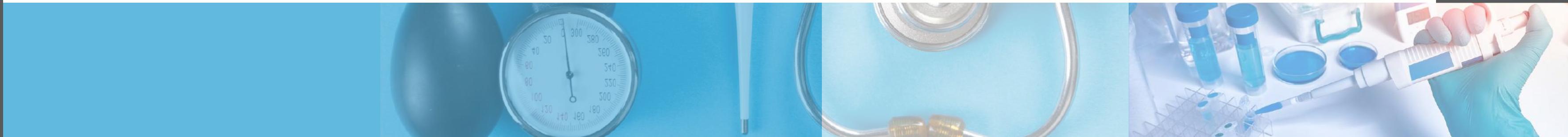




**ALLIANCE OF  
PATIENTS'  
ORGANIZATIONS  
SINGAPORE**  
Patients Co-creating Healthcare

# CULTURAL CHANGE IN CLINICAL RESEARCH PATIENT PARTICIPATION

Ms Nidhi Swarup



# c h a n g i n g p h y s i c a l i s s u e s



## TWO YEAR JOURNEY 2009 -11

- Severe Headaches
- Dizziness
- Extreme Fatigue
- Weight loss
- Sensitive skin
- Very Dry Eyes
- Palpitations
- Diarrhea



NUMEROUS  
EXPERTS  
CONSULTED

# LOOKING FOR ANSWERS



1. ENT
2. Neurosurgeon
3. Neurologist
4. Psychiatrist
5. Immunologist
6. Cardiologist
7. Ophthalmologist
8. Dermatologist
9. Gynecologist
10. Gastroenterologist
11. Rheumatologist



### Crohn's disease & Ulcerative colitis

- Two main types of Inflammatory Bowel Disease (IBD)

Inflammatory Bowel Disease (IBD) are non-infectious lifelong illnesses that can be painful, debilitating and sometimes lead to life-threatening complications

As of 2023 - Singapore Population 5.92 Million

- Estimated 3,000 IBD patients
- Estimated 300 children

Tremendous increase in newly diagnosed IBD patients the last 15-20 years



# M I X E D E M O T I O N S

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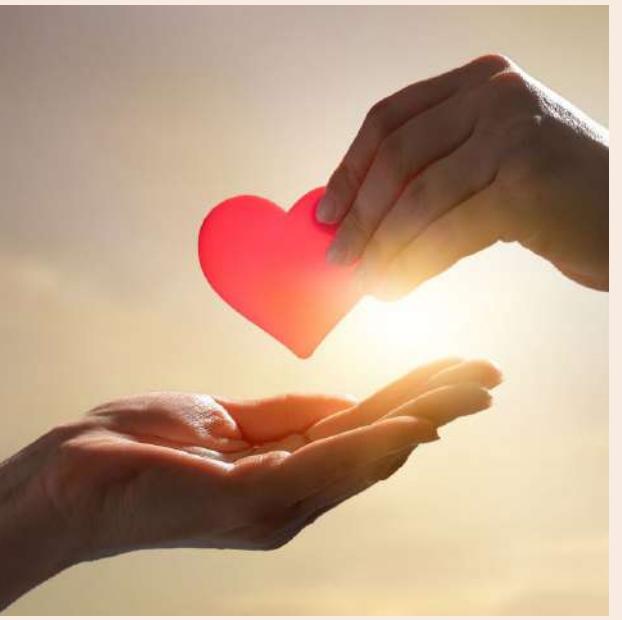
## SAD, UPSET, CONFUSED

- NOT curable
- Cause unknown
- Can be debilitating

## RELIEVED, HAPPY

- Not a term in a illness
- Not infectious
- Can be managed with meds

# POLYPHARMACY



## MULTIPLE DIAGNOSIS

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1. Crohn's Disease | GASTROENTEROLOGIST
  2. Fibromyalgia | RHEUMATOLOGIST
  3. Eczema | DERMATOLOGIST
  4. Small Fibre Neuropathy | NEUROLOGIST
  5. Sleep Apnoea | SLEEP PHYSICIAN
- +** MENOPAUSE | GYNAECOLOGIST

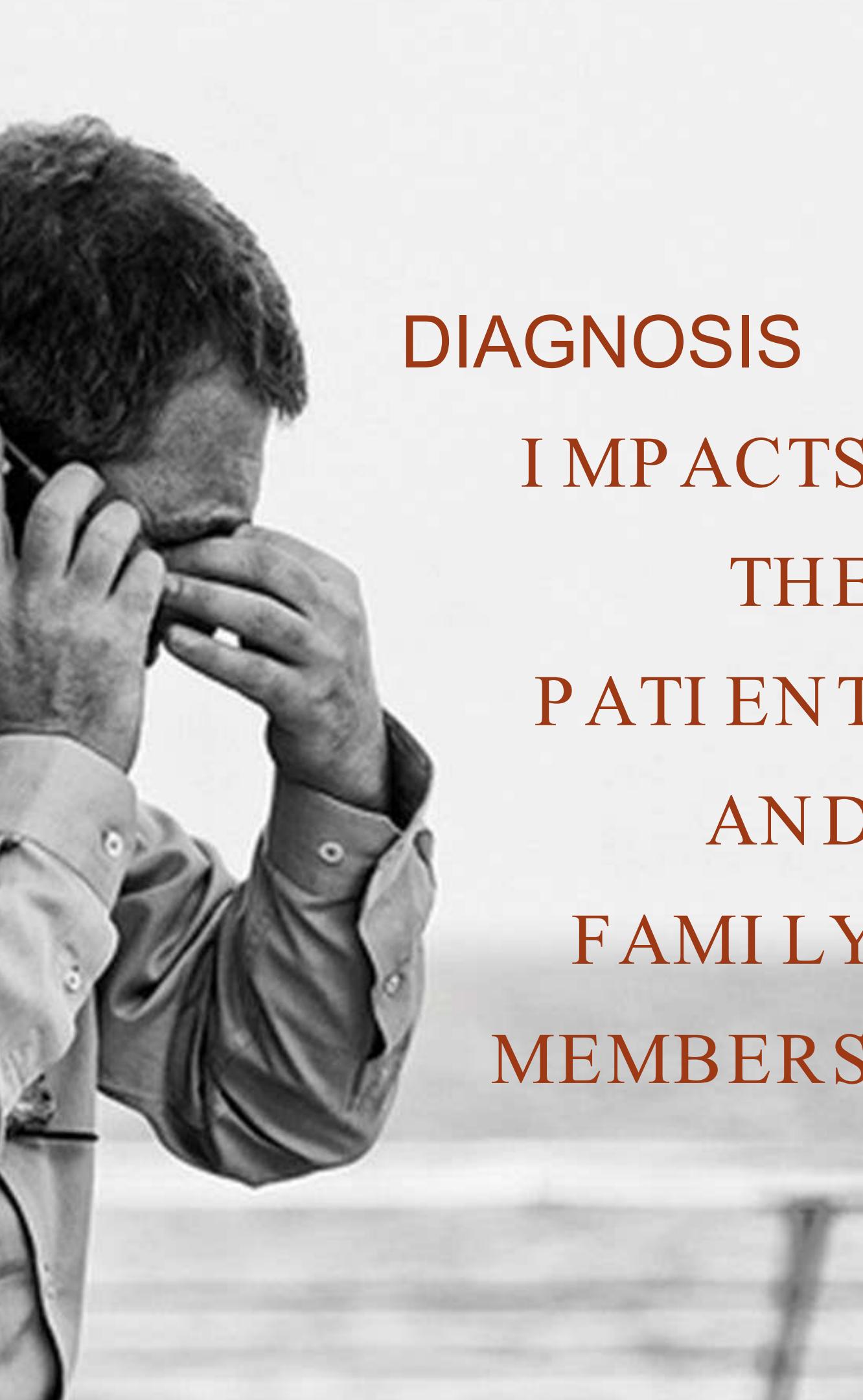


# alternative medicine

REFERENCE | WHO TECHNICAL REPORT | MEDICATION SAFETY IN POLYPHARMACY

LONG-TERM & LATENT EFFECTS | POST MARKETING SURVEILLENCE | HERB-DRUG, DRUG-FOOD INTERACTIONS

- TCM
- ACUPUNCTURE
- MEDICAL QIGONG
- NATUROPATHY
- HOMEOPATHY
- MEDITATION



# DIAGNOSIS IMPACTS THE PATIENT AND FAMILY MEMBERS

## PHYSICAL

“For months I have been so sick and fatigued. I had so many tests, scans and biopsies. I must take medicines for the rest of my life?”

## FINANCIAL

“I don’t have insurance. Each injection is \$2,000 after subsidy. Are biosimilars effective? I don’t want to burden my family.”

## EMOTIONAL

“I have this chronic illness that I have never heard of before. Now if I take these medicines, there are so many risks. I am confused.”

## SOCIAL

“My family and friends don’t understand how tired I feel. I have bloody diarrhea 5 -6 times everyday. How can I go out?”

# PATIENT JOURNEY MAP

ADULT PATIENT | MULTIPLE DIAGNOSIS

## GP VISIT

Infectious illnesses considered |  
Treated, rule-out | Weeks-to-months | Referral to Specialist

01.

## SPECIALISTS' CLINIC

Consultation | Numerous blood, urine, fecal tests | CT Scan, X-Ray, Colonoscopy, MRI ++|  
Getting Appointments | Waiting for Results

02.

## HOSPITALIZATION

Acute episode | A&E | Tests, Scans |  
Admission & Diagnosis | Unheard of illness| Surgery | Post-procedure care

03.

## TREATMENT OPTIONS

Multiple Prescriptions | Online info overwhelming | Inadequate options to clarify doubts | Side effects

06.

## CO-MORBIDITIES

Repeat Steps 1,2,3 | Medications, Diet, Post-discharge care | IMPACT on Career, Finances & Family Life | Appointments Calendar

05.

## DISCHARGE/HOME CARE

Mobility, Diet, Exercise | Safety, Numerous Medicines, Mental Health

04.

## FOLLOW-UP

Monitoring each illness | Food, Feelings, Symptoms Diary | Report to Specialist after x#weeks

07.

## PALLIATIVE CARE

Patient and Family Education | Institutional vs Home Care | Mental Wellness | Caregiver Support

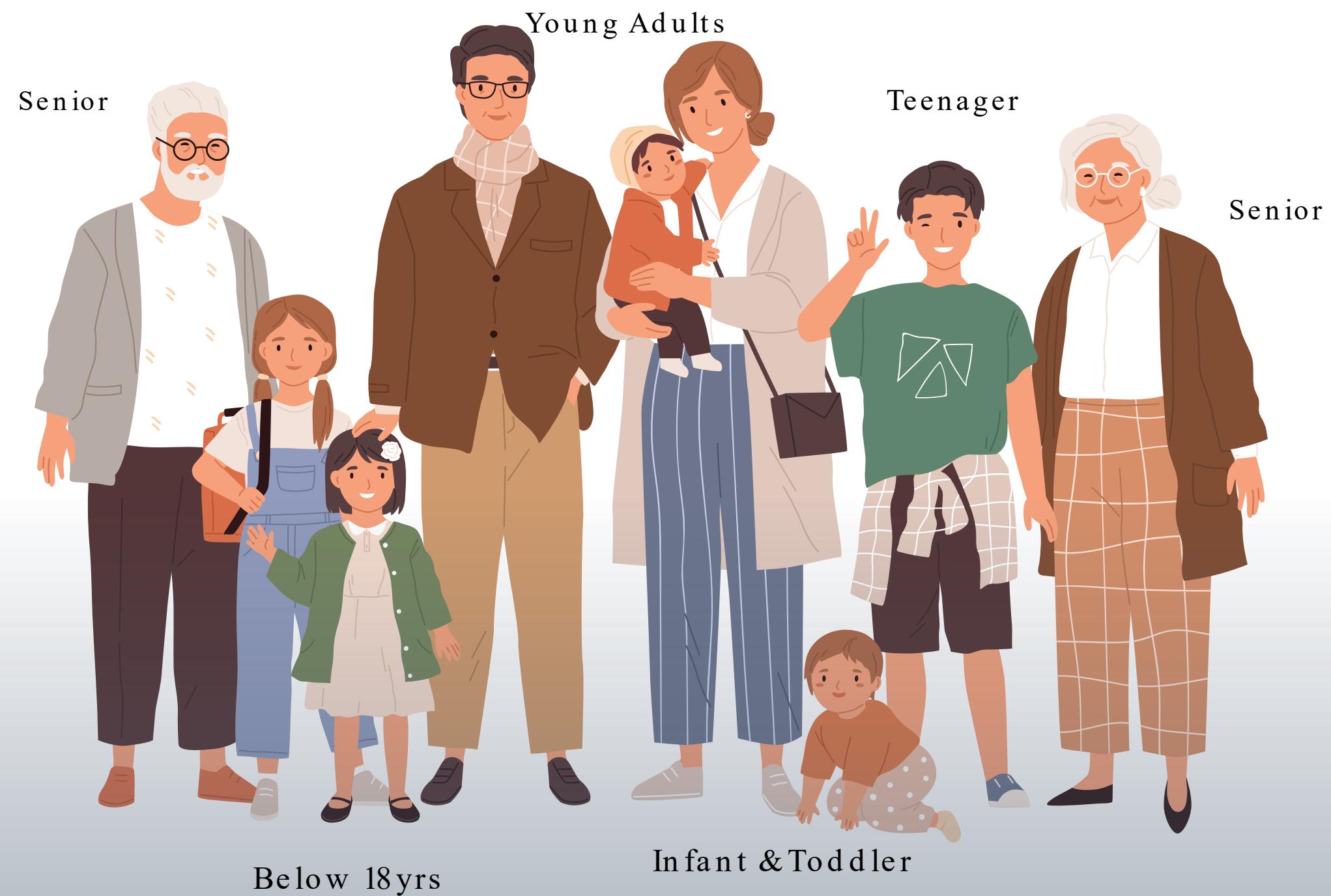
08.

## END OF LIFE

Asian Culture | Role of Family Members | Advanced Medical Directive | Critical Care Decisions

09.

# DECISION-MAKING BY PATIENTS IN SINGAPORE



# MENTAL HEALTH

The WHO defines mental health as “more than the absence of mental disorders. It is a state of well-being in which the individual realizes his or her own abilities, **can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.**”

The prevalence of diabetes among Singapore residents aged 18 to 74 years was **9.5%**

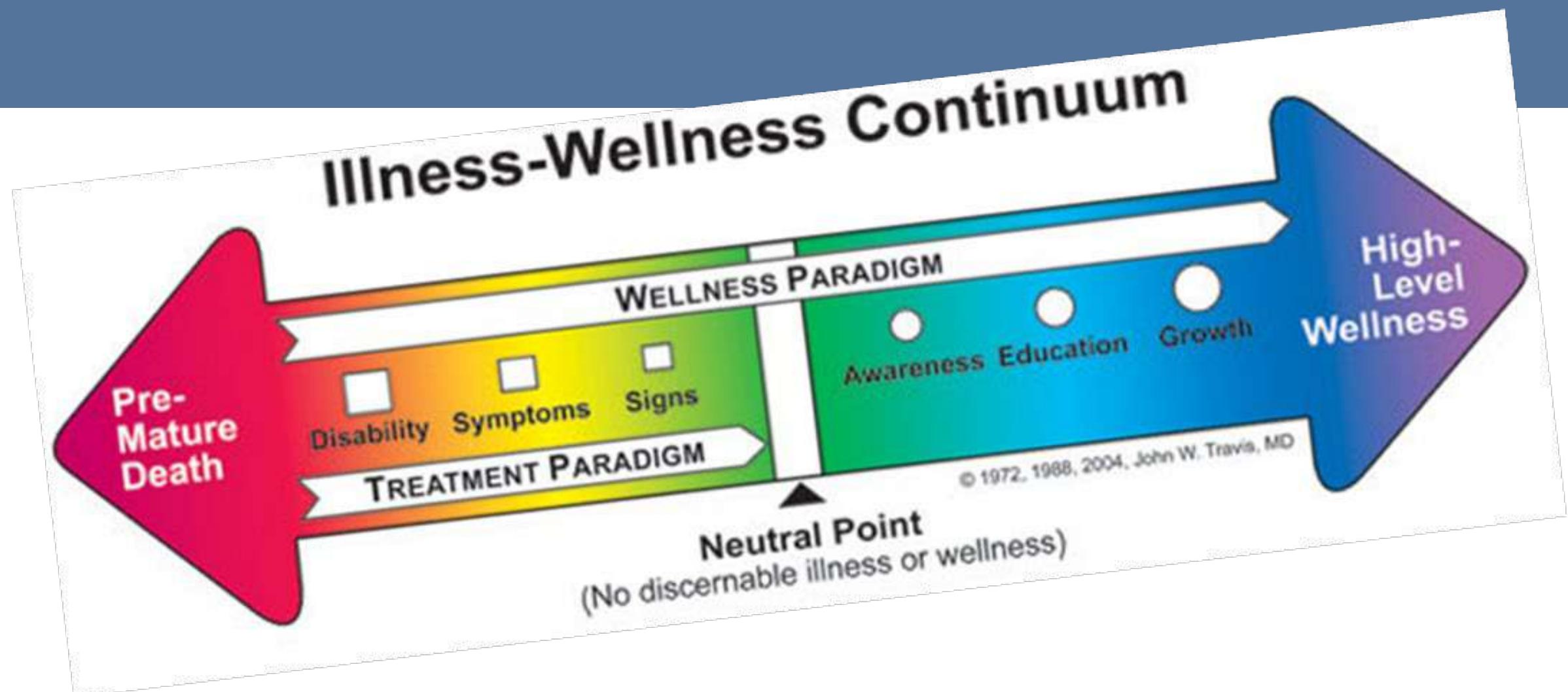
The prevalence of poor mental health as measured by GHQ-12 among Singapore residents aged 18 to 74 years was **13.4%**



Younger adults aged 18 to 29 years **21.5%** had the highest proportion with poor mental health.

Source: National Population Health Survey  
2020, MOH Singapore

# c o p i n g w i t h d i a g n o s i s



# EFCCA survey: People with IBD Aged 60 and Over

## Preliminary results

Stockholm, 22 February 2024



EFCCA European Federation of Crohn's & Ulcerative Colitis Associations

L U M C Leiden University Medical Center

Anne Fons Isabella Haaf

MD, PhD candidate, Leiden University Medical Center, The Netherlands

Head of Communications Coordinator World IBD Day

## 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



## Aims of the Survey

To study in the global, older ( $\geq 60$  years) IBD population:

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



## PRELIMINARY RESULTS

FEBRUARY 2024 |

STOCKHOLM, SWEDEN

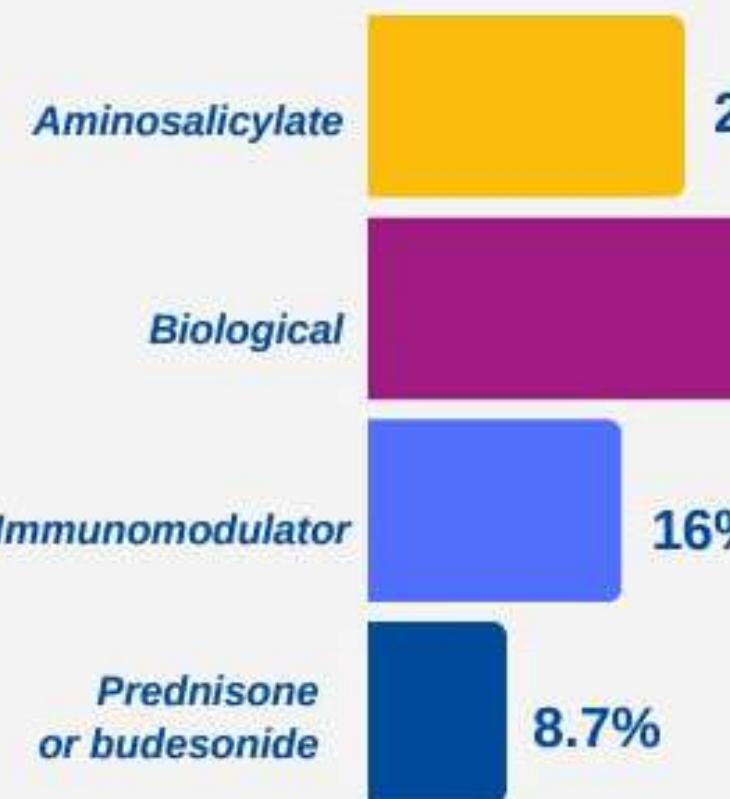
~2,000 RESPONSES

# IBD Medication



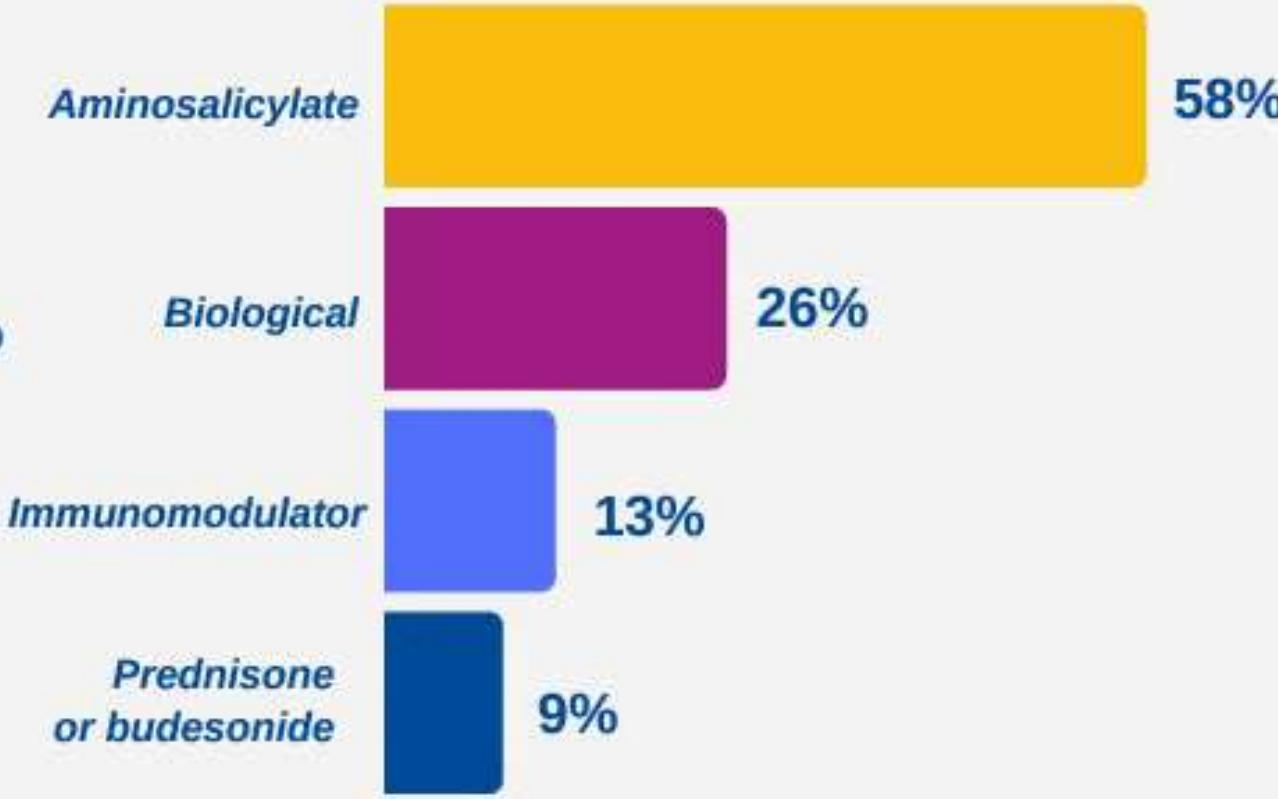
## Crohn's disease

Any medication: 79%



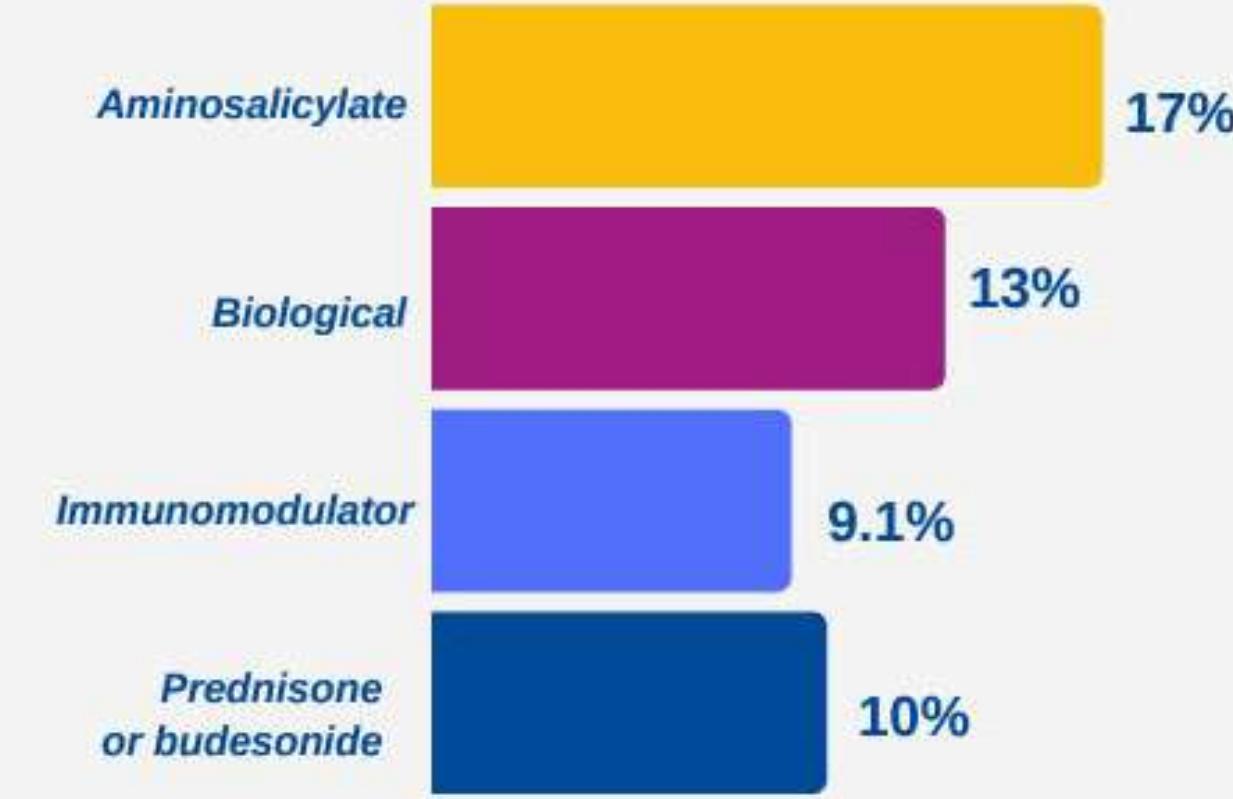
## Ulcerative colitis

Any medication: 89%



## IBD-U

Any medication: 48%



## Reported Therapy goals



43%

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



56%

Not feeling **fatigued**



32%

Decrease  
**diarrhea/incontinence**  
(going less to the toilet /  
not experiencing urgency)

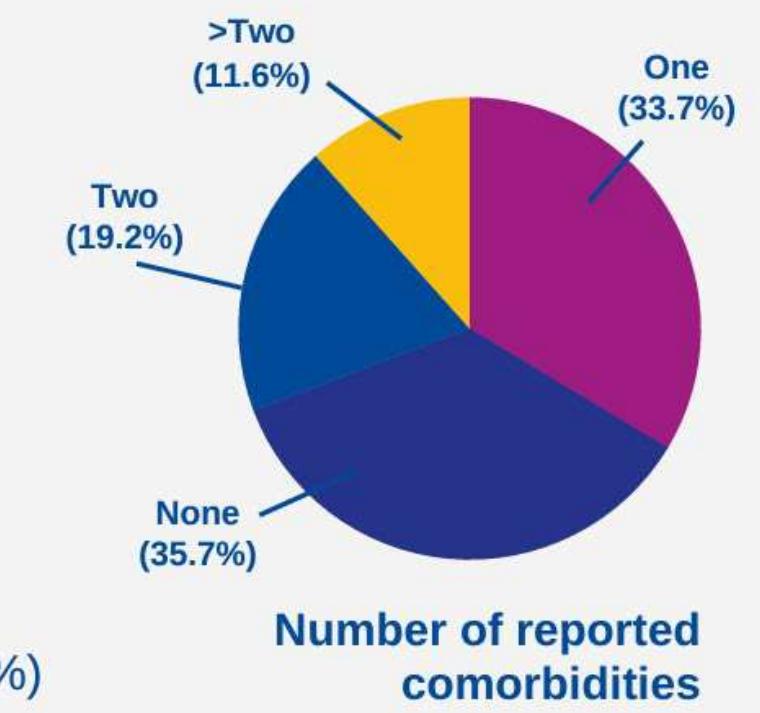
## Comorbidity



- 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%)



# COLONOSCOPY PREPERATION IN SINGAPORE

COST + PATIENT EXPERIENCE = VALUE



**WATER | The Institute of Medicine of the National Academies recommends drinking**

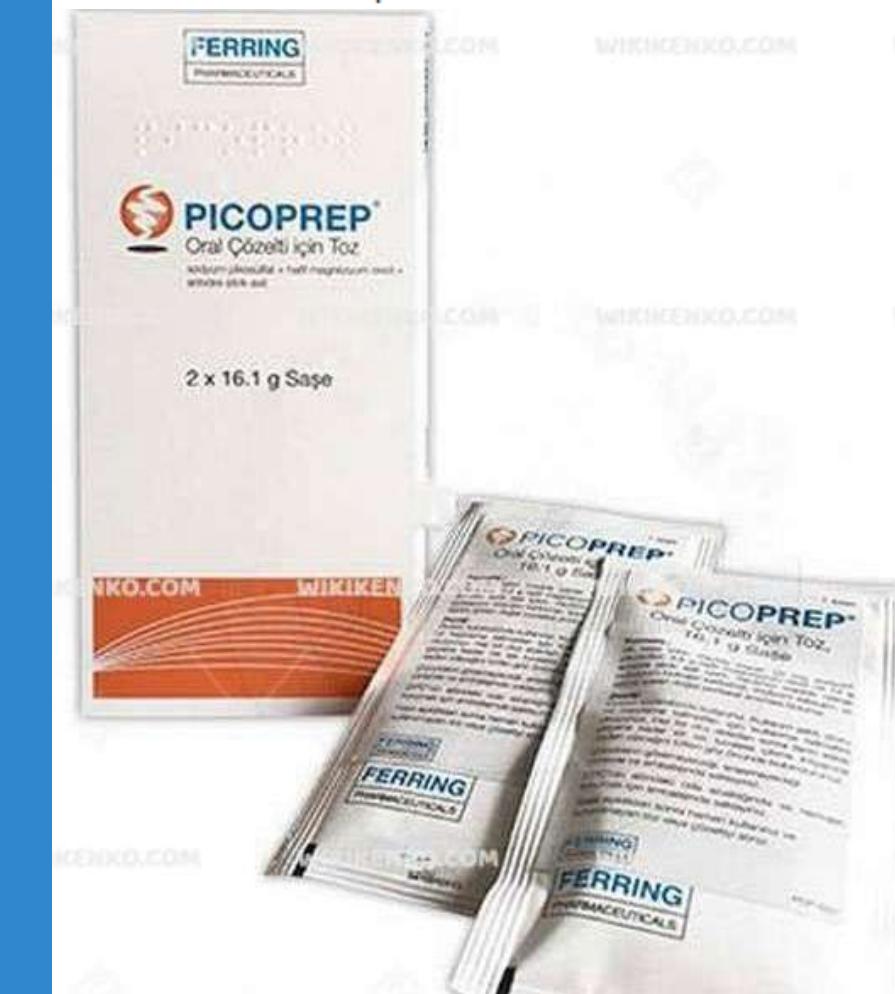
- **2.7 liters (or 91 ounces or 11 cups) for adult women a day**
- **3.7 liters (or 125 ounces or 15 cups) for men**

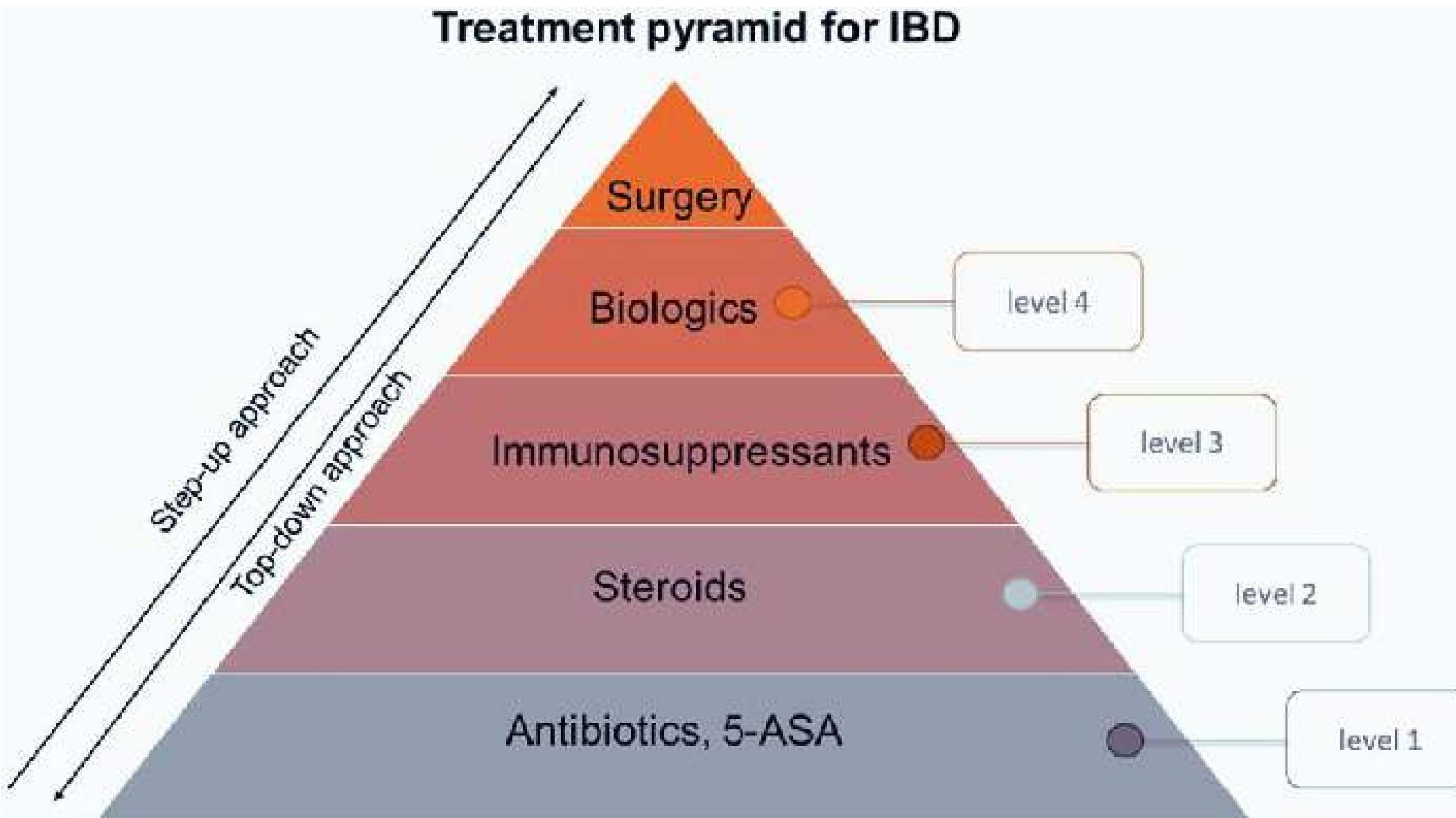
FORBES HEALTH, 2 April 2024

PRESS RELEASE 2016

Ferring Pharmaceuticals announces approval of new tailored dosing regimen in the PICOPREP® (sodium picosulfate, magnesium oxide, citric acid) label in MRP countries in Europe

Ferring Pharmaceuticals has successfully finalised a Mutual Recognition Procedure (MRP) submitted in Europe on 28 October 2015 with the UK as a Reference Member State (RMS).





SOURCE Schnur, S., Wahl, V., Metz, J.K. et al. Inflammatory bowel disease addressed by Caco-2 and monocyte -derived macrophages: an opportunity for an in vitro drug screening assay. *In vitro models* 1, 365 –383 (2022). <https://doi.org/10.1007/s44164-022-00035-8>

## M U L T I P L E D I A G N O S I S

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5. Sleep Apnoea | SLEEP PHYSICIAN

MENOPAUSE | GYNAECOLOGIST

# WHERE ARE YOUR PATIENTS

CLINICS | HOSPITALS | NURSING HOMES | COMMUNITY HOSPITALS | HOSPICE CARE



## SIX POTENTIAL ROLES OF PATIENTS

**RESEARCH PARTICIPANT**  
Contribute with DNA, cells etc. for clinical trials

**INSIGHT PROVIDER**  
Provides general or disease specific info about a patient population

**ADVISOR**  
Member of clinical research prog committee, HTA, disease specific workshop

**REVIEWER**  
Various patient related content eg brochures, videos, awareness campaigns

**DRIVING FORCE**  
Owns or collaborates as a partner in projects with POs or Industry, influencing policy & implementation

**CO-DESIGNER**  
Research results, product brochures & clinical material into patient friendly information

# FACTORS AFFECTING APAC Patient Engagement

01

Accessibility & Ease of Access

02

Trust in Authority

03

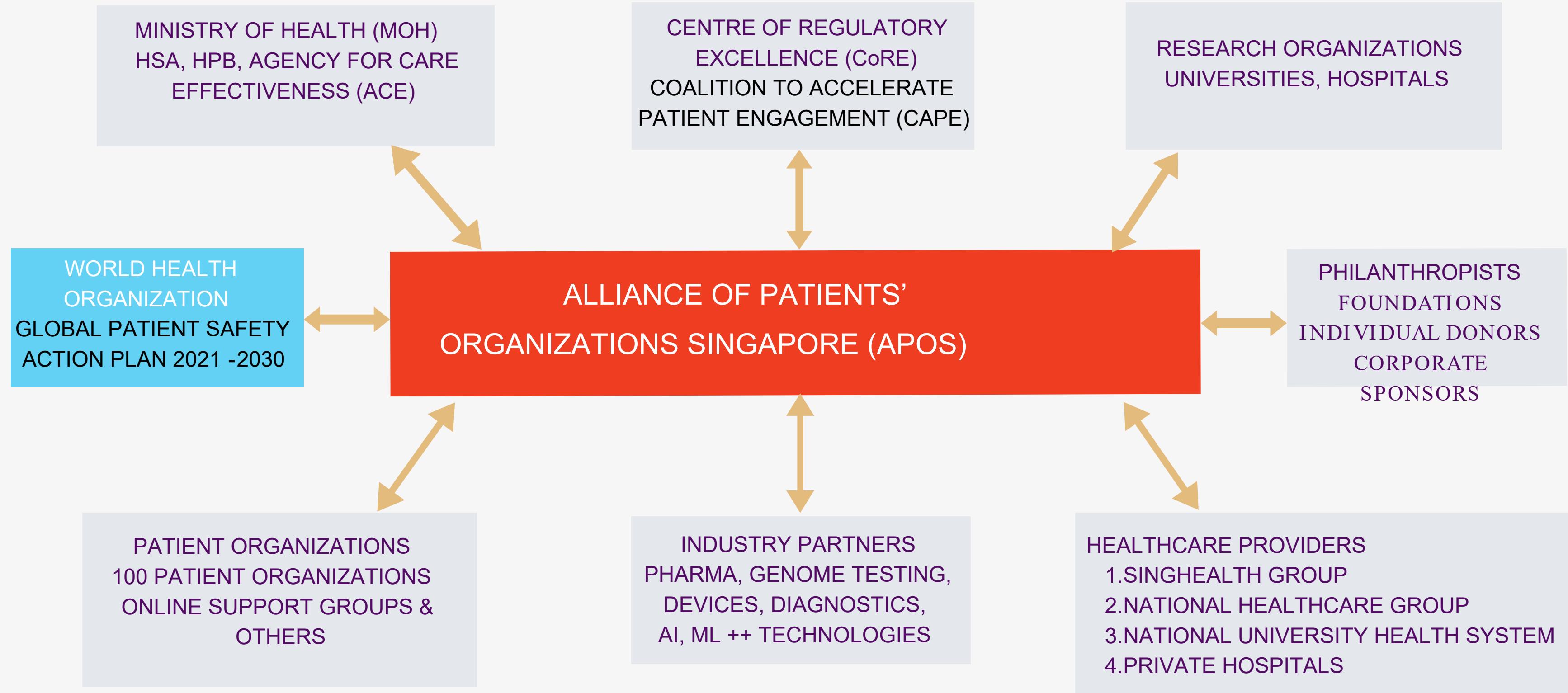
Culture

SOURCE: WORLD ECONOMIC FORUM

<https://www.weforum.org/agenda/2022/11/asia-pacific-patient-engagement-healthcare/>



# MULTIPLE STAKEHOLDERS IN HEALTHCARE



# Research, Innovation and Enterprise 2025 Plan

2000 -2025  
\$25 BILLION  
INVESTMENT



## RIE2025 Structure

Our RIE2025 efforts will be organised along four strategic domains, supported by three cross-cutting horizontals.

### Manufacturing, Trade and Connectivity (MTC)

Leveraging R&D to reinforce Singapore's position as a global business and innovation hub for advanced manufacturing and connectivity

### Urban Solutions and Sustainability (USS)

Renew and build a liveable, resilient, sustainable and economically vibrant city for tomorrow

### Human Health and Potential (HHP)

Better transform and protect health, advance human potential and create economic value for Singapore

### Smart Nation and Digital Economy (SNDE)

Develop technology leadership to drive our Smart Nation ambition, and anchor Singapore's position as a trusted digital innovation hub

### Academic Research

Build a robust base of research capabilities and peaks of international excellence

### Manpower

Nurture a strong research and innovation talent pipeline

### Innovation and Enterprise

Accelerate enterprise innovation

HEALTHCARE GAPS: SINGAPORE



# GLOBAL PATIENT SAFETY ACTION PLAN 2021 -2030

## CALLS FOR PATIENT AND COMMUNITY ENGAGEMENT

- 1. POLICYMAKERS**
- 2. REGULATORS**
- 3. HEALTH TECHNOLOGY ASSESSMENT (HTA)**
- 4. PROVIDERS: SINGHEALTH, NHG, NUHS, PRIVATE SECTOR**
- 5. ACADEMICS, CLINICIANS, RESEARCHERS**
- 6. PHARMACEUTICAL, DIAGNOSTIC, MEDTECH COMPANIES**
- 7. INVITE PATIENTS & FAMILY MEMBERS AS CO-CREATORS**



# NEXT 25 YEARS: INVEST IN EMPOWERING & INVOLVING PATIENTS



- 1. INCLUDE** Patients-as-partners with 'Lived Experience'
- 2. IDENTIFY** Unmet Needs of Patients
- 3. CO-DESIGN** Clinical Research Questions, Patient-relevant Endpoints, trial design and conduct, inclusion and exclusion criteria and patient priorities in terms of benefit and risk\*
- 4. CREATE** Patient Advisory Boards for Hospitals, Research Institutes, Pharma, MedTech, Diagnostics and CROs
- 5. CO-CREATE** Awareness and Educational Materials, CT Results' Report

SOURCE: <https://doi.org/10.1038/s43856-022-00156-x> | [www.nature.com/commsmed](http://www.nature.com/commsmed)

PATIENT  
AND  
PUBLIC  
INVOLVEMENT  
FOR  
SUSTAINABLE  
HEALTHCARE



# ALLIANCE OF PATIENTS' ORGANIZATIONS SINGAPORE

Patients Co-creating Healthcare

# THANK YOU



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