How to engage people in their own health and care: a complete guide.
April 2015
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This guide aims to help commissioners get up to speed on ideas that enable people to get more engaged in their own health care. There is lots of evidence, products and case studies out there and a few are referenced herein to give readers a flavour of a much wider menu. We hope that spending 20 minutes or so reading this guide will help you begin to tackle this still quite new area. Let us know what you think using the Feedback form. The inclusion of case studies, reports, etc. does not indicate endorsement by NWCSU nor Monmouth Partners.

For those interested in legal drivers, the relevant duty is under 13H (NHS England) / 14U (CCGs) of the NHS Act 2006:

*The [Commissioner] 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.*
WHY?

A patient story - Andy Lavender

I am a 60’s diabetic. I felt like I was never given help to take control of my diabetes in my teens. For me, the change happened when I was sent on a carb (hydrate) counting course. Never before had I gone days with total control - it was amazing. I felt a real passion to change something, it was a mission now to make this course available and to demand it be funded. My determination to bring this to the masses unknowingly led me to become more engaged in my own care.* Armed with the tools to do this it became easier and the more I worked at it the easier it became.

When I was told that my toe would have to be removed to save my foot, I challenged the medical professional and managed to save my toe. That was the point when I realised that I could affect what happens to me and how I am treated. I grew in confidence and became more focused on what I wanted and needed and less on what the NHS thought I wanted and needed. I now have more say in the insulin I take and make sure it works effectively for me.

I am the chairman of our local Diabetes UK group, I sit on our Diabetes Network and I am the patient representative for the CCG Senate. I have taken control and I now enjoy my life with my diabetes - I may not always like it but I feel like the power is now in my hands. Most recently I have been asked to support a Patients in Control project within work and this has spurred me on more to get the message out there and to drive a social movement to get people to wake up and take control themselves.

* More information on how to measure the knowledge, skills and confidence essential to managing one’s own health and healthcare is in the Measures section of this guide.
WHY?

We’re all aware that healthcare globally is under increasing pressure with an ageing population and a growing number of people with Long Term Conditions (LTC). Around 15 million LTC patients consume 70% of all NHS resources. So doing more of what we’ve done before, even more efficiently, is not going to suffice.

We need to think of new ways to deliver care. And this means embracing the currently greatest untapped resource in healthcare – patients and carers. Retail, travel and finance have all embraced the ‘self-service’ culture. Indeed, NHS England’s Five Year Forward View supports this ambition by stating ‘when people do need health services, patients will gain far greater control of their own care’.

Back in 2002, the Wanless Report, Securing Our Future Health: Taking a Long-Term View, was delivered to HM Treasury. Derek Wanless explained that a ‘fully engaged public’ (i.e. a public actively engaged in better lifestyles and patients self-managing) was required to maximise the benefit of, and indeed maintain our NHS. Such an engaged public was calculated to release £30 billion – yes billion – to the NHS. The very deficit we now face.

Nesta’s Business Case for People Powered Health report, April 2013 states ‘The NHS in England could realise savings of at least £4.4 billion a year if it adopted People Powered Health innovations that involve patients, their families and communities more directly in the management of long term health conditions. These savings are based on the most reliable evidence and represent a 7% reduction in terms of reduced A&E attendance, planned and unplanned admissions, and outpatient admissions’. A review of 779 papers collated by National Voices in June 2014 is available at www.nationalvoices.org.uk/evidence - spend 90 seconds watching the introductory video.

Evidence presented in KPMG’s Creating new value with patients, carers and communities document, clearly illustrates that patients who are more activated can save provider organisations between 8-21% of costs. That’s a bigger impact than any medicine or medical device, which we commission all the time. Empowering patients to take more control is more than just fancy rhetoric or the ethical and moral thing to do. It’s a clinical and financial imperative which is fundamental to the long term sustainability of the NHS.

Diabetes UK’s State of the Nation 2015 starkly states that 80% of amputations are avoidable (see Andy’s Story) if patients are educated. Yet only 1.8% of patients with diabetes get access to structured patient education courses. Put simply ‘The tools are available to help people live well with diabetes, but we’re still not getting it right.’ A diabetes snapshot included in a report from the ABPI Pharmaceutical Diabetes Initiative, February 2015.

The evidence is overwhelming and so is the need to change. This guide aims to help you commission services that make the ‘No decision about us with us’ rhetoric, a reality.
So what does this talk of individual participation actually mean? Firstly we need to frame where this fits in in the context of Patient and Public Involvement (PPI) or Participation as outlined in NHS England’s September 2013 publication *Transforming Participation in Health and Care*. Broadly speaking we have **Public Engagement** which involves people in shaping services; **User Experience** (or Insight) which collects, collates, analyses and informs service improvement based on feedback; and **Individual Participation** which this document focuses on.
In a nutshell, Individual Participation is about giving patients, carers and others who use health and care services information and support to express their preferences for care. It means delivering care with an equal and reciprocal relationship between healthcare professionals, people using services, their families and their neighbours.

The vast majority of healthcare is actually self-care where patients look after a self-limiting condition (headache, cut, sprain, etc.) themselves.

Self-management is where patients, usually with long term condition(s) look after themselves – on average they only spend around 5 hours a year with the NHS so the rest of the time we want to make them as self-sufficient as possible.

A range of other mechanisms from access to health records, structured patient education, information prescriptions, patient decision aids, personal health budgets and care planning for example, help support patients and carers – we outline what these are and where you can find out more.

Be aware that you also have to think about how you change clinical culture – usually through education and training and how you encourage patients to become more involved, usually through good communications and engagement work.

So what?

Commissioners need to think carefully about what individual participation means to you and your local health economies – how to build these products and services into commissioning strategies and contract documentation. As outlined above, we can’t keep commissioning the same thing and hoping outcomes will changes.

If you’re not sure about this area, ask others for help – it’s a new area and we’re all learning. The EIs and Lead Provider Frameworks have lots for Patient and Public Involvement. Most of all, ask the patients and people you’re commissioning services for – they will tell you what they need.
This diagram looks to tie various components of individual participation into the patient journey, albeit many of these type of interventions cover all four quadrants. The teal inner ring identifies where savings can potentially be made; the purple outer ring looks to bring in the relevant commissioning disciplines associated with this quadrant of care; the green outer quadrants identify 12 Individual Participation interventions. Each of these is explained more fully in the How? section of the guide and hyperlink you to the relevant content.
## HOW?

This section provides more detail on 12 components of Individual Participation (as identified in the **What?** section of this guide).

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<tr>
<th>Item</th>
<th>Definition</th>
<th>Examples of how and reported benefits</th>
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| 1a) Health Coaching | Helping patients gain the knowledge, skills, tools and confidence to become active participants in their care so that they can reach their self-identified health goals. | **Clash**  
  - Evidence increasingly underlines that, when health coaching programmes have been deployed, patient satisfaction levels have soared and outcomes have improved  
  - What's more, as a consequence of individual behavioural change, unplanned emergency care across all sectors of the NHS and social care naturally reduces, resulting in positive implications for the local health economy.  
**OwnHealth**  
  - OwnHealth Birmingham is a tele-coaching programme which reports success in reducing key clinical metrics such as HbA1c levels, blood pressure and cholesterol in people with CVD or diabetes  
  - 76% of people in OwnHealth service feel more confident in looking after themselves  
  - 84% of people in OwnHealth state that the Care Manager involves them in making decisions about their healthcare.  
**The Health Foundation**  
  - Individualised coaching may be especially beneficial when combined with personalised written materials or other mechanisms to support self-management  
  - Individual education was the most effective single strategy for improving blood pressure control, but combining individual education and group sessions was even more effective  
  - Other reviews have found similarly positive results for people with heart failure, arthritis, diabetes, and asthma. |

* Disclaimer: The inclusion of any services or product in this publication is for illustrative purposes only and is not an endorsement by NWCSU nor Monmouth Partners.*
### HOW?

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| **1b) Self Care** | The patient developing an understanding of how their condition affects their lives and how to cope with their symptoms. | Kings Fund: A document on [Avoiding hospital admissions](#)  
- Evidence from systematic reviews indicate self-management seems to be effective in reducing unplanned admissions for patients with COPD and asthma  
- Self management education for patients with COPD reduces the risk of at least one hospital admission by about 36% compared with usual care.  
**The Health Foundation**  
Randomised trials in different countries suggest self-monitoring has some clinical benefits:  
- Germany: found that a self-monitoring blood glucose device for people with diabetes improved glycaemic control and general wellbeing  
- Taiwan: Found that an empowerment programme in 50 people with end stage renal disease showed improvements in empowerment, self-care, self-efficacy and depression. |
| **2) Medicines Optimisation** | Having a patient centred approach to medicines use, making sure we improve patient outcomes, reduce wastage, improve safety, increase compliance & realise the full value of medicines as a consequence. | Royal Pharmaceutical Society: A paper on [Medicines Optimisation: Helping patients to make the most of medicines](#)  
Medicines play a crucial role in maintaining health, preventing illness, managing chronic conditions and curing disease. This good practice guidance provides four guiding principles for medicines optimisation that will help all healthcare professionals to support patients to get the best outcomes from their medicines use.  
**Public Health England**  
Consolidating and developing the evidence base and research for community pharmacy's contribution to public health: a progress report from Task Group 3 of the Pharmacy and Public Health Forum.  
**NMS and MUR - top tips from pharmacy teams**  
Top tips on overcoming challenges such as recruiting patients, managing workload and selling the services to GPs.  
**NICE - A paper on The safe and effective use of medicines** |
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<td>3) Care Planning</td>
<td>An agreement between the patient and their health professional (or social services) to help manage their health day-to-day as a written document or recorded in patient notes.</td>
<td>- 70% of individuals with a long term condition say their care has improved as a result of personalised care planning (GP survey 2009 / 10)</td>
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<td>- A wide evaluation of 16 pilots (Ling and others, 2010; RAND Europe and Ernst &amp; Young, 2012) found that integrated care interventions led to process improvements such as an increase in the use of care plans and the development of new roles for care staff (Nuffield Trust)</td>
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<td>- Diabetes UK <em>State of the Nation</em> report - Section 9: Personalised care planning</td>
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<td>- RCGP video on <a href="https://www.rcgp.org.uk/">Collaborative Care and Support Planning</a></td>
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<td>- Think Local Act Personal report which offers councils practical examples for delivering Care &amp; Support plans that are both Care Act compliant and person-centred in their approach</td>
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<td>- <a href="https://www.healthfabric.com/">Health Fabric</a> are supporting commissioners with their Personalised Care Planning in digital form</td>
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<td>- The <a href="https://www.gov.uk/government/publications/nhs-mandate">NHS Mandate</a> 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.</td>
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<tr>
<td>4) Personal Health Budgets</td>
<td>A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team.</td>
<td>NHS England</td>
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<td>- NHS England's evaluation demonstrated Personal Health Budgets greater than £1,000 represent an overall cost reduction of £3,100 compared with control groups</td>
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<td>- <a href="https://www.gov.uk/government/publications/personal-health-budgets">Personal Health Budgets</a></td>
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| 5) eLearning | The use of electronic educational technology in learning and teaching, providing information for patients. | HeLP-Diabetes  
An online structured education self management programme which is being rolled out to CCGs across England as an integrated NHS service. The HeLP-Diabetes programme was developed using substantial user input from both patients and Health Professionals, and was developed by a multi-disciplinary group of clinicians, diabetologists, dieticians, psychologists, web-developers and web-programmers. It’s an extremely comprehensive programme offering many advantages for patients, Health Professionals, and the NHS.  
See the Help section of this guide for apps to support personalisation.  
Advances in digital communication now make it possible for video content to be personalised and delivered directly to a patient’s mobile phone either via email or text message. Personalised Health Communication supports increased levels of patient activation and higher levels of self management capability by enabling the communication of: personal, relevant, timely and actionable support to patients. This innovation is currently being piloted in South Cheshire, please contact [http://warl.com/campaign/personalised-health-communication/](http://warl.com/campaign/personalised-health-communication/) for further information. |
| 6) Structured Patient Education | NICE definition: "... a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual’s clinical and psychological needs, and adaptable to his or her educational and cultural background". | NICE recommends that people with diabetes are offered patient education programmes, both at the time of diagnosis and on a regular basis ([Diabetes UK](https://www.diabetes.org.uk)).  
The Health Foundation  
- People receiving individual education had increased knowledge and less emergency GP call outs in the four months after hospital discharge  
- There has also been success when using individual person centred discussions initially, followed by referral to other self-management support strategies (such as educational groups) once needs have been established  
Arthritis Care provides high quality information and support to empower patients to take control of their arthritis.  
Self Management UK is a registered charity which works with patients and carers to help manage the day to day impact of living with a long-term condition. |
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| 7) Support Brokerage | A Support Broker works with patients, family, carers, friends and loved ones to source, plan and manage patients' care and support. | My Support Broker  
A registered social business, working nationally and bringing together people locally who have expertise, insight and knowledge of support and care for young and old, for those with long term illnesses, disability, dementia, mental health and other conditions. |
| 8) Patient Decision Aids (PDAs) | Specially designed information resources to help people make decisions about healthcare options. | Evaluation studies from a [Cochrane systematic overview of trials and 2 general reviews](#) suggested it:  
- Increases patients' knowledge of the condition, options, and outcomes  
- Creates realistic personal expectations of outcomes  
- Improves the agreement between choices and a patients' values  
- Increases participation in decision making without adversely affecting anxiety. |
| 9) Access to Health Records | Online access to patient records. | Examples include:  
- [myRecord](#): clear evidence has been found that enabling online patient access benefits patients and GP practices alike. Being able to view their medical records from anywhere, anytime makes people feel more in charge of their own health and improves relationships between patients and their practice  
- People who have access to their records self-care better – e.g. people are more likely to stop smoking or comply with their medication ([The Health Foundation](#))  
- [Patient online](#) - an NHS England programme designed to support GP practices to offer and promote online services to patients, including access to records, online appointment booking and online repeat prescriptions. |
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| 10) Experience Based (re) Design | Experience Based Design (EBD) is a technique developed by the NHS Institute for Innovation and Improvement that enables patients and staff to share the role of improving care and re-designing services. | **The Patient Centred Care Project**  
- Patients and staff in breast cancer and lung cancer services worked together over a period of two years with eight co-design groups implementing changes in aspects such as communication of diagnosis, day surgery, information provision and consultation at time of discharge  
- Dozens of changes were made to make processes more efficient and relational care better – e.g. through customer care training for administrative staff, interpersonal skill testing introduced in healthcare assistant recruitment  
- A recent evaluation has shown the majority have been sustained.  
**Oxleas NHS Mental Health Trust**  
In 2012, Oxleas NHS Mental Health Trust used an experience-based co-design approach to make improvements to its mental health inpatient service. Complaints were reduced by 80% over 14 months. |
| 11) Asset / Community Development | NICE definition: "A health asset is any factor or resource which enhances the ability of individuals, communities and populations to maintain and sustain health and well-being." | **The Asset-Based Community Development Institute**  
A large and growing movement that considers local assets as the primary building blocks of sustainable community development. Building on the skills of local residents, the power of local associations, and the supportive functions of local institutions, asset-based community development draws upon existing community strengths to build stronger, more sustainable communities for the future.  
**iDeA**  
A publication on how an asset approach can improve community health and well-being.  
Public Health England - [A guide to community-centred approaches for health and wellbeing](#) |
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| 12) Telehealth | The Telecare Services Association definition: 'The remote exchange of data between a patient at home and their clinician(s) to assist in diagnosis and monitoring typically used to support patients with Long Term Conditions.' | The Department of Health carried out research into the benefits of telehealth and telecare in the management of long term conditions and found that correct use of technology reduced:  
- Death rates by 45%  
- Visits to accident and emergency departments by 15%  
- Emergency admissions to hospital by 20%.  
Early findings from the Whole System Demonstrator trial indicated that utilising telehealth resulted in:  
- 15% less A&E visits; 20% reduction in emergency admissions; 45% reduction in mortality rates. |
| 13) Social Prescribing | A mechanism for linking patients with non-medical sources of support within the community. | Nesta  
A review of the evidence base for social prescription suggests that it increases people’s confidence, provides opportunities to build social networks and increases self efficacy and that it can increase people’s engagement with weight loss and exercise programmes.  
Voluntary Action Rotherham  
The lead body for supporting, developing and promoting the voluntary and community sector in the Rotherham borough. Its core activities and associated projects are a keystone for local community engagement and development.  
Wellbeing Enterprises CIC  
Wellbeing Enterprises is an award winning social enterprise with a mission to support individuals and communities to achieve better health and wellbeing. They do this by educating the general public; unlocking the assets within communities and working collaboratively with partners to tackle the underlying causes of poor health. |
This section outlines tools and measures that provide insight into the impact that interventions have on putting patients in control of their own care.

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<tr>
<th>Name</th>
<th>What it measures</th>
<th>Where to find out more</th>
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<tr>
<td>Patient Activation Measure (PAM)</td>
<td>The PAM assessment gauges the knowledge, skills and confidence essential to managing one’s own health and healthcare.</td>
<td><a href="http://www.insigniahealth.com/solutions/patient-activation-measure">www.insigniahealth.com/solutions/patient-activation-measure</a></td>
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<tr>
<td>Health Literacy Questionnaire (HLQ)</td>
<td>The HLQ is a comprehensive measure of health literacy. It captures fine detail on an individual’s health literacy and provides detailed information about what needs to be done to improve systems and services.</td>
<td><a href="http://www.deakin.edu.au/health/research/phi/health-literacy-questionnaire.php">www.deakin.edu.au/health/research/phi/health-literacy-questionnaire.php</a></td>
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<td>SHARED questionnaire</td>
<td>Evaluating how engaged patients are in their healthcare choices.</td>
<td><a href="http://www.nice.org.uk/proxy/?sourceurl=http://www.nice.org.uk/usingguidance/sharedlearningimplementingniceguidance/examplesofimplementation/eximpresults.jsp?o=646">www.nice.org.uk/proxy/?sourceurl=http://www.nice.org.uk/usingguidance/sharedlearningimplementingniceguidance/examplesofimplementation/eximpresults.jsp?o=646</a></td>
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<td>Decision Quality Measure (DQM)</td>
<td>Measuring and evaluating shared decision making activity - the collaborative process in which patients are supported by their healthcare professional to select which of the available options they wish to choose.</td>
<td><a href="http://shareddecisionmaking.health.org.uk/measurement-and-evaluation/example-tools-to-measure-outcomes/%20-%20decision">http://shareddecisionmaking.health.org.uk/measurement-and-evaluation/example-tools-to-measure-outcomes/%20-%20decision</a></td>
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<td>CollaboRATE</td>
<td>Measuring the level of shared decision making in the clinical encounter from the patient's perspective.</td>
<td><a href="http://www.collaboratescore.org/collaborate.html">www.collaboratescore.org/collaborate.html</a></td>
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<td>Name</td>
<td>What it measures</td>
<td>Where to find out more</td>
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<td>SURE score</td>
<td>Measures personal perceptions of:</td>
<td><a href="http://decisionaid.ohri.ca/eval_dcs.html">http://decisionaid.ohri.ca/eval_dcs.html</a></td>
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<tr>
<td></td>
<td>a. Uncertainty in choosing options;</td>
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<td>b. Modifiable factors contributing to uncertainty such as feeling uninformed,</td>
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<td>unclear about personal values and unsupported in decision making; and</td>
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<td></td>
<td>c. Effective decision making (in full version) such as feeling the choice is</td>
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<td>informed, values-based, likely to be implemented and expressing satisfaction</td>
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<td>with the choice.</td>
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<td>Health Literacy Scale for Europe</td>
<td>Measuring health literacy in populations in Europe.</td>
<td><a href="http://www.maastrichtuniversity.nl/web/Institutes/FHML/CAPHRI/DepartmentsCAPHRI/InternationalHealth/Research/INTHEALTH/Projects/HealthLiteracyHLSEU.htm">www.maastrichtuniversity.nl/web/Institutes/FHML/CAPHRI/DepartmentsCAPHRI/InternationalHealth/Research/INTHEALTH/Projects/HealthLiteracyHLSEU.htm</a></td>
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<td>LTC6 survey – focus on self-management</td>
<td>The LTC6 Questionnaire asks patients with a long term condition about their healthcare over the last 12 months. It includes questions about involvement in decision-making, although the focus is on self-management. The measure can be used to drive improvements at both the population and provider level.</td>
<td><a href="http://personcentredcare.health.org.uk/resources/ltc6-questionnaire">http://personcentredcare.health.org.uk/resources/ltc6-questionnaire</a></td>
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<tr>
<td>CCG Patients in Control Rapid</td>
<td>Assessing an organisation’s maturity around supporting individual participation.</td>
<td><a href="http://apps.monmouthpartners.com/pic/">http://apps.monmouthpartners.com/pic/</a></td>
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<tr>
<td>Assessment</td>
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National Sources of Help

There is a wealth of resources available to support Individual Participation initiatives. We have listed just some of these below:

- **Coalition for Collaborative Care** - an alliance of people and organisations committed to achieving person-centred care.
- **Monmouth Partners** - experts in understanding and using information to improve healthcare outcomes.
- **National Voices** - the national coalition of health and social care charities in England.
- **NESTA People Powered Healthcare** - an innovation charity with a mission to help people and organisations bring great ideas to life.
- **NHS Improving Quality** - working to improve health outcomes for people by providing improvement and change expertise.
- **Patient Information Forum** - the UK's largest membership organisation for people working in health information.
- **Point of Care Foundation** - an independent charity working to improve patients’ experience of care and increase support for the staff who work with them.
- **Self Care Forum** - formed to further the reach of self-care and embed it into everyday life.
- **The Health Foundation** - an independent charity working to improve the quality of health care in the UK.
- **The King's Fund** - an independent charity which helps to shape policy and practice through research and analysis.
- **Think Local Act Personal** - a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support.
- **Year of Care Partnerships** - an NHS based organisation that is dedicated to driving improvement in long term condition care using care planning to shape services which involve people in their own care, provide a more personalised approach and which supports self management.
Apps to support personalisation

There are a multitude of mobile and web apps that support the personalisation agenda. As is often the case, finding those of value in amongst the high volume of web content can be difficult.

Users can go to their relevant app store (iTunes, Play etc.) and change the category to Health and Fitness, or for web applications perform a targeted search, then browse the results for an app that suits your needs. If connected with like-minded individuals via social media, many people choose to crowdsource apps and get peer recommendations to save time.

Another alternative though is the NHS Health Apps Library at [http://apps.nhs.uk/](http://apps.nhs.uk/). A subsection of NHS Choices, the Health Apps Library is a repository of apps (mobile and web alike) that have been clinician reviewed to ensure they are safe and trusted before receiving the NHS seal of approval. There are a number of apps contained within that support personalisation and put patients in control, with more available as they are released and reviewed.

Apps are presented in an “app store” like interface and can be rated and reviewed by end users. Beyond apps being clinician reviewed, one notable benefit is that since all contained apps are Health and Social Care focussed, available categories are more granular.
Additional useful resources

FEEDBACK

Evaluating This Guide

Please take a few moments to respond to 6 quick questions here.

For further information about the issues raised in this guide, please contact:

Hilda Yarker
Head of Patients and Information
North West Commissioning Support Unit (NWCSU)
Email: hilda.yarker@nhs.net

Mark Duman
Director
Monmouth Partners
Email: mark.duman@monmouthpartners.com