

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

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NHS Shropshire CCG

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## Patients in Control Programme

Shropshire 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

Shropshire CCG sits in the West Midlands. It has a mixture of urban centres and sparsely populated rural communities covered by 44 General Practices. Over the past 10 years, it has seen its over 65 population increase by 25% with many of those living with multiple long term conditions

There is commitment in the CCG Governing Body to develop its strategic approach to person centred care and particular interest in the potential of self management to help the CCG move towards a more sustainable future. It has published ***Future Fit – shaping healthcare together*** – a developing strategy about keeping people healthy and well, supporting independent living and minimising unnecessary use of hospital services.

*PiC gives us a different tool to do some work upstream and really understand what people want.*

Bharti Patel-Smith, CCG Commissioner

The motivation in joining the PiC programme as an early adopter was the opportunity to look at conditions that are not common place: i.e Crohn's and Colitis which affects a wide range of ages with the aim of learning how we may provide may shape future commissioning work. Although the CCG has in place a number of self management programmes, it was felt the co design approach might add value in that it was "more searching" and started the conversation with patients earlier on in the process.

The CCG identified a local lay representative who was committed to help improve the support available to people with Crohn's or Colitis and as an 'insider', this person provided valuable support and advice in accessing participants, voluntary sector involvement and workshop design.

Critically, the CCG has seen its involvement not as a time limited, well meaning initiative but the continuation of working with patients and carers across the breadth of its commissioning activity.

## Gathering insight and building local understanding

The CCG hosted the online survey about self management support needs of patients. It received strong local interest and participation. The responses reflected the emerging consistency of the national picture about priorities – easily accessible information, emotional support, GP knowledge of condition and highlighted access to specialist teams as a particular stand out local priority.

The online survey report helped the CCG understand the priorities identified by local patients and gave them a head start in thinking about local focus for early adopter activity. Alongside its interest in self management, the CCG was keen to explore how it might secure the participation of a younger group of people who had not historically engaged with CCG using more traditional consultation methods.

Crohn's and Colitis UK was identified at the outset as an ideal partner, well placed because of its established local membership networks to reach and recruit a good range of participants. Early work with other early adopters had reinforced the importance and benefits of recruiting a mixed group of patients with different levels of experience of managing their conditions and engaging with health services.

Crohn's and Colitis UK ran a social media campaign to support and encourage recruitment, promoting the initiative widely within their membership network in Shropshire using email, Facebook and their website. Their recruitment campaign included a flier promoting the event and clearly established expectations about purpose, content and time required of participants. The campaign was successful and yielded 10 participants with a mix of conditions, gender, age and self management experience.

Two sessions of insight gathering were held in January 2015 attended by 8 participants and a representative from Crohn's and Colitis UK as an observer. The sessions were held at the Shrewsbury Town Football Club – an easily accessible and well known, non-health venue that provided a good welcome and quality of space and easy parking.

The two facilitated sessions of insight gathering supported patients in identifying and prioritising self management support needs and exploring what good support might look like.

*The patients were asked what would be better for them which I think is key – asking the patients directly.*

Patient

Three themes emerged as most important to patients:

- **GPs having better knowledge of my condition** – patients valued the continuity of care provided by their GPs and its focus on the whole person rather than the condition, but felt some GPs were not always well informed about their condition and some struggled to signpost to sources of available support.
- **personalized and timely information supporting personalised care planning and shared decision making** – patients had mixed experiences of accessing good quality, timely and relevant information about their conditions but identified this as being critical in helping them feel in control and empowered to share decisions with clinicians about their care.
- **accessing specialist advice easily and swiftly** - patients highly valued the telephone advice and support offered by specialist nursing staff who responded swiftly to requests for help and advice, helping them live more confidently and avoid inappropriately accessing services.

Some patients wanted to ‘give back’ and help strengthen self management support available to newly diagnosed patients so that young people don’t have to face up to the challenges of living with the condition in isolation without support. They wanted to explore how something like ‘buddying’ might help provide practical and emotional support on diagnosis when it is most needed.

### Patients and carers as partners in innovative commissioning

A co-design session was held at the start of April 2015, with a good mix of patients who had attended the previous sessions as well as representatives from the CCG, Crohn’s and Colitis UK, and a specialist nurse from the Royal Shrewsbury Hospital.

The session recapped the findings from the insight gathering stage and then went on to discuss the opportunities and possible actions arising from these. Some of the key elements of the discussion focused on the work that the CCG is currently undertaking that helps to meet some of the identified needs around personalised care planning. A prototype of a patient handbook has been developed, and this was handed round for initial comments. Further feedback will be provided by the IBD Patients group when it next meets, and it was also suggested that a further co-design session should be convened to provide a more detailed review and feedback on this handbook, and to develop a section specifically for IBD.

Further discussions explored the issues around accessing specialist medical advice, and included understanding the potential trade-offs between investing in specialist IBD nurses, or broadening the role of Community Care Co-ordinators to help people to access services and support. The issue of GP knowledge was also discussed, and it was felt that specialist IBD nurses might have a

role to play in helping to boost the knowledge of GPs through spending time in the community as well as in hospitals.

Key action points from the meeting included:

*Co-design is crucially important. I can imagine that it's extremely difficult, as a Commissioner, to understand the real needs and impact on patients and carers with different conditions without hearing from them and having them involved. It's absolutely key to involve them. We very much support the co-design approach.*

Jackie Glatter, Crohn's and

- establishing a further co-design session/s to review and input into the Patients Handbook; to provide input into the advice and resources on offer on the website being developed by the CCG; and to help develop an IBD 'roadmap' for use by patients
  - explore the possible development of a database of IBD patients to help improve service provision and inform decision-making
  - to explore the business case for Faecal tests
  - to investigate the business case for further specialist IBD nurses, to be fed into the next CCG priority planning phase September- December 2015

## Value and benefits

### For the commissioner

#### In the short term:

The co-design approach has helped the CCG:

- continue to focus on the needs of the patients by putting patients at the centre of commissioning activity
- move upstream by involving patients much earlier so that they are involved in helping define the issues to be tackled as well helping design the solutions
- secure greater ownership and support from patients for change because patients have been involved at the forefront in

*Some of the things that came out of our two co-design workshops, would not have been something that I had proactively thought about. It gives a deeper understanding of what people with different conditions really need.*

Bharti Patel-Smith, CCG  
Commissioner

originating the case for change

- enhance its partnership working with patients and other partners with a shared focus around the holistic 'joined up' needs and preferences of individuals
- build momentum for conversations around integration with a wider healthcare and social care network, as a result of the co design activity.

### In the longer term:

*If we can generate ongoing commitment for embracing such programmes through the – CCG, Local Authority and programmes such as the Better Care Fund, –we will be able to build momentum, which in the long run will benefit both service users and commissioners.*

Bharti Patel-Smith, CCG Commissioner

The CCG has always had a Lead for their Patients' self-management programmes whose role it is to support people with long-term conditions access support, education and other relevant provisions. The PiC programme has helped the CCG tap into the rich assets offered by patient insight and reinvigorate its own self-management programmes so as to make them more dynamic, characterised by earlier discussions with a range of patients at different stages of living with their conditions.

### For the patient

Being involved in the PiC programme helped patients feel:

- **Listened to and valued** - Participants involved in co-design have felt listened to, which they valued as they feel that people with Inflammatory Bowel Disease are rarely given a voice.
- **Empowered and in control** -As well as providing emotional support for participants (feeling less isolated, sharing experiences), the sessions have demonstrated that they can influence the outcomes, giving them a sense of empowerment and control.
- **Part of the decision making with equal standing** - patients felt more in the centre of commissioning activity and engaged in defining the agenda and making the decisions
- Participants also welcomed the opportunity to work together as an independent group with the facilitator first prior to interacting with the CCG Commissioner and others as part of a wider co-

*I would get as many people as possible around the table – patients, consultants, surgeons, GPs, dieticians, other relevant health professionals.*

design group. This enabled the group to “gel” and to share some deeply personal experiences which they may not have been comfortable discussing with a wider audience from the outset.

- **More positive at a personal level** – being involved and sharing experiences of living with the same condition with other patients had been a valuable experience and helped reduce feelings of isolation.

### For the voluntary organisation

*We'd certainly be involved again. So far it's all positive. Most voluntary organisations would support a co-design approach. The only limitations are capacity.*

Jackie Glatter, Crohn's and Colitis UK

Hearing first-hand the experiences of patients had provided valuable insight that helped it feel better placed to:

- assess their own service provisions against the needs expressed in the co-design sessions.
- offer support to the CCG and other partners with the development and delivery of services and activities arising as outcomes from the co-design sessions.
- contribute to driving up standards across the whole of England by delivering an “economic model of best practice

### Learning and reflection

Getting key partners (such as voluntary organisations, Local Authorities, providers) round the table with patients as equals in the co design stage can help mobilise and build momentum for more joined up, cost effective care pathways that better meet the expressed needs of patients for greater self management support.

Senior leadership and organisational commitment to putting patients at the centre of commissioning is vital as approaches can often require investment of time upfront to really understand what matters to patients. But the return on investment from well supported, self managing communities of patients can be high and help local health and care economies achieve sustainable transformation.

Self managing patients that are well supported not only value the greater control over their lives and resulting feelings of empowerment but their health outcomes are improved and they make better decisions about accessing services.

## Contact

Bharti Patel –Smith, Director of Governance and Involvement, Shropshire CCG

[bharti.patel-smith@shropshireccg.nhs.uk](mailto:bharti.patel-smith@shropshireccg.nhs.uk)

## SECSU

<http://www.southeastcsu.nhs.uk/participation>

Or contact Rebecca McClymont:

[Rebecca.mcclymont@nhs.net](mailto:Rebecca.mcclymont@nhs.net)

Tel: 03000 424348/ 07768 421350