

Patients as partners in developing self- management solutions: Co-design Case Study

Supporting older people with
heart disease – NHS Solihull
CCG

NHS Solihull Clinical Commissioning Group (Solihull CCG) took part as an early adopter in the Patients in Control (PiC) Programme in 2014/15. This case study describes the journey as an early adopter and highlights important learning.

An interest in self management

Solihull CCG sits in the West Midlands and has a history of innovative approaches to working with patients and communities as a way of tackling health inequalities and improving outcomes. CCG leaders had shown previous interest and enthusiasm for participation and exploring new ways of working with people and community partners to improve health.

They were keen to see how the PiC offer might enhance existing work on commissioning redesign and securing sustainable commissioning models based on extended self management support for people with Long Term Conditions. Solihull CCG had hosted and promoted the online survey about the self management needs of patients and carers so it knew there was interest and appetite among patients for greater self management support. Responses to the survey reflected the emerging national picture of priorities – easily accessible information, GPs having better knowledge and communication and coordination between professionals.

Through a particular focus on older patients with heart disease, the Commissioning Redesign Manager wanted to better understand how these patients could be empowered and supported to feel more confident in self managing their conditions and staying healthy and well for as long as possible.

Gathering insight and building local understanding

To help with recruitment of patients, the CCG identified a local volunteer leader of a British Heart Foundation-affiliated activity/support group for people with heart disease. The volunteer leader helped support the recruitment of 10 patients to participate in the PiC programme. The 10 participants were members of the activity group – all were aged over 50 but the participants were at various stages of living with their conditions –some were recently diagnosed and some had lived with their conditions for many years.

Two sessions of facilitated insight gathering were held over the period of a fortnight. Each session lasted 2 hours and was held in the morning at a local Day Centre. Participants were busy, motivated individuals who wanted to get the most out of their lives and not be defined or limited by their conditions.

The first session explored the topic of self management and discussed the areas of self management support that mattered most drawing on the 11 self management themes previously identified by patients.

The second session developed the themes identified as priorities capturing the essential characteristics of good self-management support and benefits valued by patients.

(Time remaining in the programme constrained the ability to further progress co design activity, but the patients were strong advocates of the benefits of self-management support so video filming was undertaken in Solihull involving participants in the programme and the Commissioning Redesign Manager reflecting on the benefits of self management and involvement in the PiC programme).

What mattered to participants

Participants were strong and passionate advocates for self management support. They highly valued feeling in control of their conditions and felt empowered by self management support as it was felt to be a major contributor to their confidence about life and sense of wellbeing. Not only was it valued by them as patients, they expressed the considerable economic and social benefits for wider communities. They wanted the benefits that they enjoyed to be more widely available to other people living with long term conditions.

Participants identified the following as self management support priorities:

Information and shared decision making – they felt this underpinned a good personal care plan and encouraged them to take a more pro active approach to target setting and monitoring their own health outcomes. They also felt it helped avoid having to explain about their lives and their health condition to new professionals again and again. Information was particularly important on diagnosis or following treatment but experience had been mixed and some had left hospital with too little or too much information that had been hard to take in and understand.

GP knowledge of condition and access to specialist services– they valued the continuity and holistic approach offered by General Practice but wanted to be able to more easily access specialist support and expertise. This was important because they needed expertise and time to discuss and understand future possible scenarios and prognosis so they can make informed choices about how to live their lives.

Exercise and peer support – they felt exercise not only helped improve health and maintain independence, it also provided valuable emotional support to be in contact with people living with similar conditions or who have experienced what they have been through before. There was lots of fear and anxiety about exercising with a heart condition (existing gyms would not accept people with heart conditions), so the supervision and encouragement of someone trained in cardiac rehabilitation was reassuring and confidence building.

Learning and reflections

Information is the low hanging fruit of self management support - good information at the right time in the right way to the right people can help individuals make good decisions about how they want to live their lives and thereby feel more empowered and less defined by their condition

There is challenge and importance in extending the reach of self management programmes to a wider population that may benefit – for example younger and working age people living with long term conditions may be more easily reached and supported by approaches using social media and more proactive promotion of self management and sources of support in hospital settings.

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