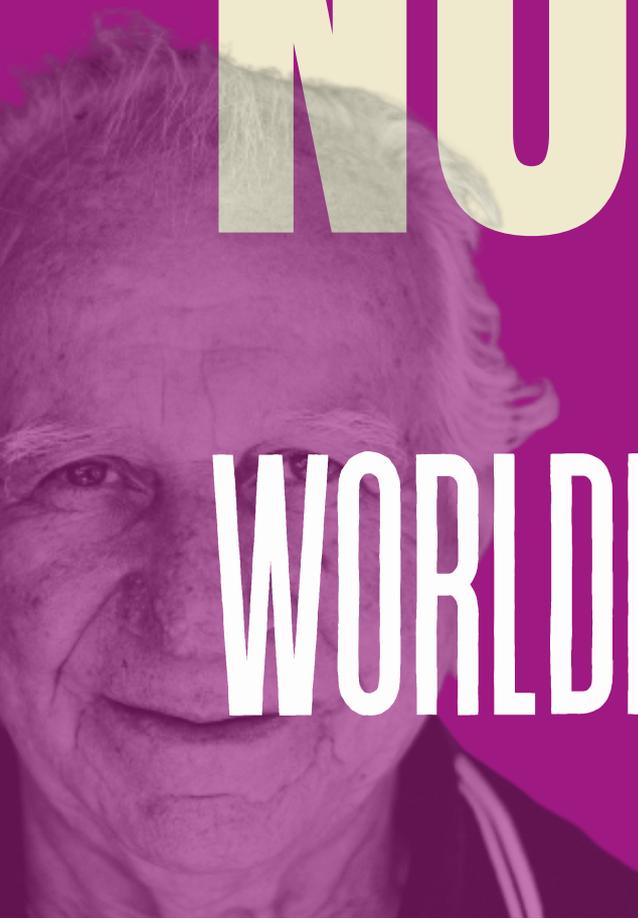




# IBD HAS NO AGE



WORLDIBDDAY 2023

19 May



## IBD HAS NO AGE

is an EFCCA campaign started in 2022 in order to raise awareness of how Inflammatory Bowel Disease (IBD) is impacting on the life of people aged 60 years and over.

### Why are we focusing on this particular age?

First of all, because it concerns all of us, no matter our age. Sooner or later we will be reaching old age and we need to know more of how our IBD is going to affect us at this stage.

IBD is evolving! and in the next decade around 1 in 3 IBD patients will be 'older' adults. Yet, clinical data on the characteristics and the outcome of the disease in advanced age are scarce.

As part of our World IBD Day 2023 (19th May) campaign EFCCA will be launching a survey on people with IBD aged 60 years and over to investigate more on this topic with questions related to both quality of **life** and quality of **care**.

There are important issues such as comorbidities, polypharmacy and the cognitive decline in people aged 60 years and over that warrant further research.

We need such scientific data in order to better understand the disease amongst the older population and develop better

management and treatment strategies enabling equal access to best treatment options for all patients.

EFCCA is calling for more comprehensive actions to meet these challenges and to better prepare our healthcare systems for an ageing IBD population.

As there is **no "typical" older IBD** patient there needs to be a person-centred care approach to treatment tailored to the individual.

Ultimately we need to change our mindset around ageing so that **WE ALL** can enjoy old age as best as possible!

### Join our campaign!

SOONER OR LATER  
WE ALL  
WILL BE REACHING  
OLD AGE



# INTRODUCTION

## The incidence and prevalence of Inflammatory Bowel Disease (IBD) in older people is steadily rising.

While IBD commonly peaks in young adulthood, a significant 10% to 15% of newly diagnosed people with IBD are 60 years or older. Moreover, it is estimated that in the next decade, 1/3 of all patients with IBD will be older adults (60 and above)<sup>1</sup>.

This clearly indicates that the IBD patient community is moving towards an older age. Yet, there is little scientific evidence to understand how IBD impacts adverse health outcomes or quality of life in older people with IBD.

For example, if we look at the involvement of older IBD patients in clinical trials related to IBD, we found that only 6% of people aged 65+ and 0% above 85 years were included in such trials .

**ONLY 6 %**

PEOPLE AGED 65+ ARE INCLUDED IN  
CLINICAL TRIALS

Older adults with IBD are also more likely to be affected by other age-related chronic conditions such as diabetes, arthritis and heart disease resulting in the use of multiple medications known as polypharmacy. This makes the diagnosis and management of the disease in people aged 60 years and over more challenging compared to that in younger adults.

## IBD HAS NO AGE

EFCCA, representing patient associations from 46 countries, has started to raise awareness around these issues. Under the slogan, IBD has no age, we started the dialogue on how IBD in people aged 60 years and over impacts their quality of life and care.

A Focus Group with representatives from the older patient community discussed the main challenges and concerns of IBD in people aged 60 years and over. The discussions fed into EFCCA's social media awareness-raising campaign for World IBD Day 2022.

On World IBD day itself, we organised the EFCCA Purple Talk to discuss the issue of IBD in people aged 60 years and over and the need for more comprehensive scientific evidence. **We also represented a survey we plan to launch on this topic in 2023.** The survey has been elaborated with researchers from Leiden Medical University (the Netherlands). It aims to get a better understanding of IBD in people aged 60 years and over with questions related both to quality of life and quality of care.

# WHAT'S THE PROBLEM ?

1

## LACK OF SCIENTIFIC DATA

There is an urgent need for more scientific research. Currently, only a tiny proportion of participants enrolled in IBD clinical trials or long-term pharmacovigilance initiatives are made up of people with IBD aged 60 years and over. This results in a relatively poor evidence base to guide appropriate therapeutic management decisions in this population.

2

## NO TYPICAL IBD PERSON

There is no typical IBD patient. There are various ways that IBD can affect a patient; some 60-year-olds will have the same physical capacities as many 20-year-old IBD patients. Other people experience declines in physical and different abilities at much younger ages.

3

## COMORBIDITIES

People with IBD aged 60 years and over are at much higher risk of age-related comorbidities and complications due to their condition. This is exacerbated when considering immunosuppressant drugs. Surgical management of IBD in older IBD patients also comes with a higher risk due to higher comorbidity and/or frailty.

4

## POLYPHARMACY

Given the higher incidence of age-related comorbidities, people with IBD aged 60 years and over are more likely to take a wide range of medicines to treat other conditions.

5

## COGNITIVE DECLINE

Cognitive decline and psychiatric diseases, which are relatively common in people aged 60 years and over, can result in poor adherence to therapy in managing their IBD.



# WHAT NEEDS TO CHANGE ?

## EQUAL ACCESS TO BEST TREATMENT OPTIONS

Currently, clinical data to inform treatment options practices are based on observational data or indirect evidence because people with IBD aged 60 years and over are underrepresented in clinical studies. Therefore there is a risk of IBD patients in this age group not benefitting from best treatment options.

For example, a UK study that looked at the *"impact of comorbidities in patients with IBD, on first-line biologic prescribing habits of IBD-specialist healthcare practitioners in the UK"* found that physicians adapt their biologic prescribing habits in patients with IBD with comorbidities, considering known<sup>3</sup> contraindications and precautions . A study from Sweden showed that people with IBD aged 60 years and over used fewer biologics and immunomodulators but more systemic corticosteroids compared with patients with pediatric or adult-onset IBD<sup>4</sup> .

We need a better understanding of the disease epidemiology among the older population and specific knowledge for the management and treatment of IBD in advanced age. There needs to be more research on specific issues related to comorbidities, polypharmacy, drug effectiveness and interactions.





# WHAT NEEDS TO CHANGE ?

## BEING BETTER PREPARED

The fact that the IBD population is shifting towards an older age calls for comprehensive actions to meet these challenges and to better prepare our healthcare systems for an ageing IBD population.

As such, health systems must be capable of providing older person-centred and integrated care and focus on maintaining capacities as people age. The approach to treatment must be tailored to the individual.

## OUR MINDSET

Our mindset around ageing needs to change! Ageism – discrimination against a person based on their age – has severe consequences for older people and societies at large. Older people are often assumed to be frail or dependent and a burden to society. Health professionals, patient associations and other stakeholders must tackle this discrimination and strive towards comprehensive approaches and policies to enable a good quality of life for people with IBD aged 60 years and over.

## OUR VISION IS

TO ENSURE THAT IBD TREATMENT STRATEGIES INCLUDE  
PEOPLE AGED 60 YEARS AND OVER, ALLOWING THEM TO

ENJOY OLD AGE AS BEST AS  
POSSIBLE.



# GET INVOLVED

## LEARN



The more we know about a topic the easier it is to better advocate for it! Watch EFCCA discussing this topic with representatives from a focus group that involved 8 patient associations. The videos highlight some of the main concerns and realities of living with IBD aged 60 years and over.

[VIEW OUR RESOURCES](#)

## ENGAGE



Help us become more visible. Share this campaign on social media, using our graphics and hashtags (#ibdhasnoage, #worldibdday2023). Use our Facebook banner (to be uploaded soon).

[ENGAGE WITH US](#)

## ACT



In 2023 we will be launching our survey on people with IBD aged 60 years and over. Help us by either responding to the survey (if eligible) or spreading the word about it so that we can increase participation and get a better picture of the current situation.

[HELP US](#)

**FOR MORE INFORMATION PLEASE VISIT OUR CAMPAIGN  
PAGE AT:  
[HTTPS://EFCCA.ORG/PROJECTS/WORLD-IBD-DAY-2023](https://efcca.org/projects/world-ibd-day-2023)**



# REFERENCES

1. Hong SJ, Katz S. The elderly IBD patient in the modern era: changing paradigms in risk stratification and therapeutic management. *Therap Adv Gastroenterol.* 2021 Jul 3;14:17562848211023399. doi: 10.1177/17562848211023399. PMID: 34276809; PMCID: PMC8255562.

2. This data has been extracted from publicly available European clinical trials registers using EFCCA's new working approach DIVA: The percentages show the involvement of people over 65 years in IBD Clinical Trials in Europe since 2019. For more information, please contact EFCCA.

3. Akbar A, Orchard T, Powell N, Selinger C, Tibbatts C. Influence of comorbidities on treatment considerations for first-line biologic prescribing in patients with inflammatory bowel disease in the UK. *Frontline Gastroenterol.* 2022 Mar 17;13(6):490-496. doi: 10.1136/flgastro-2021-101995. PMID: 36250175; PMCID: PMC9555136.

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