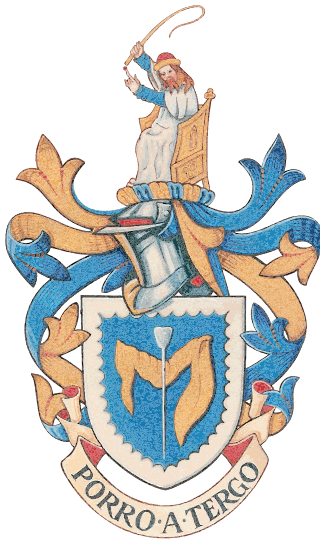




Ileoanal Pouch Report

2017

Association of Coloproctology
of Great Britain and Ireland

Sponsored by



The ileostomy & internal pouch
Support Group

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Foreword from the President of the ACPGBI

The ileal pouch operation was introduced in the 1970s by Sir Alan Parks and has transformed the lives of countless patients worldwide with ulcerative colitis and familial adenomatous polyposis (FAP). With around 400 new pouch surgeries being performed nationally each year, this registry becomes an important resource for professionals and patients looking to understand more about surgical outcomes, quality of life and early insights into areas of research.

The Association of Coloproctology of Great Britain & Ireland established the Pouch Registry in 2005. This was re-launched in 2010 with a grant from the Bowel Disease Research Foundation and in collaboration with Dendrite Clinical Systems. The principal aim of the Registry is to promote high standards of care for patients undergoing restorative proctocolectomy. Although this is a voluntary database (at present 50% of surgeons contribute), surgeons increasingly recognize the need for recording the outcomes of complex operations.

The First Ileal Pouch Registry Report was published in July 2012. It was the first of its kind to be published anywhere in the world and described the national experience of nearly 2,400 patients with ulcerative colitis and FAP undergoing restorative proctocolectomy.

This 2017 report is published with generous support from IA (The ileostomy & internal pouch Support Group). The number of patients registered has increased to over 5,000, entered into the Registry by around 150 pouch surgeons, including from 4 centres outside the United Kingdom. Data on 567 children and adolescents aged 19 and under are included in this Report.

Important information is also presented on outcome, volume *per* institution, re-admission rates, and length-of-stay derived from the newly available SWORD HES data. This resource has added much new information to the report. The topic of centralising pouch surgery is addressed, particularly with reference to training.

ACPGBI hopes that the Ileal Pouch Registry will achieve its primary aim of raising standards in the performance of restorative proctocolectomy in the United Kingdom and abroad. The continued support of IA is vital for this work and is greatly appreciated. I believe it will be widely read and endorsed by patients, surgeons and professional bodies alike.

Mr Peter Dawson

President 2016-2017, Association of Coloproctology of Great Britain & Ireland

Foreword from the President of IA (The ileostomy & internal pouch Support Group)

IA (The ileostomy & internal pouch Support Group) is pleased to be supporting the Second Ileal Pouch Report. A further acquisition of anonymised patient data and outcomes has been put together since the first report was published in 2012, and the new report provides an important resource for research and future strategy.

IA was established by patients with IBD just over 60 years ago, with the help and inspiration of the man who has given his name to the spouted ileostomy we use today, Prof. Bryan Brooke. At a recent national meeting of IA, several of the original patients who had the first successful ileostomies gave their compelling and moving stories about their struggles with jobs, relationships, careers and appliances, such was the ignorance and prejudice at the time. They needed the encouragement of professionals and fellow patients to get to the point where an ileostomy became a routine procedure with reliable outcomes.

The pouch operation has also gone through a similar period of development and today's pouch patients deserve even more reassurance in a changed world with social media and access to many sources of information and advice. Someone considering a pouch operation needs to know what they can really expect, from complications to outcomes and bowel function, and we hope this report will help drive up success rates and create increasing transparency for both professionals and patients.

Prof. Neil Mortensen

President, IA (The ileostomy & internal pouch Support Group)



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Executive summary

Overview

- The ACPGBI 2017 Pouch Report includes contributions from around 150 surgeons on over 5,000 patients who have had pouch surgery, mostly in the United Kingdom but also from 4 centres in Europe.
- Data on patients in the Pouch Registry has been collected without being able to identify individual patients and case submission is entirely dependent on voluntary engagement by pouch surgeons.
- Pouch surgery is recorded from its infancy (dating back to 1980) up until the present day. This makes the Pouch Registry by far the largest and longest repository of information about pouch surgery in the world.
- Data in the Pouch Registry covers all age groups and includes over 500 children and adolescents. Pouch surgery is mostly offered to fitter patients who do not have serious medical comorbidity.
- This report also includes centrally-collected data on 1,908 pouch procedures carried out in England during the last 5 years.

What we know about pouch surgery from SWORD

- The Surgical Workload and Outcome Reporting Database (SWORD) provides information about pouch surgery in England based on administrative data. It is impossible to know exactly what proportion of pouch procedures are included in the Pouch Registry but it is probably, at best, around 50%. The ACPGBI's Inflammatory Bowel Disease Clinical Advisory Group continues to explore ways of improving the case ascertainment rate throughout Great Britain & Ireland.
- Length-of-stay has remained relatively constant throughout England at around 10 days.
- There is a high re-admission rate with a quarter of patients requiring re-admission within 30 days of surgery. The reasons for this are probably multi-factorial, and may be influenced by local resources. This is a key target for future improvements in care.
- The SWORD database draws immediate attention and potential concern to the phenomenon of the *occasional* pouch surgeon. In the past 5 years, only 26 surgeons in England have performed more than 15 pouch operations while 126 surgeons have performed just one operation in the same time period.
- Volumes of pouch surgery at institutional level highlight a similar phenomenon: the average number of pouch procedures *per* English Trust was 15 in the past 5 years. Of 126 English institutions carrying out pouch surgery during this time, 108 carried out less than 5 operations *per annum*. Such low volumes have significant implications for collective experience at institutional level, particularly with respect to training and in proactive management of complications.

What we know about pouch surgery from the Pouch Registry

- The database predominantly includes patients undergoing pouch surgery for ulcerative and indeterminate colitis, but familial adenomatous polyposis (FAP) is the indication for surgery in around 10% of patients, or just over 400 cases.
- Although pouch surgery tends to be an elective procedure in the younger population, 15-20% of operations were done for patients with restrictive or life-threatening conditions. Importantly, these data are largely historical as the refinements to the minimum dataset mean that ASA grade is no longer collected routinely in the Registry.
- About 50% of patients with colitis who subsequently come to need pouch surgery need surgery within 3 years of initial diagnosis. In contrast, about 1 in 5 patients do not undergo pouch surgery for more than 10 years after diagnosis of colitis. This may in part reflect improvements in medical management of colitis.
- Unsurprisingly the use of biological therapy in treatment of ulcerative colitis before patients undergo pouch surgery has increased exponentially since 2007. In 2016-17, around 30% of patients received biological therapy before undergoing pouch surgery.

- Laparoscopic surgery has become more frequent in the last decade with about one-half of pouch procedures reported in the Registry being carried out with a laparoscopic or laparoscopically assisted approach in the past 5 years. It is worth noting that selective reporting bias may contribute to these figures as SWORD data indicates that only a third of pouches have been done *via* a laparoscopic approach during the same period. SWORD also demonstrates wide variation in use of the laparoscopic approach to pouch surgery.
- Where recorded, close rectal dissection (CRD) was the plane of choice for proctectomy during pouch surgery until 2012, but total mesorectal excision (TME) is now more commonly used, with two out of three patients undergoing TME proctectomy during a pouch operation in the past 5 years. The facility of CRD with transanal approaches to proctectomy may, in time, bring a swing back towards CRD as the nerve-sparing plane of choice during proctectomy.
- The stapled J-pouch is currently by far the most common technique for pouch construction. Other techniques are now mainly historical. A recently reported small resurgence in interest in offering the K-pouch has not been reflected in the Pouch Registry dataset.
- Data from the Pouch Registry suggests that there is continued routine use of diverting ileostomy, as over three-quarters of patients will have an ileostomy at the time of pouch surgery.
- Complications are common occurring in about 1 in 5 patients. There is a suggestion that the incidence of complications may be decreasing slightly, but the data collection in this area is undeniably poor.
- The Pouch Registry also includes information on around 250 patients who have undergone revisional surgery, with around 80 patients in the last 5 years. One-quarter of patients who have revisional surgery undergo surgery within one year of pouch construction. Revisional surgery is challenging and one-third of patients will experience complications.

What is the future for pouch surgery?

- Although substantially incomplete, data collected on trainee operating hints at the fact that most pouch procedures are not performed by trainee surgeons under appropriate specialist supervision. This fact combined with SWORD data suggesting a preponderance of occasional pouch surgeons is concerning for training. Training the next generation of pouch surgeons requires professional focus and infrastructure in terms of directing trainees to the training opportunities available in high-volume and high-performing centres.
- Centralisation offers the obvious practical solution to concentrating experience and improving outcomes for future patients needing pouch surgery.

Summary of the pouch report for patients and the public

About Pouch Surgery

People who have diseases of the large bowel (colon) such as inflammation of the large bowel (colitis) or multiple pre-cancer growths that are highly likely to become cancerous (polyposis) sometimes need surgery to remove the large bowel to treat the problem. Often surgery to remove the colon is the best & most sensible treatment choice.

If the large bowel needs to be removed, this may be carried out in a number of ways and doctors will advise on the best course of action in specific circumstances:

- Removal of the colon (colectomy) first with creation of a temporary stoma (ileostomy) and then another operation at a later date which would be one of the these options:
 - i. either joining the small bowel (ileum) to the anus by creating an internal (ileoanal) pouch known as a J-pouch,
 - ii. or having a reservoir made with an opening like an ileostomy but with a one-way valve that allows it to be emptied with insertion of a drainage tube (continent ileostomy or Kock pouch),
 - iii. or removal of the back passage or rectum (proctectomy) and anus with a permanent bowel bag (ileostomy).
- Removal of the colon and back passage all in one surgery (proctocolectomy) with the same three options of having:
 - i. either a J-pouch,
 - ii. or a continent ileostomy (Kock pouch),
 - iii. or permanent ileostomy.
- In some very specific circumstances, it may not be necessary to remove the back passage (rectum) and this then gives the option of joining the small bowel (ileum) directly to the top of the back passage (rectum) in an operation called ileo-rectal anastomosis.

A temporary ileostomy may be needed when an ileoanal J-pouch is made and this will need to be closed (reversed) at a later surgery to put the bowel back in circuit.

About the 2017 Pouch Report

What is the ACPGBI?

The Association of Coloproctology of Great Britain & Ireland is a professional group of mainly surgeons, but also nurses and other healthcare workers, who look after people with problems with their bowels & bottoms. ACPGBI is a registered charity.

Number of patients

The 2017 Pouch Report includes data on over 5,000 patients who have had pouch surgery under the care of around 150 surgeons.

Where pouch surgery took place

The Pouch Registry mostly includes information on patients from throughout the British Isles, but also includes data on patients who have had surgery in 4 centres throughout Europe.

Period of time covered

The Pouch Report looks at what has happened to patients having pouch surgery over the past 40 years.



How soon do patients have pouch surgery?

About 1 in 2 patients who have pouch surgery for colitis will undergo surgery within 3 years after first diagnosis.

How old are the patients?

Although mostly adults have pouch surgery, the Pouch Report includes children and teenagers.

What about use of biological therapy?

Biological treatment for ulcerative colitis is increasingly common before a patient has pouch surgery.

Is an ileostomy always necessary?

Currently three quarters of patients will have a temporary ileostomy at the time of pouch surgery. Some surgeons think this is not routinely necessary in all patients.

What is the commonest journey to pouch surgery?

The commonest current surgical pathway is initial colectomy followed by planned pouch surgery.

Do things go wrong?

Complications occur in about 1 in 5 patients, but may be decreasing slightly. 1 in 17 patients will need an early second operation to sort out a complication.

What technique is most used?

The stapled J-pouch is currently by far the most common technique used for pouch construction.

What about keyhole surgery?

Keyhole (laparoscopic) surgery is currently used for pouch surgery in 1 in 3 patients.

Do patients need to go back into hospital?

1 in 4 patients will need to be readmitted to hospital with problems within a month of having pouch surgery.

What about revision surgery?

1 in 4 patients who have re-do pouch surgery have it within just one year of initial pouch surgery. Re-do pouch surgery is challenging and 1 in 3 of patients will have complications.

How do we make things better for future patients needing pouch surgery?

Training the new generation of pouch surgeons requires focus in terms of directing trainees to high-volume and high-quality specialist centres.

Contributing data to the **Pouch Registry** about patients having pouch surgery should be seen as a **quality marker** for a good IBD surgical unit.

The place for **alternatives to pouch surgery** including ileo-rectal anastomosis and continent ileostomy (Kock pouch) needs to be explored further.

The **long-term functional outcomes** that may be expected by most patients should be better described. Even more importantly, there is a real need to establish how having a pouch impacts on **quality of life**.

An institution's **experience of pouch surgery** depends on more than just the surgeons carrying out pouch surgery. All other **services that support pouch patients**, including gastroenterology, radiology, pathology, specialist nursing and even surgical colleagues who may not be specialised in pouch surgery, need to be part of an integrated service to provide support for pouch patients.

Centres that only occasionally carry out pouch surgery need to be sure that their **outcomes are satisfactory**.

Quality improvement programmes in pouch surgery should focus both on managing re-admissions and **avoiding potentially unnecessary re-admissions** through specialist nursing involvement and good follow-up in the community after leaving hospital.

If you are interested in research into bowel disease, or would like to make a donation, please do consider supporting the **Bowel Disease Research Foundation**.

Sources for further information:

- <http://pouch.iasupport.org/>
- <https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease/publications/surgery-for-ulcerative-colitis>
- <https://www.acpgbi.org.uk/research/audits/#ileal-pouch-registry>
- <https://www.acpgbi.org.uk/patients/conditions/ulcerative-colitis/>
- <http://www.bdrf.org.uk/>



ACPGBI and the Pouch Registry

IBD Clinical Advisory Group

The Inflammatory Bowel Disease Clinical Advisory Group was established by ACPGBI in 2015 as a multi-disciplinary committee to provide guidance on all areas relating to Inflammatory Bowel Disease (IBD). The committee currently consists of the following members, many of whom have contributed personal views to this report:

Mr Austin Acheson	Research & Audit Committee Representative (IBD Lead)
Prof. Steven Brown	Chair of IBD CAG
Ms Elaine Burns	Dukes Club (Trainee) Representative
Mr Scott Clifford	IA (The ileostomy & internal pouch Support Group) Representative
Mr Justin Davies	Elected IBD Subcommittee Member
Prof. Malcolm Dunlop	Elected IBD Subcommittee Member, Scottish Representative
Mr Omar Faiz	IBD Subcommittee Chair
Miss Nicola Fearnhead	Honorary Secretary of IBD CAG
Mr Nader Francis	Education & Training Committee Representative
Mr Richard Guy	Elected IBD Subcommittee Member
Dr Jimmy Limdi	British Society of Gastroenterology IBD Representative
Mr Charles Maxwell-Armstrong	Multi-disciplinary Clinical Committee Chair
Ms Maria Pettman	Association of Coloproctology Nurses Representative
Mrs Jenny Pipe	ACPGBI Patient Liaison Group Representative
Mr Thomas Pinkney	Elected IBD Subcommittee Member
Prof. Peter Sagar	ACPGBI Council Representative
Mrs Helen Terry	Crohn's and Colitis UK (CCUK) Representative
Ms Azmina Verjee	ACPGBI Patient Liaison Group and CCUK Representative
Mr Gethin Williams	Welsh Representative
Mr Guy Worley	Trainee, IBD Subcommittee
Mr Graeme Wilson	Elected IBD Subcommittee Member, Scottish Representative

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About the Pouch Registry

The Pouch Registry was originally established in the mid-2000s by Prof. John Nicholls with the aim of reporting outcomes after ileoanal pouch surgery. The first report with combined data from ten units on long-term outcomes of pouch surgery between 1976 and 2006 was published in 2010¹.

The Registry was re-launched in 2010 with a £10,000 grant to Prof. Paris Tekkis from the Bowel Disease Research Foundation. The database was then established on a Dendrite web-based platform under the guidance of Dr Peter Walton, Managing Director of Dendrite Clinical Systems. The Dendrite team administer the database on a day-to-day basis. Mr Richard Lovegrove, Ms Elaine Burns and Mr Guy Worley have all contributed to curation of the Registry since that time.

Oversight and governance of the Registry are now managed by Mr Omar Faiz as Clinical Lead for the Registry. The ACPGBI Inflammatory Bowel Disease (IBD) Subcommittee provides clinical input into running the Registry. Financial and governance oversight are provided by the ACPGBI multi-disciplinary IBD Clinical Advisory Group chaired by Professor Steven Brown.

The First Ileal Pouch Report was successfully published as a hard copy document in 2012. Announcement of this first Pouch Report provided an impetus to clinicians uploading details. 1,770 historical pouch cases were added to the database in July 2012 just prior to the closing date for inclusion in the first report.

The IBD Standards generated through a collaboration of patient support groups and professional associations, including ACPGBI, and published by the Royal College of Physicians include the recommendation:

Given the specialist nature and low volumes of pouch surgery performed, it is essential that all pouch surgery outcomes are captured within the national pouch registry. The UK IBD audit must continue to work alongside the pouch registry to monitor this important area of IBD care.

The National Institute for Clinical Excellence (NICE) quality standard 81 on IBD published in February 2015 stated:

People having surgery for inflammatory bowel disease have it undertaken by a colorectal surgeon who is a core member of the inflammatory bowel disease multi-disciplinary team.

In consequence, the ACPGBI Council voted in 2015 to continue financial support for the annual running costs of the Pouch Registry and for a Second Pouch Report in 2017. A minimum data set was agreed and implemented. As part of their 60th anniversary celebrations, IA (The ileostomy & internal pouch Support Group), kindly offered to cover annual running costs of the database from 2016 and contribute to the costs of this second report.

Once again, the advent of a report has encouraged participation in the Registry with 2,146 patients-records entered in the six months prior to the deadline for data entry for this report. It also includes a significant data contribution from Scotland for the first time, with the support of Prof. Malcolm Dunlop and Mr Graeme Wilson, who are both current members of the IBD Subcommittee.

This Second Pouch Report includes data on 5,352 pouch operations carried out for 5,248 patients, and concentrates on outcomes from the minimum dataset during the 5 years since the last report. The success of the Pouch Registry is ultimately due to the willingness of clinicians to contribute data on their patients, and is a tribute to our profession that surgeons are prepared to do so, for the benefit of patients, and in the face of increasingly competitive demands on their time.

1. Tekkis PP, Lovegrove RE, Tilney HS, Smith JJ, Sagar PM, Shorthouse AJ, Mortensen NJ, Nicholls RJ. Long-term failure and function after restorative proctocolectomy - a multi-centre study of patients from the UK National Ileal Pouch Registry. *Colorectal Disease*. 2010; **12**(5): 433-41.

The patient's view

Julia Spanswick, IA Patient Representative

At 25 I was diagnosed with ulcerative colitis and for the next four years I struggled with the disease. After time, there was discussion of a stoma and as I became more unwell the decision was made. I was soon to be married and told my husband-to-be that I would understand if he felt the need to leave. Thankfully he was totally supportive and we married nine months later, with my stoma in place. I was full of life and loving it. A far cry from the earlier days of surgery struggling to get my head around it.

I discussed J-Pouch surgery with my surgeon and my family thinking why should I go through surgery again and risk having to sit on the loo all the time when, for the first time in years, I was in control. A year on, I had a J-Pouch formed and once it was working I spent quite a bit of time on the toilet. My memories of living with UC came back to haunt me. Eventually I learned to hold that urge to go and worked on my sphincter muscles and it worked: I go to the toilet on average 2 or 3 times a day.

Eight months after J-Pouch surgery I fell pregnant. My obstetrician kept a very close eye on me as he was aware of my pouch and potential complications. It was decided that I would have a C-section.

Towards the end of my pregnancy I did have a bit of difficulty draining the J-Pouch, so a C-section was performed at 38 weeks. All went well with my daughter's birth and over two years later my son arrived.

My J-Pouch has been terrific and I have great control. I have had to have my tail end stretched twice, as it narrowed, so I now use a rectal dilator twice a week to stop any future narrowing.

IA (The ileostomy & internal pouch Support Group) supported me with another patient to talk to during my darkest time and now I am a visitor for IA so that I can help others. My J-Pouch has been so successful because I built my health back up and remained healthy, active, and maintained a positive attitude.

The patient's view

Kenny Graham, IA Patient Representative

I had been experiencing bowel problems, on and off, since a bad bout of gastroenteritis in 1991. The frequency to empty the bowel increased over time and it wasn't until 2003 when I was hospitalised that I was eventually diagnosed with UC. For the following nine years, the disease was controlled until a nasty flare resulted in the need for surgery. I had very mixed emotions; concern and fear being two, but these were outweighed by the prospect of illness coming to an end. I remained positive with a stoma knowing that J-pouch surgery was ahead but for now, in control, I made the most of it.

Beyond my family, I have two passions in life; the countryside and music. I took up walking again and living in Scotland, climbed several Munros and walked many hills. If I wasn't walking, I was travelling to concerts both in and out of the UK seeing some of my favourite artists.

Whilst further surgery was ahead I was becoming more comfortable with the stoma. In 2016 I had a J-pouch formed. My recovery was challenging due to suffering post-operative ileus followed by high stoma output resulting in dehydration and a further hospital stay. I continued my love of walking, however just remembering to take it a bit easier and experience the peace and tranquillity of areas closer to home.

With my J-pouch finally live in September 2016, recovery was much smoother and I was soon back to work. It felt strange with bowel function again but frequency was still only 5-6 times daily so soon after surgery. As a relatively new pouch owner, I have been monitoring the impact of different foods, learning how to manage what I believe to be wind and the odd bout of 'butt burn' following an enjoyable glass of white wine.

After my final surgery and being signed off by my surgeon, I found it quite an emotional moment given the 25 year journey I'd been on. I have been lucky to receive information and support from IA (The ileostomy & internal pouch Support Group) speaking to many who have walked before me. I also use my experience through IA listening to and reassuring others who are suffering the same issues that life can improve.



An introduction to pouch surgery

The concept

The concept behind pouch surgery is to create an ileal reservoir that can mimic the mechanical storage function of the rectum. As such, pouch surgery affords many patients the choice of restoration of intestinal continuity rather than a permanent ileostomy. The decision whether to undergo pouch surgery is complex and involves the surgeon and the multi-disciplinary team understanding which options patients may prefer, and importantly those to which they may be best suited, and then advising in the patient's best interests.

The history

Restorative proctocolectomy (RPC) was pioneered in the 1970s by two British surgeons: Sir Alan Parks and Prof. John Nicholls. Prof. Nils Kock from Sweden had previously innovated a continent ileostomy in the 1960s. The Kock ileostomy involves the formation of an ileal reservoir that is sited immediately beneath the abdominal wall and may be emptied voluntarily through use of a tube inserted into the ileostomy by the patient. In recent years, the continent ileostomy has been applied much less frequently with surgeons and patients opting instead for RPC, otherwise known as ileo-pouch-anal anastomosis (IPAA).

The diseases

The principal diseases for which pouch surgery is undertaken are Ulcerative Colitis (UC) and Familial Adenomatous Polyposis (FAP). In UC there are three principal indications for surgery: severe acute colitis, chronic colitis that is refractory to medical therapy and dysplastic or neoplastic change. Ileal pouch surgery for polyposis is undertaken less frequently than for UC. Many patients with FAP where the rectal polyp burden is low can be safely managed with total colectomy and ileo-rectal Anastomosis (IRA). As such there are three principal indications for pouch surgery in FAP: heavy colonic and rectal polyp burden in FAP known carriers, excessive rectal polyp burden (or polyps not amenable to endoscopic management) in patients who have previously undergone total colectomy and IRA, and symptomatic patients who are new polyposis diagnoses but have already developed cancer.

The technique

IPAA is carried out at the time of either full proctocolectomy or proctectomy (in those who have undergone prior subtotal colectomy). An ileal reservoir is then fashioned and anastomosed to the anus. A number of ileal pouch configurations have been used including the J-, W- and S-pouch reservoirs. Overall, the J-pouch remains the most commonly used variety. The anastomosis between the pouch and the anus can be performed either as a stapled anastomosis or be hand-sewn following mucosectomy. Stapled anastomosis using a linear stapler across the rectum at the level of pelvic floor followed by a circular stapler between pouch and anus is the most commonly applied technique.

New advances

In recent years, enthusiasts for minimal access surgery have undertaken restorative proctectomy and proctocolectomy employing laparoscopic techniques. In most cases these represent multi-port approaches, but some surgeons have applied single-incision techniques. In addition, one very recent innovation has been the retrograde dissection of the rectum using transanal approaches. The latter employs insufflation with the use of trans-anal minimally invasive surgery (TAMIS). The double purse-string anastomosis that accompanies the trans-anal technique may offer a robust join as well as a reliable method for achieving a consistent level to the anastomosis.

The morbidity

The morbidity associated with pouch surgery has to be considered in context. The disease modifying element of the surgical intervention is brought about through the excision of the diseased bowel. Restoration of continuity (*i.e.*, construction and anastomosis of a pouch) is optional. As such, major morbidity brought about through the pouch component of the surgery is an important consideration. Evidence suggests that for most patients (80-90%) undergoing pouch surgery a successful outcome is achieved. A significant minority of patients will, however, experience some temporary complication(s). The latter include peri-operative problems such as wound sepsis and early stoma-related problems. In a small proportion of patients a serious complication will be encountered. Pelvic sepsis, arising from an anastomotic leak, represents a serious complication and accounts for approximately half of all cases of ultimate pouch failure.

Pouch failure is defined by a failure to ever reverse a defunctioning ileostomy created at the time of pouch surgery, subsequent defunctioning of a failing pouch or pouch excision and a permanent ileostomy. While pelvic sepsis is the major cause, mechanical, inflammatory and functional causes account for the remainder of the cases of pouch failure. The literature suggests that pouch failure over the long term is between 10 and 15%.



Pouch surgery then and now

Professor R John Nicholls, Professor of Colorectal Surgery, Imperial College, London and Emeritus Consultant Surgeon, St Mark's Hospital, London

Restorative proctocolectomy was first introduced at the end of the 1970s and has transformed the treatment of ulcerative colitis and familial adenomatous polyposis. At the beginning surgeons were concerned with the assessment of the initial clinical results. During the next few years technical modifications were made to the type of pouch and the ileoanal anastomosis. Pouchitis was defined and as time went on the late results including function and failure rates were reported. In the last ten years minimally invasive surgery has been increasingly applied to pouch surgery with no difference in morbidity or failure compared with open surgery. Further technical modifications of the ileoanal anastomosis are currently being studied.

Restorative proctocolectomy restores the colitic patient to health with satisfactory anal function in about 80% of cases. Over the last forty years it has been established that female fertility is reduced by about 50% and pouchitis and other complications are more common in patients with Crohn's disease and sclerosing cholangitis. The operation should not be performed in acutely ill patients for whom a colectomy and end-ileostomy with preservation of the rectal stump should be carried out. Medical treatment has changed out of recognition over the last twenty years and its influence on surgery is being defined. The concern is whether immunosuppression by biologicals increases the chance of septic complications.

Among the most important developments over the last forty years has been the establishment of systems aimed to improve the quality of treatment. These include the establishment of the IBD multi-disciplinary team and various databases. National databases have revealed variation in the results of the operation and have indicated that restorative proctocolectomy is preferably done in specialist IBD centres with high activity. Registries have been shown to improve results. The Ileal Pouch Registry supported by the Association of Coloproctology of Great Britain & Ireland moved to Dendrite Clinical Systems in 2010. The Registry includes over 5,000 patients. Very encouragingly the Registry has received submissions from four units outside the United Kingdom and has the potential to become an international repository for the results of pouch surgery. It is vital that this is expanded.

Overview of ileoanal pouch surgery from SWORD

Regional data from SWORD

Data on 1,908 pouch operations carried out in England over the last 5 financial years (April 2012 to March 2017) have been provided from SWORD. The following table gives the breakdown according to regional area in England.

Table 1.01 Ileo-anal pouch surgery data from SWORD: financial years 2013-2017

		Metrics from SWORD				
Region		Operation count	Laparoscopic surgery rate	Average stay / days	30-day re-operation	30-day re-admission
	East Midlands	182	15.4%	8.4	10.6%	31.3%
	East of England	160	39.4%	10.1	3.8%	30.6%
	London	369	37.7%	11.2	4.6%	26.1%
	North East	177	53.1%	8.9	8.0%	27.3%
	North West	161	23.0%	10.9	3.1%	21.0%
	South Central	189	38.1%	8.6	3.7%	25.4%
	South East Coast	102	43.1%	10.2	5.8%	31.1%
	South West	200	33.0%	10.4	7.5%	30.8%
	West Midlands	159	37.1%	9.9	6.8%	26.5%
	Yorkshire & Humber	209	23.9%	10.9	6.7%	26.2%

Comparisons with SWORD on Pouch Surgery

Miss Nicola Fearnhead, Consultant Colorectal Surgeon, Addenbrooke's Hospital, Cambridge

The Surgical Workload Outcomes Audit Database (SWORD) hosts web-based audit tools constructed from administrative data from Hospital Episode Statistics (HES). ACPGBI has commissioned and helped build a module examining volume and outcomes from pouch surgery in England (as HES data are only used in England). HES data have improved in accuracy in recent years due to increasing use for financial reimbursement in the NHS.

The introduction of SWORD has allowed scrutiny of pouch surgery activity in England with reasonable confidence about volume of cases, indications for surgery and surgical approach in both adults and children on an annual basis since 2009. Outcomes include average length-of-stay, 30-day re-admission and re-operation rates, with funnel plots available to allow comparisons among institutions.

The current Pouch Report concentrates on the financial years ending 2013 to 2017. For the same period, SWORD includes 1,908 patients (1,794 adults and 114 children under 18 years) undergoing pouch surgery in England alone as compared to this Registry, which includes just 1,291 patients across all nations in the British Isles and several major European centres. While there has been much enthusiasm for including patients in the Registry in anticipation of this Report, participation is voluntary and so case ascertainment falls far short of actual numbers.

The average number of pouches performed *per* English institution in the five years 2013 to 2017 is 15.3 (range 1 to 159) or just 3 *per annum*. Of 125 institutions offering pouch surgery in England in the past 5 years, just 5 carried out 10 or more pouch procedures on average each year. In contrast, 107 institutions carried out less than 5 pouches *per* year. Just under 400 surgeons carried out pouch surgery in England during this 5-year period, of whom over a quarter performed just one pouch operation.

Perhaps the time has come to concentrate institutional and individual experience of pouch surgery in fewer centres with the specific aim of improving patient outcomes through optimal patient selection, best surgical technique and proactive management of complications, as well as training the next generation of pouch surgeons?

Fig. 1.01

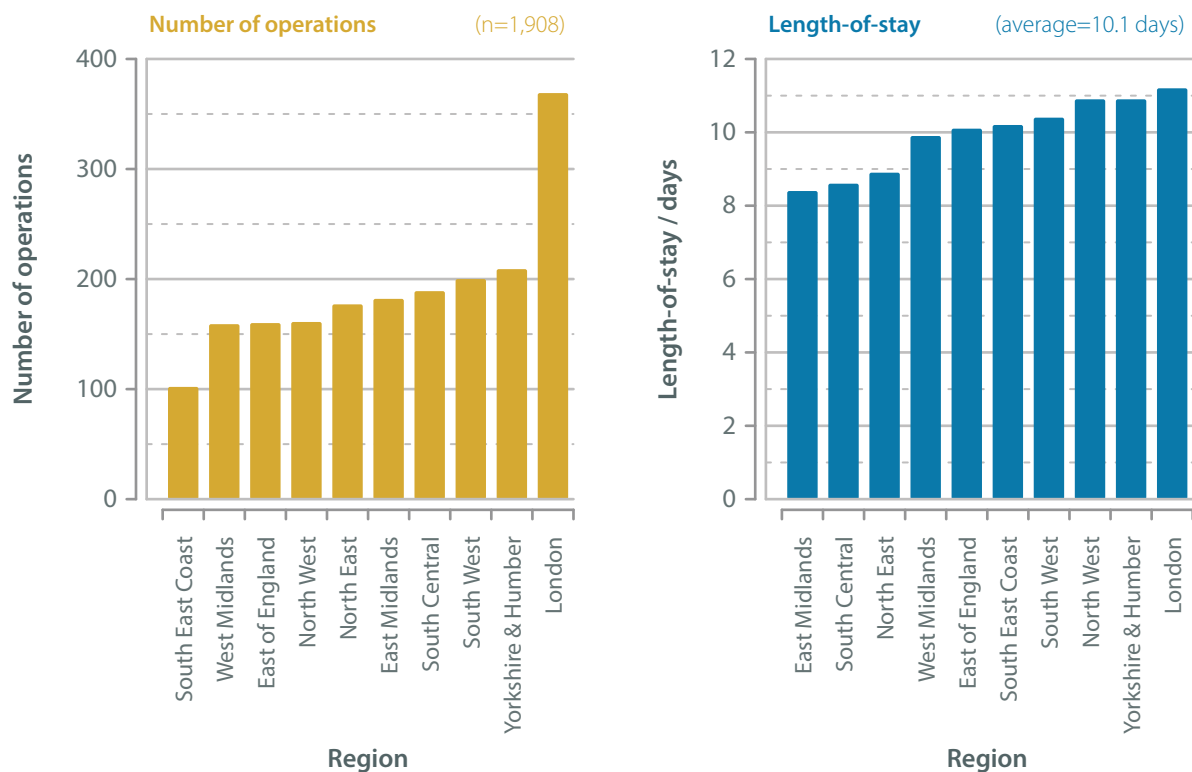
Data from SWORD: Basic information; region by region; financial years 2013-2017

Fig. 1.02

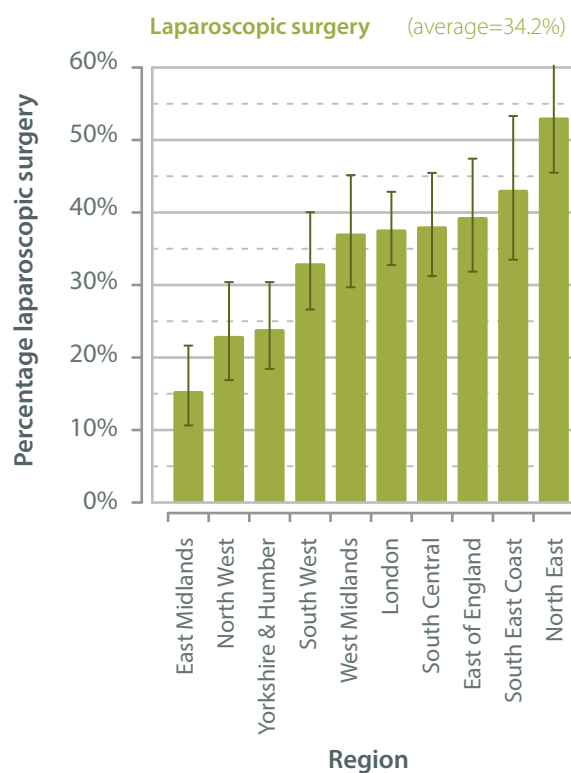
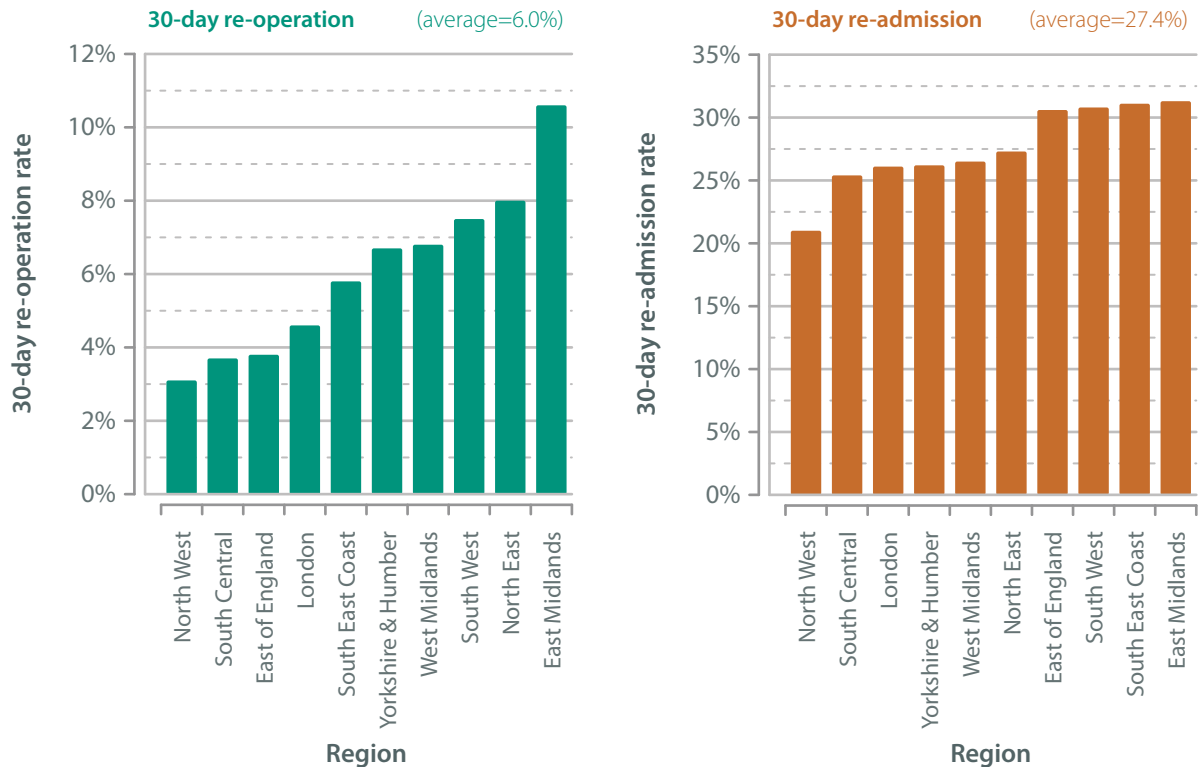
Data from SWORD: Laparoscopic surgery rates; region by region; financial years 2013-2017

Fig. 1.03

Data from SWORD: Complications; region by region; financial years 2013-2017

Regional data on pouch surgery demonstrate that most regions in England have carried out around 150 to 200 pouch procedures in the past five years. Not surprisingly, more procedures were carried out in London, which includes 159 patients who had surgery at St Mark's Hospital, Harrow.

The laparoscopic-assisted approach is used in about a third of pouch operations. Length-of-stay is remarkably constant across regions with the national average at just over 10 days. This is perhaps not surprising given the complexity of pouch surgery.

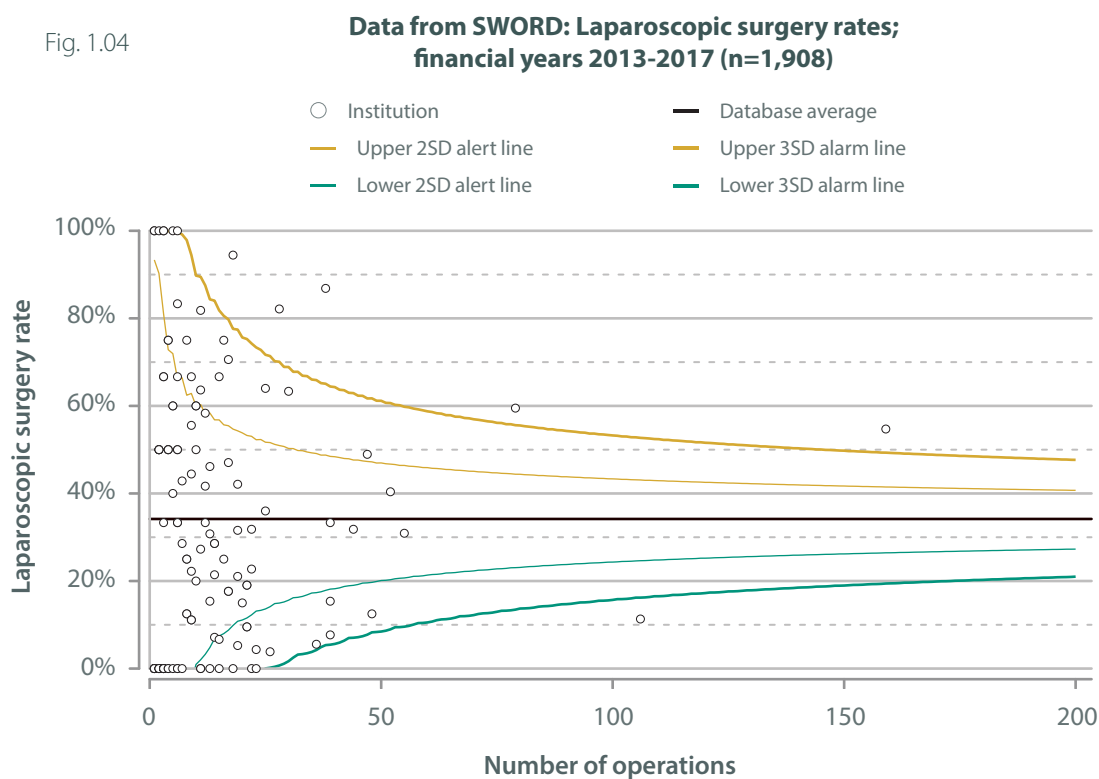
Re-operation rates vary across regions with the highest re-operation rate reported at just over 10% and a national average of 6%. Re-operation rates should ideally be low but definitely not zero, as proactive management of complications or potential complications after pouch surgery may well result in improved salvage and better long-term outcomes. Untreated pelvic sepsis is unfortunately a potent predictor of pouch failure in the medium-term.

Perhaps the most unexpected finding from SWORD is the 27.4% 30 day re-admission rate after pouch surgery. Morbidity from pouch surgery has always been appreciable with expected complication rates of about 40%, but a re-admission rate of 1 in 4 is particularly important when it comes to counselling future patients about pouch surgery.

Institutional data from SWORD

Pouch procedures have been carried out at 126 institutions in England during the past 5 financial years. The funnel plots are anonymized with respect to institution, but show considerable variation in rates of laparoscopic surgery, length of hospital stay after pouch surgery, and 30 day re-operation and re-admission rates.

Fig. 1.04



Although it appears that there are both positive and negative institutional outliers in laparoscopy rates, this fact should be interpreted with caution, as laparoscopy rate is not necessarily a quality indicator.

Fig. 1.05

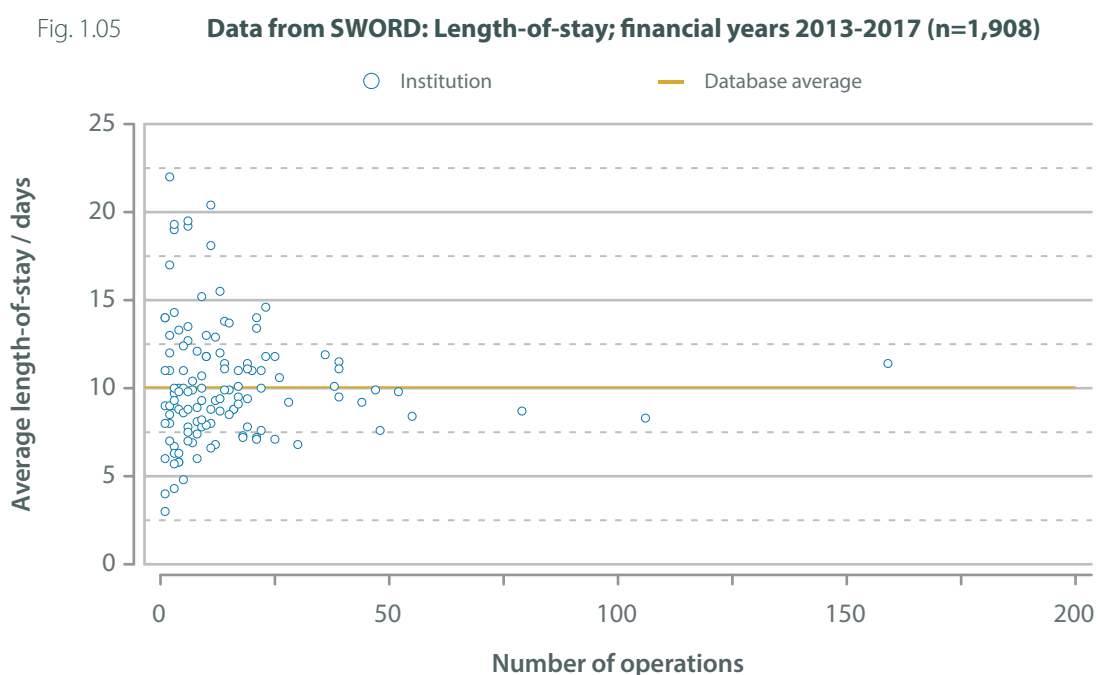
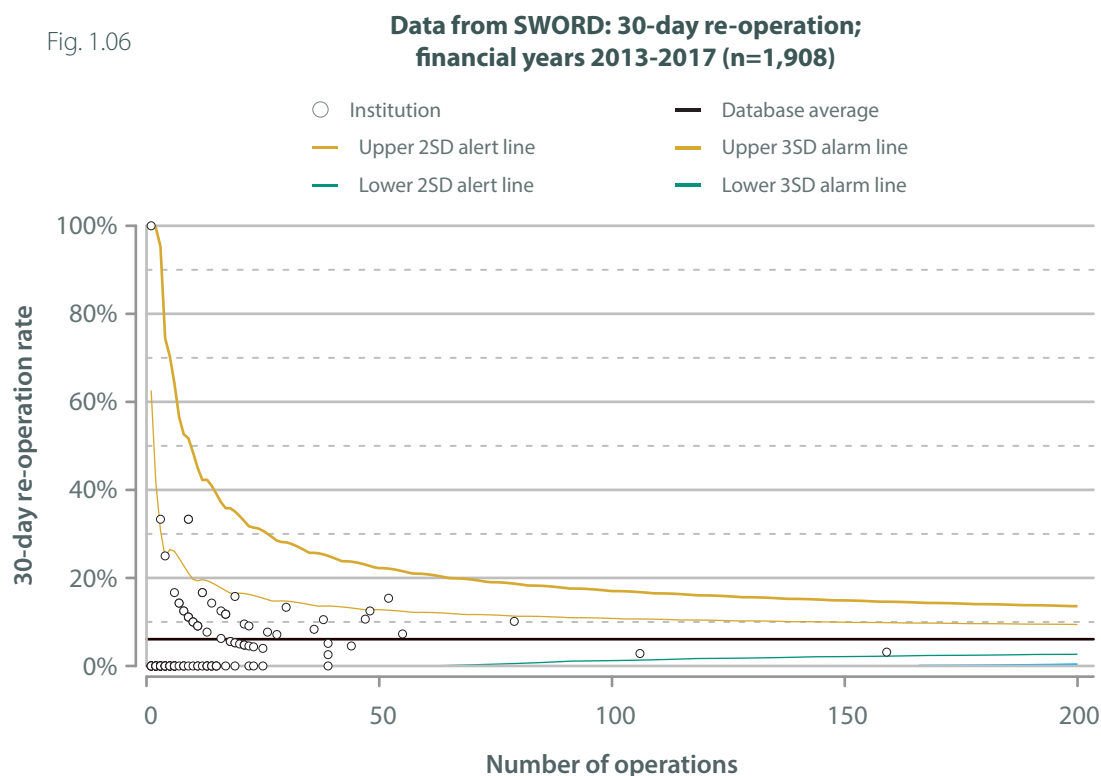


Fig. 1.06



Thirty day re-operation rates after pouch surgery

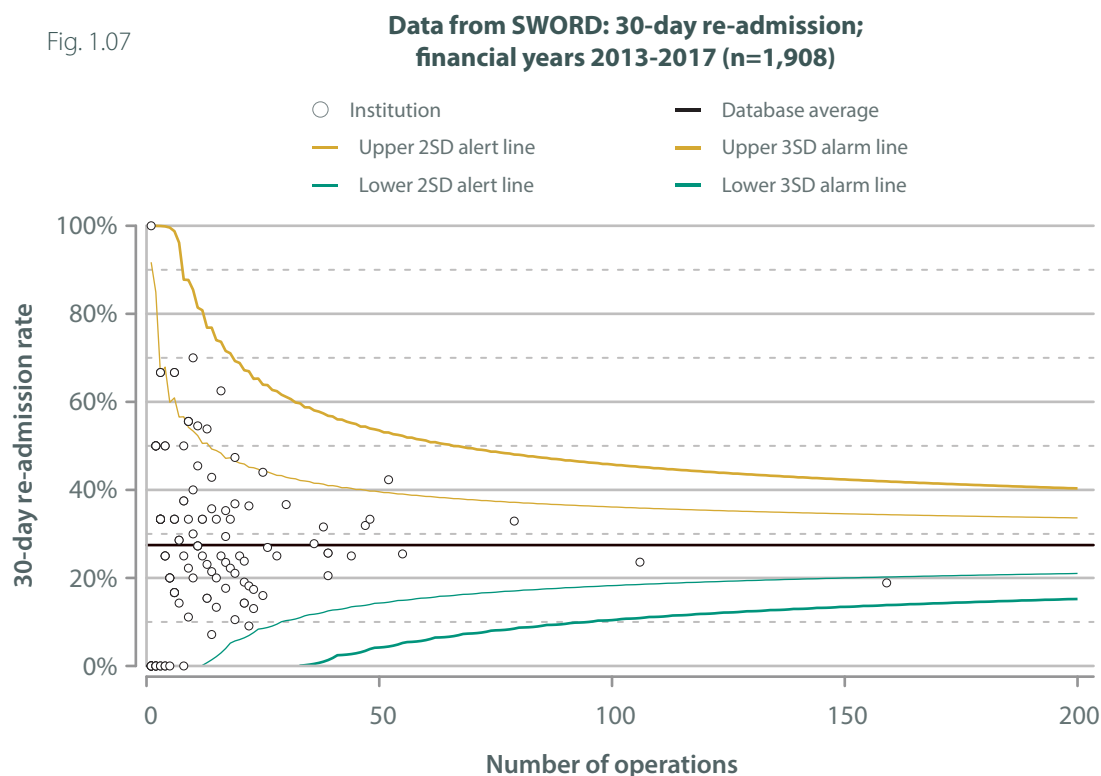
Mr Austin Acheson, Consultant Colorectal Surgeon, Queen's Medical Centre, Nottingham

The Surgical Workload Outcomes Audit Database (SWORD) is an online system that uses Hospital Episode Statistics (HES) to identify all operations performed in England. The recently developed ileoanal pouch database on the SWORD platform shows wide variation in case ascertainment throughout the country.

Thirty-day re-operation rates are available through SWORD and this data suggests that the national rate in England is 6% over the 5-year period April 2012 to March 2017. There are wide variations from region to region with some areas in England having rates of only 3% whereas others are as high as 10%. These figures are as expected and are not really surprising.

There have been concerns raised in the past that low-volume surgical centres and low-volume surgeons may have poorer outcomes particularly for complex procedures such as ileoanal pouch surgery. However, there is little evidence from current literature that this is the case. There is no evidence to substantiate this concern from SWORD re-operation rate data in that high-volume centres and high-volume surgeons have comparable and very variable 30-day re-operation rates to those who perform fewer cases. However, re-operation rates are only one important outcome measure and there is much need for an accurately maintained database that will look at all other important clinical outcomes such as pouch function / failure and other complications. Ongoing accurate collection of such outcome data through registries is crucial and must be encouraged if we are ever going to be able to answer some of these ongoing concerns.

Fig. 1.07



There is wide variation in 30 day re-admission rates after pouch surgery in England. The national average is high at 27.4% or 1 in 4 patients. Potential reasons include legitimate complications such as sepsis, early obstruction and high output stomas. It is possible though that some re-admissions are due to poor support or heightened anxiety in the community, given the relative infrequency and complexity of pouch surgery. Similarly, some re-admissions may be due to inadequate access to post-operative specialist nursing advice, as consequence of lack of resources or appropriate experience.

It is worth noting that a number of centres lie at *alert* level for 30-day re-admission rate, which is a quality indicator. Improving re-admission rates is undoubtedly a ripe target for a quality improvement initiative in pouch surgery.

The contribution of the Nurse Specialist in pouch surgery

Cheryl Hamilton and Anna Brewer, Nurse Specialists in Stoma and Pouch Care, Addenbrooke's Hospital, Cambridge

The Nurse Specialist is an essential component for the package of care provided to any patient who is considering a pouch procedure. He or she provides information and support and ensures a holistic approach to patient care that may be lacking in a busy consultant outpatient clinic.

The decision to choose between permanent ileostomy and having an ileoanal pouch is not easy for most patients. An empathetic approach to potential issues is essential. How having a pouch may impact on an individual's lifestyle both in the short- and long-term period should be explored carefully and thoroughly. Explanation of the process of surgery should be given along with details of post-operative care and long-term pouch management. Patients are offered contact with an established patient or support groups to help facilitate their decision making.

Support while in hospital is given at each stage of their pouch surgery; this would include either stoma care or pouch training. Dietary and lifestyle advice and reassurance will be provided.

Nursing care does not stop after discharge; support should continue particularly in the first few weeks after surgery where patients and community services are more anxious. Specialist nurses continue to support patients following discharge by providing expert follow-up care in the form of nurse-led outpatient clinics and telephone help lines.

Patients who are well informed and prepared at each stage of the surgery usually deal better with their surgery. The comprehensive care provided by Nurse Specialists has become central to achieving successful recovery and rehabilitation for pouch patients, thus enabling patients to have a better quality of life.

Pouch registry overview

Additions to the Pouch Registry

Contributing hospitals

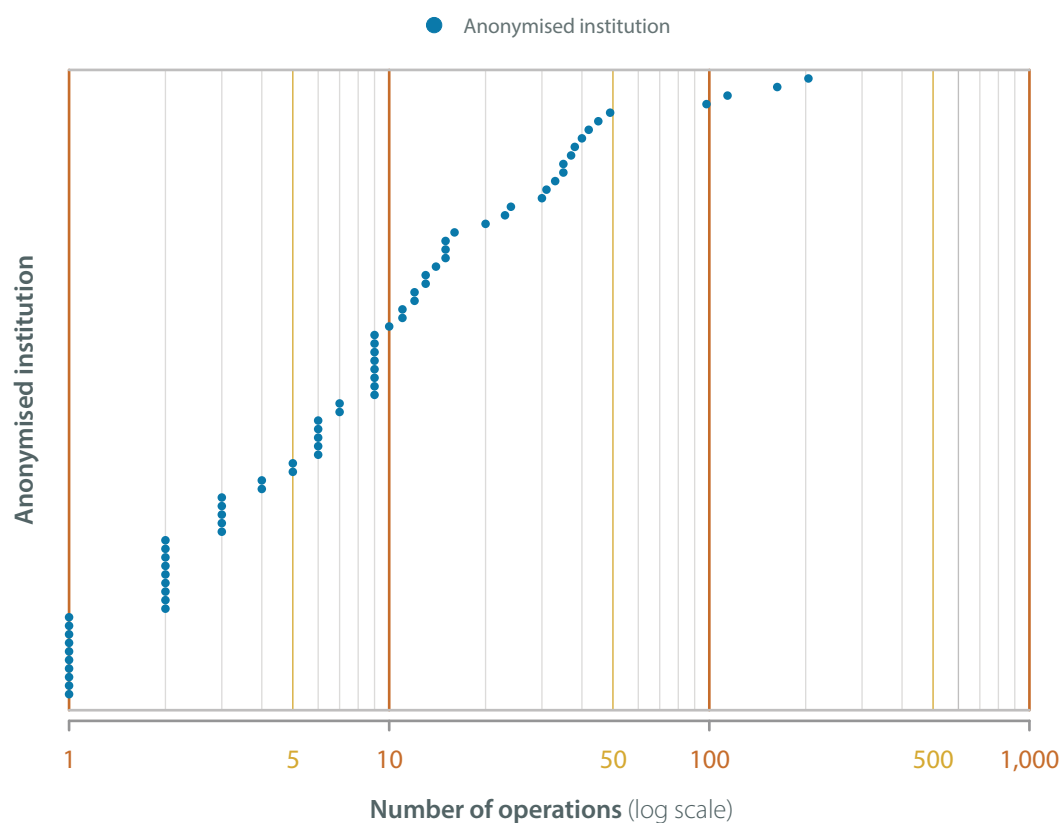
The Pouch Registry contains data on 5,352 operations carried out in 5,248 patients. The number of procedures recorded *per* institution varies between 1 and 204 over the past five years. Those institutions that have uploaded information on the most patients undergoing pouch surgery in the last 5 financial years (April 2012 to March 2017) are listed in the table below.

Table 2.01 Top ten contributor-hospitals; financial years 2013-2017 (n=1,395)

		Count of operations	Percentage of entries
Hospital	St Mark's Hospital, Harrow	204	14.6%
	Universitair Ziekenhuis Leuven, Belgium	163	11.7%
	Western General Hospital, Edinburgh	114	8.2%
	Churchill Hospital, Oxford	98	7.0%
	Royal Liverpool & Broadgreen Hospital, Liverpool	49	3.5%
	Derriford Hospital, Plymouth	45	3.2%
	Queen Elizabeth Hospital, Birmingham	42	3.0%
	Addenbrooke's Hospital, Cambridge	40	2.9%
	The Great North Children's Hospital, Newcastle	38	2.7%
	Manchester Royal Infirmary, Manchester	37	2.7%

Fig. 2.01

Number of procedures *per* hospital; financial years 2013-2017 (n=1,395)



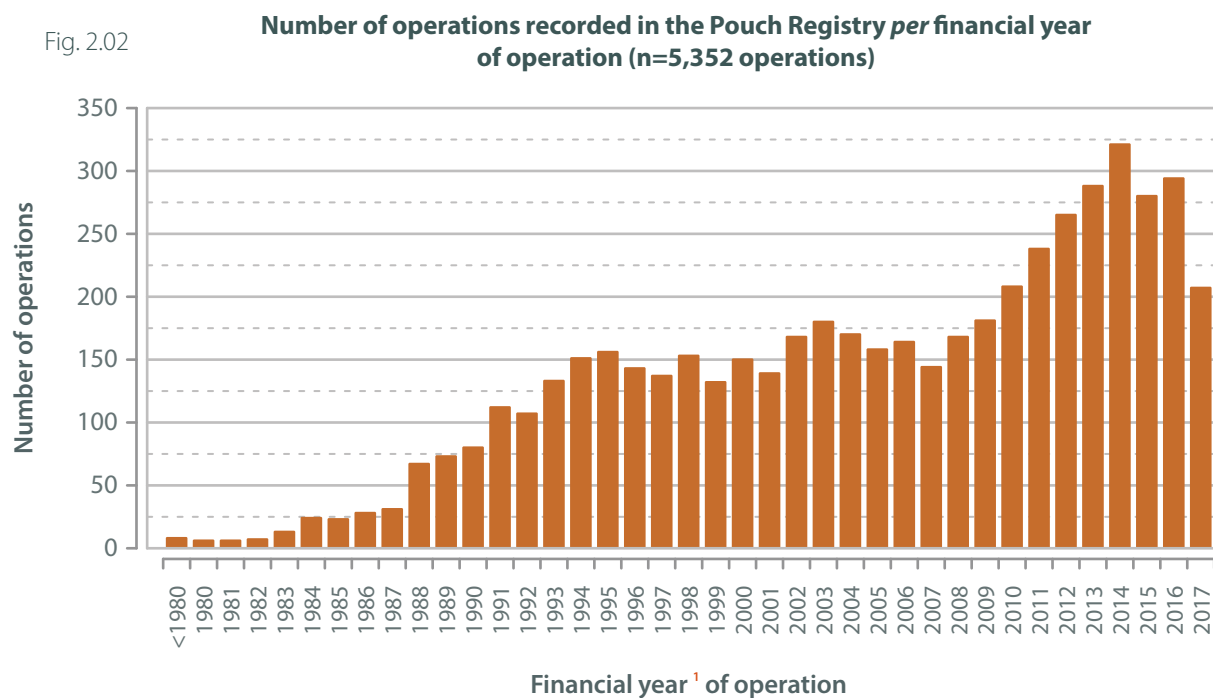
Impact of volume on outcomes

Mr Omar Faiz, Consultant Colorectal Surgeon, St Mark's Hospital, London

The decision to undertake pouch surgery is considered complex by many surgeons. Moreover, the procedure itself can be technically challenging. Gaining experience in pouch surgery is difficult as the procedure is performed infrequently across many acute NHS trusts. Overall, national English caseload approximates only 400 procedures *per year*. Hospital Episodes Statistics data suggest that in recent years the average number of pouches performed in English institutions was just 3 cases *per year* and one-quarter of the pouch surgeons undertaking this surgery had performed only one case over the last five years. As such, the question arises whether patients would benefit from fewer trusts, and fewer surgeons, undertaking pouch surgery, thereby permitting greater institutional and individual surgeon experience?

Surgical volume, or caseload, is often used as a surrogate to describe the operative experience of institutions and /or individual surgeons. In many areas of complex surgery, a clear relationship exists between the annual operative caseload carried out and surgical outcome. This volume-outcome relationship exists in many types of surgical procedures across many healthcare systems and has underpinned the call for centralisation of many services. Such a relationship has also been demonstrated in pouch surgery. Specifically, a number of countries have demonstrated that low-volume pouch providers are associated with higher rates of pouch failure than higher volume counterparts. The relationship is however complex as some low-volume institutions may achieve excellent results. Conversely not all high-volume providers are necessarily high-quality providers. As such there is a need to quantify outcome and the Pouch Registry will represent an essential tool to enable measurement of outcome against benchmarked standards.

Any decision to centralise pouch surgery must recognise that the delivery of this surgical procedure is just one component part of complex Inflammatory Bowel Disease care. The latter necessitates the expertise afforded by specialist nursing staff, gastroenterologists, radiologists and pathologists with dedication, and sufficient exposure, to IBD management. In my opinion, the ideal institution to undertake pouch surgery is one where complex IBD surgery is performed routinely. At such institutions the staff involved in the care of such patients possess the prerequisite technical and non-technical skills required to undertake pouch surgery as well as to manage the complications associated with this surgery when they arise. Lastly, such institutions should be able to demonstrate with transparency to patients and all stakeholders that outcome is of a high standard. The Pouch Registry represents a mechanism for achieving exactly this.



1. Financial years run from April to March. The 2017 data cover less than a full financial year, as data entry closed for this report prior to the year end in March 2017.

Type of operation

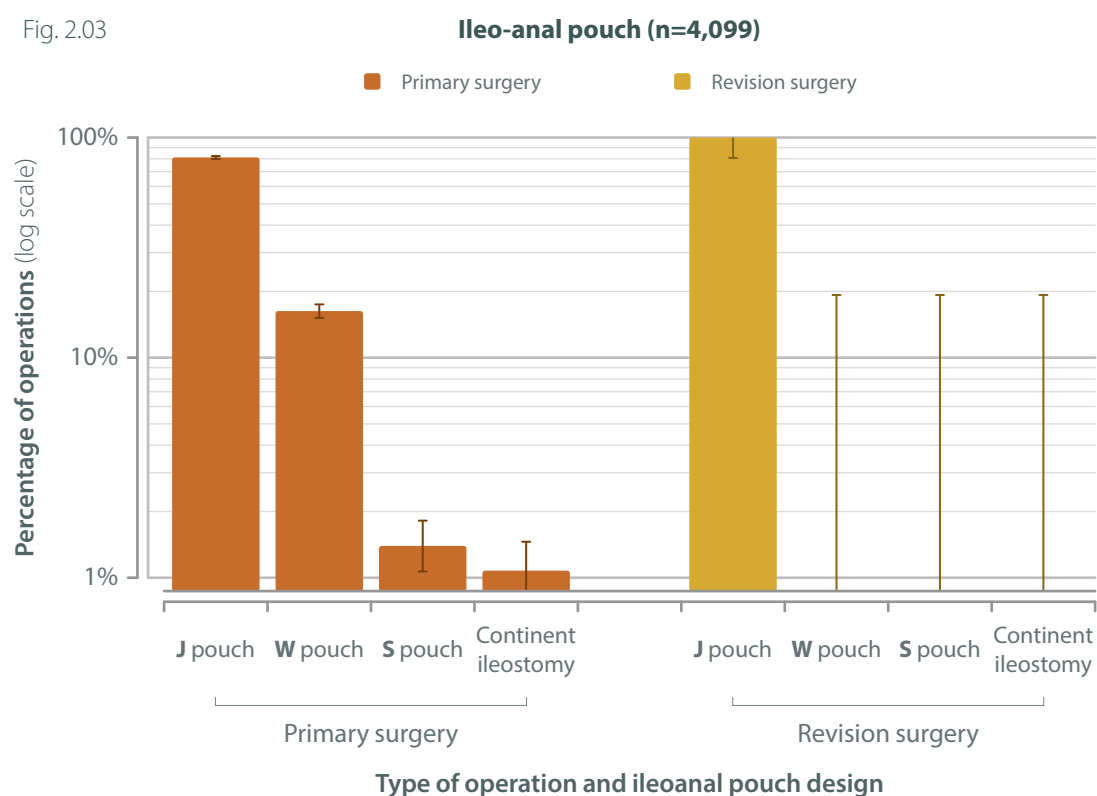
The J-pouch is by far the most common configuration of pouch used in current practice, and has largely superseded the W- and S-pouches.

Alternatives to pouch surgery in highly selected patients include the continent ileostomy (Kock pouch) and ileo-rectal anastomosis. A small but appreciable number of continent ileostomies are now included in the Pouch Registry.

Table 2.02 An overview of the procedures recorded in the registry: operation type and pouch design

	Pouch design					All
	J pouch	W pouch	S pouch	Continent ileostomy	Unspecified	
Type of operation						
Primary	3,319	665	57	44	998	5,083
Revision	14	0	0	0	243	257
Unspecified	12	0	0	0	0	12
All	3,345	665	57	44	1,241	5,352

Fig. 2.03



The continent ileostomy (Kock pouch) as an alternative to pouch surgery

Mr Richard Guy, Consultant Colorectal Surgeon, Churchill Hospital, Oxford

An ileoanal pouch is the most likely operation following proctocolectomy, but permanent end ileostomy is a valid alternative for some, avoiding anastomotic and septic complications associated with pouch failure and unpredictable pouch function. An end ileostomy brings an array of medical, surgical and social issues from which there may be no permanent relief. Ileio-anal pouch and permanent ileostomy are radically different operations for the same disease, and frustrations exist over an inadequate middle ground.

There has been renewed interest in the continent ileostomy. Popular in Scandinavia, particularly Sweden where Nils Kock pioneered his method, the Kock pouch can be a convenient reservoir fulfilling the needs of IBD patients looking for a pelvic pouch alternative. Clearly not all plain-sailing, Kock pouch durability comes at the expense of high revision rates, mainly for nipple valve failure, and perhaps this has stifled progress in the United Kingdom. But revision of an abdominal pouch is often less demanding than re-do pelvic pouch surgery, and ingenious alternatives exist for multiple revisions to maintain integrity, for which motivation of patients and surgeons is paramount. This translates into long-term durability rates exceeding those of pelvic pouches, but patients must be carefully chosen and counselled, and surgeons must only undertake this type of surgery after appropriate training. It makes sense for expertise to be concentrated in only a few centres, relying as it does on multi-disciplinary teams, particularly specialist nurses.

Success and expertise with Kock pouches comes through high-volume surgery and construction of them as alternatives to a primary pelvic pouch, rather than exclusively for failure, which has tended to be the UK position; physical and psychological consequences of surgery for failure may further serve to compromise outcome. Perhaps we should be offering more Kock pouches up-front as a genuine primary alternative to a pelvic pouch or end ileostomy?

Ileo-rectal anastomosis as an alternative to pouch surgery

Prof. Peter Sagar, Consultant Colorectal Surgeon, St James' University Hospital, Leeds

The principal aims of the surgical treatment of ulcerative colitis are to alleviate symptoms, minimise the risk of cancer and avoid the need for immunosuppressive medication. Ideally, surgical treatment should also achieve good functional outcome and a good quality of life. Although most patients opt for an ileal pouch procedure, both anoproctocolectomy with permanent ileostomy and ileo-rectal anastomosis also have their place.

Patients with minimal rectal involvement and no dysplastic change in the rectum can be considered for ileo-rectal anastomosis. However, good rectal compliance and capacity as well as normal anal sphincter function are critical for good long-term outcome. Anal function can be assessed by digital rectal examination, but any concerns about the strength of the anal sphincter are more accurately assessed by means of anal manometry. Ileo-rectal anastomosis would be contraindicated in patients with a poorly distensible rectum, severe rectal disease and poor anal sphincter function. Furthermore, ileorectal anastomosis should not be offered in patients who have colonic high grade dysplasia or cancer, due to the associated risk of further neoplastic development in the retained rectum. An exception may be patients with colitis associated colorectal cancer, with or without metastatic disease, who are considered to have a short life expectancy and wish to avoid a stoma.

Ileo-rectal anastomosis avoids significant pelvic dissection and thereby significantly reduces the risk of sexual and urinary dysfunction associated with a panproctocolectomy or ileal pouch procedure. In addition, higher fertility rates would be anticipated in female patients after ileo-rectal anastomosis, compared with either panproctocolectomy or ileal pouch. Current advice would be to consider ileo-rectal anastomosis when treating women at their reproductive age who have not yet completed their families.

It is important to advise patients about the risk of dysplasia in a retained rectum and to have a high index of suspicion of dysplasia and the risk of rectal cancer. Patients with long-standing ulcerative colitis who are unwilling to undergo surveillance should not be offered an ileo-rectal anastomosis.

In summary, whilst the ileal pouch procedure may be considered to be the optimal procedure for the majority of patients, ileo-rectal anastomosis has its merits, albeit for a small group of selected patients with ulcerative colitis.

Training in pouch surgery

Data on training opportunities are unfortunately largely missing in the Pouch Registry. The following table provides the limited information available.

Of just under 2,000 procedures where the grade of operating surgeon is recorded, only 5.8% of cases are carried out by a supervised trainee. This may reflect lack of confidence among trainers who are only carrying out occasional procedures, or lack of opportunity among trainees to be present at sufficient cases due to the relative infrequency of pouch surgery in most centres. There may also be an understandable perception among consultants that training in pouch surgery should only be reserved for trainees with a defined IBD interest.

Training needs must be addressed to ensure that there is a well-trained next generation of pouch surgeons who are skilled in the technical aspects of pouch surgery, but also in all the nuances of patient selection and counselling, and in pro-active management of complications.

Table 2.03 The grade of the surgeon

		Grade of surgeon				Derived data	
		Consultant	Trainee	Unspecified	All	Proportion trainee surgeon	Proportion missing data
Financial year ending	1992	8	2	98	108	20.0%	90.7%
	1993	14	1	119	134	6.7%	88.8%
	1994	17	1	134	152	5.6%	88.2%
	1995	21	0	136	157	0.0%	86.6%
	1996	19	2	123	144	9.5%	85.4%
	1997	11	2	125	138	15.4%	90.6%
	1998	24	1	129	154	4.0%	83.8%
	1999	16	0	117	133	0.0%	88.0%
	2000	29	0	122	151	0.0%	80.8%
	2001	22	0	118	140	0.0%	84.3%
	2002	27	2	140	169	6.9%	82.8%
	2003	40	1	140	181	2.4%	77.3%
	2004	43	7	121	171	14.0%	70.8%
	2005	64	2	93	159	3.0%	58.5%
	2006	70	8	87	165	10.3%	52.7%
	2007	71	1	73	145	1.4%	50.3%
	2008	83	7	79	169	7.8%	46.7%
	2009	82	2	98	182	2.4%	53.8%
	2010	100	2	107	209	2.0%	51.2%
	2011	131	7	101	239	5.1%	42.3%
	2012	121	19	126	266	13.6%	47.4%
	2013	137	18	134	289	11.6%	46.4%
	2014	143	11	168	322	7.1%	52.2%
	2015	146	5	130	281	3.3%	46.3%
	2016	192	7	96	295	3.5%	32.5%
	2017	158	5	45	208	3.1%	21.6%
		All	1,845	114	3,393	5,352	5.8%

Training the next generation of pouch surgeons

Prof. Steven Brown, Consultant Colorectal Surgeon, Northern General Hospital, Sheffield

Training in any aspect of surgery is challenging for the current generation. However, it is particularly acute for pouch surgery as unit volume is low in almost every UK hospital that offers the service. Of course the number of cases needed to overcome the learning curve is difficult to define, but the weak evidence we have suggests around 20. Only a handful of UK hospitals carried out 10 or more pouches in the financial year 2016, so achieving those sort of numbers as a trainee is almost impossible.

There are perhaps 3 ways to tackle this issue and ensure high-quality experienced surgeons for the future.

- Concentration of experience through tightly regulated specific IBD clinical fellowships (that include detailed trainee feedback).
- Training to continue post-consultant appointment with joint operating with a more experienced colleague.
- Centralisation of pouch surgery to create higher volume units.

Of course, volume is not necessarily the only indicator of quality training, but each of these propositions are consistent with more nebulous definers such as post-operative care, dealing with complications, including pouch dysfunction, and appropriate management of the complex pouch.

A fourth arm that ensures adequate training for the future is audit, in the form of the Pouch Registry. Those units that have engaged with the Registry have illustrated a desire for improved quality and this should be a beacon for attracting interested and talented trainees.

The trainee perspective

Ms Elaine Burns, Specialty Registrar, on behalf of the Dukes Club

Exposure to complex inflammatory bowel disease surgery during higher surgical training is *ad hoc* and sporadic.

At the end of higher surgical training, the general surgery curriculum requires the trainee to be able to perform a pouch procedure to the level of *capable of doing whole procedure but may need assistance*. Such a level does not suggest competence for independent practice. Currently, there are no indicative numbers required for pouch surgery at CCT. For the majority of trainees a further period of training will be required to achieve sufficient experience in pouch surgery to start progressing along their learning curve and operate independently.

Such training can be achieved through a post-CCT fellowship. Such fellowships should be carefully planned to allow high-volume exposure and experience in dedicated inflammatory bowel disease units. These fellowships should be tailored to those centres that can offer such training. In an ideal world, they should be credentialed and transparent. Publication of objective measures of a Fellow's experience in a training unit may allow future trainees to choose the fellowships that will meet their individual needs. We would suggest careful thought to the future workforce planning in IBD surgery and in particular pouch surgery. It would be beneficial for fellowships to meet future predicted workforce needs.

Even after completing such a fellowship, we must be aware that in the early years of a new consultant's practice two-surgeon operating should be seen in a positive light and actively encouraged by more senior surgeons and management.

Finally, to demonstrate that high-quality surgery is being offered and people can be trained safely in pouch surgery, ongoing audit is essential.

Primary ileoanal pouch surgery

Patient demographics and disease profile

Diagnosis

The commonest indication for pouch surgery is colitis with 81.4% of patients in the Pouch Registry having ulcerative colitis, and 3.7% indeterminate colitis. Familial adenomatous polyposis accounts for around 10% of patients having pouch surgery, and this figure is mirrored in the SWORD data.

Unsurprisingly, very few patients with Crohn's disease have pouch surgery. It is not possible to define if the diagnosis of Crohn's disease was made prior to, or after, pouch surgery from Registry data.

Table 3.01 Patients having primary ileoanal pouch surgery: recorded diagnosis

Diagnosis	Count		Percentage	
Ulcerative colitis	3,603		81.4%	
FAP	449		10.1%	
Indeterminate colitis	162		3.7%	
Other neoplasia	31		0.7%	
Crohn's disease	29		0.7%	
Constipation / functional	16		0.4%	
Other	134		3.0%	
Unspecified	659			
All	5,083			

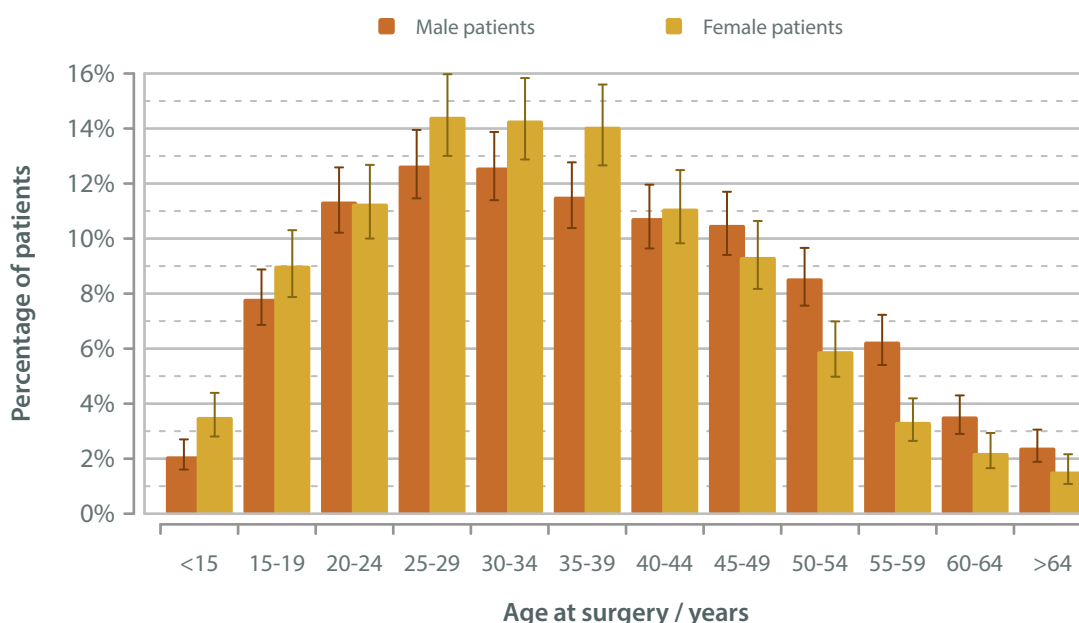
Age and gender

The majority of patients undergoing primary pouch surgery are in the third and fourth decades of life, but there are also appreciable numbers of children and adolescents in the Pouch Registry.

The distribution between the sexes is roughly even with 2,838 men and 2,230 women included.

Fig. 3.01

Primary ileoanal pouch surgery: Age and gender (n=5,047)



Pouch surgery in children

Mr Bruce Jaffray, Consultant Paediatric Surgeon, The Great North Children's Hospital, Newcastle

We know several things. The age of onset of ulcerative colitis has a bi-modal distribution, with the first peak in childhood. Approximately 20% of these children will require resection. Quantitative assessment of quality of life consistently shows that an ileal pouch anal anastomosis (IPAA) offers a better life than an ileostomy. However, most British children coming to resection do not receive an IPAA.

The reasons for the reluctance of UK paediatric surgeons to embrace restorative proctocolectomy are complex. My view is that this is largely based on the misconception that IPAA mandates use of a circular end to end anastomosis device (CEEA). Paediatric surgeons lack the experience of routine use of the CEEA for resection of rectal cancer, making the device unfamiliar. It is also technically difficult, or impossible, to apply a transverse stapler at the correct level of the top of the anus following close rectal dissection in a child.

Descriptions of everting the anus to apply a transverse stapler extra-corporeally are unconvincing.

My experience of utilising a trans-anal approach in children suggests a solution. With the patient prone, using gentle anal retraction, the mucosa is dissected within the anus to the top of the canal where the close rectal plane is entered and continues to the peritoneum. Colectomy is completed laparoscopically, which makes the deep pelvic dissection straightforward. A J-pouch is formed extra-corporeally utilising the eventual stoma wound and passed through the pelvis for a hand sutured anastomosis.

This approach leads to a low leak rate and excellent functional outcomes.

Ironically, paediatric surgeons have extensive experience of rectal resection for Hirschsprung's disease, and the approach described is essentially the same as contemporary resections for Hirschsprung's disease. Hopefully, attitudes and prejudices can change and fewer UK children will be left to cope with a stoma through childhood.

Pouch surgery in adolescents

Mr Justin Davies, Consultant Colorectal Surgeon, Addenbrooke's Hospital, Cambridge

There is no doubt that this can be done. Perhaps the more pertinent question is whether it should be done?

Some adolescents require subtotal colectomy and ileostomy for medically resistant ulcerative colitis, and we should certainly not underestimate the potential negative impact to a young person's life of living with a stoma. However, surgery for adolescents not only improves disease-related symptoms, but also allows physical growth, sexual maturation and a return to school with improved access to educational opportunities.

Once an adolescent has recovered from this initial surgery and reached these goals, there is the understandable wish to explore the option of living without a stoma. We must remember that the sole indication for pouch surgery is for the quality of life that is associated with not having a stoma.

It is my personal practice to ideally wait until adolescents have at least reached the age of 16 years, preferably 18, in order to be able to have a full and open discussion about the risks, benefits and alternatives to pouch surgery. The potential risks of impotence, retrograde ejaculation, infertility, dyspareunia, inability to orgasm and pouch-vaginal fistula, as well as other potential complications, mandate thorough discussion and appreciation. Some of these relate to themes that are largely adult in nature, and whilst a young adolescent may understand some of these issues superficially, one has to question whether there is a true and deep enough understanding to allow fully informed consent (whilst appreciating that the parents will be closely involved in these discussions). The option of ileo-rectal anastomosis in adolescents does not have a strong evidence base, but may be a consideration in this particular patient group.

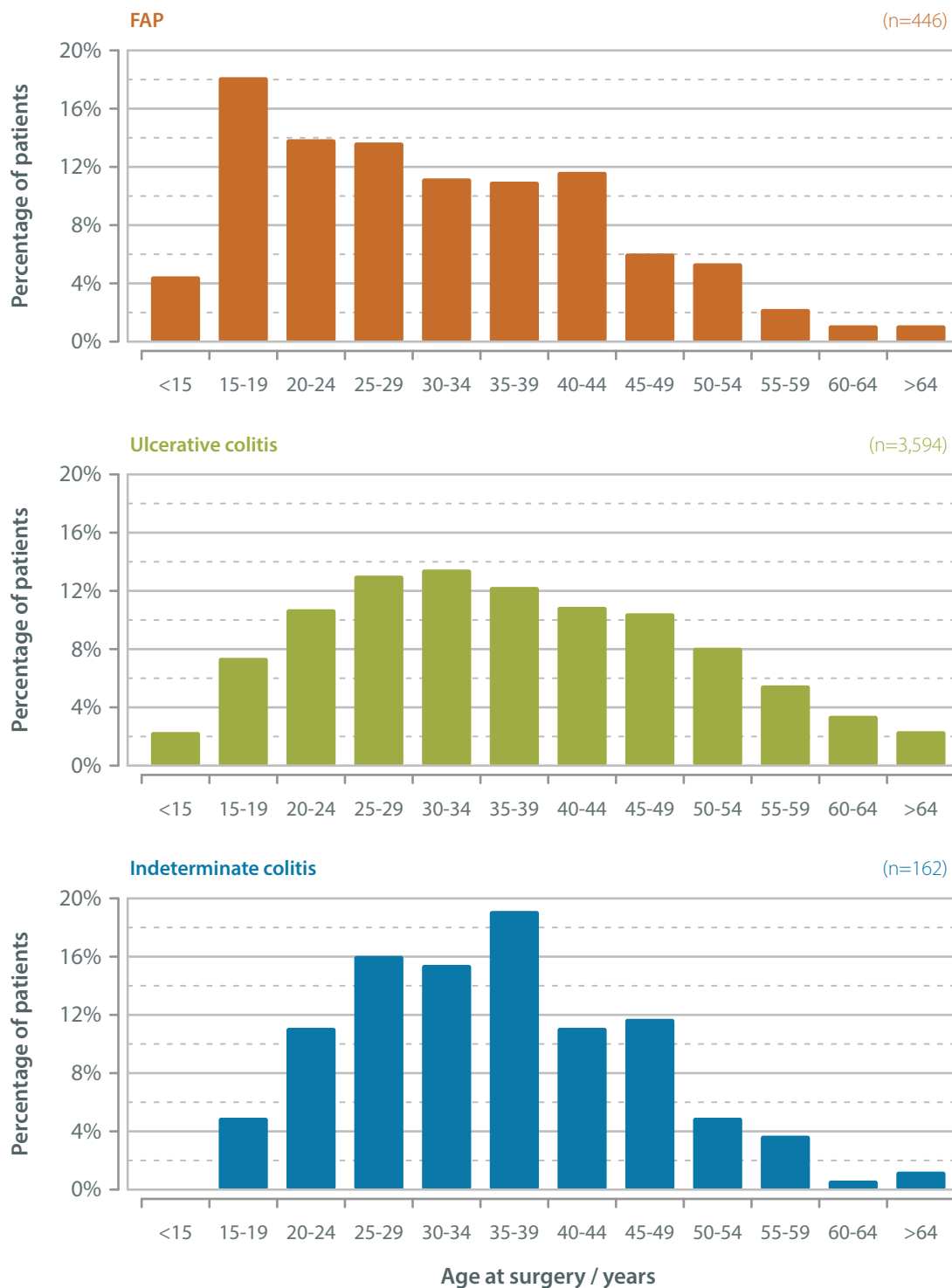
Pouch surgery in adolescents is possible, but perhaps best deferred until such a time that fully informed consent can include the patient too.

Age and diagnosis

Familial adenomatous polyposis tends to be diagnosed during adolescence, and so there is a skewed distribution towards younger age for patients undergoing pouch surgery for this indication.

There is a more normal distribution of age at time of surgery when the indication is colitis, with the peak incidence centred around the third and fourth decades of life.

Fig. 3.02 **Primary ileoanal pouch surgery: Age distributions for selected diagnoses**



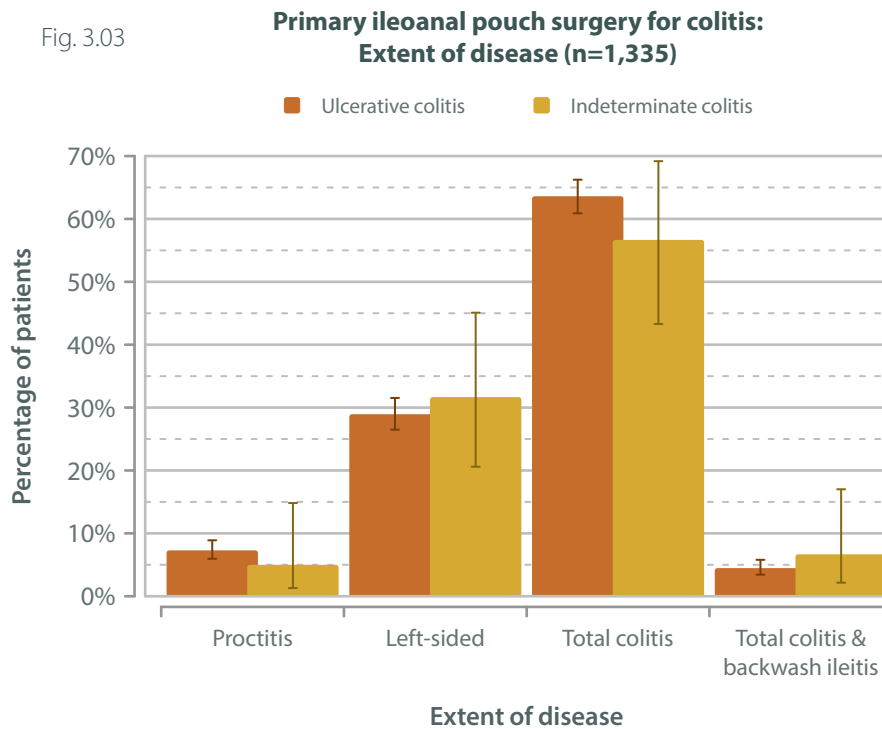
Extent of disease

Data on extent of disease is only available for around a third (35.5%) of patients with colitis.

Perhaps unsurprisingly, the vast majority of patients with colitis who subsequently undergo pouch surgery have either **pancolitis** (affecting the whole colon and rectum) or **predominantly left-sided colitis** (affecting the left colon and rectum).

Backwash ileitis only affects a minority of patients with pancolitis and, importantly, it is now well-established that this does not affect their outcomes with respect to pouch surgery.

Fig. 3.03



Time from diagnosis to surgery

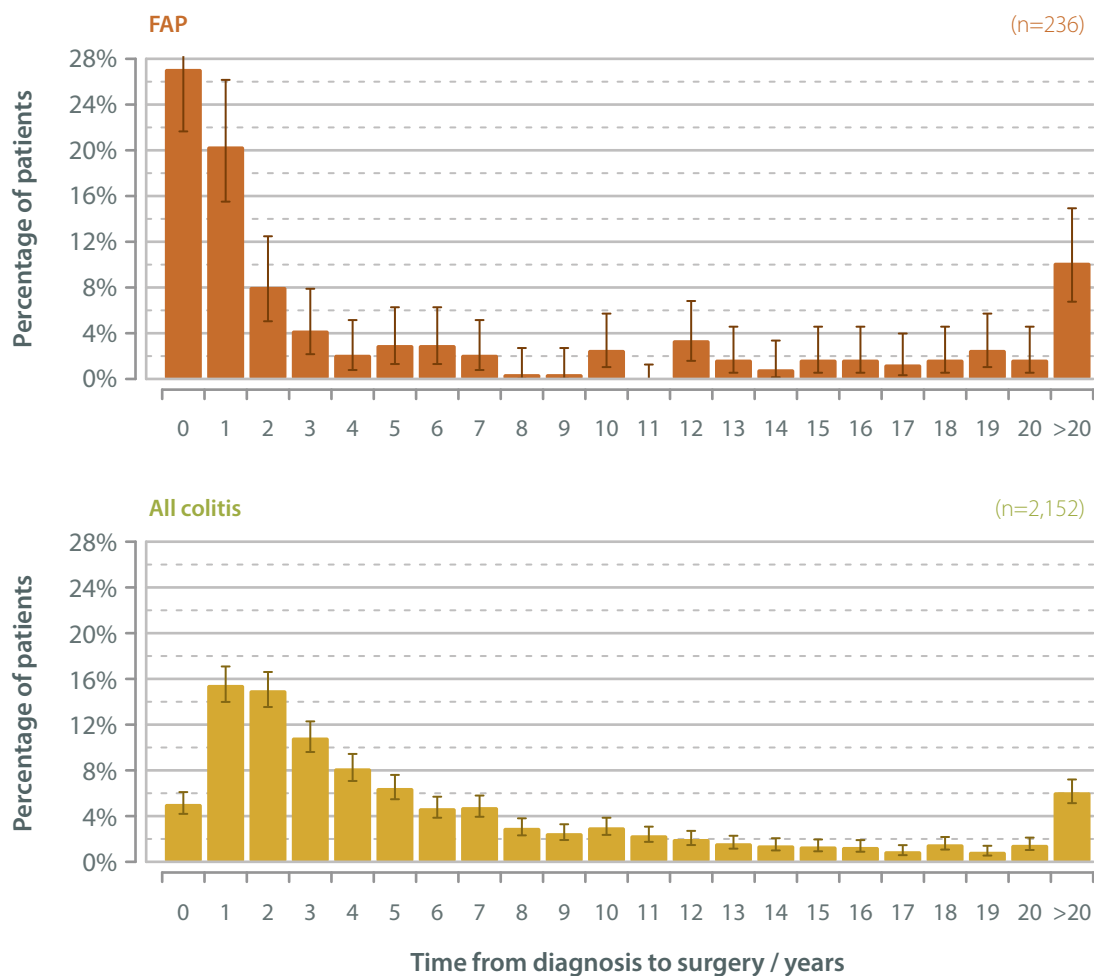
Around a quarter of patients with familial adenomatous polyposis have pouch surgery within a year of diagnosis, and a further 20% have surgery between 12 and 24 months. By two years, more than half of patients who will eventually have pouch surgery have already undergone the procedure.

In contrast, there is a delay of about a year for patients with ulcerative colitis who then go on to have pouch surgery. In this group, about 5% have pouch surgery within a year of diagnosis, but over half will then come to surgery within the next three years.

Both groups have a small late blip after 20 years, which may reflect the fact that both groups of patients are at risk of cancer over time, either through progression of adenomatous polyps in FAP or with development of dysplasia or cancer in colitis.

Fig. 3.04

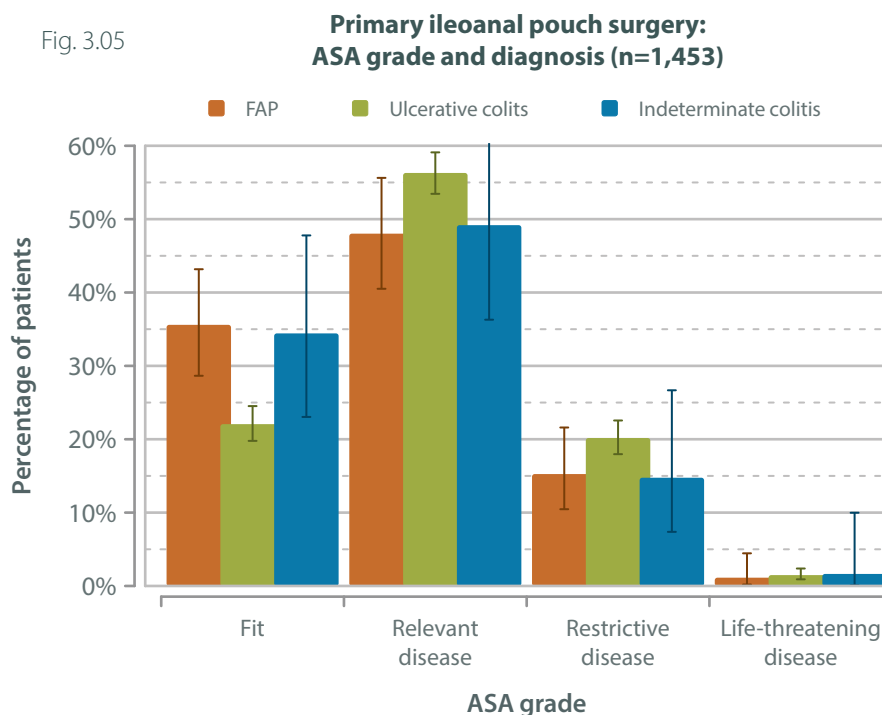
Primary ileoanal pouch surgery: Time from diagnosis to surgery



ASA grade

Pouch surgery is usually reserved for younger fitter patients with chronic conditions requiring proctocolectomy. Interestingly, the Pouch Registry also includes a substantial proportion (15 to 20% depending on indication for surgery) of patients with significant comorbidity (ASA 3 or more) on the American Society of Anesthesiologists (ASA) physical status classification system incorporating five categories of fitness for surgery.

Fig. 3.05



Quality Performance Indicators in pouch surgery

Mr Charles Maxwell-Armstrong, Consultant Colorectal Surgeon, Queen's Medical Centre, Nottingham

The capacity to ruin young lives with poorly performed pouch surgery is real. This Registry of over 5,000 patients is a testament to the desire of IBD surgeons to document outcomes and ultimately define standards. The issue, however, is what surgical outcomes can we measure to help maintain standards in those units performing this type of complex surgery, and what is most meaningful to patients and surgeons?

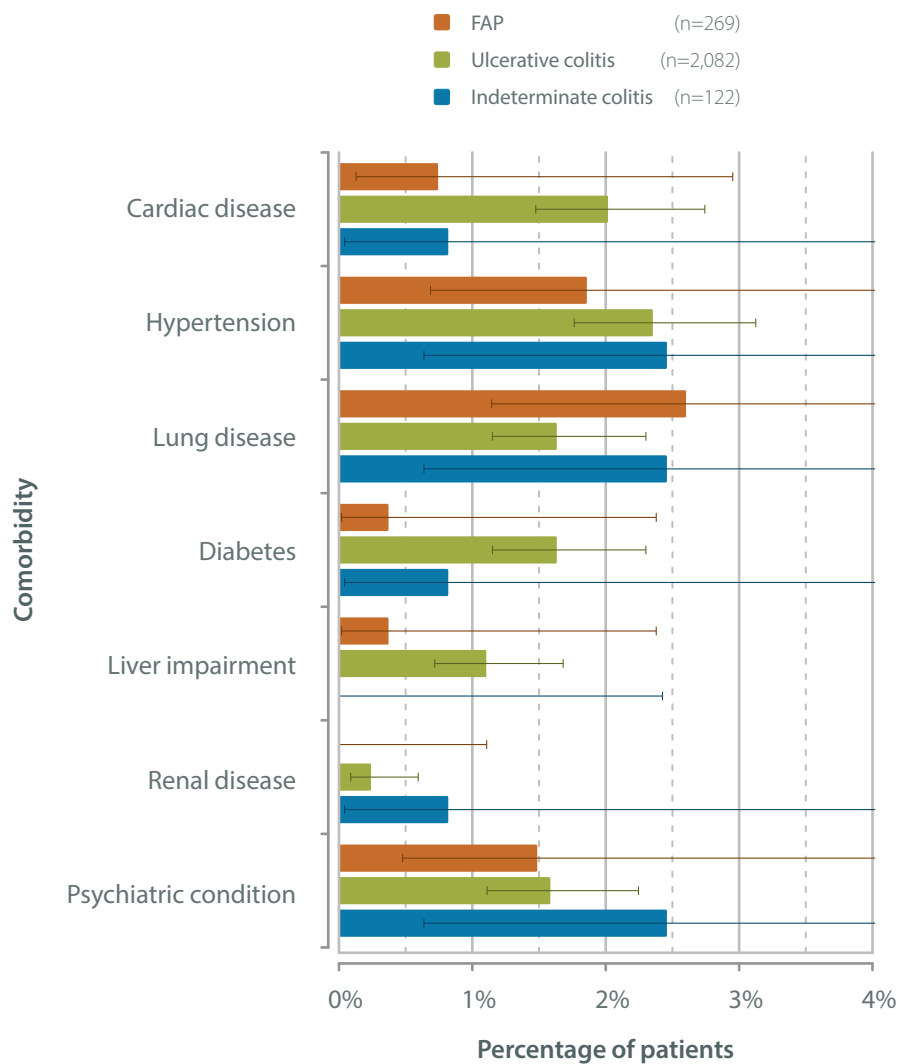
The initial temptation is to look at colorectal cancer surgery and simply extrapolate potential Quality Performance Indicators (QPI). Ninety-day mortality is not a meaningful way of comparing outcomes between surgeons in such a young patient group, and yet should probably still be included. Potential variables to consider will include anastomotic leak/ pelvic sepsis rates, return to theatre, pouch-vaginal fistulae, and proportion of loop ileostomies closed within 6 months. Other indicators of quality might include patient reported outcome measures (PROMS) data, laparoscopic/robotic surgery rate, pelvic nerve damage, management of the complications by a pouch-performing colorectal surgeon, and percentage of cases performed by a trainee. Outcomes such as pouch function, pouchitis and rate of pouch removal could be considered, but have problems associated with subjectivity, and are potentially too long-term to allow action should they fall below the required standard. They are also not always indicative of poorly performed surgery.

As we move towards accreditation and standards in numerous areas, it is now incumbent on colorectal surgeons to determine which QPIs in pouch surgery are most useful and specify 5-6 that can be easily measured. Whatever QPIs are ultimately used, they cannot be applied to individual surgeons given the small numbers performed by all but a handful of individuals. In addition gaming needs to be discouraged, namely focusing on the small numbers of outcomes being measured at the expense of other quality variables not necessarily being measured. And then there is the issue of numbers; numbers needed to be performed by a trainee/ Fellow before independent practice and numbers of pouches performed *per annum* by a Consultant.

Comorbidity

Pouch surgery is usually reserved for younger fitter patients and this is reflected in the low incidence of significant systemic comorbidity in the Pouch Registry. The revised minimum data set for the pouch Registry does not include comorbidity and so it is likely that data collection in this area will diminish with time.

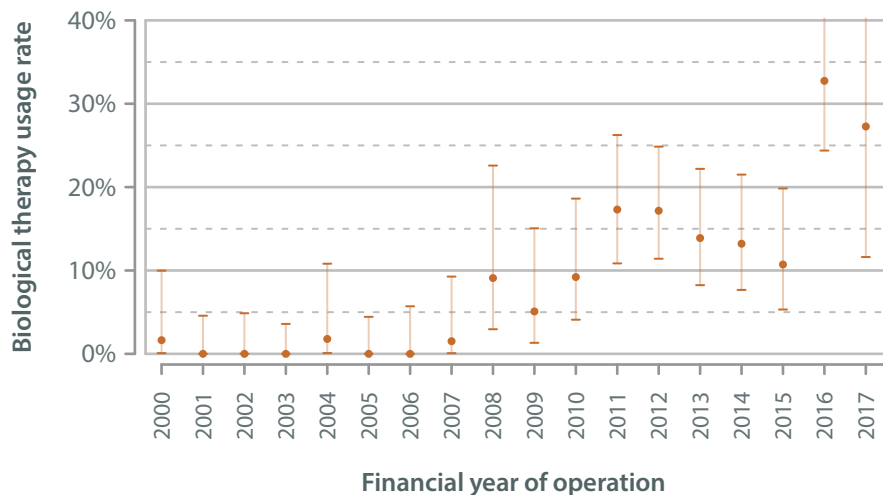
Fig. 3.06 **Primary ileoanal pouch surgery: Comorbidity and diagnosis**



Use of biological therapy

Medical treatment options for ulcerative colitis include aminosalicylates, corticosteroids, immunosuppressants and biological agents. During the last decade, there has been increasing use of biological therapies such as infliximab, adalimumab, and vedolizumab. The following graph charts the proportion of patients receiving biological therapy prior to having colectomy and pouch surgery, and how this has changed over time.

Fig. 3.07 **Primary ileoanal pouch surgery for colitis:
The use of biological therapy over time (n=1,488)**



Has biological therapy had an impact on pouch surgery?

Prof. Ronan O'Connell, Professor of Surgery and Head of Surgical Specialties, St Vincent's University Hospital, Dublin

Use of biological agents including anti-TNF α and other molecules targeting the inflammatory response in Ulcerative Colitis and Crohn's Disease has revolutionized medical treatment of IBD. Frequently used as rescue therapy for patients with acute fulminant ulcerative colitis, biologic therapy has undoubtedly reduced the need for emergency and urgent colectomy. However, up to half patients so rescued fail to have sustained remission and ultimately will require interval colectomy due to disease recurrence, progressive side effects of medical treatment, or, in the medium-term, dysplasia or malignancy in the colon.

The data presented in the present audit show that up to one-third of patients now undergoing ileoanal pouch surgery for colitis in the UK have had treatment with biologics. The immunosuppressive effects of these agents are profound, and as such may impact on the outcomes of surgical resection. Recent data from New York State¹, found that patients undergoing surgery for ulcerative colitis in the era of biologic therapy are more likely to have multiple staged procedures, to have increased post-operative morbidity and a greater risk of re-admission following hospital discharge. The GETAID Chirurgie group in France has found similar results in respect of surgery for ileo-colonic Crohn's Disease².

These findings underline the need to appreciate the risks as well as the benefits of biologic therapy. It is a self-fulfilling prophecy that surgery represents a failure of treatment when performed on nutritionally depleted, immunosuppressed patients. Whenever possible, biologics should be discontinued for a period, perhaps 6 weeks, before elective IPAA. When this is not possible, a staged procedure with initial colectomy (preferably laparoscopic) is to be preferred with interval completion proctectomy and pouch construction. As in all treatment of IBD, close collaboration between gastroenterologist and surgeon is the key to successful outcome.

1. Abelson JS, Michelassi F, Mao J, Sedrakyan A, Yeo H. Higher Surgical Morbidity for Ulcerative Colitis Patients in the Era of Biologics. *Annals of Surgery*. 2017. Apr 26. (e-pub ahead of print) PubMed PMID: 28448381
2. Brouquet A, Maggiori L, Zerbib P, et al. on behalf of the GETAID Chirurgie Group. Anti-TNF Therapy is Associated with an Increased Risk of Postoperative Morbidity After Surgery for Ileocolonic Crohn Disease: Results of a Prospective Nationwide Cohort. *Annals of Surgery*. 2017 (e-pub ahead of print) doi: 10.1097/SLA.0000000000002017

Technical factors

Pouch design

The J-pouch is now well-established as the current pouch design of choice. Although the W-pouch was used in about a fifth of pouch operations prior to 2013, it is now very rarely used.

Fig. 3.08

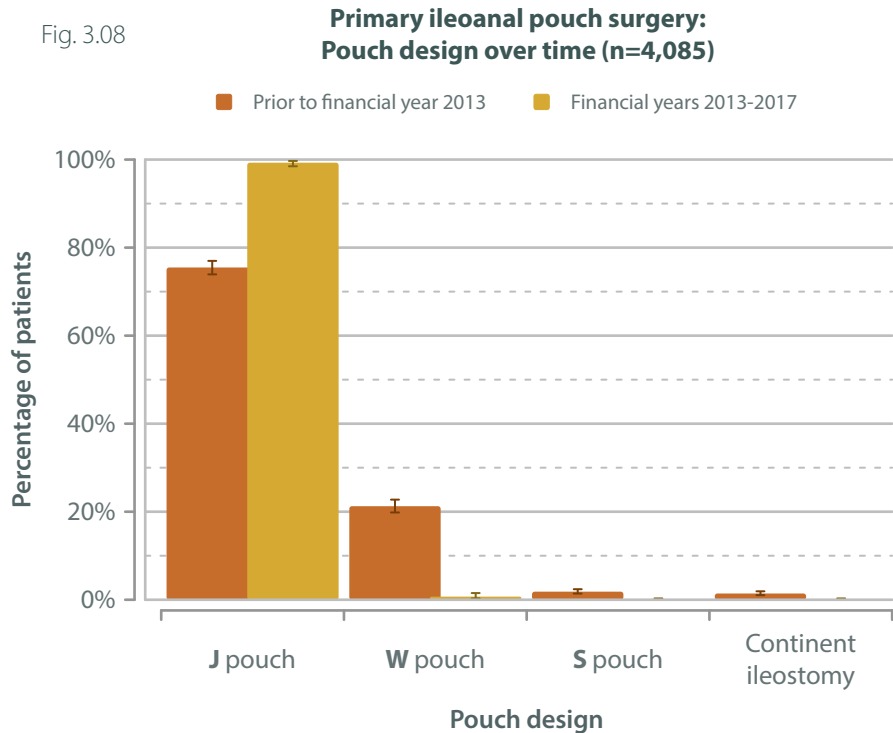
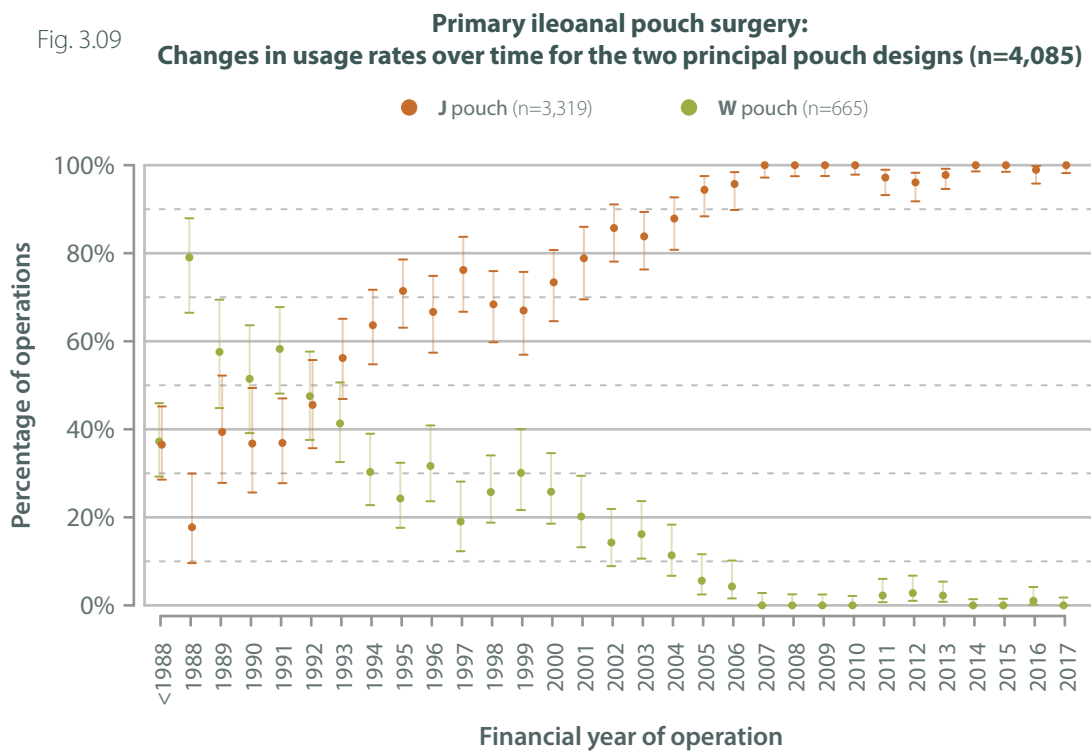


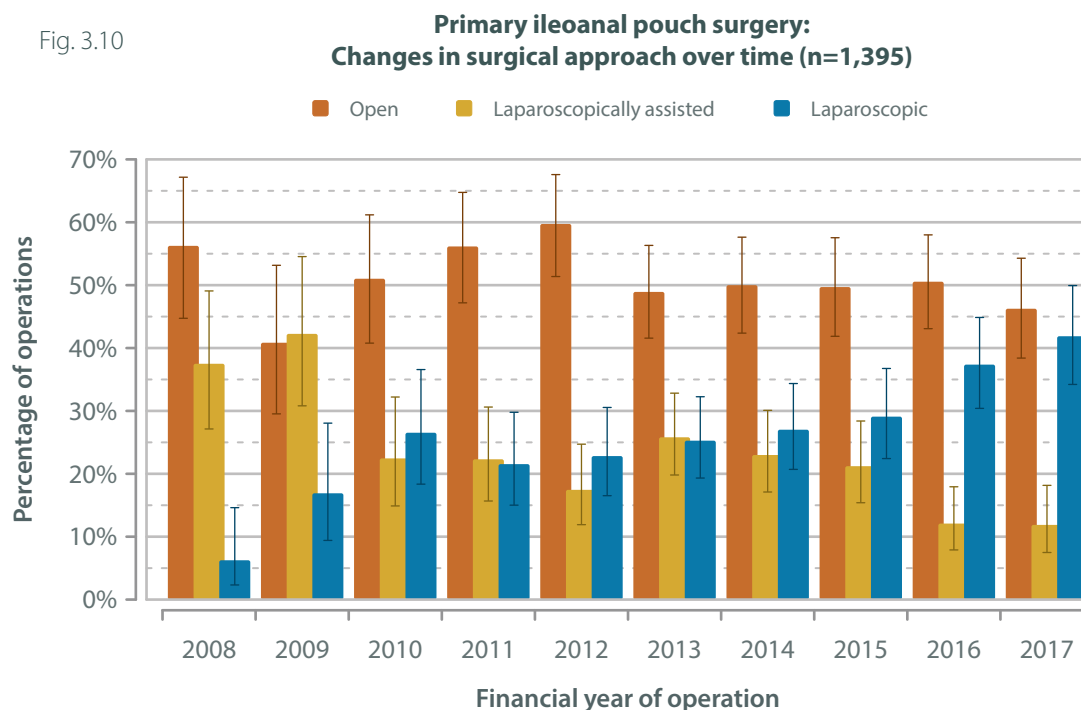
Fig. 3.09



Surgical approach

There has been a gradual rise over the past decade in the use of laparoscopic-assisted and laparoscopic approaches to pouch formation. In the most recent year, the Registry indicates a near 50:50 split between open and laparoscopic approaches. This contrasts with SWORD data on laparoscopic rates, and suggests a reporting bias in contributions to the Registry.

Fig. 3.10



Trans-anal TME approach and single port for ileoanal pouches

Mr Janindra Warusavitarne, Consultant Colorectal Surgeon, St Mark's Hospital, London

Ileo-anal pouch procedures are mostly performed for ulcerative colitis or polyposis syndromes and it is the preferred approach for most young patients requiring a proctocolectomy. The ultimate outcome of the procedure should be an improved quality of life especially where ulcerative colitis is concerned. The single-port approach to colectomy and proctectomy has the advantage of allowing the procedure to be carried out through the ileostomy site, which reduces the need for additional abdominal incisions. Some studies have also shown that this technique is associated with reduced post-operative pain. Combining the single-port with the trans-anal approach confers the added benefit of making the rectal dissection easier especially in the narrow male pelvis. Approaching the distal 3–4 cm of the rectum can be challenging laparoscopically and this can be overcome by the trans-anal approach.

Stapling the distal rectum laparoscopically can be difficult and performing a single staple across the rectum is not often possible. The number of stapler firings is directly associated with an increased risk of anastomotic leak. When the trans-anal approach is used, the rectal dissection is commenced with a rectotomy and the anastomosis carried out by the double purse string technique. This ensures that there are no dog ears and the chance of a complete anastomosis is high. The anastomosis can also be reinforced through the anus further reducing the risk of leak owing to technical reasons. As long-term pouch failure is related to anastomotic leak and sepsis, any approach to reduce this risk has to intuitively reduce the risk of pouch failure, and this is why I believe this technique confers a significant advantage to patients. There is a learning curve associated with this procedure and care has to be taken to avoid complications such as urethral injuries and rectovaginal fistulas.

Planes of rectal dissection

The two principal approaches to proctectomy are in the close rectal dissection (CRD) plane and the total mesorectal excision (TME) plane. The CRD plane potentially offers a perceived lower risk of sexual dysfunction through increased preservation of posterior and anterior autonomic nerves within the pelvis. Somewhat limited data from the Registry suggest that there may be trend away from CRD towards TME.

Transanal TME facilitates the CRD plane. As this technique becomes more established, the trend towards TME may swing back in favour of CRD over time.

Table 3.02 Patients having primary ileoanal pouch surgery for colitis: planes of dissection

	Counts			Percentage		
	<2013	2013-2017	All	<2013	2013-2017	All
Planes of dissection						
Close rectal dissection	513	179	692	61.3%	31.2%	49.0%
Total mesorectal excision	324	395	719	38.7%	68.8%	51.0%
Unspecified	1,861	493	2,354			
All	2,698	1,067	3,765			

Planes for dissection in proctectomy

Mr Graeme Wilson, Consultant Colorectal Surgeon, Western General Hospital, Edinburgh

The principal aim when performing proctectomy should be preservation of autonomic nerve function. When Parks and Nicholls developed restorative proctectomy, they aimed to achieve this by close dissection of the upper rectum with high division of the rectum and mucosectomy leaving a long distal rectal tube. This procedure was technically challenging and would soon be refined to close rectal dissection with low transection and trans anal mucosectomy. A disadvantage of close rectal dissection is that it is a technically demanding procedure within a vascular plane. A further disadvantage is the length of the surgery necessitating prolonged exposure of the patient to the inherent risks of the Lloyd Davis position. Close rectal dissection is also contra-indicated in the presence of severe dysplasia or cancer in the upper two-thirds of the rectum.

All colorectal surgeons are familiar with total mesorectal excision (TME) dissection and cross stapling with preservation of the anorectal transition zone. Combined with intraluminal circular stapled anastomosis, dissection in the TME plane is the preferred technique for the majority of surgeons. This has been further refined to include sub mesorectal fascial dissection by some surgeons. This plane is, however, quite difficult to maintain and may not serve any great advantage over standard TME techniques.

Close mesorectal dissection of the upper rectum will protect the inferior hypogastric nerves and reduce the risk of potential retrograde ejaculation. However, nerve injury leading to impotence is sustained during anterior lateral dissection of the rectum and this dissection is the same for both close rectal and mesorectal excision techniques. With the introduction of new energy sources such as the LigaSure™ device, there has been resurgence of interest in partial or complete close rectal dissection. Dissecting in an intra mesorectal plane over the sacral promontory is easy to do laparoscopically and thereafter the intra-mesorectal fascial dissection can be developed whilst working distally to the pelvic floor. Sharp dissection posterior to Denonvilliers' fascia completes mobilisation of the rectal tube. This hybrid technique is my preferred approach when performing laparoscopic pouch surgery.

Whatever technique is used, the surgeon must be conversant with their own outcomes when counselling potential patients.

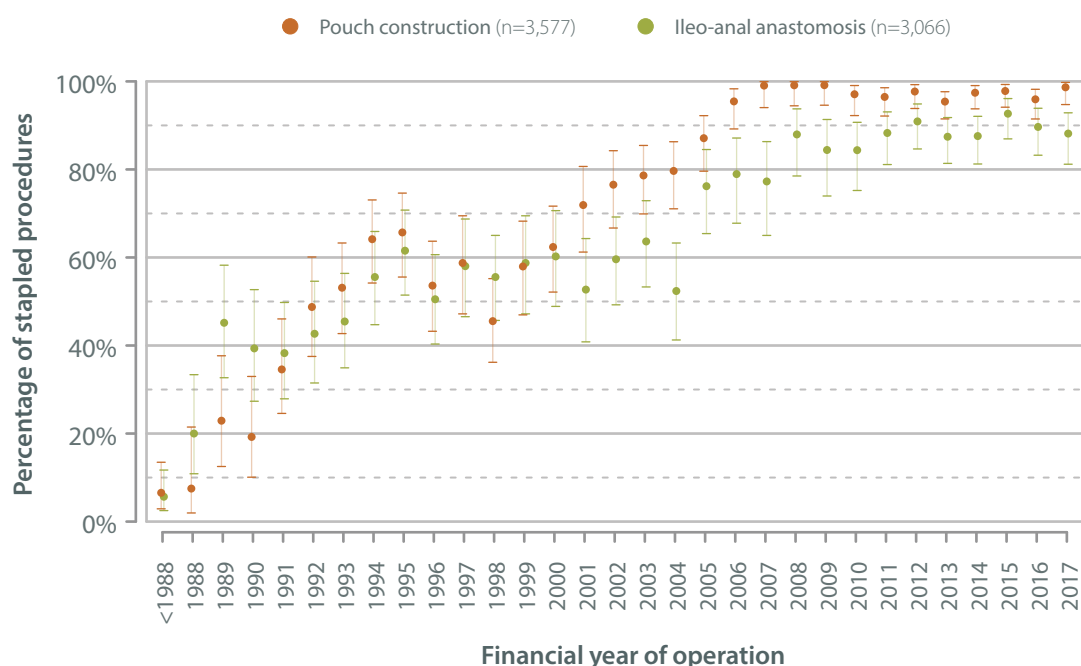
Stapling in pouch construction and ileoanal anastomoses

Technological advances with linear and circular stapling devices over the past three decades are clearly reflected in data submitted to the Pouch Registry with respect to both pouch construction and pouch-anal anastomosis, as charted in the graph below.

The W-pouch was hand-sewn and required a hand-sewn pouch-anal anastomosis. As the W-pouch has given way to the J-pouch, there has been increasing use of linear staplers in pouch construction.

Circular stapling devices that facilitate pouch-anal anastomosis have also become the norm, although there is a definite plateau below universal use. This observation suggests that technical difficulty at the time of surgery, or the clinical need for mucosectomy, mean that there is ongoing need for technical familiarity among pouch surgeons in performing hand-sewn pouch-anal anastomosis.

Fig. 3.11 **Primary ileoanal pouch surgery: Changes in the use of staples over time in pouch construction and ileoanal anastomosis**



Use of a defunctioning ileostomy

Despite several major centres now championing pouch formation without diversion in selected patients, data from the Registry indicate that over three-quarters of patients have a diverting ileostomy created at the time of pouch surgery. There has been little apparent change in diverting ileostomy rates during the last five years.

Table 3.03 Patients having primary ileoanal pouch surgery: diverting ileostomy

	Counts			Percentage		
	<2013	2013-2017	All	<2013	2013-2017	All
Diverting ileostomy						
No	392	192	584	17.1%	22.7%	18.6%
Yes ¹	1,900	654	2,554	82.9%	77.3%	81.4%
Unspecified	1,475	470	1,945			
All	3,767	1,316	5,083			

1. Yes means that either diverting ileostomy was recorded under **Technical details** or there was a **Date of ileostomy reversal** recorded

The balance of risk and benefits of diverting ileostomy for IPAA

Prof. Malcolm Dunlop, Chair of Coloproctology and Honorary Consultant Colorectal Surgeon, Western General Hospital, Edinburgh

Few aspects of pouch surgery polarise opinion more than loop ileostomy diversion of the newly constructed pouch. The controversy centres on *avoidance* of a stoma, given it is self-evident that we are not born with a stoma by default. Careful consideration of the rationale for diversion and weighing up attendant risks is crucial, set against the mindset that diversion is an integral part of pouch surgery, which might sometimes be *avoided*.

Perceived advantages of diversion include: minimising severity of anastomotic leak, thereby enabling conservative management; avoiding defaecatory frequency whilst recovering from major surgery; opportunity for patients to *experience an ileostomy* as the alternative to reconstruction and endpoint of pouch failure.

Adverse consequences of ileostomy are well established: patients managing their ileostomy put their life *on hold* during the interval until closure; closure mandates a second operation with attendant hospital stay and well-described complications, including obstruction and anastomotic leak; excess treatment costs of stoma appliances and ileostomy closure.

The rationale for routine diversion is far from persuasive when set against an anastomotic leak rate of 2-3% achievable in the context of around 90% of all pouch constructions being performed without diversion in our institution. Several critically important elements make this feasible; patient optimisation avoiding catabolic, nutritionally deplete states; maximising the proportion of therapy-free patients undergoing elective surgery at the *goldilocks* point when steroid-free with relative disease quiescence; patients with fulminant colitis refractory to medical therapy undergo staging emergency colectomy and ileostomy; operative expertise and caseload; early post-operative pouch catheterisation; team familiarity with one-stage pouch procedures; infrastructure and sufficient surgical critical mass affording daily colorectal review, supported by 24-hour imaging, and rapid expert action to identify / remediate complications. The handful of patients suffering leaks from undiverted pouches can be salvaged by early expert intervention with excellent functional outcome, superior to that from unresolved pelvis sepsis from leaks arising from diverted pouches managed conservatively.

My stance is that *avoidance* of a stoma is a misnomer; pouch reconstruction does not include diversion by default. I acknowledge the logical extension of this view is centralisation of pouch surgery to ensure sufficient critical mass and expertise of the entire team.

Complications

Although complication rates are significant, and some are potentially serious, there is a suggestion that complication rates overall may be falling. However, recent data on pouch failure must be interpreted with caution given inadequate length of follow-up in this cohort.

Table 3.04 Patients having primary ileoanal pouch surgery: post-operative complication rates with 95% confidence intervals

		Financial year of operation		
		<2013	2013-2017	All years
Post-operative complications	None recorded	74.3% (72.9-75.7%)	83.8% (81.7-85.7%)	76.8% (75.6-77.9%)
	Any complication	25.7% (24.3-27.1%)	16.2% (14.3-18.3%)	23.2% (22.1-24.4%)
	Pelvic sepsis ¹	11.1% (10.1-12.2%)	4.6% (3.5-5.9%)	9.4% (8.6-10.3%)
	Anastomotic leak	3.5% (2.9-4.1%)	3.0% (2.2-4.2%)	3.3% (2.9-3.9%)
	Fistula	5.9% (5.2-6.7%)	1.2% (0.7-2.0%)	4.7% (4.1-5.3%)
	Abscess	3.6% (3.0-4.3%)	1.2% (0.7-2.0%)	3.0% (2.5-3.5%)
	Wound infection	3.0% (2.5-3.6%)	1.4% (0.9-2.3%)	2.6% (2.2-3.1%)
	Obstruction	6.6% (5.8-7.4%)	1.7% (1.1-2.6%)	5.3% (4.7-6.0%)
	Haemorrhage	0.8% (0.5-1.1%)	0.9% (0.5-1.6%)	0.8% (0.6-1.1%)
	Pouch failure	6.0% (5.2-6.8%)	1.1% (0.7-1.9%)	4.7% (4.2-5.4%)
	Other	8.2% (7.4-9.2%)	10.1% (8.6-11.9%)	8.7% (8.0-9.5%)
Patient denominator		3,767	1,316	5,083

1. Includes any one or more of the following complications: anastomotic leak; fistula; abscess.

Quality of life after pouch surgery

Mr Gethin Williams, Consultant Colorectal Surgeon, Royal Gwent Hospital, Newport

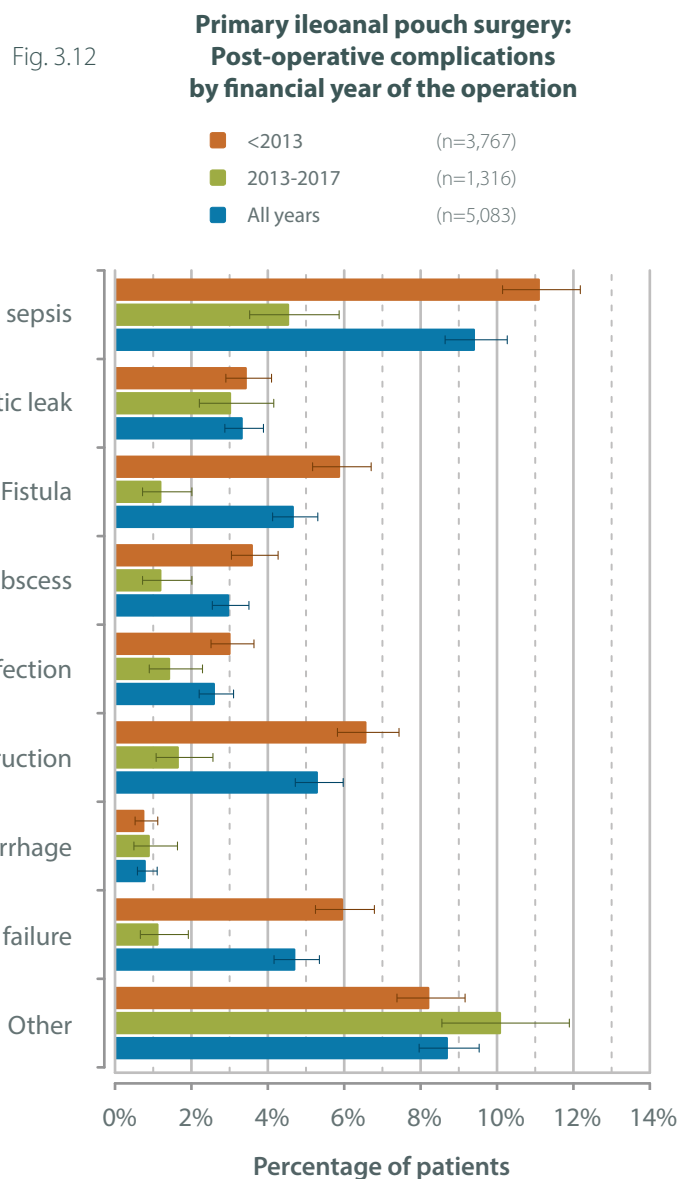
The patient with ulcerative colitis should be at the centre of the decision-making process when choosing between ongoing medical therapy, permanent ileostomy or restorative proctocolectomy. How may we as surgeons best advise these patients? We are well versed and assured at discussing difficult topics such as potential mortality and morbidity of pouch surgery. But, how well do we counsel about long-term quality-of-life (QoL) for that patient? Nowadays we are in the post-Montgomery age of informed consent: it is our legal duty to fully discuss all options available to the individual patient and address any specific concerns they have well before surgery. This is a new era where *doctors advise and patients choose*. Consideration of long-term QoL is therefore vital for both patient and surgeon prior to selecting pouch surgery.

Pouch surgery is associated with significant early and late complications that can seriously impact long-term QoL, nevertheless most pouch patients generally have high satisfaction rates and improved QoL compared to their pre-operative state. Conversely, Gastroenterologists attest that biological therapy improves QoL in medical patients once it induces remission. Comparative studies have shown no difference in QoL and disability between pouch patients, those with ileostomy and patients treated with biologicals. It was shown that stool frequency and anti-diarrhoeal medication use is higher in pouch patients along with worse perianal irritation. Another recent comparison between pouch patients and those on biologicals showed better general health perspectives (SF36) in the pouch patients. This study included surgical patients with post-operative complications and/or pouchitis; medical patients with loss of response/toxicity of biologicals and active disease were also included to give a more realistic study population.

The 2017 Pouch Registry Report does not contain any data on QoL; this is a weakness of the Registry. Efforts should be made to develop an easy to use specific QoL scoring system for pouch patients akin to the well described LARS scores after rectal cancer resection. Hence QoL can be accurately recorded and assessed in future Registry reports. This will help UK surgeons get realistic data to comprehensively advise and inform their patients on this important issue.

Voluntary submission of data to the registry almost certainly results in under-reporting of complications, especially pelvic sepsis which is normally reported at rates of 12-17% in large series from expert centres.

Similarly, wound infection rate is likely to be artificially low due to reporting bias, even if increasing use of laparoscopic surgery has lowered the rate over time.



Revisional ileoanal pouch surgery

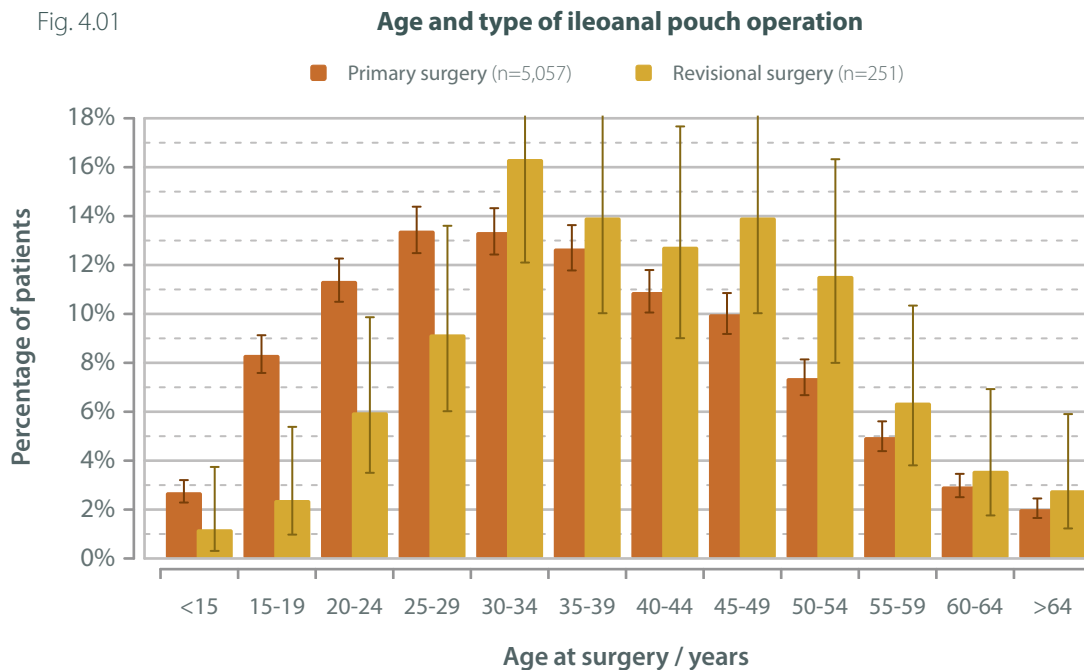
In the last 5 years, the Registry includes data on 79 pouch revision or excision procedures, under the care of 18 surgeons from 11 institutions.

Patient demographics and disease profile

Age at surgery

When compared to proportions of patients undergoing primary surgery, it is not surprising to observe that the small numbers of patients having revisional pouch surgery do so at a slightly older age.

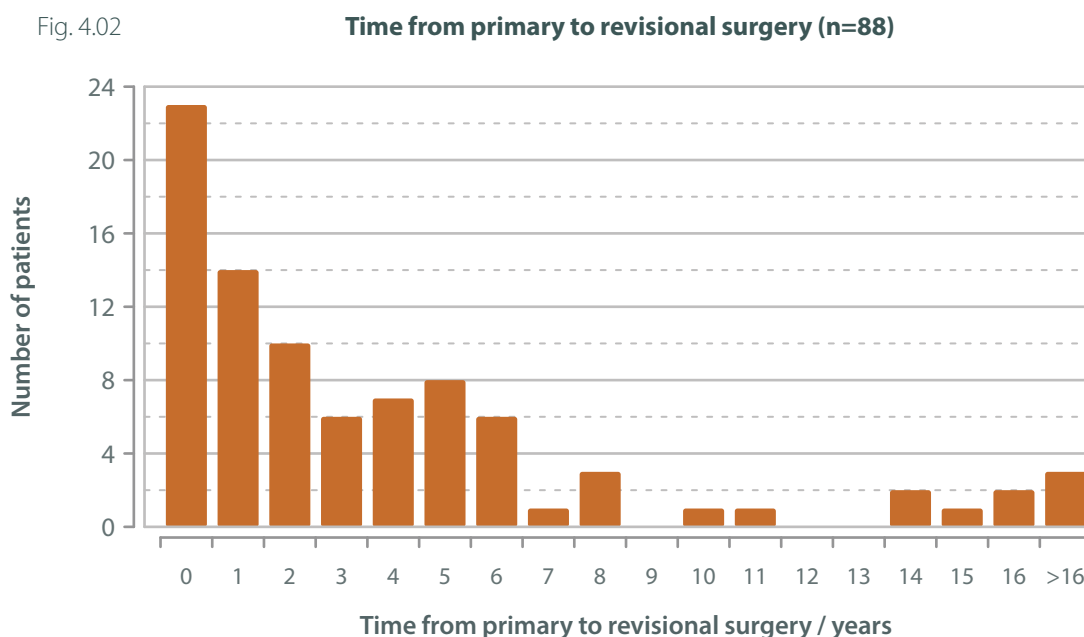
Fig. 4.01



Time to revisional surgery

The majority of pouch revisions occur within the first 5 years of primary pouch surgery.

Fig. 4.02



Technical factors

Type of revision operation

Pouch revision surgery includes a variety of procedures to improve the pouch. Pouch excision may be indicated for a range of indications including pouch failure, chronic pelvic sepsis and new onset malignancy.

Table 4.01 Patients having revisional ileoanal pouch surgery: type of revision operation

Revision operation		Count	Percentage
	Pouch revision	103	51.5%
	Pouch advancement	44	22.0%
	Pouch augmentation	1	0.5%
	Perineal / local repair	6	3.0%
	Pouch excision	30	15.0%
	Defunctioning ileostomy	3	1.5%
	Other	13	6.5%
	Unspecified	57	
	All	257	

Challenges of revision and excision pouch surgery

Prof. Sue Clark, Consultant Colorectal Surgeon and Dean of St Mark's Academic Institute, St Mark's Hospital, London

Pouch failure occurs in 10-24% of patients following restorative proctocolectomy, and is the end-point of failure to correct pouch complications or dysfunction sufficiently for the patient to be better off remaining with a functioning pouch than reverting to a permanent ileostomy.

There is no doubt that surgical pouch revision or excision is sometimes necessary. Some pouch complications can only be managed by surgical revision; in others, more conservative options are available, but are not always successful.

Eventually the point may be reached where the patient needs to decide whether to struggle on with chronic poor function, to face attempted surgical revision with its associated risks and potentially poor outcomes, or to accept pouch failure. In the management of pouch related problems a balance must be struck between thorough, timely investigation and treatment and desire to avoid a permanent ileostomy on the one hand, and the fact that some patients will have better health and quality of life with an ileostomy than with a poorly functioning pouch on the other.

The low volume of pouch surgery undertaken in most centres in the UK means that few clinicians have significant experience of pouch related problems. Algorithms have been published that can guide logical and comprehensive management. Some specialist centres have more experience, due to the volume of pouch surgery undertaken and tertiary referral patterns.

Pouch revision and excision is difficult and hazardous. Outcomes, including pouch failure and function, are poorer after re-do than after initial pouch formation, but in selected patients satisfaction levels are high. It is imperative that patients who might benefit from such surgery are seen in centres with significant experience and are offered appropriate counselling and optimal surgery. Provision of high quality ileoanal pouch surgery is incomplete without excellent care for the minority of patients who run into problems as a result of their surgery.

Complications

Pouch revision has an appreciable complication rate and patients considering revisional surgery will need to be counselled accordingly. The Registry data on complications arising from revision surgery is lower than in most large series likely due to under reporting bias.

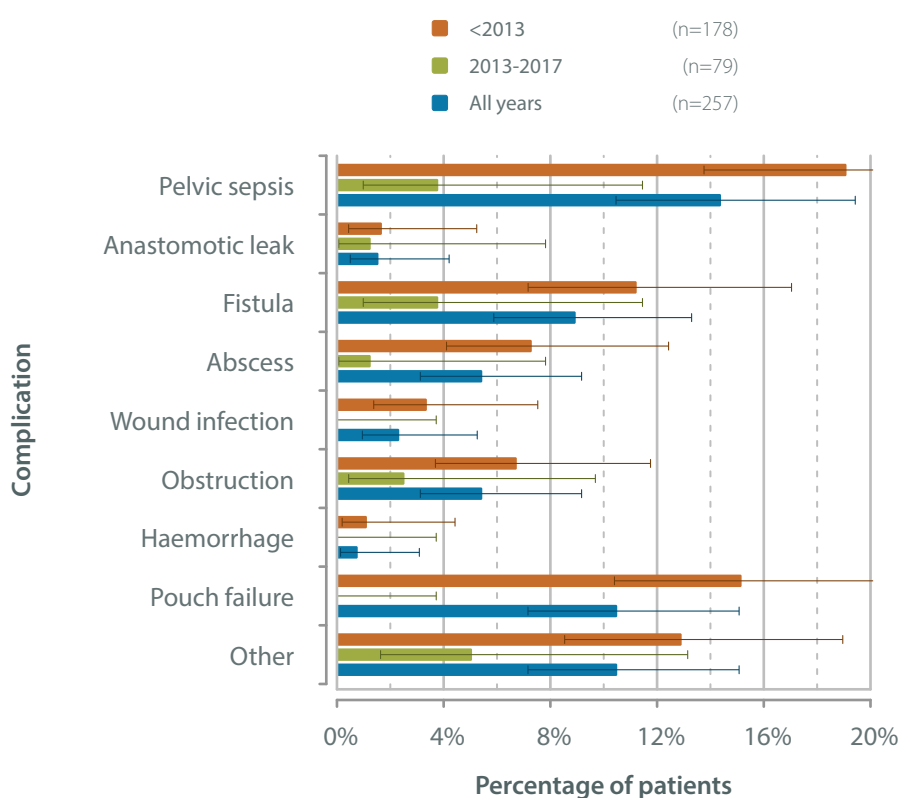
Table 4.02 Patients having revisional ileoanal pouch surgery: post-operative complications

	Financial year of operation		
	<2013	2013-2017	All years
Post-operative complications			
None	55.6% (48.0-63.0%)	89.9% (80.5-95.2%)	66.1% (60.0-71.8%)
Any complication	44.4% (37.0-52.0%)	10.1% (4.8-19.5%)	33.9% (28.2-40.0%)
Pelvic sepsis ¹	19.1% (13.8-25.8%)	3.8% (1.0-11.5%)	14.4% (10.5-19.4%)
Leak	1.7% (0.4-5.2%)	1.3% (0.1-7.8%)	1.6% (0.5-4.2%)
Fistula	11.2% (7.2-17.0%)	3.8% (1.0-11.5%)	8.9% (5.9-13.3%)
Abscess	7.3% (4.1-12.4%)	1.3% (0.1-7.8%)	5.4% (3.1-9.2%)
Wound infection	3.4% (1.4-7.5%)	0.0% (0.0-3.7%)	2.3% (1.0-5.3%)
Obstruction	6.7% (3.7-11.8%)	2.5% (0.4-9.7%)	5.4% (3.1-9.2%)
Haemorrhage	1.1% (0.2-4.4%)	0.0% (0.0-3.7%)	0.8% (0.1-3.1%)
Pouch failure	15.2% (10.4-21.5%)	0.0% (0.0-3.7%)	10.5% (7.2-15.1%)
Other	12.9% (8.5-19.0%)	5.1% (1.6-13.1%)	10.5% (7.2-15.1%)
Patient denominator	178	79	257

1. Includes any one or more of the following complications: anastomotic leak; fistula; abscess.

Fig. 4.03

Revisional ileoanal pouch surgery: Post-operative complications by financial year of the operation



Research in pouch surgery

Current trials in pouch surgery

There is certainly a need for well-designed trials in the technical and functional aspects of pouch surgery.

Ongoing trials from around the world focus on important topics including:

- **surgical technique** (need for close rectal dissection, anastomotic techniques, whether a diverting stoma is necessary).
- **investigation of pouch dysfunction.**
- **avoidance or optimal treatment of adverse sequelae** (pouchitis, rehabilitation for pouch dysfunction, pouch adenomas in FAP).

Key areas for pouch research

Mr Thomas Pinkney, Senior Lecturer and Consultant Colorectal Surgeon, Queen Elizabeth Hospital, Birmingham

Anastomotic leak remains the most feared early complication after all reconstructive colorectal surgery, and the same holds true for pouch operations. There remains debate about whether any adjunctive measures, in addition to sound surgical technique, have the potential to reduce leak rates. Such measures currently under appraisal, such as anastomotic flexible external sealants and synthetic or biological internal reinforcement systems, could easily translate into the pouch population if proven effective. Other interventions aimed at verifying adequate perfusion of bowel ends are perhaps less relevant in the context of the better vascularised ileum.

Whilst originating from rectal cancer surgery, newer trans-anal approaches are now being employed by some surgeons for the proctectomy component of pouch surgery. We do not yet know the real-world benefits, and the enhanced view obtained needs to be offset against likely increased costs and/or logistics involved. Whilst proponents cite the ability to obtain a truly complete rectal resection, others remain concerned about the potential for disruption to the sphincter complex from the technique, and the ability for surgeons to go too low. An interesting hybrid variant may arise still - regardless of how the rectum itself is dissected out, using the associated principle of placing a purse-string into the stump from below, the IPAA can be fashioned with a single firing of a circular stapler. This technique eliminates the dog ears created by the rectal stump transection staple line and may therefore reduce leakage rates. Further prospective research is needed.

Pouchitis remains an unsolved problem. Whilst there is increasing evidence supporting the role that the microbiome plays in the development of pouchitis, we have not yet harnessed the ability of manipulating the mucosal micro-environment to treat or prevent the condition. It is conceivable that faecal microbiota transplant (FMT) may have a part to play here; studies are in-progress.

The numbers of pouches created annually is dropping; whether this is due to improved medical options or a reflection of patient choice remains to be seen. Whilst inter-patient communication is vital, the potential for a disproportionately negative impact from online patients with a bad pouch has the potential ability to unduly influence others considering reconstructive options. The option of ileo-rectal reconstruction in UC went out of vogue some years ago in many countries, but is being compellingly championed at present by the Swedish, who have good datasets supporting this choice in selected patients in terms of complications, quality-of-life and bowel function profiles being roughly comparable to pouches. Further prospective and patient-centric research is needed.

Conclusions

Points for discussion

The mass of data presented here in the 2017 Pouch Registry represents a significant achievement given voluntary support for input of data from busy clinicians. Each and every contributor should be congratulated. Those who have contributed are no doubt driven by recognition of the importance of such a Registry in maintaining and improving standards of care for patients who have pouch surgery.

This is the first time that centrally collected administrative data in England (SWORD) has allowed the Registry to draw some important conclusions for adults as well as children and adolescents. It is an aspiration to see how administrative datasets from devolved nations and Europe may add to our knowledge base in the future.

Trends and changes in practice may be seen over the years since pouch surgery was first described. For instance, the stapled J-pouch is by far the commonest technique used today with other pouch formation and anastomosis techniques now largely historical. The use of close rectal dissection (CRD) has decreased with total mesorectal excision (TME) now more common. This presumably reflects surgeon comfort; most modern colorectal surgeons are familiar with the nerve-sparing TME plane and perceive little advantage for CRD provided there is caution with the anterior rectal dissection.

Improvements in medical therapy are also influencing practice, with perhaps slightly fewer pouches being done, and certainly patients who undergo pouch surgery receiving medical therapy for longer before the procedure. This may in part relate to the increased use of biological therapies.

Laparoscopic and laparoscopic assisted surgery have certainly become more commonly used as the surgical approach although perhaps not as common as the Registry would suggest. SWORD data suggests there may be an element of reporting bias and that there is significant regional variation. A defunctioning ileostomy is carried out by the majority of surgeons. Nevertheless a significant minority of surgeons continue to believe that defunctioning is not an essential component of pouch surgery in all patients, and argue that the leak rate is low despite a stoma, and that many post-operative complications relate to having a stoma.

Both Registry and SWORD databases reveal some data that has remained consistent with time and which may be concerning. Despite usually an elective operation on fit patients, one in five patients have had surgery with restrictive or life-threatening conditions. Complications and re-admission rates remain high and are even higher for revisional surgery.

The Registry and SWORD database also highlight some important key questions for future research and audit. Despite an era of enhanced recovery and increasing use of laparoscopic techniques, the average length-of-stay is relatively and consistently high throughout England. Why is this the case? Why is the 30-day re-admission rate so high? Do health professionals continue to be nervous about these patients, keeping them in hospital longer and having a low threshold for re-admission if recovery is not perfect? Should we be striving to change this practice or would it be detrimental? How do we go about changing practice? Would either more community support or centralisation make a difference?

There is clearly a compelling argument for centralisation of pouch surgery. The procedure is performed infrequently within a repertoire of surgical options available to patients having had a colectomy or needing proctocolectomy. Intimate knowledge of all surgical options, considered experience in guiding patients to the option that may best suit them, and back-up from the specialised multi-disciplinary team is paramount in providing the best possible service for patients.

While there are undoubtedly some centres that are currently offering pouch surgery at low volume with good outcomes, this report indicates that they are probably the exception rather than the norm. And the future is likely to take a more pragmatic view when it comes to ensuring good outcomes and training the next generation of specialist surgeons. Centralised experience may ultimately facilitate proactive management of complications, minimize the impact of functional pouch disorders, prioritise optimisation of long-term outcomes, and draw on collective institutional knowledge from all the specialties that support pouch surgery. Concentration of experience also offers unique opportunities to make real inroads into improving outcomes through quality improvement initiatives.

Despite representing the largest and longest repository for data on pouch patients, there are significant limitations to this report. Incomplete case ascertainment is by far the most major limitation. SWORD data has indicated that the proportion of pouch procedures included in the Registry is at best about 50% of those carried out in England. This low figure can probably be extrapolated to the whole of the United Kingdom and certainly to Europe. Reporting bias is undoubtedly occurring: a good illustration is the high rate of laparoscopic approach in this report when compared with SWORD. Although baseline data ascertainment is poor, follow up data is even

worse, making attrition bias a significant problem in terms of outcome reporting. Outcome data, and especially effect of pouch surgery on quality of life, are severely lacking. This makes it very difficult to draw any except the broad conclusions listed above and in the executive summary.

How can we improve on these limitations for the next report? Questionnaire fatigue probably played a role in the previous report as the original dataset was huge. We have already taken steps to reduce the minimum dataset for inclusion of patients in the Registry. Incentives to input data are difficult to establish in a voluntary system and we remain reliant on professionalism and altruism. Credit is given to those who have contributed data on patients having pouch surgery, and all contributors are highlighted at the beginning of the report. Perhaps the absence of contribution from an institution performing pouch surgery should in itself be perceived as a negative quality indicator?

There is no doubt that recruitment to the Registry is enhanced before a report is due and undoubtedly the same prompts that successfully increased ascertainment in 2017 will be used for the next report. However, maintaining data acquisition in between reports is more challenging. Targeting high-volume surgeons and centres is one possibility, but there is a need to identify and target new registrants. In England SWORD allows easy comparison for case ascertainment in the Registry. A reporting mechanism could potentially be established. For Scotland, Wales and Ireland, this is more difficult unless similar reporting mechanisms based on administrative data can also be established.

Perhaps the most powerful tool is patients themselves, with IA (The ileostomy & internal pouch Support Group) and Crohn's and Colitis UK encouraging patients to question surgeons about their data input and outcomes, in recognition of data contribution as a marker of quality. Finally, both UK and European surgeons will be encouraged to input data if the Registry can be shown to successfully produce more and more meaningful outcome measurements that may produce robust recommendations for quality improvement.

Final words

A European perspective on pouch surgery

Prof. Willem Bemelman, Professor in Minimal Invasive and Colorectal Surgery, Academic Medical Center, Amsterdam

Most patients requiring surgery because of therapeutic refractory ulcerative colitis are in their thirties. They still have a long life ahead. A good functioning pouch is paramount for their quality of life. The preferred type of reconstructive surgery, proposed in the early eighties, is still the ileoanal pouch. Over time we have learned that the best pouch is the stapled J-pouch because of its simplicity to perform, superior continence and emptying.

Important long-term issues of restorative proctocolectomy include fertility in women, bowel obstruction, pouch failure due to late sequelae of anastomotic leaks and pouchitis. This makes pouch surgery susceptible to failure compromising quality of life in all aspects of these young patients.

Evolving evidence has shown that laparoscopic (procto)colectomy helps preserve fertility and reduce adhesion related bowel obstruction, and that chronic presacral pouch sinuses can be prevented with vacuum therapy and primary closure of the anastomotic defect. Pouchitis remains on the research agenda, because neither the aetiology nor the therapy in refractory cases is understood. Combined data of three referral centres has shown that one and two staged restorative proctocolectomies do worse in terms of anastomotic healing because of recent therapy with biologic agents and steroids, and that the optimum surgical intervention is either modified two-stage or three-stage surgery.

As in all surgical procedures the key to perfection is proficiency, which comes with practice. The surgeons of the European Crohn's and Colitis Organisation recommended in the ECCO guidelines a volume of at least 10 cases *per* institute annually. This figure should be considered as a starting point. The higher the volume, the fewer the complications, and the greater the capability to salvage a leaking pouch and to deal with chronic pouch dysfunction.

A Pouch Registry is of utmost importance in evaluating the results of pouch surgery. Even better might be a cross-sectional prospective registration of all pouch surgery in various European units (snapshot research) providing substantial data in a short period of time. Due to variation in care important research questions can be addressed *e.g.*, pouch salvage after a leak, the optimal size of the pouch and volume outcome relationship. Particularly, in Europe we can make this happen.

Future of pouch surgery

Professor James Hill, Consultant Colorectal Surgeon, Manchester Royal Infirmary, Manchester, and President Elect, ACPGBI

The 2017 Pouch Report provides important insights into the future. The consistency of pouch design and stapling seen in recent years is likely to continue. The laparoscopic approach to colectomy will undoubtedly become the standard of care and the laparoscopic-assisted approach to pouch surgery is likely to become more common. Newer techniques such as the combined perineal and pelvic approach will need to meet the test of time with respect to their safety.

There are consistent themes in the opinions expressed in the expert personal commentaries. Ileo-anal pouch surgery is technically demanding. Surgeon and institution volume will on balance of probability affect the quality of surgical outcomes. Expert multi-disciplinary care is essential.

The opinions are irrefutable and these aspects of pouch surgery will not be different in the future. The results of ileoanal pouch surgery have a profound effect on the quality of patient's lives over many decades. The patients' views documented in this report are testimony to the results of good pouch surgery. The converse also holds true: when pouch surgery goes wrong, it is so detrimental to quality of life. We are surely duty bound to ensure that patients undergoing pouch surgery are given the best chance of a good outcome.

Areas of uncertainty remain and are unlikely to be answered in the immediate future:

- To defunction or not to defunction?
- What are the causes and best treatments for pouchitis?

A disease or disorder is defined as rare in Europe when it affects fewer than 1 in 2,000. It is difficult to dispute that concentration of pouch patients will increase our ability to optimise outcomes and improve patient care for this rare procedure.

Afterword from the Director of Policy, Public Affairs & Research, Crohn's and Colitis UK

The IBD Standards Group is a collaboration of patient and professional organisations, including ACPGBI, and chaired by Crohn's and Colitis UK. This group has published the Standards for the Healthcare of People who have Inflammatory Bowel Disease (the IBD Standards) that define the core requirements for safe, effective, patient-centred, high quality IBD services. As such, these Standards, alongside audit and registry data, have a fundamental role in driving improvements in the quality and management of IBD care.

The Ileoanal Pouch Report is instrumental in enabling patients to make informed choices about their treatment and care and, by shining a light on the variations in the quality and safety of pouch surgery, is key to identifying targets for future improvements towards reaching the IBD Standards. For example, the report identifies the number of surgeries performed in low-volume units, and raises a question about the lack of opportunity for training in high-volume and high-performing centres.

The report, which is based on data from over 5,000 operations in the Pouch Registry, demonstrates an ongoing commitment to quality improvement and recognises the importance of a patient-centred approach. Crohn's and Colitis UK values the opportunity to contribute to this through our membership of the ACPGBI IBD Clinical Advisory Group. Our involvement in this group, and the quality and transparency of the data presented in this report, will also help to inform and shaping our health service development work, and the support we offer to IBD Services to deliver the IBD Standards from a patient perspective.

Mrs Helen Terry

Director of Policy, Public Affairs & Research, Crohn's and Colitis UK

Afterword from the IBD CAG Representative, British Society of Gastroenterology

The last two decades have seen unprecedented advances in our understanding of the aetiopathogenesis of IBD with an expanding armamentarium of biological therapies. Despite this, 10-30% of patients with ulcerative colitis face proctocolectomy after 10 years of disease. An ileal pouch-anal anastomosis (IPAA) offers patients the prospect of an unchanged body image, with no stoma and a preserved anal route of defaecation. Complexities of pouch surgery itself notwithstanding, the manifold variables that may determine successful surgery and deliver desirable outcomes, underpin the need for a repository of experience with pouch surgery.

The ACPGBI and IA (The ileostomy & internal pouch Support Group) are to be commended for leading this collaborative initiative, culminating in what is truly the longest and largest database of outcomes from pouch surgery. Perhaps the greatest strength of this report is its incisive identification of myriad factors that drive successful outcomes, asking important questions in seeking the right answers. It provocatively challenges the notion that *it should be done if it can be done* but in doing so, seeks to recognize and promote excellence, fostering a multi-disciplinary approach and providing impetus for better models for training and overall delivery of care.

The BSG welcomes this report, as a significant step towards meeting IBD Standards and providing much needed transparency for physicians, patients and stakeholders. Moving forward, it is now incumbent upon clinicians and stakeholders to promote this pursuit of excellence. The Pouch Report elegantly sets the stage for this. The prospect of realizing of these objectives is now more realistic than ever before.

Dr Jimmy Limdi

IBD CAG Representative, British Society of Gastroenterology



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Appendix

Conventions used throughout this report

There are several conventions used in the report in an attempt to ensure that the data are presented in a simple and consistent way. These conventions relate largely to the tables and the graphs, and some of these conventions are outlined below.

The specifics of the data used in any particular analysis are made clear in the accompanying text, table or chart. For example, many analyses sub-divide the data on the basis of the type of operation (primary *versus* revision), and the titles for both tables and charts will reflect this fact.

Conventions used in tables

On the whole, unless otherwise stated, the tables and charts in this report record the number of procedures (see the example below).

Table 7.01 Primary ileoanal pouch surgery: age at operation and gender

	Gender			
	Male	Female	Unspecified	All
Age at operation / years				
<20	269	276	0	545
20-29	664	553	3	1,220
30-39	659	609	5	1,273
40-49	589	447	2	1,038
50-59	410	203	0	613
60-69	142	71	0	213
70-79	21	8	0	29
>79	2	2	0	3
Unspecified	9	12	5	26
All	2,765	2,181	15	4,961

Each table has a short title that is intended to provide information on the subset from which the data have been drawn, such as the patient's gender or particular operation sub-grouping under examination.

The numbers in each table are colour-coded so that entries with complete data for all of the components under consideration (in this example both age and gender) are shown in regular black text. If one or more of the database questions under analysis is blank, the data are reported as unspecified in orange text. The totals for both rows and columns are highlighted as emboldened text.

Some tables record percentage values; in such cases this is made clear by the use of an appropriate title within the table and a % symbol after the numeric value.

Rows and columns within tables have been ordered so that they are either in ascending order (age at procedure: <20, 20-29, 30-39, 40-49, 50-59 years, *etc.*; post-procedure stay 0, 1, 2, 3, >3 days; *etc.*) or with negative response options first (No; None) followed by positive response options (Yes; One, Two, *etc.*).

Row and column titles are as detailed as possible within the confines of the space available on the page. Where a title in either a row or a column is not as detailed as the authors would have liked, then footnotes have been added to provide clarification.

There are some charts in the report that are not accompanied by data in a tabular format. In such cases the tables are omitted for one of a number of reasons:

- editorial preference.
- there would be more rows and / or columns of data than could reasonably be accommodated on the page (for example, Kaplan-Meier curves).
- the tabular data had already been presented elsewhere in the report.

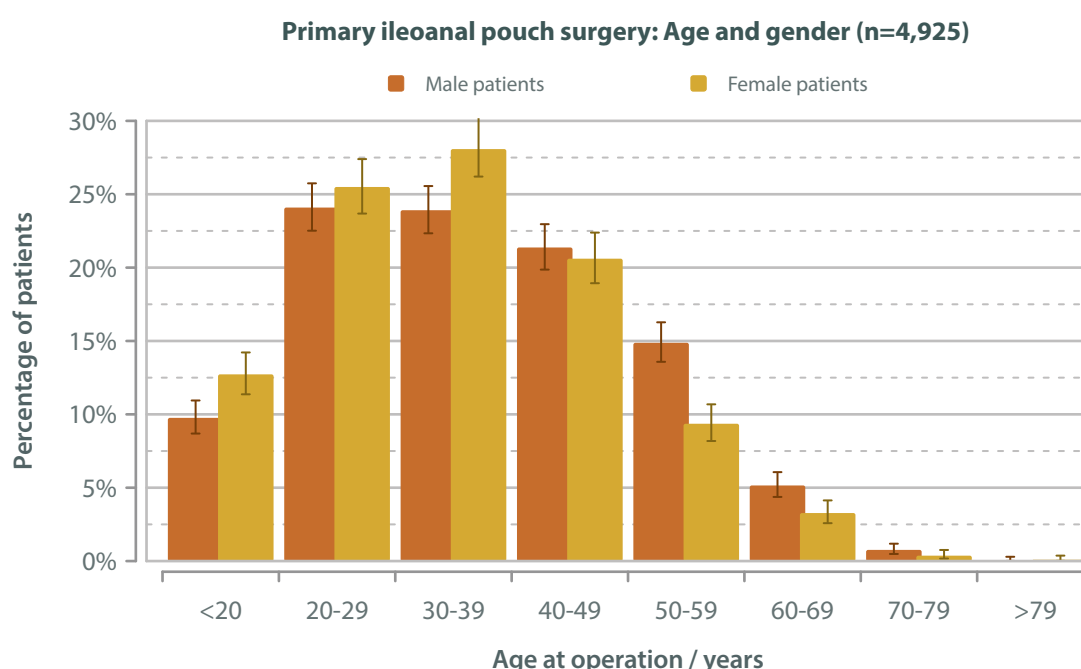
Conventions used in graphs

The basic principles applied when preparing graphs for this Second Ileoanal Pouch Report were based, as far as possible, upon William S Cleveland's book *The elements of graphing data*¹. This book details both best practice and the theoretical bases that underlie these practices, demonstrating that there are sound, scientific reasons for plotting charts in particular ways.

Counts: The counts (shown in parentheses at the end of each graph's title as n=) associated with each graph can be affected by a number of independent factors and will therefore vary from chapter to chapter and from page to page. Most obviously, many of the charts in this report are graphic representations of results for a particular group (or subset) extracted from the database, such as primary operations. This clearly restricts the total number of database-entries available for any such analysis.

In addition to this, some entries within the group under consideration have data missing in one or more of the database questions under examination (reported as unspecified in the tables); all entries with missing data are excluded from the analysis used to generate the graph because they do not add any useful information.

For example, in the graph below, only the database entries where the patient is having primary surgery and both the patient's age and gender are known are included in the analysis; this comes to 4,925 patient-entries (269 + 664 + 659 + 589 + 410 + 142 + 21 + 2 + 276 + 553 + 609 + 447 + 203 + 71 + 8 + 2; the 36 entries with unspecified data are excluded from the chart).



Confidence interval: In the charts prepared for this report, most of the bars plotted around rates (percentage values) represent 95% confidence intervals². The width of the confidence interval provides some idea of how certain we can be about the calculated rate of an event or occurrence. If the intervals around two rates do not overlap, then we can say, with the specified level of confidence, that these rates are different; however, if the bars do overlap, we cannot make such an assertion.

Bars around averaged values (such as patients' age, post-operative length-of-stay, etc.) are classical standard error bars or 95% confidence intervals; they give some idea of the spread of the data around the calculated average. In some analyses that employ these error bars there may be insufficient data to legitimately calculate the standard error around the average for each sub-group under analysis; rather than entirely exclude these low-volume sub-groups from the chart their arithmetic average would be plotted without error bars. Such averages without error bars are valid in the sense that they truly represent the data submitted; however, they should not to be taken as definitive and therefore it is recommended that such values are viewed with extra caution.

1. Cleveland WS. *The elements of graphing data*. 1985, 1994. Hobart Press, Summit, New Jersey, USA.

2. Wilson EB. Probable inference, the law of succession, and statistical inference. *Journal of American Statistical Association*. 1927; **22**: 209-212.



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