

crohn's and
colitis
UK



Inform
Support
Research

11:00 – 11:10: Welcome and Introductions:

Heather Baumohl: Director : Crohn's and Colitis UK

11:10 – 11:20: New Legislation; New Structures; New Regulators - New Opportunities for Patient involvement & Influence?

Peter Canham Patient Involvement Adviser: Crohn's and Colitis UK

11:20 – 11:45: Designing an Inpatient Survey on your Local Gastro Ward

Exercise in small groups

11:45 – 12:30: Patient Involvement in Planning a New Service: North Tees

William Horsley: Doctoral Research Student: Durham University

12:30 – 1:30 – Lunch and Networking

1:30 – 1:45: A Local IBD Patient Panel - an Overview of Achievements

Elaine Steven: Cumberland Infirmary IBD Patient Panel

1:45 – 2:00: IBD Patient Panels – 2011: Where next?

Peter Canham Patient Involvement Adviser: Crohn's and Colitis UK

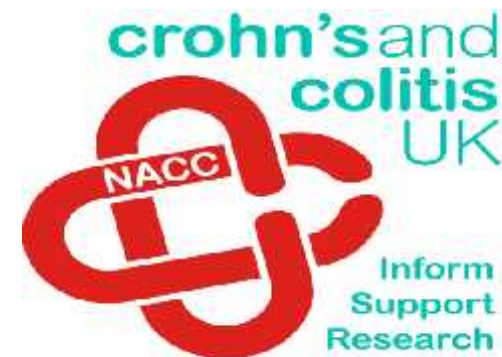
2:00 – 3:00: Planning a Campaign to Retain IBD Nurse

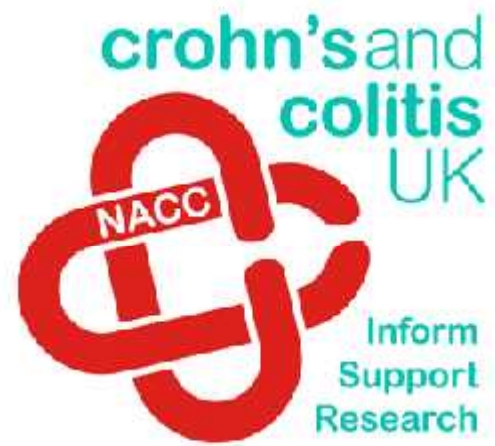
Exercise in small groups

3:00 – 3:15 Tea & Biscuits

3:15 – 4:00: Group Discussion: Q&A

4:00 Close





NHS Reforms – New Opportunities?

Nationally

(the regulatory bodies are similar ie picture is not that different):-

- HealthWatch
- Care Quality Commission
- NICE (Guidelines/Quality Standards/Drug Appraisals and NHS Evidence)
- MONITOR
- NHS Commissioning Board

NHS Reforms – New Opportunities?

Locally (ie the level at which PtP's work):-

- PCT's & SHA's replaced by GP Consortiums/
Clinical Commissioning Group/Clinical
Senates/Clinical networks – but not yet clear where
the Patients voice will be (lay member on the CCG)
- LINK's replaced by local HealthWatch – but with a
greater emphasis on Public Engagement and local
picture will vary
- Greater involvement of Health and Wellbeing
Boards
- Public Health moved (back) to Local Government
- All hospitals will become Foundation Trusts

Key levers that PtP's can pull



 **Quality Care**
Service standards for the
healthcare of people who
have Inflammatory Bowel
Disease (IBD)



THE IBD STANDARDS GROUP
Association of Coloproctology of Great Britain and
Ireland • British Dietetic Association (Gastroenterology
Group) • British Society of Gastroenterology • British
Society of Paediatric Gastroenterology, Hepatology
and Nutrition • National Association for Colitis
and Ulcerative Disease • Primary Care Society for
Gastroenterology • Royal College of Nursing (GIBS)
and Colitis Special Interest Group

UK Inflammatory Bowel Disease Audit 3rd Round

Report of the results for the national organisational audit of adult inflammatory bowel disease services in the UK

Prepared by the UK IBD Audit Steering Group on behalf of

- Association of Coloproctology of Great Britain and Ireland
- British Society of Gastroenterology
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition
- Clinical Effectiveness & Evaluation Unit, Royal Physicians of London
- Crohn's and Colitis UK

May 2011



IBD Audit - Started 2006 4 years charity funding 2010 – 2012 DoH funding Third round 2010 includes information for patients

Section 6: 2010 Individual Site Key Indicator Data

The tables in this section give named site data in alphabetical order of site by Strategic Health Authority in England and by Trust and Local Health Board in Northern Ireland, Scotland and Wales. Please note this describes the self reported site status on the 1st September 2010. These data items were agreed by the UK IBD Audit Steering Group as giving an indication of how an IBD Service is resourced and organized in relation to the IBD Standards. They are not a definition of clinical quality. The combined UK results from 303 participating sites are shown for comparison.

Key indicators	How many IBD patients does your IBD Service manage?		Does the IBD Service have a named clinical lead?	Are there at least 1.5 WTE IBD Nurse Specialists in the IBD Team?	Are there at least 0.5 WTE Dietitians allocated to gastroenterology?	Is there a designated gastroenterology ward on site?	Is there a multidisciplinary nutrition team?	Does the IBD Service provide written information for patients with IBD on whom to contact in the event of a relapse?	Can relapsing IBD patients expect to be seen for specialist review within 7 days of referral?	Are regular (scheduled) IBD Team meetings held to discuss IBD patients?	Are joint or parallel gastroenterology/colorectal surgery clinics held?	Are there guidelines for the management of Acute Severe Colitis?	Is a written care plan available for IBD patients?	Is there a shared care agreement with Primary Care?	Is there a specific paediatric to adult transition policy?
	Median = 703	25% = 418	Yes = 70%	Yes = 21%	Yes = 60%	Yes = 69%	Median = 4	Yes = 72%	Yes = 70%	Yes = 80%	Yes = 70%	Yes = 50%	Yes = 30%	Yes = 30%	Yes = 30%
East Midlands SHA															
Chesterfield Royal Hospital	700	F	Yes	No	Yes	Yes	1.5	Yes	Yes	Yes	Yes	Yes	No	No	No
Kettering General Hospital	1300	E	No	No	No	Yes	7	No	Yes	Yes	Yes	Yes	Yes	Yes	No
Lincoln County Hospital	1317	D	Yes	No	Yes	Yes	4.5	Yes	Yes	Yes	No	Yes	No	Yes	No
Northampton General Hospital	800	E	No	No	Yes	No		Yes	Yes	Yes	No	No	Yes	No	No
Nottingham University Hospital NHS trust (Queen's Medical Centre & Nottingham City Hospital Combined)	3662	D	Yes	Yes	Yes	Yes	5	Yes	Yes	Yes	Yes	Yes	No	No	Yes

IBD Standards PtP's can pull

- Standard C5 – Involvement of Patients in Service Improvement - Patient Panels/Open Forums/Questionnaires
- Standard E1- IT & Audit – Every IBD Service should maintain a register of **ALL** diagnosed IBD patients in the catchment area
- Standard A8 – In Patient Facilities - one easily accessible toilet per 3 beds
- Standard A1 – The IBD Team - 1.5wte clinical nurse specialists per 25,000 catchment population
- Standard A1 – The IBD Team – 0.5 wte Dietitian per 25,000 catchment population

Key levers that IBD PtP's can pull

- **Care Quality Commission**

Core Standard: C17

The views of Patients, their carers and others are sought and taken into account in designing, delivering and improving healthcare services

Key levers that IBD PtP's can pull

Government Support - response to the NHS
Future Forum Report:

'No decision about me without me' ...

The Bill is to be amended to underline the
importance of Patient Involvement in
Commissioning decisions and their duty to
promote it.

P14. para's 57 & 58

Key levers that IBD PtP's can pull

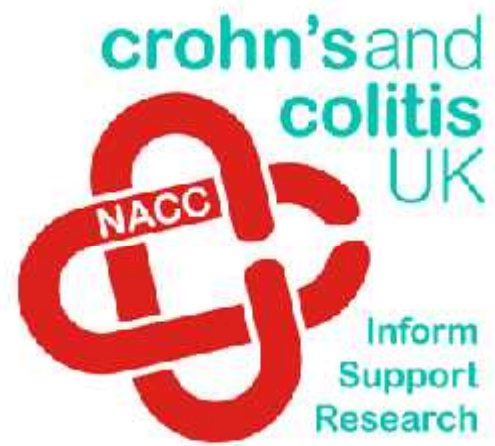
Your local NHS Foundation Trust must demonstrate that it listens to patients and responds to their concerns

It must also be able to demonstrate that it involves its Patients in planning and improving its services

It is required to produce evidence of this in its publicly available annual Quality Accounts

Key levers that IBD PtP's can pull

- ❑ People who have experience of IBD services can offer suggestions for improvements to that service that the people who provide it may never have thought of - or may not give have given sufficient priority to. The Patient's perspective.
- ❑ No service will be as good as it could be without the input of patients at every stage of delivering, planning and development



Patient Involvement in Planning a New Service: North Tees

William Horsley
Doctoral Research Student
Durham University

Involving patients in
the development and
use of care pathways:
Experiences from Stockton

William Horsley
PhD Student
Durham University

*No decision about me
without me*

Department of Health press release, July 2010

Patient Involvement: A key NHS policy

- Major feature of previous (Labour) government
- Continues in enhanced and emboldened form in coalition government:
'shared decision making'
- Much focus and guidance for NHS organisations on how to involve patients

Care Quality Commission

Core standard: C17

The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services

... legitimise decisions that would have been made whether or not patients supported them.

Systematic review of involving patients in the planning and development of health care.
BMJ 2002;325:1263

Early Involvement

What are the advantages of involving patients / users early in specific projects?

(take a few minutes to think about it)

Early Involvement

- Patients (users) will *always* be a key component
- Consider the impact if user views are brought in later
- Increases long-term efficiency
- Longer period in which to form relationships
- Enhances credibility and legitimacy with users and other parties

The Stockton IBD Pathway

- Integrated care pathway for new, existing and 'silent' patients with IBD
- Patient representation from the outset ...
... BUT not necessarily 'textbook perfect'
- Implicitly designed to deliver the IBD Standards of Care (2009)
- Explicitly expected to serve as an exemplar model for replication elsewhere

Patient Representation in Stockton

Project Board:

- Academic adviser
- Consultant gastroenterologist
- IBD specialist nurse
- Patient representative (1)
- Patient representative (2)
- Patient representative (3)
- Primary care medical lead
- Project manager

Patient representative 1:

Chief Executive Officer of NACC

Patient representative 2:

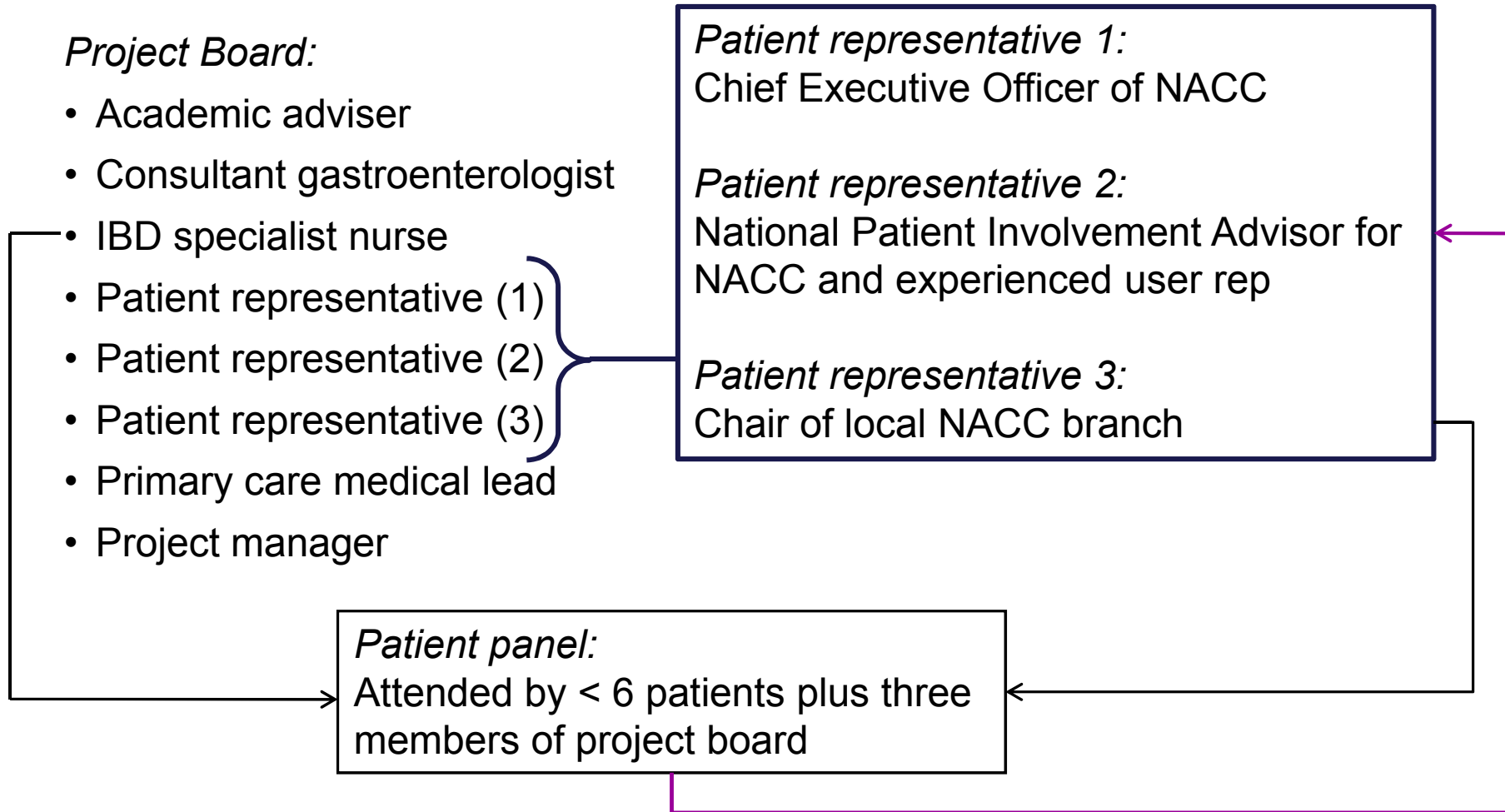
National Patient Involvement Advisor for NACC and experienced user rep

Patient representative 3:

Chair of local NACC branch

Patient panel:

Attended by < 6 patients plus three members of project board



Stockton

What do you notice about the patient representatives on the project board?

Project Board:

- Academic adviser
- Consultant gastroenterologist
- IBD specialist nurse
- Patient representative (1)
- Patient representative (2)
- Patient representative (3)
- Primary care medical lead
- Project manager

Stockton Patient Representatives

- Not actual patients
- All are members or employees of a leading patient charity
- None live in Stockton
- Not specifically trained for this role but they are already experienced user representatives
- Not paid or reimbursed for expenses or time. In-put is voluntary or part of primary employment.
- Not chosen or invited by other members

- What are the potential advantages and disadvantages of these factors?
- What are **your strengths** as a representative?
- What are **your potential weaknesses** as a representative?
- Think about how you will be viewed **AND** your character

Stockton Patient Representatives *additional strengths*

- Detached from NHS politics, influences and inherent biases
- Not directly influenced by contemporary NHS organisational changes
- Have experience and contacts beyond the locality

Beyond representation ...

... and into real and effective involvement

- Co-design of the pathway
- (Co-)Production of information products
- Treated as an equal partner
in all discussions
- Helping to implement the pathway
- Involved and informed with the
management of the pathway

Co-Design

- Ensuring that the pathway is complimentary to relevant published standards of care
- Affected organisational and financial flow of patients and not just position of care (removal of one element of patient choice that was considered unnecessary – from patient panel)
- Ensuring timeliness of care within the pathway
- Contributed to defining content of annual patient review

(Co-)Production of information sources

- Patient panel consulted on, and contributed to, acute care service pamphlet
- Produced introductory letter to inform patients
- Provided information packs via NACC for clinicians and patients
- Helped design the content of patient assessment tools

An equal partner in all discussions

- Determined composition of the project board
- Ensured **local patient** representation from non-patient organisation members
(**the patient panel link**)
- Brought in experiences of practice outside of the locality
- Able to confirm acceptance of, and confer good practice to, aspects of the project **
- Involved in most ex-meeting discussions and sometimes prompt meeting arrangements
- Often set the agenda during meetings

Implementing the pathway

- Participated in the launch event and presentation to commissioning consortia
- Participated in, and attended, practice training and education session
- Communicating to the wider patient audience including organising a presentation for local branch members

Management

- Scope for involvement is restricted
- Charity is major contributor to the academic evaluation
- Design contributions will have direct impact on management aspects
 - Maintaining a generic model which can be more easily replicated elsewhere

Contributions

- What do you think about the individual contributions described?
- What impact do these have individually within the greater project?

Summary of Stockton patient involvement so far

- Singularly subtle and small contributions
- Cumulatively these changes have had a substantial impact
- Faced challenges positively
- Have conducted themselves in a manner conducive to continued co-operation
- *At least* one representative has attended every project board meeting and all significant events

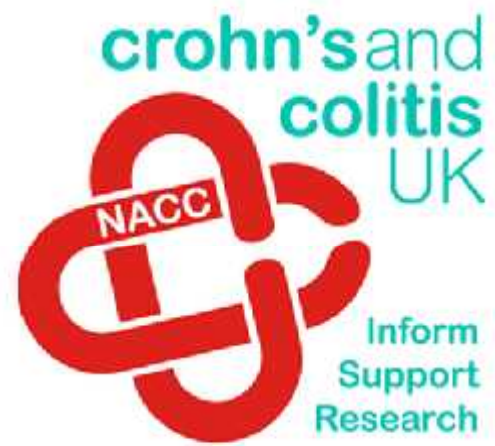
Further reading

User involvement in healthcare.

Greenhalgh T *et al.* BMJ Books 2011

Acknowledgement

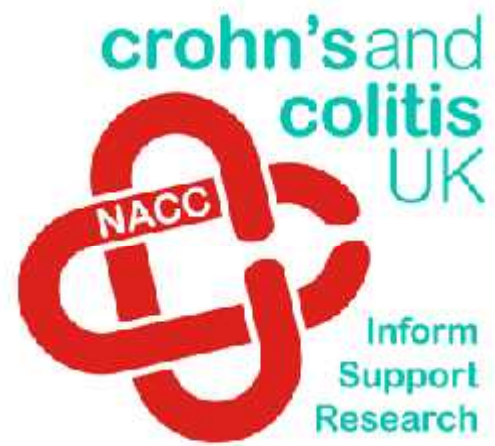
Research funded by NACC & PPRT (*bias?*)



PLANNING AN IBD IN-PATIENT SURVEY

Think about:

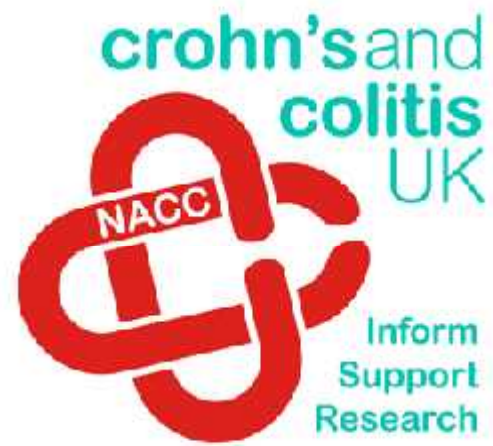
- Background research
- Who would you involve?
- What you want to get out of the survey?
- The methodology (numbers, distribution and collection)
- The questionnaire design and the key areas/sections to be covered
- Collation and report
- What would you do with the report?



Elaine Steven: Cumberland Infirmary IBD Patient Panel

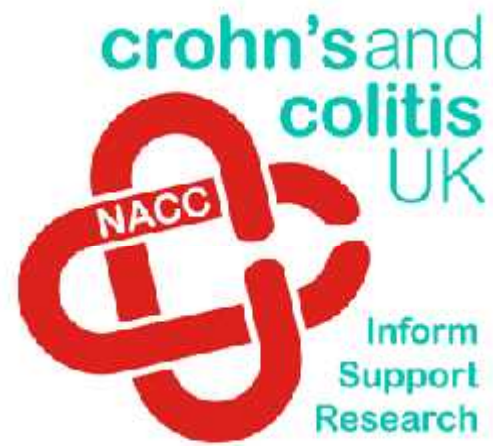
A Local IBD Patient Panel - an Overview of Achievements

- Bigger Changes
 - ✓ Contributed thoughts to draft IBD Standards
 - ✓ Dietetic Services
 - ✓ With local Group organised an Open Day
- Smaller but important improvements
 - ✓ Use of language
 - ✓ Admission through A&E
 - ✓ Now an informed and useful sounding board
- Not much success
 - ✗ Engaging with PCT



IBD PTP's – Where next?

- The Ipswich NHS Trust Model of Patient Involvement
- New ways of working
 - Websites
 - Use of social networking
 - Video conferencing
 - Open days
 - Open Forums
 - Parent & Family PtP's
 - IBD Standards
 - Surveys
- England - NHS Reforms
- Scotland/Ireland & Wales

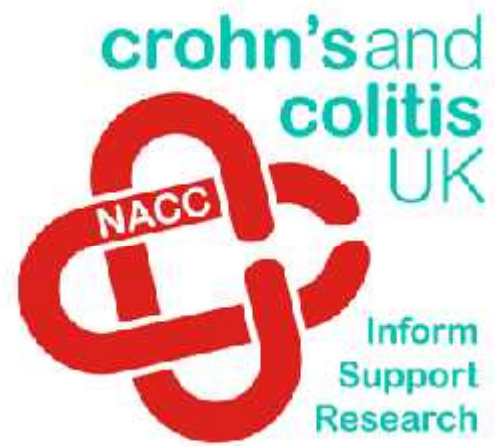


PLANNING A CAMPAIGN TO RETAIN YOUR IBD NURSE

Produce an Action Plan with clearly defined key action points

Think about:

- Who do you involve?
- What allies might you have
- What background research/evidence do you need to find?
- What are the stages you might go through (think stepped escalation first within your hospital and then without)
- Who and how would you take your case to? (Think about the key levers available to PtP's)
- Plan a meeting with your MP's
- Write a Press release/Plan a feature
- On line petition?
- Anything else?



Discussion Forum

SHARED EXPERIENCES

Q&A

