Defining & measuring high-quality patient care in the UK

Chris Lamb

24th September 2021

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

Newcastle University

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

September 2021
UK-GAS-2100108

Disclosures

Dr Chris Lamb reports grants, consultancy and/or speaker fees from Genentech, Janssen, Takeda, AbbVie, Ferring, Eli Lilly, Pfizer, Roche, UCB Biopharma, Sanofi Aventis, Biogen IDEC, Orion OYJ, Dr Falk Pharma, and AstraZeneca

A need for IBD Standards

- Over 500,000 people in the UK live with IBD
- Estimated average annual costs:
  - £3,084 UC
  - £6,156 for Crohn's disease
  - i.e. Annual cost to the NHS in excess of £900 million based on current estimates of prevalence
- Four rounds of IBD Audit: 2009-2014
  - Despite improvements over time consistently have identified inequalities in healthcare provision regarding quality and responsiveness

IBD Standards 2009 and 2013

- Version 1: 2009
  - Defined what was required in terms of staff, support services, organisation, patient education and audit to provide integrated, high-quality IBD services
- Version 2: 2013
  - Underpinned the 2015 NICE quality standard on IBD (QS81)
  - Were an integral component of the IBD Quality Improvement Programme supported by the RCP until 2015

Standards 2019: Areas highlighted by 2014 IBD Audit

- Speed of access to specialist assessment at referral and relapse
- Appropriate provision for IBD nurse specialists
- Dietetic access and psychological support
- Patient education opportunities
- Involvement of patients in service planning
- (Previous rounds of audit also identified a need for improved communication between primary and secondary care)

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

How many statements make up the IBD Standards?

1 23

16%

2 42

40%

✓ 3 59

26%

4 72

18%

Vote Now

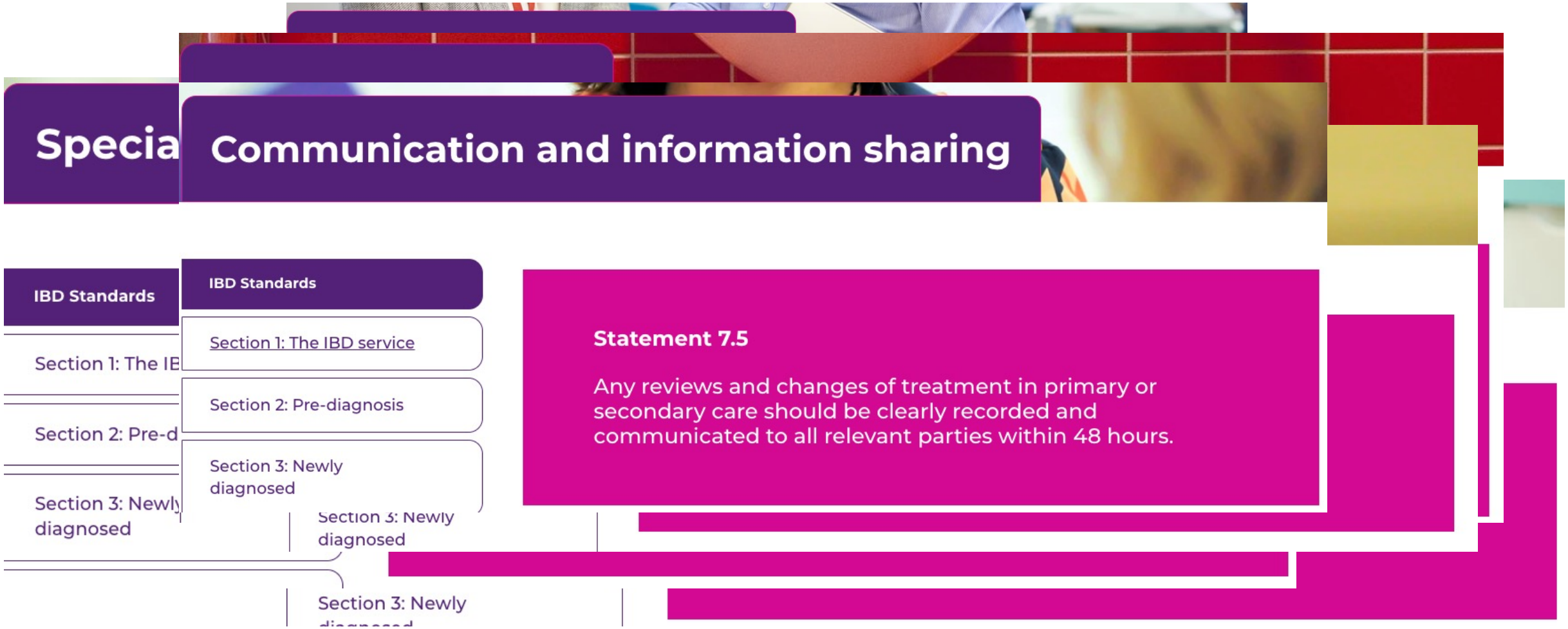
59 Statements across 7 domains

IBD UK
Strategy
Partnership
Quality Improvement

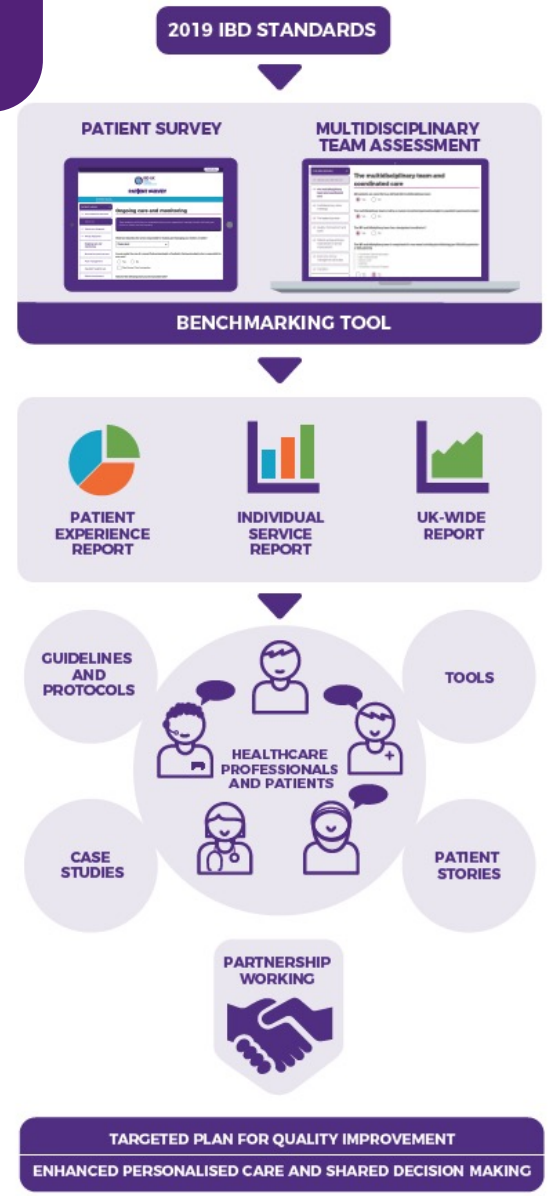
THE IBD SERVICE	PRE-DIAGNOSIS	NEWLY DIAGNOSED
The IBD Multidisciplinary Team Patient Engagement Service Development Electronic Management and Data/Registry Provision of Information Investigations and Treatment Training, Education and Research	Pathways and Protocols Faecal Calprotectin Timelines for Referral Appropriate Expertise Information	Shared Decision Making Holistic Assessment Care Plan and Treatment Information and Support

FLARE MANAGEMENT	SURGERY	INPATIENT CARE	ONGOING CARE
Pathways and Protocols Information to Patients Rapid Access to Specialist Advice and Treatment Steroid Management	Multidisciplinary Working Surgery by Specialists Information & Psych Support Laparoscopic Surgery Post-operative Care Waiting Times	Direct Admission to GI Ward Access to Toilets 24 Hour Critical Care Assessment Access to IBD Nurse Discharge Planning	Access to IBD Team Personalised Care Plan Education/Self-Management Pain and Fatigue Shared Care Ongoing Review

ibduk.org


Specia
Communication and information sharing
IBD Standards
IBD Standards
Section 1: The IB
Section 1: The IBD service
Section 2: Pre-d
Section 2: Pre-diagnosis
Section 3: Newly diagnosed
Section 3: Newly diagnosed
Section 3: Newly diagnosed
Section 3: Newly
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.

Benchmarking Tool

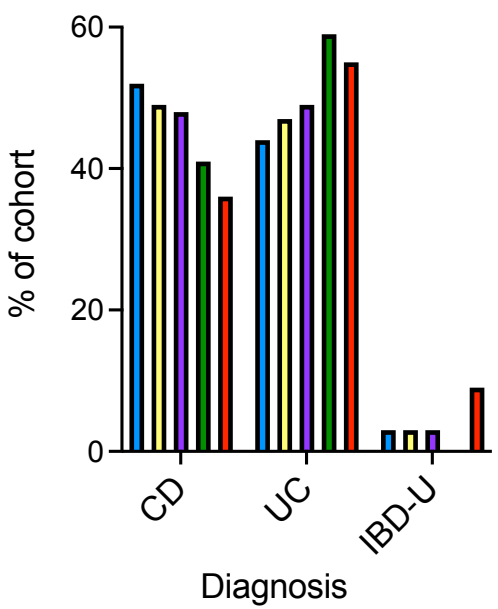


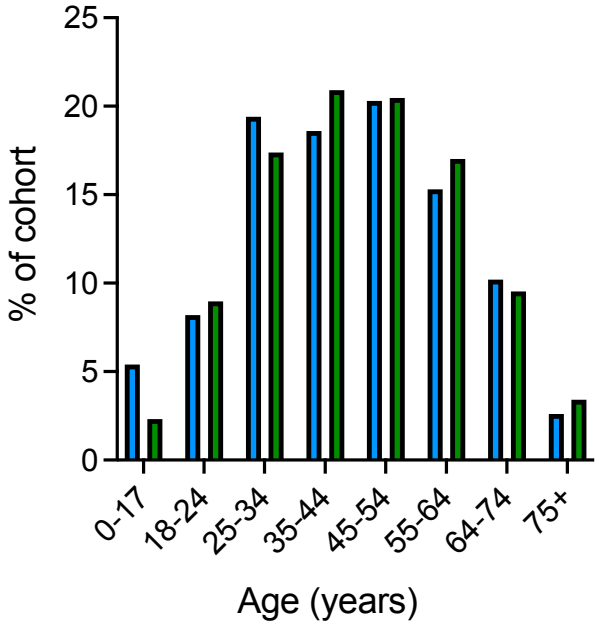
Benchmarking data

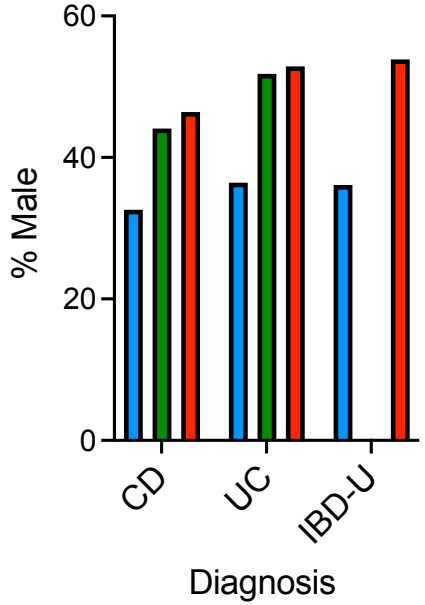
- Patient involvement in design, roll out and analysis
- Patient survey (n=10,224)
  - Open 8th July 2019 to 22nd November 2019
  - Hierarchical logic: 66-98 questions
  - Predominantly quantitative with some qualitative questions focused on experience in last year
- Service self assessment (n=166)
  - Open 1st October 2019 to 31st January 2020
  - Up to 187 questions per service, some tiered
  - Encouraged to use audit and database data where available

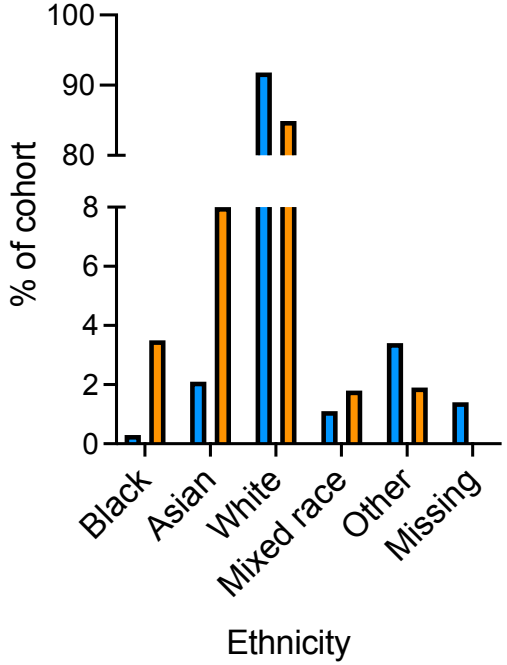
Patient survey

- 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









IBD UK Patient Survey (n=10,222)
IBD BioResource (n=34,766)
ONS (n=57 million)
Selinger (n=1,176)
King (n=63,953)
Lothian (n=10,499)

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

1 Under 18 years

2 35-54 years

3 65-74 years

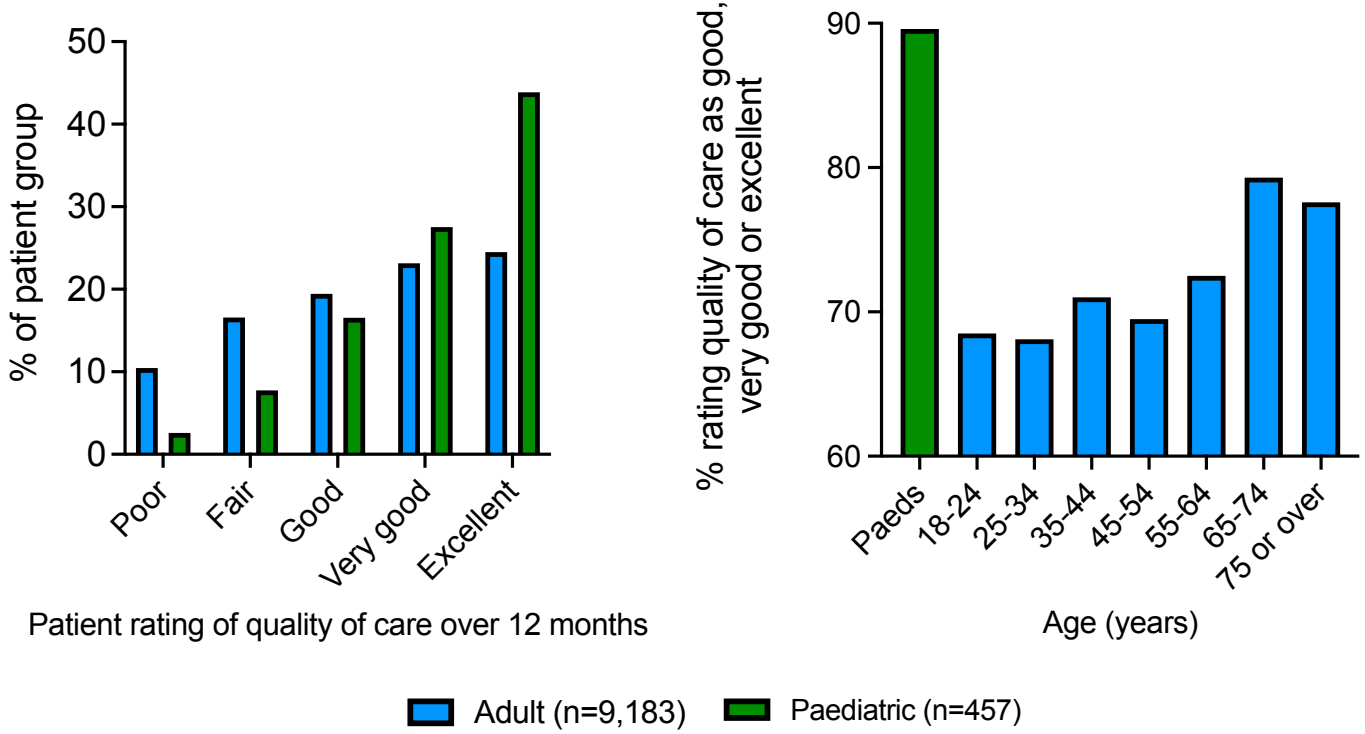
4 75+ years

Vote Now

Patient perceived quality of care

- Paediatric patients rated care more highly than adults ($p<0.001$)
- Perceived quality of care in adults increase with age if male and if diagnosis of >2 years (relative to recent diagnosis)

- Highlights importance of good transition services



How many patients reported having a personalised care plan?

1 8%

61%

2 16%

21%

3 32%

15%

4 64%

3%

Vote Now

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%***

Significant factor affecting patients' perception of quality of service using binary logistic regression: ***p<0.001

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%***

Significant factor affecting patients' perception of quality of service using binary logistic regression: ***p<0.001

Service self assessment (SSA)

- 166 services 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%

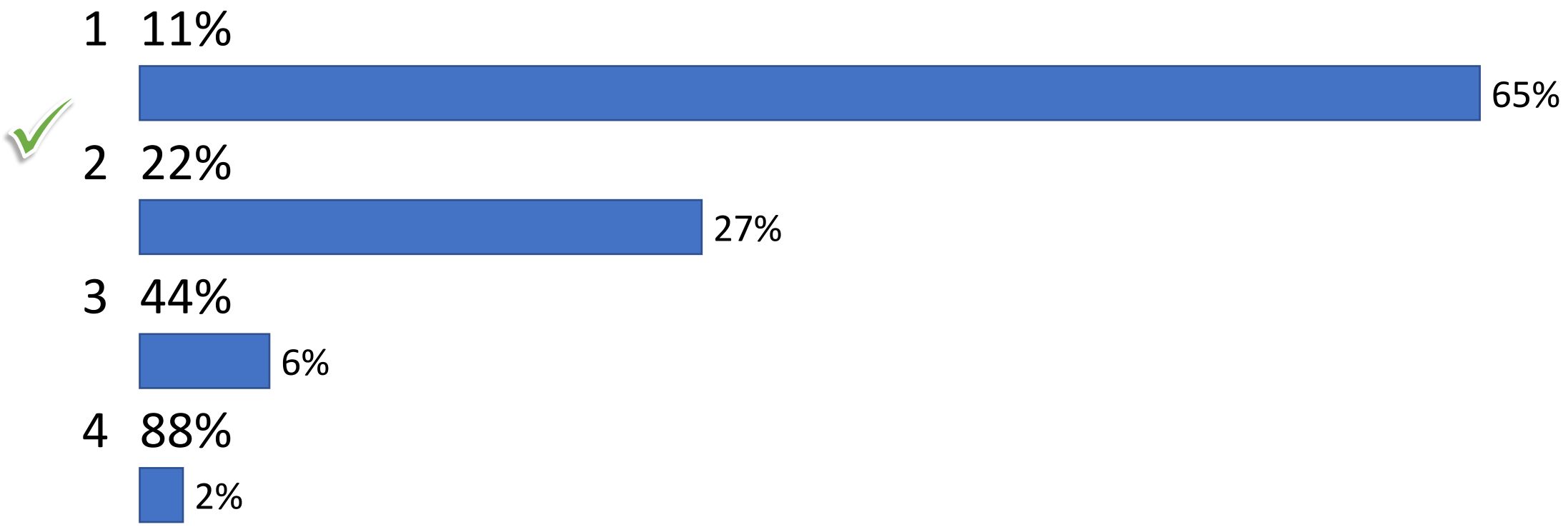
Association with patient-reported high quality care on BLR **p<0.001

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%***

Association with patient-reported high quality care on BLR *p<0.05; **p<0.001; ***p<0.001

What proportion of services reported having a protocol for prescribing steroids and audited prescriptions?



Vote Now

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%

Association with patient-reported high quality care on BLR *p<0.05; ***p<0.001

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%

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

IBD nurse specialist

- 84% of patients report contact***
- 87% feel their nurse specialist is knowledgeable about Crohn's and Colitis and how to treat the conditions***
- Only 45% were offered the opportunity to speak to an IBD nurse when an inpatient***

- Association of contact with IBD nurse and receipt of information/decision making around medications and surgery***

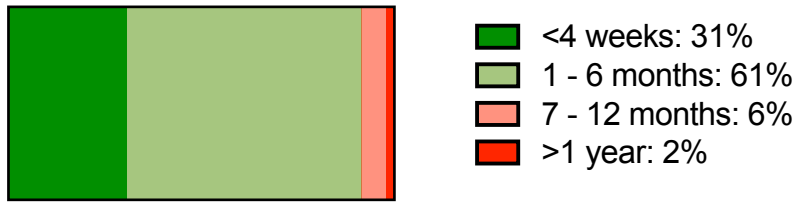
- Positive association between numbers of IBD nurses and likelihood of regular OP review

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

Adult patient-reported waiting times

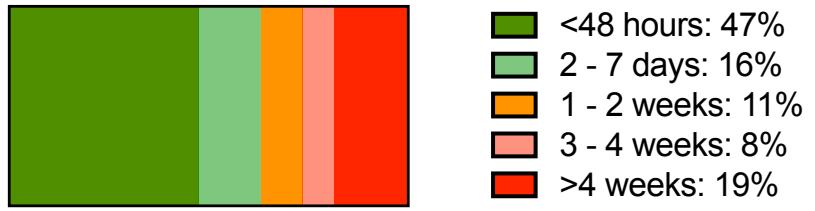
Less than a third are seen in clinic within a month of GP referral

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

Summary (i)

- IBD Standards forms a framework for QI
- Benchmarking is the largest patient reported dataset in IBD and has matched healthcare professional reported data
- Associations with high quality patient-reported care not necessarily ‘conventional’ metrics
  - IBD team leadership
  - Availability of information regarding the IBD service
  - Information and shared decision making about medication and surgery
  - Opportunities to participate in research
  - Access to joint medical and surgical clincs
  - Response to contact for advice by end of next day

Summary (ii)

- 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

The future

- Use this data for:
  - Service development
  - QI and audit
  - Expansion of the workforce
  - Making time for and expanding role of MDT meetings

- Refinement of the Benchmarking tool

Questions?

christopher.lamb@newcastle.ac.uk

Newcastle University

The Newcastle Upon Tyne Hospitals NHS Foundation Trust

National IBD Doctors Annual Meeting 2021

CLINICAL CHALLENGES & PEARLS

IN CONTEMPORARY IBD CARE

FERRING
PHARMACEUTICALS