

Patients as partners in developing self-management solutions:

Evidence review of the key
themes of self-management

Introduction

There is an increasing focus on supporting patients to be more in control of their own health care, and there is clear evidence that supporting people to self-manage can have real benefits for the individuals, their carers, families and the wider health economy (Powers BJ et al, 2010). A recent study by [Nesta](#) estimated £4.4bn could be saved in the NHS through greater participation and self-management of long term or chronic conditions. Other studies have demonstrated that patient participation improves patient outcomes, quality of life and provides value for money.

Patient Insight

However, feedback from patients (and their carers) is that:

- They generally **want** to be in control **but...**
- They don't know what they don't know
- They don't know where to go to find out
- They are not asked!

The potential impact of this, from the patient's perspective, is:

- Anxiety about what they can and can't do
- Mixed messages about their condition and how to manage it (e.g. surfing the internet for information)
- Feeling of disempowerment
- Feeling devalued
- Not feeling in control
- Reduced self-management
- Seen as being 'non-compliant'.

Self-management support and intervention can be more effective if commissioners and providers work **with** patients – and their carers – in understanding what will help people manage their own condition(s) more effectively from their perspective, and develop the tools and approaches that will be of most value to, and therefore more successfully used by the patients and their carers.

The Patients in Control (PiC) programme was funded by NHS England to drive the individualisation agenda locally. Originally Kent and Medway Commissioning Support Unit was commissioned to deliver the “Whose health is it anyway?” project across the South region during 2013/14 and 2014/15. Following the merge with South East London CSU, the newly-formed South East Commissioning Support Unit (SECSU) took on the PiC programme in the Midlands and East of England. The PiC Team supported Clinical Commissioning

Groups (CCGs) and Area Teams (AT) in responding to 'Transforming Participation in Health & Care', the statutory guidance on patient and public involvement, and putting patients in control of their own care.

The programme is based on the principles of co-design i.e. involving patients *and* commissioners in developing approaches to help patients and their carers manage their own care more successfully, based on what is important to them from their perspective. This new approach has built on extensive patient engagement work previously undertaken in West Kent, which included in-depth interviews with people with long term conditions and their carers, carrying out surveys on integrated care based on the National Voices 'I' statements (which reinforce the above findings), and local developments regarding involving people in development of a person-centric approaches to self-management. The key themes that emerged from the insight work is as follows:

Key themes that emerged from this work were:

- **Easily accessible information** - tailored as needs change
- **Emotional support** – from point of diagnosis and at key stages
- **Education and training** – for patients and carers, so they can manage the condition and their emotional responses to it
- **Personalised care plan** – developed with both patient and carer, reflecting what is important to them
- **Social activity** – to reduce social isolation (which can lead to depression, lack of motivation)
- **Peer support and networks** - sharing with others having similar experiences, to build confidence and motivation ('not alone in experiencing this') and reduce social isolation that often occurs because of their condition(s)
- **Increased access to non-medical interventions** – alternative approaches, peer support, stress management/coping techniques (often provided through voluntary organisations)
- **Fast access to specialist teams** – knowing they can access these reduces anxiety and unnecessary visits
- **Greater options for promoting exercise** and maintaining mobility
- **Better knowledge of condition at GP level** – so that the GP can give/signpost to the right information
- **Improved confidence/self-esteem through own work contribution** – paid or voluntary.

Process

The team worked with a number of CCGs across the regions in three stages:

Stage 1:

Building on patient and carer feedback already collected and analysed on this topic, and building in the feedback from individual CCG survey reports where applicable, the key themes outlined above were used to create online surveys, telephone interviews and individual case studies and to validate whether these were still priority themes.

Stage 2:

Through a series of facilitated meetings, the themes were further developed with patients and carers at a local level to gather insights to share with CCG commissioners. These insights helped to highlight the issues and priorities around self-management as perceived by people with long term conditions and carers within a locality.

Stage 3:

This is the critical co-design phase, where commissioners and patients came together to expand the themes from the patient and carer perspective in more detail and to act on these insights, considering how these may be translated into practical solutions at a local level. From this future services can be co-designed which are truly built around the needs of the patient.

This desk research looks at the data available around those insights, related literature on self-management, including policy and practice nationally, and examples of it in practice.

Evidence Base

The definition of self-management is described as: “The actions taken by individuals to recognise, treat and manage their own healthcare independently of or in partnership with the healthcare system.” (National Voices, 2014). There are a number of associated benefits of self-management interventions; these include improved knowledge, experience (people’s satisfaction, coping skills, self-efficacy, perceptions of social support and health literacy), reduction in service use, cost and ultimately health behaviour and health outcomes.

People with long-term conditions account for 70 per cent of inpatient bed days. Self-management programmes, which aim to support patients to manage their own conditions, have been shown to reduce unplanned hospital admissions for some conditions (COPD and asthma). In its report, ‘[Long term conditions and mental health: the cost of co-morbidities](#)’, the King’s Fund is more equivocal about evidence for cost savings, but messages from research¹ suggest:

- Tailoring interventions to the condition (e.g. structured education for diabetes self-care; behavioural interventions for depression)

¹ <http://www.kingsfund.org.uk/publications/avoiding-hospital-admissions>
<http://www.health.org.uk/publications/evidence-helping-people-help-themselves/>

- Involving patients in co-creating personalised self-care plans
- Telephone health coaching
- Change programmes to encourage lifestyle change

can have a positive impact for people with long-term conditions.

Policy Drivers

NHS England has attempted to foster a new approach to healthcare in delivering its aim to improve the population's health outcomes. In recent years the government has stated its commitment to greater patient participation and supporting people to manage their own conditions. Here is a summary of the key policy documents:

NHS Constitution (2012, updated March 2013)

The NHS is guided by seven principles, underpinned by core NHS values which have been derived from extensive discussions with staff, patients and the public. The fourth principle of the [NHS Constitution](#) states that, *"the NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment."* It reinforces the need for patient centred care where "there is no decision about me without me".

NHS Mandate

The [NHS Mandate 2014 – 2015](#) set 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.

By 2015, at least 80 per cent of CCGs should be commissioning to support patients in participation and decisions over their own care. CCGs should have had an implementation plan in place by December 2013, including information and support for self-management, personalised care planning and shared decision making within normal service planning and commissioning. Since April 2014, people with NHS continuing care have had the right to ask for a personal health budget, including a direct payment.

The NHS Outcomes Framework

This [Framework](#) converts the Mandate into a set of deliverable outcomes, and provides a national overview of how well the NHS is performing. It is structured around 5 domains which set out the high level national outcomes that the NHS should be aiming to improve. Domain 2 – Enhancing Quality of Life for People with Long Term Conditions contains a number of indicators which measures a CCG's achievement for its patients. This includes:

- Health-related quality of life for people with long-term conditions (2.1), for carers, aged 18 and above (2.15) and people with a long term mental health condition (2.16)
- Proportion of people who are feeling supported to manage their condition (2.2)

- Unplanned hospitalisation for chronic ambulatory care sensitive conditions (2.6) or for asthma, diabetes and epilepsy in under 19s (2.7).

NHS Five Year Forward View

Published in October 2014, the [Five Year Forward View](#) reinforces the message stated in previous policy documents. It sets out how the health service needs to change, arguing for a new relationship with patients and communities. It makes a specific commitment to do more to support people with long term conditions to manage their own health. With help of voluntary sector partners, it signals the need for significant investment in evidence-based approaches such as group based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge. Standards set out in the NHS Mandate continue to apply, but there are additional standards relating to mental health.

[The forward view into action: planning guidance for 2015/16](#) expects CCGs to work with local councils to reduce health and healthcare inequalities and to improve health and well-being outcomes. New national contracts will include a requirement for providers to make progress towards electronic health records to ensure patients have access to better information about their condition, to expand the provision of personal health budgets and to implement integrated personalised commissioning.

Putting Patients First: The NHS England Business Plan

NHS England's [Business Plan for 2013/14 – 2015/16](#), refreshed for 2014/15 – 2016/17, describes its ambitions for the next three years and reaffirms its commitment to ensuring that patients and the public are continually involved in decisions about their care. Transparency and increasing patients' voice are fundamental to improving patient care. The plan describes an 11 point scorecard which NHS England will introduce for measuring performance of key priorities, focused on receiving direct feedback from patients, their families and NHS staff.

This supports the cultural change needed to put people at the centre of the NHS, a key theme in the report by Robert Francis QC, by making sure that patients' voices are heard and used to deliver better services.

Transforming Participation in Health and Care (September 2013)

The Health and Social Care Act 2012 introduced significant amendments to the NHS Act 2006 giving CCGs and NHS England commissioners two legal duties, 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.

[Transforming Participation in Health and Care](#) supports 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. It 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, focusing on:

- Individual participation - for example, ensuring every person with a long-term condition or disability has a digital personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health.
- Public participation in decision making - for example, establishing a national Citizens Assembly that will give patients and the public a voice at the heart of decision making and hold the board of NHS England to account. It will give people a say on how services are developed locally and nationally, to ensure their communities have the services they need.
- Patient insight and feedback - for example, gathering information from patients that give the NHS genuine insight into the outcomes that matter most to them across a range of specialised conditions, helping to shape services of the future.

Better Care Fund, 2013

The June 2013 Spending Round announced the creation of a £3.8 billion Integration Transformation Fund, now referred to as the [Better Care Fund](#), described as *'a local single pooled budget to incentivise the NHS and local government to work more closely together around people, placing their well-being as the focus of health and care services'*. Guidance makes clear that the Better Care Fund will entail a substantial shift of activity and resource from hospitals to the community – *'hospital emergency activity will have to reduce by 15%'* (NHS England 2013).

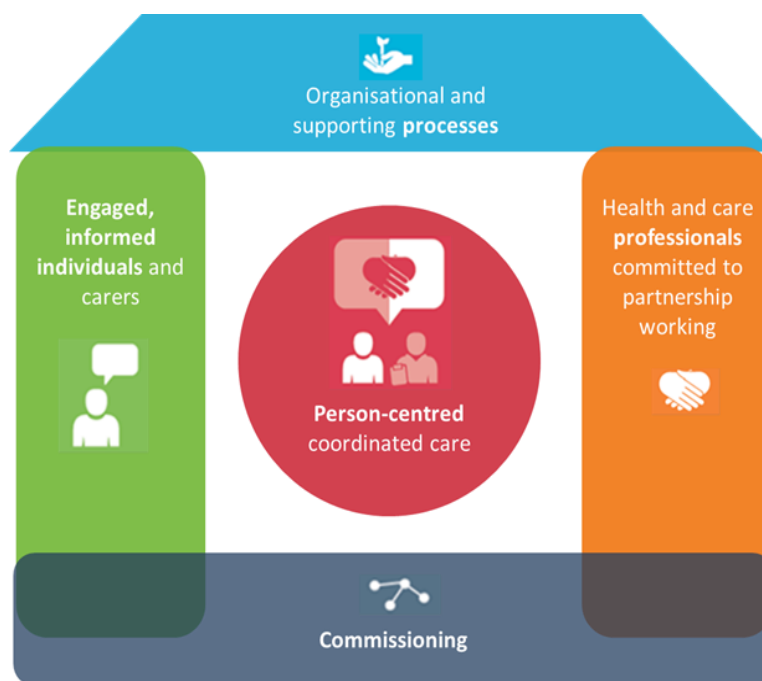
The BCF is a critical part of the NHS 2 year operational plans and the 5 year strategic plans as well as local government planning. The guidance recognises that delivering system transformation relies, in part, on widespread, meaningful stakeholder engagement and co-production.

Literature Review

National Voices (a coalition of more than 140 UK health and social care charities) developed a first-person narrative to explain what the gold standard of care looks like. This requires making the patient perspective (or that of the service user) the organising principle of integrated care, and can be summarised as follows: *'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'* (National Voices 2013).

<http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>

The [House of Care](#) model was developed by the [Year of Care](#) Partnerships to show what needs to be in place to ensure the benefits of care and support planning and 'more than medicine' activities are available to each person living with long-terms conditions. This **'more than medicine'** approach helps each person develop the knowledge, skills and confidence to manage their condition/s within a supportive community. It is a visual representation of the elements that need to be in place to deliver person-centred, coordinated care through care and support planning. Where this approach has been used it has brought benefits for people with long-term conditions and for frontline staff. To realise the full potential of personalised care and support planning will require going beyond putting single elements in place.



In January 2015, NHS England published, '[Personalised care and support planning handbook: The journey to person-centred care](#)' This handbook pulls together learning from a number of organisations and programmes that have been working on personalised care and support planning, support for self-management, and person-centred care, including National Voices, Royal College of General Practitioners, and in particular, draws on learning from the Year of Care Programme. These organisations have come together with others to form the [Coalition for Collaborative Care](#), launched in November 2014 to support the national shift towards person centred collaborative care. The Coalition wants to make person-centred, coordinated care a reality for people living with long-term conditions, by improving the relationship that people have in their day-to-day interaction with the NHS and social care so their care and support is organised around what matters to them. The handbook underlines the role that commissioners should play in helping to implement personalised care and support planning, and highlights the four main steps in the process:



It concludes that personalised care and support planning requires whole-system change - in systems, relationships, skills and services.

International evidence and best practice has shown that effective care planning relies on four key elements in the local healthcare system:

- patients feeling engaged in decisions about their treatment and care and able to act on these decisions
- professionals being committed to working in partnership with patients
- systems being in place to organise resources effectively

- having a whole-system approach to commissioning health and care services (Coalition for collaborative care, 2014).

However, there are challenges in delivering this changing the culture, particularly in this new competitive health market; one example is the difficulties faced by commissioners in procuring high quality patient centred care which was evidenced in the literature. Evidence based research was undertaken by **the Nuffield Trust** between November 2010 to January 2012 which involved an initial orientation phase followed by an in-depth examination of commissioning practice. [‘Commissioning high quality care for people with long term conditions’](#) focused on the commissioning of care for people with diabetes and dementia or stroke in Calderdale, the Wirral and Somerset. Qualitative data were collected through interviews (92), observations of meetings (27) and documents (345). Quantitative data were collected on activity levels, costs and patient experience.

The research found that commissioners often found it difficult to achieve the right balance between relational and transactional commissioning. Also, it was often unclear in all cases at which point to move on from engagement and planning, to implementation.

The report identified that commissioners may need support in shifting from the former relational commissioning model to the transactional model expected within the new competitive health market. The study highlighted the importance of patient centred care which acts as a driver for transactional commissioning and identified that commissioners may need support in undertaking consultation and engagement activity as well as accessing and analysing patient and public experience data to demonstrate sufficient evidence for actions.

Patient activation measure

In its paper, [‘Supporting people to manage their health’](#) the **King’s Fund** describes how patient activation can be used to reduce health inequalities and deliver improved outcomes, better quality care and lower costs. The patient-reported measure (PAM) measures an individual’s knowledge, skill, and confidence for self-management. Research shows that appropriately designed interventions can increase patients’ levels of activation, with associated health benefits. Patient activation is a better predictor of health outcomes than known socio-demographic factors such as ethnicity and age.

The four levels of patient activation

Level 1:	Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
Level 2:	Individuals may lack the knowledge and confidence to manage their health.
Level 3:	Individuals appear to be taken action but may still lack the confidence and skill to support their behaviours.
Level 4:	Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

People who are **more activated** are significantly more likely to attend screenings, check-ups and immunisations, to adopt positive behaviours (e.g. diet and exercise), and have clinical indicators in the normal range (body mass index, blood sugar levels, blood pressure and cholesterol).

Patients who are **less activated** are significantly less likely to prepare questions for a medical visit, know about treatment guidelines or be persistent in clarifying advice.

Patient activation scores and cost correlations show less-activated patients have costs approximately 8 per cent higher than more-activated patients in the baseline year, and 21 per cent higher in the subsequent year. Several studies have demonstrated a significant link between patient activation scores and health care costs, with more-activated patients having lower rates of hospitalisation and fewer visits to accident and emergency (A&E) departments, even after controlling for disease severity and demographics (Shively et al 2013; Remmers et al 2009). There appear to be no differences by activation scores in the use of primary care services. The cost differences between less-activated and more-activated patients appear to be largely due to differences in hospitalisations and the use of A&E departments (Hibbard et al 2013);

The increase demand on health and social care has led to the development of new approaches to shift care from hospital to community and general practice. A predictive risk stratification tool has been developed for determining how patients will be treated according to which approach is most suitable. The level of professional care will vary accordingly.

The [National Cancer Survivorship initiative](#), (2013) demonstrates how risk stratification can be used as a tool to provide appropriate after care for cancer patients. The clinical team and the person living with cancer and/or their carer make a decision about the best form of aftercare:

Supported self-management – where patients are given the information about self-management support programmes or other types of available support, the signs and symptoms to look out for and who to contact if they notice any, what scheduled tests they may need such as annual mammograms, and how they get in touch with professionals if they have any concerns.

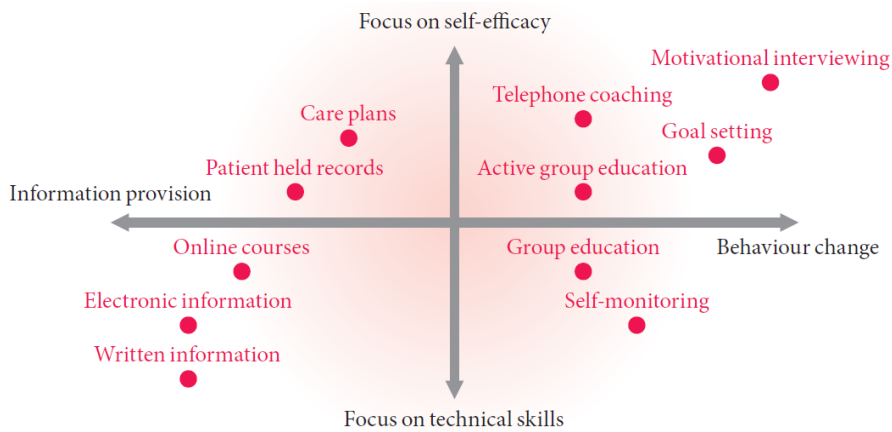
Shared care – where patients continue to have face to face, phone or email contact with professionals as part of continuing follow up.

Complex case management – where patients are given intensive support to manage their cancer and/or other conditions.



Self-management Strategies

Various approaches have been tested to support self-management. The [Health Foundation](#) describes some of these, ranging from passive information sharing approaches to more active behavioural change interventions. However, approaches can be better divided into those interventions that focus on building knowledge and technical skills compared to those that aim to build self-efficacy and confidence in self-care (The Health Foundation, 2011).



(The Health Foundation, 2011).

In 2010 the Department of Health and the NHS Institute commissioned King's College London and The King's Fund to undertake research into: [What Matters To Patients? Developing the Evidence Base for Measuring and Improving Patient Experience.](#)

The key finding was that **'relational'** aspects of care (like dignity, empathy, emotional support) are very significant in terms of overall patient experience alongside **'functional'** (access, waiting, food, noise etc.). Yet, much of what has been measured to date in terms of patient experience has focused on the more functional aspects.

The report recommends policy makers attend much more closely to relational aspects of patient experience when considering the development of indicators of patient experience, for instance compassion, empathy, emotional support, which interestingly echoes with finding from the [Francis report](#) - the public inquiry into the role of the commissioning, supervisory and regulatory bodies in the monitoring of Mid Staffordshire Foundation NHS Trust.

The economic case for patient participation

The global management consulting firm **KPMG** recently published a report, [Creating new value with patients, carers and communities](#). The key focus of their paper was on how to improve value for money and look at patient involvement as an economic argument rather than just a moral one. One of the report's conclusions was, *"It's time to use patient power and involve families and communities and work with them to improve value, safety and quality and potentially reduce costs"* (p18)

It uses KPMG's experience across the world, to outline the answers that commissioners need to develop in order to fully realise the value inherent in better patient involvement and communities to improve care. This includes:

- Is there patient and carer input into service design?
- Are systems in place to support shared decision-making?
- Does the model support self-care and help the professionals to adapt to this?

The **King's Fund** also published a research paper in November 2014, titled, ['People in control of their own health and care'](#). It discusses eight different areas of involvement which form the basis of a continuum of involvement. These areas are seen to be the foundations of the 'person-centred' health care system and can be used to turn the rhetoric into tangible experiences for people accessing services. The authors warn that these eight areas cannot be employed in isolation from each other and that, collectively, they represent a fundamental cultural shift.

This report acknowledges that despite progress, barriers still remain, and therefore action is needed now. It also makes the economic case that patient participation leads to better use of resources. One of its key conclusions is:

"the evidence is clear: overall, people are not as involved as they want to be in decisions about health and care, yet when they are involved, decisions are better, health and health outcomes improve, and resources are allocated more efficiently." (p6)

Case Studies (South)

Bristol: Personal Care Plans

Lead organisation

Bristol Community Health

Purpose

To improve **shared decision-making**. The project is mostly focused on strengthening patient engagement and activation and capacity and scope for personalisation and also promises to make to Cultural Change.

Description

Bristol Community Health uses a decision making tool called My Personal Care Plan (MPCP) to involve patients in the crucial decisions about their treatment. Dip sample research has shown that many patients are not engaged with this tool for reasons including the following:

- It is handed to the patient by clinicians as “one document among others”
- Time is not taken to support the patient to fill in the MPCP
- A relationship is not developed with the patient around teasing out the patients’ goals and capturing them in the document.

The project is focused on recruiting, training and supporting volunteers to help patients in creating and maintaining their My Personal Care Plans.

Who was involved?

Bristol Community Health is working alongside The Care Forum (TCF), an independent voluntary and community sector infrastructure organisation, who works primarily across Bath and North East Somerset, Bristol, North Somerset, Somerset and South Gloucestershire, with a core mission of supporting stronger civil society networking and patient voices in health and social care. Volunteer Cornwall and Peninsula Community Health have been involved in an advisory capacity, as the project has drawn on their work with Age UK in mapping the opportunities for shared decision making available to patients in the community.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
			✓				✓

More information:

James Picardo - Volunteer Coordinator, Bristol Community Health, South Plaza, Marlborough Street, Bristol BS1 3NX

jamespicardo@thecareforum.org.uk

Canterbury: Peer Support

Lead organisation

Canterbury and Coastal CCG

Purpose

Peer Support Groups for people with eating disorders among the student-aged population. The aim of the initiative is to reduce the suffering, stigma and discrimination surrounding the disease.

Description

This programme will develop a peer support group for student-aged people with eating disorders, targeting an unmet need across the area. Support groups for young people with personality disorders and physical disabilities are also planned. Peers will be trained to run the groups and to deliver practical tips to ease the difficulties typically experienced by sufferers, including how to conserve energy, cope with feelings, boost concentration and exchange ideas on living a healthier lifestyle.

Who was involved?

NHS Canterbury and Coastal Clinical Commissioning Group working with Canterbury and District Mental Health Forum.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
					✓		

More information:

Neil Fisher, Canterbury and Coastal CCG. Email: c4.ccg@nhs.net

Dorset: Dorset Voices Person Centred Care

Lead organisation

Access Dorset

Purpose

To enable local people to engage directly with Dorset CCG, 4 local NHS Trusts and 3 Local Authorities. It will give patients and carers a real voice in shaping how health and social care is delivered by bringing their experience to the heart of the Better Together Programme, the goal of which is to develop integrated commissioning and workforce delivery teams to deliver sustainable, person-centred services across Dorset.

Description

Co-production of a series of films to support patients and carers to be more active in developing strategies to self-manage their own health care, puts their voice at the heart of the Better Together programme, while also providing valuable tools for the training of integrated workforce teams. The working titles of each film are:

- 'We're in control' (focusing on promoting self-management)
- 'We're working in partnership' (supporting shared decision making processes)
- 'We're in the know' (raising awareness of where to access information about available support and care options)

- 'We're joining it up where we live' (focusing on the benefits of integrated care pathways)
- 'We're having our voice and using our experience' (promoting better connections and sharing of patient experience)

An introductory film is being produced that will outline what the project aims to achieve.

Who was involved?

Access Dorset (umbrella for 20 voluntary organisations) has worked with Dorset CCG, local PPGs, Healthwatch and the Better Together Programme Team.

Outcomes and benefits

To educate and empower the general public to become more involved in 3 key aspects of their own health care (self-management, shared decision making and personal care planning), and to raise awareness, giving examples of new approaches being developed to support shared decision making and outline processes for personal care planning by sharing patient's experiences of using personal health budgets and setting personal goals.

Fast access to specialist services	Easily accessible information ✓	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP ✓	Access to non-medical interventions	Patient activation ✓
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More information:

Project Manager: Jonathan Waddington-Jones, Tel. 01202 771336 jonathan@accessdorset.org.uk,

Website: www.accessdorset.org.uk or <https://www.patientvoicesouth.swcsu.nhs.uk/patients-in-control/award-winners/access-dorset/>

East Sussex: Bilingual Advocacy Training

Lead organisation

Diversity Resources International (DRI) - a social enterprise (not-for-profit organisation) set up by Vandu Language Services.

Purpose

DRI was commissioned by the NHS in East Sussex to deliver two Bilingual Advocacy courses and train bilinguals from Sussex in working with BME communities in the region. The aim is to empower service users to make decisions about their own health care and guide them towards informed choices about how they maintain well-being.

Description

Bilingual Advocacy is an interim advice and support service providing information and guidance to gain access to health services and maintain health and wellbeing to those who do not have English as a first language. The NHS in East Sussex wanted to develop this valuable support mechanism by helping people to discuss their needs and to access the services that best develop their sense of independence. The intention is for there to be less reliance on interpreters for support roles in the long term. This Advocacy Level 3 course is aimed at individuals who are fluent in English and another language, and consists of research, role plays and lectures. The first of the two courses to train advocates, commenced in September 2014 in

Hastings, an area identified as having many residents who could benefit from advocacy. The second course started in January 2015 and the Bilingual Advocacy Service will be promoted throughout 2015.

Who was involved

DRI was commissioned by Hastings & Rother CCG and Hastings Borough Council.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation ✓
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More information:

Mebrak – Vandu Language Services 01273 473986

www.vlslanguages.com or www.dritraining.org

East Sussex: Co-produced Self-Management Services

Lead organisation

East Sussex Community Voice CIC

Purpose

Co-production of supported self-management services for people with long term conditions.

Description

This project enables patients and carers to influence the design and commissioning of supported self-management services in East Sussex. It involves training volunteers from GP’s patient participation groups to coach patients with long-term conditions using a tried-and-tested online webinar course, developed by Know Your Own Health. The programme builds patients confidence, knowledge and skills so that they can better manage their own long-term health conditions and fulfil their goals. GP practices will also receive training on how to easily embed these supported self-management programmes within their practice.

Who was involved?

East Sussex Community Voice CIC, working with Eastbourne Hailsham and Seaford Clinical Commissioning Group, East Sussex County Council, Healthwatch East Sussex, Know Your Own Health and local patient participation groups, GP practices and patients.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP ✓	Access to non-medical interventions	Patient activation
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More information:

Richard Eyre, East Sussex Community Voice. Email richard.eyre@escv.org.uk or info@escv.org.uk

NEW Devon: Accessible Online Pathology Reporting

Lead organisation

NEW Devon CCG

Purpose

To use **pathology infographics** to help people with long term conditions to manage their own care.

Description

The initiative involves engagement with patients, IT developers, pathology departments, commissioners and public health, to ensure that the infographics present individual test results and information from the patient's care pathway in a way that can affect positive behaviour change. This project draws on established engagement methods to ensure patients are at the heart of developing, testing and evaluating innovative user-friendly pathology reporting.

Who was involved?

New Devon Clinical Commissioning Group, working with pathology departments in Royal Devon and Exeter NHS Foundation Trusts and North Devon District Hospital, Devon County Council Public Health and the North Devon Long Term Conditions Patient Forum (Healthwatch).

Outcomes and benefits

The project team believes that accessible online pathology reporting (IT generated infographics) will make it easier for patients with long-term conditions to have meaningful conversations with their clinicians, and therefore come to better-informed decisions on how to manage their own care.

Fast access to specialist services ✓	Easily accessible information ✓	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
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More information:

Durune Whiting, New Devon CCG. Email: daruneewhiting@nhs.net

NEW Devon: Freewheelers

Lead organisation

New Devon CCG

Purpose

Improving the safety and independence of children using wheelchairs.

Description

The Freewheeler's project arose from a need identified by children who use wheelchairs, and their educators, advocates and carers. They told project organisers that they can often find it difficult to manoeuvre their chairs safely on and off the special transport that takes them to school and other activities. This puts them at risk and can often limit their travelling.

To promote their safety and independence, and ensure these young people receive equal access to education and other activities, this project seeks to develop and deliver a driving course for power chair

users. Crucially, this is a co-designed project that gives wheelchair users and their advocates significant decision-making responsibilities.

The project also supports young wheelchair users, and their advocates, to devise and deliver a ‘train the trainers’ driving-skills course which will help them to gain confidence and acquire training skills that will be useful in future employment.

Who was involved?

New Devon CCG, local wheelchair users and their advocates.

Outcomes and Benefits

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
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More information:

Sally Parker, New Devon CCG. Email sally.parker5@nhs.net

Plymouth: Training to Empower Carers

Lead organisation

Plymouth Carers Forum

Purpose

Training to empower carers and those being cared-for to gain vital life skills.

Description

This programme of training will empower and enable carers - and those being cared for - with vital life skills, such as budgeting, understanding and accessing welfare benefits, personal care planning, good employment practice and effective communication (including self-advocacy). Participants will also be shown how to share their learning with other groups, using the materials and support provided.

Who was involved?

Plymouth Carers Forum - working with Colebrook Housing Society, Carers’ Hub, Plymouth Guild, Healthwatch, Plymouth City Council, Friends & Families of Special Children, Plymouth Community Health Carers, Plymouth CCG Local GP Surgeries, Plymouth Library Service and Abbott & Associates.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions ✓	Patient activation ✓
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More information

Lesley Gross, Plymouth Carers Forum. Email: lesleygross@hotmail.co.uk

Slough: Narrative-based Discharge

Lead organisation

Slough CCG.

Purpose

Narrative-based discharge from maternity care in Heatherwood and Wexham Park NHS Trust

This project aims to gather insights from over 250 people, being discharged from Heatherwood and Wexham Park NHS Trust (HWPH), about their experiences of maternity care when something unexpected has happened, such as a multiple miscarriage, induced labour or giving birth to a baby with a genetic disorder.

Description

These insights will inform improvements to maternity services, and a co-designed prototype service for ongoing narrative-based discharge that will help primary, community, social and voluntary groups to deliver more informed and sensitive care to women who've experienced a traumatic birth, and whose mental well-being is not on par with their physical recovery.

The prototype is being developed with the help of the voluntary sector and front line maternity teams at HWPH, who will help women and their families to write down their stories and associated feelings. This will be tried-and-tested with the aim of disseminating the learning nationally, and narrative-based maternity discharge becoming standard practice in the area by 2015/16.

Who was involved?

Slough CCG – working with key partner, Slough Council for Voluntary Services and the maternity team from Heatherwood and Wexham Park NHS Trust, amongst others.

Outcomes and benefits

Fast access to specialist services	Easily accessible information ✓	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation ✓
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More information:

Sangeeta Saran, Head of Operations, Slough CCG. Email sangeeta.saran@nhs.net

Somerset: Personal Care Plans

Lead organisation

Somerset CCG

Purpose

My Life Plan: Training volunteers to deliver personal care planning for heart failure patients.

Description

An initiative that provides training to the voluntary sector in the delivery of holistic personalised care planning (PCP) for patients with heart failure, who are discharged from Taunton and Somerset NHS Foundation Trust.

In the long run, the model will also be applied to patients with diabetes, dementia, COPD or multi-morbidities, including patients attending outpatient clinics

Who was involved?

Somerset CCG working in partnership with Taunton and Somerset NHS Foundation Trust, South West Commissioning Support Unit, Age UK Somerset, Somerset Sight, Alzheimer’s Society Somerset, Diabetes UK South West England and British Heart Foundation.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
		✓	✓				

Learning

Listen to Sophie Wickins, a My Life Plan project member, giving an update on the programme's progress to date, plus lessons learnt and what's exciting about this work. Download the .mp3 audio file (4 mins 50secs).

[My Life Plan November Update \(.mp3 audio file\)](#)

More information:

Nicola Thorne, Somerset CCG. Email nicola.thorne@somersetccg.nhs.uk.

Southampton: Person-centred Care Plans

Lead organisation

Southampton City CCG

Purpose

Person-centred planning with patients who have long term conditions.

Description

This project focuses on developing person-centred care plans for around 60 patients with long term conditions who are intensive users of health and social care services. These care plans will be drawn up with the patients, exploring their past experiences and wishes surrounding their healthcare and wellbeing, including emotional, financial, and social wellbeing.

Patients will have a single case manager to help integrate care across primary, community, social care and housing, and all future services for the patient will aim to respond to the their recorded wishes and aspirations. The care plans will be available to patients and professionals via a central database (the Hampshire Health Repository).

The aim is for this initial project, training and support to be rolled out to all communities across the city and all sectors of society; and that patients involvement in PCPs will put them in a strong position to engage in self-management, shared decision-making and personal health budget management.

Who was involved?

Southampton City CCG – working with voluntary sector organisations, including Age UK, Alzheimer’s Society, Marie Curie, Carers Together, Healthwatch, Woolston Timebank and local faith groups.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
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More information:

Adrian Littlemore, Southampton City CCG. Email adrian.littlemore@southamptoncityccg.nhs.uk

South Devon and Torbay: Peer Support

Lead organisation

South Devon and Torbay CCG

Purpose

Peer support for patients in crisis assessment from those with lived-experience of mental distress.

Description

A peer support service from those with a lived-experience of mental distress to enhance the experience of patients attending statutory crisis assessment. The initiative will inform the on-going development of peer support at each stage of the acute-care pathway, facilitating self-management and shared decision-making.

Who was involved?

South Devon and Torbay Clinical Commissioning Group - working with Cool Recovery, Devon Partnership NHS Trust, Be Involved Devon, Devon Partnership NHS Trust Research and Development Department and Leeds Survivor Led Crisis Service.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan ✓	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
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More information:

Jo Hammond, South Devon and Torbay CCG. Email: jo.hammond@nhs.net

West Kent: Peer Group Support in Primary Care

Lead organisation

West Kent CCG.

Purpose

Co-designed peer support delivered through GP practices for patients with long term conditions. It aims to reduce patients' reliance on medical intervention and help them to manage their own health and care.

Description

This programme supports the testing of a peer support model for patients at risk of, or being diagnosed with, long-term conditions. It was co-designed by local patients and carers with the lead commissioner, and will be provided through GP practices. The approach will be tailored according to participating Practices' particular

needs and patient profiles. The initiative will be tested in two different GP practices. One is in a major town with high levels of deprivation and diversity, and these issues will be taken into account within the programme design.

The model of peer support, involves establishing 'pool' of volunteers consisting of patients with long term conditions/carers, who will be recruited at GP Practice level to provide peer/group support on request. Patients will be offered either 1:1 or group peer support, to guide and signpost them to relevant support and provide a 'listening ear'. This is based on local research where patients and carers have reported how highly they value not only receiving peer support (knowing they're not alone in how they feel) but also in giving support (because they know what it's like to have a LTC). Many have found that volunteering gives them a sense of self-worth/value.

YouTube: <http://youtu.be/4wCzoF6u7nw>

Download link: <https://onedrive.live.com/redir?resid=F7727458020C66D4%21899>

Who was involved?

NHS West Kent Clinical Commissioning Group working with Kent & Medway Commissioning Support, West Kent CCG Patient and Carers Special Interest Group, two voluntary umbrella organisations and GP practices.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
				✓			

More information:

Rachel Parris, West Kent CCG. Email: rachel.parris@nhs.net

Case Studies (London)

Ealing: Voluntary Sector Health Programme

Lead organisation

Ealing CCG.

Purpose

To increase prevention and self-management in seldom heard groups, reduce social isolation for older people and those with mental health issues, and to ensure GPs and health professionals are aware of VCS support for patients and carers.

Description

A consortium of voluntary, community and BME groups commissioned to train community health champions, deliver health outreach sessions, produce a self-help directory and VCS guide, deliver disability/LGBT

awareness training for CCG staff, and to deliver volunteering programme for people with long term conditions.

Who was involved?

Ealing CCG, working in partnership with local voluntary organisations.

Outcomes and benefits

Increased patient knowledge of community services and direct investment in activities to increase patient ability to make healthier lifestyle choices.

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
						✓	✓

More information:

<http://www.ealingccg.nhs.uk/contact-us.aspx>

Tower Hamlets: Diabetes Education and Befriending

Lead organisation

Tower Hamlets CCG.

Purpose

Better self-management and promotion of diabetes within the Bengali and Somali communities, which face the most difficulty in accessing health services.

Description

Voluntary organisation, Women’s Health and Family Service, has been commissioned to recruit 56 volunteers to befriend and support 107 people with Type 2 diabetes through lunch clubs and healthy living activities such as exercises.

Who was involved?

Tower Hamlets CCG working in partnership with Women’s Health and Family Service.

Outcomes and benefits

Diabetic patients and their carers/family will be better able to manage their long term conditions with access to healthier lifestyle choices, appointments kept, positive response to informal education and befriending by volunteers within the Bengali community.

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
		✓		✓		✓	

More information:

<http://www.towerhamletscg.nhs.uk/contact/>

Tower Hamlets: Maternity Mates

Lead organisation

Tower Hamlets CCG.

Purpose

Supporting socially isolated expectant mothers at high risk of experiencing poor pre-natal, birthing and post-natal services e.g. newly-arrived migrants with no knowledge of the healthcare system and limited English, lack of a partner and family support, drug users and victims of domestic violence.

Description

Voluntary organisation, Women’s Health and Family Service, has been commissioned to recruit and train volunteer mothers from BME community to befriend and support vulnerable expectant mothers e.g. provide advice, attend appointments.

Who was involved?

Tower Hamlets CCG working in partnership with Women’s Health and Family Service.

Outcomes and benefits

103 women offered support of a maternity mate and 83% of mothers on the programme initiated breast-feeding, compared with the national rate of 73.9%. Some of the most vulnerable expectant mothers are empowered to navigate their way through maternity services and decide on positive lifestyle choices.

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
				✓			✓

More information:

<http://www.towerhamletsccg.nhs.uk/contact/>

Tower Hamlets: Cancer Awareness

Lead organisation

Tower Hamlets CCG.

Purpose

Increased awareness of cancer, preventive lifestyle choices and use of screening services in community groups. Cancer is the largest cause of premature death in Tower Hamlets with the worst survival and mortality rates in the country.

Description

A women’s community group has been commissioned to recruit 31 community leaders then trained to run educational workshops in mosques, children’s centres and markets – barriers to accessing cancer screening, potential solutions and motivators are discussed.

Who was involved?

Tower Hamlets CCG working in partnership with voluntary groups.

Outcomes and benefits

The target group will be better informed of cancer services, prevention and management.

Fast access to specialist services	Easily accessible information ✓	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
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More information:

<http://www.towerhamletsccg.nhs.uk/contact/>

Case Studies (Midlands and East)

Newark and Sherwood and Mansfield and Ashfield: Self-Care Signposting and Referral Hub

Lead organisation

Newark and Sherwood CCG and Mansfield and Ashfield CCG.

Purpose

To improve outcomes for people with long term conditions including cancer and reduce costs within long term condition pathways.

Description

Voluntary organisation (Self-Help Nottingham) has been commissioned to co-design a self-care hub with patients and carers, run by volunteers and fully integrated into LTC pathways. The Hub will support an increase in self-care by patients at low risk of hospital admission.

Who was involved?

Newark and Sherwood CCG and Mansfield and Ashfield CCG are working in partnership with Self-Help Nottingham, a local voluntary organisation.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions ✓	Patient activation
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Learning from the project will inform a training programme for health staff to support culture change in self-care support across Mid Nottinghamshire.

More information:

<http://www.selfhelp.org.uk/nottinghamshire/>

Nottingham: Dementia.net

Lead organisation

Nottingham North and East CCG.

Purpose

To enable and empower carers of people with dementia and their families to promote greater self-care, maintain independence and provide support for the cared for.

Description

A website with supportive resources and videos, co-produced with carers and voluntary groups. On-going collaboration with Skills for Care, Skills for Health and NHS Choices to develop website and disseminate resources to carers.

Who was involved?

Nottingham North and East CCG working in partnership with carers and voluntary groups, plus Skills for Care, Skills for Health and NHS Choices.

Outcomes and benefits

For people with dementia to remain within their residence of choice.

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks ✓	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
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More information:

<http://www.nottinghamnortheastccg.nhs.uk/contact-us/>

South West Lincolnshire: Personalised Care Plan

Lead organisation

South West Lincolnshire CCG

Purpose

One plan, shared by all but owned by the patient so they are in control and can self-manage more effectively. The aim is to reduce hospital stays, reduce delays in discharge, promote independence and improve patient involvement in care decisions and delivery, putting patients in better control of their health and well-being.

Description

Hand-held care planning booklet owned by the patient, which communicates the patient’s care and support needs for daily living and well-being. Developed and completed with the patients and carers, from pre-diagnosis to end of life across health and social care, it ensures an individual’s personal values, concerns, usual behaviours and lifestyle choices are taken into account in shaping how they will be supported to live with and manage their condition(s).

Who was involved?

South West Lincolnshire CCG, supported by 20 partners across health, voluntary, community and social care.

Outcomes and benefits

Reduced stay in acute care, safer pathways, planned discharge leading to a more effective releasing of time to care. Patients will be empowered to be ‘included and in control’, increasing positive patient outcomes and self-management.

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
			✓				

More information:

<http://southwestlincolnshireccg.nhs.uk/contact-us>

Case Studies (North)

Newcastle, South Tyneside & Gateshead: Shared decision making

Lead organisation

Newcastle upon Tyne NHS Foundation Trust.

Purpose

To embed shared decision-making in core clinical practice of mainstream health services.

Description

MAGIC (Making Good decisions In Collaboration) is a cross-cutting programme. In Newcastle, shared decision-making is used in breast care, obstetrics, urology and GP practice. In South Tyneside and Gateshead it is being built into clinical culture and practice through GP MAGIC champions and training 68 GPs from 33 practices. MAGIC is about developing practical solutions that work and are transferrable across the health service. This means more than just working with practical decision-making tools, it means creating a culture where shared decision making thrives.

Who was involved?

Newcastle upon Tyne NHS Foundation Trust, Newcastle, South Tyneside and Gateshead CCGs.

Outcomes and benefits

Success criteria were:

- To change attitudes and culture of the health service and inspire staff to work closely with patients
- To prove the benefits of shared decision making to health professionals and patients
- To help teams build the skills they need to use decision-making tools and techniques
- To show how shared decision making fits into the existing health system, overcoming time and resource limitations.

There has been increased patient involvement and high quality shared decision-making consultations – 100% of renal services patients were involved in the options appraisal when dialysis was recommended. In 93% of cases, the patient’s values and preferences were elicited.

Fast access to specialist services	Easily accessible information	Education and training ✓	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation ✓
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More information:

Health Foundation website: <http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/>

Newcastle West: Social Prescribing

Lead organisation

Newcastle West CCG.

Purpose

To develop a linking service within the voluntary and community sector, enabling health professionals to refer vulnerable people with long term conditions to community services and networks.

Description

Care planning training and support rolled out to local practices – a comprehensive web-based information resource is being developed to support the project.

Who was involved?

Newcastle West CCG, working in partnership with voluntary organisations.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
						✓	✓

124 patients were referred to the project, of whom 69 per cent experienced an increase in their mental well-being score, and 64 per cent reported an increase in confidence in managing their long term condition.

More information:

<http://www.newcastlewestccg.nhs.uk/contact-us/>

Rotherham: Social Prescribing

Lead organisation

Rotherham CCG.

Purpose

To help people with long term conditions access a wide variety of services and activities provided by the voluntary sector.

Description

GP practices refer patients to Social Prescribing Workers, managed by voluntary organisations that, in partnership with the patient, help the patient to access services and activities which improve their health and well-being, and meet their needs such as poor mobility, transport and low confidence. The service is integrated with the case management scheme involving health, social care and voluntary sector to ensure the patient's care plan is co-ordinated and updated.

Who was involved?

Rotherham CCG, working in partnership with voluntary organisations.

Outcomes and benefits

Fast access to specialist services	Easily accessible information	Education and training	Personalised care plan	Peer support networks	Better knowledge of condition by GP	Access to non-medical interventions	Patient activation
						✓	✓

The service aims to deliver 20 per cent reduction in A&E attendances, 21 per cent reduction in in-patient stays, with a potential cost reduction of £415,000 in the first year, and an estimated well-being value of £920,000. 83per cent of patients made progress towards self-management.

More information:

<http://www.rotherhamccg.nhs.uk/contact-us/>