



IBD BENCHMARKING WHERE ARE WE NOW? WHERE ARE WE GOING?

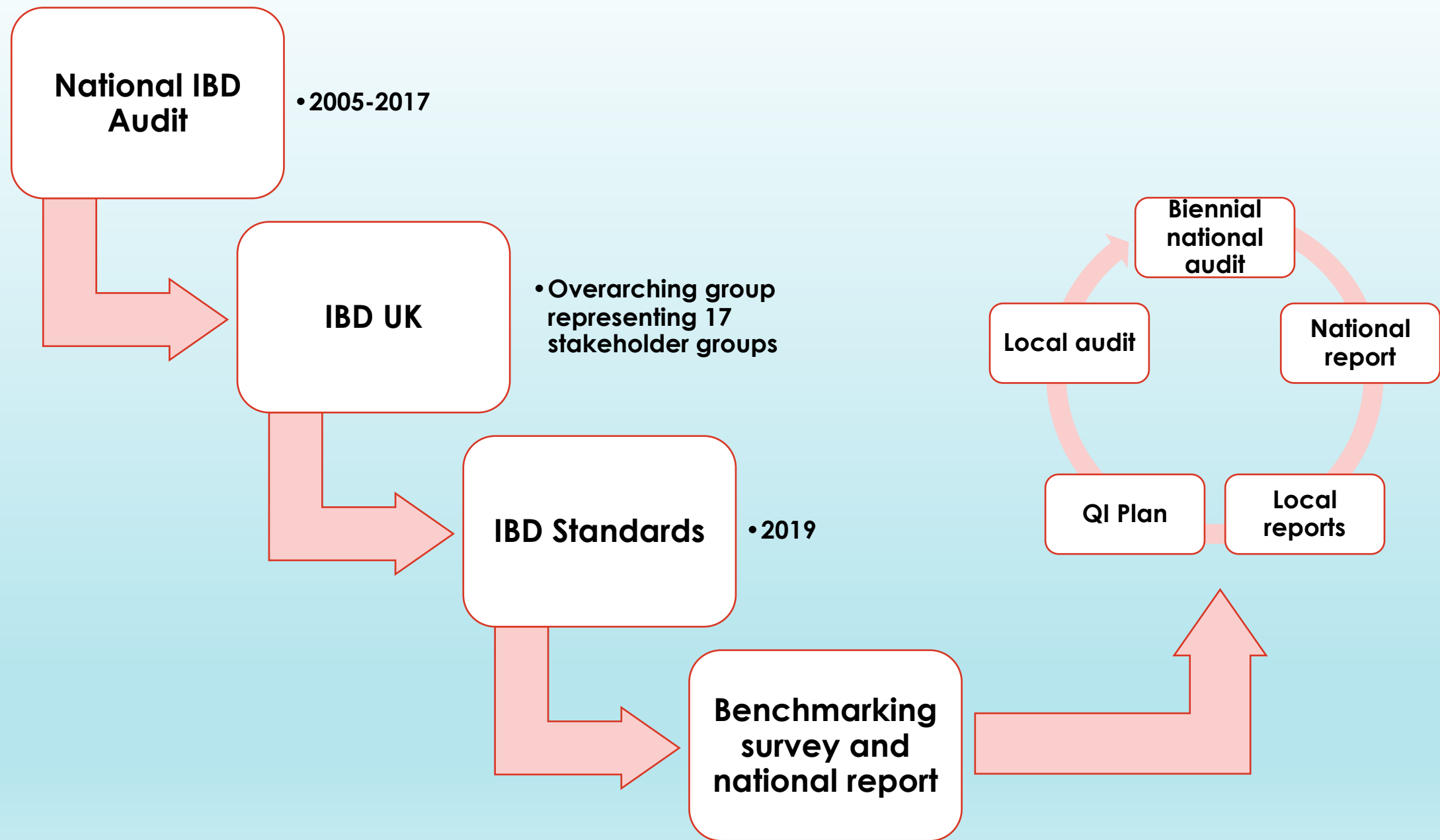
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Cardiff

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The slides have been reviewed for off label information by Ferring Pharmaceuticals

Disclosures

Dr AB Hawthorne has had consultancy/speaker fees/expenses in the last 3 years from Janssen, Dr Falk Pharma UK, Ferring Pharmaceuticals, Takeda UK Ltd,





IBD Standards Methodology

Online survey of 151 health care professional, 689 patients & 17-patient reference group to determine what impact the Standards have had and should have

'Standards help to plan and develop local services, to understand what a 'great' service should look like & with business case development for new resources'

The consensus IBD Standards following three rounds of modified e-Delphi
Patient journey : referral, diagnosis, treatment & long-term management

Question

How many statements make up the IBD Standards?

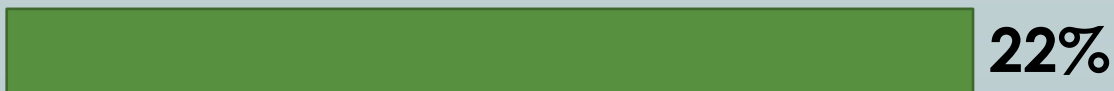
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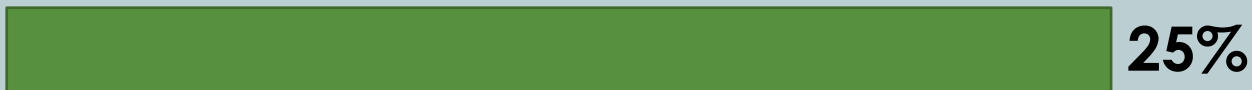
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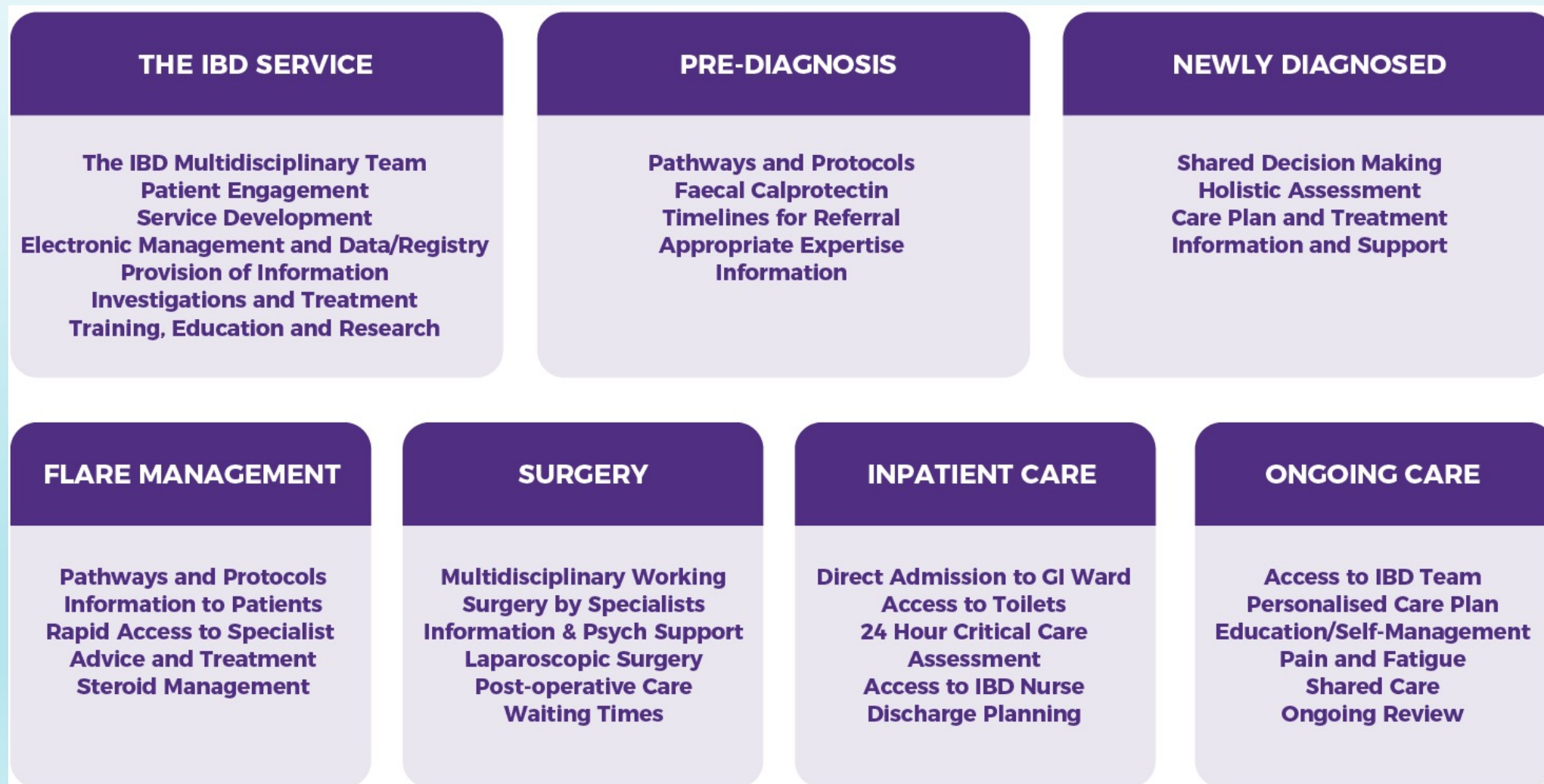


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Vote
Now

59 Statements across 7 domains



Specialist Communication and information sharing

IBD Standards

IBD Standards

Section 1: The IBD service

[Section 1: The IBD service](#)

Section 2: Pre-diagnosis

Section 2: Pre-diagnosis

Section 3: Newly diagnosed

Section 3: Newly diagnosed

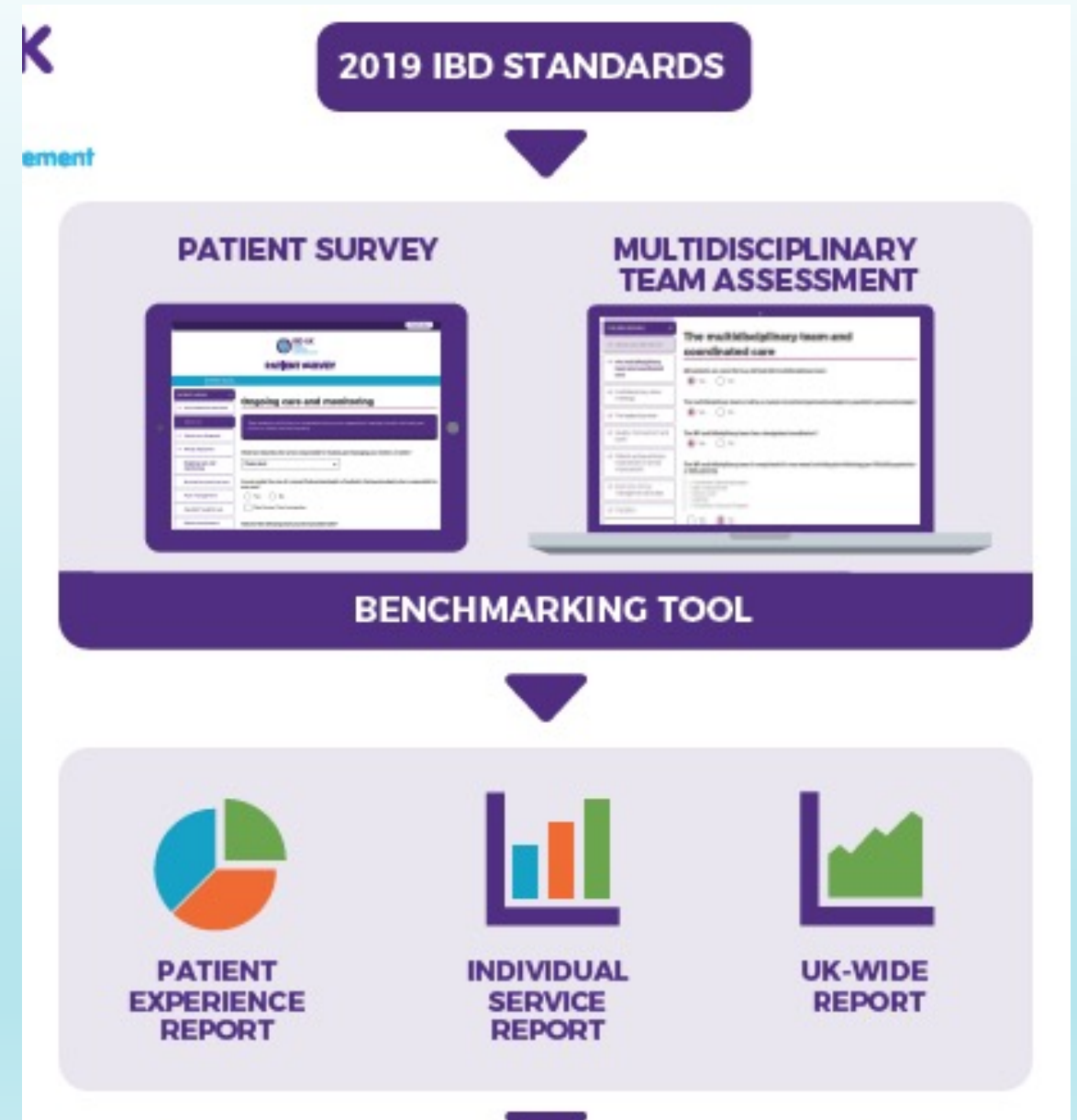
Section 3: Newly diagnosed

Section 3: Newly diagnosed

Statement 7.5

Any reviews and changes of treatment in primary or secondary care should be clearly recorded and communicated to all relevant parties within 48 hours.

IBD care in the UK: A comprehensive, novel service assessment with feedback from 10,222 patients and 166 NHS organisations to inform a vision for quality improvement



Crohn's and Colitis Care in the UK

The Hidden Cost and a Vision for Change



Association of Coloproctology of Great Britain and Ireland · British Association for Parenteral and Enteral Nutrition · British Dietetic Association · British Society of Gastroenterology · British Society of Gastrointestinal and Abdominal Radiology · British Society of Paediatric Gastroenterology, Hepatology & Nutrition · CICRA (Crohn's in Childhood Research Association) · Crohn's & Colitis UK · Ileostomy & Internal Pouch Association · IBD Registry · Primary Care Society for Gastroenterology · Royal College of General Practitioners · Royal College of Nursing · Royal College of Pathologists · Royal College of Physicians · Royal Pharmaceutical Society · UK Clinical Pharmacy Association

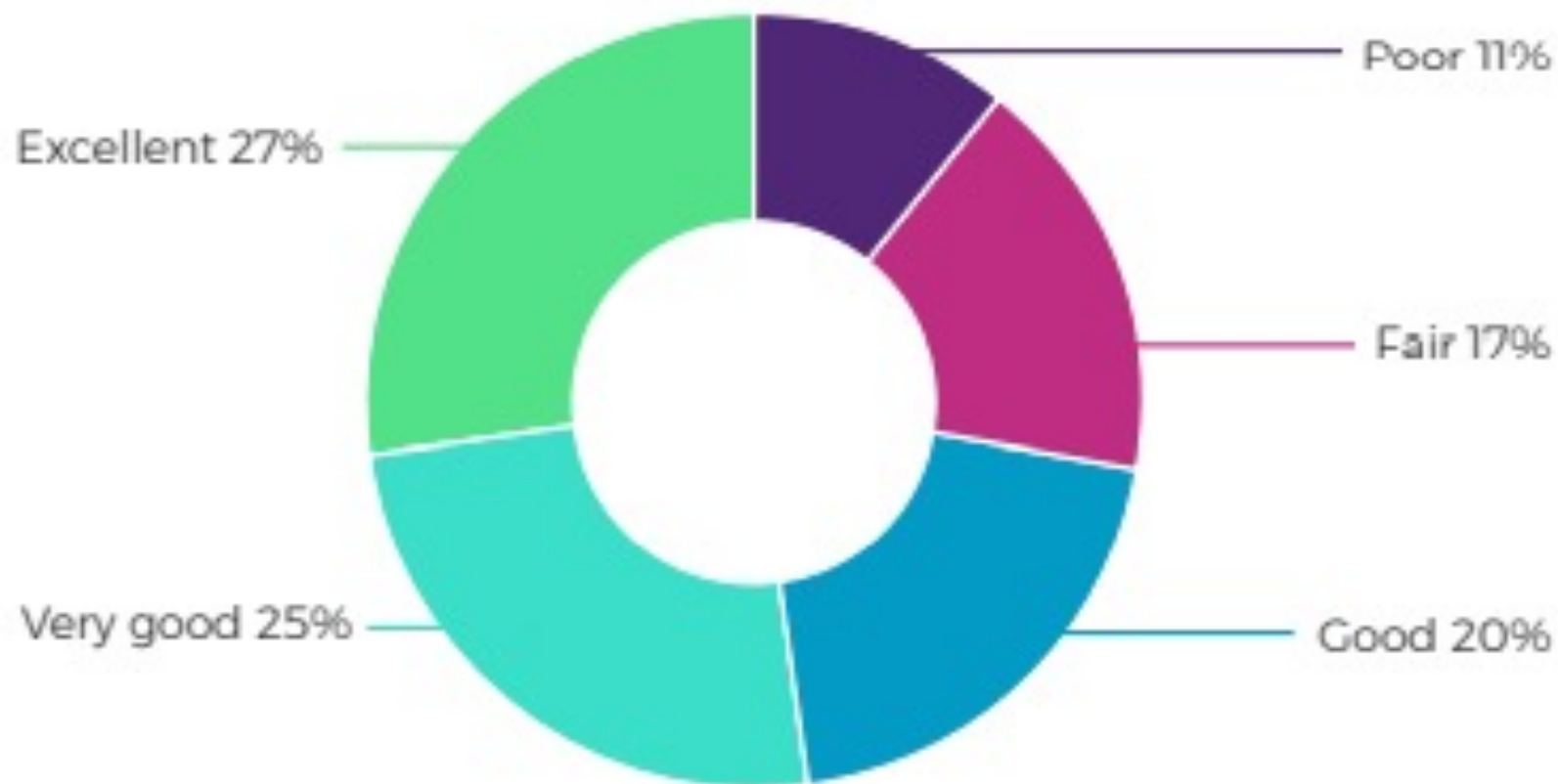
The data in this presentation is derived from the IBD UK benchmarking surveys and the paper in preparation. This data has informed the report launched April 27th 2021 and available at

[CROJ8096-IBD-National-Report-WEB-210427_\(2\).pdf](#)

Patient survey

- 52% Crohn's diagnoses
- Under-representation of men
- Under-representation of Black and Asian ethnic groups
- Relatively severe disease with approx. 50% reporting steroids in past year

Figure 1: Overall, how would you rate the quality of your Crohn's or Colitis care over the last 12 months?



Question

What age group of patients have the highest perception of the care they receive?



1. Under 18 years

2.7%

2. 35-54 years

31.5%

3. 65-74 years

52.1%

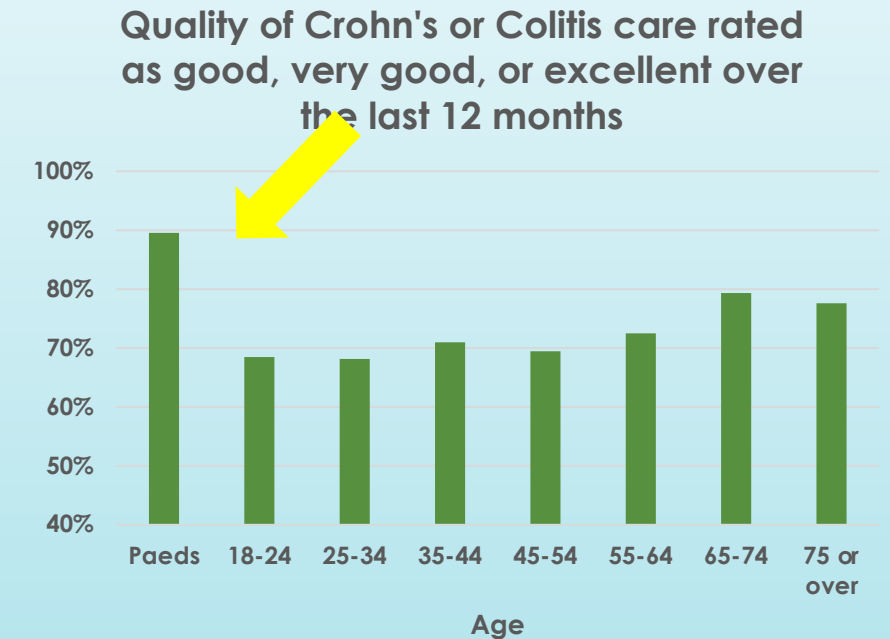
4. 75+ years

13.7%

Vote
Now

Patient factors impacting on perceptions of service quality

		Adult	Paediatric
		% of group rating quality of care as good, very good or excellent	
Gender*	Female	68%	89%
	Male	77%	91%
Date of diagnosis*	within last 2 yrs	64%	87%
	more than 2 yrs ago	73%	92%
Over the past 12 months, have you found it hard to cope with having Crohn's or Colitis?**	All of the time	46%	83%
	Most of the time	57%	69%
	Regularly	65%	85%
	Occasionally	78%	93%
	Never	90%	100%



* = all characteristics independent predictors of adult patients rating of service quality using binary logistic regression ($P < 0.001$);

** characteristic independent predictor of adult and paediatric patients rating of service quality using binary logistic regression ($p < 0.001$)

Service self assessment (SSA)

- 166 services (adult 132, paed 34) of possible 228 (73%)
 - Significantly less patients reported high quality care if from non-responding services
- Collectively care for 354,000 patients
- Median (IQR) patients per service:
 - Adults 2000 (1482-3500)
 - Paeds 168 (95-295)
- 23% self identify as tertiary centre (strong association with patient perceived high quality of care on BLR)



Completed
Registered
Not registered

Centres meeting IBD Standards staffing recommendations

IBD team staffing meets the WTE requirements of the IBD Standards 2019 for team members per 250,000 population (%Yes):		
	Gastroenterologists (2 WTE)	31%
	Colorectal surgeons standard (2 WTE)	18%
	IBD nurses standard (2.5 WTE)	14%**
	Stoma nurses standard (1.5 WTE)	34%
	IBD Pharmacist (0.6 WTE)	27%
	Dieticians standard (1 WTE)	9%
	Psychologists standard (0.5 WTE)	18%
	GI Radiologists standard (0.5 WTE)	44%
	GI Pathologists standard (1 WTE)	12%
	IBD administrators standard (0.5 WTE)	47%
Services meeting IBD Standards across all professional groups for WTE staffing		0%

Association with patient-reported high quality care on BLR **p<0.001

Access, information and care coordination

	Agree or Strongly agree (%)
When I contact the NHS IBD service advice line, I get a response by the end of the next working day (n=5,851)	72%***
I was given information in a format that helped me understand the benefits and risks of surgery	82%***
I am supported by a team of IBD specialists who help me manage my condition (n=9,483)	64%***
We discuss my wider life goals and priorities, as part of planning my Crohn's or Colitis care (n=9,495)	30%***
I felt what mattered to me was taken into account when making decisions about treatments and care (n=1,868)	52%***
I was involved as much as I wanted to be in decisions about my care and treatment (at diagnosis) (n=1,851)	32%***
I was involved as much as you wanted to be in decisions about your care and treatment? (overall) n=9,556)	47%***
In my opinion, my GP is knowledgeable about Crohn's and Colitis and how to treat the conditions (n= 9,029)	34%***

	% Yes
Do you have a regular review for your Crohn's or Colitis, regardless of whether you are well or not? (n=9,646)	64%***
Do you have a personalised written care plan? (n=8,728)	8%***

SSA: Service organisation

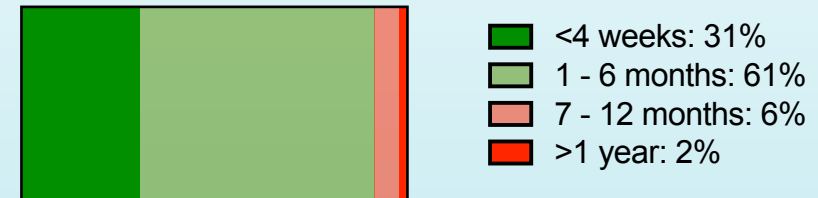
	Proportion of services graded A or B on 4-point scale for quality of service:
IBD team Leadership	74%*
Occurrence of MDT meetings	69%
Referral pathway for support services (eg rheumatology, dermatology, ophthalmology)	17%
Pharmacist involvement in IBD team leadership	34%
Availability of nutrition support	64%
Presence of adolescent transition services	31%
Engagement with audit	34%
Database for clinical and audit work	16%*
Patient feedback and involvement in service design and delivery	23%*
Availability of patient information regarding local IBD service	19%***
Professional support and development for local IBD team	91%
Availability of participation in research	76%***

SSA: Flare management

	Proportion of services graded A or B on 4-point scale for quality of service:
Provision of information regarding flare management	44%
Access to specialist review urgently	72%***
Proportion of telephone advice line support response times by the end of the next working day	78%*
Protocol for prescribing and audit of corticosteroid prescribing	22%

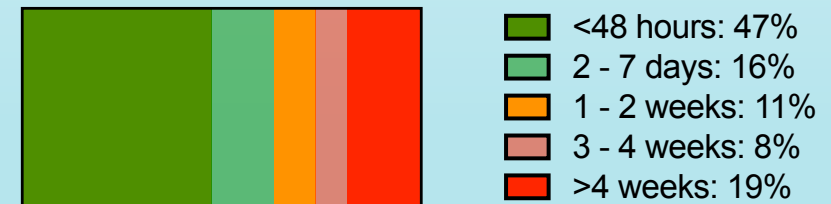
Adult patient-reported waiting times

Less than a third are seen in clinic within a month of GP referral
The majority are seen by 6 months....



Patient reported wait from GP referral to first appointment (n=1,452)***

Many patients report waiting more than a week to start treatment



Patient reported wait from diagnosis to treatment (n=3,744)***

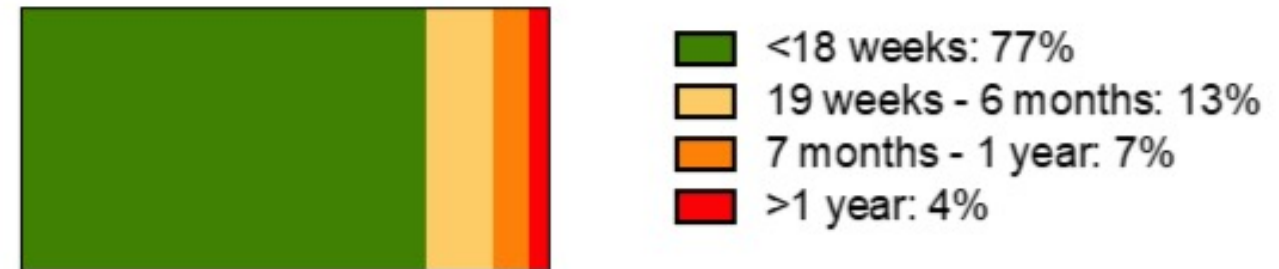
Association with patient-reported high quality care on BLR ***p<0.001

Patient reported waiting times to investigations and elective surgery

If you had an investigative test in the last 12 months, on average how long did you wait?*



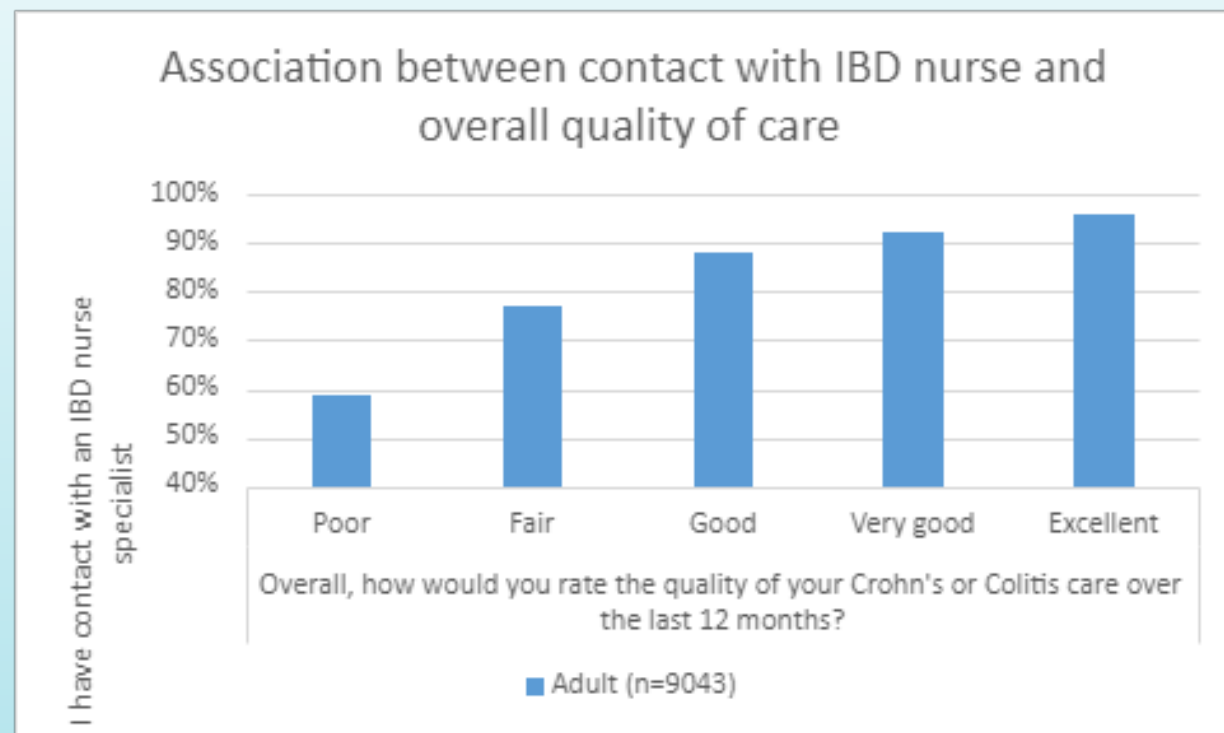
If you were referred for an operation: how long did you wait? (n=541 adult, 38 paediatric)*



* Significant factor affecting patients' perception of quality of service (after correction for patient factors using binary logistic regression): $p < 0.001$

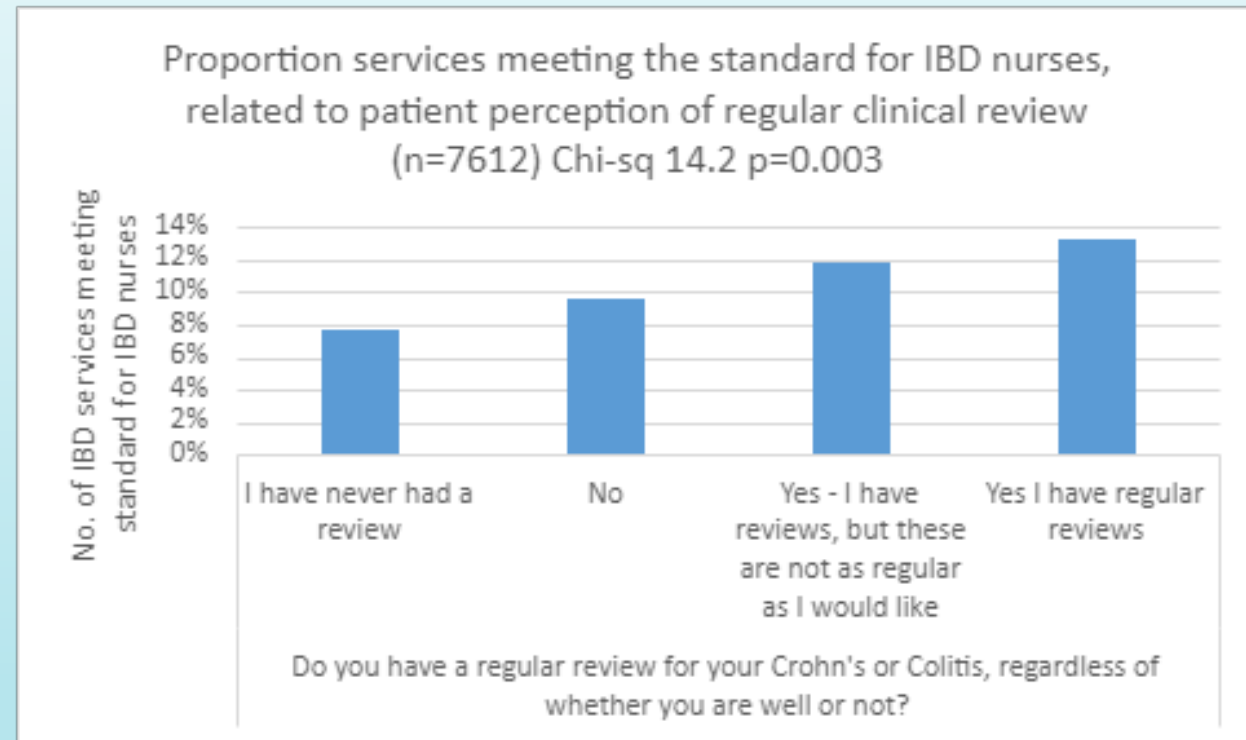
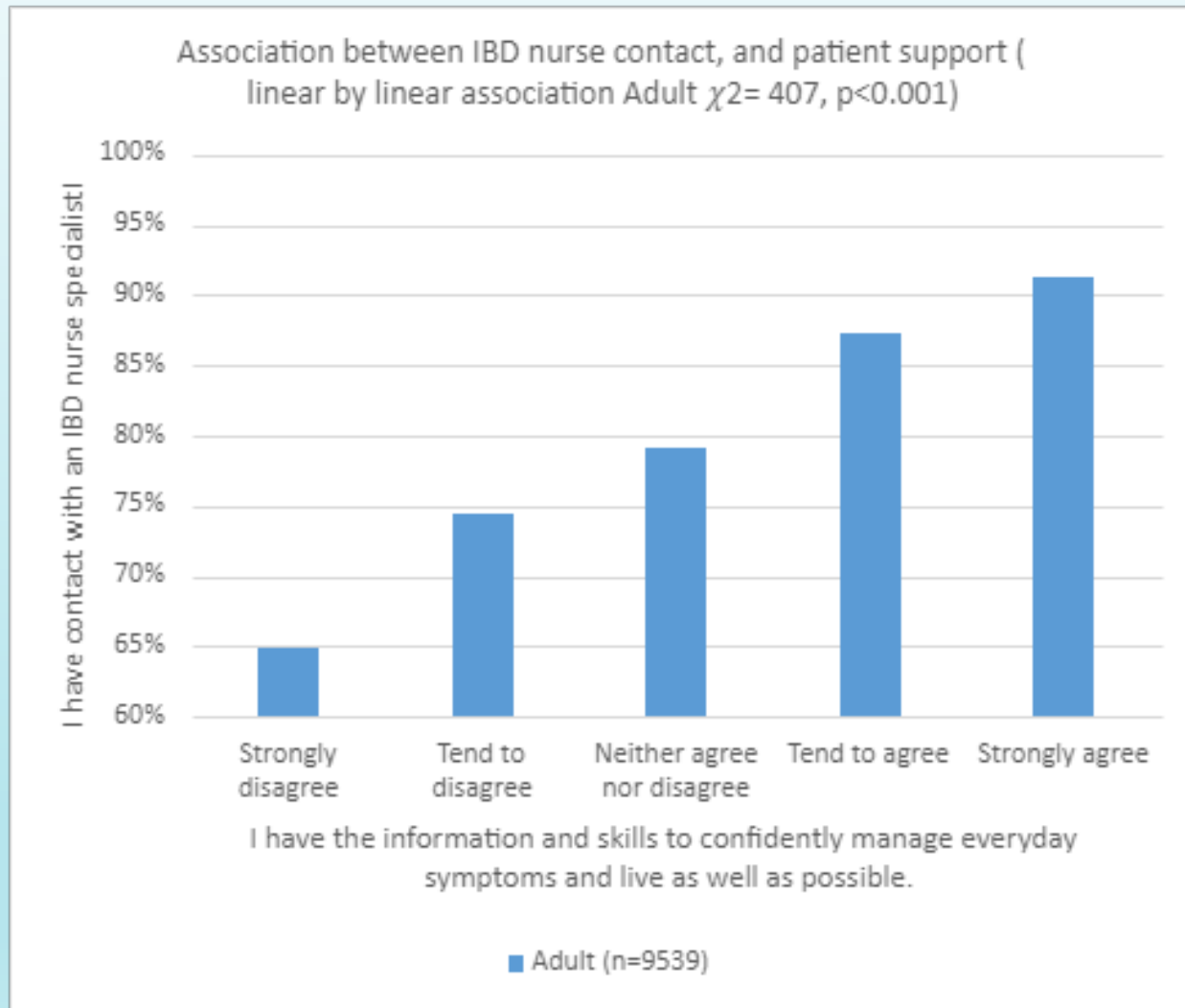
Specialist IBD nurses

<u>Service responses:-</u>	
No. WTE nurses in IBD services (n=132 adult, 34 paediatric) median (IQR)	2.0 (1.0-3.0)
Patients whose IBD service has the recommended no. of IBD nurse specialists (n=7704) % Yes	12.4%*
<u>Patient questions:-</u>	
Do you have contact with an IBD nurse specialist? (n=9593 adults, 459 paediatric) % Yes	83.8%*
In my opinion, the IBD Nurse Specialists who treat me are knowledgeable about Crohn's and Colitis and how to treat the conditions. (n=7792 adult, 438 paediatric) % who tend to agree or strongly agree	86.6%*
Were you offered the opportunity to speak to an IBD Nurse Specialist while you were an inpatient? (n=1988 adult, 162 paediatric) % Yes	44.5%*



Significant factor affecting patients' perception of quality of service (after correction for patient factors) using binary logistic regression: * $p < 0.001$

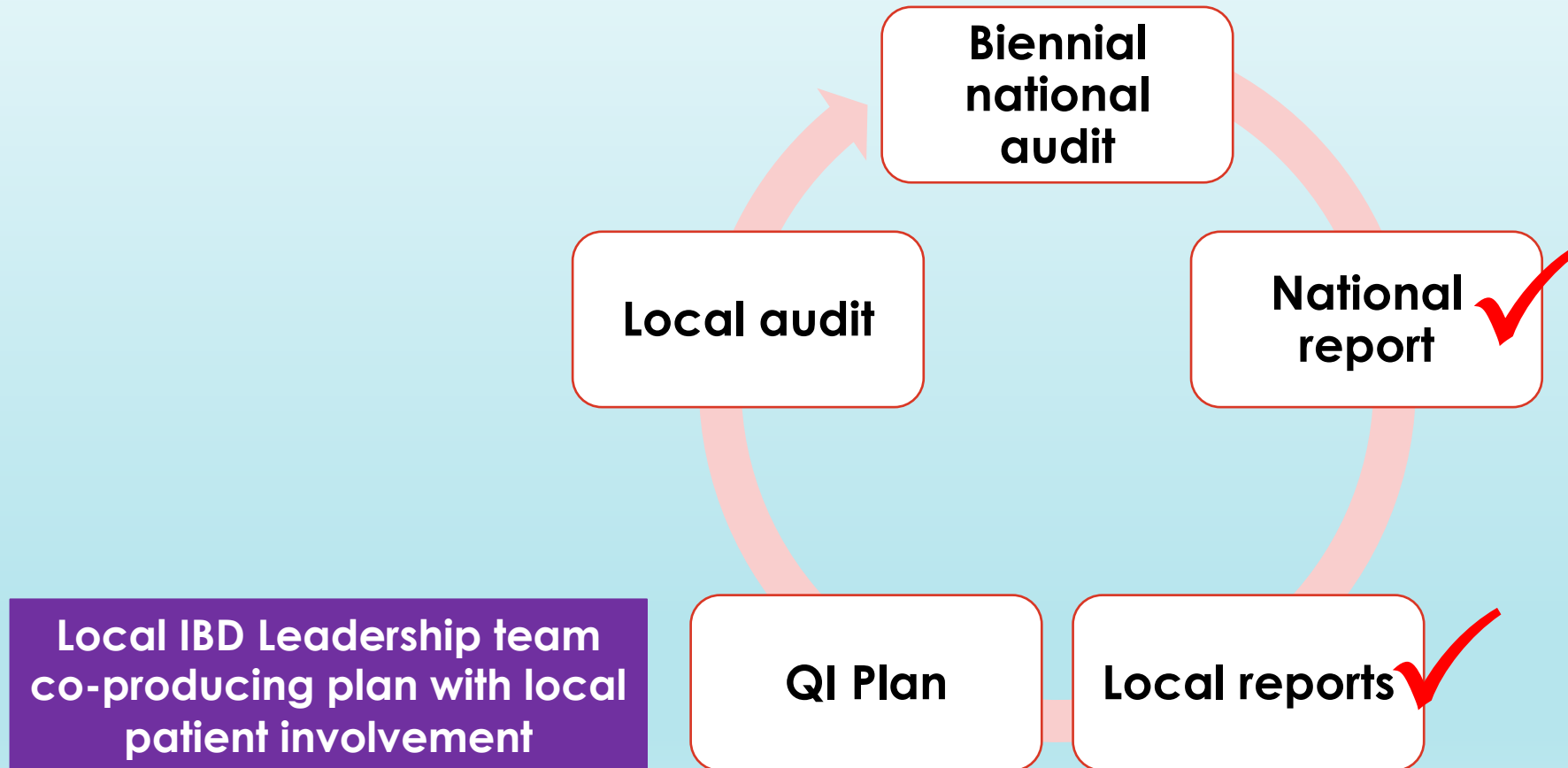
Specialist IBD nurses



Importance of overall well-being

- Less than 1 third of patients think their wider life goals are discussed or feel involved in decision making
- Only a small proportion think emotional wellbeing e.g. fatigue is discussed
- The IBD nurse relationship is essential for patients
 - Positive association with regular reviews
 - Associated with higher confidence to self manage and cope with IBD
 - However <1 in 8 adult services have the recommended numbers of nurses

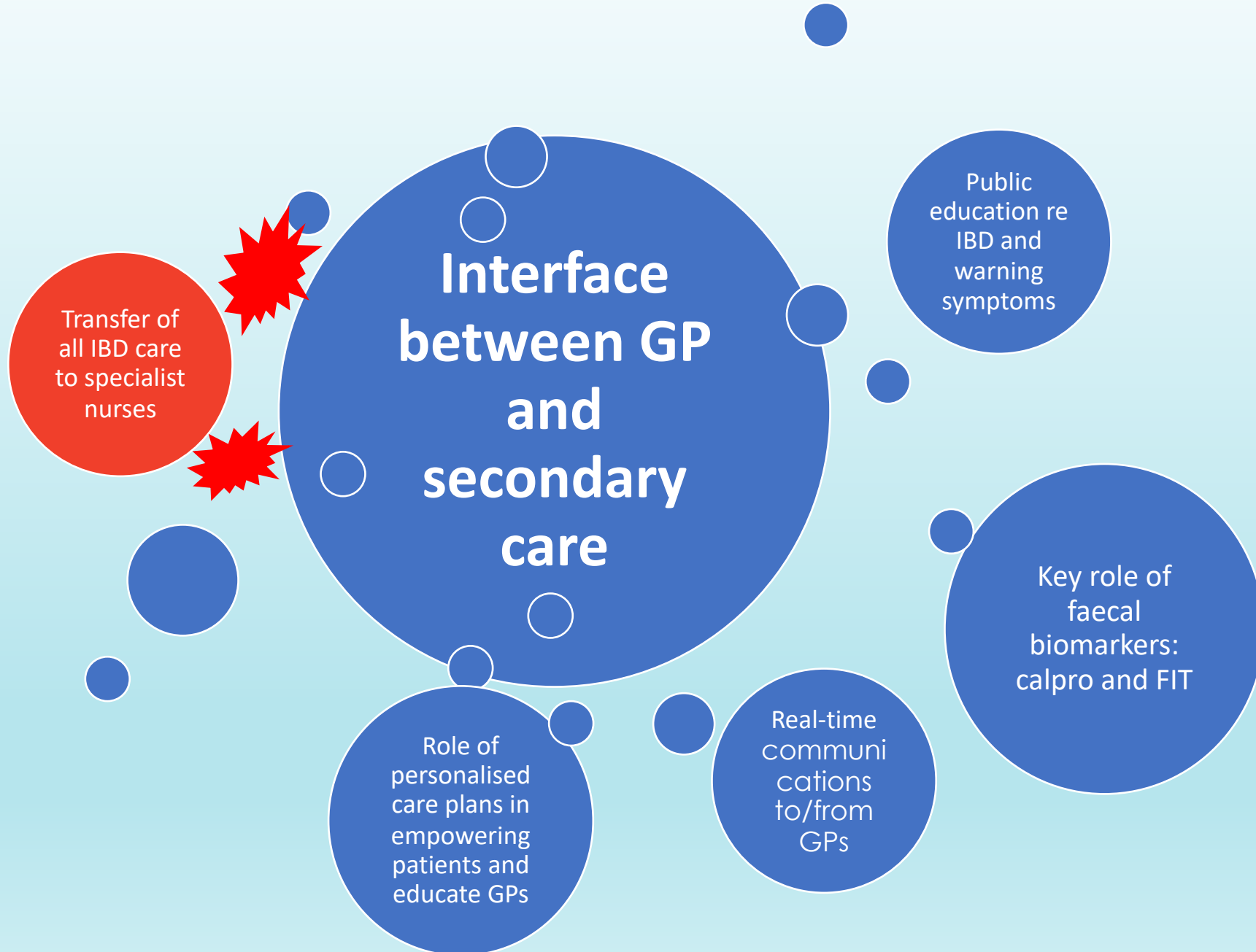
Where do we go next?



Key Improvement Targets

Informed by: -what patients want;
 -what is lacking at present;

- Diagnosis
- Information provision & shared decision-making
- Personalised care and support for self-management
- Faster access to specialist advice and treatment
- Multidisciplinary team (MDT) working
- IBD Leadership team (Doctor/Nurse/Manager)

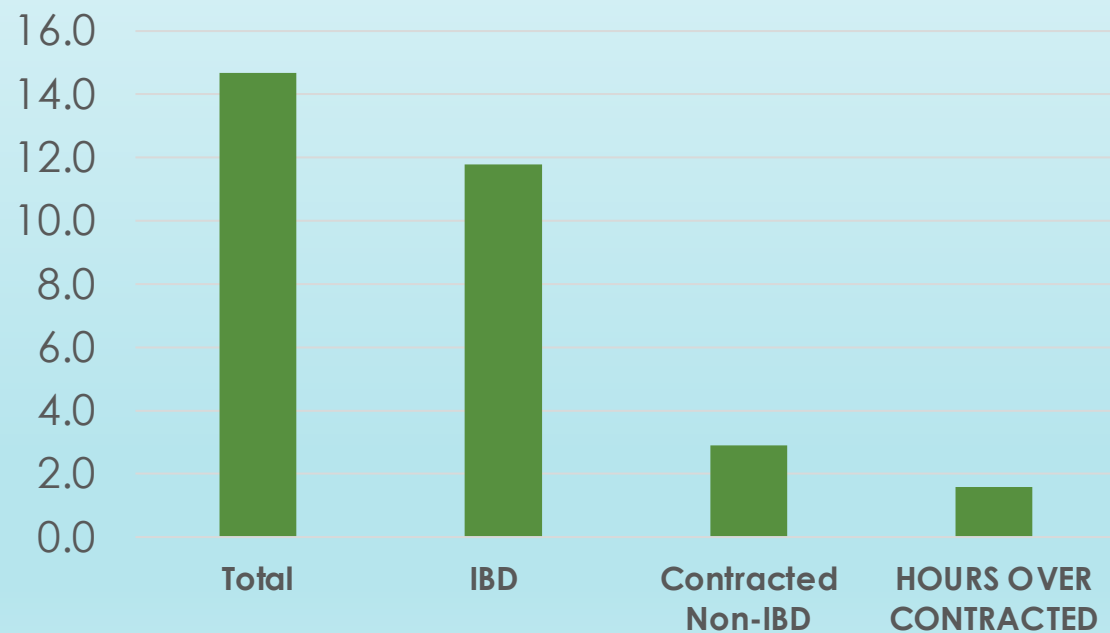


Business cases

Informed by: -what patients want;
 -what is lacking at present;

- Nurses
- Clerical staff
- Pharmacists
- Psychologists
- Gastroenterologists
- Elective theatre capacity and colorectal surgeons

TOTAL WTE from 18 nurses in WALES



TOTAL WTE from 18 nurses in WALES



► Service Communications Toolkit

What are the IBD
Standards and why do
they matter?

A guide to your IBD
Benchmarking Tool
reports

Service Communications Toolkit

This toolkit is intended to help you to share the results for your service with your Stakeholders, including hospital press teams.

To access a copy of your service's report:- email info@ibduk.org

Service Communication Toolkit

How to use this toolkit

Engaging colleagues and stakeholders

Key dates: raising awareness of your results with the media

Ideas for headlines

Social media

Appendix: overview of resources available

This toolkit provides all you need to communicate your service's results from the IBD Benchmarking Tool 2019/2020 – a new way to assess how well services across the UK are providing care against the 2019 IBD Standards. This includes the Service Self-Assessment completed by your IBD team and the results of an IBD Patient Survey completed by those using your IBD service.

The information in this toolkit will help you to communicate about the IBD Standards and your results to patients, healthcare colleagues within your hospital, hospital management and the local population.

The toolkit will help you deliver:

External communications

- achieving positive stories in the media about your IBD service
- sharing results with patients
- providing content for your social media platforms and stakeholder newsletters
- equipping you to respond to questions and queries

Internal communications

- sharing your results with NHS leaders, managers, clinical champions and colleagues
- gaining support from these key stakeholders and others
- delivering on Quality Improvement
- engaging in future IBD Benchmarking

To access a copy of your service's report:- email info@ibduk.org

Case studies



Case study: The role of a specialist IBD pharmacist in a virtual biologic clinic, Lancashire Teaching Hospitals

Case study: New psychological service, Liverpool University Hospitals NHS Foundation Trust



Local IBD QI Plan

- Leadership team with management involvement
- Local patient input
- Agree priority list
 - SMART (specific/measurable/achievable/Realistic/Timely)

National Plan – IBD UK

- Repeat benchmarking with modified surveys – likely to be 2023
 - Incorporation of KPIs with collected patient level data:
 - Time to diagnosis and treatment
 - Excess steroid use
 - Biologics/immunosuppressive therapy screening and response to treatment
 - Key role for National IBD Registry in Data collection

Acknowledgements

IBD UK board members and key contributors

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With thanks to everyone who has participated in the IBD Patient Survey and Service Self-Assessment and contributed to the development of this work and report

Supplementary slides

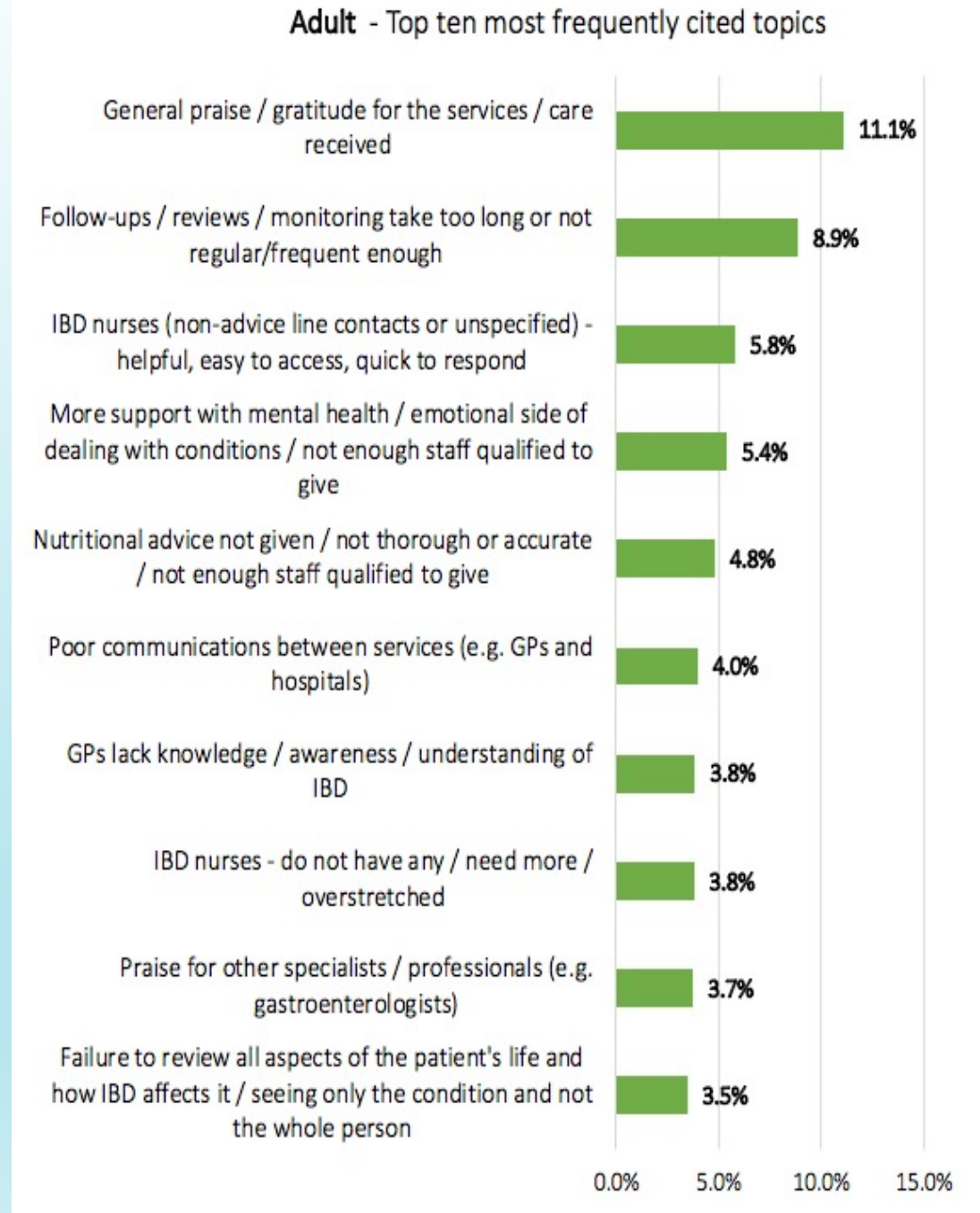
Fatigue and mental health

	Agree or Strongly agree (%)
During appointments, I am asked about fatigue/tiredness and treatment options are discussed to manage this (n= 9,251)	36%***
During appointments, I am asked about pain and treatment options are discussed to manage this (n= 9,158)	55%***
During appointments, I am asked about my mental health or emotional wellbeing and treatment options are discussed (n= 9,236)	23%***

SSA: Surgery

	Proportion of services graded A or B on 4-point scale for quality of service:
Joint medical and surgical clinics	49%***
Written patient information on drug treatment and surgery	91%***
Elective surgery available within 18 weeks	63%
Elective IBD surgery by specialist IBD surgeon	78%
Complex IBD surgery	20%
Availability of laparoscopic IBD surgery	98%
Provision of information regarding surgery	76%***
Provision of post-operative information and support	92%

Free-text patient comments:



15th National IBD
Nurse Forum 2021

EVER INCREASING CIRCLES THE EVOLUTION OF THE IBD NURSING ROLE

FERRING

PHARMACEUTICALS

