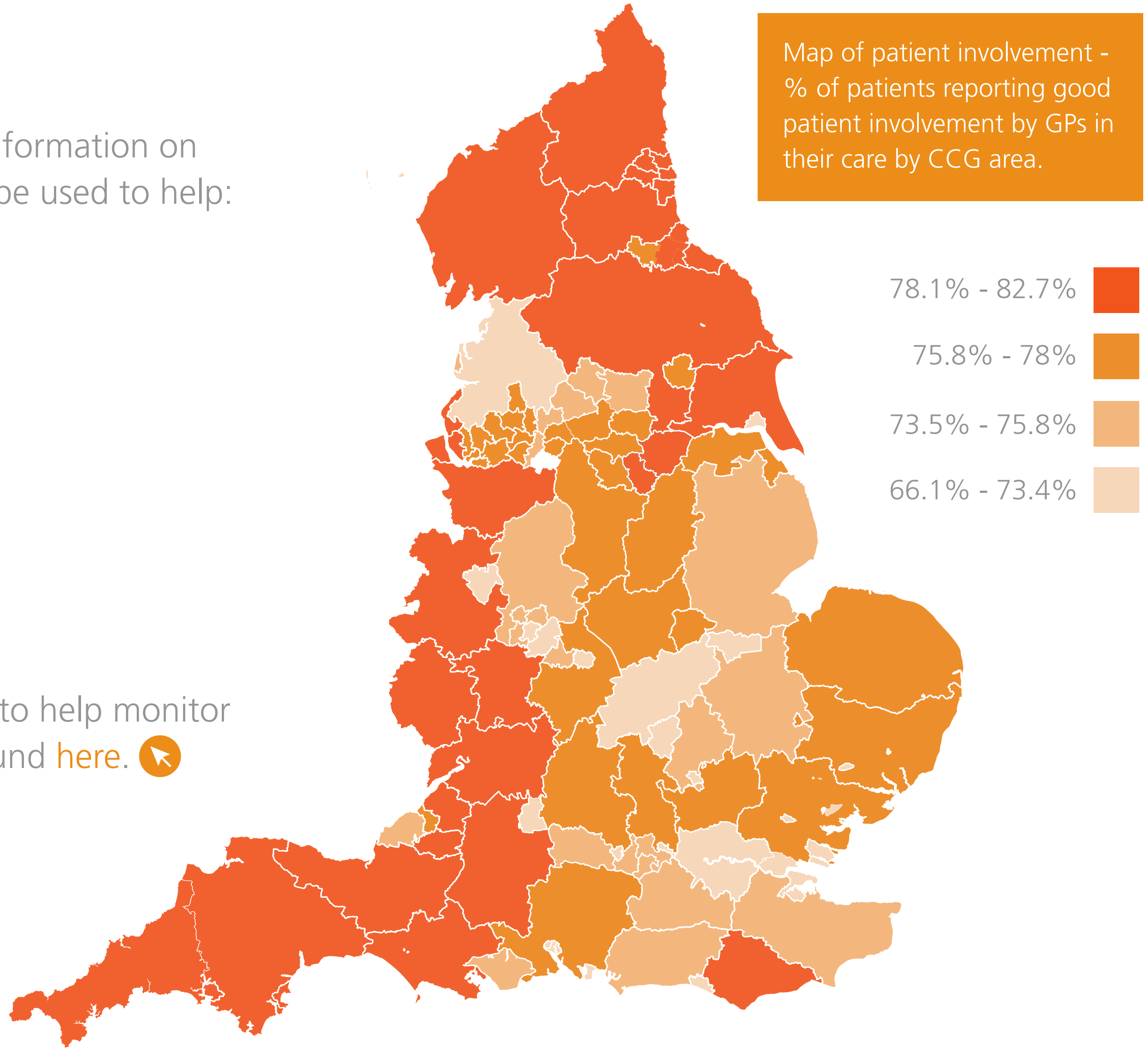
How?

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).

Details of a range of existing measures and tools available to help monitor and evaluate progress in individual participation can be found here.

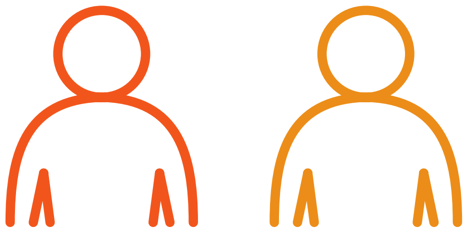


Map of patient involvement - % of patients reporting good patient involvement by GPs in their care by CCG area.

How?

Suggested action plan 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. Consider how information and support can be targeted to ensure it reaches appropriate audiences, for example support for those who lack capacity.

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 though local, regional or national networks.

Help & support

Click to read a full list of participation resources here

Practical support from NHS England

NHS England will work with partners to:

1| Ensure that every person with a long-term condition or disability has a personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health. NHS England will develop and implement a best practice standard that defines what good, personalised, digital care plans and planning processes look like, in order to support GPs and health professionals during 2014.

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Help & support

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Practical support from NHS England

NHS England will work with partners to:

4 Develop agreed approaches to including personalisation and person-centred approaches in all aspects of health professionals training, development and accreditation.

5 Develop further tools and resources that will support NHS commissioners to make patient participation a reality.

6 Launch an online health literacy programme with **The Tinder Foundation** to train 100,000 people from disadvantaged communities by April 2014.

Case studies & viewpoints

View all case studies for download **here**

Personal Health Budgets .... Download

Shared Decision Making .... Download

Vitrucare™ Phoenix .... Download

Newcastle FT MAGIC .... Download

Birmingham - Living Well .... Download

View all case studies for download here.

Christian Raphael, Vicky Raphael, (Christian's mum and carer) and Matthew Clark (Christian's Personal Assistant)

Sir David Nicholson Chief Executive, NHS England

Public Participation

Communities with influence & control

Faiza Khan

Deputy Chief Executive and Director of Policy and Communications, National Council for Voluntary Youth Services

What is our vision of public participation?

Download the glossary **here**

> ‘We must put citizen and patient voice absolutely at the heart of every decision we take in purchasing, commissioning and providing services.’
>
> *Tim Kelsey*
>
> *National Director of Patients and Information, NHS England*

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 and responsiveness, 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.

Our approach recognises, works with and strengthens the assets in our communities; and takes a collaborative approach to working with partners. Skills, resources and connections across the system are harnessed through effective partnerships including local HealthWatch, health and wellbeing boards, CCGs, local authorities patient groups, patient leaders and the voluntary and community sector.

Why?

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. Public participation can also help to build partnerships with communities and identify areas for service improvement. NHS England will work with partners to identify any further evidence and disseminate it widely.

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.

See case studies here.

Building partnerships

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.

The recent report, Changing care, improving quality (June 2013) developed by the Academy of Medical Royal Colleges, NHS Confederation and National Voices, calls for meaningful engagement of key stakeholders, including the public, patients and health professionals in proactive well planned service changes.

Participation for 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.

How?

The principles of participation

NHS England has developed some principles of participation based on a review of research, best practice reports and the views of stakeholders.

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.

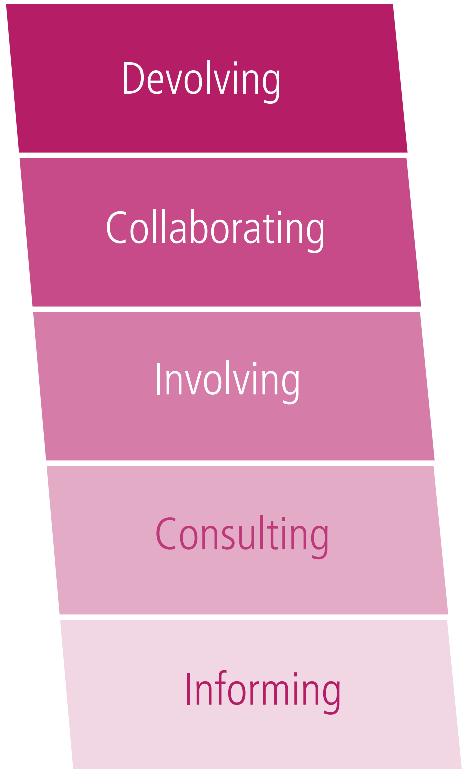
6/ We will provide support, training and the right kind of leadership so that we can work, learn and improve together.

How?

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[7]). Patient and public voice activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

Devolving	Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.
Collaborating	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.
Involving	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.
Consulting	Obtaining community and individual feedback on analysis, alternatives and / or decisions. For example, surveys, door knocking, citizens' panels and focus groups.
Informing	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.

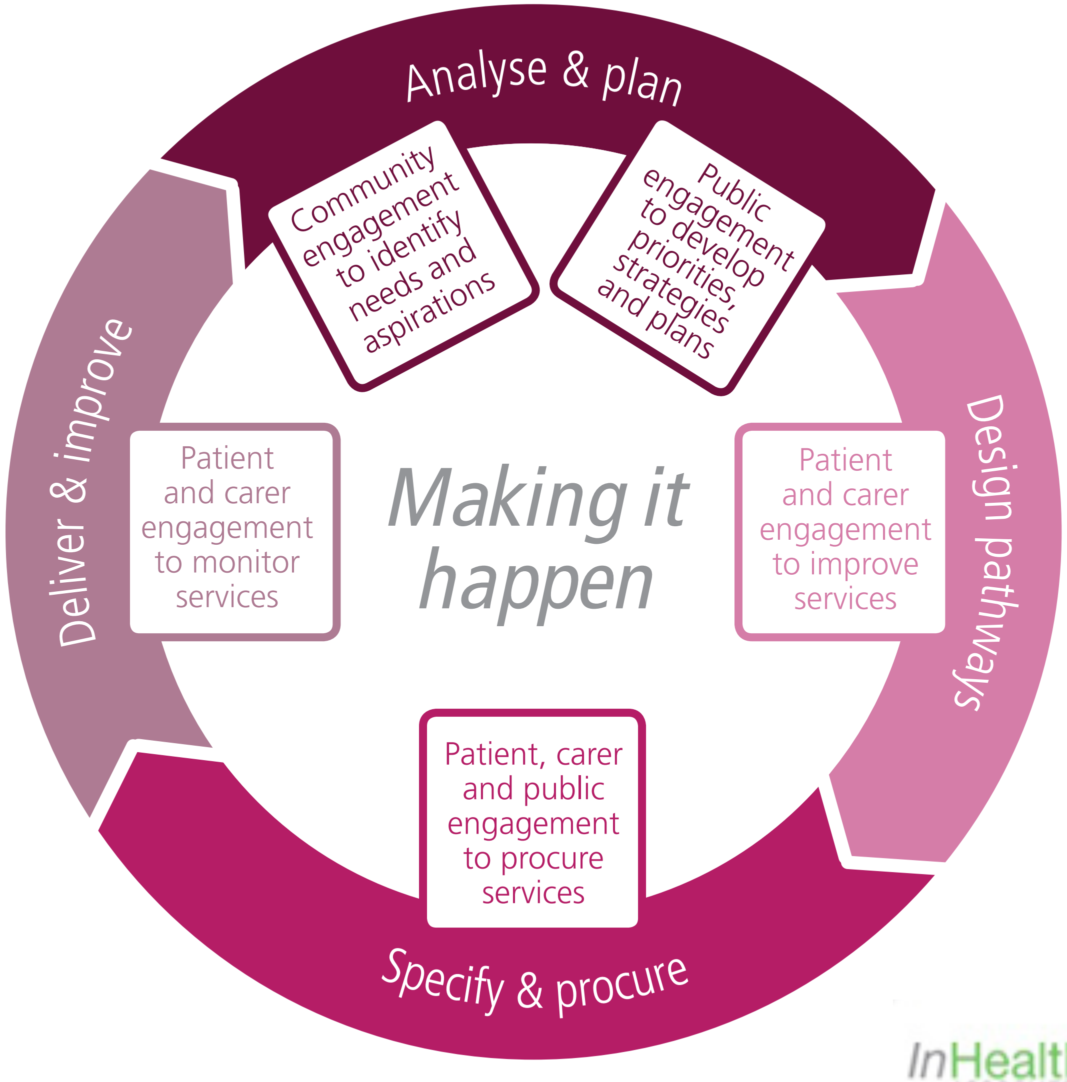


How?

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.

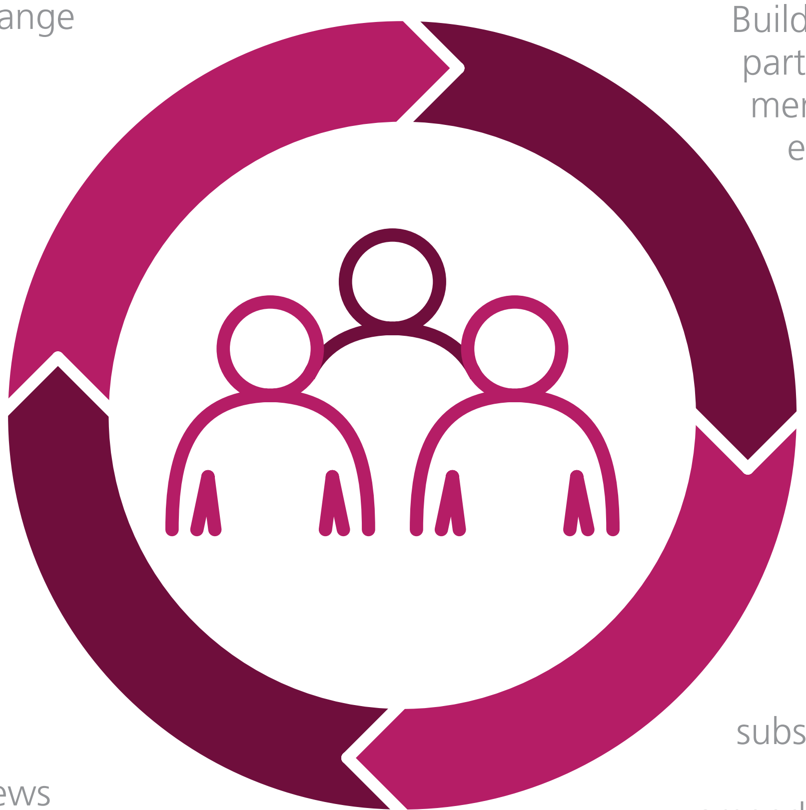


InHealth ASSOCIATES

By kind permission.

How?

Engaging the public in the planning and delivery of service change



Engage early:

If you identify the need for a major service change programme through working with all local partners including local Healthwatch and other members of the health and wellbeing board. Discuss the need for change with communities and work together to design options. It is good practice that proposals for major service change build upon engagement that has already been undertaken locally on commissioning plans and priorities.

Consult:

Build on the insight and early engagement work with partners to develop and implement detailed engagement and consultation plans. Commissioners should ensure they use an appropriate and proportionate spectrum of engagement activity that reaches their communities. There are no additional specific duties for commissioners with respect to consultation with the public around major service change proposals.

Consult the Local Authority Health Scrutiny Committee:

Where commissioners are considering any proposal for a substantial development of the health service in the local authority area, or for a substantial variation in the provision of a service. This is underpinned by S244 of the NHS Act 2006 (as amended), and explained further by the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

Implementing the outcome:

Finalise the proposal and move to implementation or retest revised proposals, taking into account the early engagement, views gained through any consultation, input from the Local Authority Health Scrutiny Committee, and views gained from the communities affected.

How?

Features of public participation

Providing good quality information

Ensuring that your local community understands and knows about all commissioning plans and opportunities available for participation. Options could include:

- Regular e-bulletins;
- Information posted locally on notice boards in GP practices, pharmacies, dental practices etc.;
- Information disseminated through local voluntary and community organisations;
- Local authority newsletters and circulations.

Providing a range of opportunities for participation

Not everyone will want to participate in the same way or at the same times and therefore it is essential that a range of options is provided. This could include:

- Online survey tools;
- Dedicated events to enable discussion about proposals;
- Seeking views from the community at local events or venues e.g. attending festivals, markets, schools, leisure centres, libraries etc.;
- Understanding the assets within your local community and collaborating to identify and solve problems together;
- Pro-active work through local voluntary and community sector organisations, including small grass roots organisations in order to collaborate and solve problems together, particularly with communities of interest e.g. mental health charities, homeless organisations.

How?

Features of public participation

Working with patients and the public from the initial planning stages

Working with the public right from the initial stages of service redesign or strategy planning will enable a richer level of participation and the opportunity to truly influence plans. This could include:

- Providing the facility for patients and the public to proactively suggest improvements at any time e.g. a suggestion box or online feedback page;
- Ensuring all plans are communicated to patients and the public as soon as they begin to be considered;
- Providing regular opportunities for patients and the public to meet commissioners.

Pro-actively reaching out to diverse communities

Good public participation reaches all the local community, not just those who are already informed and engaged. Options to reach more diverse communities could include working with and through groups and their wider networks such as:

- Patient leaders and local grass roots organisations that understand and can reach communities that do not currently participate;
- Local Healthwatch;
- The Patient Participation Group (PPG) at GP practices.
- Local voluntary and community networks.

How?

Suggested action plan 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. Work with community development workers to identify assets in your community and develop collective approaches.

4| Work with health and well-being boards and local Healthwatch to plan shared approaches with communities. Invest collectively in building assets and growing patient leaders.

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 process, ensure you seek feedback from your partners and communities about what is working well and areas for improvement.

7| Make sure your participation plans reach those who experience the greatest health inequalities.

8| Feed back to communities about the impact of their involvement, and the difference they have made.

Help & support

Click to read a full list of participation resources **here**

Practical support from NHS England

NHS England will work with partners to develop:

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. We will work together to develop tools and resources that support NHS commissioners to have great participation from children and young people.

2| The Patient and Public Voice Commissioning Support Programme. This will build networks of specific expertise to offer practical support to develop greater participation, provide support to CCGs and area teams and engage effectively with the voluntary sector to provide high quality commissioning support.

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.

Help & support

Click to read a full list of participation resources **here**

Practical support from NHS

NHS England will work with partners to develop:

4 A national Citizens Assembly that will aim to put a citizen voice at the heart of decision-making and hold the board of NHS England to account. We will also work with the British Youth Council and other children and young people's groups to establish a Children and Young People's Forum for NHS England.

5 A digital 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 including those who do not participate digitally.

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

Click to read a full list of participation resources **here**

Practical support from NHS England

NHS England will work with partners to develop:

7 A 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.

8 The Building Health Partnerships Learning Network that brings together innovative projects that aim to improve health outcomes through development of best practice in partnerships and relationships between CCGs, health and well-being boards and the VCS.

9 A Participation Academy, a programme of learning and development for people who want to explore their roles as patient and community leaders in health and care. In collaboration with partners, including local Healthwatch and health and wellbeing boards, we will work with communities to identify routes to reach a diverse range of people who can champion the health needs and interests of their local communities and citizens.

Case studies & viewpoints

View all case studies for download **here**

Improving outcomes through public participation .... Download

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

Further reading

Elaine Mulvenna (Volunteer) and Helen Jones (Chief Executive) Leeds GATE

Helen Jones (Chief Executive), Leeds GATE

Shaun Webster, Co-ordinator, CHANGE. Tracey Rose, Head of Quality and Compliance, Joseph Rowntree Foundation/ Trust. Catherine Carter, Trainer and Auditing Co-ordinator, CHANGE. Victoria Pickles, Director of Corporate Affairs, Leeds Community Healthcare NHS Trust.

Insight & Feedback

Understanding people’s experiences

Kerry Bloodworth

Assistant Director of Nursing, Nottingham University Hospitals NHS Trust

What is our vision for insight and feedback?

Download the glossary **here**

> ‘We can gather data about the services that informed patients want, and work collectively with patients to co-design systems and services that will be what our populations deserve.’
>
> *Alf Collins*
> *Clinical Associate, The Health Foundation*

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.

Why?

The NHS Constitution is clear that every individual deserves to have as good an experience of the NHS as we can possibly provide. To ensure this happens, we need to listen to people in order to understand what they need and what works for them. This is what we mean by insight and feedback. Any service industry listens to the people it serves and the NHS should be no different. Insight is an important way of understanding the need and experiences of all communities and a key tool in tackling health inequalities.

Improving patient experience

Insight and feedback enable us to understand how to improve patient experience. Qualitative methods (for example interviews, focus groups or observational work) help us to find out what matters to people, so that we can design services which better meet their needs. See case studies here.

By listening and learning from patients, carers and their families, both when things go well and when they go badly, we can understand what we need to do to improve their experience. This can be achieved through feedback methods ranging from complaints, social media, the Friends and Family Test (see case study here) and feedback websites such as CareConnect or PatientOpinion.

Improving health outcomes

Beyond the right that people have to expect a good experience as patients, there is a great deal of evidence which demonstrates the wider health benefit of seeking and using insight and feedback[8]. For example positive patient experience has been associated with:

- better outcomes and enhanced recovery rates[9];
- better patient safety and clinical effectiveness.[10]

Improving health services

We know that the type of interventions highlighted in this guidance work because they have been measured using insight and feedback, as in the case study here. A range of methods, from conversations with individual patients to large-scale national surveys such as the GP Patient Survey, allow us to understand how well the NHS is doing at delivering health services that meet people's expectations.

There is also clear evidence of the link between positively engaged staff and positive patient experiences.[11] This demonstrates the importance of ensuring we seek feedback and views from staff as well as patients. From 2014 onwards we will introduce a Friends and Family Test question for staff alongside the national NHS Staff survey.

There is evidence to show that using patient experience and feedback in the design of services can lead to lower overhead costs.[12]

How?

There are a wide range of insight and feedback tools available. Each one will be applicable in different situations, depending on which audience you are trying to reach and what information you are trying to obtain. These tools fall into two main categories:

- Qualitative - more suitable for answering questions about why something is happening and what we could do to change things;
- Quantitative – tells you the extent to which something is happening.

Surveys

Large scale surveys allow us to measure patient experience and establish differences between groups and areas over time. Examples of this quantitative method at a national level include the GP Patient Survey and the CQC Inpatient Survey plus a range of other national surveys. Local surveys allow us to supplement national survey data, because there may be more specific questions you need to ask or particular groups in your local population that you need to know more about.

Friends & Family Test

The Friends and Family Test (FFT) is a simple single question survey which asks patients whether they would recommend the service they have received to their friends or family should they need it. This creates a net promoter score which is best accompanied by a brief comment from the patient which explains the reason for his/her scoring. FFT is different from more traditional surveys because it allows all patients to feedback rather than taking a sample approach. The feedback is near real-time meaning healthcare providers can make improvements to their services in a faster more responsive way. Real time feedback often highlights positive as well as negative comments which enables staff to celebrate success, boosting morale. See a case study here.

How?

Patient stories

Patient stories are an incredibly rich, powerful but underused source of information. They bring to life issues that really matter to people, in their own words. They can be collected through a number of sources including social media, letters, complaints and websites like PatientOpinion, PatientStories and the Life Story Network.

Focus groups and in-depth interviews

Focus groups and in-depth interviews allow us to understand subjects in greater detail and depth than surveys because questions are less structured, allowing room for exploration of the issues. They can often be used to inform the development of questionnaires for subsequent surveys.

Enagagement and consultations

Engagement and consultations with citizens and communities provide rich sources of insight and feedback beyond the specific issue under consideration. They are, therefore, not only an important tool for collective participation but also a key source of insight that can be used for wider purposes.

How?

Social media

Social media is an emerging, fast growing and important source of insight. There are some 500,000 comments about the NHS in England every week. These data sources can be harnessed to provide a deeper and richer understanding of people's concerns and interests relating to health services. Using social media can also help to engage a wide range of people who are often already discussing the issues you are trying to address.

Observational work

Observational work is particularly useful when designing interventions which people might not want to talk about or where actual behaviour differs from reported research, as in this case study looking at how to reduce violence in A&E. View the case study here.

Peer research

Training people to undertake research themselves in their own communities is an excellent way of obtaining insight into aspects of people's lives and cultures, as in the case study here.

How?

Suggested action plan for comissioners

1 | 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.

4 | Working together

The particular insight you need may be of benefit or interest to other organisations in your area such as the local authority, health and wellbeing board, local Healthwatch, other NHS organisations or voluntary sector bodies. It could be of greater benefit and more cost effective to collaborate with partners in gathering and using insight from local people and communities.

2 | What information already exists?

There is a lot of good insight material readily available including national surveys, and information held on particular patient groups or local communities by voluntary sector organisations, which might provide what you need or at least ensure that anything you are designing draws on existing evidence. This evidence should be used in conjunction with more specific information needed at a national level.

5 | 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.

3 | Commissioning new work

In commissioning new insight work for a particular information requirement from a target audience, think through the most appropriate methodology available. There are many different organisations specialising in this area who will be able to offer help and advice, including the voluntary sector, academic bodies and market research companies.

6 | Act on results

Make sure you work with key stakeholders to agree an action plan, based on the results of your insight work, to ensure that the learning is used to inform change and improvement. The action plan should include ways to feed back to people who participated to show how their involvement has made a difference.

Help & support

Click to read a full list of participation resources here

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.

2 Offer support and advice to CCG and NHS commissioners on the different forms of insight available through our Insight Strategy. This will include a series of case studies and will provide guidance on which methodologies are most suitable for which projects. We will also compile a list of suppliers of insight services, both quantitative and observational.

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.

Help & Support

Click to read a full list of participation resources here

NHS England will work with partners to:

4 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.

5 Develop Patient Centred Outcome Measures that put patients in control of assessing their own health, illness and outcomes. For twenty different specialised services, we will design measurement systems to understand what outcomes people want and create ways these can be shared, compared and understood. This will help build the evidence base for the effectiveness of treatments, therapies and interventions. As well as being a rich source of data, it will provide a network of online communities that enable patients with rare conditions, or requiring speciali-sed treatment, to establish peer networks providing mutually beneficial help, advice and support.

Case studies & viewpoints

View all case studies for download **here**

Hillingdon A&E	Download
Design Council ethnography & design	Download
Experience Based Co-design	Download
Macmillian Cancer and the Cancer Patient Experience Survey	Download
Liverpoool Heart & Chest Friends and Family Test	Download
RNIB Patient Journey Mapping	Download
Tower Hamlets peer research and cervical screening	Download

Graham Foulkes (Lay Member and Vice Chair) and Mark Drury (Head of Public Affairs), NHS Oldham CCG

Shahid Ali, General Practioner, Phoenix Medical Practice, Bradford, West Yorkshire

A final viewpoint

Download the glossary **here**

Dr Alf Collins
Clinical Associate, The Health Foundation

Resources and further information

Contents

In this chapter you will find the references and further reading for this guide. You will also find the following downloadable information and resources:

- Legal duties for commissioners.
- Policy context.
- Measuring individual participation: measures and tools to help monitor and evaluate progress.
- Surveys measuring patient experience: 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 or would like to work with us to develop resources, please contact the Patient and Public Voice Team:

☎ Telephone 0113 825 0861

✉ Email england.nhs.participation@nhs.net

References & further reading

References

1 ‘Self-care reduces costs and improves health: the evidence’, Expert Patients Programme 2010.

2 Stacey Cochrane Review and NHS Atlas of Variation in Healthcare, 2011.

3 Hibbard J.H. and Green J., ‘What the evidence shows about patient activiation; better health outcomes and care experiences; fewer data on costs’. Health Affairs 2013; 32:222207-14

4 The Health Foundation 2012, evidence review of self management

5 The Health Foundation 2012, evidence review of SDM and Coulter & Collins.

6 Hibbard J.H. and Green J., ‘What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs’. Health Affairs 2013, 32:2207-14

7 Arnstein, Sherry R. “A Ladder of Citizen Participation, “Journal of the American Planning Association, Vol. 35, No 4, July 1969, pp. 216-224

8 Robert G and Cornwell J (2011) What matters to patients? Developing the evidence base for measuring and improving patient experience. Project Report for the Department of Health and NHS Institute for Innovation & Improvement.

9 Weinman et al (2008) Enhanced wound healing after emotional disclosure information BJ Health Psychol 13(1) pp.95-102.

10 Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open 2013;3:e001570. doi:10.1136/bmjopen-2012-001570

11 West M and Dawson J, Employee Engagement and NHS Performance (2012)] [Maben et al, Patients Experiences of care and the influence of staff motivation, affect and wellbeing Patients Experiences of care and the influence of staff motivation, affect and wellbeing. Final report (2012).

12 DiGioia A 3rd, Greenhouse PK, Levison TJ (2007) ‘Patient and family-centered collaborative care: an orthopaedic model’ Clinical orthopaedics and related research, Oct; vol 463, pp 13-9

To return to a reference within the guide simply click on relevant reference number

References & further reading

Further reading

The following are sources of information and good practice of particular relevance to public participation. NHS England plans to update this list of further reading and to include further reading relevant to individual participation and to gathering insight and feedback.

- Changing Care, Improving Quality (June 2013), The Academy of Medical Royal Colleges, the NHS Confederation and National Voices

  http://www.nhsconfed.org/Publications/reports/Pages/Changing-care-improving-quality.aspx

- Community Development in Health – a literature review, compiled and edited by Dr Brian Fisher MBE

  http://www.healthempowerment.co.uk/wp-content/uploads/2012/11/HELP-Literature-Review.pdf

- Evidence base for the Community Health Champion approach, Altogether Better

  http://www.altogetherbetter.org.uk/evidence-and-learning

- Smart Guides to Engagement series

  http://www.networks.nhs.uk/nhs-networks/smart-guides

- The Asset Based Community Development Institute, School of Education and Policy, Northwestern University. Downloadable resources.

  http://www.abcdinstitute.org/publications/downloadable/

- Nesta, People Powered Health Co-production Catalogue

  http://www.nesta.org.uk/home1/assets/features/people-powered-health_catalogue

- Nesta, The Business Case for People Powered Health

  http://www.nesta.org.uk/areas_of_work/public_services_lab/health_and_ageing/people_powered_health/assets/features/the_business_case_for_people_powered_health

- NICE Community Engagement Guidance

  http://publications.nice.org.uk/community-engagement-ph9

Legal duties

Legal duties for clinical commissioning groups and NHS England

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Legal duties for clinical commissioning groups and NHS England

The Health and Social Care Act 2012 introduced significant amendments to the NHS Act 2006, especially with regard to how NHS commissioners will function. These amendments include two complementary duties for clinical commissioning groups with respect to patient and public participation. This document sets out the relevant statutory duties and provides a summary of related legislation that commissioners will find useful when developing their response. All references are to the NHS Act 2006 (as amended) ('the Act') unless otherwise stated.

Individual participation duties

Clinical commissioning groups (CCGs) and NHS England must promote the involvement of patients and carers in decisions which their care or treatment. This requires

This includes

- personalised care planning, including 'patient choice' and the option of a personal health budget when a person is eligible.

Download resource 1.0

Policy context

This resource provides an overview of relevant policy for commissioners developing their response to the statutory rights 'Transforming participation in health and care'.

A summary of the legal duties with respect to participaton, and other related legislation, is available as a complementary resource and can be downloaded below.

Download resource 2.0

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Policy context

This resource provides an overview of relevant policy for commissioners developing their response to the statutory guidance 'Transforming participation in health and care'.

A summary of the legal duties with respect to participation, and other related legislation, is available as a complementary resource and can be found here.

The NHS Constitution[1]

The NHS Constitution sets out the rights of patients, public and staff. It outlines NHS commitments to patients and staff, and the responsibilities that the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. All NHS

A series of rights for patients are specified, including (p6-10):

- The right to be given information about the test and treatment options available to you, what they involve and their risks and benefits.
- The right of access to your own

Measuring participation

There are a range of existing measures and tools available to help monitor and evaluate progress individual participation. A list can be downloaded here.

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Measuring participation

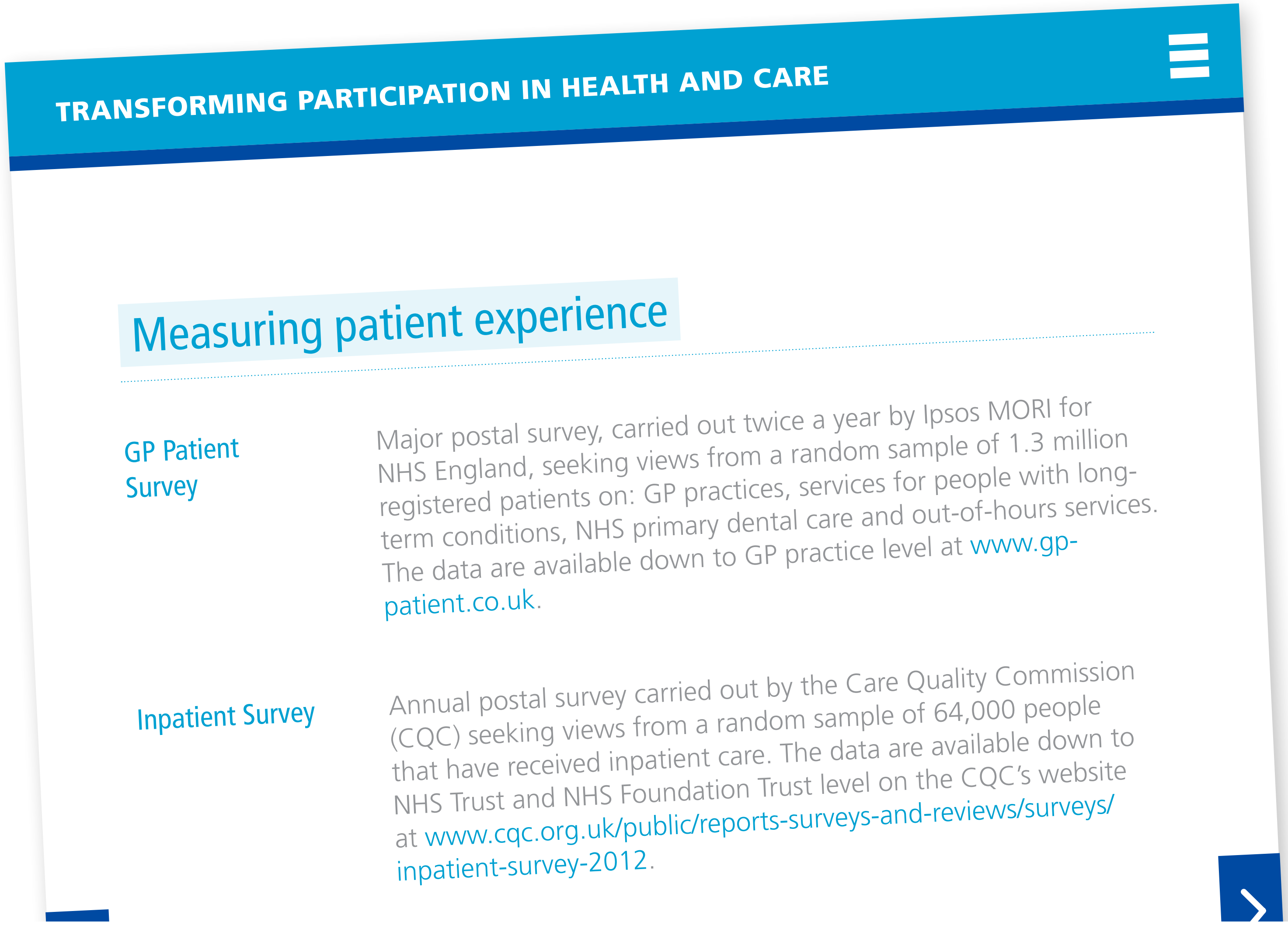
There are a range of existing measures and tools available to help monitor and evaluate progress in individual participation.

Measure/ tool	Key facts
National inpatient survey	- Annual survey of hospital inpatients (adults). - National questionnaire implemented locally by NHS providers. - Measures patient experience and includes a question about 'involvement in decision-making.' - Opportunity to use data about providers' performance in terms of involving patients in decisions about their care and treatment for local / national benchmarking and determining quality

Download resource 3.0

Measuring patient experience

There are a range of surveys and insight tools available to support commissioners. A list can be downloaded below.



TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Measuring patient experience

GP Patient Survey	Major postal survey, carried out twice a year by Ipsos MORI for NHS England, seeking views from a random sample of 1.3 million registered patients on: GP practices, services for people with long-term conditions, NHS primary dental care and out-of-hours services. The data are available down to GP practice level at www.gp-patient.co.uk.
Inpatient Survey	Annual postal survey carried out by the Care Quality Commission (CQC) seeking views from a random sample of 64,000 people that have received inpatient care. The data are available down to NHS Trust and NHS Foundation Trust level on the CQC's website at www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/inpatient-survey-2012.

Download resource 4.0

Communication 'top tips'

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

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 that 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

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

Download resource 5.0

Case studies

Download all case studies **here**

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 decision making
- Virtucare™ Phoenix
- Newcastle FT MAGIC
- Birmingham - Living Well

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Individual participation case study

'Living Well, Taking Control' chronic disease education programme

Who

Heart of Birmingham Primary Care Trust (PCT) and Health Exchange Community Interest Company (CIC).

Outcomes

Over 1500 patients have completed the programme each year since 2009. As a result of taking part, patients take more control of their own health and care. Those with a long-term condition develop an

Public participation case studies

- Improving outcomes through public participation
- Dorset Pain Management
- Vision, aims and values Leeds West
- Teenage cancer South West
- People's Panel Hull
- Healthvoice Eastern Cheshire

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Public participation case study

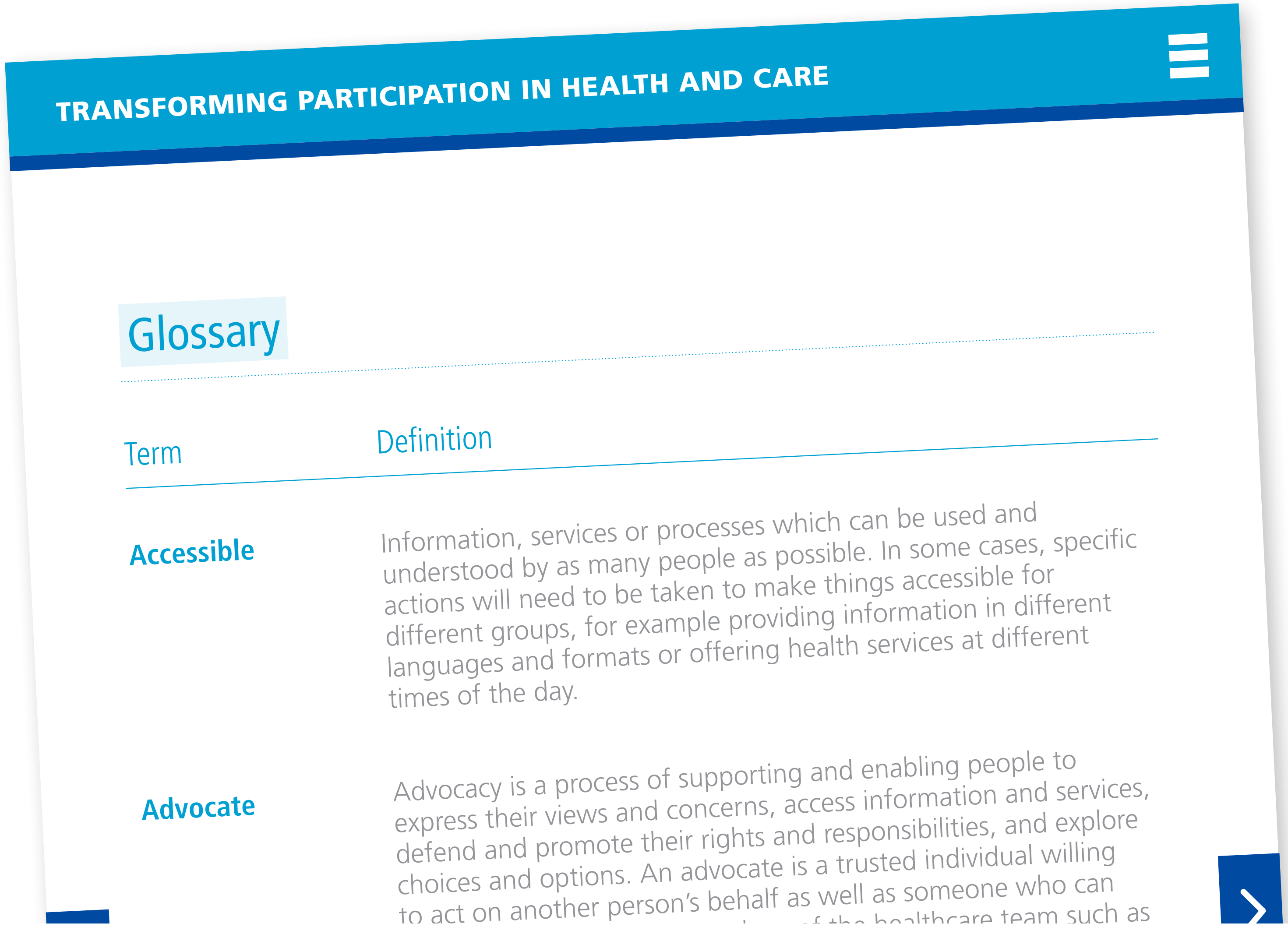
Dorset patients involved in redesign of pain services

Insight & feedback case studies

- Hillingdon A&E
- Design Council Ethnography & Design
- Experience Based Co-design
- Macmillian Cancer Support and the Cancer Patient Experience Survey
- Liverpoool Heart & Chest Friends & Family Test
- RNIB Word of Mouth patient journey mapping
- Tower Hamlets peer research and observational work

TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Glossary



TRANSFORMING PARTICIPATION IN HEALTH AND CARE

Glossary

Term	Definition
Accessible	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.
Advocate	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

Download resource 7.0

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