

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

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**NOTTINGHAM NORTH
AND EAST CCG**

Nottingham North and East 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

Nottingham North and East CCG sits in the East Midlands. It was an early enthusiast about the PiC offering and the Deputy Chief Officer and Director of Operations were convinced of the potential benefits of self-management for patients, communities and commissioners. The CCG was committed to good engagement with its local population but working with a particular group of patients with long term conditions on an ongoing basis appealed as it offered the prospect of transferable learning that might inform future models of participation.

The CCG took the decision to focus on the self-management support needs of patients with diabetes or coeliac disease. There were already with pockets of good practice and valued self-management support for patients with diabetes in particular localities but less so for patients with coeliac disease. This was seen as a useful opportunity to compare and contrast the experience of patients and learn from what worked best and was valued by patients.

Gathering insight and building local understanding

The CCG took the lead on recruiting patients and promoted involvement using a flier distributed through its existing patient database and patient networks and support groups. Particular attention was paid to the patient led support group hosted by the Peacock Road General Practice. The Practice was supportive of the approach and sought to empower patients in taking more control of their health and wellbeing.

The first insight gathering session lasted 2 hours and took place in the early evening at the Peacock Road General Practice in September. It was attended by a large (20+) mixed group of patients with diabetes and coeliac disease at various stages of living with their conditions. A representative from the CCG attended.

There were challenges in working with a large group of patients with different conditions. Although the session generated valuable insight about the different needs and starting points of patients with the different conditions, it was clear that some participants were expecting a different kind of engagement session and it is likely the numbers discouraged the sharing of more sensitive and personal matters around living with a condition as patients were keen to continue the discussion in smaller groups after the end of the session.

With the CCG, it was agreed to focus the second insight gathering session on patients with coeliac disease only so that activity may be focused on a smaller group of patients where the potential for co designed solutions was perceived to be greater.

What mattered to participants

Participants identified the following challenges and priorities in self-management support:

- **Caring for a friend or family member can be difficult and complex** - there are often gaps in knowledge and information about food and understanding the emotional needs of patients. Getting the caring balance right can be tricky.
- **Diagnosis can often be a big change in life and emotional shock** - this is the time when peer support would be valuable, in particular somebody who has been through it before and is prepared to act in a 'buddying' role.
- **GPs have poor knowledge of coeliac disease**- many had struggled to secure an initial diagnosis and found GPs had limited knowledge about their condition. Some felt that the GP was not always the best person to be discussing their emotional needs and stresses with as a result of living with the condition.
- **Peer support** is helpful in keeping motivated when managing weight and exercising – they felt gyms were not always positive and welcoming places where they felt comfortable. They liked the idea of an alternative that was more sociable and enjoyable and focused on 'moving more' rather than formal exercise.
- The diabetic **patient led support group was highly valued**. It helped signpost patients to other services, provided emotional support and access to expertise through the **support of the Specialist Nurse** and visiting speakers. Patients with coeliac disease did not have access to anything similar and recognised this as a gap.

Learning and reflections

Patients like accessing services locally (at Practice level) but don't always see the GP as the person best placed to provide the breadth of emotional support, clinical expertise and help with navigating to other sources of support that patients say they value.

Diagnosis is often the critical time when the need for information and support may be greatest – the best self-management support encourages and empowers patients to make informed choices about how they want to live their lives and to put in place personalised packages of support that work for the individual.

Accessing specialist advice is greatly valued by patients but it is not always about more face to face time with medical specialists. Patients report high levels of satisfaction in being able to access specialist nurses at the end of a phone.

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