Patient involvement in *Frontline Gastroenterology*

Richard Driscoll,¹ Elaine Steven²

¹Chief Executive, National Association for Colitis and Crohn's Disease

²Chair of the National Association for Colitis and Crohn's Disease

Correspondence to

M R Driscoll, National Association for Colitis and Crohn's Disease (NACC), 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH, UK; richard.driscoll@nacc.org.uk

In the past few years there has been continuing discussion within the inflammatory bowel disease (IBD) community of professionals and patients on how best to provide high quality care. The regional meetings run by the IBD Audit brought together professionals from all disciplines to discuss the findings and many other professional or pharmaceutical meetings have included a focus on service development. This has undoubtedly been helpful to the overall objective of improving care and created a sense of momentum for improving service delivery, but perhaps has felt somewhat limited in terms of achieving a widespread and enduring impact on patient care. The benefit of the individual ideas and approaches has often been limited to those attending the particular meeting.

The National Association for Colitis and Crohn's Disease (NACC) therefore welcomes the launch of *Frontline Gastroenterology* with its primary aim of giving health professionals the information they need to provide better care for their patients. Improving care can be a straightforward matter at a basic level—for example, ensuring there is good quality written information available—but in many aspects improvement can be complex and multidimensional, involving a pragmatic synthesis of an ideal conceptual approach with what is feasible given local resources and variable support from professional colleagues and management. In our view, the new peer reviewed journal gives status and credibility to service development in gastroenterology and will provide both an invaluable central resource and a means of sharing ideas and good practice across the whole professional and patient community. The fact that the journal covers all gastroenterology should also help the drive for improvement to transcend the usual professional and organisational boundaries—medical/surgical,

primary/secondary, paediatric/adult, etc—and facilitate knowledge sharing across the various gastrointestinal conditions.

There are many service design and delivery issues that might benefit from the exchange of experience and ideas that the journal will hopefully generate. Some will be issues arising from guidelines such as the IBD Standards—for example, defining the role of managed clinical networks in IBD—or debating the role of general practitioners in IBD care. Other issues may be a response to wider National Health Service initiatives—for example, how information prescriptions or care plans could be developed for gastrointestinal conditions.

One of the more complex areas that could usefully be explored is that of patient involvement. There is now a requirement to include patients' views in many aspects of professional work—service development, staff appraisals and revalidation, research design and governance. To 'tick the box' is relatively easy and painless but identifying ways of genuinely and thoroughly including patients' views is far from easy for both professional and patient organisations. *Frontline Gastroenterology* can help to advance the effective inclusion of patients' views by enabling experiences from hospitals or projects to be shared, by debating the pros and cons of different approaches and perhaps through inviting articles which present experience from other areas of medicine and relate these to gastroenterology.

Patient involvement is just one example of how the journal might have an impact beyond simply sharing knowledge and experience. We hope it will provide a place in which conceptual approaches can be debated. One candidate for this might be 'self-management'—a term that is often presented as good practice but which is used with different meanings and implications ranging from improving adherence to medication through to the more ideological

beliefs underpinning the Expert Patient Programme. By exploring such concepts, the journal could help to develop better understanding of these issues across the gastrointestinal community and gradually foster the development of a consensus view or at least a shared vocabulary.

A stated aim of the journal is to include accounts of patients' experiences. There is a real opportunity, which we hope will be realised, for the journal to give a voice to patients' views on their experience of their illness and their perceptions of the quality of care. (The plural 'views' is intentionally used here—rather like the opinions of health professionals, patients' views are multiple, different and sometimes conflicting!)

We have learnt in NACC that the aspects of care most often highlighted by patients when they talk about quality are the understanding and attitude

of professionals, communication, having a holistic rather than a strictly medical approach, etc. It can be easy for the importance of these individual qualities in the daily interaction of professionals and patients to become lost in our concern to focus on better resources and efficient service design. Yet each time we listen to a patient's individual story we can learn so much, not just about the different ways in which people live with their illness but also about the impact, positive or negative, that the attitudes and behaviours of individual healthcare staff can have on the patient's experience and life. We hope that there will be a regular place in the journal for such individual contributions from a diverse range of patients.

Competing interests None.

Provenance and peer review Commissioned; not externally peer reviewed.