IFCCA
International Federation of Crohn's & Ulcerative Colitis Associations

Conference Report

ACCESS TO IBD CARE: TOWARDS ONE GLOBAL STANDARD

Organised by International Federation of Crohn's & Ulcerative Colitis Associations (IFCCA)
Hosted by the Crohn's & Colitis Society of Singapore (CCSS)

#IBDHasNoBorders

Singapore
World IBD Day 2026

I. Executive Summary

On 16 May 2026, IFCCA – the International Federation of Crohn's & Ulcerative Colitis Associations – in collaboration with the Crohn's & Colitis Society of Singapore (CCSS), organised the World IBD Day 2026 meeting in Singapore under the theme *"Access to IBD Care: Towards One Global Standard."*

Bringing together patient leaders, healthcare professionals, advocates and international partners from the Asia-Pacific region and beyond, the meeting represented another important milestone in IFCCA's growing global efforts to strengthen international collaboration among stakeholders and improve patient access to quality IBD care worldwide.

Building on the momentum created through previous IFCCA World IBD Day roundtables in Mexico City (2024) and Brussels (2025), the Singapore meeting introduced a strong regional focus through a dedicated Asia-Pacific Networking Meeting held in the morning, followed by an International Roundtable discussion in the afternoon.

The networking session provided patient organisations from across the Asia-Pacific region with a platform to openly discuss the realities facing people living with IBD in their respective countries and communities. Discussions highlighted that barriers to care are not limited to treatment access alone, but are also deeply shaped by stigma, social perceptions, geography, mental health challenges, cultural approaches and inequalities in healthcare infrastructure.

Participants repeatedly emphasised the burden of living with an often invisible disease in societies where digestive diseases remain difficult to discuss openly. Fear of judgement, social stigma, employability concerns and limited public awareness emerged as common themes across multiple countries.

At the same time, major disparities in access to diagnosis, biologic and other recent treatments, IBD specialist care and long-term disease management continue to affect patients throughout the region, particularly in rural areas and lower-resource settings.

The afternoon International Roundtable expanded these discussions to a global level, bringing together perspectives from Asia-Pacific, North America, Europe and other World IBD Day founding members. Speakers explored common international challenges related to healthcare inequalities, policy gaps, patient advocacy and equitable access to care.

A central outcome of the Singapore meeting was the continued development of the Global IBD Patient Charter initiative. Insights gathered during both the regional and global discussions will contribute to a broader patient-led framework aimed at defining shared principles for quality IBD care while taking into account regional realities and healthcare contexts.
The meeting reinforced a shared conviction among participants: although healthcare systems differ significantly around the world, access to quality IBD care should not depend on geography, financial status or social circumstances. Through collaboration and partnerships with patient representatives and stakeholders, the global IBD community continues to move towards a more equitable future for all people living with Crohn's disease and Ulcerative Colitis.

II. Introduction

Why Singapore?

Following the World IBD Day Roundtable held in Mexico City in 2024 and Brussels in 2025, Singapore marked the next step in IFCCA's growing global initiative to strengthen collaboration among additional patient organisations and advocate for more equitable access to IBD care worldwide.

The Singapore meeting carried particular significance due to its strong Asia-Pacific focus. While IBD prevalence continues to rise globally, many countries across Asia-Pacific are simultaneously facing rapidly evolving healthcare challenges, increasing disease incidence and significant disparities in access to diagnosis, treatment and specialist care.

Recognising the importance of regional perspectives within the global IBD movement, IFCCA designed the Singapore meeting as a two-part event:

- a morning **Asia-Pacific Networking Meeting** dedicated to regional exchange and discussion, and
- an afternoon **International Roundtable** connecting regional experiences with broader global advocacy efforts.

The meeting also represented an important step in the development of a Global IBD Patient Charter — a patient-led initiative aimed at defining shared global principles for quality IBD care while recognising the realities and limitations faced in different regions of the world.

The overall objectives of the meeting were to:

- identify common barriers affecting access to IBD care,
- strengthen collaboration among patient organisations,
- support regional and international advocacy efforts,
- encourage exchange of experiences and best practices, and
- contribute patient perspectives to the Global IBD Patient Charter process.

III. Conference Details

The World IBD Day 2026 Meeting took place on 16 May 2026 in Singapore and was organised by IFCCA in collaboration with the Crohn's & Colitis Society of Singapore (CCSS).

The event brought together representatives from IBD patient organisations, healthcare professionals and international partners from across the Asia-Pacific and other world regions.

The morning **Asia-Pacific Networking Meeting** focused on identifying shared regional priorities and challenges affecting people living with IBD, while the afternoon **International Roundtable** expanded the discussion to a global level, bringing together patient leaders, healthcare professionals, and other stakeholders to explore common barriers to IBD care, the importance of patient engagement, and opportunities for international cooperation to improve outcomes for people living with IBD worldwide.

The overall meeting theme, *"Access to IBD Care: Towards One Global Standard"*, reflected the growing recognition that, although healthcare systems differ greatly across countries, all people living with IBD should have access to timely diagnosis, quality treatment, psychosocial support and dignified care.

The programme included keynote interventions, panel discussions, interactive workshops and patient-led exchanges, creating opportunities for participants to compare realities, share experiences and identify common priorities for future advocacy efforts.

IV. Asia-Pacific Networking Meeting

Building Regional Priorities for Global Impact

The morning Asia-Pacific Networking Meeting created a dedicated space for 14 patient organisations from across the region to exchange experiences, identify common priorities and reflect on the realities facing people living with IBD within very different healthcare, cultural and social contexts. It included representatives from:

- Crohn's & Colitis Australia
- China Crohn's & Colitis Foundation
- Hong Kong Crohn's & Colitis Society
- IBD Patient Support Foundation (India)
- NPO IBD Network (Japan)
- Crohn's & Colitis Malaysia
- Crohn's & Colitis New Zealand
- Crohn's & Colitis Philippines
- Love UC (UC사랑회) and the Group of Korea Crohn's Disease Patients (South Korea)
- Crohn's & Colitis Society of Singapore (CCSS)
- Taiwan Intestinal Health Association and Taiwan Crohn's and Colitis
- Strategic Alliance for Intercultural Advocacy in GI (SAIA).

While participants represented countries with diverse healthcare systems and varying levels of access to specialised care, the discussions revealed strikingly similar concerns across all regions. Many of the identified barriers extended beyond medical treatment itself, highlighting the social, psychological and structural challenges that continue to shape the daily lives of people living with IBD.

The session also reinforced the importance of creating stronger regional connections among patient organisations. Participants repeatedly stressed the value of learning from one another's advocacy experiences while building a more coordinated Asia-Pacific patient voice within the wider global IBD movement.

Challenges in Accessing Care

Participants also identified substantial inequalities in access to IBD care across the region. Access to biologic treatments and newer therapies remains uneven, with affordability a major barrier in several countries.

Participants from Taiwan highlighted how time reimbursement limitations for biologic treatments can create interruptions in continuity of care. Under current reimbursement policies, some patients may lose treatment coverage after a fixed period of time and are required to wait until disease activity worsens before requalifying for reimbursement. Participants stressed that these interruptions can lead to worsening symptoms, hospitalisation, emotional distress and major disruptions to employment, social engagement and overall quality of life.

Representatives from India explained that treatment duration can be limited by healthcare system constraints and financial realities, leaving many patients without long-term continuity of care. Others pointed to shortages of IBD medication, delays in diagnosis and unequal access to specialist care.

Geographic disparities between urban centres and rural areas were also identified as a major challenge. In many countries, specialised IBD services remain concentrated in large cities, forcing patients from rural regions to travel long distances for consultations, treatment or hospital care.

"Access to care should not be understood solely in terms of treatment availability, but also in terms of continuity, long-term disease stability and the ability of people living with IBD to participate fully in society."

Participants also raised concerns regarding access to paediatric IBD care and participation in clinical trials for children and adolescents. The transition from paediatric to adult care was recognised as another important gap requiring greater attention.

The discussion reinforced that access to care should not be understood solely in terms of treatment availability, but also in terms of continuity, long-term disease stability and the ability of people living with IBD to participate fully in society.

The Invisible Disease: Stigma, Silence and Fear of Judgement

One of the stronger themes emerging from the discussions was the continuing stigma surrounding IBD. Participants described how digestive diseases remain deeply private and taboo subjects in many societies across the Asia-Pacific as well as worldwide, making open conversations about symptoms, treatment and daily realities extremely difficult.

Several organisations highlighted that the "invisible nature" of IBD (i.e., the absence of socially detectable evidence of disease) often leads to misunderstanding from employers, schools, healthcare systems and society at large. Patients frequently feel pressured into hiding their disease due to fear of judgement, discrimination or being perceived as weak.

Representatives also discussed the emotional burden associated with constantly having to explain an illness that is not immediately visible. In some countries, this invisibility contributes to reduced recognition of the seriousness of IBD and creates additional barriers to accessing support.

Participants from Japan highlighted another important dimension: the fear many patients experience of becoming a burden to society. This social pressure can lead patients to avoid discussing their disease openly or seeking support.

The discussions clearly demonstrated that stigma remains one of the most significant yet often overlooked barriers affecting quality of life for people living with IBD.

A representative from Taiwan shared examples of public awareness initiatives aimed at increasing understanding of IBD and reducing stigma. These included patient storytelling campaigns, educational activities, and media projects highlighting the often invisible impact of living with IBD, including treatment interruptions and their consequences on daily life.

Beyond Treatment: Mental Health and Social Participation

Mental health emerged as a major concern throughout the networking discussions. Participants described the close connection between chronic disease management, anxiety, isolation and uncertainty about the future.

Employment-related challenges were repeatedly raised, including concerns around job security, workplace understanding and the long-term impact of IBD on career opportunities. Participants noted that many patients fear discrimination or negative consequences if they disclose their condition to employers.

For younger patients, bullying and exclusion in schools remain important concerns. A representative from South Korea particularly highlighted the impact that stigma and bullying can have on children and adolescents living with IBD, many of whom struggle not only with the physical symptoms of the disease but also with social isolation and misunderstanding among peers. Participants stressed the need for greater awareness in schools and stronger psychosocial support for young patients.

These discussions reinforced the need for more holistic approaches to IBD care that include psychological support, school awareness and stronger workplace protections for people living with chronic illnesses.

Information, Communication and Patient Empowerment

Another recurring theme was the need for clearer and more accessible information for patients and families. Participants stressed that scientific and medical information is often difficult for patients to understand and should be translated into accessible, patient-friendly language.

Improving communication between healthcare professionals and patients was identified as an important priority. Participants emphasised that stronger partnerships between patient organisations, healthcare providers and policymakers are essential to improve trust, awareness and quality of care.

The discussions also addressed practical daily realities affecting people living with IBD, including access to toilets, travel information for patients and more patient-friendly hospital environments. While these issues may appear secondary within policy discussions, participants stressed that they are fundamental to preserving dignity, independence and quality of life.

Participants also highlighted the challenges many people living with IBD face in managing their diet and identifying potential food triggers. While nutrition plays an important role in disease management and quality of life, participants noted that there is often limited practical guidance available to help patients understand how different foods may affect their symptoms. Discussions emphasised that dietary management is highly individual, with food tolerances and intolerances varying considerably from person to person. The diversity of dietary traditions, food availability and cultural practices across the Asia-Pacific region further complicates the development of broadly applicable recommendations.

Participants expressed a need for more accessible, patient-centred dietary guidance, including educational resources and access to trained professionals who can support patients and caregivers in identifying dietary triggers and making informed nutritional choices.

Building a Stronger Regional Voice

Throughout the networking discussions, participants repeatedly returned to the importance of collaboration.

Many organisations expressed a desire for stronger regional exchange, greater sharing of advocacy experiences and closer cooperation with IFCCA and international partners. Participants recognised that while healthcare realities differ across countries, many of the challenges affecting people living with IBD are shared.

Patient Organisations' Role in Research

Several participants also highlighted the important role patient organisations can play in advancing research. Beyond advocacy and support, patient organisations can facilitate connections with patient communities, support recruitment for research initiatives, and help ensure that research priorities reflect the needs and experiences of people living with IBD.

The networking meeting concluded with the identification of key regional priorities that would feed directly into the afternoon International Roundtable and contribute to the broader Global IBD Patient Charter initiative.

V. International Roundtable

Access to IBD Care: Towards One Global Standard

The afternoon International Roundtable expanded the conversation from regional realities to a broader global perspective on access to IBD care.

Moderated by Luisa Avedano, IFCCA CEO, the session brought together international patient leaders, healthcare professionals and advocacy representatives to discuss healthcare inequalities, patient rights and opportunities for international collaboration.

Opening remarks from Salvo Leone, IFCCA Chairperson and Nidhi Swarup, President CCSS, reaffirmed the importance of ensuring that patient perspectives remain central in global discussions on healthcare access and quality of care.

Salvo Leone (IFCCA Chairperson) and Nidhi Swarup (CCSS President) opening the meeting.

The meeting was honoured by the participation of Prof. John C. W. Lim, Executive Director of the Centre of Regulatory Excellence (CoRE) at Duke-NUS Medical School and Senior Advisor to Singapore's Ministry of Health, who joined the event as a Guest of Honour invited by CCSS. In his intervention, Prof. Lim highlighted the importance of policy leadership, innovation and international cooperation in addressing the growing burden of chronic diseases worldwide.

IFCCA also presented the ongoing "IBD Has No Borders" campaign, reinforcing the message that while healthcare systems may differ, the challenges faced by people living with IBD often transcend national borders.

A keynote presentation by Prof. Claudio Fiocchi, internationally recognised as one of the world's leading experts in Inflammatory Bowel Disease, provided a global clinical perspective on the increasing prevalence of IBD and the challenges this poses for healthcare systems worldwide. A long-standing supporter of IFCCA and the World IBD Day initiative, Prof. Fiocchi has contributed to previous World IBD Day roundtables, including the 2024 meeting in Mexico City. His presentation highlighted the importance of integrated, patient-centred approaches to care, greater collaboration between healthcare professionals and patient organisations, and continued investment in research to improve outcomes for people living with IBD.Prof. Fiocchi also highlighted how artificial intelligence (AI) will be incorporated not only in practical IBD care but also in substantially improving access to care.

Prof. Claudio Fiocchi during his keynote speech

"While healthcare systems may differ, the challenges faced by people living with IBD often transcend national borders."

The panel discussion brought together perspectives from Australia, Canada, Europe, the United States and the Asia-Pacific region. Speakers addressed issues including healthcare inequalities, treatment access, patient advocacy, rural access challenges, mental health and the role of patient organisations in driving policy change.

The Asia-Pacific contributions added an important dimension to the global discussion, highlighting how stigma, cultural perceptions of chronic illness, affordability and geographic inequalities continue to shape the experiences of people living with IBD across the region. Participants also noted that these factors can influence when people seek medical care, how they engage with treatment, and their willingness to discuss the disease openly.

Despite differences in healthcare systems and resources, participants agreed that many of the challenges discussed resonate globally and require coordinated international action.

International Roundtable Speakers and organisations

John C. W. Lim – Executive Director, Centre of Regulatory Excellence (CoRE)
Duke-NUS Medical School

Prof. Claudio Fiocchi
Cleveland Clinic

Leanne Raven – CEO
Crohn's & Colitis Australia

Laura Wingate – Chief Education, Support & Advocacy Officer
Crohn's & Colitis Foundation

Kate Lee – Vice President, Research & Patient Programs
Crohn's & Colitis Canada

Isabella Haaf – Global Engagement and Partnerships Lead
IFCCA

Roberto Saldaña – IFCCA Innovation & Patient Engagement Coordinator Asia-Pacific patient representative
IFCCA

VI. Towards the Global IBD Patient Charter

One of the key objectives of the Singapore meeting was to contribute to the ongoing development of the Global IBD Patient Charter.

The Charter aims to create a patient-led global framework outlining core principles and expectations for quality IBD care while recognising regional variation and differing healthcare realities.

Throughout both the networking session and the International oundtable, participants identified common priorities that could help shape the Charter process, including:

- equitable access to diagnosis and treatment,
- recognition of mental health needs,
- reduction of stigma,
- improved communication and patient information,
- stronger multidisciplinary care,
- support for paediatric patients and child-to-adult transition care,
- greater patient involvement in healthcare decision-making,
- patient involvement in research, recognising patient organisations as key partners in identifying priorities and engaging patient communities.

Participants stressed that the Charter should not simply represent an aspirational document, but rather a practical advocacy tool capable of supporting national and regional efforts to improve care and influence policy discussions.

The Singapore meeting represented an important Asia-Pacific contribution to this evolving global initiative.

VII. Conclusions and Recommendations

The World IBD Day 2026 meeting in Singapore highlighted that barriers to quality IBD care are complex and interconnected. While access to treatment remains a major concern, participants repeatedly emphasised that social stigma, mental health, communication barriers, geography and healthcare inequalities profoundly affect the lives of people living with IBD.

The meeting reinforced the importance of creating spaces where patient organisations can openly exchange experiences, compare realities and collectively identify priorities for future advocacy. It also highlighted the value of bringing together patients, healthcare professionals, researchers and policymakers to develop solutions that reflect both global priorities and regional realities.

"While access to treatment remains a major concern, social stigma, mental health, communication barriers, geography and healthcare inequalities profoundly affect the lives of people living with IBD."

Strengthen regional and global collaboration

The World IBD Day 2026 meeting in Singapore highlighted that barriers to quality IBD care are complex and interconnected. While access to treatment remains a major concern, participants repeatedly emphasised that social stigma, mental health, communication barriers, geography and healthcare inequalities profoundly affect the lives of people living with IBD.

Address stigma and increase public awareness

The discussions demonstrated that stigma continues to be one of the most significant barriers affecting people living with IBD in the region. Participants emphasised the need for public awareness initiatives that promote greater understanding of IBD and help reduce the social, educational and workplace challenges experienced by many patients.

Improve equitable access to diagnosis, treatment and specialist care

Access to quality IBD care remains highly variable both between and within countries. Participants called for efforts to reduce disparities in access to timely diagnosis, specialist services and effective treatments, particularly for people living in rural and underserved communities. Ensuring continuity of care and addressing barriers to long-term disease management were identified as important priorities.

Promote holistic and patient-centred care

Participants stressed that quality IBD care extends beyond medical treatment or surgical treatment alone. Mental health support, effective communication with healthcare professionals, support during key life transitions, including the transition from paediatric to adult care, and practical measures that improve quality of life should all be recognised as essential components of comprehensive care.

Improve patient information and self-management support

There was broad agreement on the need for accessible, patient-friendly information that helps people living with IBD better understand their condition and make informed decisions about their care. This includes translating scientific and medical information into accessible language, strengthening communication between healthcare professionals and patients, and providing culturally relevant dietary guidance and nutritional support to help patients and caregivers better understand and manage individual food triggers.

Strengthen data collection, research and patient involvement

Participants highlighted the importance of reliable patient registries and improved epidemiological data to better understand the burden of IBD, monitor trends and support evidence-based policy development. Patient organisations were also recognised as important partners in research, helping to identify priorities, engage patient communities and ensure that research reflects the lived experiences of people affected by IBD.

Advance the Global IBD Patient Charter

The meeting reaffirmed support for the continued development of the Global IBD Patient Charter as a patient-led advocacy framework. Participants recognised its potential to define shared principles for quality IBD care, strengthen patient rights and support advocacy efforts at national, regional and international levels while recognising differences in healthcare systems and resources.

The Singapore meeting concluded with a strong sense of solidarity and shared purpose. While healthcare realities differ across countries and regions, participants reaffirmed a common principle: access to quality IBD care should not depend on geography, financial status or social circumstances.

Through continued collaboration, patient leadership and international dialogue, the global IBD community continues to move closer towards a future where no person living with IBD is left behind. IFCCA stands ready to assist world-wide IBD communities in any way possible.

Annex:

Country/Regional Perspectives

Australia

Australia has a universal healthcare system through Medicare, with subsidised medicines available through the Pharmaceutical Benefits Scheme. However, despite this strong healthcare foundation, Australia has one of the highest rates of IBD globally, with an estimated 179,420 people living with IBD in 2025 and more than 200,000 projected within the next decade.

IBD has a significant impact on young and working-age Australians. The peak age of onset is between 15 and 29 years, meaning that the disease often disrupts education, early career development, family planning and social participation. Crohn's & Colitis Australia also highlighted the particular impact on people living in regional and remote areas, people on low incomes, older Australians and young adults.

Delays in diagnosis and achieving disease remission remain major concerns. One in three people with IBD in Australia wait more than a year for diagnosis, while one in ten wait more than five years. On average, it takes three years from diagnosis to remission, and 41% of patients take five years or more to achieve remission. These delays contribute to a high use of hospital and emergency services.

Looking ahead, Crohn's & Colitis Australia has identified three key priorities for 2030: improving access to multidisciplinary care, improving access to novel therapies, and increasing investment in IBD research. These priorities include the development of clinical care standards, virtual multidisciplinary team networks, workforce development, improved paediatric access to new treatments, streamlined prescribing processes and stronger use of real-world data.

Australia's contribution to the discussion highlights that even in countries with universal healthcare and strong medical infrastructure, significant gaps remain in timely diagnosis, equitable access to care, long-term disease control and research investment. Its message to the international community is that high-quality IBD care requires not only treatment availability, but also integrated care pathways, faster diagnosis, multidisciplinary support and sustained investment in research and innovation.

China

China has made significant progress in the diagnosis and treatment of Inflammatory Bowel Disease, with a growing number of specialised IBD centres across the country. However, equitable access to care remains a major challenge. Specialist services are still largely concentrated in major cities such as Beijing, Shanghai and Guangzhou, while patients living in smaller cities and rural areas often face delays in diagnosis, limited access to specialist care and difficulties in receiving long-term follow-up.

IBD in China most commonly affects people between the ages of 15 and 35, making its impact particularly significant during key stages of education, employment, family life and social participation. Although biologic medicines and other innovative therapies are becoming increasingly available, the long-term cost of treatment continues to place a considerable financial burden on many patients and their families. Participants also highlighted the psychosocial impact of living with IBD, including anxiety, depression and the challenges of managing an unpredictable chronic disease, while access to integrated psychological support remains limited.

The China Crohn's & Colitis Foundation (CCCF) has sought to address these challenges by strengthening patient education, expanding peer support, promoting public awareness and encouraging greater patient participation through partnerships with hospitals, healthcare professionals and volunteers. These initiatives aim to improve disease awareness, support self-management and ensure that patients play a more active role in their own care.

Looking ahead, the Chinese IBD community identified strengthening chronic disease care, improving access to comprehensive multidisciplinary support, increasing patient advocacy capacity and expanding international collaboration as key priorities. Continued cooperation with regional and global partners was recognised as an important opportunity to improve long-term care, raise public awareness and promote more equitable access to quality IBD care.

Hong Kong

People living with IBD in Hong Kong rely predominantly on the public healthcare system, where access to specialist care can involve long waiting times. The limited number of gastroenterologists with expertise in IBD means that many patients experience delays in diagnosis and treatment, with some only receiving a diagnosis once their disease has become more advanced. Raising public awareness of IBD remains an important priority to promote earlier recognition of symptoms and improve timely referral to specialist care.

Access to newer therapies also presents significant challenges. Before innovative medicines are included in government reimbursement schemes, patients are often required to self-fund treatment while sufficient clinical evidence is gathered to support public funding decisions. This process can take considerable time, placing a substantial financial burden on many individuals and potentially delaying access to effective treatment.

Encouraging progress has been made in the delivery of more holistic care. Several public hospitals have established dedicated IBD nurse services to provide ongoing monitoring, patient education and support. These specialised nursing services represent an important step towards more coordinated, multidisciplinary care and have helped improve disease management and the overall patient experience.

Looking ahead, the Hong Kong IBD community continues to advocate for earlier diagnosis, improved access to specialist care, faster reimbursement of innovative therapies and the further expansion of multidisciplinary services to ensure that people living with IBD receive timely, comprehensive and patient-centred care.

India

India is experiencing a growing incidence and prevalence of Inflammatory Bowel Disease, while continuing to face significant challenges in ensuring equitable access to diagnosis, treatment and long-term care. Specialist IBD centres are concentrated in a limited number of locations, meaning that many patients, particularly those living outside major cities, must travel considerable distances to access specialised care.

The financial burden of living with IBD also remains substantial. Health insurance coverage is limited, leaving many patients to pay out of pocket for consultations, diagnostic tests and treatments, including biologic therapies. While the availability of biosimilars and newer therapies has improved affordability for some patients, the long-term costs of managing a chronic disease continue to place considerable financial pressure on individuals and families.

Participants also highlighted the impact of cultural perceptions of chronic illness on IBD care. Stigma surrounding digestive diseases, misconceptions that IBD can be cured through diet or lifestyle changes alone, and reluctance to accept advanced therapies or surgery can contribute to delays in accessing appropriate treatment and may adversely affect long-term health outcomes. Many patients also explore complementary and traditional approaches alongside conventional medical care, underlining the importance of patient education and shared decision-making.

Looking ahead, the Indian IBD community identified increasing public awareness, strengthening patient education, improving access to specialist care, supporting healthcare professional education and reinforcing policy advocacy as key priorities. Participants also emphasised the value of continued collaboration with regional and international patient organisations to address shared challenges and improve care for people living with IBD.

Japan

Japan is often recognised for its universal healthcare system and comprehensive social security framework. However, for many people living with IBD, a gap remains between the support provided by the system and the realities of daily life.

Patients continue to face challenges that go beyond medical treatment alone. Access to specialist care can vary depending on where people live, long-term treatment costs remain a concern, and support is often fragmented during key life transitions such as moving from paediatric to adult care, progressing through education, and entering employment. There is also a growing recognition that mental health, social participation, and quality of life need to be better integrated into IBD care.

Japan has highlighted the importance of ensuring that patient voices are more meaningfully reflected in research, healthcare delivery, and policy development. While patient involvement is growing, there is still a need to move towards a model where patients are recognised as partners whose lived experience contributes to better research, better policies, and better care.

As a country frequently affected by natural disasters, Japan also brings valuable experience in supporting people with chronic conditions during emergencies. The IBD community has worked to promote disaster preparedness, continuity of treatment, access to medication, and practical support in evacuation settings, recognising that resilience extends beyond the healthcare system itself.

Looking ahead, the Japanese patient community hopes to see stronger support throughout all stages of life, wider adoption of shared decision-making, greater incorporation of patient experience into healthcare and research, and advances in personalised medicine that reduce the current trial-and-error approach to treatment.

Japan's message to the international community is that even within a highly developed healthcare system, important challenges remain. By sharing experiences, learning from one another, and strengthening international collaboration, we can work together to build more patient-centred, responsive, and equitable systems of care.

New Zealand

New Zealand has a publicly funded healthcare system that provides access to specialist care for people living with Inflammatory Bowel Disease (IBD). Access to advanced therapies, including biologic medicines, is influenced by New Zealand's pharmaceutical funding model. Medicines are funded through Pharmac, a government agency that operates separately from the healthcare delivery system and works within a fixed national budget. While this model helps control costs, it has traditionally focused on the price of medicines rather than the wider impact on the health system.

This approach has sometimes led to delays in access to newer treatments. For example, patients and clinicians in New Zealand previously needed to advocate for access to medicines such as ustekinumab, which remained on Pharmac's "Options for Investment" list for several years before funding was approved. This has contributed to a perception that access to innovative therapies can be slower than in some comparable countries.

Workforce capacity remains a key challenge. There is an ongoing shortage of gastroenterologists across New Zealand, particularly in regional areas, which affects timely access to specialist care. Similarly, there has been a shortage of IBD nurse specialists across the sector; while this has improved somewhat in recent years and is currently stable, it remains an area to monitor.

In terms of disease burden, a 2017 estimate suggested that approximately 20,792 New Zealanders were living with IBD. However, there are no precise or current national figures, as New Zealand does not yet have a comprehensive IBD registry. To address this gap, research is exploring the use of the Integrated Data Infrastructure (IDI), a secure national database that links de-identified health, hospital, and pharmaceutical data.

The IDI has strong potential to improve understanding of IBD by allowing researchers to identify cases, track disease progression, and analyse patterns of care across the population.

Despite these challenges, the IBD community in New Zealand remains highly active. Crohn's & Colitis New Zealand (CCNZ) delivers a range of patient-focused programmes, including education seminars, support networks, Camp Purple and awareness initiatives, helping to empower patients and improve understanding of the condition.

Looking ahead, CCNZ will continue to play an important role in advocating for people living with IBD. This includes strengthening patient education and support, increasing engagement with policymakers and clinicians, and ensuring that the patient voice is clearly represented in decisions about access to care and treatment.

Philippines

Crohn's and Colitis Philippines, the IBD patient community in the Philippines faces a multi-layered crisis rooted in systemic healthcare gaps, financial toxicity, and a critical lack of institutional recognition. Patients living with Crohn's disease and Ulcerative Colitis navigate prolonged and precarious diagnostic timelines. Misdiagnosis is highly prevalent across the archipelago, with IBD frequently mistaken for intestinal or colon tuberculosis (and vice versa), leading to inappropriate, harmful treatment regimens and extended physical suffering. Once a correct diagnosis is established, accessing life-altering therapies remains a monumental barrier.

Essential advanced medications, particularly biologics, are entirely excluded from coverage under the national government healthcare system. Even when utilizing manufacturer-sponsored patient access programs, the financial burden remains completely prohibitive for the vast majority of families, creating profound disparities in clinical outcomes based strictly on income and geography.

Beyond the medical and financial hurdles, the landscape is further complicated by a severe deficit in patient education and comprehensive support systems. A widespread lack of accessible, reliable medical literacy regarding IBD and biologic therapies breeds deep-seated misconceptions, causing many patients to fear necessary treatments.

This educational gap leaves individuals ill-equipped to make informed choices or provide meaningful peer support within their communities. Furthermore, formal psychological and emotional guidance is virtually nonexistent. Because the general public and patient families themselves lack fundamental awareness of the chronic, fluctuating nature of IBD, patients are routinely left without the crucial moral and psychosocial support required to cope with the disease. This isolation is exacerbated by a severe shortage of specialised gastroenterologists, a deficit felt most acutely in provincial areas outside major urban medical centers, which hinders proactive doctor-patient collaboration and modern, shared clinical decision-making.

Compounding these daily hardships is a profound institutional invisibility. Currently, the Philippines possesses no official national research initiatives, localised clinical registries, or comprehensive baseline data to accurately quantify the epidemiological footprint of IBD. From a policy perspective, the disease has historically suffered from disruptive misclassifications-shifting administrative designations from a psychosocial disability to a rare disease. This bureaucratic ambiguity, coupled with a pervasive lack of awareness among frontline government and civil service personnel, results in eligible IBD patients being routinely denied official Persons with Disability (PWD) identification and its associated statutory healthcare discounts and protections.

The Filipino IBD advocacy community stands firmly committed to establishing equitable access to comprehensive care as a fundamental, cross-cutting human right. The overarching objective is to secure formal, explicit recognition of IBD as a public health priority by the Philippine government, ensuring its permanent integration into national health policies and universal healthcare frameworks. To achieve this, the community aims to implement widespread, culturally sensitive patient education campaigns and structured awareness initiatives designed to dismantle medical misconceptions, empower patients with health literacy, and build resilient, localised psychosocial support networks.

Concurrently, the community seeks to address systemic inequalities by optimising care standards across all geographic regions, advocating for the subsidisation and inclusion of biologics in government formularies, and expanding the availability of specialised clinical care in remote provinces. Central to their forward-looking vision is the institutionalisation of a collaborative healthcare model that champions shared decision-making between patients and clinicians. Finally, the Philippine IBD community calls for the immediate launch of robust, state-supported research initiatives to build localised baseline data. They strongly emphasise that patient organisations must be integrated as essential, co-equal partners in defining national research priorities, mobilising local communities, and actively shaping unified Asia-Pacific and global standards of care.

Taiwan

One of the most pressing challenges facing people living with IBD in Taiwan relates to access to biologic therapies under the National Health Insurance system. Current reimbursement policies often require patients to discontinue biologic treatment after a defined period of coverage and wait until their disease relapses before reimbursement can be approved again. Combined with administrative and clinical review processes, this can result in lengthy interruptions in access to effective treatment.

For many patients, these interruptions have significant consequences. Disease symptoms may worsen, leading to emergency visits, hospitalisation, reduced quality of life, and increased emotional stress. At the same time, continuing treatment without reimbursement is often financially unfeasible, particularly for younger patients. The impact extends beyond health, affecting employment, social participation, family life, and overall productivity.

Taiwan's patient community also emphasises that improving quality of life for people with IBD requires more than healthcare policy alone. Public awareness, patient empowerment, community support, and collaboration across sectors all play an important role in helping individuals live well with the disease. This commitment is reflected in awareness initiatives such as *The Battles You Don't See*, a public campaign highlighting the often invisible challenges faced by people living with IBD.

Looking ahead, Taiwan advocates for a broader understanding of remission—one that goes beyond clinical outcomes to include the ability to work, build relationships, travel, and participate fully in society. Ensuring sustainable access to effective treatments, while promoting whole-person support and quality of life, remains a key priority and an important topic for international discussion.

South Korea

People living with IBD in South Korea continue to face challenges in accessing timely diagnosis and appropriate treatment. Delays between the onset of symptoms and diagnosis remain a concern, as early symptoms may be mistaken for temporary enteritis or other gastrointestinal conditions. As a result, some patients experience a prolonged journey through the healthcare system before receiving a definitive diagnosis and the opportunity to begin effective treatment. Although awareness among healthcare professionals in primary clinics has improved, public awareness remains limited, which can delay referral from primary clinics to tertiary medical institutions and postpone timely treatment initiation.

South Korea's National Health Insurance system provides broad healthcare coverage, and patients diagnosed with IBD may benefit from a copayment reduction programme. However, access to advanced therapies can still be limited by strict and time-consuming reimbursement requirements. New and advanced therapies may become available in the country but remain practically inaccessible until reimbursement is granted. In addition, patients are often required to follow a step-up treatment approach, trying conventional therapies before becoming eligible for biologic medicines. Because these drugs are prohibitively expensive without reimbursement, such requirements can significantly restrict access to treatment and delay the use of therapies that may be most effective for some individuals, potentially affecting long-term disease outcomes and quality of life.

Patient representatives in South Korea have highlighted delayed diagnosis and restricted insurance access to advanced treatment as major barriers. They have also pointed to regional disparities in access to specialist care, particularly between the Seoul metropolitan area and other regions, where patients may face greater difficulty reaching specialist centres in a timely way. For children and adolescents living with IBD, delayed or limited access to appropriate treatment can have a significant impact not only on health outcomes but also on school life, growth, and daily functioning.

Organisations such as the Korean Association for the Study of Intestinal Diseases (KASID), together with patient representatives, have contributed to raising awareness of these issues through policy discussions, educational initiatives, and public engagement activities, including World IBD Day-related advocacy efforts. In recognition of World IBD Day, KASID also held a policy symposium on these issues. The cooperative relationship between patient organisations and the IBD physician community in South Korea provides an important foundation for future advocacy and policy engagement.

Looking ahead, there is growing recognition of the need to reduce diagnostic delays, improve public awareness, address regional disparities, and shorten the time required for reimbursement decisions on new and advanced therapies. Strengthening referral pathways and improving timely access to appropriate treatment remain important priorities for people living with IBD in South Korea.

Acknowledgements

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