

crohn's and
colitis
UK



Inform
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Research

What is an IBD Patient Panel?

In essence they are a group of people (and sometimes their carers) who have Colitis or Crohn's Disease who believe that by working with the NHS staff who provide their care they can help bring about improvements to their local IBD Service.

Patient Panels

Why set up an IBD Patient Panel?

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Quality Care
Service standards for the
healthcare of people who
have Inflammatory Bowel
Disease (IBD)

THE IBD STANDARDS GROUP
Association of Gastroenterology of Great Britain and
Ireland • British Dietetic Association (Gastroenterology
Group) • British Society of Gastroenterology • British
Society of Paediatric Gastroenterology, Hepatology
and Nutrition • National Association for Colitis
and Crohn's Disease • Primary Care Society for
Gastroenterology • Royal College of Nursing (Crohn's
and Colitis Special Interest Group)

IBD Standards - 2009

Standard C5 – Involvement of Patients in Service Improvement

Patients should have a voice in the development of the IBD Service. The service must be able to demonstrate that mechanisms are in place to obtain and respond to patient feedback about their IBD Service and to provide opportunities for more direct involvement. Possible mechanisms include:

- Patient satisfaction questionnaires or user surveys
- Regular meetings or open forum sessions with patients about the service (eg NACC Patient Panels)

Why set up an Patient Panel?

Quite simply because:-

□ People who have experience of IBD services can offer suggestions for improvements to that service that the people who provide it may never have thought of - or may not give have given a priority to

□ No service will be as good as it could be without the input of patients at every stage of delivering, planning and development

Patient Panels

Some FAQ's:-

- *When were they established?*
 - First pilots in 2005
- *How many are there?*
 - Currently about 25 around UK
- *How often do they meet?*
 - A minimum of 4x pa
- *What have they achieved?*

Some examples of Patient Panel Achievements:-

- Nottingham Children's Hospital - appointment of a paediatric gastroenterologist
- East Kent – two IBD nurses
- Cumberland Infirmary – IBD Dietician
- Bradford – a review of out Patient services
- Brighton – Departmental Open Day
- Wigan – IBD Nurse

Patient Panels can help in different ways:-

- Acting as a conduit for information regarding the Patients' experience and providing the IBD team with feedback on current service provision. Sharing experiences – not of the condition but of the service received
- Acting as an independent advocate for local IBD Services (this model is often particularly popular with the IBD Professionals) and will usually involve going **outside** the IBD Department in an attempt to secure additional resources from the Hospital Trust or PCT

....ways Patient Panels can help

- Acting as a sounding board by reacting to proposals put forward by NHS professionals and giving the patient's perspective
- Acting as a think tank pro-actively offering suggestions for future developments and service improvements

....ways Patient Panels can help

- Helping inform and empower the Parents, Carers and Children who may be involved in the Panel
- Giving support to IBD patients who are not Crohn's & Colitis UK Members
- Helping raise awareness of Colitis & Crohn's disease at a local level

....ways Patient Panels can help

- Attracting resources from Crohn's & Colitis UK (training, information, advice etc)
- Assisting the Trust meet its Patient & Public Involvement requirements – particularly Foundation Trusts
- Meeting good practice as suggested by National IBD Standards
- Acting as a sounding board for research proposals as required by local clinical audit

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