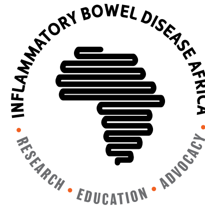
SAGES STATEMENT ON THE CRISIS FACING INFLAMMATORY BOWEL DISEASE (IBD) PATIENTS IN SOUTH AFRICA



Adopted following a meeting at the SAGES Congress, CTICC, 18th May 2024

1. Autoimmune diseases are increasing globally and it is estimated nearly 5% of humans live with autoimmune or inflammatory diseases such as Crohn's disease and ulcerative colitis. In South Africa, the IBD Africa Registry has seen an exponential increase in IBD incidence over the past 50 years. The vast majority of patients do not die from autoimmune diseases, so compounding prevalence results in an ever-increasing number of patients requiring care.
2. Evidence for the early introduction of advanced therapies (biological drugs and small molecules) to prevent permanent gut damage and disability in IBD is now well established.
3. South African IBD patients are fortunate in that we are one of the few countries on the continent to have access to advanced IBD therapies. In addition, a legal framework, enshrined in the Medical Schemes Act 131 of 1998, enables access to these therapies provided this is clinically appropriate.
4. In the public sector, advanced therapies such as anti-TNFs are listed on the EDL but funding restraints limit their use for the treatment of IBD.
5. Despite drug availability in the public and private sectors, overwhelming clinical evidence of efficacy and the legal imperative to support therapy, very few patients receive these treatments.
6. Certain funds refuse to support any advanced IBD therapies unless patients upgrade to the highest, often unaffordable, scheme plans without exceptions.
7. Other funders have a short-sighted approach to funding advanced therapies for IBD. Treatment algorithms are not based on scientific evidence, do not appreciate the clinical heterogeneity of IBD and are adjusted annually based on prevailing financial circumstances. This rigid and short-term approach to managing a lifelong, chronic and incurable disease is illogical and fails to appreciate the long-term health costs and loss of QALYs of such a strategy. The administrative burden imposed by annual changes to scheme rules is particularly onerous.
8. Clinicians treating IBD find themselves in a conflicted situation. On the one hand trying to uphold ethical principles of beneficence and non-maleficence, while on the other hand being forced to make treatment decisions at the discretion of third parties.

To clinicians

We encourage doctors to avoid wasteful healthcare expenditure on ineffective IBD therapies, particularly unnecessary combination therapies and to limit unnecessary endoscopy and cross-sectional imaging procedures

To funders

We caution that ignoring the needs of the increasing number of patients with IBD and other autoimmune diseases is reckless, and by doing so, the problem will not vanish but reappear in the future with a far greater financial burden to your scheme.

We request schemes look at alternative reimbursement models that would allow for cost-effective, and consistent treatment of IBD with advanced therapies.

We encourage engagement with all relevant stakeholders to reach consensus on the funding of advanced IBD therapies.

To the pharmaceutical industry

We appeal to keep drug prices affordable and consistent with our socioeconomic environment and to work with schemes to find alternative reimbursement models that allow timeous and appropriate access to advanced therapies.

To the Council of Medical Schemes

We appeal to allow for the setting of precedent when it comes to adjudicating the merits of advanced therapies in IBD. Your current process is heavily biased toward funders in that:

- Patients who are suffering with chronic ill health do not have the physical or emotional resilience to embark on the arduous CMS process
- Funders obfuscate the issues using medical and legal jargon beyond the comprehension of most patients.
- The ability to delay and appeal rulings by funders frequently leads to the patient resigning from their scheme and switching to another scheme in order to access appropriate therapy before the conclusion of their CMS case.

Drafted by:

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