

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

Personalised Care Plan and
Practice-based Peer Support –
West Kent CCG

An interest in self-management

NHS West Kent Clinical Commissioning Group (CCG) has a relatively long-standing interest in improving self-care and self-management provision, which pre-dates the Patients in Control (PiC) Programme. Work was conducted in 2009 which explored self-care and self-management, under PCT¹ structure and prior to South East Commissioning Support Unit (SECSU), and identified support groups as an option of interest to local patients and carers. However, insight work was not seen to fit health commissioning at the time, so was not pursued further. Recently West Kent CCG was keen to revisit self-care, particularly as self and informal care is a central component of the CCG's Strategic Blueprint, called "Mapping the Future". It was suggested that this approach could help divert people with long term conditions - or those at risk of long term conditions - away from not always valued, expensive medical interventions in traditional pathways, by offering them a range of non-medical alternatives that are highly regarded, more cost effective and deliver as good - if not better - health outcomes.

Gathering patient/care insight

The PiC Programme built on the extensive patient engagement work undertaken previously by the PCT, in which in-depth interviews were carried out with people with long term conditions and their carers, the PiC Team. This gave insight into how they managed their long term health condition, and what would enable them to take more control. These findings were further reinforced in surveys and interviews undertaken as part of the PiC Programme. 135 people from West Kent responded to the survey, of whom over 70 had expressed an interest in doing further participation work. About thirty people subsequently took part in in-depth telephone interviews.

Building local understanding

Of the key themes which emerged from the insights, **Emotional support** was valued highly by patients and carers in helping them manage conditions, and over three-quarters of surveyed respondents agreed that **'peer support'** would help them manage their condition more effectively in the future. Those managing a mental health condition were significantly more likely to prioritise having 'access to peer support'. Over half of surveyed respondents say that **'contributing to paid or unpaid work'** would help them manage their condition more successfully. Those who take part in volunteering said that it is an invaluable experience in terms of psychological well-being.

"The insights were really, really valuable. They've not only fed into the discussions with patients and carers, but also into our Strategic Delivery Plan at a strategic level."

Martine Mccahon, CCG
Commissioner

NHS West Kent CCG immediately saw the importance of using this patient insight and could see the value of patients and carers contributing to – and helping to shape – its Strategic Commissioning Plan 2015/19, and in particular, the Self Care Delivery Plan.

¹ PCT: Primary Care Trust

Working with patients as partners in innovative commissioning

After initial discussions with the commissioning managers at the CCG, SECSU, on behalf of the commissioners, set up a members group (named the Special Interest Group – or SIG) consisting of patients and carers who were recruited through the survey and drawn from the local Health Network. The first two SIG meetings were held without commissioners, who then attended the third. Sessions were convened about once every 4 to 6 weeks, and continued throughout the year.

The group started by defining ‘self-care’ or ‘self-management:

‘...The ability to live with my condition in my own way, with the best possible advice, appropriate support and information, so I can make my own medical and lifestyle choices.

My life, in my hands, with the best possible support to help me live as I want to.

Patient Charter

Using the definition of self-care as a foundation, the group developed a ‘Patient Charter’ - a set of principles, to be adopted by both the healthcare professional and the patient. These principles are patient-centred, patient-driven and based on shared decision-making and risk-sharing. This Charter was tested and developed at a Patients and Carers Forum meeting held in November 2014 during ‘National Self Care Week’, where participants were invited to consider what ‘My life in my hands’ meant to them and to explore what might help them live ‘with my condition in my own way’.

The sessions laid robust foundations for co-designing solutions by:

- validating insights,
- fleshing out the language used by patients/carers in describing the key themes that were most relevant to them in relation to self-care,
- and only then, evolving co-designed solutions.

As the groups moved towards co-designing actual solutions, two areas emerged as being particularly relevant to patients and carers in West Kent: peer support and personalised care planning. Both areas were explored extensively in co-design sessions and are gradually giving rise to tangible, co-designed outcomes.

Personalised Care Plan

The group advised commissioning managers on the development of a Personalised Care Plan – to help patients take charge of their own recovery and help them get on with life in their own way. The plan is in two parts, the Care Plan and Life Plan.

Peer Support System in GP Practices

Members discussed how patients' emotional needs could be addressed, and highlighted the multiple benefits of support groups, which were seen as providing emotional support, education and advice and motivation and raising morale. They highly valued peer support (knowing they're not alone) and many had found that volunteering gave them a sense of self-worth/value.

The Group took this a step further and created a peer support model whereby a 'pool' of volunteers, consisting of patients with long term conditions/carers, would be recruited at GP practice level to provide peer/group support on request. These volunteers would be trained and checked, to act as a first point of contact for newly diagnosed patients. Accessed via the GP surgery, they would provide both emotional support (coping strategies, empathy) but also practical advice (managing injections, diet etc). Patients could be offered either one-to-one or group peer support from a patient volunteer. It was further suggested that the development of this approach in practice could be supported by a voluntary organisation for recruitment, selection and governance.

Outcomes and benefits

To the commissioner

The insights have delivered value to the commissioner who has been able to use them as stimulus materials in the co-design sessions, but also to feed into a strategic delivery plan. Listening to the realities of patients and carers with long-term conditions validated insights at a local level and helped shape up tangible solutions.

By having both patients and commissioners in the room at the same time, commissioners could respond immediately to any queries that were raised and helped to keep the proposals within the remit of the CCG. It made sure the voices of patients and carers were at the centre of decision-making about future commissioning priorities.

To the patients and carers

The co-design approach had also been intrinsically valuable in moving patients and carers closer to influencing commissioning and has really enabled them to shape solutions of value to them, with the CCG commissioner taking these views on board to develop tangible solutions. The involvement of the CCG commissioner was a fundamental part of the value of co-design, and within that, the attitude of the commissioner in listening to proposals from patients/carers and being open to work with their suggestions was key.

"This was shaped by reality. It was very helpful for the commissioner to see it from our point of view as this would influence what would be commissioned in future."

Carer

The feedback mechanism put in place by the facilitator to keep the commissioner informed of what the patients/carers group was developing – when the commissioner was unable to be physically present - added to the value perceptions, as it meant the commissioner was fully on board at all times and helped demonstrate that the ideas arising from the group were indeed having an influence on the commissioning approach.

Putting patients/carers at the heart of the decision: it is the patients and carers that develop proposals based on ideas that they have initiated and discuss these with the Commissioners – not the other way round

Arriving at realistic solutions: Involving patients and carers meant that the proposed solutions reflected the realities of life with a long-term condition, not a theoretical model

Delivering tangible outcomes: This is absolutely the critical stage, in that it evidences the ability of patients/carers to influence commissioning and justifies their participation in the programme.

Supporting a business case: Pilot schemes are a way of demonstrating the value of specific self-care and self-management solutions

Some patients had found the co-design sessions to be a valuable experience on a personal level: the sessions had been enjoyable and sharing their experiences about the challenges they faced, per se, had been personally beneficial to them.

To the voluntary organisation

The voluntary organisation used the insights as the basis of their proposal for the peer support pilot scheme, and deemed the principle of involving patients/carers in a discussion forum to be very valuable both on a practical level (information sharing, increase awareness of what is available locally) and emotionally (increased sense of control, sense of empowerment). Having a direct patient perspective gave the CCG a “reality check” which could lead to more realistic, evidence-based commissioning.

Benefits of involving the voluntary organisation

CCGs looking to use a co-design approach should give some thought about when and how to involve (umbrella) voluntary organisations in relation to designing or piloting solutions. Involving them early would benefit all parties, not just the voluntary organisation:

- They may bring additional expertise and knowledge to the table, which could feed into the co-design activities themselves
- By participating in co-design sessions, they would hear the patients’ voices directly which could help them shape pilot schemes with full knowledge of the context in which they will operate
- The planning and deployment of pilot schemes could be even more effective thanks to the relationship that would develop between the CCG representative, the voluntary organisation and any Commissioning Support Unit representatives
- The way in which successful outcomes should be measured can evolve organically / benefit from more time in which to design, tailor and agree what success looks like.

There were tangible benefits from having the voluntary organisations on board. Earlier the CCG had contacted GP practices directly to test the peer support model. Some practices, while agreeing in principle to pilot the initiative, had expressed concerns over the practicalities of setting up and running the groups and wanted clarity on what would be expected of them, governance etc. The voluntary organisation’s experience in volunteer recruitment, selection, training and generally

setting up volunteer-run schemes designed to be sustained over time meant that they were able to liaise with GP surgeries in setting-up and monitoring the pilot scheme.

There is a sense that bringing the voluntary organisation on board has also delivered **efficiencies** to the commissioner by taking on the task of organising and monitoring the groups.

Other lessons learnt from the project

Support

Commissioners will need the right level of support to undertake co-design work – this includes preparing, convening and facilitating the patient and carer groups, and then sharing the key outputs from the groups. This is particularly important for those CCGs with little or no experience of this type of work, who may require additional support to gain the confidence to deploy the approach in their area.

Patient and carer selection

The selection of participants for the co-design sessions needs considerable thought and preparation. Not only should the people selected be representative of patients in the area, but in order to leverage as much value as possible from the sessions, the participants also need to be able to think beyond their own specific circumstances and to broaden out the discussion to the whole patient population. This is because their role is to act as representatives of a bigger group, not just as individual cases.

CCG commitment

CCGs need to ensure that, when looking to use a co-design approach:

- Commissioners develop their listening skills and do not make assumptions
- Enough time is given in order to develop relationships with and within the groups
- There is consistent CCG representation involved throughout - to maintain relationships
- The whole CCG is involved, not just the advocate commissioner. Thought needs to be given on how to cascade information. This could be seen as the key issue that could further enhance the value of the programme.

Setting expectations

Participants in the West Kent co-design work have suggested that it should be explicitly stated when approaching potential participants that the ‘ability to influence decisions’ will be a key outcome, as it a strong motivator). They are not coming to a “group discussion” but to help design solutions that will make a tangible difference.

Preparation

- It might be helpful to provide some background information on the structure of the NHS, where the co-design fits in against the overall commissioning process, and what the role of the key participants are.

- Ensure participants are given a detailed introduction and session structure to clarify their role in the sessions.
- Be clear on time commitment upfront – i.e. length of sessions, number of meetings. An open-ended approach can be disruptive to group cohesion.

How the CCG has taken the co-design work forward

Peer support pilot

NHS West Kent CCG decided to pursue the peer support model locally, and following a successful bid for funding from the South West's PiC programme, the CCG commissioned Voluntary Action West Kent (VAWK) – a local voluntary organisation to set up a pilot to test the peer support model in practice in a number of self-nominated GP practices.

Care plan management system

The Life Plan section of the Personalised Care Plan, has been used in a tender document to procure a care plan management system - a tangible piece of work that the CCG can then use. It has been included in the draft Self-care Delivery Plan, and is being reviewed by the CCG Patients' Forum, for assurance that the CCG has listened to what they said. This personalised care plan is now becoming part of a care plan management system (a pre-existing project set up distinctly from PiC), which itself has involved the development of a web-based patient portal. Some members of the Special Interest Group (SIG) were invited to attend a presentation from potential suppliers of how they would deliver the care plan management system. These SIG members took part in the scoring of presentations based on their assessment of how user-friendly the presented system was, and the extent to which they felt it met their needs.

Patients and carers evaluating pilots and initiatives

The commissioner has asked patients and carers who have been involved in the discussions and in the design of the solutions to feed back on pilot schemes, so that the eventual solutions in place will have been designed by and assessed by patients and carers before it is fully launched.

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