

Shared decision making in long term management of Inflammatory Bowel Disease

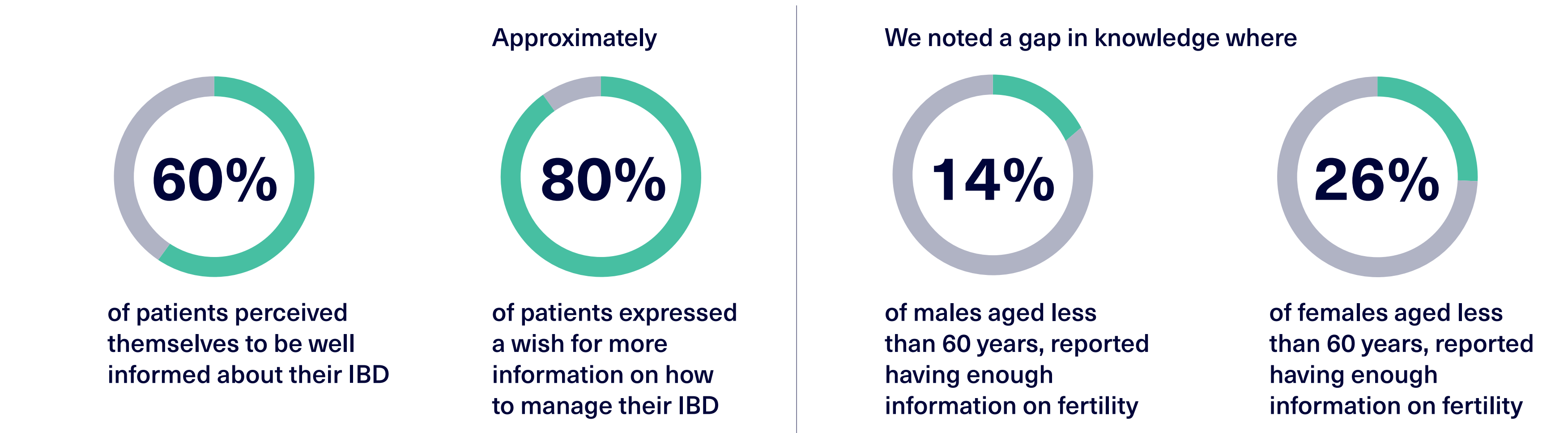
Patient Information Forum
and St Mark's Institution

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The challenge

Inflammatory Bowel Disease (IBD) is a lifelong inflammatory gut condition, characterised by periods of relapses and remission. Patient centred care is one dimension of high-quality care and included in IBD Standards Care Statements.¹ **Shared decision making** is one aspect of patient centred care that depends on disease education.

In a recent survey of 150 patients attending St Mark's Hospital, London, 60% of patients perceived themselves to be well informed about their condition and yet reported low levels of knowledge on self-management during a flare. There was no framework by which to offer regular education to support **shared decision making** early in the disease course.



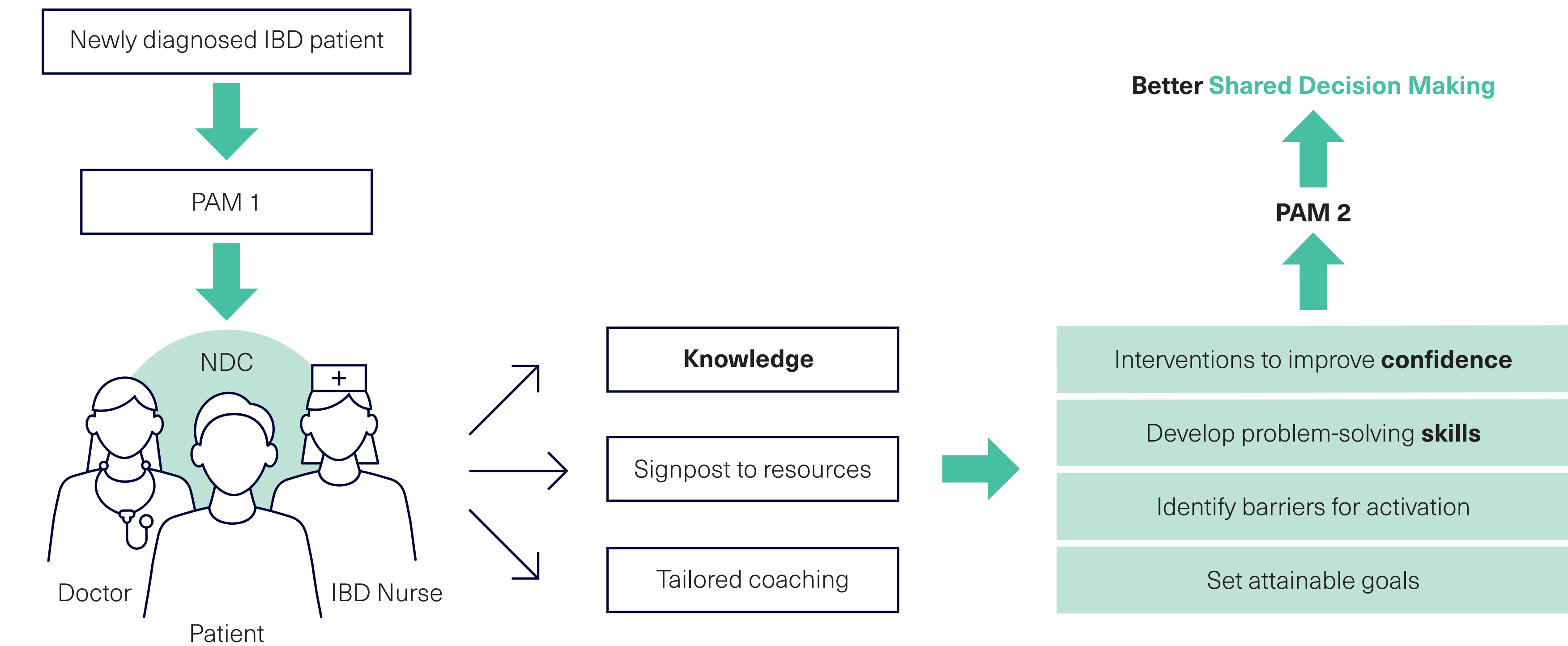
The solution

Patient empowerment with knowledge, skills and confidence ('patient activation') is associated with better outcomes in many chronic diseases, including IBD.^{2,3} A study of 1222 patients with diabetes showed that higher levels of patient activation were associated with better **shared decision making** outcomes.⁴ A New Diagnosis Clinic (NDC) was set up at St Mark's Hospital to offer patients education, and signpost to information resources. Patient empowerment was measured using the Patient Activation Measure (PAM®) tool (Insignia Health) before and after the first consultation. PAM® is a validated questionnaire that generates a score from one to four. Non-activation was defined as PAM® score one and two. Baseline demographic data and anxiety and depression (using Generalised Anxiety Disorder scale [GAD-2] and Patient Health Questionnaire [PHQ-2]) were collated at the first clinic visit.

The outcomes

28 patients completed the PAM® questionnaires at the NDC. 14 patients were non-activated before the clinic. With tailored education, **57.1% of the patients had an improved PAM® score**. GAD-2 and PHQ-2 scores were available for 16 patients. **Four patients scored for anxiety and/or depression**, and were found to have non-activated PAM® scores. **Twelve patients out of 16 were deemed to be non-anxious/depressed**. Of those, **50% had an activated PAM® score**. **Anxiety and depression should therefore be recognised as a potential barrier to patient empowerment**.

In conclusion, the majority of non-activated patients showed an improvement in their levels of activation by attending the NDC, and having tailored education. The diagram below shows how PAM® is being used in our new diagnosis IBD clinics to improve on **shared decision making**.



A snap-shot survey of inflammatory bowel disease patients at a tertiary centre: a focus on knowledge and willingness to self-manage



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INTRODUCTION

- Good quality of care in Inflammatory Bowel Disease (IBD) includes the provision of patient-relevant information¹
- Studies on the level of patient understanding are sparse
- Education on self-management increases the likelihood of remission ²
- We studied IBD patients’ understanding of their condition and willingness to self-manage

AIM

- To examine IBD patients’ understanding of the disease process and impact on fertility, their attitude to self-management and access to information

METHODS

- A questionnaire was co-designed by the IBD multi-disciplinary team and patient representatives
- The questions covered demographic data, access to online information, knowledge on disease progression, fertility and medication and self-management of mild flares were included (Table 1)
- Answers denoting ‘Yes’ were scored positively and a sum (Q-sum) of the individual questions was expressed as median (range); maximum Q-sum score was 16, when all questions are answered positively
- Effect of age and disease duration was analysed

1. When you were first diagnosed did you attend a Nurse-led ‘New Diagnosis’ clinic?	YES	NO
2. When you were first diagnosed, do you feel you were given enough information about your condition in the initial few weeks?	YES	NO
3. Are you aware you can contact the St Mark’s IBD Advice Service:		
a. via telephone,	YES	NO
b. via email?	YES	NO
4. Are you aware of the information and patient support charity, Crohn’s & Colitis UK?	YES	NO
5. Have you ever been given:		
a. The St Mark’s IBD Patient Information booklet,	YES	NO
b. The Crohn’s & Colitis UK IBD information pack at time of diagnosis?	YES	NO
6. Are you willing to access online information and resources about IBD?	YES	NO
7. Do you understand how your condition might progress in the future?	YES	NO
8. Do you sometimes forget to ask questions at your outpatient appointment?	YES	NO
9. Are you confident in recognising the symptoms of a flare?	YES	NO
10. Would you find it useful to have more information about self-management and first steps to take during a mild flare?	YES	NO
10. Do you feel you have enough information about the medicines you are taking?	YES	NO
11. Do you feel you have enough advice on how to manage your lifestyle with your condition?	YES	NO
12. Are you confident in recognising the symptoms of a flare?	YES	NO
13. If you are planning to have/have had children since you were diagnosed, did you have enough information on how your condition may or may not affect fertility/pregnancy?	YES	NO
14. How well informed do you feel about your condition at present? Please circle on the following scale:		
1 2 3 4 5 6 7 8 9 10		
Less Informed ← → Fully informed		

Table 1: List of questions in snap-shot survey.

RESULTS

Population

- 150 patients from outpatient clinic and biologics day unit responded ; 49% were males
- 39 patients were <30 years old, 94 between 30-60 years of age (n=133 <60 years) and 15 ≥ 60 years old
- 39% of the patients had Ulcerative Colitis, 51% Crohn’s Disease and 10% IBD-unclassified
- Median Q-sum scores was 9 (1-16)

Level of patient understanding according to characteristics

- The median Q-sum scores for patients aged ≥60 years was 7 (1-13) compared with a score of 10 (2-16) for age <60 (p=0.02)
- 62% in the <60 age group and 60% of the ≥60 years cohort perceived themselves to be well informed, (p=0.9)
- Patients with shorter disease duration had better levels of understanding according to Q-sum scores (Table 2)
- There was no difference in scores for IBD subtype, or IBD medications

Disease duration	Median Q-Sum score
≤ 1 year	12 (1-4)
1-15 years	10 (2-16)
≥ 15 years	8.5 (3-14)

Table 2: Disease duration and mean Q-Sum scores, (p<0.05).

Access to Information

- Willingness to access online information was reported in 96% and 60% in the < 60 and ≥60 age groups (p<0.01)
- More patients on conventional treatment than on biologics expressed willingness for information on self-management (87% vs 76% (p=0.1)

Disease knowledge

- 86% of the <60 age group recognised a flare compared to 60% of the ≥60 age group, (p=0.01)
- Patients aged <60 years had better understanding of disease progression compared to those aged ≥60 years: 66% versus 40%, (p<0.05)
- Low levels of knowledge on self-management of mild flares was noted in 46% of patients who were not on biologic therapy
- 14% of males and 26% of females aged <60 years reported having enough information on fertility

CONCLUSIONS

- Patients aged <60 years are more likely to access online resources, and to recognise the symptoms of a mild flare, and self-manage
- Shorter disease duration was associated with better Q-sum scores for overall understanding
- These observations may reflect more openness about the disease with patient education core to routine IBD care

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Patient empowerment in Inflammatory Bowel Disease: early education at a new diagnosis clinic

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Background

- Inflammatory Bowel Disease (IBD) is a chronic condition
- Patient centred care is a recognised dimension of high quality care that includes education and support to empower patients¹
- Patient empowerment with knowledge, skills and confidence (*‘patient activation’*) is associated with better outcomes in many chronic diseases ²
- High patient activation was previously associated with IBD clinical remission³

Aims

- To measure patient empowerment in recently diagnosed IBD cohort
- To identify factors associated with activation levels

Methods

- A New Diagnosis Clinic “NDC” was set up at St Mark’s Hospital to offer patients education and signposts to information resources
- Patient empowerment was measured using the Patient Activation Measure (*PAM®*) tool (Insignia Health) before and after the first consultation
- PAM®* is a validated questionnaire that generates a score between 1-4
- Non-activation was defined as PAM levels 1 and 2
- Demographic data (age in years (SD)), disease specific characteristics and anxiety (Generalised Anxiety Disorder scale, GAD-2) and depression [Patient Health Questionnaire (PHQ-2)] were collated at the first visit
- The National Statistics Socio-economic classification (NS-SEC) was used to classify socio-economic status (SES)
- Categorical variables were analysed with chi-square test and numerical variables with student’s t-test

	n=28
Male, <i>n</i>	15
UC/CD/IBD-U, <i>n</i>	15/10/3
Mean age, <i>n</i>	43.2
Family history of IBD, <i>n</i>	5
Smokers, <i>n</i>	6
Another chronic condition, <i>n</i>	11
Non-white ethnic background, <i>n</i>	16
Active disease, <i>n</i>	20

Fig. 1: Characteristics of patients attending NDC
 [UC=Ulcerative colitis, CD=Crohn’s disease, IBD-U=unclassified IBD]

Results

- 28 completed PAM questionnaires at the NDC [Fig. 1]
- 50% (14/28) were non-activated before NDC; 57.1% (8/14) improved after NDC
- There was no association between age, gender, family history, smoking, co-morbidity, ethnic background and SES with activation
- SES were available for 14/28; 0/7 in intermediate or higher SES were activated compared with 43% (3/7) of lower SES (p=0.05)
- GAD-2 and PHQ-2 scores were available for 16/28 patients; 4/16 scored for anxiety or depression and none were activated; 12/16 were non-anxious/depressed and 50% were activated (p=0.07)

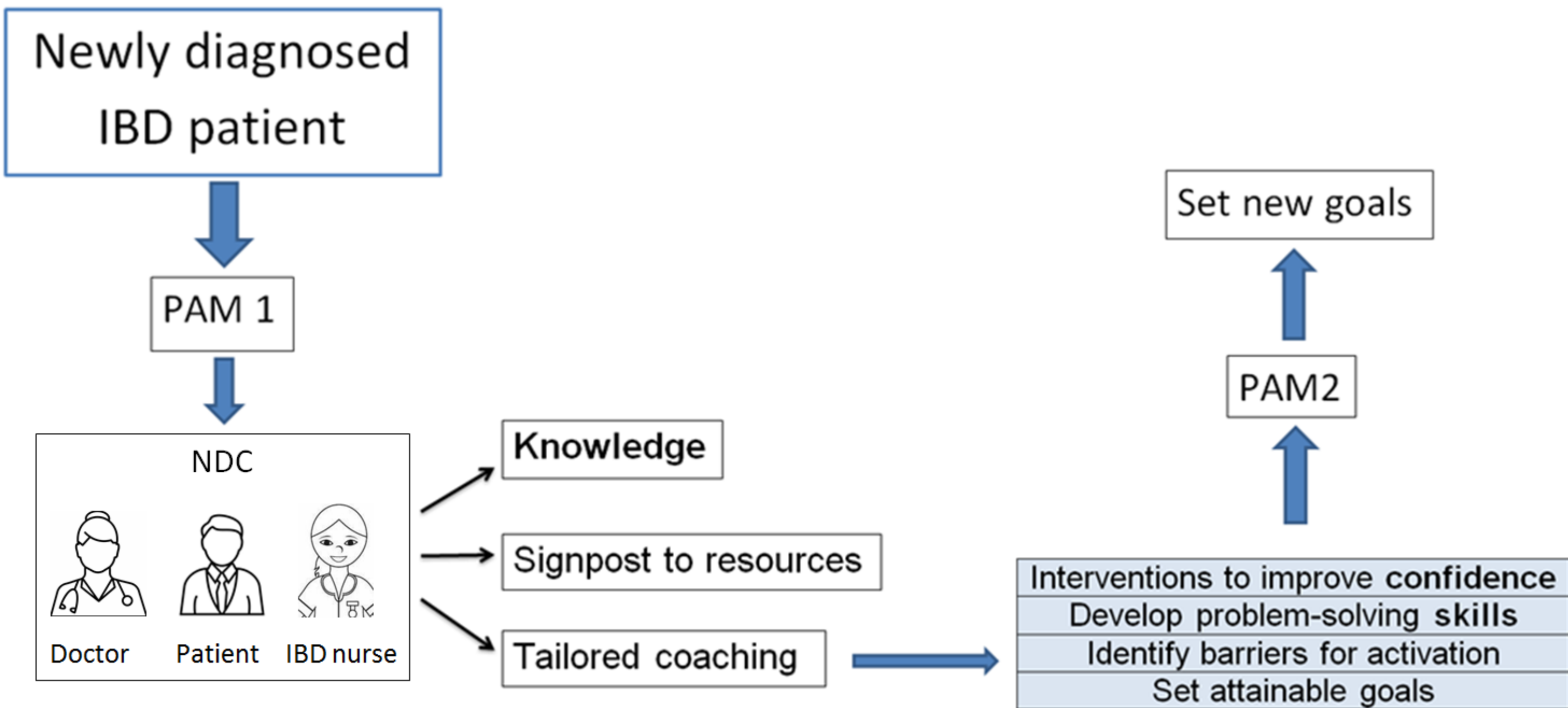


Fig. 2: Pathway for newly-diagnosed IBD patients to assess and improve activation

Conclusions

- The majority of non-activated patients showed improved activation after attending the NDC
- Anxiety and depression may contribute to non-activation
- It is important to elicit and address psychological comorbidity as a potential barrier to patient empowerment
- Further studies to evaluate the sustainability of patient activation and its effect on clinical outcomes are ongoing
- We propose early assessment of patients’ activation level to guide healthcare providers to offer individualised care [Fig. 2]

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The acceptability and utility of United Registries for Clinical Assessment and Research (UR-CARE) database to improve clinical care in a single centre setting



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Background

- The United Registries for Clinical Assessment and Research (UR-CARE) is a validated pan-European database developed by the European Crohn's and Colitis Organisation (ECCO)¹
- The purpose of this database is to support clinical practice for patients with inflammatory bowel disease (IBD)
- ECCO has published guidelines to reduce variation in care²

Aim

- To examine the value of UR-CARE database as a measure to improve care in a cohort of newly-diagnosed IBD patients

Methods

- All patients with a new diagnosis of IBD within 6 months attended a New Diagnosis Clinic (NDC)
- Prior to registering patients, the purpose of UR-CARE database was explained and patients signed the relevant consent form
- Mandatory fields and additional data that reflected quality of care were input
- Descriptive statistics summarised the findings
- Continuous variables were expressed as mean (standard deviation, SD) and categorical variables as number (*n*, %)
- The association between consent and disease activity or gender was examined using a chi-square test and for age using a two-sample t-test

Results

- Twenty-five out of 29 newly diagnosed patients consented for data inclusion in UR-CARE [Fig. 1]
- Four patients did not consent (2 males)
- The mean age of consenters was 36.3 (19.4) vs 44.4 (16.1) of non consenters (*p*=0.37)

	n=25
Male, <i>n</i>	13
Mean age, <i>n</i> [SD]	36.3 [19.4]
UC/CD/IBD-U, <i>n</i>	14/8/3
Presence of extra-intestinal manifestations, <i>n</i>	2
Active disease, <i>n</i>	17

Fig. 1: Characteristics of the 25 newly diagnosed patients who consented for inclusion in UR-CARE database
 [UC=Ulcerative colitis, CD=Crohn's disease, IBD-U=unclassified IBD]

Results continued

- 68% of consenters had active disease compared to 75% of non consenters (*p*=0.78)
- Only 4 out of 14 UC patients and 2 out of 8 CD patients were prescribed steroids within 6 months of their diagnosis
- We detected variation in care: 4/14 UC patients lacked a full colonoscopy and 3/8 CD patients lacked small bowel imaging or capsule endoscopy [Fig. 2]
- The 7 patients with missing investigations were identified and tests subsequently booked in line with guidelines

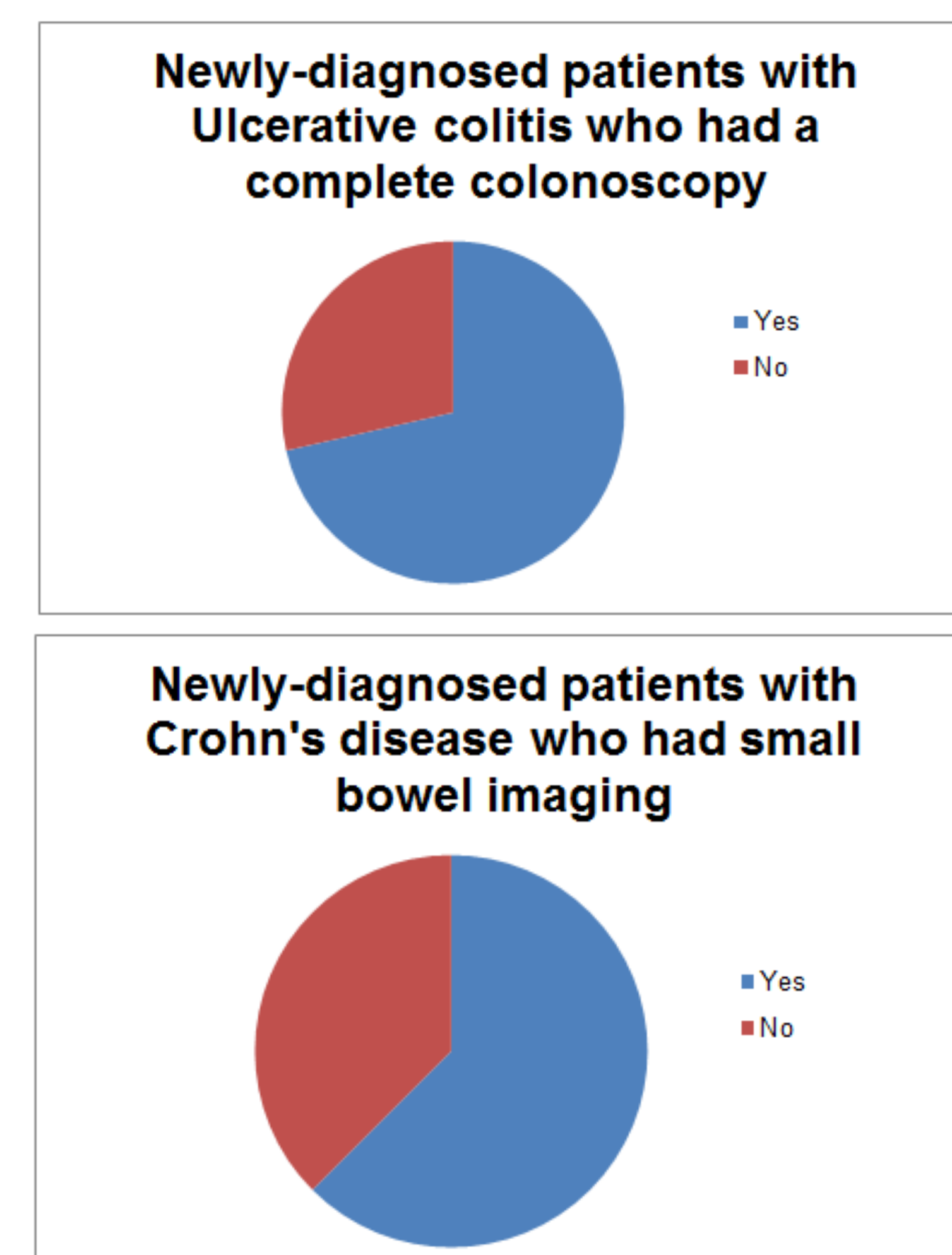


Fig. 2: Mandatory investigations performed in newly-diagnosed IBD patients

Conclusions

- In our newly diagnosed IBD cohort, most patients consented to inclusion in UR-CARE database
- There were no contributing factors associated with patient consent
- The easily accessible visualisation of our data detected incomplete diagnostic tests and initiated actions to improve care early on in the disease course
- UR-CARE offers potential to deliver high quality IBD care by aligning practice with ECCO guidelines and detecting deviation early in the disease course
- Attention to data-sharing legal and administrative barriers offers a promise for large scale studies and foster collaborative research networks

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