

Engaging with individual patients

{Smart Guides}
to ENGAGEMENT

For better commissioning

Engaging with individual patients

Part of the **Smart Guides to Engagement series**, this guide helps clinical commissioning groups (CCGs) and service providers to enable and support the engagement of individuals with healthcare services. It describes what works and points to sources of help to achieve success. It should be read with *Unlocking the Power of Information*, which can be accessed with the rest of the Smart Guides at www.networks.nhs.uk/nhs-networks/smart-guides

What is individual patient involvement?

Everyone manages their own health to a greater or lesser extent. The key questions are: how successfully are they able to do so? Do they have the confidence to succeed?

Patient involvement is about how individuals can have a say in decisions about their own care and treatment and therefore have more control and influence over their own overall health. This can be supported by services and professionals taking a “person centred” approach in their relationships.

The World Health Organisation describes the characteristics of person centred healthcare as:

For individuals, patients and their families:

- Make it easier for CCGs to talk to communities and find out about their needs and aspirations
- Access to clear, concise and intelligible health information and education that increase health literacy
- Equitable access to health systems, effective treatments, and psycho-social support
- Personal skills which allow control over health and engagement with health care systems: communication, mutual collaboration and respect, goal setting, decision making, problem solving and self-care
- Supported involvement in health care decision making, including health policy.

For health practitioners:

- Holistic approach to the delivery of health care
- Respect for patients and their decisions
- Recognition of the needs of people seeking health care
- Professional skills to meet these needs: competence, communication, mutual collaboration and respect, empathy, health promotion, disease prevention, responsiveness and sensitivity
- Provision of individualised care
- Access to professional development and debriefing opportunities
- Adherence to evidence-based guidelines and protocols
- Commitment to quality, safety and ethical care
- Team work and collaboration across disciplines, providing co-ordinated care and ensuring continuity of care.

WHO People at the Centre of Care programme:

<http://bit.ly/Je2WW4>

Some of the most important forms of patient involvement are:

- Developing health literacy
- Support for self-management
- Participative care planning
- Shared decisions about treatment options.

How can commissioners benefit from patient involvement?

Actively involved patients have better outcomes and a better experience of healthcare – and healthcare resources are used most appropriately.

The effectiveness of specific interventions is greatest when they are delivered within an overall service, pathway or system that is designed to optimise patient participation.

Commissioners can ensure that the services people use are designed to maximise support for successful patient involvement.

Much of the NHS is not organised around patient engagement but reflects a conventional medical model (diagnose and fix). Commissioners can refocus pathways to reflect a social model (care and support of the whole person), by

- Changing the culture of primary care through their constituent practices to support patient participation
- Having discussions with existing providers, then asking and requiring through contracts that they monitor, reflect and change their service culture to one which supports patient involvement
- Redesigning services and pathways to focus on patient involvement throughout the journey
- Commissioning holistic packages of care, including contributions from voluntary and community organisations.

The duty to involve

The Health and Social Care Act 2012 gives commissioners a statutory duty “to promote involvement of each patient”. It states: “Each clinical commissioning group must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to—

- (a) the prevention or diagnosis of illness in the patients, or
(b) their care or treatment.”***

The phrase “in the exercise of its functions” means “in everything it does”.

To help the NHS live up to that commitment, new guidance from NHS England on Transforming Participation in Health and Care shows commissioners and service providers how to involve patients and carers in decisions affecting their health and care. This is essential reading for everyone involved in planning, delivering or receiving healthcare services.

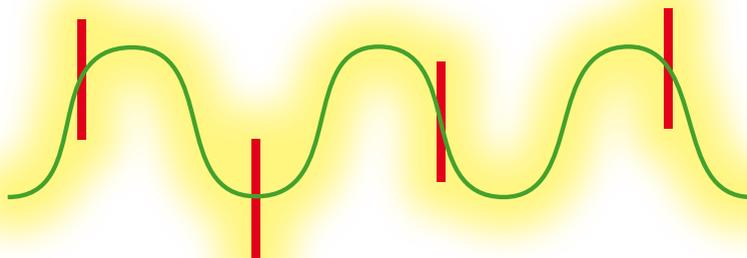
Transforming Participation in Health and Care, NHS England, 2013
<http://bit.ly/1aJ6N37>

Do patients want to be involved?

The vast majority of people want to – or simply have to – have some level of participation in decisions about their health, care and treatment.

Seventy-five percent of adults say they expect to make treatment decisions either themselves or in partnership with their doctor.

All people with long term conditions make management decisions every day of their lives. This is how someone with long term conditions pictured the course of their own life (green line) and the occasional but significant contacts they have with health services (red lines).



For 8757 hours a year the person is managing their condition at home. For just three hours a year they may see health and social care professionals, and less than half of that time is spent discussing how to live with the condition.

Health professionals should not assume that they know, or can judge, which patients want more or less involvement (based on presentation, class, ethnicity, education level and so on).

Part of good patient involvement is to elicit from the patient the level of involvement they want, and can commit to and sustain.

Involvement as an equality issue

There is a risk of overlooking health inequalities if we simply accept people's expressed feelings about active involvement at face value. That is because poor health is strongly correlated to a lack of knowledge, skills and above all confidence to try. These are signs of low "health literacy".

It is possible to assess an individual's level of health literacy and then take steps which are agreed with them to increase it, so that they are enabled to become more involved in their care and management of their overall health. This is about engaging with individual patients to help them move from mere compliance to seeing themselves as being in control and sharing in decision making about their health and care.

Patient activation to raise health literacy and involvement

Patient activation refers to people's ability and willingness to take on the role of managing their health and health care. The concept focuses on skills and knowledge required for day-to-day management of one's own health. Positive changes in patient activation can lead to positive self-management behaviour changes in patients with chronic conditions.

*Summary of the Evidence of Patient Activation Measure (PAM)
NHS Kidney Care 2012 www.nhs.uk*

What is the evidence for patient involvement?

There are hundreds of systematic reviews and other research looking at the effectiveness of interventions to increase people's involvement in health and healthcare. The following interventions have proven effectiveness:

Patient information and support to use it

- Tailored, personalised patient information that helps people to understand and cope with their conditions. This covers, not just medical aspects but the emotional, social and financial impacts
- Information provided as part of the health and care service, with the opportunity for people to ask questions and receive answers they can understand
- Accessible information in language and formats that people can easily use, including information directed towards people with low levels of health literacy, and/or cognitive or sensory impairments

Patient education for self-management

- Practical programmes and coaching that give people knowledge, skills and advice on managing their conditions. These are most effective when tailored to their condition and integrated with their continuing healthcare (for example, setting and reviewing goals with their regular professionals)

Shared decisions about treatments

- Patients are enabled to understand information about all the relevant treatment options and their risks and benefits, and to participate with their professionals in choosing the one most appropriate to their lifestyle, circumstances, values and preferences
- Patient decision aids for specific conditions or treatments that help patients to work through this process and weigh up treatment options so they can take informed decisions

Patient access to health records

- Supported access enables people to refresh their knowledge about their medical history, get further information, review their goals, check the accuracy of information held about them and prepare for consultations

Participative care planning

- The process of being involved in creating a care plan helps patients to look at their combined needs, to set their own goals for better health and prevention, and to become “activated” in managing their health and care
- Active follow-up such as a regular telephone call from a specialist nurse that helps people follow up their plans and achieve their goals

Training and education for health professionals

- Health professionals need awareness, knowledge and skills to work in partnership with patients
- Training in health coaching, motivational interviewing and risk communication is shown to have an impact on patient involvement and knowledge.

Peer support

Formalised peer support – the active deployment of experienced, trained service users to help others with their condition – has been shown to engage people with their care, reduce emergency treatment, increase people’s sense of hope, control, and ability to effect changes in their lives and reduce depression for people with long term conditions and/or mental health needs.

Distilled evidence from research on the effectiveness of patient involvement is available from the following websites covering patient experience, health literacy, self-management, shared decisions and health promotion.

www.investinengagement.info

<http://selfmanagementsupport.health.org.uk>

<http://shareddecisionmaking.health.org.uk>

Service context is vital for effective patient engagement

The interventions described above have been shown to

- Increase patient knowledge
- Improve patient experience
- Lead to patients being actively involved in achieving better outcomes
- Support appropriate use of limited healthcare resources – because people are more likely to engage in prevention and to adhere to treatment.

However, these interventions need to be integrated with services, not commissioned as standalone or one-off interventions, otherwise their effectiveness will be limited.

Successful engagement requires a redesigned service with a significant change of culture where supporting patients to become informed, active and confident to manage is an explicit goal. Some things that might be done to achieve this include:

- Changing the organisation of clinics and surgeries; providing patients with access to records; more flexible appointment systems; more online services
- Consultation options: longer and multidisciplinary consultations for care planning; group consultations to educate patients for self-management; a series of meetings to work through a treatment decision
- Changing care pathways by planning patient information interventions at the right stages, such as support from a fellow patient or peer group (peer to peer support) or an adviser from a local community or voluntary sector group
- Coordinating people's care, support and treatment across multiple services
- Ensuring health professionals are trained in relevant skills such as health coaching and motivational interviewing.

Patients, carers and users can promote patient involvement through being “patient leaders”, promoting a culture of shared decision-making, being ambassadors for improving patient experience and working with professionals to influence change.

The Centre for Patient Leadership <http://centreforpatientleadership.com/>

Some ideas for redesigning services

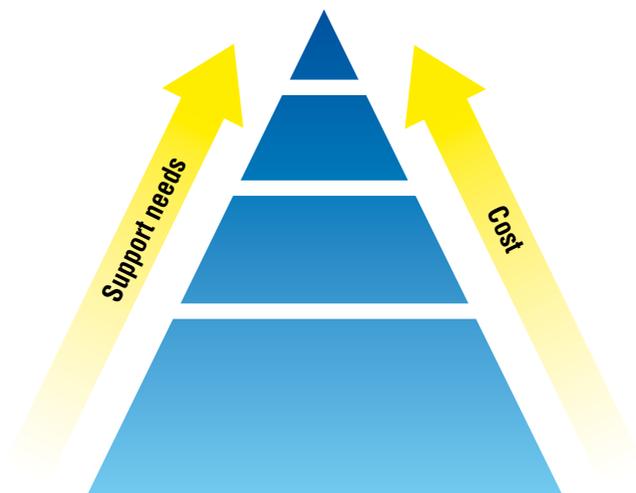
Patient involvement approaches are particularly appropriate for people with long term conditions or continuing healthcare needs. The following approaches can support better commissioning.

Population identification/risk stratification

To target patient involvement approaches effectively, it is important to know which individuals in the patient population could benefit.

Risk stratification tools help to analyse data on service use across the population, helping commissioners not only to plan their overall provision but also to identify which individuals can benefit from targeted, preventive support.

At the top are small numbers of patients at high risk of needing expensive interventions, requiring lots of support.



In the middle sections are people who, with well targeted, low cost support and activation can minimise their risk of frequent recourse to urgent or emergency care and hospital admission.

There are many tools available to help commissioners map their population. Among them:

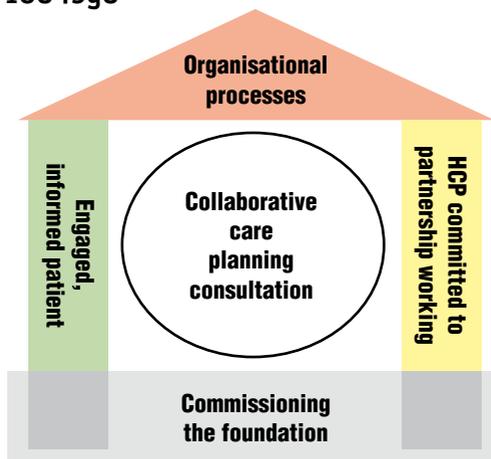
Choosing a Predictive Risk Model: a Guide for Commissioners in England, Nuffield Trust, 2011 <http://bit.ly/1fjpPC8>

Information Governance and Risk Stratification: Advice and Options for CCGs and GPs Using Risk Stratification, NHS England, 2013 <http://bit.ly/1bvuwE3>

The House of Care

The House of Care is a conceptual model to help deliver better care. It is recommended by the Royal College of General Practitioners as a generic model for long term conditions. It has a central place in NHS England's vision for Domain 2 of the NHS Outcomes Framework about "enhancing the quality of life for people with long term conditions".

<http://bit.ly/18U45gU>



This concept shows the necessary elements to support a culture of care that embodies patient involvement.

Co-design with commissioners and co-production with providers

Services are more likely to encompass effective patient involvement where their end users are involved as equals in designing them. This can happen through co-design (where commissioners engage patients, service users or carers) or co-production (where providers do likewise).

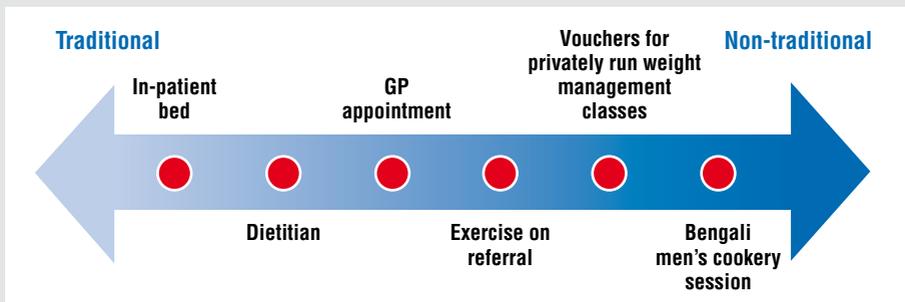
Many voluntary sector organisations can help commissioners use this approach and adapt it for different sorts of people. Neurological Commissioning Support, for example, combines the approach with reference to best practice standards and a costing template for service change: www.ncssupport.org.uk

Local groups can help providers with co-production through providing

- Comprehensive patient information covering the emotional, social and financial impacts of health
- Support for health literacy
- Peer support
- Motivational activities
- Education for self management.

Voluntary sector organisations can increase engagement effectiveness

Results from the Diabetes Year of Care pilots included lessons on using non-traditional provision to help people move to a less expensive, person centred and goal oriented approach to managing conditions as shown in this diagram:



See *Thanks for the Petunias: a Guide to Developing and Commissioning Non-traditional Providers to Support the Self Management of People with Long Term Conditions*, 2011: <http://bit.ly/1bPOBN8>

Nesta (National Endowment for Science, Technology and the Arts) built on these approaches to investigate the co-production of health between the NHS and community sector in its *People Powered Health* programme: <http://bit.ly/1dXfqil>

Measuring patient involvement

To do this, it is important that both commissioners and providers know what matters overall to patients. One good starting place is the Narrative for Person-centred Coordinated Care, developed by National Voices for the national integrated care initiative: <http://bit.ly/1dXfqil>

Measures are available that will help commissioners to know whether their patients are experiencing good involvement in their care and treatment.

Validated indicators for many of these aspects of engagement can be found in the CQC's national patient survey questionnaires, the general practice patient survey, and the VOICES questionnaire for end of life care.

Get Smarter – find out more

Measuring Shared Decision Making – review of research evidence, 2012
<http://bit.ly/1bP0QaN>

Involving patients and carers in pathway design is discussed in Developing Pathways Using Patient and Carer Experiences
www.networks.nhs.uk/nhs-networks/smart-guides

Invest in Engagement – analysis of the best evidence for patient involvement in healthcare www.investinengagement.info

Experience Based Co-design Toolkit – focuses on co-design of cancer services Kings Fund, 2011 <http://bit.ly/19pNZG9>

Big Changes, Small Steps – Southend Estuary CCG and InHealth Associates, 2011. Describes how a CCG thought about what it would look like as a “patient engaged organisation” and the steps it could take to achieve that objective.
<http://bit.ly/1kz0Mvt>

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Smart Guides to Engagement are a co-production by organisations and individuals passionate about engaging patients, carers and the public more fully in healthcare.

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