

Enablers and barriers for engaged, informed individuals and carers:

left wall of the House of Care framework

INTRODUCTION

Engaged and informed individuals and carers can mean different things to different people. In this article we use the definition from the Coalition for Collaborative Care:

*'... people have the right support, knowledge, skills, power — and of course confidence — to [manage their care and support] and live the lives they want.'*¹

In the recent editorial on rhetoric and reality in person-centred care Mathers and Paynton provide a persuasive narrative as to why person-centred care (PCC) should be adopted as 'the norm' and how the introduction of collaborative care and support planning (CCSP), as a manifestation of this approach, will facilitate its implementation, particularly for people with long-term conditions (LTCs).²

Key to the delivery of both PCC and CCSP, are the four components of the House of Care (HoC):

- engaged, informed individuals and carers (left wall);
- health and care professionals committed to partnership working (right wall);³
- commissioning including 'more than medicine' (floor); and
- organisational and supporting processes (roof).

This article, the second in a series of four articles considering each of the four components of the HoC model, will address both the enablers and barriers pertinent to individuals and carers being engaged and informed, to enable the delivery of CCSP.

WHY ENGAGED AND INFORMED INDIVIDUALS AND CARERS?

There are over 15 million people with LTCs in England, whose care accounts for over 50% of all GP appointments and 70% of all inpatient episodes. In total, people with LTCs

account for over 70% of the total NHS and Social Care expenditure, and as the number of people with LTCs is set to increase then these costs will rise accordingly in future years. Yet, individuals with LTCs spend only a few hours with GPs or other healthcare professionals each year and spend the majority of their time managing their conditions themselves, although the use of self-management varies between condition. It therefore makes sense for the Health and Social Care system to work with individuals and carers to encourage them to be informed and engaged, to facilitate them to manage their conditions to the best of their ability and thereby to enable them to have a lower utilisation of healthcare resources.

In addition to financial advantages, individuals who are engaged and informed are more likely to have a greater sense of control, increased confidence, knowledge and skills, and to experience better health outcomes, including better mental health, reduced depression, and decreased severity of symptoms.

BARRIERS TO ENGAGED, INFORMED INDIVIDUALS AND CARERS

Even though many strategic policies have promoted this approach⁴⁻⁷ barriers continue to exist to making it 'the norm' within the health and social care system. These barriers are multifaceted, and arise from within all components of the HoC model. Health and care professionals have a key role to play in supporting people to become engaged and informed, yet a recent survey facilitated by NHS England showed that clinicians varied significantly in their support of people taking an active role in their health care.⁸

Patients and carers say that they want to be more actively involved in decisions about their own care yet it has been shown that 43% of the UK population lack adequate literacy skills to understand food labels, medicinal instructions, and information given by the NHS in leaflets and online.⁹ Even more concerning is that 61% do not have

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Further information

For more information on RCGP's Collaborative Care and Support Planning programme visit www.rcgp.org.uk/care-planning.

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the numeracy-specific health literacy skills needed to maintain their health.⁹

Organisational factors are repeatedly identified as barriers; time constraints within consultations, insufficient resources and support services, and poor communication between service providers represent significant constraints.⁸ Finally, present contracts for health services, established to improve productivity in the NHS, may not be best placed to support individuals to be engaged and informed. Meanwhile the voluntary sector, which has historically supported individuals to be engaged and informed, has struggled to access NHS funds.

ENABLERS TO ENGAGED, INFORMED INDIVIDUALS AND CARERS

In order for the health and social care system to embed PCC and provide the most effective environment for engaged, informed individuals and carers, we need a whole system approach as described by the HoC model. Evidence suggests that there are many ways to support people to become more engaged and informed, and that a range of initiatives as part of a wider array of interventions at several levels is required.

At a national level, supporting health and care professionals to develop the skills needed to work in partnership with patients and carers is essential. Curriculums at all levels from undergraduate to postgraduate will need to be modified, ensuring that people with 'lived experience' are supported to be part of the learning experience. Learning from 'new models of care' that look to create new relationships with patients and communities, as articulated in the *NHS Five Year Forward View*, will help to provide new opportunities for service provision that has PCC at their centre.⁷

Without appropriate information on health services and conditions and evidence to promote self-management, individuals and carers will struggle to be engaged and informed. Therefore, there is a need for consistent and trusted information delivered through recognised sources, which individuals, carers, and professionals can use. Regionally, local organisations such as voluntary sector groups can help to disseminate the information and promote self-management, prevention, and engagement.¹⁰ Also, Healthwatch (www.healthwatch.co.uk/) may assist with encouraging individuals and carers to have a say in helping to improve services, increasing people's knowledge and confidence in the process.

At an individual level there is an increasing body of evidence demonstrating that 'more than medicine' or holistic approaches are

effective.¹¹ These utilise a range of social interventions, for example, peer support groups or community cooking classes can enable people to feel more in touch with others and so more able to participate more effectively in their own care.⁷ Personal health or social care budgets allow greater choice and control for both individuals and their carers, and can be used to purchase such services, in particular from the voluntary sector, which has demonstrated effectiveness in this area.¹⁰

Effective communication is central to improved engagement. Many people have indicated that having a named contact to telephone or email directly about day-to-day health issues would support them to self-manage. For a significant number, a healthcare professional would be the person of choice; however for many, this could be an experienced patient with a similar condition.

Finally, access to electronic health records is important for both patients and professionals. For patients, their health data needs to be presented in accessible, understandable formats, to assist their participation. This includes access to records through one single portal, rather than multiple portals offered by the different providers. Professionals need to be able to share patient information, with patient consent, across all health settings so patients only need to tell their story once.

CONCLUSION

Our present care system, designed to manage acute disease and where patients were perceived to be passive recipients of care, is failing to respond to escalating demands placed on it by the increasing number of people with LTCs. Health and care professionals need to recognise that engaging and involving individuals is not only ethically correct but also a person's democratic right.

In addition, as individuals and carers become more engaged and informed, and as consumers of publicly-funded services, people will increasingly demand services responsive to their needs and providers will need to change to ensure guaranteed ongoing funding.

General practice is in a unique position to ensure PCC becomes 'the norm'. Working in partnership with local communities to address the barriers and deliver CCSP in a trusted environment can help to enable individuals to self-manage, feel more engaged and informed and ensure that patients are given the recognition that they deserve, as one of the NHS's greatest untapped resource.