# - EFCCA survey: People with IBD Aged 60 and Over

Preliminary results

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L U Leiden University
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#### Aims of the Survey



To study in the global, older (≥ 60 years)
IBD population:

- The epidemiology of IBD
- The impact of IBD on Quality of Life (QoL)
- Reported therapy goals
- Self-reported comorbidity and frailty



#### Design of the Survey



- Initiated and developed **by EFCCA**In collaboration with Leiden University Medical Center, The Netherlands
- Online, web-based survey (Paper copies available in several countries)
- Available in 21 languages and 46 countries
- From 19 May (World IBD day) to 30 November 2023
- Distributed through national IBD associations





#### **Design of the Survey**



#### 31 questions:

- **Demographic** (age, gender, working situation)
- IBD characteristics (type of IBD, disease activity)
- IBD medication (current IBD treatment)
- Treatment goals reported by patients
- Self-reported comorbid conditions and frailty

#### **Inclusion criteria:**

- Age ≥ 60 years
- IBD diagnosis (Crohn's, Ulcerative Colitis, IBD-u)

#### **Exclusion criteria:**

- Any patient not able to **understand** and/or **fill out** the questionnaire
- Any questionnaire with 1 or more missing answers





# Preliminary results







### Preliminary results

**Total responses:** 2191 194 excluded (not completed questionnaires) Used in final **Evaluable responses:** analyses





# Geographical distribution

Top 6 Countries	Number of respondents	%
1. The Netherlands	847	42.4
2. Norway	162	8.1
3. Italy	151	7.6
4. Czech Republic	134	6.7
5. Belgium	115	5.8
6. United Kingdom	101	5.0







# Respondents 200 400

#### Geographical distribution

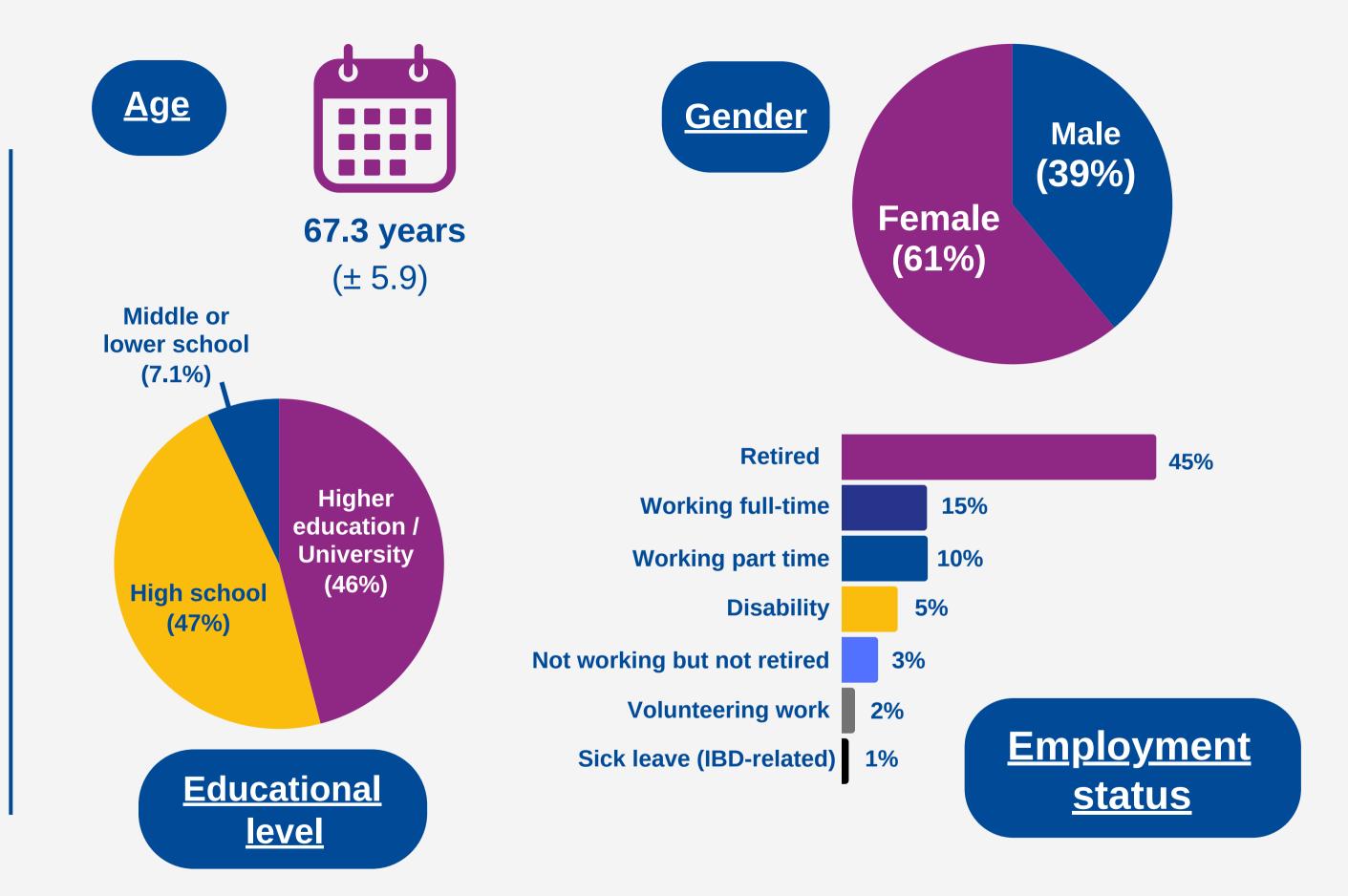






# **General Characteristics**



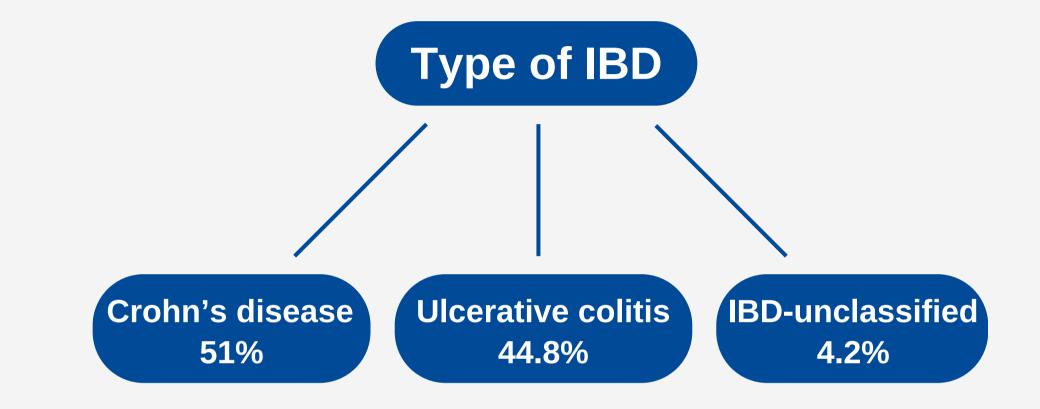






#### IBD Characteristics





IBD duration (years), median (IQR)

Clinical disease activity (%)

28 (14-40) 31% 19 (8-32) 31% 10 (3-21)

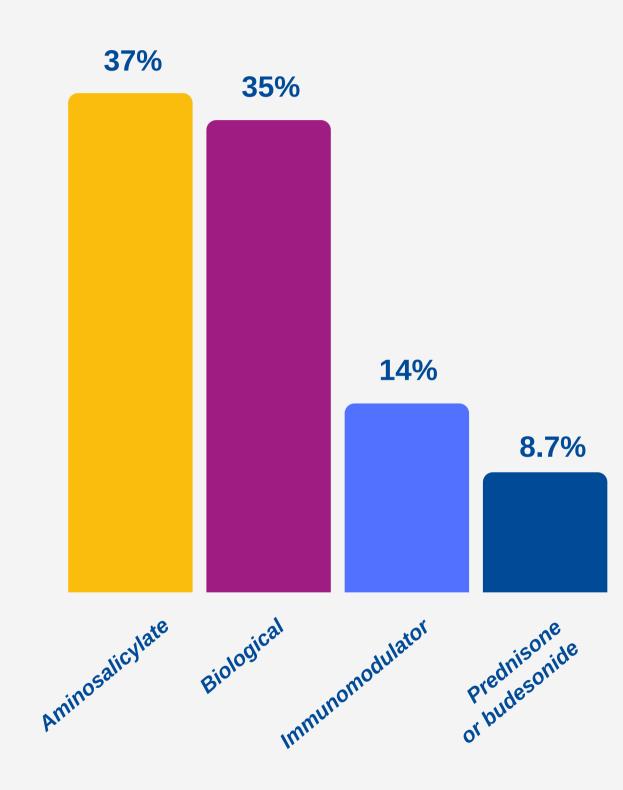
**57%** 





#### IBD Medication





82% reported use of <u>1 or more</u> IBD medication





#### Crohn's disease

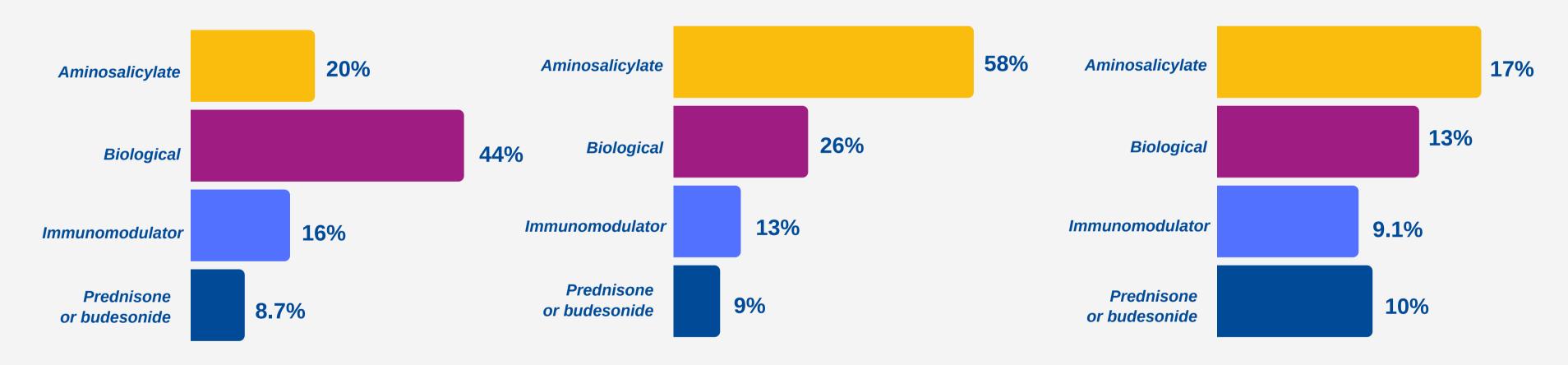
Any medication: 79%

#### **Ulcerative colitis**

Any medication: 89%

#### **IBD-U**

Any medication: 48%









- 12 therapy goals in total
- Categorized into medical and quality of life-related
- Patients had to pick the three most important to them

#### **Quality of Life Medical therapy goals** Experiencing less abdominal pain Preserve/restore my mobility and Decrease inflammation as seen on become more independent endoscopy or in stool/blood Preserve/restore my social life Prevent/postpone surgery for my IBD Preserve/restore my good mood Being able to maintain or getting to the (feeling relaxed, free of tension) weight I would like to be Being comfortable with my **body image** Stop using corticosteroids (prednisone/budesonide) Not feeling fatigued Decrease diarrhea/incontinence (going less Preserve/restore my **sexual activity** to the toilet/not experiencing urgency)





# Reported Therapy goals



Preserve / restore my good mood (feeling relaxed, free of tension)





Decrease

diarrhea/incontinence

(going less to the toilet /
not experiencing urgency)



# Therapy Goals by type of IBD





Medical therapy goals	Crohn's disease N = 1,019	<b>Ulcerative colitis</b> N = 896	Unclassified IBD N = 82	p-value
			04 (000()	10.001
To experience less abdominal pain	195 (19%)	146 (16%)	31 (38%)	<0.001
To decrease diarrhea incontinence	<b>3.</b> 324 (32%)	273 (30%)	<b>1.</b> 44 (54%)	<0.001
Decrease inflammation	172 (17%)	223 (25%)	15 (18%)	<0.001
Stop corticosteroids	36 (3.5%)	52 (5.8%)	8 (9.8%)	0.006
Preserve/restore body weight	249 (24%)	224 (25%)	7 (8.5%)	0.003
Avoid IBD surgery	185 (18%)	117 (13%)	3 (3.7%)	<0.001
Quality of Life				
To not feel fatigued	<b>1.</b> 602 (59%)	<b>1.</b> 470 (52%)	<b>2.</b> 42 (51%)	0.010
Preserve/restore good mood	<b>2.</b> 416 (41%)	<b>2.</b> 412 (46%)	<b>32</b> (39%)	0.057
Preserve/restore social life	311 (31%)	<b>3.</b> 280 (31%)	32 (39%)	0.3
Being comfortable body image	186 (18%)	158 (18%)	8 (9.8%)	0.2
To preserve/restore mobility	283 (28%)	248 (28%)	15 (18%)	0.2
Preserve/restore sexual activity	98 (9.6%)	85 (9.5%)	9 (11%)	> 0.9







#### 'Age-related state of increased risk for adverse health outcomes'

Relatively "new" concept in IBD

Two prospective studies, others retrospective

**Prevalent** in older patients with IBD: ~ 48%<sup>1</sup>

In IBD patients **increased risk** for: (IBD-related) hospitalizations, readmissions, low QoL and mortality <sup>2</sup>

Clegg, Andrew et al. *The Lancet Diabetes & Endocrinology,* Volume 6, Issue 9, 743-752

Stressor event

Independent

Dependent

Time

<sup>1.</sup> Vera E.R. Asscher, et al. Deficits in Geriatric Assessment Associate With Disease Activity and Burden in Older Patients With Inflammatory Bowel Disease, *Clinical Gastroenterology and Hepatology*, Volume 20, Issue 5, 2022, Pages e1006-e1021, ISSN 1542-3565.

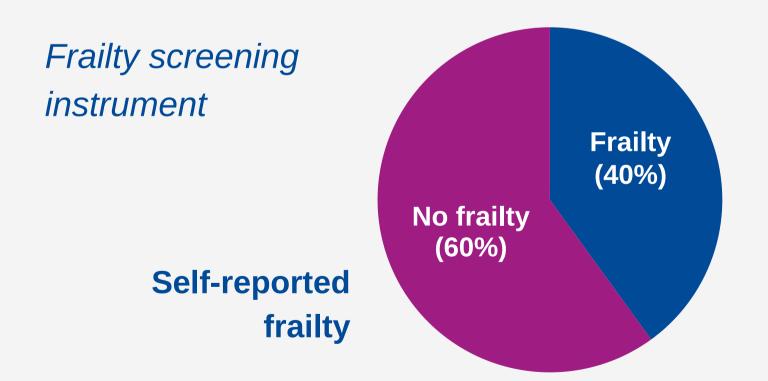
<sup>2.</sup> Fons A, Kalisvaart K, Maljaars J. Frailty and Inflammatory Bowel Disease: A Scoping Review of Current Evidence. *J Clin Med.* 2023 Jan 9;12(2):533. doi: 10.3390/jcm12020533. PMID: 36675461; PMCID: PMC9860672.







- Several ways to screen/measure frailty
- In the survey: **Geriatric-8 (G8) incorporated** (cut-off value ≤ 14)



Geriatric-8	"Abnormal"	
1. Food intake in the last three months	30.7%	-> A little less (26%) -> Much less (4.7%)
2. Weight loss in the last three months	35%	-> 0-2 kg (15%) ->3 kg (10%)
3. Mobility	1.9%	-> No independent moving (0.2%) -> Partial independent moving (1.7%)
4. Neuropsychological	32.5%	-> "a bit forgetful or depressed" (30%) -> "seriously forgetful or depressed" (2.5%)
5. Body Mass Index (BMI)	23%	-> BMI < 19 (3.9%) -> BMI 19 to 21 (9.0%) -> BMI 21 to <23 (14%)
6. The use of more than three medications per day	13%	-> 1-3 non-IBD medications per day (8.7%) -> 3 non-IBD medications per day (4.3%)
7. Self-rated health status	17.8%	-> Less healthy (7.8%) -> I do not know (10%)
8. Age	2.5%	Age 60-80 (97%) Age 80-85 (1.6%) Age 85-90 (0.9%)







**Top-3 Therapy** goals of older IBD patients with and without selfreported frailty



#### **Self-reported frailty**

1. Not feel fatigued (57%)

2. Good mood (44%)

3. Decrease diarrhea incontinence (37%)

No self-reported frailty



1. Not feel fatigued (55%)



2. Good mood (43%)



3. Social life (32%)





#### Comorbidity



Extraintestinal manifestations v.s. comorbidity

Increased risk for certain comorbidity, i.e. cardiovascular disease, neuropsychological disorders and metabolic syndrome <sup>3</sup>

May complicate treatment

<sup>3.</sup> Argollo, Marjorie et al. Comorbidities in inflammatory bowel disease: a call for action. *The Lancet Gastroenterology & Hepatology*, Volume 4, Issue 8, 643 – 654.





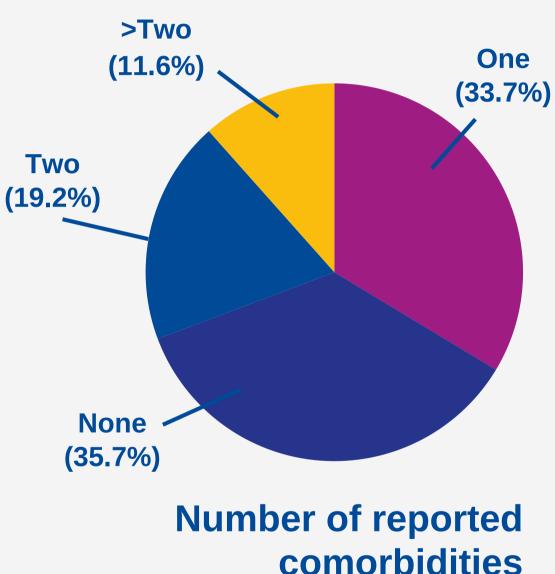
#### Comorbidity



 Patients were asked to report their comorbidities from a 13-item list (incl. one open question)

#### **Top 5 reported comorbidities**

- 1. Arthritis (29%)
- 2. Asthma (13%)
- 3. Heart disease (10%)
- 4. Diabetes (9.5%)
- 5. Cancer, in last 3 years (6.4%)







## Summary



- EFCCA initiated a survey among older patients with IBD
- Patient-centered, targeting a **broad**, **diverse** and **global** representation of older patients with IBD
- Large number of respondents (!)

Mean age: **67.3 years**, ~ **2/3 female** 82% of the respondents reported to use **one or more IBD medication** 

Very promising preliminary results

Therapy goals most important related to **fatigue**, **mood** and **diarrhea/incontinence** 

Frailty and comorbidity are common





# A great thank you to all the patients who participated, all national IBD associations and the EFCCA members of the team!

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