

# Framework of IBD Care Delivery Across Ages

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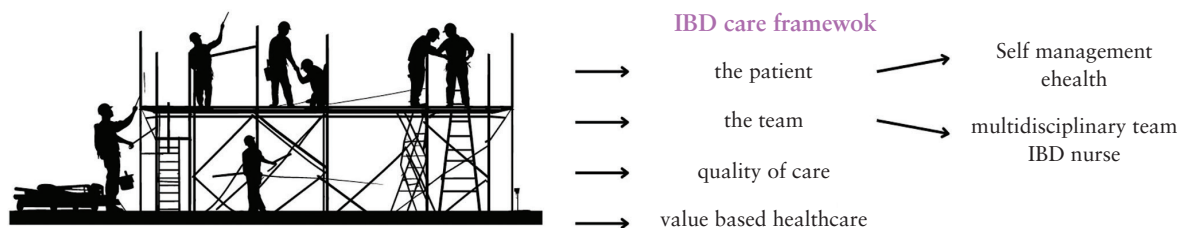
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## Abstract

IBD care has gone through a real transformation over the last century, moving from the mere unidirectional interaction between the physician and the patient to a stronger framework with multiple stakeholders who interconnect and strengthen each other. The patient has evolved from a passive subject to the central pole in the care pathway. Key elements of the future framework include patient self-care and empowerment, and remote monitoring [eHealth]. This care will be delivered by a multidisciplinary team acknowledging the pivotal role of the IBD nurse, and emphasising and measuring the quality of its work. The big challenge for the future is to establish a financially viable model to make this evolution durable in the long term, and this by using the principles of value-based health care.

**Key Words:** Multidisciplinary team; IBD nurse; ehealth; value based health care

## Graphical Abstract



## 1. Introduction

Ulcerative colitis [UC] was first described in 1793 by Matthew Baillie, and in 1932 the now-called 'Crohn's disease' [CD] was recognised as a separate entity.<sup>1,2</sup> In the early periods since their recognition, both diseases were seen as 'untreatable'. In that era, surgical resection and/or palliation were the preferred treatment approaches.<sup>3</sup> As the understanding about inflammatory bowel disease [IBD] increased, medical approaches to treatment were proposed, including sulphonamides and antibiotics. The first evidence-based treatment was established in 1955 with the introduction of cortisone in the historical, randomised, placebo-controlled trial of Truelove and Witts.<sup>4</sup> Since then, the framework of IBD care has seen a step-by-step evolution. Over the past century, the standard of living has dramatically increased, not only in the Western world but in the past decades potentially even faster in newly industrialised countries as well. Health care delivery has seen revolutionary changes in parallel with the overall societal changes. We have seen an improvement in the access to health care, the quality of care, and consequently in the

long-term outcomes. In relation to IBD, globalisation has a potential impact on the gradually increasing incidence and burden of IBD worldwide.<sup>5,6</sup> All this taken together with the changing expectations of patients and society towards medicine, make previous models of health care delivery difficult to maintain, facing issues in both quality of care and financial constraints.

In the 20th century, the care for patients with IBD was mainly provided by a small group of specialists, and care with expert clinicians focusing on IBD did not exist. The interaction with the patient was rather paternalistic and mainly unidirectional, with little input from the patient. However times are changing, and along with this, patient expectations and physician perspectives on care, with shared decision making, entering the medical field.<sup>7</sup> In order to involve the patient, the health care professional [HCP] has to inform the patient and his relatives in an unbiased, unframed way about the risks and benefits of a proposed treatment.<sup>8</sup> This requires more time. However, patients and HCPs feel restrictions and overall reduction in quality time during scheduled clinic appointments, which is hampering communication and reducing

the overall satisfaction of the inter-individual interaction.<sup>9</sup> One of the reasons for the limited time is the lack of expansion of staff in IBD care facilities, which is not aligned with the increasing prevalence of IBD.<sup>6</sup> This causes reduced access and longer waiting lists, which may result in an individual risk of a more complicated disease course and lower patient satisfaction.<sup>10</sup> Consequently, there are increasing frustrations among HCPs, with increased risk of physician burnout.<sup>11</sup>

The overall cost of care for IBD has increased exponentially across the world due to the rising prevalence of IBD, the chronic nature of the disease, introduction of advanced therapies [biologics and small molecules], and intensive monitoring strategies.<sup>12</sup> One would expect that this enormous investment in resources should lead to a reduction in societal cost. However benefit in direct cost, based a reduction in hospitalisation and surgery, and on indirect cost, based on increased 'financial productivity' of the patient, has not been materialised yet.<sup>13</sup> One of the main reasons is that we are still facing a therapeutic ceiling in relation to disease remission.<sup>14</sup> Thus, objective long-term outcomes have not yet dramatically changed, as illustrated by the only modest reduction in colectomy rates in UC despite the expansion of the medical treatment possibilities.<sup>15</sup>

The key elements of a new framework should be based on what patients set as priorities and major concerns in their care. Patients' expectations vary, being highly dependent on their age, gender, and psychosocial context.<sup>16</sup> It is not always easy to capture specific concerns based on quantitative research. Qualitative research, however, can capture the unique experiences of patients, the social consequence of the disease, and the impact of delivered care.<sup>17</sup> An IBD Qorus survey shows that specific concerns are associated with typical patient phenotypes.<sup>16</sup> but overall, HCPs and patients have similar concerns about symptom control and treatments. For this reason, the major focuses in current care pathways are control of inflammation and achieving remission.<sup>18</sup> To fulfil patient expectations even better, a broader, holistic approach is necessary. This includes aspects like family planning, travelling, nutrition, anxiety, body image, and fatigue.<sup>19</sup> This holistic approach may improve patients' experience but can only be applied in a context that creates the right environment to address these concerns.<sup>20</sup>

For this we should adopt an optimal framework for IBD care, integrating different modalities that have evolved in the past decades. This framework should focus on several key parameters: [1] better long-term outcomes; [2] optimal use of health care resources; [3] patient satisfaction; and [4] HCP involvement. The shift from a paternalistic approach to a new, patient-centred, optimal approach is a long and demanding process. It requires commitment of the patient, the HCP, and society. We see that this evolution is already ongoing as multiple new approaches and concepts find their way to the IBD clinic.

In this paper, we will highlight some key concepts that could strengthen the IBD care delivery in the future. The framework should be patient centric, in which the patient is contributing maximally to the care by eHealth modalities and patient self-care. The patient should be supported by the IBD team where the nurse specialist plays the central role in the multi-disciplinary team. We should strive with in this framework to maximise the quality of care in a financial stable structure [Figure 1]. It should be stressed that clinical and translational research is an essential part of all the key concepts

that we describe. Research indeed provides new insights in the daily care for patients with IBD, and although not formally included in the quality indicators of the European Crohn and Colitis Organisation, should be continuously encouraged.<sup>21</sup> Participation in clinical trials opens opportunities for patients and learning points for HCPs.

## 2. Key elements for improved care

### 2.1. The patient

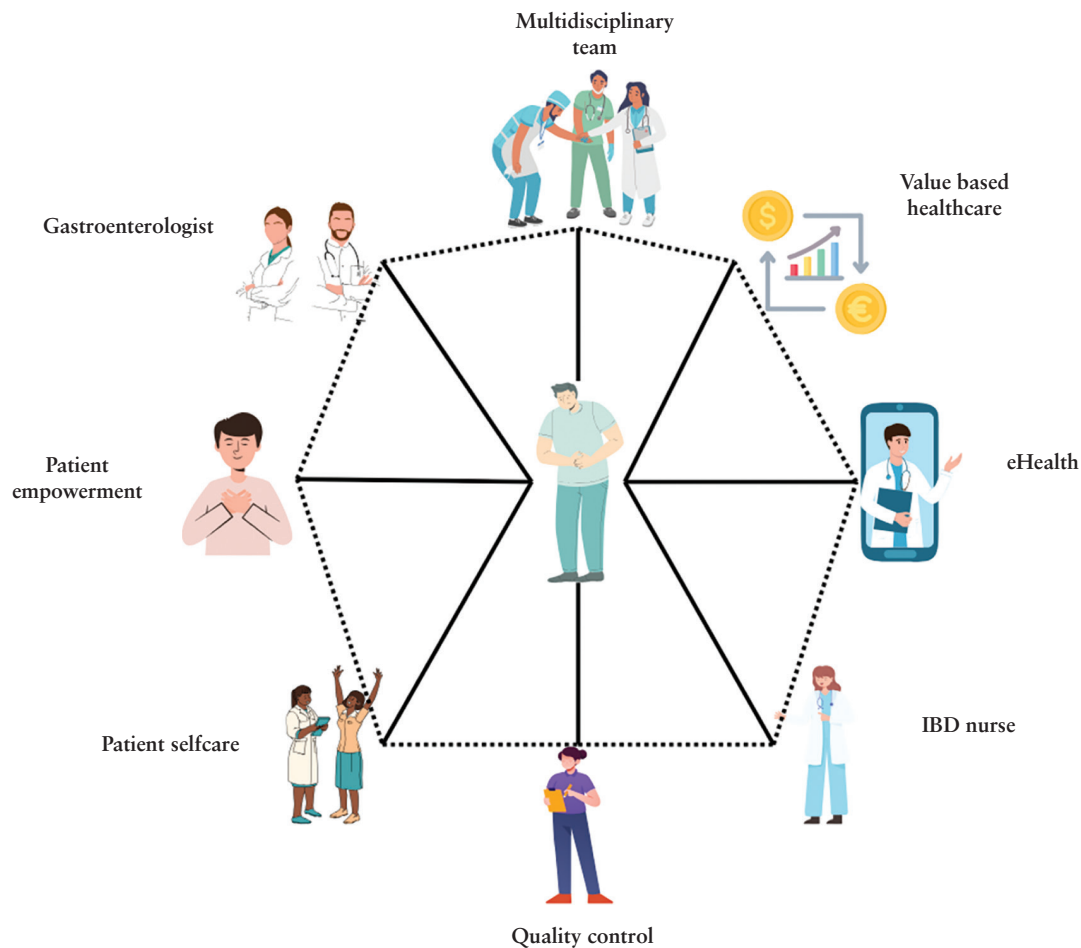
#### 2.1.1. Self-management by the patient

Prearranged clinic visits in relapsing-remitting diseases are unlikely to correspond with disease activity, and patients experiencing an exacerbation often need to wait for an outpatient appointment, ultimately delaying initiation of appropriate treatment. Patient self-care or patient self-management is defined as 'an individual's ability to manage the symptoms, treatment, physical and psychological consequences, and lifestyle changes inherent in living with a chronic disease'. Self-management also includes the patient's ability to monitor their condition and maintain a good quality of life.<sup>22</sup> The concept of patient self-care is widely recognised in conditions such as heart failure, diabetes mellitus, cognitive impairment, and rheumatoid arthritis,<sup>23-25</sup> and has gradually gained importance in IBD as well.

From the start, the focus of patient self-management in IBD has been on information provision, symptom management, handling of psychological effects, and coping.<sup>26</sup> In 2001, the first randomised, controlled trials [RCTs] about patient self-care compared a patient-centred self-management training and follow-up with a standard follow-up, and involved 203 patients with ulcerative colitis.<sup>27</sup> The main outcome was the interval between relapse and treatment initiation, which differed significantly in favour of the self-care group. Patients in that group also made fewer visits to the hospital and to the primary physician.<sup>27</sup> Early research following this landmark trial confirmed that self-management programmes in IBD had the ability to improve health-related quality of life.<sup>26</sup> Furthermore, an advantage for distant or remote self-management was already suggested; however evidence was still limited at that time, and the most appropriate content and best approach for delivery of patient self-care interventions remained unclear.<sup>26</sup>

In an updated systematic review looking at the impact of patient self-care on symptom severity and health care resource use, 33 out of 50 studies [66%] reported effective self-management interventions in one or more measured outcomes.<sup>22</sup> Interventions that combined symptom management with information led to positive effects on the use of health care resources and patient-reported psychological wellbeing. Many effective interventions were conducted with individualised and patient-participatory activities, and were delivered by both physicians and other health-care providers.<sup>22</sup> With the advent of new treatment strategies such as treat-to-target and tight control,<sup>28,29</sup> more studies focused on therapeutic monitoring, often remote, and early intervention.<sup>30,31</sup>

Self-management with mesalazine, a first-line treatment option for ulcerative colitis, is probably one of the most used self-care initiatives in real-world clinical practice. Prospective work, using self-registration on a web application of a combination of patient-reported outcome measure and faecal calprotectin levels, provided evidence for this.<sup>32</sup> After 3 months, an individualised dosing of mesalazine



**Figure 1** Essential components of the framework for inflammatory bowel disease [IBD] care delivery

and an improved adherence to the medication contributed to a reduction of symptoms and biomarker levels in the studied population.<sup>32</sup> The iSupport Therapy-Access to Rapid Treatment [iSTART] initiative builds further on this knowledge.<sup>33</sup> Patients with mild-to-moderate ulcerative colitis follow a training to improve their ability to self-assess ulcerative colitis symptomatology and to increase the dosing of first-line therapy to an optimised level if needed. They are also provided with a prescription for a short-course, second-line treatment, to initiate when optimised first-line treatment seems insufficient and while waiting further instructions from their clinic, which should be contacted in that case.<sup>33,34</sup>

Self-care tools have the potential to treat more than only the classical [stool- and abdominal pain-related] symptoms, tackling a variety of issues that IBD patients might face but that are often underestimated by physicians. A large RCT [ISRCTN71618461], conducted in the UK, compares a facilitator-supported, online, cognitive-behavioural self-management programme [BOOST] versus care as usual in a large cohort of patients with IBD.<sup>35</sup> Interestingly, the outcome is the effect of this intervention on a global, patient-reported scale looking at fatigue, pain, and faecal urgency, common but difficult-to-treat symptoms in patients with IBD.<sup>35</sup> The elements of self-management can go even broader, also including diet, exercise, sport, social support, and psychology.<sup>23,36</sup> For example, acceptance and commitment therapy improved stress and other indices of psychological health in

patients with IBD, in an Irish randomised study.<sup>37</sup> The intervention was a combination of acceptance and mindfulness procedures, along with commitment and behaviour change strategies. Although leading to positive outcomes, the programme was quite intensive, with 90-min, weekly, group sessions for all participants, and this for a total period of 8 weeks.<sup>37</sup>

Despite the potential of patient self-management interventions to improve IBD outcomes, several points need to be carefully considered [Table 1]. Even though the assessment of symptoms might be similarly done by patients and their physicians,<sup>38</sup> this does not lead automatically to the desirable action by the patient. A French cross-sectional study showed that a high proportion of patients with IBD use corticosteroids without medical prescription or support,<sup>39</sup> and self-initiated, unnecessary dietary restrictions are frequent and lead to unfavourable outcomes.<sup>40</sup> Although social media and internet access have improved availability of patient-tailored information,<sup>41</sup> this alone will not sufficiently alter quality of life and physical and psychological wellbeing if not combined with a symptom management plan.<sup>22</sup> Probably careful patient selection is another key factor for successful patient self-care programmes. The iSTART consortium advised offering the programme only to patients with a high risk of relapse, those with limited access to health care services, and those who take an active interest in their disease and treatment.<sup>33</sup> Depending on the specific outcome aimed for, these selection criteria will likely need to differ slightly in other

**Table 1** Advantages and hurdles for the key concepts of the IBD care of the future

Key concepts of the IBD care framework	Advantages	Hurdles
Multidisciplinary team	<ul style="list-style-type: none"> <li>• Increasing standards of care</li> <li>• Standardised care pathways</li> <li>• Improved long-term outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Time consumption</li> <li>• Cost</li> <li>• Coordination task</li> </ul>
IBD nurse	<ul style="list-style-type: none"> <li>• Liaison in multidisciplinary team</li> <li>• Low threshold for interaction</li> <li>• Patient education</li> <li>• Increased patient knowledge</li> <li>• IBD care pathway</li> <li>• Annual contacts and regular follow-ups</li> <li>• Financial savings</li> <li>• Holistic approach</li> </ul>	<ul style="list-style-type: none"> <li>• Cost</li> <li>• Standardised nurse education</li> <li>• Differences in nurse role and levels of responsibilities</li> </ul>
eHealth	<ul style="list-style-type: none"> <li>• Distant monitoring</li> <li>• Patient empowerment</li> <li>• Reduction of hospitalisations</li> <li>• Continuous data collection</li> </ul>	<ul style="list-style-type: none"> <li>• Cost</li> <li>• Attrition</li> <li>• Administrative burden</li> <li>• Digital literacy</li> <li>• Interconnectivity eHealth platforms and electronic medical devices</li> </ul>
Quality indicators	<ul style="list-style-type: none"> <li>• Continuous improvement</li> <li>• Health care professional empowerment</li> <li>• Health care structure optimisation</li> <li>• Benchmarking of care</li> </ul>	<ul style="list-style-type: none"> <li>• Selection of applicable set of quality indicators</li> <li>• Outcome measurement tools</li> <li>• Patient-centric quality indicators</li> </ul>
Patient self-management	<ul style="list-style-type: none"> <li>• Shared decision making</li> <li>• Broad range of intervention improving multiple outcomes, including difficult-to-treat symptoms and psychological wellbeing</li> <li>• Implementable in treat-to-target and tight control algorithms</li> <li>• More effective use of health care resources</li> </ul>	<ul style="list-style-type: none"> <li>• Unfavourable outcomes if poorly guided</li> <li>• Active support and follow-up by an MDT team strictly necessary</li> <li>• Careful patient selection needed</li> <li>• Information provision alone is insufficient</li> </ul>

IBD, inflammatory bowel disease; MDT, multidisciplinary team.

programmes. Last, development of patient self-care pathways is team work. Given the diversity of interventions and targeted outcomes beyond mere symptom recognition and improvement, it requires the input of a multidisciplinary team, as well as the input of the patients themselves. Patient self-care is indeed an example par excellence of shared decision making, and this should already be practised during the development of the self-management programmes, since the patients' feedback will eventually contribute to a successful implementation.<sup>42,43</sup>

### 2.1.2. eHealth, remote monitoring, and wearables

Traditionally, care for patients with IBD is organised in an outpatient clinical setting with direct contact between patient and physician. These interactions take generally about 15 to 20 min and are built on a standardised care flow with questions on disease activity, disease impact, physical examination, and potential therapeutic approaches. Over the years, this model is evolving towards a more flexible and dynamic interaction. Due to an increase in therapeutic options and specialised care for IBD patients, an overall decrease in hospitalisation is observed<sup>44,45</sup>; however, emergency department admission is increasing gradually.<sup>46</sup> Improving the accessibility of the IBD caregiver could potentially affect this trend.<sup>47</sup> It has been shown that low threshold contact with an IBD nurse could decrease emergency department admissions.<sup>48,49</sup> Furthermore, digitalisation has revolutionised society. The COVID 19 pandemic has accelerated the adoption of eHealth technologies in IBD.<sup>50</sup> This, without any doubt, also impacts on the way HCPs and patients interact. Currently, the majority of the patients uses smartphones and most are

connected via social media.<sup>51</sup> The internet and social media are an important source of information for patients.<sup>41,52</sup> Some caution, however, is required as not all information on the web is reliable. Generally taken, information provided via official health care institutions, research associations, and patient organisations are most balanced and trustworthy.

There are different reasons why eHealth technologies might improve the framework for care delivery in IBD. IBD is a chronic disorder with a relapsing and remitting nature. The reduction of flares can prevent structural damage to the bowel and improve long-term outcomes. Traditional, planned, outpatient clinics insufficiently anticipate this unpredictable nature.<sup>50</sup> The increasing prevalence of IBD worldwide leads to an increased burden for the health care system.<sup>53</sup> This, combined with limited accessibility to care facilities, may lead to reduced level of care. In this context, eHealth technologies can be helpful by reducing the workload for the caregiver. Apart from this, a shift from intravenous biologics, administered at the day hospital, to more oral and self-administered biologic therapy in a home setting can be helpful in reducing the burden of clinical visits. Nevertheless, patients with advanced treatments still require close monitoring. eHealth could improve the efficiency of the monitoring of these patients without increasing the burden for the health care system itself. Finally, treat-to-target has been shown to be an effective approach in IBD.<sup>28</sup> For this, close monitoring and early adaptation of the treatment are essential to achieve better outcomes. eHealth technologies are an elegant tool to apply treat-to-target also from a distance.

Multiple types of eHealth interventions exist. Overall, they can be classified in three subgroups.

[1] Telemedicine refers to live, synchronised interaction via a video platform. This allows direct communication between the patient and the HCP.<sup>54</sup>

[2] Telehealth includes all interactions via technological interfaces in a remote fashion. This covers multiple modalities like email, web-based services, and mobile applications. Via these systems, patients provide information about their condition and health status. The HCP can review this information in a direct or semi-automated way and provide feedback to the patient.<sup>55</sup>

[3] Digital health information sources, where patients can find high quality and patient-level information on treatments, symptoms, nutrition, and extra-intestinal manifestations.<sup>56</sup>

Apart from digital information provided by HCPs, patients also find very concrete information via patient platforms and social media.<sup>57</sup> All types of eHealth interventions may have important overlap, where one intervention can be an adjunct to another.

The question remains whether eHealth technologies really can fulfil all the expectations. Several RCTs have been performed, testing eHealth interventions in an IBD population.<sup>58,59</sup> These studies show promising results, but all have certain shortcomings. An important hurdle in the gathering of evidence for eHealth technologies is the length of the intervention. In most studies, the intervention period is a maximum of 12 months.<sup>59</sup> Nevertheless, the attrition rates are high, with up to 40% of the patients dropping out for several reasons during the studies. This is even more remarkable since most of the studies have the tendency for an intrinsic selection bias for patients with higher digital health literacy. Attrition is associated with the educational level of the patient.<sup>60</sup> For this, it is important to tailor the eHealth intervention according to the patient characteristics.

The results of the RCTs evaluating eHealth applications are not as satisfactory as would be expected. Overall, there is no additional beneficial effect on disease outcome compared with usual care.<sup>55,59</sup> For quality of life, eHealth interventions have comparable impact to standard care approaches. This was confirmed in a non-inferiority study suggesting that digital health interactions can replace face-to-face interaction without negative impact on quality of life.<sup>31</sup> The largest impact of eHealth interventions is found in the reduction in health care use. This was clearly demonstrated in the randomised Dutch trial using myIBDcoach, a telehealth system that monitors and registers disease activity.<sup>30</sup> After a period of 12 months, there was a significant reduction in number of outpatient visits in the eHealth interaction group, as was the mean number of hospital admissions. This approach also led to a better cost-effectiveness with a lower mean annual cost of €547/patient, without impact on the quality-adjusted life-years.<sup>61</sup>

The big challenge is to implement eHealth tools in daily practice [Table 1]. Importantly, current financing and organisation of health care is often not adapted to this new approach. A transition to value-based health care may offer advantages for the financial stability of the health care system, promoting population health management.<sup>62</sup>

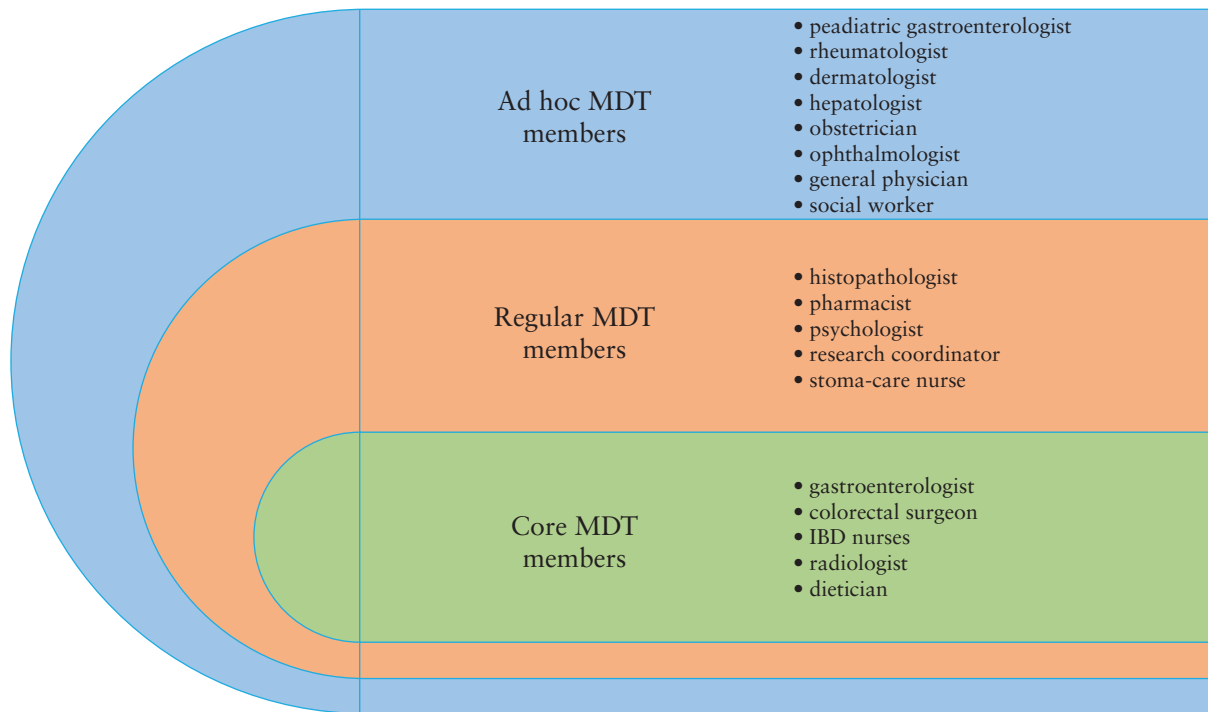
## 2.2. The team

### 2.2.1. The multidisciplinary team [MDT]

During the past decade, top-down strategy with early intervention, tight monitoring, and treat-to-target strategies were introduced to improve clinical outcomes.<sup>18,28</sup> Implementation

of these strategies requires an MDT. The exact composition of an ideal multidisciplinary IBD team is difficult to define and highly dependent on the local situation and resources [Figure 2]. However, a core team can be composed, and should include a gastroenterologist, a colorectal surgeon, an IBD nurse, a radiologist, and a dietitian. Other members can be included on a more regular basis [histopathologist, pharmacist, psychologist, research coordinator, stoma-care nurse] or ad-hoc for specific clinical problems [paediatric gastroenterologist, rheumatologist, dermatologist, hepatologist, obstetrician, ophthalmologist, general physician, social worker]. The latter two groups may vary depending on the size of the care team and patient population.<sup>21,63</sup> A holistic approach requires good coordination and communication between disciplines. In recent years, specialised care managers coordinate the care delivery in chronically ill patients, providing not only direct patient care, but also helping patients to navigate the system.<sup>64</sup> In the IBD field this role has been taken up by the IBD nurse [see below]. Actual impact data of the inauguration of an MDT on patient outcomes in IBD are scarce. Yanai *et al.* prospectively studied a structured MDT approach in patients [ $n = 67$ ] with newly diagnosed Crohn's disease.<sup>65</sup> A structured MDT approach was applied and the rates of recommended therapeutic targets at 1 year after diagnosis, particularly sustained corticosteroid-free clinical remission [SCFCR], were measured. Cases were discussed in weekly MDT meetings, including IBD-oriented gastroenterologists, a dedicated radiology expert, a surgical team, an IBD-oriented registered dietitian, an IBD registered nurse, coordinators, and additional experts relevant to the respective case. Patients communicated with the IBD team via email, messages, or phone calls between clinic visits, which speaks for a very close, patient-centred, communicational approach. After a median time of 1.9 (interquartile range [IQR] 1.2–4) months from diagnosis, 71% of patients were recommended to start biologic therapy [60.5%] or undergo surgery [6.6%]. Overall, 77.6% of patients received dietary therapy after being assessed by the IBD-oriented dietitian, and 82.9% received guidance from an IBD specialised nurse. Most of these patients [90%] maintained real-time contact with the nurse.

At 1 year, 77.6% of patients were in clinical remission and 64.5% were in sustained corticosteroid-free remission. This subsequently led to the achievement of other therapeutic targets such as significant improvement in biomarkers, endoscopic healing, and improved quality of life.<sup>5</sup> The rates achieved can be considered similar or even superior to those achieved in most registration trials or real-world cohorts. The favourable results may have been influenced by short disease duration, rapidity of intervention, and high rate of anti-tumour necrosis factor [TNF] therapy, but the highly tailored, personalised, therapeutic approach provided by a specialised MDT could have added benefit as well. Multiple modalities of MDTs have been proposed and each specific member has demonstrated its added value. Pathologists' input can improve medical and surgical outcomes by better diagnosis.<sup>66</sup> In specific settings, such as acute severe colitis and perianal fistulising Crohn's disease, close collaboration between the surgical and medical team is required to improve outcomes.<sup>67–69</sup> A clinical pharmacist as part of the MDT may reduce the occurrence and severity of therapy-related adverse drug reactions and improve patient satisfaction.<sup>70</sup> The corresponding therapy algorithms must be implemented in close contact with the patients to maximise its benefit. The exact composition and frequency



**Figure 2** Suggested composition of a multidisciplinary team. Three levels are distinguished: a core team that always needs to be present, regular members who are invited for the majority of the patients and ad hoc members who are invited for specific indications.

of the meetings depend on the local staff availability and case load. At least a weekly meeting with the core team and a monthly meeting with the broader MDT seems feasible and guarantees continuity, avoiding undesired delay in decision making. Not all cases need to be discussed in an MDT. The focus of the MDT should be on patients with complex disease manifestations, surgical indications, and associated, immune-mediate, clinical problems.

### 2.2.2. The IBD nurse

Patients with IBD have a complex chronic condition and having access to an IBD nurse can be very beneficial for the quality of life. Across Europe, the level of education of IBD nurses varies and differences in nursing roles with varying levels of responsibility exist.<sup>71</sup> The N-ECCO Consensus Statements are used throughout Europe as a gold standard and have served as benchmark for the role of the IBD nurse, both fundamental and advanced IBD nursing care.<sup>72,73</sup> Fundamental nursing care focuses on the general aspects of paramedical tasks like education, patient support, and counselling. Advanced IBD nursing refers to a nurse caring for people with IBD at an advanced level, thereby working partly independently while also dealing with more complex clinical problems.<sup>73</sup> A recent quality review of IBD nurse practising indicated that the application of the gold standards in daily practice remains a challenge [Table 1]. To strengthen the framework of IBD care in the coming years, focus should be on structured assessment via questionnaires, patient databases, and nurse-led research initiatives.<sup>74</sup>

Although the role of the IBD nurse is quite new, it already has gone through an evolution in getting more established over the past 25–30 years. In the early 2000s, with the advent of infliximab as first biologic,<sup>75</sup> the IBD biologics nurse-led service began to spread. The impact of the IBD nurse on

the management of patients with IBD was shown in a study from the UK in the early 21st century, and had a pioneering role in applying an individualised, patient-centred approach. Several different information sheets were made available for patients and only those applicable for a specific need of an individual patient were offered.<sup>76</sup> Additionally, a direct access to a specialised IBD nurse was established by a telephone helpline, and treatment guidelines allowed the IBD nurse to modify treatment when necessary.

The IBD nurses are the first point of contact, providing the patients with advice and counselling through different media. Two decades ago, the nurses predominantly had a rather administrative task arranging outpatient contacts with the physician. Nowadays, triage of medical questions and requests for advice are considered a key task for the IBD nurse, improving clinical and service outcomes.<sup>73</sup> The low threshold, and fast access to information, education and support, make patients rate their disease knowledge higher and feel more confident in self-management, and improves their ability to cope with the disease.<sup>49,76–79</sup> The direct access to the IBD nurse saves time for the physician and boosts the compliance of the patient through better follow-up.<sup>49,78,80</sup> Today, most IBD centres have advice lines managed by IBD nurses.

Previously, patient education was mainly given by the physician and remained too often concise due to lack of time. IBD nurses are able largely to take over this important part. The IBD nurse assesses health literacy of the patient and provides individualised, evidence-based education in a holistic manner to patients with IBD and their significant others. By adapting the information to the preferences and coping abilities of the patient, they aim to improve the quality of life of the patient with IBD.<sup>73</sup> Several IBD centres have transformed many of the regular outpatient visits to a gastroenterologist into contacts with IBD nurses.<sup>81–85</sup> This approach has been well received by

the patients and has shown a better overall patient experience and improved health-related quality of life.<sup>83–85</sup> Moreover, it shortens the interval from the beginning of a relapse to the adaptation of the treatment.<sup>83</sup> A study from Denmark confirmed that managing the annual visits by nurse-led phone appointments led to shorter waiting times and increased cost-effectiveness.<sup>82</sup> Finally, transition clinics are an ideal setting to be coordinated by an IBD nurse, ensuring continuity of care.<sup>86,87</sup>

### 2.3. Quality of care and quality control of the IBD care framework

Quality of care was long an under-recognised item in IBD care. It was only at the beginning of this century that governmental institutes identified the difference in care delivery and the impact this had on complications and deaths.<sup>88</sup> Also for IBD care, these gaps were gradually recognised, indicating important room for improvement.<sup>89</sup> A recent survey demonstrated major differences in how IBD care is organised in relation to the gross domestic product per capita [GDP] of the specific country. In countries with low GDP, IBD nurses and other IBD paramedics were less available. Also, implementation of eHealth tools and access to advanced therapies differed significantly between countries in Europe.<sup>90</sup> The reasons for these differences are not only based on economic inequality. Quality gaps might also be based on lack of knowledge, insufficient infrastructure, inadequate structure of the organisation, and non-implementation of standard operating procedures.

Quality improvement initiatives in health care are mirrored in the way industrial processes and structures are optimised. Thus, lean management and continuous improvement initiatives have entered health care.<sup>91,92</sup> The underlying idea of the implementation of industrial process optimisation techniques is that resources, also in health care, are limited and that the high variability in care may lead to inadequate use of resources, leading to suboptimal outcomes. Areas of overuse in IBD are, for example, reflected in the increase in emergency department admissions.<sup>46</sup> This may expose the patient to unnecessary examinations and potential iatrogenic complications. On the other hand, underuse might also lead to suboptimal long-term outcomes. Examples of underuse are inadequate vaccination, lack of thromboembolic prophylaxis in admitted patients with IBD, or delayed introduction of advanced therapies in severe IBD.

Quality indicators are generally subdivided into three subgroups: structure, process, and outcome indicators. Multiple scientific organisations have developed core sets of IBD quality indicators. In 2020, ECCO published an extensive list of 111 quality indicators grouped into three main domains: structure [ $n = 31$ ], process [ $n = 42$ ], and outcomes [ $n = 38$ ].<sup>93</sup> ECCO recognised that these quality indicators should be adapted to the local circumstances, since health care systems and regulations vary considerably between countries. Several countries have developed local, applicable sets of quality indicators via a Delphi consensus process.<sup>94–97</sup>

The description of the quality indicators is only a first step in the process of quality improvement, as implementation and auditing of the different parameters are needed for continuous improvement. In an initial evaluation, based on a self-reported survey, it seems that the structure of IBD units across Europe is consistent with the ECCO standards, although some gaps still exist.<sup>98</sup> The only way to establish an objective

assessment of quality indicators is by a systemic, independent measurement and subsequent benchmarking of the results. ECCO has planned these initiatives within the E-Quality project, using the ‘UR-CARE’ platform to assess outcomes.<sup>99,100</sup> An elegant example of continuous improvement by benchmarking is IBDQorus.<sup>101</sup> In this initiative, 10 outcome measures were selected and assessed at site level and patient level in 27 IBD centres in the USA. By implementing 19 process changes, an improvement was noted across multiple measures, including need for urgent care, hospitalisation, steroid use, and opioid use.<sup>102</sup> These types of programmes may require a large amount of human resources. Automated data, capturing by extracting data systematically from electronic medical records and automated, patient-reported outcomes, may facilitate the application. In this context, the implementation of artificial intelligence and big data analysis may facilitate this process. Pilot projects have shown this is feasible in daily practice.<sup>103</sup>

### 2.4. A financial structure to support the IBD care framework

Making predictions on the future of IBD care cannot be done without looking at the future of health care in general. The framework of our IBD care is embedded in the broader health care system, for which we can foresee a variety of hazards and challenges in the near future. There is an increasingly aging population with more chronic diseases, a massive increase in costs, an increasing digital transformation, and changing expectations of patients and society towards medicine.

If we want to make our IBD care future-proof in this fast-evolving society, we need to rethink our framework of care and align this with the expectations and the ultimate goal of IBD care. When targeting improved patient care in an era of restricted resources, we might need to move away from supply-driven, hospital-based care [based on fee for service, which is more volume-driven] to a more patient-oriented value-based care.

When we talk about value-based care, we have to consider what value means and the optimal way to deliver this value to our patients. Value can be defined in two ways. First there is public value, which is an economic approach and defined by the balance between outcomes and costs. Otherwise, there is the personal value from the patient’s perspective, more subjective but equally important. Achieving value in health care is primarily based on four key components, which we can translate to IBD care.<sup>104</sup>

#### 2.4.1. Accurate measurement of health outcomes and costs

The total cost of chronic diseases like IBD can be separated into direct costs [as a result of providing health care treatment] and indirect costs [due to loss of economic productivity and disability]. This total cost is increasing worldwide and is mostly due to an increased prevalence of inflammatory bowel diseases and expanding costs associated with the use of expensive drugs, mostly biologic agents.<sup>12</sup> Biologics have become the predominant driver of direct costs in high-income countries.<sup>105,106</sup>

In aiming to reduce the high direct costs, we need to look critically at the price, appropriateness, and efficiency of our treatments and we need more cost-controlling mechanisms. For example, the use of biosimilars reduces treatment costs and needs to be further supported.<sup>107</sup> Ideally, high direct costs are countered by reduction of the indirect costs with

less disability and improvement in health-related quality of life. For this, it is of high importance to gain better insights into the effective costs of health care on a national level. This requires collaboration between the HCP and the regulatory authorities.

#### 2.4.2. Transparent reporting of outcomes

In a model of value-based care, value can be added by diminishing the costs or by creating better outcomes for the same cost. Outcome can be seen as quality of care. To improve the outcome, systematic adoption of tools to monitor and ensure provision of guideline-specific care by all providers is essential. Therefore, PROM [patient-related outcome measures] and quality indicators of care need to be installed in a standardised manner that is applicable to all IBD centres. These quality indicators should be well defined and broadly adopted with transparent reporting, as described above.

#### 2.4.3. Improvement of care delivery in an organised fashion which is patient centred

Traditional IBD care is supply driven and centralised in hospitals, as it is frequently episodic and reactive in nature. In our search for more patient-oriented, value-based care, newer models of care should pave the way to a more proactive and participatory model centred on the patient. In this model, patients become more active participants in their care that facilitates patient empowerment, shared decision making, and self-management.<sup>108</sup>

New digital technologies can be very helpful tools in achieving these goals. Remote monitoring with telemedicine, mobile applications, and the use of wearables seems very promising in delivering proactive care and data-driven decision making.<sup>109</sup> This is based on a decentralised approach with reduced outpatient clinic visits, and fewer emergency visits and, potentially, hospital admissions.<sup>30</sup> EHealth trials indeed mainly show a reduction in outpatient visits and in thus in health care costs. However, more health economic studies including the use of the new technologies should

be done to make this clearer. If we want to use these new digital technologies to add more value to our care, a thorough cost-benefit analysis should be performed for each of the applications.

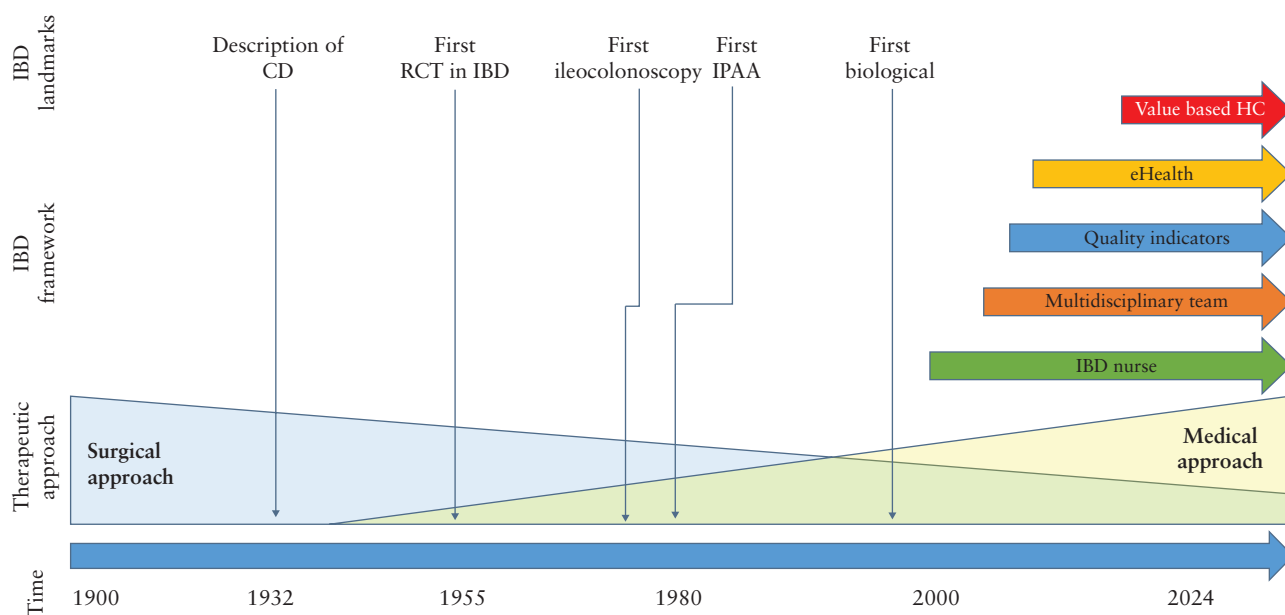
#### 2.4.4. Payment reforms for health care participants to reward value [other than volume]

More decentralised, multidisciplinary, holistic patient-centred care [with the aid of new technologies] is only possible when reimbursement models change. This implies a shift from fee for service to fee for outcome. The payment model should reward positive outcomes and cost-effective care more than volume of care.

For the future of IBD care, the concept of value-based care focuses on proactive, patient-centred strategies that optimise outcomes while minimising costs. This concept not only enhances the quality of care but also addresses the economic burden to society associated with IBD management.

### 3. Conclusion

IBD care has gone through a real transformation over the past century [Figure 3]. The IBD care of tomorrow is no longer built on a unidirectional interaction from the physician to the patient. The patient has evolved from a passive subject to being the central pole in the framework. In this strong framework, the patient [eHealth tools, remote monitoring] and the the IBD team [MDT and IBD nurse] are interconnected and strengthen each other. The big challenge for the future is to ensure high quality and to keep the framework financially stable. With the current epidemiological evolutions in the different parts of the world, we might anticipate that this will even become more important in the coming decades.<sup>6</sup> The projected burden of IBD in the newly industrialised parts of the world will create challenges similar to those seen in the Western world and this might create more inequity in the IBD care. Currently even within countries with an established health care



**Figure 3** Timeline showing emerging components of the framework for IBD care delivery over time. IBD, inflammatory bowel disease; CD, Crohn's disease; RCT, randomised controlled trial; IPAA, ileal pouch-anal anastomosis; HC, health care.



infrastructure, important differences may be noticed related to health care access that lead to worse outcomes.<sup>90,110</sup> The proposed framework [with low threshold for patients to contact HCPs, adequate MDT collaboration, and patient education] might improve the equality, but broader societal action is required to improve inequalities.

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## Author Contributions

PB: concept of the study, coordination of the manuscript, writing, and critical revision. SD, SJ, IB, LP: writing and critical revision.

## Data Availability

Data available upon request.

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