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# Summary of the pouch report for patients & the public 2017

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Association of Coloproctology  
of Great Britain and Ireland

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The ileostomy & internal pouch  
**Support Group**

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## **An introduction from our sponsor**

IA (The ileostomy & internal pouch Support Group) is delighted to sponsor the second Ileoanal Pouch Report. IA has been supporting people living with an ileostomy for over 60 years through collaboration between surgeons and patients. IA was instrumental in developing the specialist nurse role in the early 1970s. IA expanded to support patients undergoing ileoanal pouch surgery in 1993, and support has also been extended to patients living with a Kock pouch (continent ileostomy) in recent years.

Development of the ileoanal pouch in the late 1970s has offered suitable patients an alternative to living with an ileostomy. This has had such a positive impact on the lives of many patients who need surgery to remove the large bowel.

Such complex surgery is not without complication. With around 400 new pouch surgeries being performed in the UK each year, the Pouch Registry becomes an important reference for patients wishing to learn more about surgical outcomes and success rates.

IA puts patients considering pouch surgery in touch with someone living with an ileoanal pouch. This report also helps patients make an informed decision when choosing the best option for their lifestyle preference.

**Anne Demick**

**Chairman, Executive Committee,**

**IA (The ileostomy & internal pouch Support Group)**

## **Support for the Pouch Report from Crohn's and Colitis UK**

We welcome the 2017 Pouch Report, which tells us about the outcomes of over 5,000 people who have had pouch operations. We are very pleased to see such comprehensive information being made available directly to patients and the public.

Having pouch surgery is a life-changing option offering hope for many people with Ulcerative Colitis, but it's so important that they have the best possible information about what to expect. This report will help people considering pouch surgery to have open and honest discussions with their surgeons about their expectations and any personal concerns. That way, they can make an informed decision together.

**Helen Terry**

**Director of Policy, Public Affairs and Research,**

**Crohn's and Colitis UK**



## 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.



## Facts from the 2017 Pouch Report

### **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.

### **What about use of biological therapy?**

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

### **What is the commonest journey to pouch surgery?**

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

### **What technique is most used?**

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

### **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.

### **How old are the patients?**

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

### **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.

### **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 about keyhole surgery?**

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

### **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/>



## 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.

