



IBD2020

CREATING A FORUM FOR
GREATER QUALITY OF CARE IN IBD



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GREATER QUALITY OF CARE IN IBD

INTRODUCTION

IBD2020 aims to be a global forum for professionals and patients where they can discuss how best to improve the quality of care for patients with inflammatory bowel disease (IBD). This report comes from the initial meeting in Oxford in September 2013, with 55 participants from 18 countries including 15 representatives from national IBD patient organizations. The purpose was to share aspirations, describe different initiatives, learn from each other and seek common ground. IBD2020 is a forum for discussion, not a working group, and the views are those of individuals passionate about improving the quality of care, not a formal representation of IBD organisations.

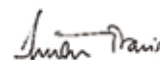
The **motivation** in establishing the forum was to increase awareness of the variation in the quality of IBD care and of the various national initiatives that have been developed to address this. The present situation was aptly summarized as:

'There is no question that the current state of quality in IBD is somewhat confusing. There are multiple groups involved in parallel efforts, the reporting systems are not integrated directly into the typical flow of care, and the reimbursement implications are not totally clear.'

The **starting point** was the **IBD2020 Survey** of over 5000 patients with IBD from six countries. The findings identified deficits and variation in key aspects of good quality IBD care. Compared to an earlier (2009) European survey, improvement has been slow. Selected results are included in this report, pending publication of a full analysis.

The **aspirations** for IBD healthcare shared at IBD2020 are included in this report. The Forum enabled an understanding of the different initiatives, exploring the future global context of healthcare within which the IBD professional and patient communities will need to operate. Quality assessment and quality improvement are seen as integral to best practice in IBD care. Examples of good practice and a summary of do's and don'ts for initiating quality improvement were shared at the Forum and are highlighted in this report.

The **next steps** are to refine the Aspirations through the IBD2020 microsite (www.IBD2020.org) and facilitate wider discussion, to allow initiatives to inform each other and to gauge progress in 2014. This will assist countries wishing to embark on quality improvement. We would like to thank all the participants for their contributions and acknowledge the tremendous support from the sponsors of IBD2020, without whom the Survey and the Forum could not have taken place. We need all to work together to raise the floor and to raise the ceiling of IBD Health Care.



Simon Travis, Oxford, UK



Richard Driscoll, London, UK

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LIVING WITH INFLAMMATORY BOWEL DISEASE (IBD)

Imagine that you are at work, attending an important meeting, when you suddenly discover that you have to rush out to find the nearest toilet. You know that you just have about two minutes to find one, or a catastrophe will occur. Phew! Found a toilet just in time. While there, you need to sit for at least 20 minutes. There is blood on the paper and in the toilet. When you are back, the meeting is already over.

You know that you should take the day off and call in sick, but you don't want the employer to find out about your disease - after all, not all days are like this. Sometimes you are almost perfectly fine. Also, you feel quite embarrassed about your condition. You should probably see a doctor more often, but when there are days when you are fine, it feels like it is not necessary.

When you arrive home, you are exhausted. You call your friend and tell her that she can't come over for a visit like you had planned to. Too tired to make dinner, you jump straight into bed. You desperately want to sleep, but know that you will probably spend the night awake in fever and sweats. The feeling of returning from the toilet to a cold, wet bed is all too familiar by now.

This is an account about what a day for a person with inflammatory bowel disease (IBD) can be like.

This is the reality for millions of people suffering from IBD - and the number suffering is growing rapidly.

With this report, we aim to increase the awareness of IBD and the work that the IBD community is doing to turn improved quality of care for IBD patients into improved quality of life.

The report is written by the Swedish consultancy Kairos Future on behalf of the attendees of the IBD2020 Forum held in Oxford on 10-11 September 2013.



IBD AT A GLANCE

FIVE KEY FACTS ABOUT IBD

Millions are affected: IBD is a common condition

IBD stands for Inflammatory Bowel Disease, a group of chronic inflammatory conditions mainly affecting the colon and small intestine. It is estimated that more than 4 million people in Europe and North America alone live with IBD – around 1 in every 240 individuals.^{2,3} The major types of IBD are Crohn's disease and ulcerative colitis.

Economic costs of IBD are high, both for the individual and for society

The economic impact of IBD on the individual is often high, as are the costs incurred by society. Direct care costs have been estimated at around €5 billion annually in Europe and around \$1.7 billion in the US.^{4,5} Indirect costs are even higher. For instance, studies have shown a 3-fold risk of early retirement in 30-49 year olds with Crohn's disease compared to the general population.⁶

IBD has a severe impact on the quality of life of those affected

IBD significantly affects all aspects of patients' lives – education, work and social. For example, a recent international survey found that around half felt their career prospects had been affected negatively, and almost as many said that IBD had hindered them in their personal life and relationships.⁷

Prevalence is set to increase worldwide: IBD is a growing concern

For reasons still not entirely understood, the incidence of IBD seems to increase with urbanization and modernization of societies. Consequently there are now sharp increases of IBD incidence in large parts of the emerging world, as well as continuing increases in the developed world.⁸

IBD is a disease that hits the young generation

Around half of those diagnosed with IBD are under 40 years old, with a peak between the ages of 25-39.¹⁰ Thus IBD hits young people especially hard at a time when they are just about to establish their career and family life, with significant costs to the individual and society.

FIVE KEY FACTS ABOUT IBD TREATMENT

There is no definitive cure: IBD is a chronic condition

While IBD has been recognized as a diagnosis for over 80 years, there is still no known cure to the condition. The condition can only be managed and contained.

Best practice treatment guidelines are often not followed

Several studies have shown frequent failure to observe established clinical guidelines. For instance, over- as well as under-medication has been shown to be commonplace.¹¹ Access to multidisciplinary teams in treatment, identified as a core component in good Quality of Care for IBD, is often lacking.¹²

There are great inconsistencies in care

A high level of unwarranted variation in care is often used as an indicator of low overall quality of care. For IBD, studies have shown high levels of inconsistency in care both within and between countries. This points to a lack of agreement on, and adherence to, best practice of treatment.^{13,14,15,16}

Great improvements can be achieved by relatively easy means

Several recent initiatives have shown that significant improvements in Quality of Care for IBD can be achieved by relatively easy means, as long as there is broad stakeholder support including both patient and professional organisations, and commonly agreed and monitored standards of care.¹⁷

There are great opportunities in the coming years

In the years leading up to 2020 there is great potential to raise both the floor and the ceiling in terms of quality of care in IBD. Across the globe, researchers, caregivers and patients are coming together to establish and build on best practices in IBD care. At the same time, much interesting research is being carried out into new therapy that will potentially revolutionize treatment.^{18,19} Now is a great time to concentrate efforts on IBD, in order to add further momentum to progress already in motion, to improve the quality of life of the millions affected.

THE IBD2020 FORUM: IT'S ALL ABOUT IMPROVING QUALITY OF CARE

“Our aim is to seek common ground and identify differences, so that the territory of quality assessment and improvement in IBD can be defined”

Dr. Simon Travis, IBD2020 Forum

The IBD2020 Forum, held in Oxford 10-11 September 2013, gathered 55 of the world's leading IBD stakeholders for a programme of presentations, discussions and workshops. Represented were clinicians, academia and representatives from patient associations.

Aiming to improve the quality of care for IBD patients worldwide, the objectives of the meeting were to:

- 🌐 Share current examples of **best practice** and **future perspectives** for improving the quality of IBD care
- 🌐 **Define a vision** for global quality of care, incorporating **clinician** and **patient perspectives**
- 🌐 Acknowledge the need for **standards and potential metrics** for changing the healthcare landscape in IBD



- 🌐 Discuss **practical approaches** to enable improvement in the quality of care
- 🌐 Discuss **strategies to ensure that delivering high quality IBD care** becomes a focus in all countries
- 🌐 Gauge the level of interest and engagement for **continuing this initiative**

Hosts for the seminar were **Dr. Simon Travis**, Translational Gastroenterology Unit, Oxford University Hospital and current President of the European Crohn's & Colitis Organisation (www.ecco-ibd.eu) and **Richard Driscoll**, independent healthcare consultant and the former chief executive of an IBD patient organisation.

Sponsors of the event were: AbbVie, Bühlmann, Enterome, Hive, StratX, KPMG, Health Solutions and Veryday. For a full list of participants see Appendix A.

WHAT IS QUALITY OF CARE FROM AN IBD PERSPECTIVE?

There is no single, clear-cut definition of quality of care from an IBD perspective. Inflammatory Bowel Disease is a complex disease and as a consequence, quality of care can be defined from a number of different perspectives.

One general definition of quality of care from the Institute Of Medicine (IOM 1990) reads:

- *The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with professional knowledge*

Another definition (IOM 2001) is summarized in the word STEEEP:

- *Safe, Timely, Effective, Efficient, Equitable, Patient Centered Care*

Elaborating on the subject, Corey A. Siegel, MD, MS, and Associate Professor of Medicine of the Dartmouth Institute for Health Policy and Clinical Practice, presented his own definition at the IBD2020 Forum:

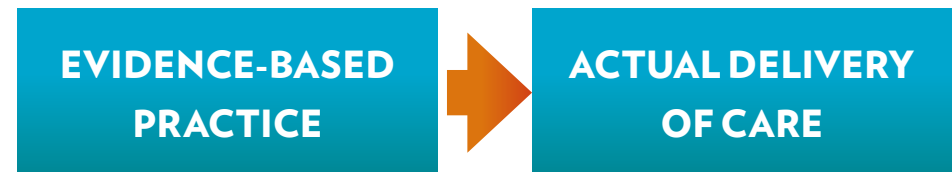


COREY SIEGEL

“Quality of care” is a mechanism to ensure that the best new research and ideas do not get left behind in journals, but get applied equally to all patients”

Corey Siegel, MD, MS

One common approach to gauging quality of care in practice is to examine the degree of consistency in care: if there is a high degree of variation in the care received by patients that cannot be readily explained, this suggests a clear need for translating evidence-based practices into the actual practice and follow-up provided for patients. As pointed out in the section “IBD at a glance”, there is a high degree of variation and inconsistency both within and between countries in IBD care.



The Donabedian framework

Using the often quoted Donabedian Framework, there are three kinds of measures for quality of care in IBD.

- **Process Measures** - use of evidence-based practice
- **Structural Measures** - setting in which the care is delivered (e.g., who, where, how)
- **Outcome Measures** - what happens to patients as a result of the care they receive

Naturally, in the end, the outcome measures are what actually count from a patient perspective.

As became evident during the IBD2020 Forum, the current state of quality of care in IBD leaves much to be desired, regardless of definition.

WHERE DO WE STAND TODAY? PATIENTS' PERSPECTIVES ON THE QUALITY OF CARE

In a new survey of over 5000 IBD patients from 6 countries, carried out by Kairos Future, patients reported on the quality of their IBD care.

In June-August 2013, the Swedish consultancy company Kairos Future carried out a survey of 5003 patients in association with national patient associations from the UK, Canada, Spain, Italy, France and Sweden, with the aim of capturing the IBD patients' perspective on quality of care.

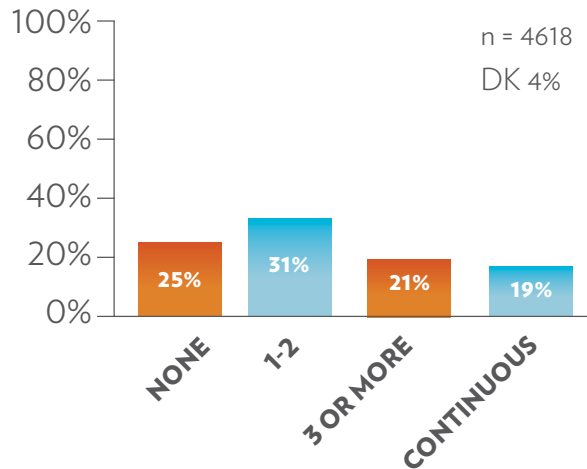
One out of five responding patients state that their flare-ups have been “continuous” in the last 12 months.

During the same period, more than one out of three respondents have been absent from work for more than five days due to IBD.

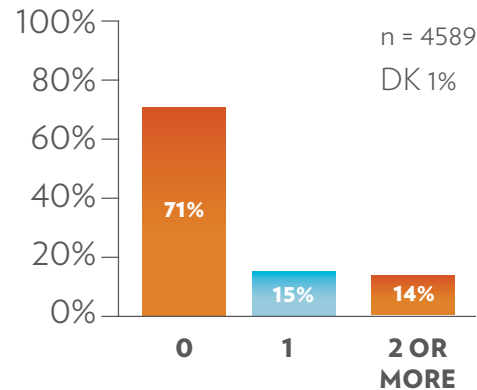
About three out of ten have had emergency admissions in the last 12 months.

For more about the profile of patients answering the survey, see Appendix B.

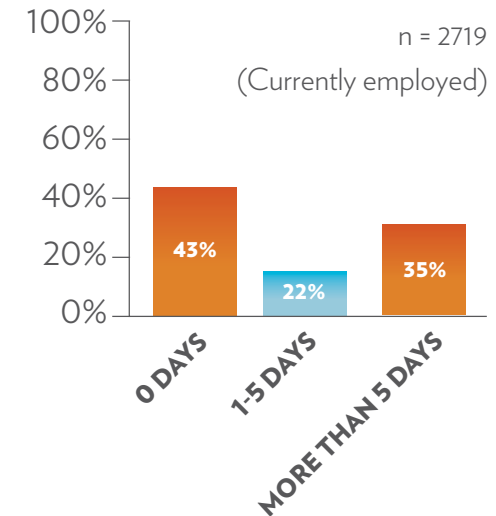
FLARE UP LAST 12 MONTHS



EMERGENCY ADMISSIONS LAST 12 MONTHS



ABSENCE FROM WORK LAST 12 M DUE TO IBD



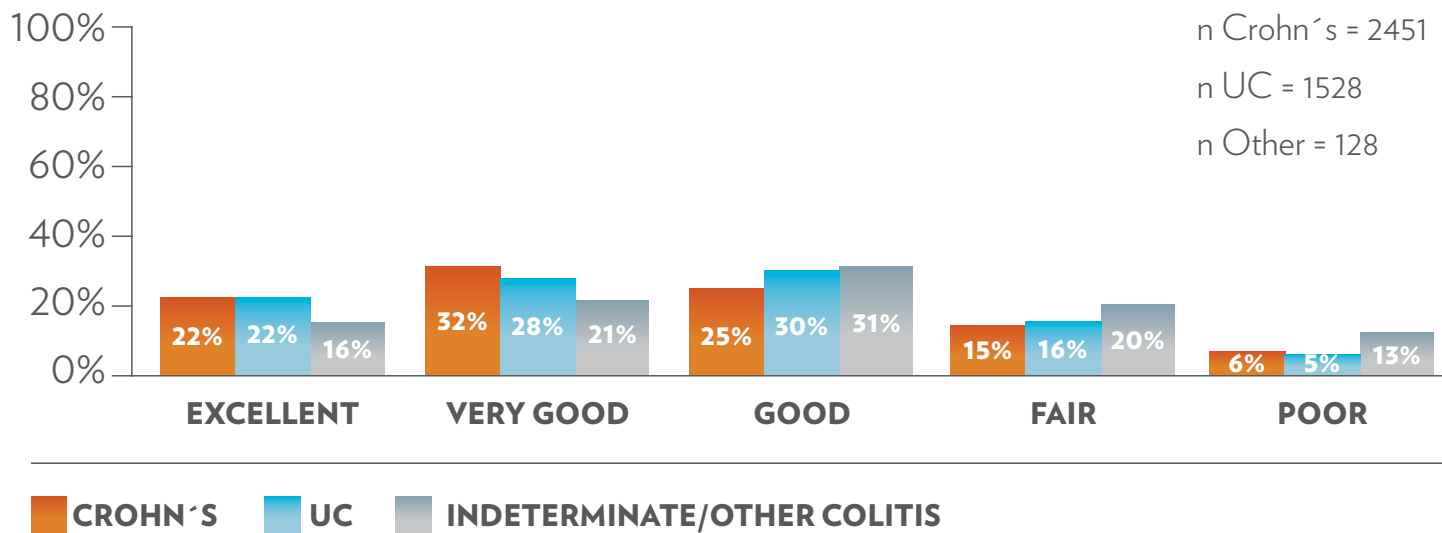
DK=Don't know

The pattern and impact of disease among responding patients.

Patients are often satisfied with the overall quality of IBD care

Around half of the patients surveyed state that the overall quality of the IBD care they receive is either “very good” or “excellent”, but this is not measured against published standards of care. A look at the answers to specific questions shows several important areas where the quality of care needs to be improved.

OVERALL, HOW DO YOU RATE THE QUALITY OF THE IBD CARE THAT YOU HAVE RECEIVED IN THE PAST 12 MONTHS

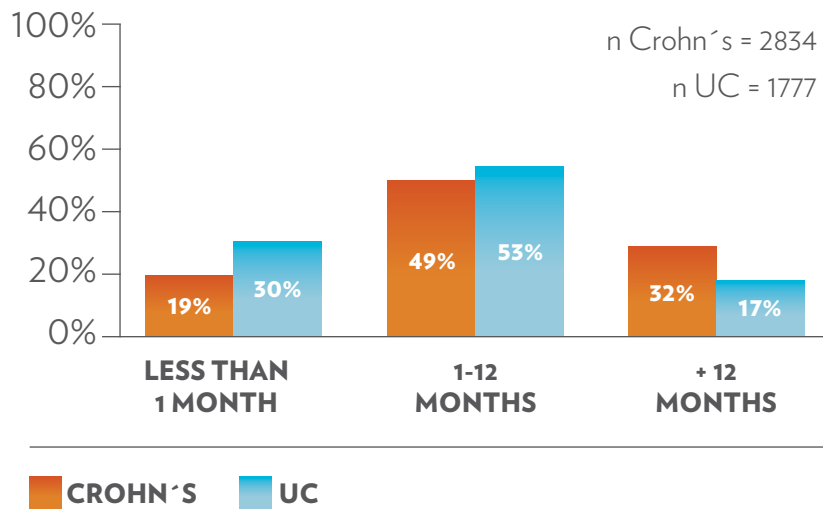


Around half of respondents in the survey state that the quality of care is either “very good” or “excellent”.

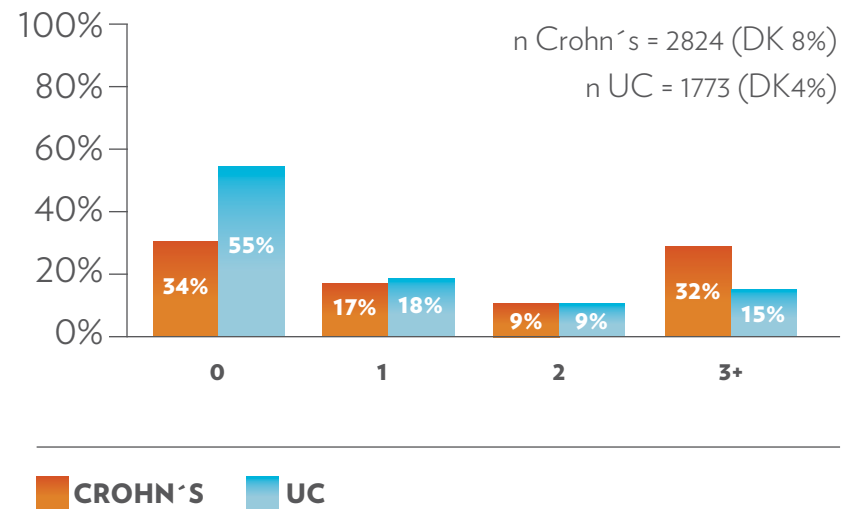
Long waiting times for diagnosis

Around one in four patients diagnosed with IBD have had to wait over a year from the time of seeking care for symptoms to receive a final diagnosis. For Crohn's disease this figure is even higher, with a third of respondents saying that it took over a year from seeking care for IBD symptoms before receiving a final diagnosis. It is also very common for patients to have multiple visits to the emergency department due to IBD symptoms before receiving a diagnosis.

TIME FROM SEEKING CARE TO DIAGNOSIS



EMERGENCY VISITS BEFORE DIAGNOSIS

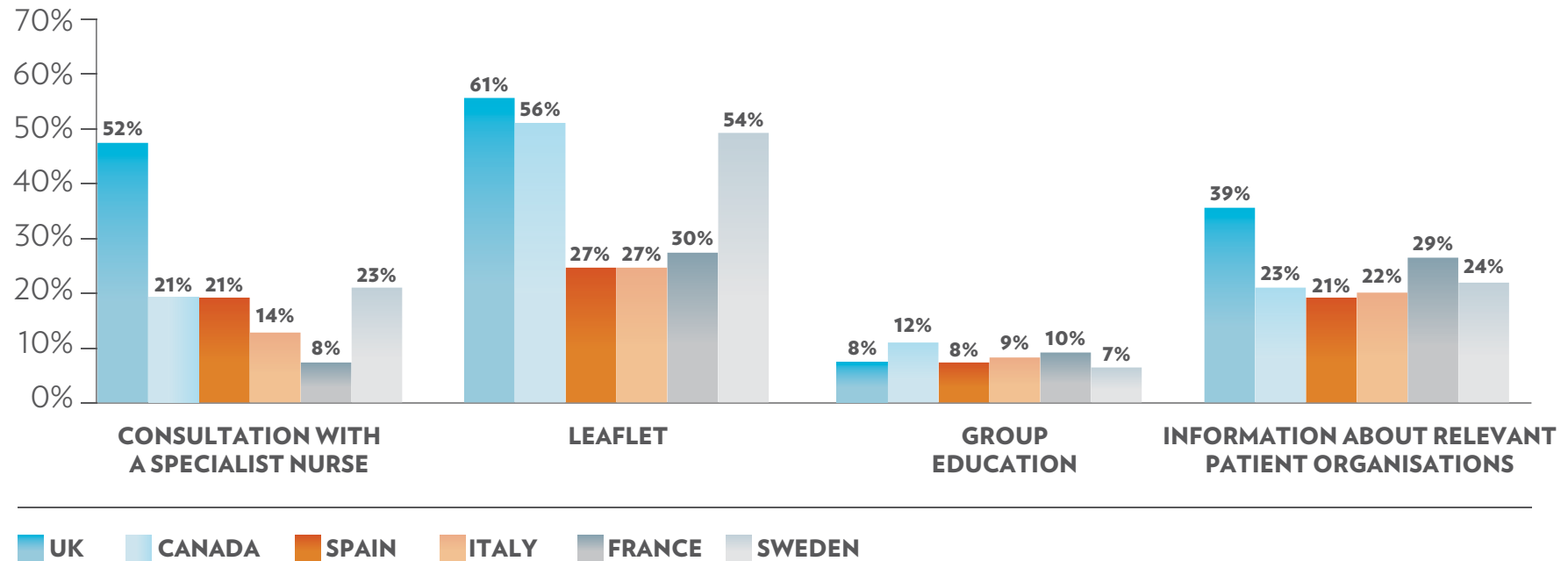


For IBD patients there are long waits for diagnosis.

Patients are often not provided with basic information after diagnosis

It is common for patients to be left with too little or even no information about their disease after receiving their diagnosis. For instance, in most countries, not even half of the patients state that they have received a consultation with a specialist nurse, group education, information about relevant patient organizations, or even information in the form of leaflets/brochures within 12 months of getting their diagnosis.

OFFERED WITHIN 12 MONTHS OF DIAGNOSIS, BY COUNTRY



After diagnosis, many patients with IBD are not offered information, education, or specialist nurse consultation within 12 months.







Aims of care/treatments rarely discussed







Results from the patient survey also show that there is not much discussion between patients and their health care professionals about the main objectives of their care and treatments. There are differences between countries and a majority

of patients state that they have not discussed these with their health care professional. Fewer than one out of every four patients state that a health care professional has helped them make a plan that they could carry out in their daily life.

THE AIMS OF CARE/TREATMENT RARELY DISCUSSED

Q: DURING THE PAST 12 MONTHS WHEN YOU RECEIVED CARE, HAS ANY HEALTH CARE PROFESSIONAL YOU SEE FOR YOUR IBD...

			CAN	FRA	ITA	ESP	SWE	UK
	RESPONSE	AVG.						
...DISCUSSED WITH YOU MAIN GOALS OR PRIORITIES IN CARING FOR YOUR CONDITION(S)?	Yes	44%	50%	63%	51%	38%	25%	39%
	No	50%	45%	33%	43%	56%	67%	55%
	Don't know/remember	6%	5%	5%	5%	7%	8%	6%

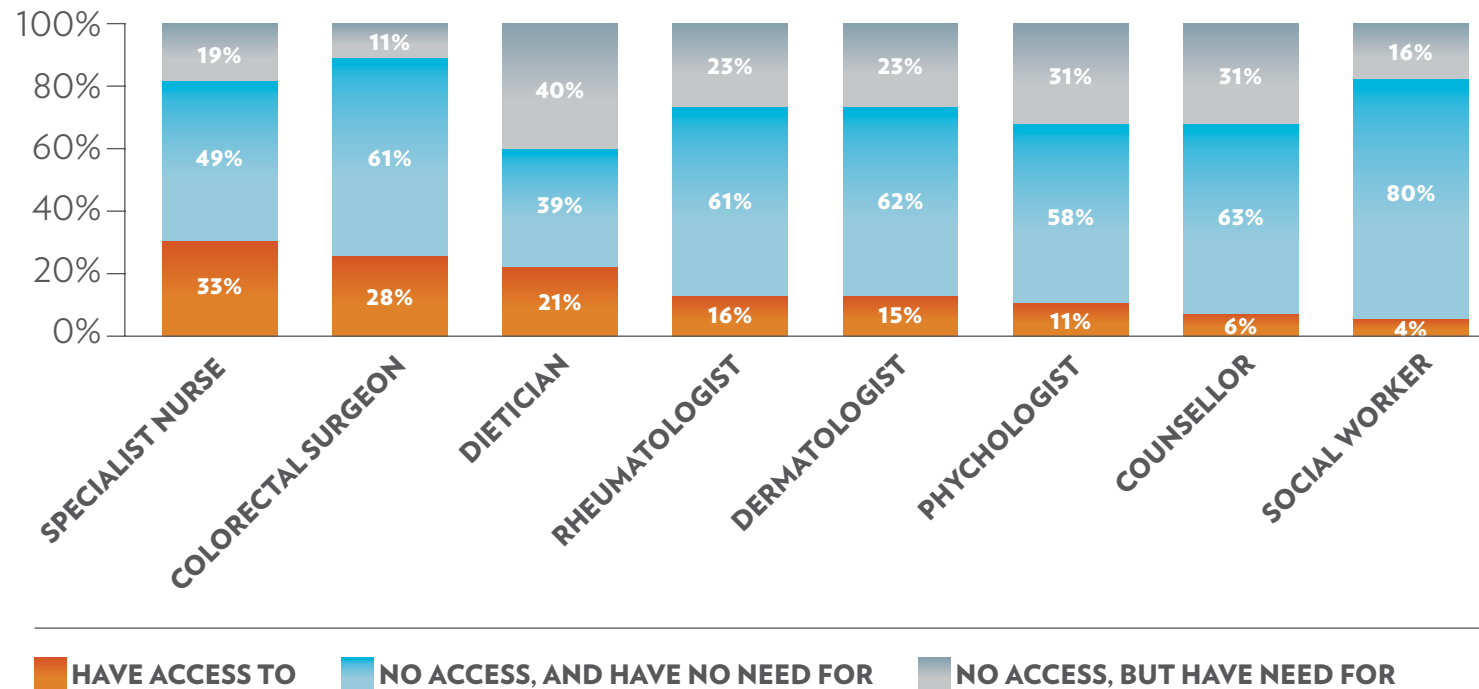
			CAN	FRA	ITA	ESP	SWE	UK
	RESPONSE	AVG.						
...HELPED YOU MAKE A PLAN THAT YOU COULD CARRY OUT IN YOUR DAILY LIFE?	Yes	22%	25%	20%	38%	17%	15%	15%
	No	72%	69%	73%	55%	78%	76%	80%
	Don't know/remember	7%	7%	7%	7%	5%	9%	5%

Aims of IBD care are rarely discussed, according to responding patients.

Lack of access to multidisciplinary teams

A key component of high quality care for IBD is access to multidisciplinary teams, but this is often lacking in practice. For instance, 40% of respondents say that they are in need of access to a dietician, but do not have such access today. Almost one in three report an unmet need for access to a psychologist.

ACCESS TO PROFESSIONALS FOR TREATMENT OF IBD



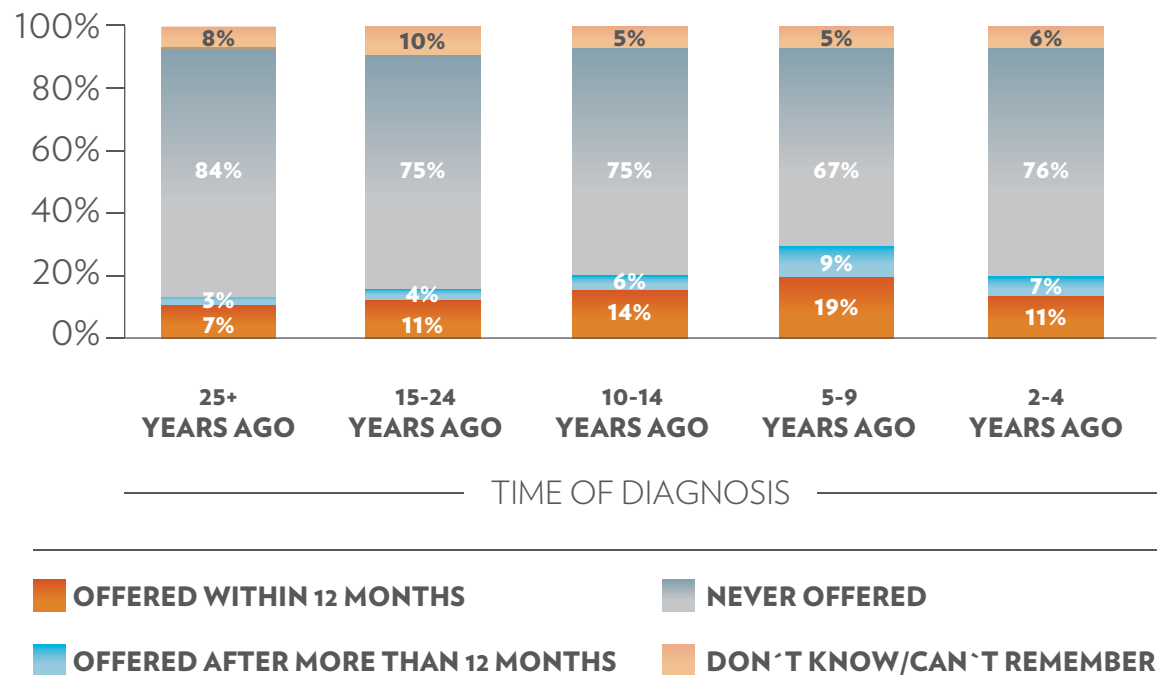
Many patients who have IBD lack access to multidisciplinary teams.

Best practices of care are not applied

A clear example of best practice not being applied is that the vast majority of respondents with Crohn's disease who are currently smokers have never been offered a smoking cessation programme after diagnosis - something that is widely recognised to benefit patients suffering from the disease.

The results from the survey show that even though patients state that they are satisfied with the quality of IBD care, there is certainly room for improvement. Patients may be knowledgeable about their own condition, but are often not aware of what quality of care they should have the right to expect. When analysed by years of diagnosis, the survey results also showed that for most aspects of care there has been quite marginal improvement over time.

OFFERED AFTER DIAGNOSIS: SMOKING CESSATION PROGRAMME (CROHN'S DISEASE, CURRENT SMOKERS)



The majority of patients with Crohn's disease answering the survey who are current smokers have never been offered a smoking cessation programme.

SHARING BEST PRACTICE: INITIATIVES FOR IMPROVED QUALITY OF CARE

In country after country, the current deficiencies in IBD care are starting to be recognized. As a consequence, researchers, caregivers and patients across the globe are seeking ways of establishing and building on best practices in IBD care. At the IBD2020 conference, clinicians, academics and representatives from patient associations came together to share their experiences and highlight ongoing initiatives, as summarized below.

Lessons from the US: AGA experience and Physician Quality Reporting System (PQRS)

In his message, Ashish Atreja, MD, MPH, FACP from Icahn School of Medicine at Mount Sinai, New York, described the Bridges To Excellence program for IBD care recognition.

USA: The Bridges to Excellence Initiative

The initiative in brief: The American Gastroenterological Association is working together with the Health Care Incentives Improvement Institute to establish care performance standards for IBD and reward adherence to best practice.

Project aims: The initiative aims to address issues of variability in care, such as inconsistent guidelines, disconnected systems, and unclear incentives through establishing performance standards in IBD care, and also to put in place clear monetary incentives for clinicians to adhere to and to measure and report against these standards. The accreditation also demonstrates quality to patients.

Moving forward: An App will be developed with a pragmatic randomised controlled trial in 2014, rolled out 2015, with the aim of integration with other initiatives.

Conference speaker: Ashish Atreja, MD, MPH, FACP, Icahn School of Medicine at Mount Sinai, New York.

Web link:
http://www.hci3.org/recognition_programs/IBD_Care_Recognition



The CCFA experience: Process and outcome measures

Gil Y. Melmed, MD, MS and Co-Chairman of the CCFA (Crohn's & Colitis Foundation of America) Quality of Care Committee stressed in his address that before quality can be improved, it must be defined and measured.

USA: Defining, Implementing and Measuring Quality of Care in IBD

The initiative in brief: The Crohn's and Colitis Foundation of America is working together with an interdisciplinary panel of stakeholders to define standards of care for IBD and develop an implementation programme to measure and deliver this care.

Project aims: The aim of the initiative is to define standards of care for IBD, develop an implementation program to measure and deliver this care, continuously evaluate and refine this process, and to measure and improve the impact on patient outcomes.

Moving forward: The next step is to conclude and evaluate the results from pilot testing. Long-term goal is widespread implementation of the agreed standards based on demonstration of improved outcomes.

Conference speaker: Gil Y. Melmed, MD, MS, Associate Professor of Medicine, Director, Clinical Inflammatory Bowel Disease, Cedars-Sinai Medical Center, Los Angeles, CA. Co-Chair, CCFA Quality of Care Committee.



Web link: http://journals.lww.com/ibdjournal/Abstract/2013/03000/Quality_Indicators_for_Inflammatory_Bowel_Disease_.25.aspx

IBD Network: Improve Care Now

In his presentation, Michael D. Kappelman of University of North Carolina at Chapel Hill shared his experience from the ImproveCareNow network.

USA: The ImproveCareNow Initiative

The initiative in brief: The American Board of Pediatrics is working within the ImproveCareNow network to establish a sustainable collaborative network where patients, families, clinicians and researchers work together in a learning health care system.

Project aims: The aim of the initiative is to transform health, care and costs for all children and adolescents with IBD by building a learning health care system, defined as a system that generates and applies the best evidence for the collaborative choices of each patient and provider, drives the process of discovery as a natural outgrowth of patient care, and ensures innovation, quality, safety and value in health care.

Moving forward: The future aim is to include more centres in the network and add more patients to the registry, in order to better promote the project aims. A key goal of the project is that by 2020, 90% of clinical decisions will reflect best evidence.

Conference speaker: Michael D. Kappelman, University of North Carolina at Chapel Hill.



Web link: <https://improvecarenow.org/>

The Canadian experience: The Practice Audit Tool

Paul Sinclair from INSINC Consulting Inc., Canada, shared his experience working with Practice Audit. Practice Audit is a web-based platform that enables physicians to share data for peer comparison.

Canada: Practice Audit Platform

The initiative in brief: Together with The Canadian Association of Gastroenterology, Paul Sinclair of INSINC Consulting Inc. has developed a Practice Audit Tool, a web-based platform that enables physicians to share data for peer review. The platform can be accessed from anywhere, at any time, and on any device, and may be used as a research tool.

Project aims: The aim of the initiative is to facilitate learning for physicians and to improve the quality of patient care.

Moving forward: The next step is to assess what change in physicians' practice the tool leads to.

Conference speaker: Paul Sinclair, INSINC Consulting Inc.

Web links: http://www.cag-acg.org/uploads/quality/quality_in_gastroenterology_endoscopy_brochure.pdf

<http://www.ncbi.nlm.nih.gov/pubmed/21258663>



PAUL SINCLAIR

European perspective: the UK IBD audits 2006-2013

In a presentation on behalf of Dr. Ian Arnott, Richard Driscoll gave a perspective from the UK, describing the work of the UK IBD Audits 2006-2013.

UK: The UK IBD Audit and Quality Improvement Programme 2006-2013

The initiative in brief: The UK Inflammatory Bowel Disease (IBD) Audit began in 2006 and has been repeated every two years, demonstrating significant variation in care and improvement in the later audits measured against national standards. Alongside the Audit is a Quality Improvement initiative using a web-based self-assessment programme and good practice resource, supported by regional meetings. The programme has been government funded from 2009-2014.

Project aims: The stated objective of the UK IBD Programme is to improve the quality and safety of care for IBD patients throughout the UK, by involving professional groups and patients in a national audit of individual patient care and of service resources and organisation in all hospitals.

Moving forward: Sustainability will be a major issue moving forward unless government funding continues. Key challenges are the extra work for staff to collect the data for the Audit and the risk of audit fatigue - 'what's new?'

Conference speaker: Richard Driscoll, on behalf of Dr. Ian Arnott

Web link: <http://www.rcplondon.ac.uk/projects/ibdaudit>



RICHARD DRISCOLL

IMPLEMENTATION: STEPS IN REAL LIFE

In the Forum, speakers from South Korea, Sweden, Denmark and Canada shared their hands-on experience of implementation – steps in real life to deliver higher quality IBD care:

Systematic data collection

Professor Suk-Kyun Yang, PhD MD, described the systematic data collection process for the Asan IBD registry, at Asan Medical Center, Seoul, South Korea.

Korea: Systematic data collection

The work in brief: New outpatients at the Asan Medical Centre generate data by going through a process of filling in an electronic questionnaire, a preliminary interview, consultation with a physician, general education on IBD and education on diet/nutrition. Returning patients enter data about their symptoms to the Asan IBD registry themselves, using a computer or a smartphone.

Conference speaker: Suk-Kyun Yang, MD, IBD Center & Dept. of Gastroenterology, Univ. of Ulsan & Asan Medical Center, South Korea.



Registries: Resolving the Angst, Relieving the Agony

In his message to the seminar, Henrik Hjortswang presented the work of the IBD Registry at the University Hospital of Linköping, Sweden.

Sweden: Registries: resolving the angst, relieving the agony

The work in brief: SWIBREG, the organization for the Swedish national IBD registry works with IBD Care - the IT programme used to register IBD patients. There are four applications for IBD Care: Planning IBD health care, Medical decision support in clinical practice, Quality assurance and benchmarking and Research and learning.

Conference speaker: Henrik Hjortswang, MD, PhD, Dept. of Gastroenterology and Hepatology, University Hospital, Linköping, Sweden.



Involving patients in Managing their Care

Pia Munkholm, Professor of Clinical Epidemiology, demonstrated examples of web-based innovations involving patients and their clinical care from Denmark.

Denmark: Involving patients in managing their care

The work in brief: Patients who have IBD can enter information regarding the current status of their disease on the web page or using the ConstantCare application available for iPad and smartphone. Based on the algorithm CC Technology empowers patients to continue medication, increase medication or contact a physician.

Conference speaker: Pia Munkholm, Professor of Clinical Epidemiology, Copenhagen University.



What is the Framework for Perfect Care

What is the framework for perfect care in IBD? Alain Bitton, MD, FRCP(C) presented his experience from McGill University Health Centre in Canada (MUHC), working with KPMG Healthcare to re-design patient pathways.

Canada: What is the Framework for "Perfect Care" in IBD?

The work in brief: Inspired by the UK IBD National Service Standards, an IBD Centre was set up - not without challenges in terms of the low priority of IBD in their Institution as well as the need for increased resources and costs. The strategy adopted was to establish IBD as an institutional priority through a sound financial and operational model, linked to quality indicators.

Conference speaker: Alain Bitton, MD, FRCP(C), McGill University Health Centre, Canada.



ARE YOU READY FOR THE FUTURE?

Transformation of systems of care is driven by demographic, technological and economic forces. We are more and more talking about Big Data, health genomics, integrated health everywhere, new business models, empowered consumers.



ARE YOU READY FOR THE FUTURE?

At IBD2020, Mats Olsson, futurist and Director of Health & Healthcare at Kairos Future, reflected on the broader development of the healthcare arena towards 2020:

‘Transformation of systems of care is driven by demographic, technological and economic forces. We are more and more talking about Big Data, health genomics, integrated health everywhere, new business models, empowered consumers.

One aspect of this transformation is care delivery: buyers of care expect greater value, improved quality and better outcomes – at a more affordable cost. Another aspect is an increased focus on the individual based on more data. A third aspect is the business model convergence: the increasing demand for healthcare and social services that is driving the formation of new partnerships.

When summarizing the future healthcare market there are two universal driving forces: Health Outcomes and Behavioural Change, which mean value creation and co-production.

HEALTH OUTCOMES - WHERE WILL HEALTHCARE BE IN 2020?

More or less all countries in the world are now focusing very much on value creation in healthcare based on more data. And the general request from buyers is: show me the evidence.

One example: The rules governing reimbursement and market access for new products are changing around the world. Existing treatments are under additional scrutiny and are being withdrawn where benefits are not

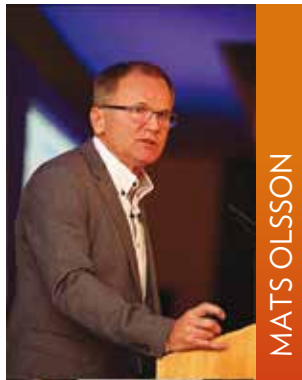
considered significant. In France there is much talk about the importance of real world data. In Italy decision-making includes a wide range of new measures. In Spain economic pressure makes economic data for pharmaceuticals a critical consideration. In Canada the focus of health care reform has the title Better health, better care, better value for all. And in UK they are now changing to Value Based Pricing.

In the UK alone it has been estimated that over the next five to ten years there is going to be a deficit of around £30 billion in the cost of providing health care. Something different has to be done to find new ways of creating better value for patients in healthcare. A model that stands out and suggests a new way forward is to get the patient – the customer – to do a lot more for themselves.

BEHAVIOURAL CHANGE - WHERE WILL HEALTHCARE BE IN 2020?

Micro sensors in your shoes can compile data on where you go and what you do. Your workout clothes can track your daily progress at the gym and tell you when to slow down or speed up. The pill you swallow reports back on the state of your digestion, vital signs, and overall well-being. And as you sleep, a headband monitors your REM patterns. A far-fetched sci-fi fantasy? Not at all. It’s merely a glimpse into what might be possible through a movement called “The Quantified Self,” which is part of the wider transformation being driven by the Internet of Everything (IoE).

Besides Health Outcomes, behavioural change linked to co-production is the second universal driving force. In this case we are talking very much about patient empowerment - individuals taking the initiative, solving problems and making decisions in different settings in health and social care - and self management. Empowerment is not about trying to wrest power from the doctors, it is essentially about helping people lead more proactive and fulfilling lives



The Internet of Everything, after all, is about connecting people, processes, data, and things in fascinating new ways. The whole point of IoE is to transform the ways in which we collaborate and innovate while arming us with unprecedented real-time insights and awareness about our environments, our workplaces, ourselves. If we can create an environment in the health service in which data and information can flow freely, it will improve the quality of patient care because it will give doctors, clinicians and patients the tools they need to measure the quality of care in their environment. It also gives patients the opportunity to make more decisions themselves, which is of benefit to people with long-term conditions who may want to take more control of their own care, but also to people who want to look after their health and well being, and avoid interaction with the health services altogether.



MOVING FORWARD

ASPIRATIONS FOR IMPROVED QUALITY OF CARE IN IBD

This report shows that there is real, global momentum for improving the quality of care in IBD. The challenge now is to build on this momentum to translate aspirations and initiatives into real value for patients.

IBD2020 is a forum for discussion across the world, so that the drivers of individual initiatives can meet, discuss and learn from each other. As an inspiration and common reference for the work ahead, those at IBD2020 agreed to develop a set of shared aspirations, designed to focus the thoughts of the IBD community on better quality of care. The text given on this page was produced at the meeting and will be further refined by participants and a final version published on the IBD2020 website.

1. All patients who have IBD should receive a specialist opinion on their disease severity and likely prognosis. This should inform evidence-based clinical management, with the goal of treatment being long-term steroid-free remission. Objective measures of disease activity should be evaluated regularly, with treatment adjusted to maintain remission, control the underlying inflammation and prevent disease progression or complications.

2. Patients who have IBD should have access to a recognised IBD multidisciplinary team, including specialist nurses, either directly or through an established clinical network relationship to ensure they can benefit from the full range of specialist expertise necessary to provide them with optimal care, taking into account their physical, emotional and social well-being.

3. Patients should have access to all the therapeutic options recommended in current IBD guidelines including medications,

colorectal surgeons, specialists in other conditions often associated with IBD, dietetic advice and professional psychological support.

4. Primary care providers should have sufficient training in IBD both to recognise when symptoms suggest a diagnosis of IBD is possible - referring such patients for specialist investigation without delay - and, after diagnosis, to manage the general health needs of the patient in collaboration with their IBD specialist.

5. All patients who have IBD should have opportunities to become more knowledgeable about their disease and the various treatments and professional support available to them, so that they understand the goals, risks and benefits of treatments and can, if they wish, become more actively involved in the clinical management of their IBD.

6. All patients who have IBD should have the opportunity for regular specialist review of their condition to ensure they are receiving optimal care. Consultations should include both explanation of clinical priorities and listening to the patient's priorities before outlining choices,

discussing and agreeing decisions with the patient. Patients should be informed about research for which they might be eligible and enabled to participate if they wish to do so.

7. Health professionals and healthcare administrations should recognise the value of patient associations for their role in supporting and representing all those affected by IBD and they should actively support their work. All patients should be informed about the IBD patient organisations available to them.

8. Government and healthcare administrations should ensure that care for patients who have IBD is appropriately resourced so that patients can receive the best possible quality of care and that systems are in place to monitor the quality of care offered by each provider against agreed clinical standards and guidelines. They should support research into the causes and impact of IBD.

PATHS TO IMPROVED QUALITY OF CARE BY 2020

Considering the future health care arena, the current work on improving quality of IBD care and the outcomes of the workshops on IBD2020, there are five paths towards 2020.

Patient involvement is essential

The participants at IBD2020 emphasised that the overall aim is to improve quality of IBD care and turn it into improved quality of life for patients who have IBD. Patients and patient organizations must play a key part in the work to improve quality of care towards 2020.

From separate units to networks – collaboration is essential

The health care arena is transforming into a large network, where a key ability for organizations is to be able to collaborate with others. Networking and collaboration are essential.

Steal shamelessly and share seamlessly

As Michael Kappelman elegantly stated during the IBD2020 meeting, a general principle should be to “steal shamelessly and share seamlessly”. This means that the IBD community must be transparent and willing to share their experiences in order to develop best practice.

Defining quality measures and improving data quality

A key challenge for improving IBD quality of care is to define quality indicators for which data can be collected, which is currently being explored by separate projects in various countries. As data become easier to collect, there is a greater need to evaluate and improve the quality of the data and to coordinate quality improvement programmes.

Incremental development – the way forward

The perfect framework for improving quality will not immediately be established. The important step is to get started.

TRANSLATING ASPIRATIONS INTO IMPROVED QUALITY OF CARE

Richard Driscoll pointed out at IBD2020 that there is no single solution or blueprint on how to achieve improved quality of IBD care. However, he presented some key messages based on his experience, summarized into three categories:

Patient and professional engagement

- Formally involve patient and professional organizations if you can
- Ensure everyone understands the overall principle is what is best for patients
- Patient leadership can be very powerful
- A professional and patient partnership can make change happen

Vision, passion and pragmatism:

- You need a philosophy of IBD care – a set of aspirations

- You need passionate champions for the cause – professionals and patients
- Identify achievable early objectives
- Think about the battles you want to avoid
- Train for a marathon not a sprint.

Learn from others and create a collaborative:

- Don't reinvent the wheel, learn from others' experiences
- Go for a refresher in change management theory
- Look for the drivers in your healthcare system that will support Quality Improvement
- Find your champions and partners – inside IBD and from outside IBD
- Create a mutual support group – a team

Summarizing the spirit of the IBD2020 Forum, Richard Driscoll finished with the words: **United we can make a difference.**

In the final session of the meeting, participants met in small groups to review and plan the next steps for quality improvement in IBD care in their countries.

APPENDIX A

LIST OF PARTICIPANTS, IBD2020



Participants at IBD2020 reviewing the aspirations and planning next steps for quality improvement in IBD care.

FIRST NAME	SURNAME	REPRESENTATIVE TYPE
Ashish	Atreja	Gastroenterologist, USA
Luisa	Avedano	Representing EFCCA (European Federation of Crohn's and Ulcerative Colitis Associations)
Laurent	Beaugerie	Gastroenterologist, France
Willem	Bemelman	Gastrointestinal Surgeon, The Netherlands
Alain	Bitton	Gastroenterologist, Canada
Bernd	Bokemeyer	Gastroenterologist, Germany
Xavier	Calvet	Gastroenterologist, Spain
Jean-Frédéric	Colombel	Gastroenterologist, USA
Silvija	Čuković-Čavka	Gastroenterologist, Croatia
Silvio	Danese	Gastroenterologist, Italy
Marc	Derieppe	Representing AFA (Association Française Aupetit), France
Richard	Driscoll	Independent Healthcare Consultant, UK
Michael	Eberhardson	Gastroenterologist, Sweden
Rick	Geswell	Representing CCFA (Crohn's and Colitis Foundation of America), USA
Subrata	Ghosh	Gastroenterologist, Canada
Kevin	Glasgow	Representing CCFC (Crohn's and Colitis Foundation of Canada), Canada
Marco	Greco	Representing EFCCA (European Federation of Crohn's and Ulcerative Colitis Associations)
Ann	Griffith	Paediatric Gastroenterologist, Canada
Wictoria	Hånell	Representing RMT (Riksfoerbundet foer Mag- och Tarmsjuka), Sweden

FIRST NAME	SURNAME	REPRESENTATIVE TYPE
Toshifumi	Hibi	Gastroenterologist, Japan
Henrik	Hjortswang	Gastroenterologist, Sweden
Daan	Hommes	Gastroenterologist, USA
Peter	Irving	Gastroenterologist, UK
Michael	Kamm	Gastroenterologist, Australia
Michael	Kappelman	Gastroenterologist, USA
Karen	Kemp	Nurse Specialist, UK
Wolfgang	Kruis	Gastroenterologist, Germany
Salvatore	Leone	Representing AMICI (AMICI Onlus, Associazione Nazionale per le Malattie Infiammatorie Croniche dell'Intestino), Italy
Bjorn	Ljung	Kairos Future, Sweden
Francesca	Manglaviti	Representing CCA (Crohn's & Colitis Australia), Australia
Makis	Mantzaris	Gastroenterologist, Greece
Patricia	McArdle	Representing ISCC (Irish Society for Colitis and Crohn's disease), Ireland
Gil	Melmed	Gastroenterologist, USA
Marjorie	Merrick	Representing CCFA (Crohn's and Colitis Foundation of America), USA
Pia	Munkholm	Gastroenterologist, Denmark
Mats	Olsson	Kairos Future, Sweden
Colm	O'Morain	Gastroenterologist, Ireland
Remo	Panacione	Gastroenterologist, Canada
Laurent	Peyrin Biroulet	Gastroenterologist, France

FIRST NAME	SURNAME	REPRESENTATIVE TYPE
Frank	Rüemmele	Paediatric Gastroenterologist, France
Magdalena	Sajak	Representing J-Elita (Polskie Towarzystwo Wspierania Osób z Nieswoistymi Zapaleniami Jelita), Poland
Alejandro K	Samhan Arias	Representing ACCU (Confederación de asociaciones de enfermos de Crohn y Colitis Ulcerosa de España), Spain
Iva	Savanovic	Representing HUCUK, (Hrvatsko udruzenje za Crohnovu bolest i ulcerozni colitis), Croatia
Stefan	Schreiber	Gastroenterologist, Germany
Corey	Siegel	Gastroenterologist, USA
Paul	Sinclair	Executive Director, Canada
Antonino	Spinelli	Gastrointestinal Surgeon, Italy
Andreas	Stallmach	Gastroenterologist, Germany
Helen	Terry	Representing CCUK (Crohn's and Colitis UK), UK
Simon	Travis	Gastroenterologist, UK
Kenji	Watanabe	Gastroenterologist, Japan
Christine	Witte	Representing DCCV (Deutsche Morbus Crohn/Colitis Ulcerosa Vereinigung), Germany
Jesús Kazuo	Yamamoto Furusho	Gastroenterologist, Mexico
Suk-Kyun	Yang	Gastroenterologist, Korea

APPENDIX B

SURVEY: RESPONDING PATIENTS' PROFILE

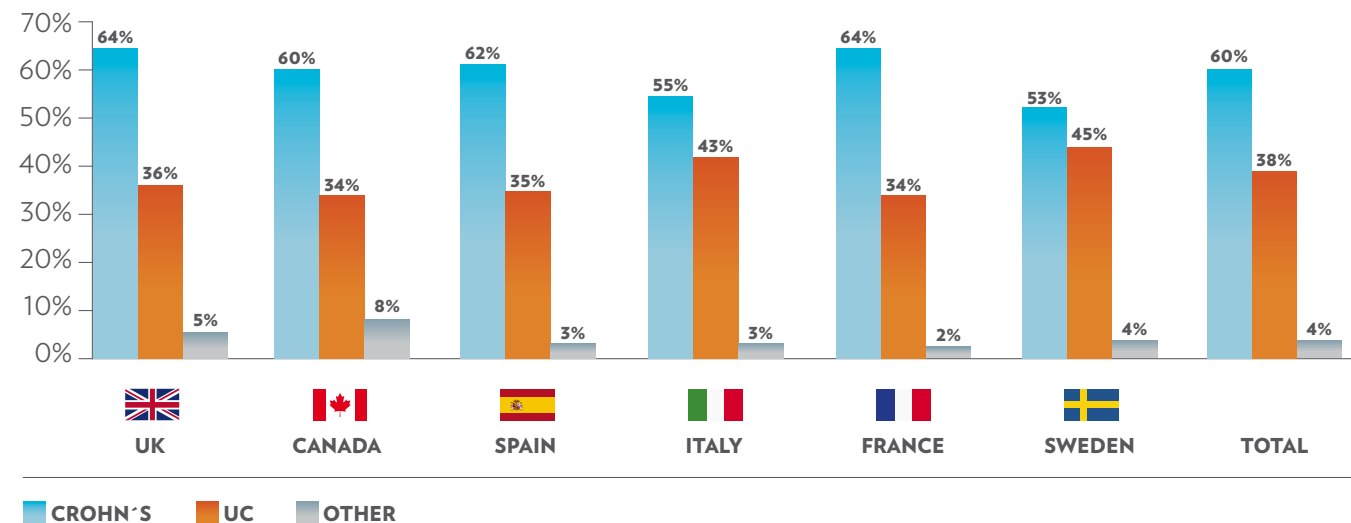
Key demographics of responding patients

DEMOGRAPHICS

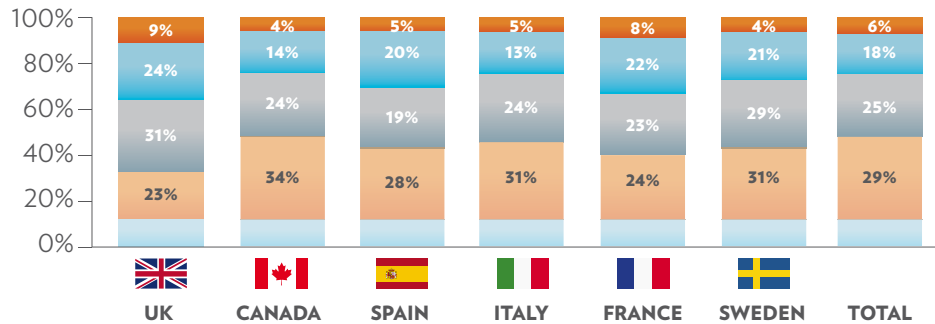
	CROHN'S (60%, n=2880)	ULCERATIVE COLITIS (38%, n=1814)	INDETERMINATE/OTHER COLITIS (3%, n=162)
GENDER	31%/69% M/F	37%/63% M/F	22%/78% M/F
AVERAGE AGE	40	42	44
MEDIAN TIMES SINCE DIAGNOSIS	10 YEARS	8 YEARS	6 YEARS
ABDOMINAL SURGERY	52%	16%	13%
CURRENT SMOKER	21%	10%	20%

Diagnosis of responding patients by country

DIAGNOSIS BY COUNTRY



PATIENT REPORTED SEVERITY



- **SEVERELY ACTIVE** (ADMITTED TO HOSPITAL)
- **MODERATELY ACTIVE** (EXTENSIVE INTERFERENCE WITH MAIN OCCUPATION OR RECREATION)
- **MILDLY ACTIVE** (SOME INTERFERENCE WITH MAIN OCCUPATION OR RECREATION)
- **MINIMALLY ACTIVE** (SYMPTOMS NOT INTERFERING WITH MAIN OCCUPATION OR RECREATION)
- **REMISSION** (NO SYMPTOMS, NORMAL BOWEL PATTERN)

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