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St Mark's Hospital

St Mark's Hospital Inflammatory Bowel Disease Service

Strategy for healthcare, clinical research and education

Report from Strategy Meeting held
7 June 2019

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Contents

Executive summary

- St Mark's Hospital inflammatory bowel disease (IBD) team held a workshop on Friday 7 June to formulate a strategy for the next five years for the delivery of high quality patient care integrated with clinical research and education

- The vision is to maintain recognition as a world-leading department for patient care, clinical research and education

- The strategy was formulated using a variation of the nominal group technique (NGT) to align the strategy with national and international initiatives in the field of IBD and to build on the quality of the existing IBD service

- Ideas from individual team members were shared, collated and ranked to identify the top 10 priorities to define strategy

- A high quality advice service, definition of team roles with specific skill sets, robust processes for clinic appointments with red flags for refractory patients with active symptoms, and educational masterclasses were then agreed as four ideas prioritised for immediate action

- Review of progress to date and action plans will be discussed at a dedicated Friday business meeting

Background

St Mark's Hospital IBD service (which also covers Northwick Park, Central Middlesex and Ealing Hospitals) runs a world-renowned specialist IBD service which encompasses all aspects of IBD care; medical, nursing and surgical treatment, psychological and nutritional support, research and education, as well as service for the transition from childhood to adulthood.

St Mark's IBD service has been at the forefront of high-quality healthcare, education, research and innovation. Within a rapidly expanding field the challenge for the team is early adoption of new research findings into clinical practice as well as leading the way with ground-breaking research.

Over the last two years the team has expanded with two additional new consultant posts, two new Clinical Research Fellow posts as well as the introduction of an IBD Advance Nurse Practitioner to support out-of-hospital care. Delivering high quality care is a priority with quality improvement initiatives addressed through timely, safe, effective, patient-centred, efficient and equitable care. We have one of the largest IBD cohorts in the UK with the potential to lead in the data revolution to improve healthcare and generate new research findings, clinical research and capturing health outcome measures.

The challenges of delivering of high-quality care are similar to other long-term illnesses, with continuing need to develop the service improvements whilst aligning with direction of study of IBD,

the political agenda and the NHS Long Term Plan. As such, this workshop was designed to discuss and agree the strategy over the next five years of the service, with a focus on the clinical care, research and education. The overall vision is to maintain recognition for clinical care, research and education and to deliver high quality care as a perfect patient pathway with personalised care. The IBD Standards set out what high-quality care looks like at every point of the patient journey, from pre-diagnosis**,** to surgery and ongoing care, as well as how IBD Services should be organised to deliver this.

The meeting was attended by 14 members of the IBD team. Consultants from Ealing Hospital were also invited. A full list of attendees and invited staff is included in Appendix 1.

Meeting objectives

1. To formulate the strategy for the next stages of the service
2. To align strategy with local needs, national and international IBD initiatives

Meeting agenda

Table 1 outlines the agenda and timings for the workshop.

Table 1: Workshop agenda

Time	Agenda topic
08.30–08.40	Welcome and introductions – What are we trying to achieve – Agenda overview – Initial questions
08.40–9.00	Overview of current service, activities and metrics
09.00–10.30	Introduction to workshop—developing our services whilst aligning to the NHS Long-term plan and IBD initiatives; methods and topics Workshop Listing ideas followed by discussion of each ideas including: – Interventions/areas for change – Potential barriers – Solutions – Priority and feasibility
10.30–10.45	*Coffee break*
10.45–11.45	Workshop summary feedback – Agree on 5–10 priorities – Agreement of next steps o Actions, responsibilities and timescales
11.44	Thank you and close of meeting

Overview of the current service

Data from the 2018–2019 annual report were presented. The key highlights and challenges were:

- High demand for telephone advice line (4,355 calls only 2,215 were logged on ICS)

- High demand of email activity (6,372 emails not funded by CCG)
- High number of outpatient clinic appointments (over 7,000 clinical appointments)
- Expansion of biologic cohort (955 patients)
- Small volume of paediatric cohort (120 patients)
- Named IBD pharmacists for the service
- Inadequate level of dietary support
- High volume of complex cases discussed at MDT meetings
- Close collaboration with IBD patient panel
- Active number of educational activities
- Broad research portfolio

Table 2 details the strengths and weaknesses of the current clinical team structure.

Table 2: IBD clinical team with strength as dedicated staff and weakness as staff to be include for a comprehensive world-class service

Strengths	**Weaknesses**
5 IBD CNS and 4 IBD nurses 5 Gastroenterologists 3 IBD surgeons 2 IBD pharmacists 1 IBD dietician Affiliated services • Specialist endoscopists • Dietitians/Nutrition specialists • Psychology team	Dedicated IBD psychologist Sexual health counsellor Smooth transition/pathway for optimal management of specific disease states • Perianal CD • Complicated CD • IBD surveillance • High-risk patients • Young adults

CD, Crohn's disease; CNS, Clinical Nurse Specialist; IBD, inflammatory bowel disease

The paediatric service is not included in this strategy workshop as it rests within a different directorate.

Workshop approach and methodology to create the strategy

Several methods were considered for the running of the workshop. Due to time limitations and breadth of participants' disciplines, a variation of the nominal group technique (NGT)[1] was adopted to gain consensus. The following approach was taken:

1. Each workshop member spent 15 minutes thinking of ideas they considered important for the IBD strategy in three areas: clinical care, clinical research and education

[1] Gallagher M *et al*. Family Practice 1993; 10(1): 76–81.

2. Each shared one idea in one cycle turn which was recorded on a flipchart. After each person shared the first idea, another cycle for the second idea completed. The cycles continued until all ideas were shared
3. Once all ideas were listed on a flipchart, the facilitator led a discussion. The purpose was to clarify, elaborate, defend or dispute the ideas and to add new ideas emerging from the discussions. Potential barriers to the suggested changes and possible solutions were also discussed
4. Thereafter each member was asked to choose 10 topics they considered most important from the full lists on the flip charts
5. The counts for each topic were ranked so come up with the ten most voted ideas.
6. The top ten list as voted by the group was transferred onto a fresh flip-chart ranked per number of votes
7. There followed an open discussion to gain agreement and agree an action plan to move forward

For the strategy report the votes from the workshop were condensed into themes and linked to the key vision of the service outlined in the introduction. Each statement is supported by information and justification from which a strategic objective was defined. Actions to deliver the objectives are described at the end of the report.

Workshop outputs

The full lists of ideas with ranking/votes across the three areas of clinical care, research and education are detailed in full in Appendix 2. The final top 10 topics were to:

1. Measure, monitor and deliver clinical care and research using a database/s
2. Generate income for the IBD service
3. Identify high risk patients at risk of complications or needing specialist reviews
4. Create a new framework for the advice services
5. Define specific roles for nursing team e.g. a surgical co-ordinator
6. Structure patient education according to need (newly diagnosed and progressive disease)
7. Develop external educational events as IBD masterclasses
8. Review follow-up of biologics cohort
9. Improve processes for clinic appointments stratified for patients
10. Deliver educational events directed at medical and hospital staff (e.g. GPs and Accident & Emergency colleagues)

Following discussion and debate, the group agreed on the priorities defined above. Within the list “easy wins” were selected as follows:

1. A new framework for the advice service

The value of the advice service is well recognised and forms part of the IBD standards. The team agreed that good quality advice as a key component of patient centred high quality care and offers personalised care. Other advisory services are available outside the Trust including charities such as

Crohn's and Colitis UK (CCUK). St Mark's IBD advisory service is busy: in 2018–2019 the nursing telephone advice line received 4,355 calls and 6,372 emails. The following issues were highlighted:

- No revenue is received for the email service
- Most enquiries are administrative-related questions better handled elsewhere
- Email activity is time consuming and creates capacity constraints
- Other departments were successful in generating income from email service (e.g. stoma care)
- A review of the advice line started 5 weeks ago

Strategic objectives

1. Fulfil purpose of telephone advice service
2. Restrict Email service to blood monitoring and GP enquiries only
3. Signpost queries to relevant places
4. Link the service with CCUK

2. Defined specific roles for nursing team

IBD standards refers to protocols that clearly define the local transition service and the personnel responsible. Patients should have access to coordinated surgical and medical clinical expertise, including regular combined or parallel clinics with a specialist colorectal surgeon (paediatric colorectal surgeon where appropriate) and IBD gastroenterologist. Patients with IBD being considered for surgery should be provided with information in a format and language they can easily understand to support shared decision making and informed consent and offered psychological support. Elective surgery for IBD should be performed as soon as the patient's clinical status has been optimised and within 18 weeks of referral for surgery. All these elements of the standards can be achieved through a dedicated nursing role.

The team raised awareness of weakness in the transitions and co-ordination of care for surgery due to lack dedicated surgical nurse. IBD is a specialised field with different sub-populations (young adults/elderly/pregnancy) or disease states (perianal/strictures/biologics/dysplasia surveillance) that may define the multidisciplinary care requirements. Monitoring can be facilitated by individuals having designated roles e.g. biologics nurse.

Strategic objectives

1. Designate nursing staff with specific roles with one nurse as surgical co-ordinator
2. Personalise care for disease populations and states

3. Clinic appointments stratified for patient cohorts

The primary goal of treating patients with IBD is to maximise long-term health-related quality of life through control of symptoms, prevention of structural damage, normalisation of function and participation in social and work-related activities. A treat-to-target strategy requires tight control with regular review of patients at specified time points to review treatment decisions. These and other patients need to be flagged for high frequency review (e.g. refractory disease, pregnancy, dysplasia on colonoscopy) by a member of IBD team in a coordinated and efficient manner.

The team recognised that there is currently no dedicated clinic time and no co-ordinator for these flagged patients who require careful monitoring and to ensure cancelled or postponed appointments are reinstated.

Strategic objectives

1. Support protected time in clinics for red flag patients
2. Agree criteria for red flag
3. Co-ordinator to register red flag patients from MDT and clinics

4. Educational events such as IBD masterclasses

St Mark's Hospital is the world's only specialist bowel hospital, supported by an academic institute that runs highly prestigious teaching activities for consultants, trainees and specialist nurses. Teaching activities are mainly focused on a yearly Frontiers conference and a few unrelated courses. The team recognised the need for a co-ordinated programme to share the expertise of the IBD MDT. The IBD standards states that all members of the IBD team should develop competencies and be educated to a level appropriate for their role, with access to professional support and supervision.

Strategic objectives

1. To create a portfolio of educational events directed at other IBD teams
2. Use educational events to raise profile of the department
3. Establish online teaching such as MSc

5. Data for clinical care and research

Databases offer the potential to measure, deliver and audit clinical care in order to improve quality of care as well as to conduct research studies. Several databases are in use tailored to defining outcomes for specific cohorts e.g. PMS for biologics and surveillance, UR-CARE new diagnosis, surgery and perianal CD, Pouch registry for pouches. Clinical datasets can be integrated with patient reported outcomes (PROMS) and show the value of interventions from a patient perspective.

Strategic objectives

1. Identify funding to support an information manager to support data studies
2. Schedule of procedure for minimal dataset for inclusion into databases
3. Develop a data science research portfolio to include studies on quality of care

6. Income for the IBD service

Income related to IBD cohort is important to show value of the team's contribution to the overall organisation. Most activity generated by the IBD clinical service is captured in outpatients, endoscopy, research or pharmacy departments. Telephone clinics, biologic clinics and the biologics day care unit have IBD-specific clinic codes where activity can be captured to reflect income for the annual report. New income generating services such as young adults' clinic or new diagnosis clinic and alternative sources of income including from research are needed to support expansion of the service.

Strategic objectives

1. Foster collaborative research project through St Mark's Foundation and Imperial College
2. Adopt IBD-specific clinic codes for new services

7. Patients at high risk of complications

IBD sub-populations at high risk of complications include the elderly on immunosuppressant/biologic therapies, dysplasia, pregnancy, perianal Crohn's and Crohn's strictures. Patients in these sub-populations may benefit from careful monitoring and specialist review by a member of the IBD team. The IBD standards specify a mechanism to ensure that colorectal cancer surveillance is carried out in line with national guidance and that patients and parents/carers are aware of the process. A surveillance protocol is written to cover the dysplasia group. The ability to identify and track progress of high-risk patients at risk of complications will improve safety of this population.

Strategic objectives

1. Agreement on the definition of complex/high-risk patients
2. Complex patients to be managed by IBD specialist team
3. Implement surveillance policy and protocol

8. Monitoring of biologics cohort

As the number of patients on biologic drugs increased the team experienced difficulty with managing the overwhelming number of infusions and homecare treatments. Alternative models were explored including delivering the service in Partnership with other providers. The current processes in place for monitoring drug therapy are in need of review in parallel with the service change. All biologics data for the national IBD audit will need to be registered.

Strategic objectives

1. Offer biologic therapy off site in partnership with external provider
2. Develop new virtual monitoring pathways

9. Personalise patient education according to need

The IBD standards state that patients should be supported in self-management, as appropriate, through referral or signposting to education, groups and support. All patients with IBD should be provided with clear information to support self-management and early intervention in the case of a flare. Patients should be signposted to information and support from patient organisations and supported to make informed, shared decisions about their treatment and care to ensure these take their preferences and goals fully into account. Information requirements are dependent on the stage of their disease.

Strategic objectives

1. Maintain awareness of potential educational events through patient panel
2. Signposting of patient information in collaboration with Patient Information Forum
3. Study and share measures of patient empowerment
4. Identify and fill gaps in educational resources

5. Develop decision aids and decision support tools to help with shared decision making

10. Educational events for GPs and non-IBD hospital staff

Education of GPs is supported by the Royal College of GPs toolkit. Better disease understanding offers patient access closer to home, reduction in admissions, better care and supported self-management. Education of Accident and Emergency (A&E) staff offers better care to patients presenting to A&E.

Strategic objectives

1. Designate a champion for the events
2. Pilot the GP advisory service

Delivering the early stage objectives

1. Improve quality of the advice service

A standard operating procedure (SOP) will be created and audited for compliance. All other emails and questions received will be signposted to other relevant areas for an appropriate response

Table 3: Advice line actions, responsibilities and timescale

Summary of actions	Responsibility	Timescale
• Keep emails for bloods and GP use only • Develop a SOP for signposting of questions • Test new system and re-direction/signposting • Audit time and activity	Madhoor Ramdeen	6 months

GP, general practitioner, SOP, standard operating procedure

2. Surgical patients with a surgical co-coordinator role

This aims to bridge gaps between physicians and surgeons and improve transition to surgical care. This should be a dedicated role for one person and responsibilities would include providing pre-/post-operative advice, pre-operative cancelling, collecting data and act as a point for research. A SOP will need to be developed and it was agreed that the role would remain part of the IBD nursing team. A job description needs to be developed. It was agreed that this role could form one of the two Band 6 nursing interviews being held w/c 10 June.

Table 4: Surgical co-ordinator actions, responsibilities and timescale

Summary of actions	Responsibility	Timescale
• Develop job description • Conduct interview as part of existing process • Develop a SOP for the role	Mr Tozer Madhoor Ramdeen	4 months

SOP, standard operating procedure

3. Improve clinic appointments stratified for patient cohorts

Ffurther discussions on definitions of high-risk and complex patient are needed and whether all clinics should include complex patients. The consultants to engage in patients booked into clinics, to ensure appropriate groups booked into right clinics. A number of ideas were discussed including protected specific slots for high-risk patients, dedicated high-risk patients clinic or alternative clinic appointments. Potential high-risk patients may be identified via the MDT. It was also proposed that each patient should have a named consultant and nurse and efforts should be made for consultants to scope their own patients where possible.

Table 5: Increase clinician involvement

Summary of actions	Responsibility	Timescale
• Define the high-risk patient • Define the complex patient • Conduct biologics service review • Each patient to have named consultant/nurse • Consultants to scope own patients where possible • Rethink how clinics work linking to discharge and repatriation	Team	1 year

4. Develop educational events as IBD masterclasses

Four different approaches were discussed including:

- Multi-disciplinary Masterclass (every 2 years)
- Annual surgical IBD Masterclass (annual)
- Rolling Masterclass on different topics
- IBD summer camp for International students

Table 6: Educational events

Summary of actions	Responsibility	Timescale
• Develop curriculum • Divide into masterclasses • Designate lead for each class • Discuss at Friday meetings • Roll out	Nik Kamperidis	9 months

Delivering the priority objectives

Action plans to deliver the following priority topics will be developed at future meetings and are not included in this report:

- Data science to link clinical care to research
- Generate and capture income for the IBD service
- Identify high risk/complex patients at risk of complications in need of specialist reviews
- Personalise patient education according to need
- Review monitoring of biologics cohort
- Deliver educational events for GPs and hospital staff

Appendix 1: Workshop attendees

Consultant Gastroenterologists
Naila Arebi
Ailsa Hart
Ayesha Akbar
Nik Kamperidis
Ravi Misra

Consultant Colorectal Surgeons
Phil Tozer
Omar Faiz
Janindra Warusavitarne

IBD Pharmacist
Riddhika Joshi

IBD Advance Nurse Practitioner – Central Middlesex Hospital
Tracey Tyrell

IBD nursing team - St Mark's Hospital
Madhoor Ramdeen (Lead)
Jitka Adio (CNS)
Babitha Joseph (IBD nurse)

Invited members – Ealing Hospital
Jay Arnold
Charlotte Bearcroft
Arabinder Pal
Arvind Sangwaiya
Sohail Shariq

Appendix 2: Initial ideas

All initial ideas from the individual workshop members across the three areas discussed are listed in the order they were shared with the group.

Table 1: Clinical services

Idea	No. of votes
High-risk clinic	6
Stable patients in the right clinic	2
More face-to-face clinics with specialist pharmacist/nurse	1
See high-risk patients every 3–4 months	1
More nurse-led services, aligned to patient need	1
More clinician control—seeing the right patients at the right time	4
Weekly rota in patients/referrals	1
Surgical co-ordinator	6
Vetting—better direction for referrals	1
Improve/re-vamp the advice line	6
Pathways for newly diagnosed, high-risk and stable patients	2
IBD App for patients	1
Telephone/electronic clinics	3
Faster access teams	2
Biologics reviews	4
Increase administrative support to capture and retrieve data (R&D dedicated)	2
Electronic platforms	-
Discharge protocols—option to refer back to the local area	-
Working with GPs—diagnosis pathways before referral	2
Working together with STPs/CCGs	-
Local surgical network for IBD to discuss complex cases	2
Joint medical/surgical clinics	5
Education for patients/carers/families	-
Generate income recognisable for the Trust	7
Review advice given—all to be same level and build on skills	1
Better use of meetings with objectives and goals	-
Hitting targets for patients	-
Standardise reporting letters with consistent language	1

CCG, Clinical Commissioning Group; IBD, inflammatory bowel disease; STP, sustainability and transformation partnerships; R&D, research and development

Table 2: Research in clinical practice

Idea	No. of votes
New roles for academic activities	-
Dedicated nursing research with protected time	2
Patient views into service	-
Overarching database to capture all data	9
Showcase clinical research	-
Integrating research into clinical environment (opt out, not in)	2
Biannual meeting for fellows to present data (expand to Network)	-
Data co-ordination role maintained	1

Integrated research nurse with IBD nurse specialists	1
Training of IBD nurses—embed research in role	3
Collaborate with Pharma—what can we get involved with	-
Co-ordination of research efforts—recognise clinical services in success of trials	-
Look at ways research income redirected to the service	4
Utilise collaborative authorship	2

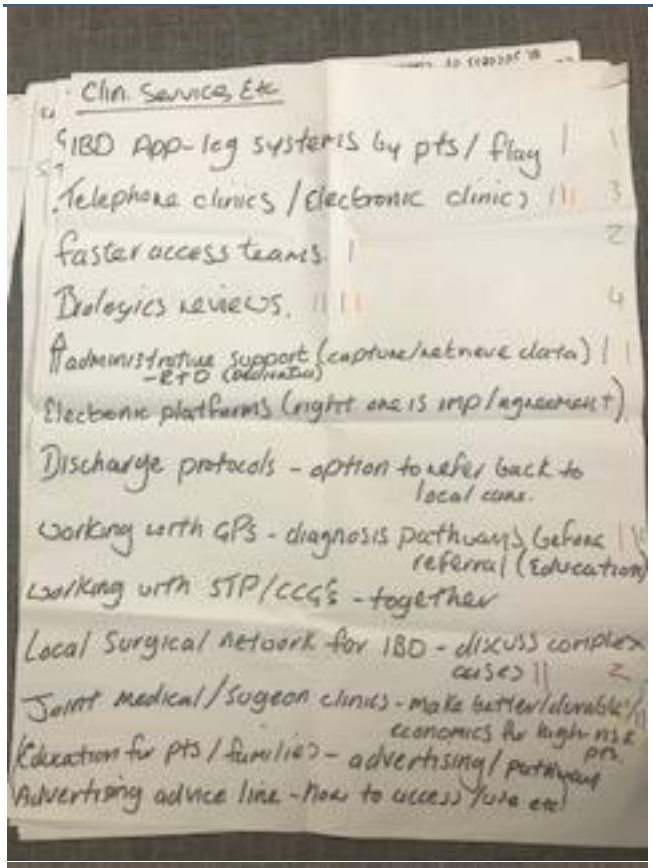
IBD, inflammatory bowel disease

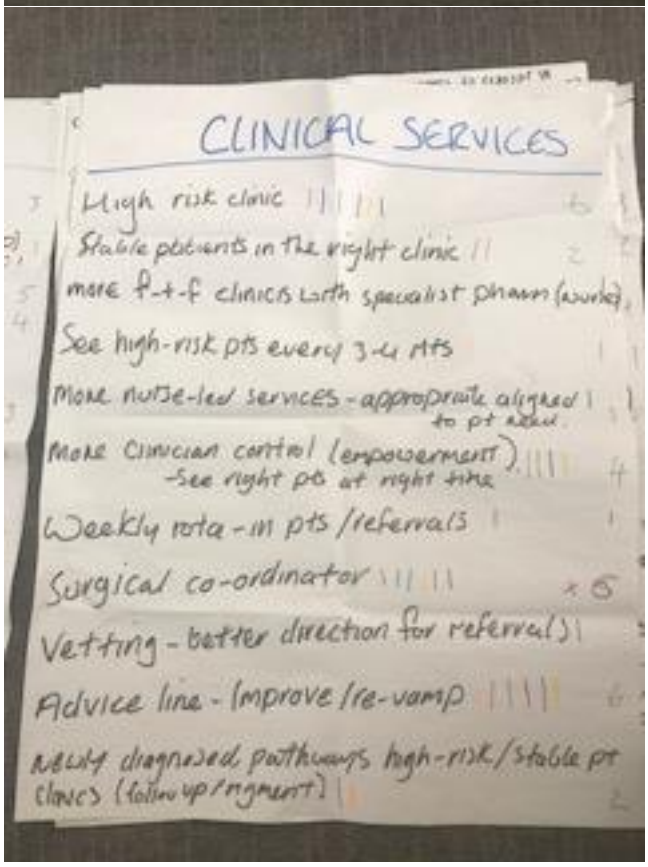
Table 3: Education

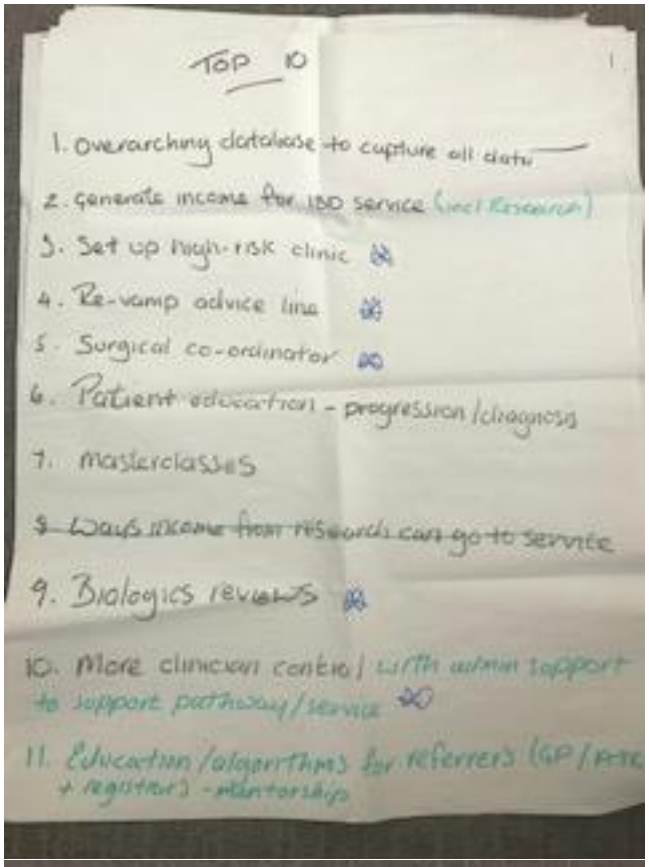
Idea	No. of votes
Training for A&E doctors	3
Education on appropriate referral for GPs	1
Masterclass (every 2 years)	5
Patient education—diagnosis and progression	4
Pan-hospital network MDT	-
Algorithms for local GPs	3
Education from patients to HCPs	1
Annual surgical IBD masterclass (annual)	-
Nursing IBD courses (yearly)	1
Patient education on self-management	1
Developing non-medical prescribers	1
Use what's already out there	-
Rolling masterclass on different topics	5
IBD leads present at Pharma study days	1
IBD summer camp for International students	1

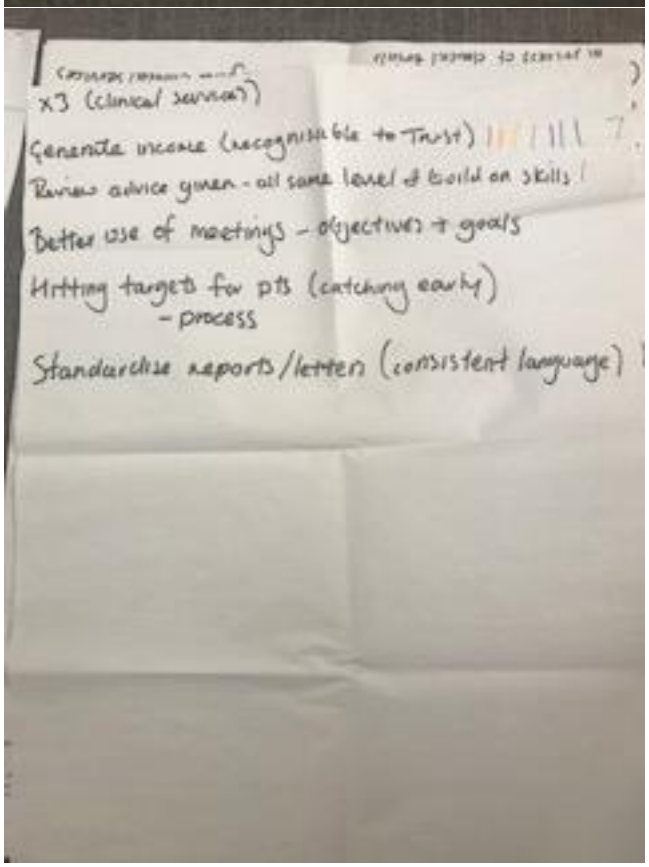
A&E, accident and emergency; GP, general practitioner; HCP, healthcare professional; IBD, inflammatory bowel disease; MDT, multidisciplinary

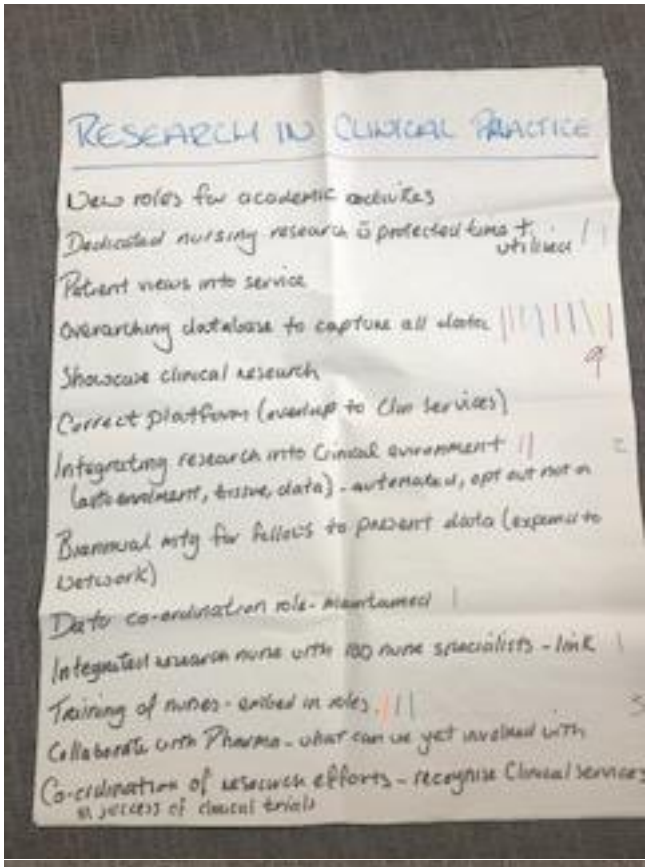
Appendix 3: Original flipchart photographs

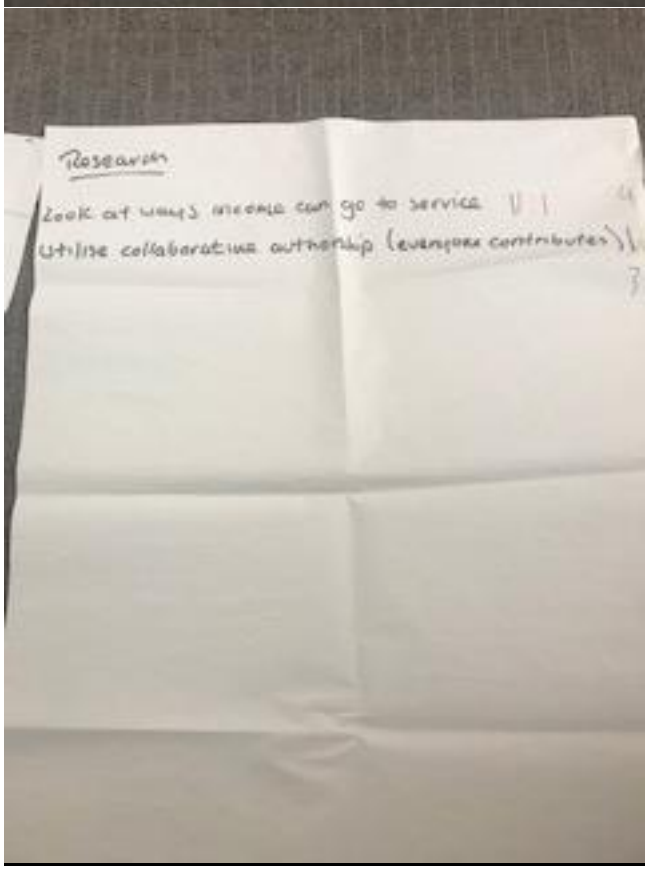


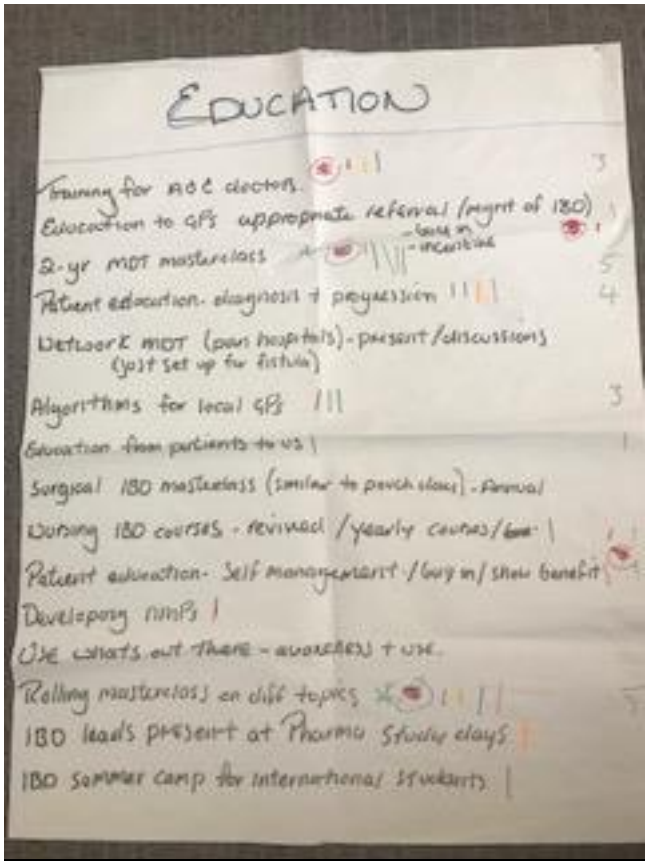



TOP 10
1. Overarching database to capture all data
2. Generate income for IBD service (incl Research)
3. Set up high-risk clinic
4. Re-vamp advice line
5. Surgical co-ordinator
6. Patient education - progression/diagnosis
7. Masterclasses
8. Ways income from research can go to service
9. Biologics reviews
10. More clinician centric/ with admin support to support pathway/service
11. Education/algorithms for referrers (GP/
+ registrar) - mentorship


x3 (clinical service)
Generate income (recognisable to Trust)
Review advice given - all same level & build on skills
Better use of meetings - objectives + goals
Hitting targets for pts (catching early)
- process
Standardise reports/letters (consistent language)


RESEARCH IN CLINICAL PRACTICE
New roles for academic activities
Dedicated nursing research & protected time + utilised
Patient views into service
Overarching database to capture all clients
Showcase clinical research
Correct platforms (overlap to Clin services)
Integrating research into Clinical environment
(auto enrolment, tissue, data) - automated, opt out not in
Biannual mtg for fellows to present data (exposure to network)
Data co-ordinator role - maintained
Integrated research nurse with IBD nurse specialists - link
Training of nurses - embed in roles
Collaborate with Pharma - what can we get involved with
Co-ordination of research efforts - recognise Clinical services
as sources of clinical trials


Research
Look at ways income can go to service
Utilise collaborative authorship (everyone contributes)


EDUCATION
Training for NOC doctors
Education to GPs appropriate referral (mgmt of IBD)
2-yr MDT masterclass
Patient education. diagnosis + progression
Network MDT (pan hospitals) - present/discussions
(just set up for fistula)
Algorithms for local GPs
Education from patients to us
Surgical IBD masterclass (similar to pouch class) - annual
Nursing IBD courses - revised /yearly courses/
Patient education - self management /buy in/ show benefit
Developing nurses
Use what's out there - awareness + use
Rolling masterclass on diff topics
IBD leads present at Pharma Study days
IBD summer camp for international students