Unlocking the power of information

{Smart Guides} to ENGAGEMENT

For better commissioning

Unlocking the power of information

Part of the **Smart Guides to Engagement** series, this guide helps clinical commissioning groups (CCGs) and service providers understand how information is the foundation for effective engagement with patients so that they can become partners in decision-making about their own health and care. It describes what works and points to sources of help to achieve success. This guide should be read with Engaging With Individual Patients, which can be accessed with the rest of the Smart Guides at **www.networks.nhs.uk/nhs-networks/smart-guides**

A service in its own right

Information is "an essential service in its own right, allowing us to understand our own health, choose healthier lifestyles, and choose the treatment and support that is right for us."
The Power of Information, Department of Health, 2012
http://bit.ly/198UhxK

Tools to ensure that information is of high quality include:

- The Information Standard, a certification scheme for organisations producing evidence-based health and care information for the public **www.theinformationstandard.org**
- QISMET for self-management education **http://qismet.org.uk**
- The Patient Information Forum – discusses approaches to quality assurance **http://bit.ly/1fjsr2Q**

Patient-centred approaches support patients, service users and carers to make informed decisions about their own health and care, including:

- Lifestyle and wellbeing
- Conditions and treatments (including self-care)
- Choice of provider.

To do this, commissioners require insights about patients as individuals. Some of this they have via demographic, public health and ethnicity data as well as from the Quality and Outcomes Framework (QOF) data generated by local practices.

Providers know about individuals, their medical history, medication and possibly their communication preferences (email, text, print, phone and so on). But the NHS has little insight about users' beliefs regarding health or treatments, their health literacy or whether (and how) they are likely to be motivated to change behaviour. Also, little information is shared between different providers or within the same care setting. Without these insights, it is hard for commissioners to tailor information, support and services to meet individual needs.

Using an asset-based model

Commissioners and providers can use asset-based models that allow them to work with patients, rather than "do to", and this helps support patients to harness their own internal resources and build on their lived experience. Potential staff benefits from this include better morale, work-life balance, and personal relationships (see table).

Moving from a deficit approach to an asset approach

Where we are now - the deficit approach	Where an asset way of thinking takes us
Start with the deficiencies and needs in the community	Start with the assets in the community
Respond to problems	Identify opportunities and strengths
Provide services to users	Invest in people as citizens
Emphasise the role of agencies	Emphasise the role of civil society
Focus on individuals	Focus on communities/neighbourhoods and the common good
See people as clients and consumers receiving services	See people as citizens and co-producers with something to offer
Treat people as passive and done-to	Help people to take control of their lives
'Fix people'	Support people to develop their potential
Implement programmes as the answer	See people as the answer

A Glass Half-full: How an Asset Approach Can Improve Community Health and Well-being, IDeA, 2010 **http://bit.ly/18gpfoR**

A deeper understanding of patients' information and support needs leads beyond provision of a leaflet or website towards changing relationships and improving outcomes. The rationale is simple: "Patients are arguably the greatest untapped resource within the NHS. The active engagement of patients is a common thread through all of our ten priorities." Transforming Our Health Care System: Ten Priorities for Commissioners, Kings Fund, 2013 **http://bit.ly/1jzRv8u**

Patient leaders can be assets for change, promoting a culture of shared decision-making, being ambassadors for improving patient experience and working with professionals to influence change. Find out more from the Centre for Patient Leadership **http://centreforpatientleadership.com/**

Information supports individual engagement

The NHS Constitution states: “You have the right to be given information about the test and treatment options available to you, what they involve and their risks and benefits.”

It pledges:

“To inform you about the healthcare services available to you, locally and nationally and to offer you easily accessible, reliable and relevant information in a form you can understand, and support to use it. This will enable you to participate fully in your own healthcare decisions and to support you in making choices. This will include information on the range and quality of clinical services where there is robust and accurate information available.”

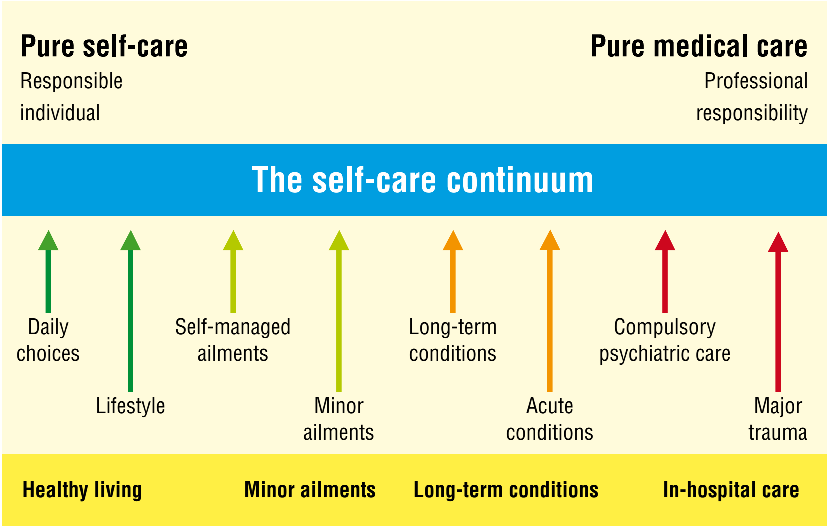
To help the NHS live up to that commitment, new guidance from NHS England shows commissioners and service providers how to involve patients and carers in decisions affecting their health and care. This is essential reading for everyone involved in planning, delivering or receiving healthcare services.
Transforming Participation in Health and Care, NHS England, 2013 **http://bit.ly/1aJ6N37**

What's in it for commissioners and providers?

Investing in high quality information and support is not just the right thing to do for patients, it is a financial and clinical imperative with impact across three main areas:

- **Experience, clinical effectiveness and safety**
  Better shared decision-making, self-management and self-care leads to more realistic expectations, improved confidence in relationships, reduced stress, better quality of life and greater patient engagement
- **Service use and health costs**
  Reduced health inequalities, better adherence to treatment and medications, increased patient safety
- **Patients' health behaviour and status**
  More appropriate screening, reductions in major surgery and variation in procedures, reduced demand for primary care, more appropriate use of services, reduced medical errors, malpractice claims and litigation costs and fewer hospital admissions.

The self-care continuum



Source: Self Care Forum **http://bit.ly/IKp74W**

The continuum illustrates the sliding scale of self care, from individual daily choices through people taking care of themselves when they have common symptoms (eg sore throats, coughs) to conditions which have more of an impact and may require more healthcare interventions. The continuum can reveal a range of care options from ‘self’ to more ‘system’ focused.

1. Self care

On average, people in the UK experience nearly four symptoms every fortnight that they mainly deal with themselves. Self-care accounts for about 80 percent of all care.

Case study

At the Bromley by Bow Centre in East London (www.bbbc.org.uk), promotion of self-care threads its way through every aspect of patient care. Despite many challenges (half the patients are not literate and a third of consultations are conducted in Seleti), the practice recognises that communication is key to self-care. As a result, 50 percent of patients now leave their consultation with an explanation prescription, often a print out signposting people to free services or facilities, phone numbers, websites or even "homework".

The surgery has also produced leaflets sent to patients' homes giving details of appropriate number to ring or person to see in many different situations, which, as well as promoting self-care and responsibility, frees up GP time from unnecessary visits.

2. Self management

Around 15 million people in England have a long-term condition (LTC) and account for about 60-70 percent of NHS resources. There is an obvious and growing need to help patients to help themselves in areas that underpin self-management:

- Getting good information
- Achieving self confidence
- Altering personal behaviour
- Ability to go online, use medical devices and write things down.

Commissioners should ask themselves what they are going in each of these four areas to support their LTC populations to self-manage. The Health Foundation's resources (**http://selfmanagementsupport.health.org.uk**) can help commissioners:

- Find evidence that self-management support works
- Write a business case for self-management support
- Put together a project plan and get started.

3. Structured patient education courses

A range of courses provide people with the skills and confidence to better manage their conditions.

Some courses are generic, teaching general principles about finding information, building confidence, and so on. Others are condition-specific. For example, Desmond is a one-day course for patients with recently diagnosed type 2 diabetes. Around eight patients (and their carers where possible) spend a day with a dietician and a diabetes nurse specialist to better understand diabetes and explore how to better manage the condition. Participants learn from their peers as well as the professionals.

An overview of such courses can be found on the **Patient.co.uk** website: **http://bit.ly/1bpEycY**

4. Patient decision aids (PDAs)

PDAs are one way to help patients explore and express their preferences when faced with treatment choices and then share decision-making with clinicians. For example, a man with an enlarged prostate has three main treatment options – surgery, drugs or "watchful waiting". PDAs help patients explore the pros and cons of each option and decide which to go for. There are many types of PDAs, many now supplied online.

See:

- http://sdm.rightcare.nhs.uk/pda
- www.patient.co.uk/decision-aids

5. Information prescriptions

Information prescriptions (IPs) are similar to medicines on prescription or exercise on prescription. IPs have five main elements:

- **Information content** – reliable and relevant sources of information
- **Directories** – repositories of information that link to individual IPs
- **Personalised process** – information specific to the condition, place and point on the care pathway
- **Issuing or prescribing** – creating and offering an IP to a user or carer
- **Access** – available to users through a range of accessible channels, such as face-to-face engagement, the internet, email, telephone and outreach.

Studies across a range of settings and conditions including cancer, cystic fibrosis, sight loss, Parkinson's disease, diabetes, arthritis and asthma, have shown:

- Three quarters of patients felt more confident in asking questions about their condition (73 percent)
- Half (52 percent) of those who received information agreed that it had helped to improve their care
- Two-thirds (66 percent) agreed that they now felt more in control of their condition
- The majority of professionals involved (66 percent) were very or fairly satisfied with how the IP process was being implemented
- Over half of the professionals (57 percent) said that the IP process compared favourably with the ways in which information had previously been given.

Commissioners can look at their own pathways and determine where IPs could contribute to improvements.

Find out more about IPs

NHS Choices: http://bit.ly/1ciGJwE

Cancer IP programme: http://bit.ly/JleG8F

NHS Employers e-learning package and self-assessment management tool to support staff in the delivery of information prescriptions: http://bit.ly/1boQCIe

Books on Prescription - originally designed for mental health settings, this allows GPs to prescribe self-help and other relevant books from local libraries: www.booksonprescription.org.uk

6. Copying letters to patients

2003 good practice guidance supports doctors copying letters to patients. Benefits include better informed patients and improved communication. Doctors had expressed concerns about making patients anxious and had said it would be difficult to write comprehensible letters that were informative to colleagues. But these fears have proved unfounded when good practice is followed.

Copying Letters to Patients: Good Practice Guidelines:
http://bit.ly/1gZlEMc

7. Care plans

Having a personalised care plan is fundamental for individual participation in care by people with long term conditions and disabilities and carers. It supports them to develop the knowledge, skills and confidence to share in the management of their own health. It is a jointly written and agreed approach. Commissioners should ensure a care plan is available to everyone who wants one.

Find out more

Personalised care plans form a core part of the CQC's Essential Standards of Care: http://bit.ly/18tgiXi

National Voices has developed the Principles of Care & Support Planning that build a common understanding of care planning among people and professionals: http://bit.ly/IKqjp5

NHS Employers' e-learning toolkit helps health and social care professionals develop the skills and knowledge to produce personalised care plans: http://bit.ly/18lPSc2

8. Access to personal health records

By 2015, every general practice is expected to make available to all patients electronic booking and cancelling of appointments, ordering of repeat prescriptions, secure communication with the practice and access to the patient's own records. The NHS Mandate in England and the Francis report reinforce this ambition (the latter recommends access for all healthcare settings not just in GP surgeries).

There is clear evidence of benefits. Commissioners can consider how to support and incentivise their GP practices to engage with records access as a platform for engaging patients in their own healthcare.

Find out more

Guide to Health Records Access, Patient Information Forum (PiF), 2012: http://bit.ly/18BsQc9

BMA FAQ on the impact of the GP contract changes 2014/14: http://bit.ly/1ee68yo

9. Personal health budgets

A personal health budget is an amount of money identified to support someone’s health and care needs. The care plan (see above) is central to this. In this case, the plan helps the patient decide their health and wellbeing goals and support needed, but also sets out how their budget will be spent. Patients can choose how the budget is held and managed and are able to spend the money in ways and at times that make sense to them.

By April 2014, people eligible for NHS continuing healthcare will have the right to ask for a personal health budget. The NHS will also be able to offer personal health budgets more widely for example to people with long term health conditions and people with mental health difficulties.

Guidance for GPs explains what personal health budgets are, who might use them and how they can be implemented in a way that will benefit patients. It encourages GPs “to provide patients with the information on personal health budgets and an opportunity to talk to someone – eg peer support, a personal health budget broker or a voluntary agency – to ensure they understand the concept of personal health budgets.”

Find out more

Personal Health Budgets, RCGP, 2012: http://bit.ly/1cAKwJt

Personal Health Budgets Toolkit, NHS England, 2012: http://bit.ly/1hG7zWU

Get Smarter – find out more

The State of Consumer Health Information: An Overview
Smith, S and Duman, M. Health Information & Libraries Journal, 2009; 26: 260–278. **http://bit.ly/1d3dwaA**

AQuA (Advancing Quality Alliance) has a shared decision making programme with a range of insight and practical support materials:
www.advancingqualityalliance.nhs.uk/sdm

The Case for Information, Patient Information Forum, 2013
http://bit.ly/IPhB96

Evaluation of Information Prescriptions, OPM, GFK and the University of York, 2008 **http://bit.ly/1f6NEwb**

Acknowledgements

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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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