

Kate - Patient Video Transcript

I'm Kate, I was diagnosed with Crohn's in 2004 after being unwell for about a year and I now work with organizations that look at how to improve services for people with IBD.

I got involved in co-developing the Boost programme through Crohn's and Colitis UK. I wanted to support research that is going to: help people manage psychological and emotional symptoms as well as physical ones, provide access to resources that can make life with IBD more manageable, and increase the general understanding of the impact that managing a chronic illness has on day to day life.

During the development process I've been able use my experiences, and draw on all of the good and bad things that have happened during my time with Crohn's, to help develop something that addresses crucial aspects of life with IBD that are often overlooked.

The meetings I've been to so far with the research team and other patients have been about everything from what I would find useful as a patient, to the look and feel of the website itself, and how the research for the programme will have a long term impact on the way that patients interact with their IBD services, and with the people around them who may not have a great understanding of what they're going through.

I've been able to review the way that people move through the online programme, and actively contribute to the content to help develop a resource that is truly engaging. I've had the opportunity to look at the individual sessions that make up the programme, and give suggestions based on how I – as a patient – reacted to the content.

From the start of my involvement I've been encouraged to contribute my opinions and ideas as much and as honestly as possible, and I think that reflects one of the central themes of Boost itself – that people are better able to self-manage if they fully address and confront the many ways that living with a chronic illness affects their lives.

Something like Boost is invaluable as it gives people the chance to explore and learn about ways that IBD affects life that they may not have realized before – it took me a long time to realize that I couldn't draw a definite line between Crohn's life, and normal life, and that in order to cope I had to find ways of dealing with the overlap between the two.

BOOST is exactly the kind of thing that I really could have used – not just when I was first diagnosed, but also as I got older and started to experience periods of more severe symptoms that increasingly intruded on the rest of my life.

It's a tool that I would have loved to have because it bridges the gap between clinical and everything else; managing Crohn's between hospital visits can be isolating and exhausting, but Boost facilitates a type of self-management that feels supported, and doable, and crucially looks at the psychological and emotional impact of a chronic illness, as well as the physical impact.