



Ileo-anal Pouch Follow-Up

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Aim

Share a novel, nurse-led pathway for patients who have had their stoma reversed following ileoanal pouch surgery for ulcerative colitis

- Discuss the design of the follow-up protocol
- Implementation of the nurse-led pathway
- Present some of the initial findings

Facts and Figures

St Mark's Hospital is the main tertiary referral centre in the UK for ileoanal pouch surgery

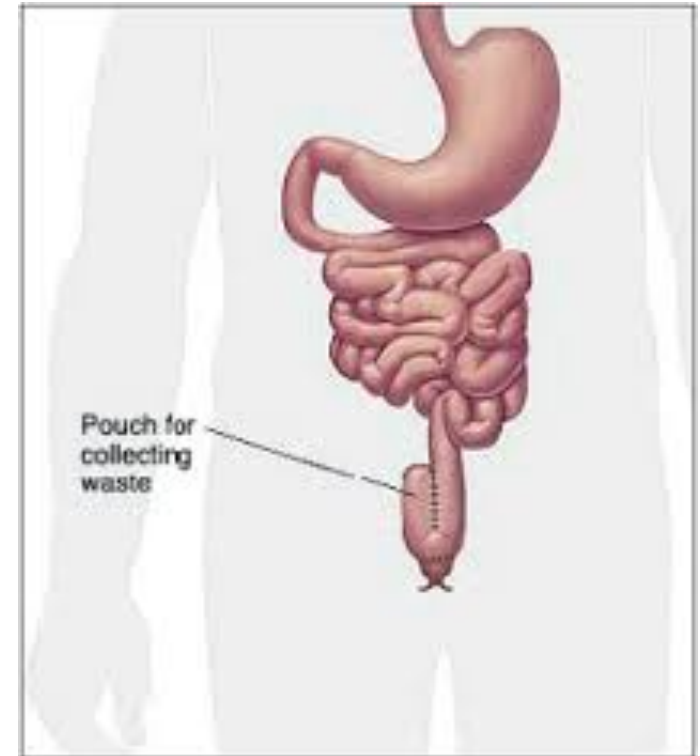
6 Consultant colorectal surgeons:

3 laparoscopic

2 open surgery

1 single incision laparoscopic surgery
(SILS)

- Pioneering work into SILS /TA
- Research facilities
- National database



Only centre in the UK with a team of dedicated pouch nurses

The Pouch Team

Unique service

Qualified stoma nurses with a specialist interest and advanced training in ileoanal pouch care

Mediator between the gastroenterologist and surgeon

Only see patients who are thinking about a pouch, have a pouch or had a pouch!



Workload

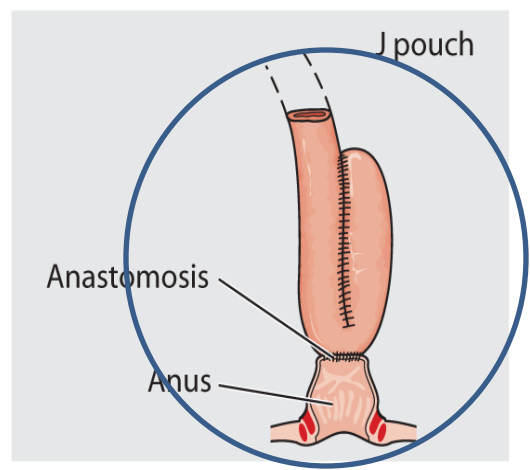
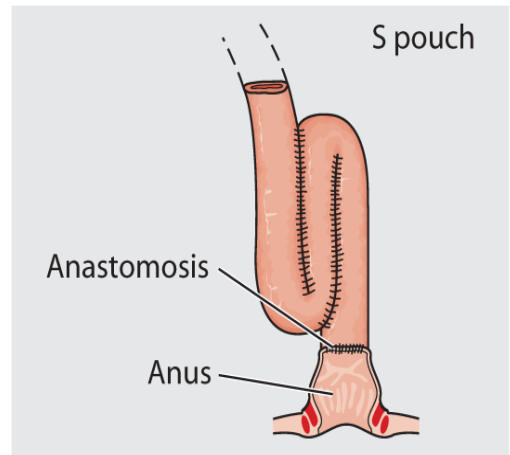
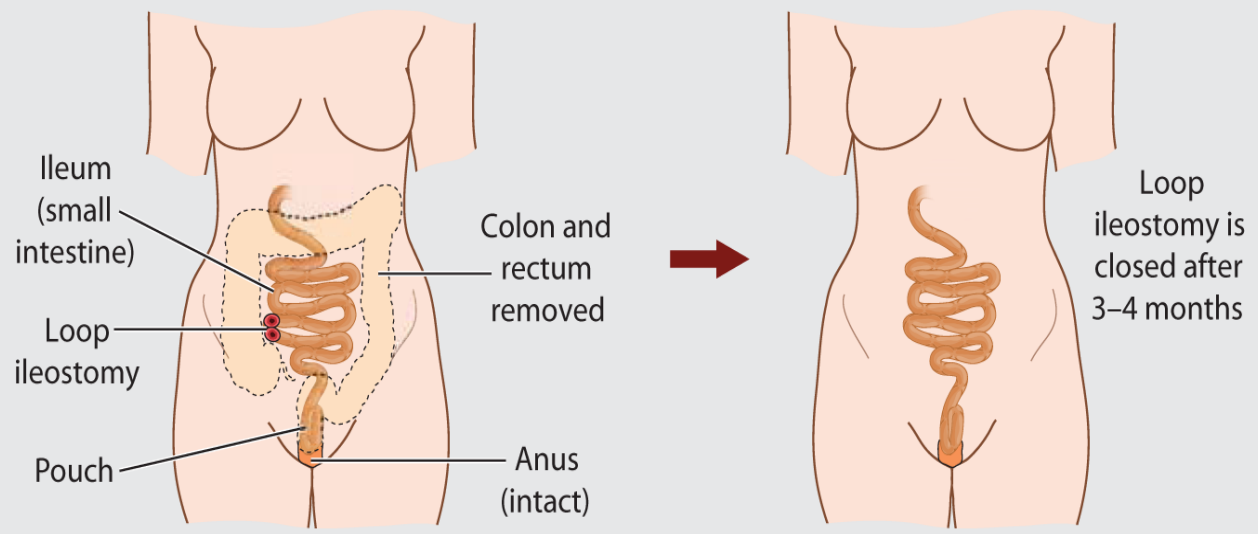
Tertiary and local referrals generate

Annual average:

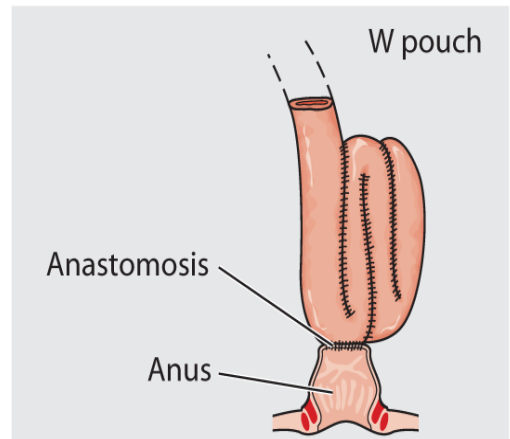
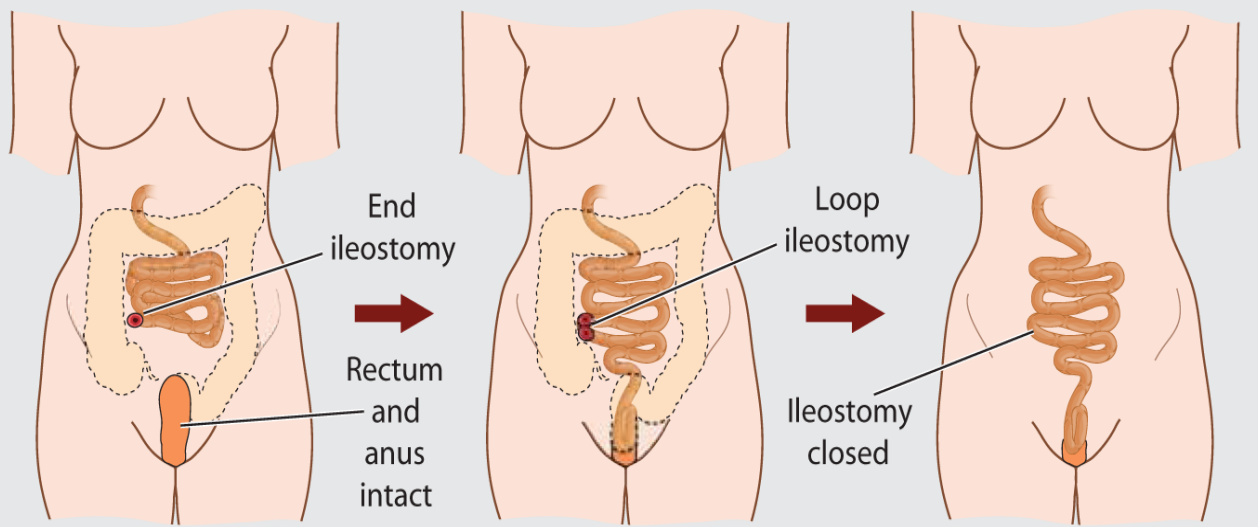
- 86 new stomas
- 43 new pouches
- 2 redo- pouches

- 40 stoma closures (including FAP)

2-stage proctocolectomy



3-stage proctocolectomy



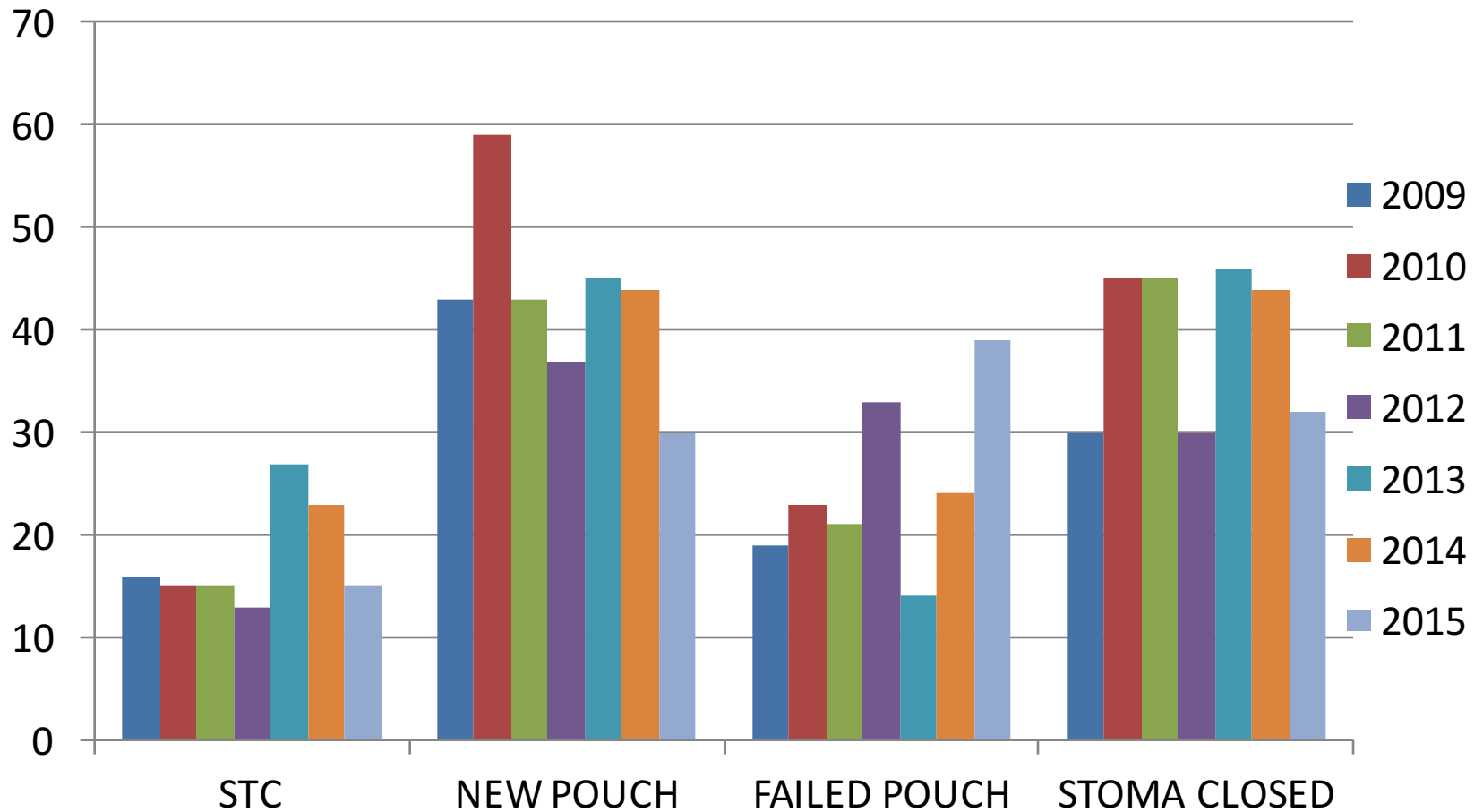
Patient Concerns After Stoma Reversal

- Felt unable to talk to their stoma / IBD nurse
- Medical staff focused on their physical recovery
- Reinstated their concerns to different members of the team
- No long term follow up plan
- Varying information on internet, forums and pouch support groups
- Frustration with lack of GP knowledge

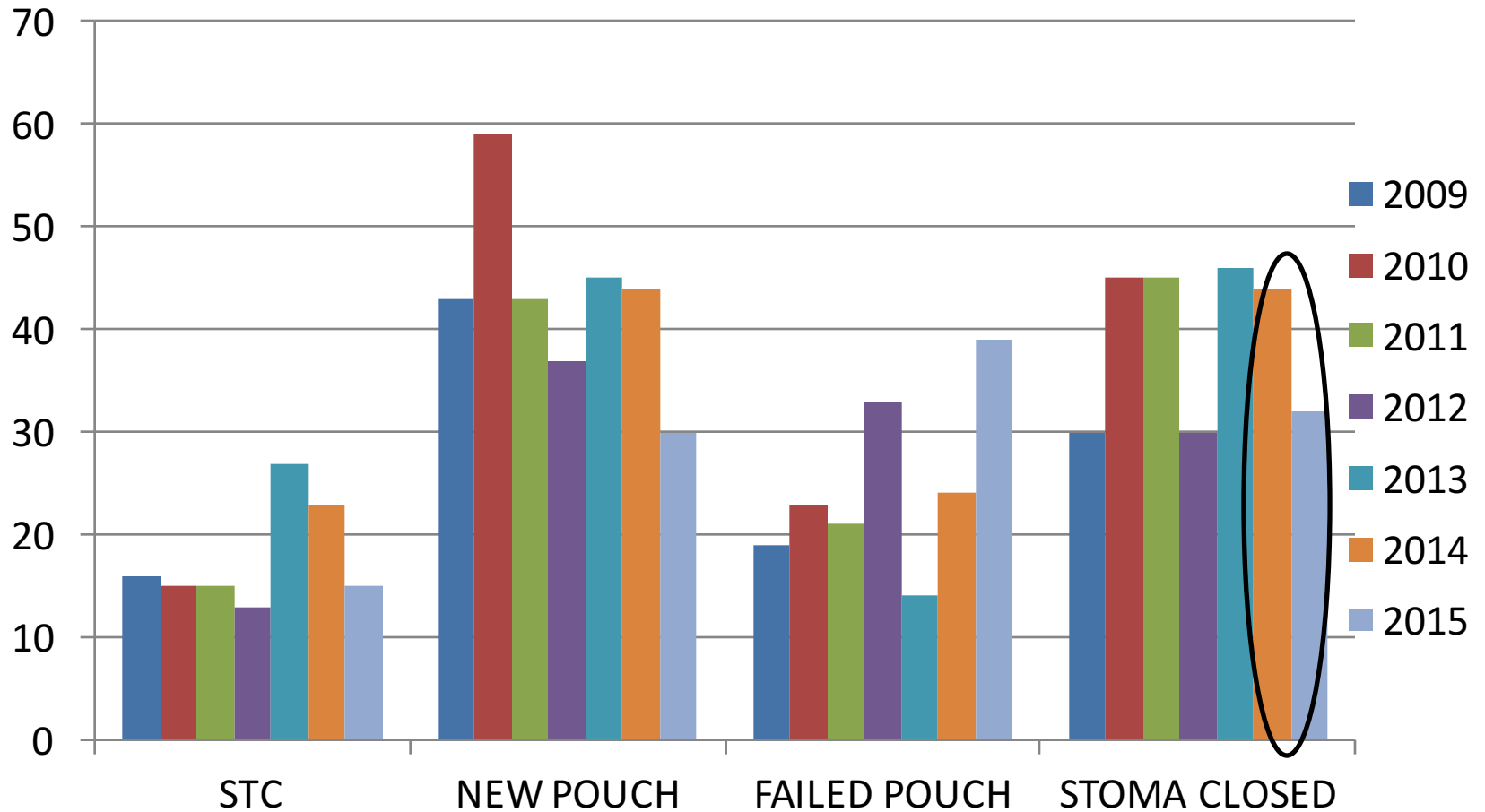
Nurses Concerns After Stoma Reversal

- No structured follow up for UC patients
- 6 surgical clinics - different guidelines
- Seen by consultant, RSO or research fellow
- Discharged at 6 weeks/not discharged
- Offered investigations eg pouchoscopy
- Varying degrees of diet/lifestyle advice
- Unable to review patients in consultant clinics

Pouch Related Operations



Pouch Related Operations



Hypothesis

Introducing a structured nurse-led follow up programme improved patient experience and quality of life after stoma reversal.

- Could we reduce hospital/clinic readmissions?
- Reduce GP appointments?
- Reduce surgical clinic appointments?
- Provide a better co-ordinated service?
- Change current practice?

Planning the 'Closure Clinic'

- Literature review
 - ❖ McGlynn B. et al (2004) The development and audit of a nurse-led clinic *Nursing Times* 100(12);54-56
 - ❖ Perrin A. (2005) Development of a nurse-led ileoanal pouch clinic. *British Journal of Nursing* Supplement 14(16), s21-24
 - ❖ Perry-Woodford Z.L. (2008) A clinical audit of the ileoanal pouch service at St. Mark's Hospital. *Gastrointestinal Nursing* 6(2), 36-39

Long term follow up relates to incidence of complication

Health related quality of life- secondary outcomes

No primary research on initial follow up

Planning the 'Closure Clinic'

- Initial discussion with surgical consultants, pouch team, secretarial staff and outpatient staff
- Discussion with patient groups
- Questionnaire design

Questionnaire Design

3 part questionnaire:

1. Cleveland Global Quality of Life Score
2. Pouch functional score - symptoms
3. Pouch functional score - restrictions

Patient Label

Part 1: Quality of Life Score

Date: _____

Approximate time since closure: 6 weeks 3 months 6 months 12 months

Date of stoma closure: _____

Date of RPC: _____

1. Cleveland Global Quality of Life Score

Please rate the following on a scale of 0-10, where 10 is the best.

Current quality of life	
Current quality of health	
Current energy levels	

Please tick the box which best describes your symptoms.

24 Hour Stool Frequency	
0-5	
6-8	
9-10	
>10	
Nocturnal Stool Frequency	
0-1	
≥2	
Urgency	
No	
Yes	
Major Incontinence	
Never	
Rarely	
Sometimes	
Mostly	
Always	
Minor Incontinence (Seepage)	
Never	
Night	
Day	
Both	
Anti-diarrhoeals eg. Loperamide	
No	
Yes	
Antibiotics	
No	
Yes	

Part 2: Pouch Function-Symptoms

Part 3: Pouch Function -Restrictions

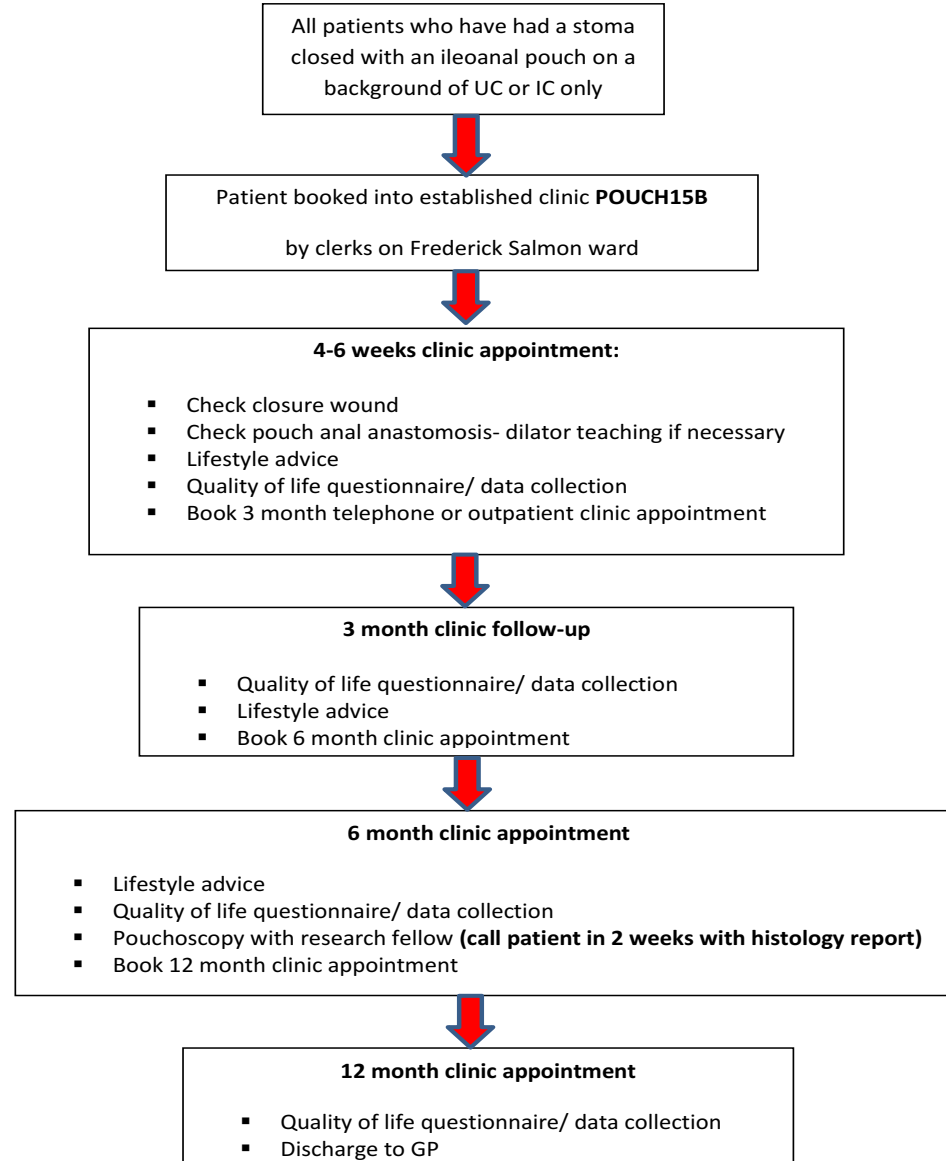
The following questions assess whether your symptoms have an impact on your life. Please circle the appropriate box and provide details if necessary.

	YES	NO	Details of restrictions		
Social Restriction	YES	NO			
Work Restriction	YES	NO			
Dietary Restriction	YES	NO			
Sexual Restriction	YES	NO			
Trying to get Pregnant	YES	NO	Pregnancy since pouch surgery	YES	NO

Protocol Design and Validation

PROTOCOL FOR NEW 4-6 WEEK STOMA CLOSURE CLINIC

OUTPATIENT NURSE-LED POUCH FOLLOW-UP



Data Collection

- Hospital discharge - patient given date for first follow up visit within 4-6 weeks
- Contact details provided
- Patient details form completed

Patient Label

Patient Details

▪ **Preferred method of contact:**

Telephone:

Email:

- **Diagnosis:** UC UC with cancer UC with dysplasia Other

- **RPC Stages:** 3 (end stoma) 2 (loop stoma) 1(no stoma)

- **STC** Date: _____ Emergency Routine

- Laps Open SILS

Complication _____

- STC Performed at St Mark's? Yes No Referred from _____

- **RPC** Date: _____

- Laps Open SILS

Complication _____

- RPC Performed at St Mark's? Yes No Referred from _____

- **Closure** Date: _____

Complication _____

- **Any other information:**

Data Collection

- Questionnaire repeated at 3, 6 or 12 months
- Data compared from previous questionnaire
- Reassurance and lifestyle advice reinstated
- Clinical advice provided or investigation requested
- OPA made for subsequent visits

- Letter dictated to GP, notes and patient

This patient was seen today in clinic for routine follow up following stoma reversal 6 weeks/ 3 6 12 months ago. She/He is doing well and the pouch frequency is within normal limits for this period approximately times in 24 hours.

The closure site is completely healed and I have performed a digital examination to ensure the integrity of the anastomosis.

We have discussed pouch compliance and urge resistance techniques and reinstated diet and lifestyle advice. They have completed the quality of life questionnaire and we have discussed any concerns that may have arisen.

The patient is not/using Loperamide.

I have/have not requested a pouchoscopy as there was dysplasia/cancer noted at colectomy.

I have made an out-patient appointment on for their 3 6 12 month follow-up appointment.

We no longer routinely follow up pouch patients therefore I am discharging him/her back into your care. I would be grateful if you can arrange annual blood tests to include full blood count, urea and electrolytes, liver function tests, ferritin, folate, Vitamin D and Vitamin B12 and treat as appropriate. I have asked the patient to make an appointment to discuss this with you.

- Discharged from routine follow up at 12 months unless history of dysplasia, cancer, chronic pouchitis or PSC

Results from 41 patients

(Jan 2014 - Jan 2016)

	6 weeks	3 months	6 months	1 year
Total	41	34	26	18
Loperamide	17 (41%)	20 (58%)	13 (50%)	12 (66%)
*Antibiotics	3	1	2	2

FAP patients not included in sample

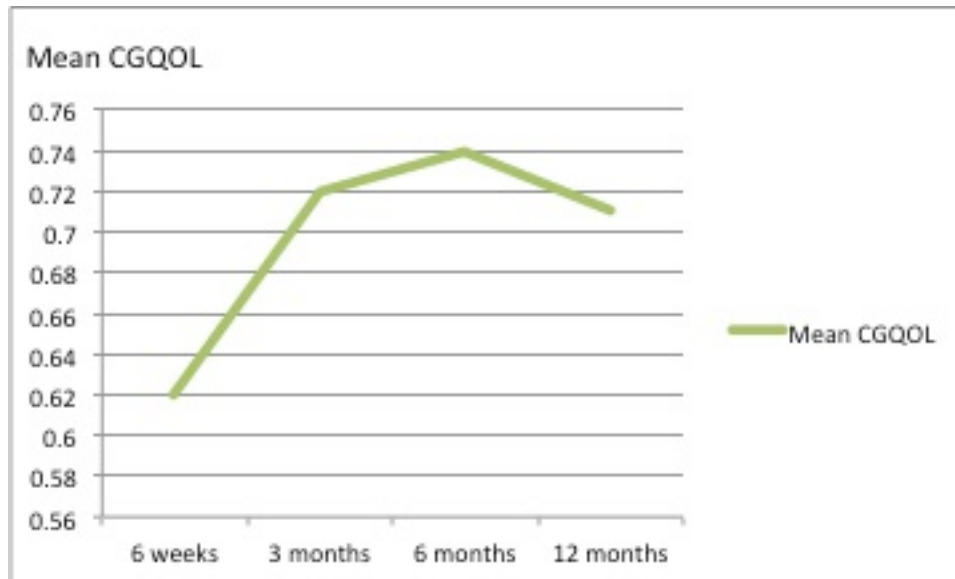
1 patient pouch defunctioned at month 10

9 patients lost to follow-up

* Antibiotic used for wound infection not pouchitis

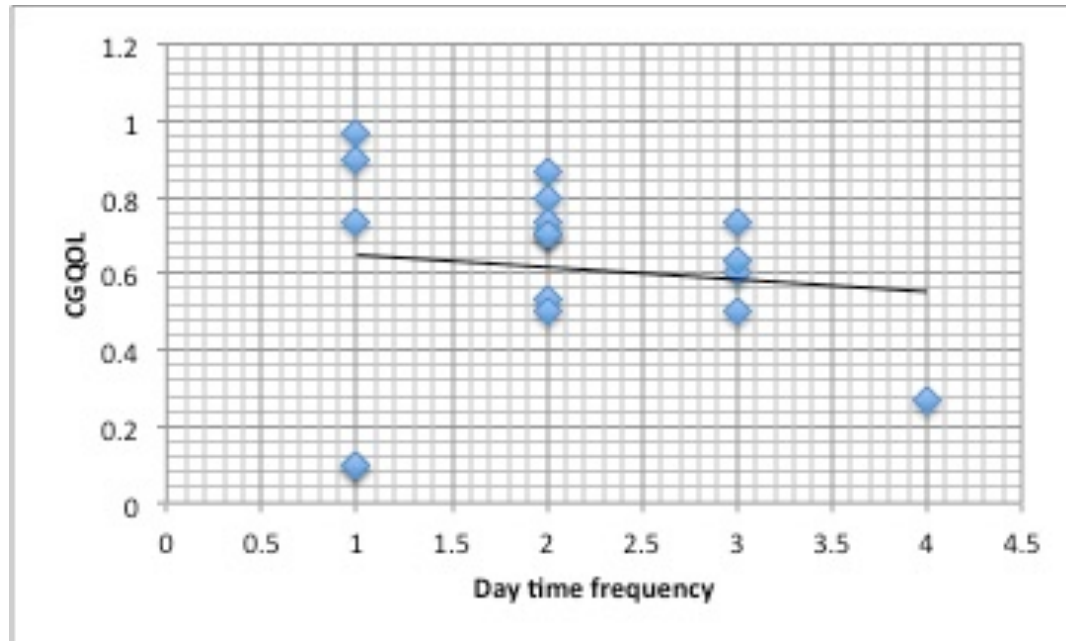
Outcomes

- QoL increases initially but then decreases.....



- ? Will plateau after 1 year

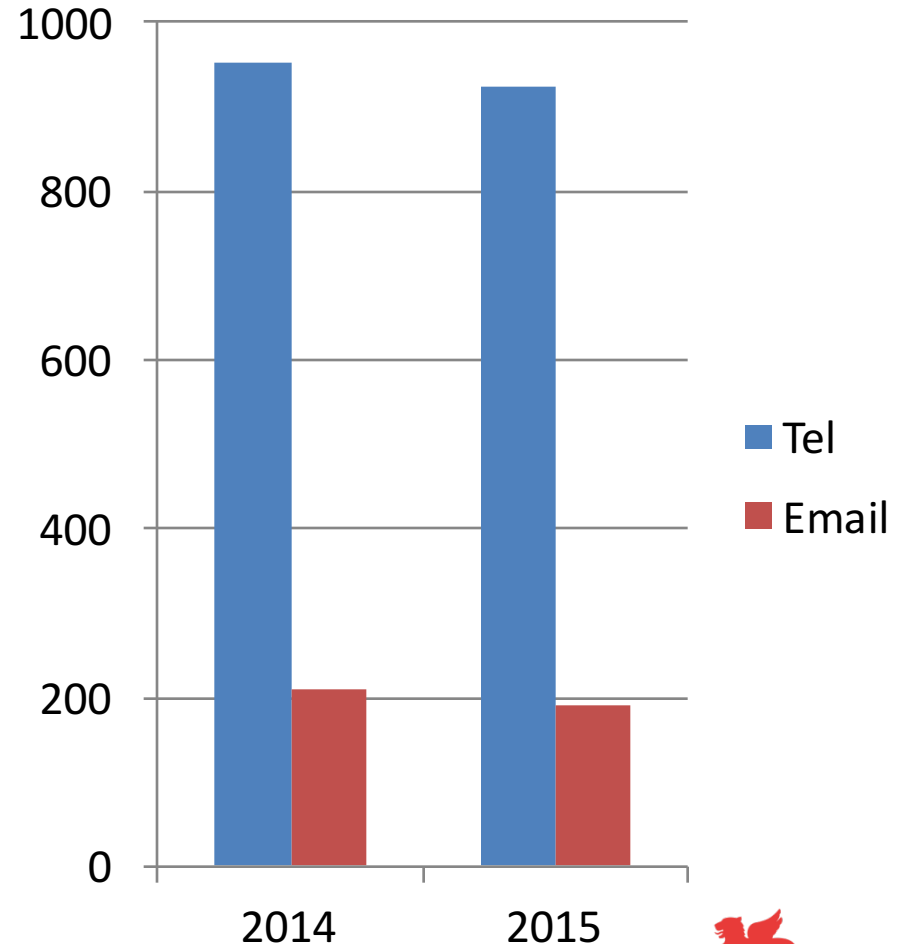
Daytime Frequency Significantly Affects QoL



12 months $p = 0.001$

Clinical Significance

- Slight reduction in outpatient telephone and email contact
- More significant reductions in nature of calls
↓
...queries about diet, lifestyle, pouch frequency, defaecation difficulties, general reassurance.



Pitfalls

Very slow uptake

- Patients booked into consultant and nurse led clinic
- Misunderstanding of service provision from patients and colleagues

Time allocation/management

- Follow up from clinic eg. appointments, further investigations, documentation
- Audit and protocol development
- Staff shortages

Patient issues

- Patient confidence in nursing staff performing 'doctor's role'
- Patient remembering appointment
- Tertiary patients telephone instead of clinic visit

Conclusion

- There is obvious benefit to patients receiving co-ordinated care we have not yet requested feedback from patients as to the effectiveness of this follow-up
- Difficult to get a similar cohort to compare (retrospective?)
- ? Ideal length of time follow up required
- Reduced patients in consultant clinics/GP/A&E
- Change practice (offer Loperamide earlier, stop patients having antibiotics at GP within 12 months)

If this proves to be of value to patients and is clinically beneficial and economical, then this pathway can be used as a national standard for follow-up for stoma closure after ileoanal pouch formation.

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