IBD patient panels: a personal reflection on three stages of development of an IBD Patient Involvement Project, initiated and supported by Crohn's and Colitis UK

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Crohn's and Colitis UK (formerly The National Association for Colitis and Crohn's Disease) first established a pilot of six inflammatory bowel disease (IBD) patient panels in 2005. There are now 20. Crohn's and Colitis UK offers a framework within which panels can function although there is built in flexibility to suit local circumstances. Patient panels are most effective when they work in partnership with their local NHS professionals. Their uniqueness in the patient and public involvement field lies in their being a disease specific patient group with a focus on their own local IBD services. Panel members are able to speak with the authority of personal experience and with the benefit of assimilated knowledge. A patient panel influences patient care by: (1) providing feedback on current service provision; (2) being a sounding board for departmental developments; (3) initiating suggestions for future developments; and (4) giving support to proposals for departmental developments (perhaps by using the IBD Standards as a benchmark). Most IBD patient panels are self supporting. Some receive assistance from their IBD department. Nationally, Crohn's and Colitis UK provides support through their patient involvement adviser and a patient panel page on their website. Some training and networking is also offered. From the appointment of IBD nurses to changing the way local services are delivered, they have been instrumental in bringing about improvements to IBD services across the country.

Patient involvement: background

The current government believes that with the greater involvement and participation of patients and the public (PPI), the National Health Service (NHS) will be able to deliver a more enhanced patient centred service and with this an overall improvement to the patient's experience.

Early on in the government's second term of office, Alan Milburn, Secretary of State for Health, launched the 'The NHS Plan' (2000) and subsequently 'Shifting the balance of power' (2002) which set out the Labour Party's vision of an NHS in which *patients* have more of a say about how healthcare is provided in their communities.

Lord Darzi's vision 'Delivering the pledge on the patient experience' (September 2008) 'is to put the patient at the heart of everything we do with the provision of health care'.

Commenting on (2010) guidance, Paul Streets, Director of Patient and Public Experience and Engagement at the Department of Health, said: "The evidence is clear, if the NHS listens to patients and acts up what it is told, this can result in new ideas, better value for money and better care".

To help achieve these aims, the Department of Health (DH) has introduced new legislation as well as producing guidance and targets for NHS trusts. The following link will take you to the DH website PPI page where (an abundance of) key documents outline the major strategic and policy objectives that the Department have undertaken to secure a 'truly patient led NHS' http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/DH_076402

A selection of these are listed at the end of this article.

Inflammatory bowel disease patient panels: background

In 2005 Crohn's and Colitis UK reviewed the existing possibilities for patient involvement in health services. Crohn's and Colitis UK then decided to test these

opportunities to see what improvements (if any) could be introduced to local inflammatory bowel disease (IBD) services. One of the models that Crohn's and Colitis UK decided on was that of an IBD patient panel. This would be a group of IBD patients who would meet and share their experiences of a hospital's IBD services and comment on ways that local IBD services could be improved. These discussions would take place in the presence of the IBD staff that helped deliver these services. The IBD patient panel would offer the opportunity to provide organised and structured feedback from IBD patients. Simple though the concept may seem, this approach differed from previous models of patient involvement (patient councils and patient forums) where the participants looked at the whole of a hospital's services and the members were generally interested lay people and not from a specific group of patients with a common illness. The uniqueness of IBD patient panels in the PPI field lies in their being a disease specific patient group with a focus on their own local IBD services. Panel members are able to speak with the authority of personal experience about the services they have received and with the benefit of assimilated knowledge.

The pilot phase: IBD patient panels

An invitation letter to take part in a pilot was sent to Crohn's and Colitis UK groups and medical advisers. About 15 positive replies were initially received and six pilot sites were identified. Crohn's and Colitis UK appointed a patient involvement adviser to support and coordinate the pilot IBD panels.

The patient panel adviser offered support by

- Attendance at preliminary meetings
- Telephone support/advice (ongoing)
- Disseminating shared experiences
- Distributing examples of flyers/posters/press articles
- A patient panel webpage on the Crohn's and Colitis UK website
- Training for patient panel members at Crohn's and Colitis UK's Annual Volunteer Conference
- Offering suggestions as to how a panel might structure its agendas and work plan.

Crohn's and Colitis UK agreed to make available pump priming funds to cover initial set up—for example, room rental and refreshments at an open meeting.

In order to suit local circumstances, Crohn's and Colitis UK offered a flexible framework within which panels could function. This was called the Interface Agreement and was based on the model of the relationship that Crohn's and Colitis UK had with its local Crohn's and Colitis UK groups and additionally emphasised the ethos of partnership between patients and professionals as being the most effective model to achieve improvements. Initially patient panels were left to decide on such matters as

frequency of meetings and where they should meet and indeed who should chair the panel. With the benefit of experience this framework was to evolve over the next few years as lessons were learnt as to what worked most effectively and what was learnt to be more sustainable.

After 12 months the panel's achievements were assessed using qualitative data—that is, through the completion of a self-evaluation questionnaire (four out of six completed the questionnaire). The questionnaire was sent out electronically and asked 16 questions, grouped into

- Setting up and the sustainability of the patient panel
- How were activities planned and structured
- Level of user and professional involvement
- Measurable outcomes/wider benefits and spin offs
- Feedback on Crohn's and Colitis UK support.

The responses were collated into a report which was considered by Crohn's and Colitis UK's IBD Health Services Committee. The Committee took an overview assessment of the collated report which was further informed by data gathered by the patient involvement adviser through a paper audit (records kept and his attendance at the panels' meetings).

Findings

There was evidence of service improvements gained through the involvement of patient panels from these pilots in the first year, including the following.

- The reopening of the Paediatric Gastroenterology Department to new patients at Nottingham University Hospital where the chair of the panel commented "The extent of user involvement in our [campaigning] project was initially very high with 30 families attending the first meeting and more letters sent. Subsequent involvement has been coordinated by a smaller group of six who were prepared to get more actively involved. The support from Crohn's and Colitis UK was excellent—it helped us to see the issue clearly and galvanised the group...."
- The appointment of a part time IBD dietician at North Cumbria Acute Hospitals Trust. Where the panel had raised the need for expert dietetic advice with the hospital managers, the Primary Care Trust and the Dietetic Department and then arranged a workshop on IBD and Diet to raise awareness of the issue.
- A review of IBD outpatient clinics at Bradford and a discussion with IBD patients from an ethnic minority background about their inpatient dietary requirements.
- The introduction of fridges (so that IBD patients can keep food which meets their individual dietary needs) on the gastroenterology ward at Brighton's Royal Sussex Hospital following feedback from an inpatient survey carried out by the IBD panel.

Professionals appreciated the development of patient panels and made the following comments extracted from the returned questionnaires.

Cultural change

“Health professionals in IBD now have access to a dynamic patient forum and it is becoming second nature for us to think of asking the patient panel if we have, or need, any ideas for service development...” *Bradford*. “Most importantly it has given the panel and the health professionals the chance to hear each other’s impression of the IBD service and an understanding of how the Health Service operates and the constraints it is under....” *North Cumbria*.

Low cost improvements

“It is having an immense impact on patient support, allowing services to be developed to meet the needs of the local population group in a way that is acceptable to them. It is also identifying small changes we can make in secondary care that do not cost money, but in fact improve quality of patient experience and are cost effective...” *Brighton*. “The patient panel has improved local services by highlighting to the professionals specific areas of concern—for example, by improving the information given at diagnosis and presently discussing an ideal patient journey” *North Cumbria*.

Models of patient panels

An examination of the responses in the evaluation to the questions, ‘What has been the extent of user involvement in the project?’ and ‘What has been the extent of professional involvement in the project?’ showed that there appeared to be three types of patient panel in evidence.

- An IBD patient panel that was professionally initiated and professionally led but with patient participation in the decision making (*Bradford* and *Wigan*).
- An IBD patient panel that was patient initiated and patient led but with close liaison with the local IBD Health Service Team (*Carlisle* and *Brighton*).
- An IBD patient panel that was a campaigning patient panel, usually arising from a threat to local services and which could develop into an ongoing feedback and dialogue model when the campaigning issue was over (*Nottingham* and *East Kent*).

Members of the IBD Health Services Committee were uncertain if there was a preferred model and initially adopted a pragmatic approach of whichever works locally, works best.

The developmental phase: IBD patient panels

In 2006, Crohn’s and Colitis UK decided, as part of its strategic development, to support IBD patient panels as part of its mainstream activities, so the pilot phase ended and the next phase began. The project remained developmental as it began to roll out—every patient

panel continued to be different—evolving as they do to their unique local circumstances.

Based on the evaluation of the pilot patient panels and on the experience from emerging new panels, Crohn’s and Colitis UK produced a leaflet which emphasised the ethos of partnership between patient and professional and listed the ways in which a patient panel could help improve IBD services.

- Providing feedback on current service provision
- Being a sounding board for departmental developments
- Initiating suggestions for future developments
- Giving support to proposals for departmental developments (perhaps by using the IBD Standards as a benchmark).

Crohn’s and Colitis UK patient panels continued to prove themselves to be a powerful agent for change. It is not always easy to directly attribute change to a single influence but (for example) in at least three instances where panels have given their support for the appointment/retention for an IBD nurse, the outcome has been successful (*Wigan*, *Brighton*, *Leicester*). Overall, their achievements have shown that by working in partnership with local health professionals that small numbers of committed patients can make a difference to the service offered to all. The improvements or changes brought about:

- Do not have to be large scale or resource intensive in order to make an impact on a patient’s personal experience of their local IBD service.
- The patient/professional dialogue raises the understanding of patients’ needs by the professionals and importantly can also raise patients’ awareness of restrictions imposed on service provision.
- Each panel’s strength lies in its uniqueness; their diversity enabling them to influence their own particular local IBD service in the most appropriate manner.

One or two patient panels (*Leeds*, *Carlisle* and *East Kent*) began taking their activities beyond the hospital trust and began to advocate for service improvements with the Primary Care Trust or the local commissioning body. A member of *East Kent* patient panel sits on the Primary Care Trust’s Long Term Conditions Service Improvement group. *Leeds* patient panel has contributed to discussions on the configuration of IBD services across the city’s hospitals. Crohn’s and Colitis UK offers members of patient panels training in the structure of the NHS and opportunities to influence IBD services.

The implementation phase: IBD patient panels

There are currently in excess of 20 in the UK with many more in the pipeline. Crohn’s and Colitis UK continues to support patient panels through their patient involvement adviser; pump priming finance;

website; and online support and training and networking opportunities.

Crohn's and Colitis UK has concluded that the primary relationship of a patient panel must rest with the NHS trust that the panel relates to and not with Crohn's and Colitis UK, and to reflect this has dropped the Interface Agreement (which spelt out the accountability the panel had to Crohn's and Colitis UK) and in its place Crohn's and Colitis UK is in the process of finalising a Good Practice Guide for patient panels which offers advice and guidance instead.

The broader acceptance of the value of patient panels is reflected by their inclusion in the National IBD Quality Care Standards—C4 of which states that “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, Crohn's and Colitis UK patient panels”).

Crohn's and Colitis UK is also currently developing guidelines for patient panels on how they can help in the implementation of the IBD Standards at a local level, including making the standards part of the panel's work programme.

At the time of writing, Crohn's and Colitis UK has submitted a Section 64 bid for funding with the DH which would increase the resource available to further develop and support IBD patient panels across England. The bid has reached the second stage. If successful, the development of patient panels would enter yet another phase, one with more coordination, training and support. Further details, including advice on getting started, can be obtained from peter.canham@nacc.org.uk and from the Crohn's and Colitis UK's website patient panel page <http://www.nacc.org.uk/content/about/patientPanels.asp>.

Note in proof

Following the general election on the 6 May 2010, there has been a change in political control. However,

there is every reason to believe that the new coalition government will continue to value the benefit of greater patient and public involvement in the NHS. In the White Paper ‘Equity and Excellence: Liberating the NHS’ (launched on 12 July), the Health Secretary Andrew Lansley said, “Patients will get more choice and control, backed by an information revolution, so that services are more responsive to patients and designed around them, rather than patients having to fit around services. The principle will be ‘no decisions about me without me’.”

Competing interests None.

Provenance and peer review Commissioned; externally peer reviewed.

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