



## **IBD Patient Panels** **Getting Involved with your Local Hospital**

### **What is an IBD Patient Panel?**

The membership of an IBD panel consists of a group of people with inflammatory bowel disease who use the same hospital services and who believe that by talking to and working with their IBD NHS professionals they can bring a patient perspective which will help improve services. Local NHS professionals will also usually attend Panel meetings and in some cases convene them. Patient Panels provide a framework for the exchange of information –as recommended in the National IBD Standards

### **What do IBD Patient Panels do?**

- Provide the IBD team with feedback on current service provision e.g. clinic times; phlebotomy services; pain relief during endoscopies; information provision, etc. It is possible that low cost interventions may offer real and significant improvements to the Patient's experience.
- Be an Independent Advocate for IBD Services. This will usually involve going outside the IBD Department in an attempt to secure additional resources from the Hospital Trust or PCT e.g. the funding of an additional IBD nurse/dietician.
- Patient support undoubtedly strengthens a Business Case for service development.
- Act as a sounding board and provide the Patient's perspective on proposals for service reorganisation and future developments.
- Pro-actively offer suggestions for future developments and service improvements.
- Help inform and empower the Parents, Carers and Children who may be involved in the Panel.
- Give support to IBD patients who are not members of Crohns and Colitis UK
- Help raise awareness of Colitis & Crohn's disease at a local level
- Assist the Trust in meeting its' Patient & Public Involvement requirements – particularly Foundation Trusts
- Act as a sounding board for research proposals as required by local clinical audit

## **What have they Achieved?**

In other hospitals the IBD Patient Panels have been instrumental in:

The appointment of an additional Paediatric Gastroenterologist enabling the department to reopen to new referrals (Nottingham).

Obtaining additional IBD nursing time (Leicester; Wigan).

Funding for IBD nursing posts (East Kent).

Funding for an IBD dietetic service (Carlisle).

Improvements to the way that IBD services are delivered; clinics run and information made available (Bradford; Liverpool).

Improvements for inpatient stays (Brighton; Carlisle)

Suggestions on future service developments (Edinburgh; Leeds; East Kent; Salford).

Input into local research (Manchester); research into access to IBD services (East Kent).

Assistance with IBD Departmental Open Days (Aintree; Brighton).

This list is by no means exhaustive but gives an indication of the work Patient Panels have carried out. The recently launched IBD Standards will give many Patient Panels a bench mark by which they can review their local IBD service and thereby point the direction for future activity and goals for the future.

## **What Support does Crohn's & Colitis UK offer IBD Patient Panels?**

Crohn's & Colitis UK's Patient Involvement Adviser (Peter Canham) is available to offer telephone and email advice on day-to-day Patient Panel queries. He can also provide examples of publicity materials and will usually attend the first patient Panel meeting.

There is a page on Crohn's & Colitis UK's website with examples of activities and contact details of IBD Patient Panels Patient Panel members are invited to attend training events - where as well as specific workshops aimed at Patient Panel members there is plenty of time for networking. Most Panel members find that their involvement is enjoyable, educational and rewarding!

Our patient panel is led by Marie Capon. If you would like to join please let your IBD nurse know so she can put you in touch with Marie.