

# Il ruolo dell'infermiere nella gestione del paziente con IBD

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**Qual è il ruolo  
dell'infermiere nella  
gestione del paziente con  
IBD?**

# Agenda

- Un ruolo o più ruoli?
- Perché un infermiere?
- Come attuare il ruolo?
- Quali risultati possiamo attendere?
- Cosa può fare un infermiere per la mia IBD Unit?

# Le risposte

## **Possiamo cercarle in letteratura**

- Articoli in riviste scientifiche?
- Libri di testo?
- Position statements?
- Linee guida?
- Standard minimi consigliati?

RESEARCH PAPER

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nurse REVIEW ARTICLE

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# Contribution of nurses to the quality management of inflammatory bowel disease: A synthesis of the evidence

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flexibility  
reflective  
enthusiasm

Roles descriptives  
for inflammatory  
bowel disease  
nurse specialists

RCN guidance

approachability

sensitivity

# Le risposte

Possiamo cercarle in letteratura

- Articoli in riviste scientifiche?
- Libri di testo?
- Position statements?
- Linee guida?
- Standard minimi consigliati?

**Oppure possiamo cercarle sul campo... come avvenne  
agli esordi di un movimento rivoluzionario...**

# Ask the boys!

- Ask the patients
  - Patient centered care
- Ask the consultants
  - Service centered care



# Restiamo in UK

(un po' più tardi dei tempi di BP)

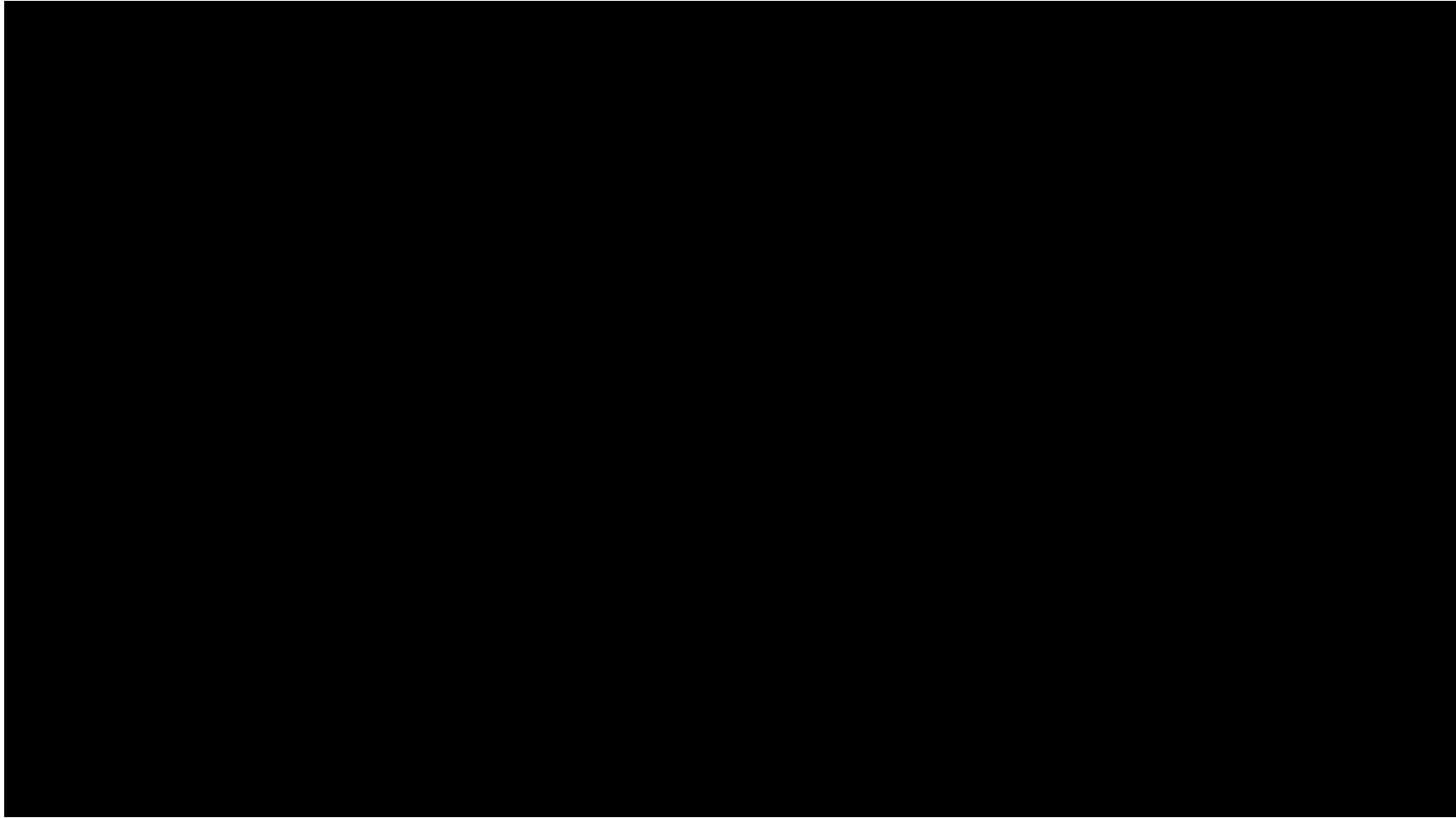
I primi “IBD nurse” compaiono negli ospedali del Regno Unito nei primi anni 90 per cercare una soluzione ad una serie di problemi percepiti...  
(...oltre ai problemi connessi con le ridotte risorse per il NHS e ai problemi connessi alla carenza di medici...)

# La definizione del ruolo

1. A patient questionnaire
2. Focus groups
3. Process mapping
  - These identified that **access to the gastroenterology team during periods of exacerbation was poor** and that prolonged periods of ill health **had an impact on patients' home lives, sexual relationships and work life.**
  - The **level of understanding** that patients with IBD had about their condition and its management **was poor.**
  - A considerable number of patients were **unable to describe the pathology of their condition and the rationale of their therapeutic management.**

# Rapid access service

- To improve access to the gastroenterology team a **telephone helpline** was established, run by the nurse specialist.
- Patients could seek general advice around IBD, while those who had an exacerbation of their condition could contact the team, and additional clinic spaces were created to enable **rapid access** review.
- This enabled patients with exacerbating IBD to be reviewed **within five working days**.
- Over the past four years 2,800 contacts have been recorded, 1,600 for general advice and 1,200 related to the management of an exacerbation.



# Outpatient clinic

- It is well documented that **nurse-led clinics** increase support and education for patients (Rowlinson, 1999), improve compliance with medication (Nyatanga, 1997) and promote self management (Robinson et al, 2003).
- The service was developed to include **three outpatient clinics each week, reviewing nine patients - normally seven follow-up patients and two with exacerbating disease.**
- During the review **patients are educated** around coping mechanisms, pregnancy, lifestyle choices, holiday and travel, smoking cessation, nutritional status, compliance with medication, colorectal cancer and osteoporosis awareness.

# Outpatient clinic

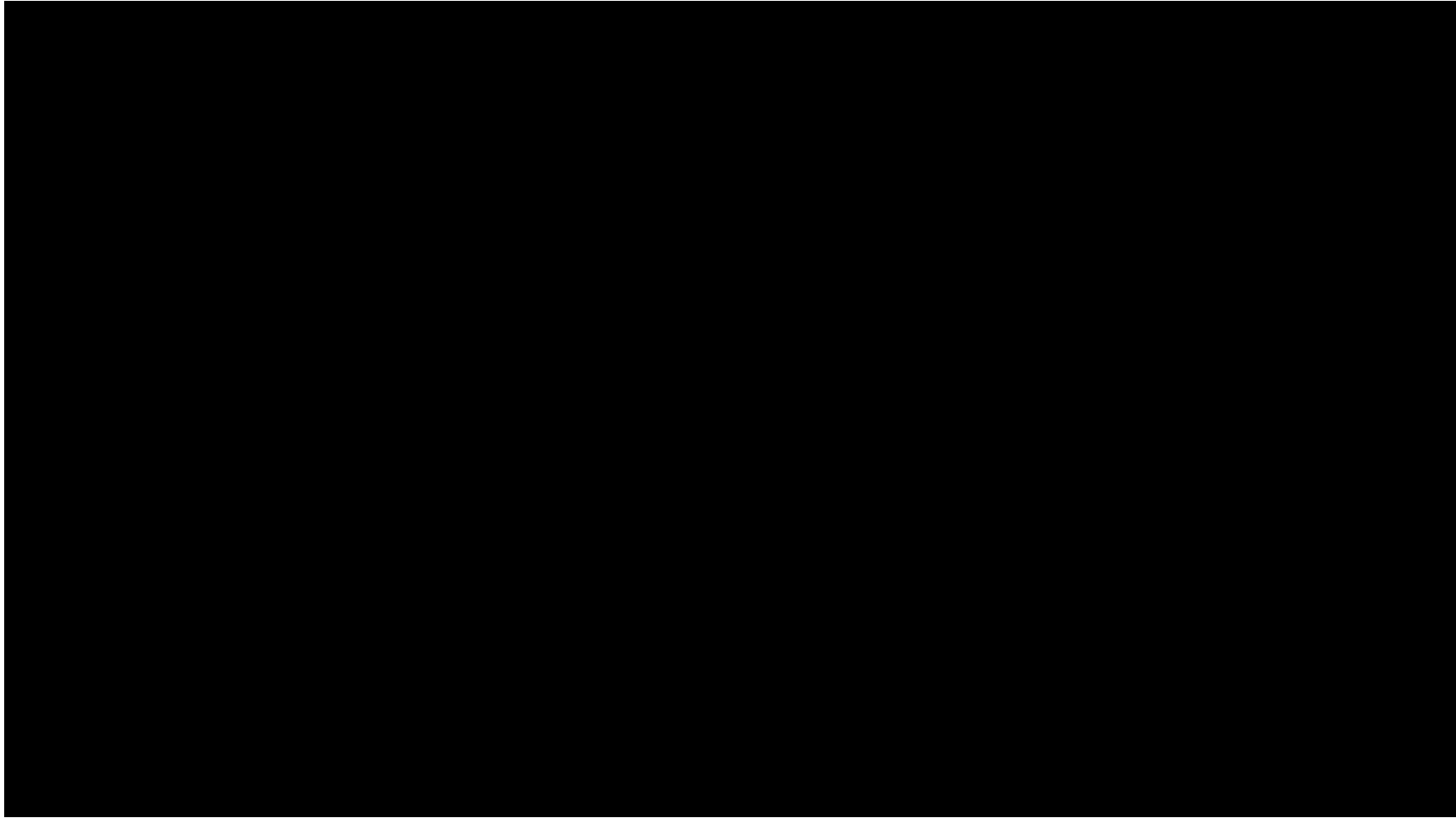
- Patients with exacerbating disease are assessed holistically and clinical examination undertaken.
- Medication is then prescribed under the supplementary prescribing guidelines (DH, 2003).

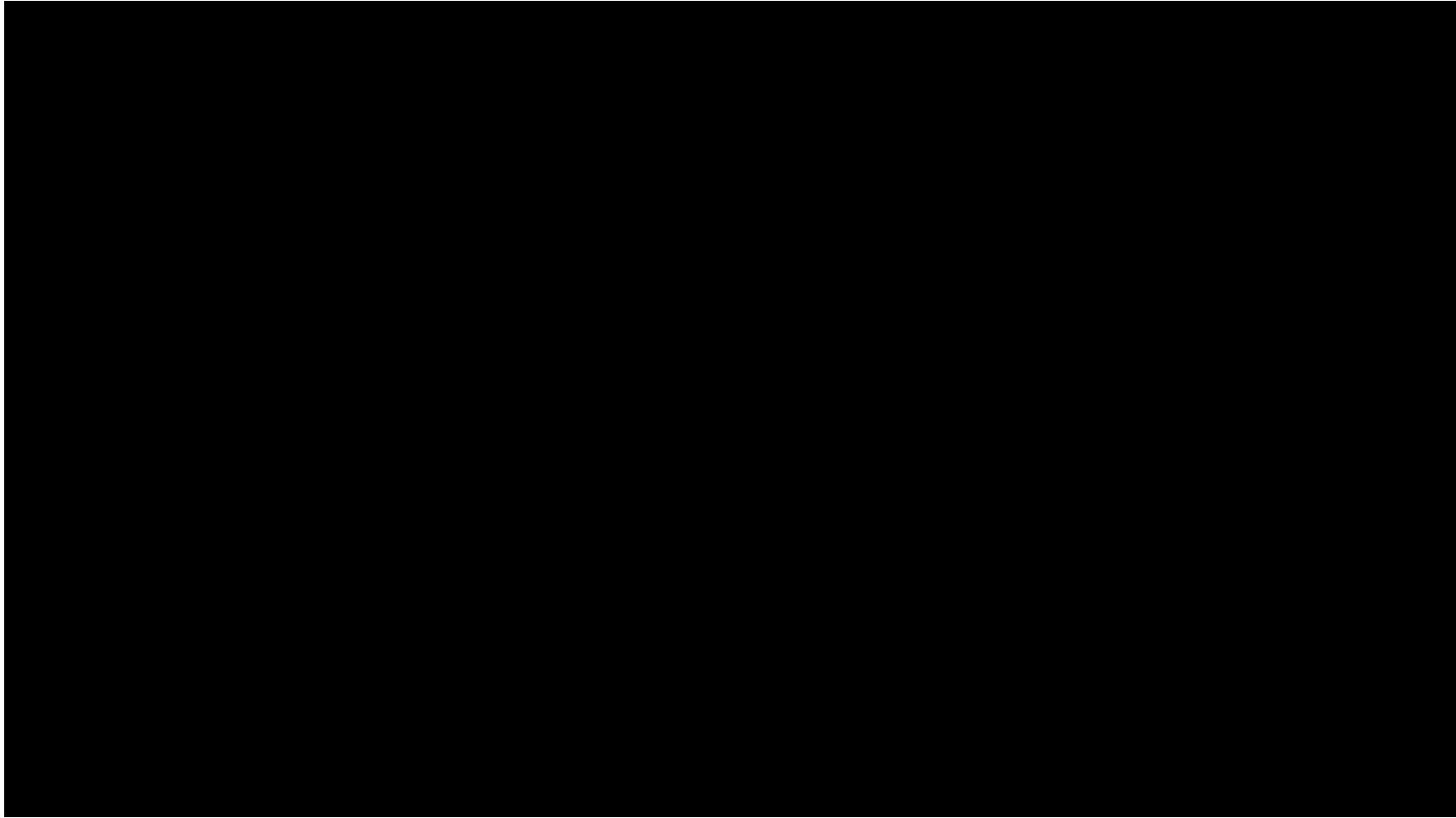
# Immunosuppression therapy

- An increasing part of the role of an IBD nurse is the **coordination of immunosuppression therapy** (Buckton, 2003).
- Approximately 20% of patients receiving immunosuppression therapy experience **side-effects** (Carter et al, 2004).
- Gastrointestinal disturbances, hepatitis, renal impairment, myalgia and bone marrow suppression are the most common (Forbes, 1997).
- As a result, **careful monitoring is essential.**

# Immunosuppression therapy

- The IBD nurse assumes responsibility for the coordination of haematological monitoring and counsels and educates patients regarding the rationale for therapy, potential side-effects and necessity of ongoing monitoring.
- The nurse is also responsible for ensuring **safe administration of infliximab or anti-tumour necrosis factor** (anti-TNF).
- The IBD nurse's role includes **supporting other nurses** through education to ensure patients make an informed choice when considering infliximab.





# Telephone clinics

- To review patients with quiescent disease.
- In response to concerns raised by the gastroenterology team regarding the care of patients discharged to primary care, and patients who identified that attending hospital appointments when well was unsatisfactory, as they had to take time off work, arrange childcare and face long waits in clinic.
- These outcomes were also identified by Miller et al (2002).
- **Colorectal cancer surveillance** is recommended in patients with IBD, who are considered to have an increased risk of developing colorectal cancer.
- This is considered in the telephone review and, with the patient's agreement, a colonoscopy is requested in accordance with British Society of Gastroenterology guidelines (Carter et al, 2004).

# Telephone clinics

- The frequency of this test is determined by the length of diagnosis, for example patients with ulcerative colitis affecting the whole colon would have a colonoscopy every nine years in the first decade, every five years in the second decade and annually thereafter.
- **Compliance with medication** is also assessed in the telephone clinic review.
- For follow-up appointments patients are given the choice to attend an outpatient clinic or to have a further telephone clinic review.
- **The telephone clinic is supported with the telephone helpline, enabling rapid review if necessary.**





# Inpatient care

- On average six IBD patients are admitted each month.
- The specialist nurse visits on alternate days, providing **expert advice and support**.
- An IBD multidisciplinary team meeting - consisting of gastroenterologists, colorectal surgeons, histopathologists, radiologists, dietitians and nurse specialists - has been established to discuss complicated IBD patients.

# Ask the colleagues!

- Ask about problems and solutions
  - Proactive approach
- Ask about experience
  - Ideas and results



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CONSENSUS/GUIDELINES

## N-ECCO Consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis



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- (1) Fundamental IBD Nursing
- (2) Advanced IBD Nursing
- (3) Nursing care for particular situations (e.g. fatigue, pregnancy, incontinence)
- (4) The Benefit of an IBD Nurse.

# Fundamental IBD nursing

N-ECCO Statement 2C

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N-ECCO Statement 2G

N-ECCO Statement 2J

Nurses may be well placed to identify, acknowledge and provide treatment and support for patients with IBD experiencing pain. Causes of pain may be multifactorial and not always linked to disease activity. Nurses, through discussion and collaboration with MDT, may help patients to manage this symptom [EL 2].

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# Fundamental IBD nursing

- Advocacy (informazione supporto nelle decisioni)
- Comunicazione, empatia, informazione, empowerment
- Lesioni cutanee – stoma care
- Supporto ad una corretta alimentazione -nutrizione
- Incontinenza fecale - biofeedback
- Counseling inerente la sfera sessuale
- Fatigue – astenia – mancanza di energie
- Corretta gestione/autogestione del dolore

# Advanced IBD nursing

## N-ECCO statement 3M

The Advanced IBD Nurse has a responsibility to document clearly and communicate where relevant beyond the direct MDT, adhering to country specific policy. Regular audit and survey to review process and ensure quality is recommended [EL5].

## Statement 3G

Consideration needs to be given to the care

## 3H

ing assessment is both wide ranging and able to focus on specific areas of concern.

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## N-ECCO Statement 3J

## N-ECCO Statement 3L

The Advanced IBD Nurse can conduct patient reviews face to face, via telephone consultation or by electronic means [EL4]. If carrying out non face-to-face assessments the Advanced IBD Nurse must be aware of the limitations of this type of contact and use skilled judgement in knowing when further review may be needed. Regular review enables the IBD nurse to monitor the patient, their treatments, and arrange appropriate investigation as required [EL 5].

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# Advanced IBD nursing

- Esperto clinico autonomo con formazione post-base
- Educazione sanitaria, ricerca, sviluppo, management
- Gravidanza
- Transition clinic
- Terapie biologiche
- Follow-up
- Advice line

# The benefit of an IBD nurse

## N-ECCO Statement 4A

The Advanced IBD Nurse provides a pivotal and important role in the care of the IBD patient, which benefits the patient, the MDT, and the healthcare provider [EL 5].

# Fabbisogno di ricerca

## N-ECCO Statement 4B

Further research is needed to assess the impact of IBD specialist nursing interventions. To achieve this, the Advanced IBD Nurse needs to participate in and conduct research activities appropriate to their role [EL 5].

# Agenda

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# Ask the boys!



- Ask the patients...
  - Patient centered care
- ...discuss with (and learn from) colleagues...
- ...and talk to the consultant...
- ...and negotiate with administrators, too!