

Patient Liaison Group (PLG) – ACPGB

2nd Annual Report 2017 since its formation in 2015.

ACPGBI PLG formed 2015 (4 persons) previously sole patient representative from 2008. For further details of members, see the patient side of the ACPGBI website.

The nature of the PLG: All volunteer; subsistence expenses only; work via email; only one face-to-face meeting per annum; proactive in raising matters of patient concern to Council; reactive in responding promptly to requests for critiques of documents and patient commentaries, prepares patient benefit statements for grant applications, patient information and other varied tasks.

The PLG acts in the best interests of colorectal patients at all times as independent individuals, able to voice honest and critical opinions. PLG members agree to abide by the comprehensive PLG Terms of Reference.

CHANGES TO THE PLG

February Council 2018 sees the retirement of Jo Church as Chair. The PLG is seeking 1 new PLG member to replace Jo Church, and this is being progressed. Any new appointment to the PLG is considered by both the ACPGBI Executive and Council following a recommendation from the PLG. Bob Arnott will take over as Chair after February 2018 Council, and a Deputy Chair has yet to be appointed.

WORK OF THE PLG DURING THE PAST YEAR

PLG/BDRF SESSION AT CONFERENCE. The PLG and BDRF had a joint session at the ACPGBI Conference this year, which involved 6 of the major colorectal charities. The theme was helping researchers with their PPI when applying for research grants. Questionnaires to attendees identified the need for an improved focus on the practical aspects of managing the delivery of PPI in research, rather than a more theoretical basis. It is hoped to involve researchers and patients who have direct experience of PPI next year. The PLG is very grateful to the ACPGBI for enabling its first involvement in the Annual Conference.

Azmina Verjee (PLG member) has attended the European Society of Coloproctology meeting in Berlin in September 2017 as a patient attendee. The interest shown by the ESCP towards adopting patient involvement in research (President's recent Newsletter) is potential future work on which the ACPGBI and its PLG can collaborate.

Contribution to the Governance Statement following the case of Mr Ian Paterson

Advice to Patients following the case of Mr Ian Paterson on Patient website

Patient Commentary for the Pelvic Floor Society Position Statement on Mesh

Input into the ACPGBI Colorectal Cancer Guidelines

Input into the Ileal Pouch Registry document for Patients

Involvement in the External Affairs Committee (Jo Church) ,

MMC and the IBD Sub-Group and Clinical Advisory Group (Jenny Pipe)

NBOCA Project Board and Clinical Advisory Group

Updating and adding to the Patient side of the ACPGBI website

Various patient benefit statements to accompany research funding applications eg ELGAR (improving intestinal motility after surgery) and Permacol Paste (to NICE).

RCS F.I. Commissioning Guidance Group

Involvement in the criteria for recruiting 2 patient trustees to ACPGBI Trustee Board

Professor Robert Arnott – Conceived, co-organised and chaired the PLG's PPI Session: Research Grants – Patient and Researcher: Coming Together To Achieve Success, held on 5th July at the ACPGBI Annual Meeting.

Attended meetings of The ACPGBI Council

As Trustee and Secretary of the BDRF, continued to build links between the Foundation and the PLG

Co-Applicant and PPI Member of The ALLEGRO study

Have advised several potential applicants to the BDRF and the NIHR on PPI requirements and am planning to develop their PPI work as a co applicant, especially in the field of GI recovery;

Participated in several Delphi meetings and the meetings to establish IMPACT

Prepared to take over as Chair of the PLG in February 2018, by acting as understudy for the current chair.

Azmina Verjee Her extensive research work is attached on a separate sheet.

The PLG remains grateful for the support of the ACPGBI Council and membership.

October 2017

Azmina's ACPGBI PLG Activities (Year 2 – Autumn 2016 to Autumn 2017)

1) ACPGBI Delphi Public & Patient Involvement (Lead: Miss Nicola Fearnhead)

Paper published: A McNair, N Heywood, **A Verjee**, S Bach, J Tiernan, N Fearnhead. A national patient and public colorectal research agenda: integration of consumer perspectives in bowel disease through early consultation. **Colorectal Dis 2017 Jan**;19(1):O75-O85. doi:10.1111/codi.13564

2) ACPGBI Consensus Exercise on surgical management of crohn's perianal fistula

Paper published: M Lee, N Heywood, P Sagar, S Brown, N Fearnhead, I Adam, S Bach, S Blackwell, S Cleeve, T Cuming, A Engledow, O Faiz, R George, R Guy, L Hancock, R Hargest, S Holtham, J Northover, P Thomas, **A Verjee**, G Wilson. Surgical management of Fistulating Perianal Crohn's Disease: a UK survey. **Colorectal Dis 2017 Mar**;19(3) 266-273 doi:10.1111/codi.13462

Paper published: M Lee, N Heywood, P Sagar, S Brown, N Fearnhead, I Adam, S Bach, S Blackwell, S Cleeve, T Cuming, A Engledow, O Faiz, R George, R Guy, L Hancock, R Hargest, S Holtham, J Northover, P Thomas, **A Verjee**, G Wilson. Association of Coloproctology of Great Britain and Ireland consensus exercise on surgical management of fistulating perianal Crohn's disease. **Colorectal Dis 2017 May**;19(5) 418-429 doi:10.1111/codi.13672

3) GlobalSurg Reducing Surgical Site Infections RCT Planning Meeting (Lead: Aneel Bhangu)

Invited Speaker: "Patient and Public Involvement: A U.K. Perspective" Birmingham, November 2016.

Patient co-applicant: NIHR Trials Hub Funding Award

4) Patient decision making in Stoma formation study Steering Group (Lead: Janindra Warusarvitane)

Paper in press: L Dibley, J Burch, J Duncan, W Czuber-Dochan, Cann, **A Verjee**, C Norton, J Warusarvitane. Decision-making about emergency and planned stoma surgery for IBD: a qualitative exploration of patient and clinician perspectives. **Inflammatory Bowel Diseases**. *Accepted for Publication July 2017*.

Poster presented: C Norton, L Dibley, J Duncan, J Burch, J Warusarvitane, M Artom, W Czuber-Dochan, **A Verjee**, D Cann. Decision-making about emergency and planned stoma surgery for IBD: a qualitative exploration of patient and clinician perspectives. Presented at **ECCO 2017** A-2256.

5) Perianal Crohn's fistula Core Outcome Set development group (Leads: Miss Nicola Fearnhead & Prof Ailsa Hart)

Poster presented: Sahnian K, Adegbola SO, Tozer PJ, Allin BSR, Lee MJ, Heywood N, McNair AGK, Lobo AJ, Brown SR, Sebastian S, Phillips RKS, Lung PFC, Faiz OD, Crook K, **Verjee A**, Blackwell S, Fearnhead NS, Hart AL. A systematic review of outcomes reported in studies on fistulising perianal Crohn's disease. Presented at **ECCO 2017**. A-2333.

Meetings attended: October 2016; November 2016; December 2016; January 2017; February 2017.

6) LaCeS Feasibility RCT Trial Steering Group & Management Group (Leads: Prof Peter Sagar & Miss Deena Harji)

Paper Submitted: D Harji, H Marshall, K Gordon, B Griffiths, C Moriarty, D Burke, H Crow, V Hiley, M Twiddy, J O'Dwyer, **A Verjee**, J Brown, P Sagar. The feasibility of a multi-centre, randomised controlled trial of laparoscopic versus open colorectal surgery in the acute setting – The LaCeS Feasibility Trial Protocol. *Submitted to **BMJ Open** July 2017*.

7) NASBO (National Audit of Small Bowel Obstruction) Steering Group

Meetings attended: November 2016; May 2017.

8) National Bowel Cancer Intelligence Hub Launch (Leads: Prof Paul Finan & Prof Eva Morris)

Invited Speaker: “Integration of Consumer perspectives through early consultation” Leeds, July 2017.

Patient co-applicant: Cancer Research UK Programme Grant Award

Teleconferences: November 2016; February 2017; April 2017;

9) IBD CAG (Clinical Advisory Group)

Meetings Attended: November 2016; June 2017;

10) ESCP Patient Involvement in Research Strategy Working Group (Lead: Prof Dion Morton)

Invited Speaker: “What is PPI and why should we do it?” ESCP Annual Meeting, Berlin, September 2017

Teleconferences: November 2016; January 2017; March 2017; May 2017; June 2017; July 2017; August 2017;

11) Efferent Limb Feeding after loop Ileostomy (ELFI) surgery study (Lead: Miss Carolynne Vaizey)

Meetings attended: March 2017; May 2017; June 2017; July 2017 St Mark’s Hospital & Norwich

12) CAF-QOL study: developing a Crohn’s Anal Fistula Quality of Life assessment tool (Lead: Mr Kapil Sahnan)

Meetings attended: January 2017; July 2017; August 2017

OTHER STUDIES

FINS study (Chris Norton) – *not surgical*

Hip Study (Dale Vimalachandran) - *ongoing BDRF-funded study but not very much activity this year*

Food related Quality of Life Study in IBD (Prof Kevin Wheelan at King’s) May 2017 – *not surgical*

IBD Boost (Chris Norton/Ailsa Hart) – *NIHR-funded 5-year programme grant start date 1 November 2017*

Elevated risk of CRC in Crohns Disease (Chris Norton/Ailsa Hart/Phil Tozer) – *proposal in preparation for submission on 22 September 2017 to Bowel Cancer UK*

Photovoice IBD study (Christ Norton, Tiffany Wade) – *proposal in preparation for submission to CCUK*

Crohn’s Anal Fistula assessment of response to Rx (Nicola Fearnhead, Phil Tozer, Kapil Sahnan Sam Adegbola formerly Nuha Yassin) – *BDRF-funded qualitative research in progress at St Mark’s hospital so no publications yet*

BAME stomas (Lesley Dibley) – *outline submission accepted for funding by Barts Hospital charity, now preparing full submission.*

Nuha Yassin CCUK application for enhanced recovery in Crohn’s Surgery – *1st round selection but ultimately application not funded March 2017*

James Lind Alliance Diet paper published – Journal of Human Nutrition (*Lead Author Miranda Lomer*)

Improving Statistical Methods for individualised predictions and understanding population variation in survival for colorectal cancer patients. University of Leicester PhD Elisavet Syriopoulou (Biostatistics Dept) – application successful – NIHR funding awarded – start date 1st October 2017 – recommendation via Prof Paul Finan & Prof Eva Morris.

Stoma and AKI Study (ACPGBI – Baljit Singh) – *not much activity this year*