The Health Foundation
Inspiring Improvement

RCGP inquiry into Patient-Centred Care in the 21st Century

The Health Foundation response to the Call for Evidence

4 August 2014

About the Health Foundation

The Health Foundation is an independent charity working to improve the quality of healthcare in the UK. We are here to support people working in healthcare practice and policy to make lasting improvements to health services. We carry out research and in-depth policy analysis, run improvement programmes to put ideas into practice in the NHS, support and develop leaders and share evidence to encourage wider change. We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable.

Introduction

We welcome the opportunity to submit evidence to the RCGP inquiry into patient-centred care and thank the Inquiry for providing an extension for us to submit this response.

The issues which the Inquiry is seeking to address are critically important but they are not new: they have been explored by policy makers, politicians, researchers and others, particularly in recent years. There is a general consensus that the NHS needs to change the way it organises, delivers and pays for care if it is to understand and meet the needs of the more than 15 million people in England living with one or more long-term conditions. There has been progress on this in recent years including a legal duty in the Health and Social Care Act on commissioners to involve patients in decisions about their care and treatment. NHS England has also produced a range of resources (Any Town and *Transforming Participation*) which emphasise self-management support as an important part of the solution to the growing demand placed on health services by the increasing numbers

of people across all age groups[1] living with one or more long-term conditions (the latter expected to grow to 2.9 million by 2018, up from 1.9 million in 2008). But despite these efforts and pronouncements we are long way from achieving the ambition.

Much has been written about the problem and possible solutions. Most recently, the King's Fund, *Supporting people to manage their health*, *Delivering better services for people with long-term conditions: Building the house of care* and the Health Select Committee's Report on its inquiry into *"Managing the care of people with long term conditions (LTCs)"* have outlined the ways in which NHS structures and processes need to be redesigned to respond to the challenge of long-term conditions.

Our submission focuses on the high level changes that are needed to existing models of care to realise the aim of a person-centred health service[2]: one that supports people with a long-term condition to develop the knowledge, skills and confidence to more effectively manage their health and care. Our submission should be read in conjunction the Health Foundation's evidence to the Health Select Committee's Inquiry into Long-term conditions, attached at Annex A, which sets out in more detail on how to achieve these changes.

1. **How do models of NHS care need to change to deliver better patient outcomes, as cost effectively as possible, for the growing number of people living with multiple long-term conditions?**

There are five key ways in which existing models of NHS care need to change to address the challenges of the growing numbers of people living with one or more long-term conditions.

Proactive not reactive: The main shift that is required is from a reactive system that treats disease to a proactive system that supports and enables people to be as healthy as possible. For people with long-term conditions, this means supporting people to develop the knowledge skills and confidence to manage their condition and to make decisions about their treatment and care.

Collaborative: Care must be truly collaborative with individuals and with their communities. A model of care and support based on the premise that the NHS must 'do it all' is unsustainable and is unlikely to meet the needs of patients or their communities.

Embrace new roles: As well as supporting health care professionals to embrace partnership working with their patients, moving from being seen as experts who do things to patients to partners who support and enable people, there is a need for new roles. These are likely to

[1] Barnett, K, Mercer, S, Norbury, S, Watt, G, Wyke, S, Guthrie, B, Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study www.thelancet.com Published online May 10, 2012 DOI:10.1016/S0140-6736(12)60240-2 (http://www.sciencedirect.com/science/article/pii/S0140673612602402) (Lancet May 2012)

[2] The Health Foundation uses the term 'person-centred care' rather than patient-centred as we believe this more accurately reflects the fact that we aspire to a system that supports and enables people to develop the knowledge, skills and confidence to manage their health and care, not only during the periods when they are in direct contact with the health service or health care professionals. In a recent thought paper for the Health Foundation, Dr Alf Collins, outlines four principles of person-centred care: dignity, compassion and respect, coordination, personalisation and enablement. These principles and the framing provided by that paper form the basis of our submission to this Inquiry.

include roles such as peer support workers, care navigators and health coaches. This needs to be within a wider system that supports and values teams to work and train together and to respect each other's contribution and capabilities.

Target interventions: Care and support interventions need to be tailored to meet people's needs. New models of care need to be able to make decisions based not just on segmentation by health need but also by characteristics such as knowledge, skills, confidence, motivation and attitudes.

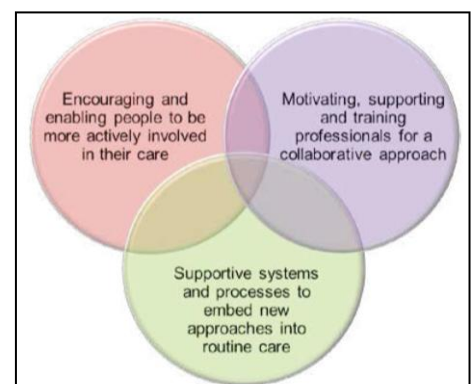
Measure what really matters: The NHS currently invests a lot of time and energy in measuring the quality of health services but very few of the measures it uses come from the perspective of patients. The development of a system which values and prioritises the outcomes that matter to patients, not simply the processes and outcomes that the system can currently measure (such as length of hospital stay or cost) is essential.[3]

So what does this mean in practice?

The Health Foundation has a substantial body of learning about how to implement person-centred care in practice. In particular, since 2005, the Health Foundation has invested over £5 million in a large-scale demonstration programme (Co-creating Health[4]) which tested the best ways to redesign routine care so that patients are well supported to manage their long-term conditions. In 2012 four NHS sites were given additional funding for two years to continue working to embed self-management in their services and to share their learning with others.[5]

The considerable learning from this work as well as our other investments in person-centred care (including through Magic, our shared decision making programme and Closing the Gap through changing relationships) highlights three essential elements for any model of care and support seeking to deliver better care for people living with long-term conditions:

i. Patients/service users must have the confidence, knowledge and skills to manage their own health and care, including making decisions in partnership with healthcare professionals.
ii. Healthcare professionals need to be committed to working in partnership with patients. Healthcare professionals need training and support to develop the confidence, knowledge and skills to work in new ways and take on new responsibilities.
iii. Systems must align to support patients and healthcare professionals in these new roles. This might include, for



[3] For more information see *Measuring what really matters*, a thought paper by Dr Alf Collins for the Health Foundation and *Helping measure person-centred care*, an evidence review of the current measures for person-centred care.
[4] For further information about Co-creating Health visit: http://www.health.org.uk/areas-of-work/programmes/co-creating-health/.
[5] For further information about our work to spread self-management support visit: http://www.health.org.uk/areas-of-work/programmes/spreading-self-management-support/.

example, computer systems that allow results to be sent to patients before their appointment, or longer consultations for people living with a long-term condition as part of a process of collaborative personalised care and support planning.

Co-Creating Health was a programme based within the health service so its design did not specifically address the role of the community. However, the important role the community plays in supporting people with long-term conditions emerged as an important learning point through the implementation of the programme. For more on the role of communities, see Nesta's work on People Powered Health.

The following table sets out the different ways in which current practice needs to shift to become person-centred.

	Current practice	Person-centred care
Roles and beliefs	Patients passive, believe clinician has the answers and will improve their health	People active partners and managers of their health
	Clinical expert gives advice, fixes and promotes dependency	Clinician listens and uses expertise to support and enable patient as a partner in decision making and management of their health and care
	Knowledge creates behaviour change	Knowledge, skills and confidence create behaviour change
Model	Primarily medical	Biopsychosocial
Outcomes	Clinical outcomes	Outcomes that matter to people
Who	Workforce = clinicians	Workforce = clinicians + peer support workers + navigators + health coaches + ...
How	Clinician shares results and information during consultation	Person receives results and information at appropriate time to enable them to set their agenda and make their decisions
	Clinical training in 'communication' skills used to enable them to get agreement to clinician determined goals	Clinical training in skills to support people to determine and enact their own goals
	Compliance with clinically determined goals and treatment plans	Collaborative care and support planning with adherence to co-produced goals

What does this mean for the way in which NHS resources are deployed across health economies in a financially constrained environment?

There is a growing body of evidence that supporting patients with long-term conditions to self manage their health and healthcare can improve clinical outcomes and has the potential to lead to more cost-effective use of services[6]. For example, people may engage more

[6] De Silva, D, *Helping people help themselves. A review of the evidence considering whether it is worthwhile to support self-management*, The Health Foundation, May 2011.

frequently with a practice nurse, but use less emergency hospital services and in-patient admissions. Patients who have the opportunity and support to make decisions about their care and treatment in partnership with health professionals are more satisfied with their care, are more likely to choose treatments based on their values and preferences rather than those of their clinician, and tend to choose less invasive and costly treatments.[7]

Models of care based on the four key elements outlined in Question One will have implications for how NHS resources are deployed. In particular, we believe, this requires a rebalancing of financial flows towards the following:

- Increased investment in patient education and training, through, for example self-management programmes.
- Ensuring community assets are properly funded to enable them to support the new models of care and support.
- Investment in development and training of new roles (health coaches, peer support workers, care navigators etc).
- Rebalancing of investment in education and training of the current and future health and social care workforce to ensure that the workforce has the knowledge, skills and confidence to work in partnership with patients including through shared decision making, supporting self-management and collaborative care and support planning.

The Royal College of General Practitioners has a key role in building momentum for person-centred care within general practice. This can be achieved through influence over the undergraduate and post graduate curricula and through building and supporting capability amongst GPs and other professionals to embrace new ways of working and through working collaboratively with education providers, regulators and funders to ensure that funding is directed to this aim. The Health Foundation is funding a Clinical Champion for Collaborative Care & Support Planning within the College. This role has the ability to provide leadership and to deliver active GP engagement in the person-centred care agenda amongst RCGP officers, members and stakeholders at national and local level. We welcome the College's foresight. The scale of the transformation required is considerable. The post holder can act as a catalyst and support for this change; for the change to be embedded it will be necessary for all of the functions of the College to align behind the goal of person-centred care and ensure that it underpins all of their work.

Further resources

Person Centred Care is a strategic priority for the Health Foundation and our Resource Centre contains an array of reports, policy document and tools on the subject at http://personcentredcare.health.org.uk/

The following publications may also be relevant for the Inquiry to consider:

Measuring what really matters
Helping measure person-centred care
Sustaining and spreading self-management support,
Evaluation of Co-Creating Health Phase 1

[7] See the Health Foundation's systematic evidence reviews *Helping people help themselves*, *Helping people share decision making* and the recent National Voices review of the evidence for person-centred care for more detail about the evidence base for person-centred care.

Helping people help themselves
Helping people share decision making

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Health Foundation response to the RCGP Inquiry into patient-centred care
Annex A

Submission of evidence to the Health Select Committee's long-term conditions inquiry

1.0 Executive summary

1.1.1 The Health Foundation is an independent charity working to improve the quality of healthcare in the UK. Informed by our research and improvement programmes, this submission of evidence considers the ability of the NHS to 'treat the patient as a person' and recommends changes needed to deliver high quality, person-centred care for people with long-term conditions.

1.2 The NHS has only a very limited ability to deliver person-centred care for people with long-term conditions. This is because patients are largely viewed by clinicians as passive recipients of care and few are supported to develop the skills, confidence and behaviour to effectively manage their conditions. Furthermore, the way that the health system is structured and its processes are organised poses a barrier to more person-centred care.

1.3 The vast majority of care for a person with long-term conditions is delivered by the individual patient themselves because they are living with their condition every day. It is therefore essential that improvement of health services is focused upon supporting people to effectively manage their own conditions.

1.4 There must be changes to the roles, mindsets and behaviours of patients and clinicians, supported by processes and infrastructure that enable a new relationship of partnership between people and health professionals.

1.5 To make the rhetoric of person-centred care a reality, action is required by clinical commissioning groups, NHS England and those bodies with influence on the education and training of health professionals.

2.0 What is person-centred care and why is it important?

2.1 Coordinated, community-based services are important, but not on their own sufficient, to deliver sustainable and effective care for people with long-term conditions. There needs to be a fundamental change in how government and the NHS think about care for people with long-term conditions.

2.2 It is vital that the improvement of long-term conditions management is focused on the role patients themselves can play in effectively managing their conditions. On average, a person with a long-term condition spends just three hours each year in

contact with a health professional, and that contact does not always coincide with the periods of time when an individual most needs support.

2.3 Person-centred care should support people to self-manage, offer personalised care planning and enable people to share in decision making.[8] It should use the limited time patients spend with a health professional to: enable patients to become knowledgeable, confident managers of their health; support people with long-term conditions to make informed decisions about and to successfully manage their own, health and care; deliver care that is responsive to people's individual abilities, preferences, lifestyles and goals.

2.4 Despite the promotion of these approaches by government and health policy leaders, truly person-centred care has not spread beyond core innovators. The ability of the NHS to "treat the patient as a person" is far too limited.

2.5 Creating this person-centred health system requires different roles, behaviours and mindsets from clinicians and patients, supported by processes and infrastructure that enable new relationships. Health professionals need to view people as partners in their care, rather than passive recipients. They need to understand the motivations and challenges that each individual faces in adopting healthy behaviours – not just the biomedical challenges, but psychological and social challenges as well.

2.6 This requires a fundamental shift in how health services are delivered, with the emphasis moving from focusing on improving clinical outcomes to quality of life, from providing specialist treatment to generic support, and from a system that reacts to people's ill health to one that focuses proactively on enabling people to live as healthily as possible.

3.0 Our evidence base

3.1 This submission of evidence is informed by the Health Foundation's improvement programmes and research, and focuses primarily upon our learning about how to effectively implement self management support and shared decision making.

3.2 Starting in 2007, the Health Foundation's Co-creating Health (CCH) improvement programme worked for five years with several NHS sites to demonstrate the best ways to redesign routine care so that patients are well supported to manage their long-term conditions. It featured training programmes for patients and health professionals and a service improvement programme. Four sites have now been given additional funding which they will be using over the next two years to continue to embed self management in their services.[9]

3.3 The Health Foundation's Making Good Decisions in Collaboration (MAGIC) improvement programme has been exploring how clinical services can support patients to share in decision making. MAGIC has not been tested specifically in the

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[8] Further information about self management support and shared decision making is available on the Health Foundation's resource centres at http://selfmanagementsupport.health.org.uk/ and http://shareddecisionmaking.health.org.uk/.

[9] Further information about CCH is available at http://www.health.org.uk/areas-of-work/programmes/co-creating-health/.

context of long-term conditions, but is relevant because people with long-term conditions are faced with care and treatment options.[10]

3.4 Our Closing the Gap through Changing Relationships[11] and Shine[12] improvement programmes have supported NHS teams to explore innovative ways to improving care. Projects have included the provision of home-based web consultations for patients with diabetes and support for people with kidney disease to use self-dialysis in hospital.

3.5 The research we draw on in this submission includes our syntheses of the evidence bases for self-management support and shared decision making[13] and an exploration of the interaction between patients and clinicians during the consultation.[14]

4.0 Barriers to person-centred care

4.1 The barriers to person-centred care are largely cultural and arise from the three key participants in healthcare: health professionals, patients and organisational processes.

4.2 **Health professionals**.
The attitudes, beliefs and behaviours ingrained in health professionals limit their ability to provide effective, person-centred care. Barriers include the following:

4.2.1 *'We already do that.'* There is a lack of a clear, shared understanding about what effective person-centred care looks like. When urged to participate in our programmes, many health professionals said they already are supporting their patients to self-manage or are using shared decision making. But after training sessions, many realised that they had not been using a truly person-centred approach.

4.2.2 *'There isn't enough time.'* A common response to our programmes was that health professionals felt they had too much to do and no time to participate in training or to engage in self-management support and shared decision making. Clinicians also feared that the approaches would lengthen the time of consultations.

4.2.3 *Health professionals lack understanding about the value of involving patients in design and delivery.* In Co-creating Health, for example, lay tutors sometimes found that health professionals questioned the role patients could play in clinician training.

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[10] Further information about MAGIC is available at http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/.

[11] Further information about Closing the Gap through Changing Relationships is available at http://www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-changing-relationships/.

[12] Further information about Shine is available at http://www.health.org.uk/areas-of-work/programmes/shine-eleven/

[13] The Health Foundation (2011). *Helping people help themselves*. London: The Health Foundation. The Health Foundation (2012). *Helping people share decision making*. London: The Health Foundation.

[14] Fischer, M. & Ereaut G. (2012). *When doctors and patients talk: making sense of the consultation*. London: The Health Foundation.

4.2.4 *Health professionals are not taught skills necessary for person-centred support.* Our programmes found that few health professionals are equipped with the knowledge and skills necessary to understand what motivates their patients and support them to change behaviours.

4.3 **Patients**

Individuals with long-term conditions may have a poorer quality of life, lower levels of support from social networks, and less confidence in their ability to manage their health than people without long-term conditions.[15] Barriers include the following:

4.3.1 *Patients lack of knowledge, skills, and confidence to effectively manage their own health.* Being diagnosed with a long-term condition is a life-changing event which may involve changes in lifestyle and require new competencies in, for example, medicines management.

4.3.2 *Patients feel 'doctor knows best'.* Feelings of deference or anxiety towards health professionals made some patients reluctant to engage in training programmes or in a new kind of consultation in which they act as partners with clinicians in planning and making decisions about their care.[16]

4.4 **Organisational processes**

Healthcare delivery systems – including the services that are commissioned, operational systems and financial incentives – can be barriers to person-centred care. These barriers include the following:

4.4.1 *Patients lack access to a range of services that fit their individual needs and abilities.* Providing information alone is not enough to support people with long-term conditions. People need proactive support to help them develop the confidence, skills and knowledge to manage their health and care.[17]

4.4.2 *Commissioners lack an understanding of person-centred care and 'how to get it'.* Commissioners who gave insights for Co-creating Health recognised the role of self-management support in reducing pressure on services. However, their understanding of effective self-management support was mixed and some were unsure about how to commission it.

4.4.3 *IT systems can prevent easy access and flow of information*. For example, one Co-creating Health team faced the problem of GPs using different IT systems, which prevented them from flagging patients participating in the training programme.

4.4.4 *Lack of access to test results or other information in advance of a consultation.* Our systems are designed to give test results or information about treatment options during the consultation, which hinders agenda setting, care planning and shared decision making within allotted consultation times.

[15] Parsons, et. al. (2010). *Self management support amongst older adults: the availability, impact and potential of locally based services and resources*. National Institute for Health Research Service delivery and Organisation programme.
[16] Fischer, M. & Ereaut G. (2012). *When doctors and patients talk: making sense of the consultation*. London: The Health Foundation.
[17] The Health Foundation (2011). *Helping people help themselves*. London: The Health Foundation

4..4.5 *Tariffs are not always aligned to provide self-management support.* In our shared haemodialysis project,[18] for example, people with kidney disease learnt to self-administer dialysis in hospital, gaining independence and freeing up staff. Patients use button holing – a means to self-administer dialysis – but the tariff acts as a disincentive because the needles necessary are more expensive than the sharper needles used in staff-administered dialysis.

5.0 What we have learned about how to overcome these barriers

5.1 Creating a culture that supports person-centred care is a significant challenge. Our programme teams have had to be creative and flexible to overcome barriers. Support from senior leadership – up to trust board levels – has been vital in gaining traction.

5.2 Changing culture and behaviours among health professionals

Health professionals need education, training, and development that gives them the knowledge and skills required for person-centred care. The Health Foundation has learnt the importance of the following:

5.2.1 *Encouraging participation in training*. Getting health professionals to participate in training required clearly setting out the benefits of self-management support and shared decision making. To address time concerns, teams had to adapt training, in some cases shortening the programme or offering mini-training sessions to support staff. Those who participated found that using shared decision making and agenda setting helped to structure consultations.

5.2.2 *Training whole teams*. Co-creating Health found it important to train whole teams of health professionals from the same service, so that everyone involved had a common understanding of self-management support and its tools and techniques.

5.2.3 *Ensuring health professionals have the right skills.* Training involved role playing as well as education in support techniques such as motivational interviewing and coaching skills, which are key to helping patients build confidence.

5.3 Changing culture and behaviours among patients

Patients who attended Co-creating Health group sessions had, on average, become more motivated and confident to self-manage.[19] As one person who took the course said: *'[I]t galvanised me, it got me going. I think I pulled myself out of a hole and decided that I was going to do it. Like the lay person [tutor], she'd obviously taken charge of her illness, and I thought well I can do that, I'm not a wimp'.* Our programmes helped overcome patient barriers in the following ways:

5.3.1 *Encouraging participation in patient training.* Co-creating Health found that patients sometimes needed encouragement from a trusted source – especially their GP – to prompt them to participate in a training programme.

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[18] Further information about this project is available at http://www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-changing-relationships/related-projects/from-dependency-to-control-enabling-self-dialysis-in-hospital/

[19] Programme evaluators used the Patient Activation Measure, a licensed tool for evaluating a patient"s level of knowledge, skills and confidence to self-manage.

5.3.2 *Offering activities that build confidence.* Co-creating Health offered biomedical, psychological and in some cases social support through peer support. Group sessions included goal setting, problem solving, and relaxation, as well as condition-specific training such as self-monitoring or managing pain. Lay and clinical tutors used techniques such as positive psychology, motivational interviewing and helping people identify unhelpful beliefs.

5.3.3 *Adapting to patients' needs and preferences*. Teams sometimes changed the length or content of sessions to suit patients. They developed creative ways to promote and carry out self-management support, such as through practice-based resource libraries or text messages to follow up on goals.

5.3.4 *Involving patients in design and delivery of training sessions*. Several project managers found that involving patients in the design, development and implementation of the programmes was vital to meet patients' needs because the patient perspective 'could not be imagined' by professionals.

5.3.5 *Promoting peer support*. Peer support at some sites also helped motivate people to engage. Peer support activities ranged from regular phone calls with a "buddy" reunions for those who had participated in training together, and a peer-led walking group.

5.4 **Changing systems**

Whole system change is needed to integrate person-centred care into care pathways. More work is needed at all levels to investigate and consider what systems or tariffs are supporting or hampering person-centred care. Our programme teams made some progress in this with help from their wider organisations. Progress included the following:

5.4.1 *Developing tools and support for clinicians*. Some teams developed agenda-setting sheets to help patients identify what they want from a consultation, confidence rulers to help assess the likelihood of a behaviour change and health plans to capture patients' commitments to their actions. Other teams developed electronic templates to prompt clinicians and help structure consultations. Administrative staff members were trained to help get information out before consultations.

5.4.2 *Creating access to home-based solutions that promote independence*. A Health Foundation project has offered diabetes follow-up consultations by web-cam.[20] Patients reported that, compared to face-to-face appointments, web consultations saved time, were more convenient and that they would be more likely to attend them.

6.0 Recommendations

We want to see as many people as possible supported to develop the skills, knowledge and confidence to successfully manage their health. To make this possible:

- commissioners should prioritise their duty to promote involvement of patients in their care and treatment, including by involving people with long-term conditions in designing and developing support services and making sure they have access to a wide menu of options providing tailored support such as training programmes and

[20] Further information about this project is available at http://www.health.org.uk/areas-of-work/programmes/shine-eleven/related-projects/newham-university-hospital/

peer support

- NHS England should support clinical commissioning groups to commission services that support self management by sharing best practice

- NHS England, working with Monitor, should ensure financial incentives encourage and support self management, and do not obstruct it

- NHS England should use the available measures to assess how well people are being supported to self manage and to invest in developing these measures further

- Health Education England, royal colleges and professional regulators should bring person-centred care principles and training into undergraduate, postgraduate and continuing professional education curricula.

7.0 Oral evidence

The Health Foundation would be pleased to give oral evidence to the committee if it would be helpful to the inquiry.

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