



The Association of Coloproctology of Great Britain and Ireland

Establishing a Patient Perspective on the ACPGBI Delphi Research Agenda Invitation to Patients and Lay Representatives

The Association of Coloproctology of Great Britain and Ireland (ACPGBI) undertook a broad survey of its membership in 2014 to establish the research questions of greatest current importance in looking after patients with bowel disease. The survey was carried out using modified Delphi methodology and has now been published in the December 2014 edition of *Colorectal Disease*.

ACPGBI members submitted over 500 questions in the first round and cast more than 400 votes subsequently in the second and third rounds to define our top 25 research questions. Of these, 15 relate to the treatment of bowel cancer while 10 relate to diverse topics including benign disease, surgical technique and clinical governance. The questions are listed below for your interest.

This important work will set the research agenda for our Association and help the Bowel Disease Research Foundation (BDRF), who supported the exercise, to prioritise areas for future funding. The initiative begins to develop a co-ordinated research framework in colorectal disease involving patients, funders, scientists and clinicians.

We are now planning to develop this research agenda more widely with the help of over 50 **Delphi Champions** who have volunteered to develop research strategies for each question. These Champions will be invited to attend the **Delphi Games** throughout 2015, a series of themed brainstorming meetings that will bring together clinicians, methodologists, patients and funders to develop our trials strategy. The ACPGBI has agreed to provide a start-up fund to help research groups grow, with additional resources available through the Royal College of Surgeons (England).

In preparation for the **Delphi Games**, the BDRF is funding a patient consultation exercise to provide patient perspective on all the Delphi research questions. This will be used to inform the research groups that are developing research strategies to ensure patient involvement from the outset. We welcome patients and lay representatives who wish to contribute to this important exercise and invite you to join us at the consultation day to be held at the Royal College of Surgeons (England) in London on Thursday 26th March 2015. You will be supported by surgeons and trainees who will help explain the clinical issues surrounding each question. It is anticipated that a draft document will be prepared by the close of that day and that this will be published.

If you are interested, or know someone who may be, please contact Glen Saffery at gsaffery@bdrf.org.uk – we would really appreciate your involvement and commitment. Reasonable second class rail travel or low cost airline flights will be reimbursed and refreshments will be available on the day.

We do hope that you will consider contributing to this important initiative.

With kind regards,

Miss Azmina Verjee
Patient Trustee, Bowel Disease Research Foundation
Co-opted Trustee, Crohn's and Colitis UK

Miss Nicola Fearnhead
Consultant Colorectal Surgeon, Addenbrooke's Hospital, Cambridge
Chair, Research & Audit Committee, Association of Coloproctology of Great Britain & Ireland

Highest priority list of non-cancer related questions.

1	How can early detection and outcome of anastomotic leakage be improved? Are there any new techniques or approaches that will reduce anastomotic leak rates in colorectal surgery?
2	What is the best method of i) preventing parastomal hernias ii) repairing parastomal hernias?
3	What are the indications for, and what is the optimal timing of, surgery for Crohn's disease in the era of biological therapy?
4	What are the short and long term outcomes of minimally invasive approaches (e.g. percutaneous radiological drainage, laparoscopic washout and drainage) to managing complicated diverticulitis?
5	How can postoperative ileus be reduced?
6	What is the optimal multimodal strategy for managing fistulating perianal Crohn's disease?
7	How does reporting and sharing of surgeon specific outcomes affect clinical practice?
8	What are the short and long-term outcomes of laparoscopic ventral mesh rectopexy (VMR), and is the mesh material important?
9	What are the predictive factors for poor outcome in patients with severe intra-abdominal sepsis? How can outcomes be improved?
10	When should a colorectal anastomosis be defunctioned? Are there predictive factors which would aid decision-making about need for diversion?

Highest priority list of cancer-related questions.

1	What is the optimal treatment for early rectal cancer? What are the relative roles of endoscopic mucosal resection (EMR), transanal endoscopic microsurgery (TEMS), radiotherapy, chemotherapy and resectional surgery? In cases of early rectal cancer amenable to local excision techniques, are there benefits from additional treatment modalities?
2	What is the best method to predict complete pathological response to chemoradiotherapy in rectal cancer treated with neoadjuvant chemoradiotherapy prior to surgery? Do these patients require immediate resectional surgery? If not, what is the best strategy for surveillance?
3	What is the optimal treatment for endoscopically removed polyp cancers? When is surgical resection necessary? What is the long-term outcome of polyp cancers treated with polypectomy alone?
4	What are the short and long-term outcomes after extralevator abdominoperineal excision of rectum (ELAPE)? Is there an oncological gain and is it justified?
5	What biomarkers (including genetic profiling) affect response to chemoradiotherapy for rectal cancer?
6	Why do some patients develop colorectal cancer metastases? Can early markers of metastatic disease be developed?
7	What is the optimal timing of resection of liver and/or lung metastases from colorectal cancer – before, during or after primary surgery?
8	What is the optimal method of wound closure after abdominoperineal excision of rectum (APER)? In which situations are mesh or plastic reconstruction indicated, and is there a benefit from these techniques?
9	Is there a benefit to preoperative (chemo)radiotherapy in T3 rectal cancer with non-threatened margins? If so, does it justify any potential additional toxicity?
10	Is chemotherapy better given before or after surgery for locally advanced colon cancer? Or both before and after?
11	Is there a price to cancer survivorship after treatment for colon, rectal and anal cancer? What is the impact of treatment on quality of life? What level of poor function is justified to avoid a permanent stoma?
12	What is the role of delayed resection of the primary tumour in chemoresponsive metastatic colorectal cancer?
13	What are the optimal methods and intervals for population screening for colorectal cancer? How can uptake of screening be improved? Are there subgroups of the population who are at higher risk and should be screened earlier or at different intervals?
14	Which colorectal adenomas indicate significantly increased risk of future colorectal cancer? What is the optimal screening strategy for these patients?
15	What is the optimal surveillance strategy for patients who have undergone transanal local excision of rectal cancer?