Statement of Consensus:

Removing Barriers for Inflammatory Bowel Disease Patients in the Asia-Pacific Region

GAfPA Global Alliance for Patient Access

Patient advocates and clinical experts from the Asia-Pacific region came together to discuss unmet needs in IBD. As an output, the stakeholders developed the following calls to action to improve IBD care.

Today, approximately 7 million people across the world live with inflammatory bowel disease IBD. IBD, whether it is Crohn's disease or ulcerative colitis, is a life-long condition with no cure. Patients often face delayed diagnosis and poor health outcomes when active disease is not well managed.

IBD is associated with high rates of morbidity and disability, an increased risk for poor mental health and colon cancer and a significant economic burden. In addition to costs incurred through managing the disease, many patients are younger adults of working age whose work capacity may also be constrained, compounding the overall financial burden.

In the Asia-Pacific region, incidence of IBD ranges from 0.5 to 3.4 per 100,000 individuals annually, while over the past 10-15 years incidence in the region has increased, including in low- and middle-income countries. As more people are impacted by IBD and its debilitating symptoms, urgent unmet needs and barriers must be addressed to improve access to earlier diagnosis and treatment to improve quality of life and prevent further debilitating complications.

Calls to Action

Leading IBD stakeholders from the Asia Pacific region identified four goals that should be prioritized among patients, clinicians and policymakers.

Reduce the time to diagnosis and treatment of IBD. Many IBD patients struggle to receive a timely diagnosis. Social stigma, low disease awareness, lack of access or long wait times to see specialists, symptom overlap, geographical location, and cultural, language or financial barriers can all contribute to delayed diagnosis and treatment. To address these barriers, greater education and awareness about IBD, its signs, symptoms and treatment options are needed among patients and healthcare providers. Policymakers must also promote policies that make advanced treatments for IBD more accessible and affordable for patients, especially for those living in rural and underserved areas.

Emphasize shared decision-making for individualized and targeted care plans. Oftentimes, patients' treatment plans are one-size-fits-all, prioritizing short-term disease management over long-term treatment outcomes. This can be due to healthcare system capacity challenges, patient health literacy and gaps in clinical education. Through policies that promote shared decision-making between clinicians and patients, and access to optimal treatment options to achieve endoscopic remission, quality of life can be as good as that of a healthy person.

Treat beyond inflammation, ensuring holistic care and optimized psychological well-being. Many patients may not realize that remission is a realistic option to pursue. However, endoscopic remission must be the goal for healthcare providers and patients, and policies should support patients in achieving it by ensuring greater education and timely access to advanced therapies where appropriate. Using a multidisciplinary care team helps treat all aspects of IBD, taking account of lifestyle factors and psycho-social needs to help manage mood and minimize the likelihood of depression and anxiety. A renewed emphasis on treating patients beyond inflammation could also help address dietary requirements and interconnected disease risks, such as cardiovascular disease, other immune-mediated conditions, certain cancers and other psychological conditions often associated with IBD.

Foster greater global collaboration among the scientific, clinical and patient communities to discover the causes of IBD. Policymakers must recognize IBD, its growing incidence and impact on patients, caregivers and healthcare systems to promote more funding and medical research into finding a cure for IBD and ways to better diagnose and manage the disease.

Conclusion

We, the undersigned, urge immediate and coordinated action to remove barriers for optimal care and innovation in IBD. We commit to advocating for national policies that promote the attainment of the above-mentioned calls to action, optimize the care environment, and thereby improve the lives of people with IBD.

Signatories

Crohn's & Colitis Australia

Crohn's & Colitis Society of Singapore

Group of Korea Crohn's Disease Patients

IBD Caring Group

Japan IBD Network

Korea Ulcerative Colitis Patient Association

The China Crohn's & Colitis Foundation

The Hong Kong Crohn's & Colitis Society

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2. https://www.mdpi.com/2624-5647/6/2/38