Multi-stakeholder Delphi consensus on future care for inflammatory bowel disease in Belgium

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Abstract

Background: Care for patients with IBD has changed over the last decades with increased prevalence and subsequent financial and organizational burden on the health care system. The aim of this work was to develop a nationwide consensus on how to organize care for patients with IBD.

Methods: We developed a consensus document through a modified Delphi process including different Belgian stakeholders involved in the care for patients with IBD. Through two voting rounds and a consensus meeting statements were developed.

Results: Thirty-three statements reached consensus through the Delphi process. The statements can be classified in six major domains: IBD registry and data utilization, Patient reported data, Multidisciplinary care, IBD nurse role and financial support, Access to diagnostic & monitoring tools and Treatment & medication reimbursement.

Conclusion: We developed a broadly supported consensus on how to organize care for patients with IBD in the Belgian healthcare environment. Selection of focus area should seek for balance between optimization of clinical outcomes, securing quality of care and maintaining financial sustainability. (Acta gastroenterol belg., **2026,** 89**, 373-383).**

Keywords: Quality of care, multidisciplinary care, Crohn, ulcerative colitis, healthcare organization.

Introduction

The incidence and prevalence of inflammatory bowel diseases (IBD) including Crohn's disease and ulcerative colitis have been steadily increasing over the last decades. Although precise epidemiological data are lacking, it is estimated that between 30,000 and 80,000 individuals are currently living with IBD in Belgium (1). In parallel, significant progress has been made in the diagnosis, monitoring, and treatment of IBD, leading to improved patient outcomes (2). However, these advancements also place a growing financial and organizational burden on the healthcare system (3).

Healthcare professionals, patients, the government, and industry are actively seeking strategies to address this increasing pressure. In Belgium, the current reimbursement and care delivery model is primarily based on a fee-for-service system, which operates largely independently of the quality or long-term impact of care provided. While short-term outcomes are included in the reimbursement of advanced treatments such as biologicals and small molecules, long-term outcomes are often overlooked. Notwithstanding, the potentially greater socioeconomic impact of the latter.

To address these challenges, a collective, reflective process involving a broad range of stakeholders is essential to identify and prioritize key areas for optimizing and reorganizing IBD care in Belgium. This work aimed to establish a structured set of actionable priorities to guide the future of IBD care and support ongoing dialogue with regulatory and governmental bodies. These priorities were established through a multi-stakeholder Delphi consensus process.

Methods

Conceptualisation and targeted literature review

This multi-stakeholder consensus was developed using a modified Delphi process (4).

To inform the initial set of action points, the steering group conducted a targeted literature review focusing on patient-centered care, integrated care models, telemedicine, and value-based approaches

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in IBD management (5-10). This review provided the scientific foundation for the draft document and guided the development of statements evaluated in the Delphi rounds. Participants included representatives from academia, patient organizations, industry, healthcare professional associations, and hospital networks. The initiative was coordinated by the Belgian IBD Research and Development (BIRD) group.

Preparation

The BIRD Board created a baseline working document outlining the key challenges and potential action points for IBD care in Belgium based on a draft document. This draft was initially provided by Takeda Belgium NV as part of an awareness campaign, but served solely as a starting point for discussion. All subsequent steps, including defining the list of action points, designing the Delphi survey, conducting the voting rounds, and managing the final consensus meeting were fully controlled by the steering group (ND, TT, PB).

Participants

Participant selection prioritized diversity, equity, and inclusivity, ensuring balanced representation across gender, geographical distribution, and stakeholder groups. These included patients, academic and non-academic centres, healthcare professional organizations, mutual health insurance funds, hospital networks, and industry representatives. A list of invited participants is provided in *Supplementary file 1*, along with the list of those who effectively participated in the Delphi process.

Two expert Delphi scoring rounds

After confirming their participation, the questionnaire (SurveyMonkey Inc., 2025) was distributed via a personal email to all participants. All surveys were made available in English. In the first round, participants reviewed and rated the importance of proposed action points using a 10-point Likert scale, where 1 indicated 'not at all important' and 10 indicated 'extremely important'. They were also invited to suggest additional action points, which were subject to approval by the steering group for inclusion in the second round.

Following the first round, scores were exported from SurveyMonkey and imported into Microsoft Excel (Version 2504) and calculated for each action point and visualized as bar charts. For each item, the median score and level of agreement (defined as the percentage of scores ≥7) were calculated for the entire dataset as well as by stakeholder group. In response to the first-round feedback, certain words and phrases were revised for clarity, and some questions were divided into parts to better refine their scope. All changes were highlighted in red in the subsequent survey. Using this revised version, and to encourage consensus, participants were then invited to complete a second round of scoring on the same 10-point Likert scale. During this second round, participants were able to see all the results of the first round.

Expert Delphi consensus meeting

All participants of the Delphi rounds were invited to attend a virtual consensus meeting on June 18th 2025. During this meeting, the steering group presented the results of the second Delphi scoring round. For each action point, the aggregated scores, broken down by stakeholder group, were presented in bar charts, following the same format as in the first voting round. Action points that scored 7 or higher on importance by more than 60 but less than 80% of all participants during the second Delphi scoring round, were discussed in detail. These were then (re-)voted on using the same 10-point Likert scale to determine the final level of agreement. Polls were closed once at least 80% of participants had submitted their response. Action points that had already reached consensus in Round 2, defined as a score of 7 or higher by at least 80% of all participants, were presented and discussed but were not subjected to a revote. The moderators (TT, ND, and PB) ensured equal participation from all attendees, fostering a balanced discussion across stakeholder groups.

Impact and feasibility exercise

To establish a practical list of action points, BIRD Board members, the steering group and representatives of patient organisations individually reviewed the proposed items and assessed each one based on its impact and feasibility. Subsequently, the action points were ranked, providing a top 15 of the most important action points. From this, a final selection of the 10 most important action points was approved by the BIRD Board.

Results

Participants

A total of 39 stakeholders were invited to particip Participant selection pri ate in the multi-stakeholder Delphi process, of which 32 completed the 1st round and 35 completed the 2nd round, resulting in a response rate of 89,7%. This provided a balanced and inclusive representation across all relevant domains of IBD care in Belgium. A detailed overview is displayed in *Supplementary file 1*.

Participants included representatives from BIRD (n=11), all of whom completed the survey. Patient organizations were represented by 7 out of 10 invited individuals (French speaking patient organization (Crohn-RCUH asbl): 5 out of 5; Flemish speaking patient organization (CCV VZW): 2 out of 5). All 7

representatives from industry completed the survey, as did all 3 representatives from professional organizations (Verbond van Belgische beroepsverenigingen van Artsen-Specialisten (VBS-GBS), Domus Medica, and Algemene Unie van Verpleegkundigen van België (AUVB-UGIB-AKVB). Academic societies (Vlaamse Vereniging voor Gastroenterologie (VVGE) and Société Royale Belge de Gastro-Entérologie (SRBGE)), both represented by two members each, were fully represented (n=4). The 3 invited representatives from hospital networks all participated. Additionally, we approached three other relevant organisations (the InterMutualistisch Agentschap (IMA), the Algemeen Syndicaat van Geneeskundigen van België (ASGB), and the Belgische Vereniging voor Verpleegkundig Specialisten (BVVS)) for inclusion in the multi-stakeholder Delphi process. However, these three organisations did not respond to our invitations.

The final composition of the Delphi panel consisted of BIRD (31,4%), patient organizations (20,0%), industry (20,0%), professional organizations (8,6%), academic societies (11,4%), and hospital networks (8,6%).

The participant composition reflects a comprehensive and inclusive approach, with stakeholders representing clinical, academic, patient advocacy, and industry perspectives.

Voting process

From the 31 statements in the first round that received feedback or suggestions for clarification, 11 were modified, of which three were split into separate components, resulting in a total of 34 statements in the second round (Table 1).

During the final consensus meeting, one statement needed a revote and received 67% agreement. Since this fell short of the 80% threshold, it was excluded from the final set of priority points.

Given the high level of agreement, with 33 out of 34 statements reaching consensus, the BIRD Board members, patient organizations, and the steering group were subsequently asked to rank their top 15 statements in order of importance to help identify key priorities for action, from which a top 10 was extracted (Table 2).

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Supplementary file 1

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Statements

The consensus statements (Table 1) were categorized across six key domains central to optimizing IBD care in Belgium (Figure 1). Below is a summary of the major findings:

1. IBD Registry and Data Utilization

Stakeholders strongly endorsed the creation of a comprehensive National IBD Registry encompassing all patients with IBD in Belgium. Integration with electronic health records (EHR) and automatic data input were viewed as essential to ensure completeness and minimize administrative burden.

High agreement was reached on the statement that a link should be established between patient registration and reimbursed care within an IBD care pathway (convention). Concerns were raised about the potential drawbacks of a convention-based model. During the virtual discussion, participants cautioned that such agreements may limit flexibility in a complex and diverse patient population, potentially negatively impacting therapeutic options and outcomes.

There was strong agreement among participants regarding the statement that data from the National IBD Registry should be made accessible for secondary use by the broader IBD research community including academics, healthcare providers, and researchers.

This access should be granted in accordance with the FAIR principles (Findable, Accessible, Interoperable, Reusable), while ensuring an opt-out mechanism to safeguard patient autonomy.

The consensus threshold was not met on the statement that data from the National IBD Registry should be accessible for secondary use in broader IBD commercial research, even with adherence to the FAIR principles and an opt-out option (67% agreement, consensus threshold: 80%). No consensus was reached after revoting. Key concerns included the vague and potentially misleading term commercial research, fears of data misuse, and the need for clear patient consent. Several participants emphasized that patients should remain in control of their own data and questioned the legal feasibility of sharing, even in aggregated form. Others stressed that sharing could benefit patients, for example by supporting reimbursement dossiers, but only under strict conditions. Legal advice and clearer definitions were seen as essential before taking this statement forward.

There was 100% agreement that the collected data could be used to initiate quality improvement projects involving patients and supporting value-based healthcare. There was also unanimous consensus that the registry could facilitate real-world evidence studies to assess both long-term treatment outcomes and healthcare resource utilization.

2. Patient-Reported Data

Consensus was reached on several key statements

Table 1. — **Results from the second voting round showing median scores and agreement percentages for statements across stakeholder groups. Priority statements as selected by BIRD Board, steering group and patient representatives are represented in yellow. Agreement is defined as percentages of votes with a score of 7 or higher.**

	ADMINISTRATIVE FRAMEWORK														
	Statements:	All stakeholders		BIRD (n=11)		Academic Institutions (n=4)		Professional Organizations (n=3)		Patient Organizations (n=7)		Hospital Network (n=3)		Industry (n=7)	
	IBD Registry and Data Utilization	**Median**	**Agreement (%)**	**Median**	**Agreement (%)**	**Median**	**Agreement (%)**	**Median**	**Agreement (%)**	**Median**	**Agreement (%)**	**Median**	**Agreement (%)**	**Median**	**Agreement (%)**
1	Belgium should establish a comprehensive National IBD Registry that includes all patients with IBD.	9	100	8	100,0	10	100,0	9	100,0	9	100,0	9	100,0	9	100,0
2	The registry should be stimulated for all IBD centres and linked to electronic health records (EHR) for automatic data input.	9	97,1	9	100,0	9	100,0	8	100,0	9	85,7	9	100,0	9	100,0
3	A link should be established between patient registration and reimbursed care within an IBD care pathway (convention).	9	97,1	9	100,0	9	100,0	8	66,7	9	100,0	8	100,0	8	100,0
4a	Data of the National IBD Registry should be accessible for secondary use to the broader IBD research community of academics, health care providers and researchers, in accordance with the FAIR-principle (Findable, Accessible, Interoperable, Reusable), with opt-out option.	9	97,1	9	100,0	8	100,0	8	66,7	9	100,0	9	100,0	9	100,0
4b	Data of the National IBD Registry should be accessible for secondary use for broader IBD commercial research, in accordance with the FAIR-principle (Findable, Accessible, Interoperable, Reusable), with opt-out option.	7	65,7	7	54,5	7	50,0	5	33,3	7	57,1	8	100,0	9	100,0
5	The collected data should be used to initiate quality improvement projects that involve patients and support value-based healthcare.	9	100	9	100,0	8	100,0	8	100,0	10	100,0	10	100,0	9	100,0
6a	The registry could also facilitate real-world evidence studies to assess long-term treatment outcomes	9	100	9	100,0	9	100,0	8	100,0	9	100,0	10	100,0	9	100,0

Table 1. **Continued.**

6b	The registry could also facilitate real-world evidence studies to assess healthcare resource utilization.	9	100	9	100,0	9	100,0	9	100,0	9	100,0	9	100,0	8	100,0
	Patient-Reported Data														
7a	Patients and healthcare professionals should be empowered to provide patient-reported outcomes (PROs) as part of routine care and data collection.	9	100	9	100,0	9	100,0	8	100,0	9	100,0	9	100,0	8	100,0
7b	Patients and healthcare professionals should be empowered to provide patient-reported experience measurements (PREMs) as part of routine care and data collection.	9	88,6	9	90,9	7	50,0	8	100,0	9	100,0	9	100,0	8	85,7
8	The integration of patient-reported data should contribute to shared decision-making and personalized treatment strategies, improving overall patient satisfaction and outcomes.	9	100	9	100,0	8	100,0	8	100,0	10	100,0	9	100,0	8	100,0
9	Digital tools and patient apps (telemonitoring) should be developed to facilitate real-time collection of PROs and PREMs and integrate them into clinical practice.	9	91,4	9	100,0	7	50,0	8	100,0	9	100,0	10	100,0	8	85,7
	Multidisciplinary care														
10	Belgium should create and fund an IBD-coordinated multidisciplinary care pathway, in line with existing care pathways (multidisciplinary oncology consultation, diabetes care, renal failure).	9	100	10	100,0	10	100,0	8	100,0	10	100,0	9	100,0	8	100,0
11	Multidisciplinary care should be enhanced by including dietitians, psychologists, and social workers to ensure holistic and personalized IBD care.	9	97,1	9	100,0	9	100,0	7	66,7	10	100,0	9	100,0	9	100,0
12	Close interaction between general practitioners and IBD specialists should be established in suspect IBD to ensure timely diagnosis.	9	100	9	100,0	9	100,0	8	100,0	10	100,0	9	100,0	8	100,0

Table 1. **Continued.**

13	Clear referral pathways between general practitioners and IBD specialists should be established in confirmed diagnosis of IBD to ensure timely intervention.	9	100	9	100,0	9	100,0	8	100,0	10	100,0	9	100,0	8	100,0
14	The multidisciplinary IBD care pathway should be reimbursed, including coverage for the IBD nurse, dietitian, psychologist, and other essential healthcare professionals, ensuring comprehensive and accessible care for all patients.	10	97,1	10	100,0	10	100,0	8	66,7	10	100,0	10	100,0	10	100,0
15	The BIRD Standard of Care guidance document should be used as the foundation for the multidisciplinary care pathway.	9	100	9	100,0	9	100,0	8	100,0	9	100,0	9	100,0	9	100,0
16	A framework should be established for regular multidisciplinary team meetings to discuss complex cases and optimize treatment strategies.	9	100	9	100,0	10	100,0	8	100,0	10	100,0	9	100,0	8	100,0
	IBD nurse role and financial support														
17	The role of the IBD nurse should be officially recognized, and transitional measures (portfolio-based) should be put in place for currently employed IBD nurses.	10	97,1	10	100,0	10	100,0	8	66,7	10	100,0	10	100,0	9	100,0
18	Belgium should invest in IBD nurse training and provide financial support for their central role in IBD care.	10	97,1	10	100,0	10	100,0	8	66,7	10	100,0	10	100,0	8	100,0
19	Standardized training programs and certification pathways should be developed for IBD nurses to ensure uniform expertise across all healthcare settings.	10	100	10	100,0	10	100,0	8	100,0	10	100,0	9	100,0	9	100,0
	Access to Diagnostic & Monitoring Tools														
20	Belgium should provide regular access and reimbursement for a wider range of diagnostic and monitoring tests, including traditional endoscopy and non-invasive options such as intestinal ultrasound and faecal calprotectin.	9	100	9	100,0	10	100,0	8	100,0	10	100,0	9	100,0	9	100,0

Table 1. **Continued.**

21	There should be no difference in the reimbursement of diagnostic and monitoring tests between Crohn's disease and ulcerative colitis.	10	100	10	100,0	10	100,0	10	100,0	10	100,0	10	100,0	10	100,0
22	Additionally, both diseases should be officially recognized as chronic severe conditions to ensure equitable access to care and treatments.	10	100	10	100,0	10	100,0	10	100,0	10	100,0	10	100,0	9	100,0
23	Reimbursement of diagnostic tests should be linked to a recognized care pathway to ensure equity and proper utilization.	9	100	9	100,0	10	100,0	9	100,0	10	100,0	10	100,0	9	100,0
24	Disparities in access to non-invasive testing methods should be addressed, ensuring equal availability across all hospitals and regions.	9	100	9	100,0	10	100,0	9	100,0	10	100,0	9	100,0	9	100,0
25	Investments should be made in infrastructure and workforce to provide timely access to diagnostics and monitoring tools.	9	97,1	9	100,0	9	100,0	7	66,7	10	100,0	9	100,0	8	100,0
26	Intestinal ultrasound (IUS) is a validated, non-invasive method for monitoring patients with Crohn's disease and ulcerative colitis and should be accessible/provided in dedicated IBD centres.	9	97,1	9	100,0	9	100,0	8	66,7	10	100,0	9	100,0	9	100,0
27	Since intestinal ultrasound (IUS) is a validated, non-invasive method for monitoring patients with Crohn's disease and ulcerative colitis, it should be reimbursed as a medical act to ensure equitable access for all patients.	9	100	10	100,0	10	100,0	8	100,0	10	100,0	9	100,0	9	100,0
28	Belgium should restructure and simplify the Chapter IV medication approval process based on existing evidence and guidelines, preventing delays in access to effective treatments.	9	100	9	100,0	10	100,0	9	100,0	9	100,0	9	100,0	10	100,0

Table 1. **Continued.**

	Treatment & Medication Reimbursement												
29	The current reimbursement rules for IBD medications should be harmonized and simplified to reduce administrative burden and ensure faster patient access to innovative treatments.	10	100	9	100,0	10	100,0	9	100,0	10	100,0	9	100,0
30	Regular benchmarking with international guidelines should be performed to ensure Belgium remains aligned with best practices in IBD care.	9	100	9	100,0	9	100,0	9	100,0	10	100,0	8	100,0
31	IBD patients are at increased risk for infections due to immunosuppressive treatments. A structured vaccination program should be implemented, ensuring coverage for recommended vaccines (e.g., pneumococcal, hepatitis B, HPV, and annual influenza vaccination).	9	100	9	100,0	10	100,0	9	100,0	10	100,0	9	100,0

Table 2. — **Final selection of the 10 most important action points.**

IBD Registry and Data Utilization
1. Belgium should establish a comprehensive National IBD Registry that includes all patients with IBD.
2. The collected data could be used to initiate quality improvement projects that involve patients and support value-based healthcare.
Patient Reported Data
3. Patients and healthcare professionals should be empowered to provide patient-reported outcomes (PROs) as part of routine care and data collection.
Multidisciplinary Care
4. Belgium should create and fund an IBD-coordinated multidisciplinary care pathway, in line with existing care pathways (multidisciplinary oncology consultation, diabetes care, renal failure).
5. Multidisciplinary care should be enhanced by including dietitians, psychologists, and social workers to ensure holistic and personalized IBD care.
6. The multidisciplinary IBD care pathway should be reimbursed, including coverage for the IBD nurse, dietitian, psychologist, and other essential healthcare professionals, ensuring comprehensive and accessible care for all patients.
IBD nurse role and financial support
7. The role of the IBD nurse should be officially recognized, and transitional measures (portfolio-based) should be put in place for currently employed IBD nurses.
8. Belgium should invest in IBD nurse training and provide financial support for their central role in IBD care.
Access to Diagnostic & Monitoring Tools
9. There should be no difference in the reimbursement of diagnostic and monitoring tests between Crohn's disease and ulcerative colitis.
10. Since intestinal ultrasound (IUS) is a validated, non-invasive method for monitoring patients with Crohn's disease and ulcerative colitis, it should be reimbursed as a medical act to ensure equitable access for all patients.

concerning the integration of patient-reported data into routine clinical care. Participants agreed that both patient-reported outcomes (PROs) and patient-reported experience measures (PREMs) should be integrated into care pathways. While patients are the primary source of this information, healthcare professionals can play an important role in supporting and empowering patients to report these data effectively.

There was consensus that incorporating patient-reported data may enhance shared decision-making and facilitate more personalized treatment approaches, thereby improving both patient satisfaction and clinical outcomes. However, concerns were raised regarding the practical feasibility of frequent data collection, including questions about how often data should be collected, how it would be stored, and how it would be acted upon in clinical workflows. Additionally, the lack of current reimbursement structures to support the time and personnel needed to manage and interpret PRO and PREM data was identified as a barrier.

Telemedicine and remote monitoring were recognized as important tools to facilitate these goals. Digital platforms can support real-time collection of PROs and PREMs, prompt early detection of disease flares, and reduce hospital visits (11-13).

Participants emphasized that the successful implementation of telemedicine requires adequate resources, proper training, and sustainable funding.

3. Multidisciplinary Care

There was strong consensus on the need to create and fund a coordinated multidisciplinary care pathway for IBD, similar to those in oncology or diabetes care. Enhanced multidisciplinary care teams, including also dietitians, psychologists, and social workers were seen as essential to providing holistic care.

Improved collaboration with general practitioners (GPs) was also prioritized. Early GP involvement in suspected IBD and clear referral pathways after diagnosis were identified as crucial to timely effective care.

Participants supported official reimbursement for the full IBD care team, including coverage of IBD nurses and allied health professionals. The BIRD Standard of Care document (14), outlining national guidance for monitoring patients with IBD on advanced therapies, was proposed as the foundation for developing this multidisciplinary pathway. This document provides structured recommendations for minimal follow-up assessments, integrating clinical, biochemical, endoscopic, and patient-reported outcomes, and serves as a framework to ensure consistent, high-quality care across Belgian centres. Additionally, a national framework for regular multidisciplinary team meetings on complex cases was endorsed.

4. IBD Nurses and Training

There was unanimous agreement on the need to officially recognize the role of the IBD nurse. Transitional recognition (e.g., portfolio-based validation) for currently active IBD nurses, public investment in nurse training, and the creation of standardized training programs were identified as critical next steps to ensuring uniform quality of care across centres.

5. Access to Diagnostics and Monitoring Tools

Consensus was reached on several key points regarding diagnostic and monitoring access for Crohn's disease and ulcerative colitis in Belgium. It was agreed that Belgium should provide regular access and reimbursement for a wider range of diagnostic tests, including both traditional methods (like endoscopy) and non-invasive options (such as intestinal ultrasound (IUS) and faecal calprotectin). There should be no reimbursement distinction between Crohn's disease and ulcerative colitis.

Both conditions should be recognized as chronic severe diseases to ensure equitable access to care and treatments. Additionally, reimbursement for diagnostic tests should be linked to recognized care pathways to ensure proper utilization. Addressing disparities in access to non-invasive testing methods across hospitals and regions was also seen as crucial.

IUS is recognized as a validated, patient-friendly method for monitoring both diseases and should be accessible in gastroenterology units, though in some centres, collaboration with radiologists may be equally valid (15).

6. Treatment Access and Reimbursement

There was 100% agreement on the statement that Belgium should restructure and simplify the advanced therapies approval process, ensuring it is based on existing evidence and guidelines. This would help prevent delays in accessing effective treatments for patients. There was also 100% agreement on the statement that the current reimbursement rules for advanced IBD medications should be harmonized and simplified to reduce administrative burdens and ensure faster patient access to innovative treatments. A key concern was the requirement to administer corticosteroids or conventional treatment for three months before granting access to advanced treatments. This practice is not endorsed by current guidelines (16,17) and it was noted that such restrictions work bidirectional, potentially delaying access to necessary therapies. Simplifying the reimbursement process could help address these issues and improve timely access to treatment. Reducing the administrative burden and aligning local practices with international standards were seen as ways to enhance patient access and clinician efficacy.

There was 100% agreement on the statement that patients with IBD, who are at increased risk for infections due to immunosuppressive treatments, should have access to a structured vaccination program. This program should ensure coverage for recommended

vaccines based on the risk associated with the specific advanced therapy. Several important points were raised during the discussion. First, it was emphasized that vaccination recommendations should be evidence-based to ensure that only the necessary vaccines are provided. Communication between specialists, GPs, and pharmacists was identified as crucial. It was noted that GPs play a vital role in coordinating patient care, including vaccinations. However, as IBD patients often don't visit their GP, pharmacists, often the key point of contact for patients, should be included in the vaccination process.

Discussion

IBD care is evolving rapidly, providing better outcomes for patients. To ensure that care remains sustainable and of high quality, collaboration among all stakeholders is essential to optimize the use of available resources. Focus should be on patient-centred care, guided by quality assurance aligned with current evidence. This consensus provides a set of action points to support the development of such a framework for IBD care in Belgium.

The proposed advancements in IBD care in Belgium, including the establishment of a National IBD Registry, the integration of patient-reported outcomes, and the implementation of streamlined care pathways, are designed to improve disease monitoring and optimize disease control. These reforms are expected to yield not only improved clinical outcomes but also significant cost savings. Cost reduction may be realized through various mechanisms, such as reduced frequency of disease flares, fewer long-term complications, and decreased hospitalization rates. In turn, this can lead to lower rates of work absenteeism, further lessening the overall economic burden. Additionally, expanding access to diagnostic tools such as IUS and faecal calprotectin may facilitate earlier intervention and help avoid more costly, invasive procedures.

Establishing the National IBD Registry was widely supported to improve disease monitoring, optimize care, and enable quality improvement initiatives. However, use of registry data beyond clinical care and quality improvement raises legal and ethical challenges, including GDPR compliance and protection of patient rights. No consensus was reached for sharing data with third parties for commercial purposes, highlighting the need for clear legal frameworks and patient consent. Integrating PROs and PREMs into routine care is valuable but requires adequate resources and funding. Additionally, improving communication between specialists, GPs, and pharmacists is crucial for coordinated, patient-centred care.

There was a unanimous agreement on the urgent need for formal recognition of the IBD nurse role, which is essential in managing patient care, ensuring continuity, and supporting treatment adherence, which further enhances disease control and reduces hospital visits. Key priorities moving forward include transitional recognition, public investment in dedicated nurse training, and the development of standardized national training programs. These measures are essential to ensure consistent, high-quality IBD care across all centres.

While this consensus outlines actionable priorities to improve IBD care in Belgium, several potential limitations may hinder their implementation. Financial constraints represent a major barrier, as many of the proposed actions such as expanding multidisciplinary teams, improving data infrastructure, or increasing access to advanced therapies, require substantial and sustained investment. Additionally, the fragmented nature of the Belgian healthcare system, with shared responsibilities between federal and regional authorities, may complicate centralized coordination and accountability. Another important factor is the lack of formal incentives for healthcare providers and institutions to adopt long-term, patient-centred care models. Resistance to change within established systems and practices, both at institutional and individual levels, may further limit the uptake of proposed reforms. Finally, the successful transformation of IBD care also depends on political motivation and alignment across stakeholders, which may be challenging to achieve in a complex, multi-actor landscape.

This consensus initiative represents an important step toward a more integrated and strategic approach to IBD care in Belgium. By bringing together a diverse group of stakeholders, including clinicians, patients, academic experts, professional organizations, hospital networks, and industry representatives, it has laid the groundwork for sustained dialogue and coordinated action. The outcomes of this process can inform structured negotiations with regulatory and governmental bodies and support the development of national care pathways, quality indicators, and funding mechanisms. Repeating this exercise at regular intervals, with updated stakeholder input and real-world data, may help monitor progress, adapt to emerging challenges, and ensure continued alignment with evolving patient needs and scientific evidence. Ultimately, such consensus efforts can contribute to a more equitable, efficient, and patient-centred healthcare system.

This broad consensus is a first step towards better care for patients with IBD.

Declarations

Conflict of interest statement:

TT: No conflicts of interest
ND: No conflicts of interest
JK: No conflicts of interest
FB: AbbVie, Abivax, Alphasigma, Amgen, Arena Pharmaceuticals, Celgene, Celltrion, Ferring, Fresenius Kabi, J&J, Merck Sharp & Dohme, Pfizer,

Sandoz, Arena Pharmaceuticals, Eurogenerics, Takeda
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