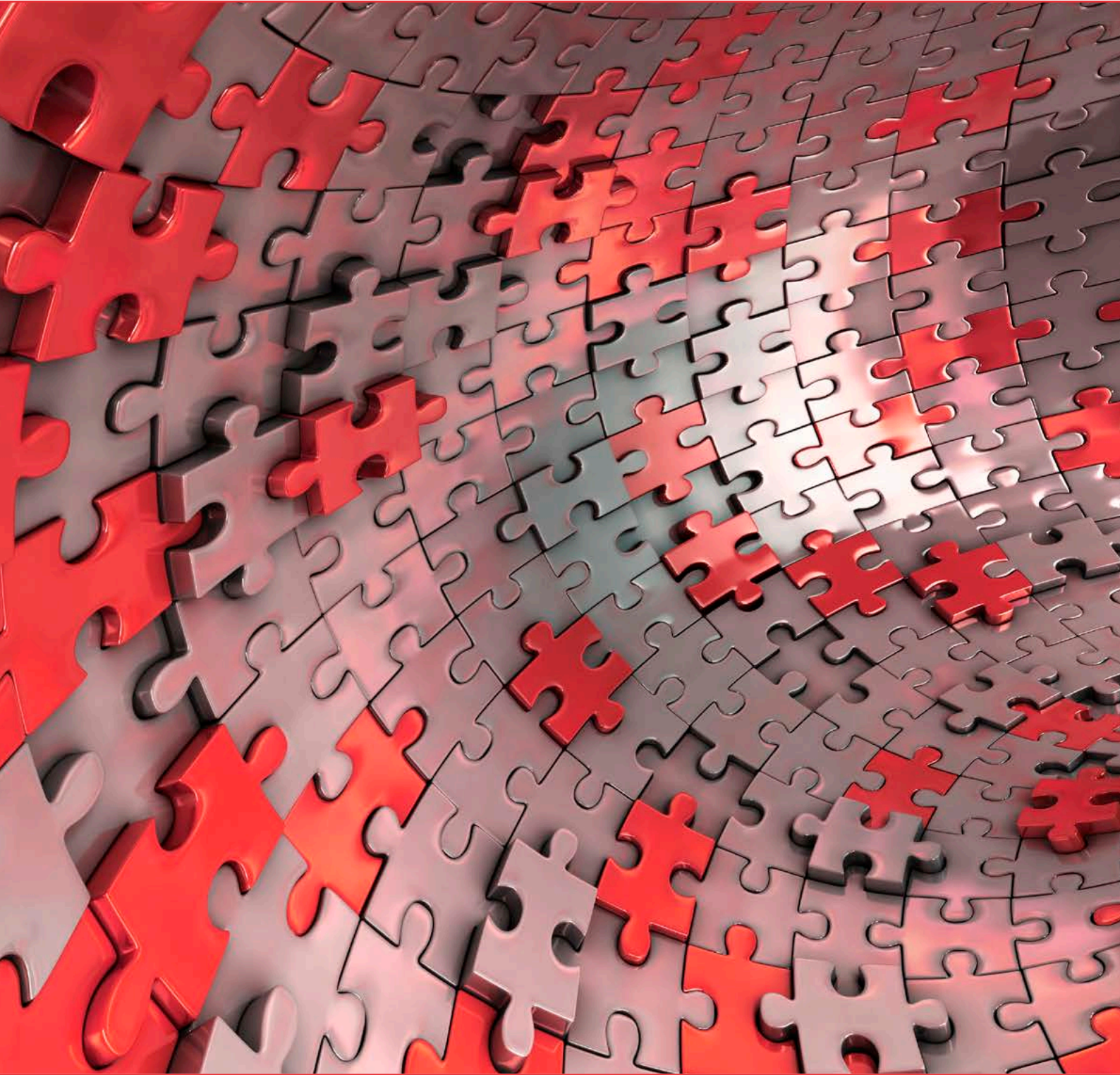
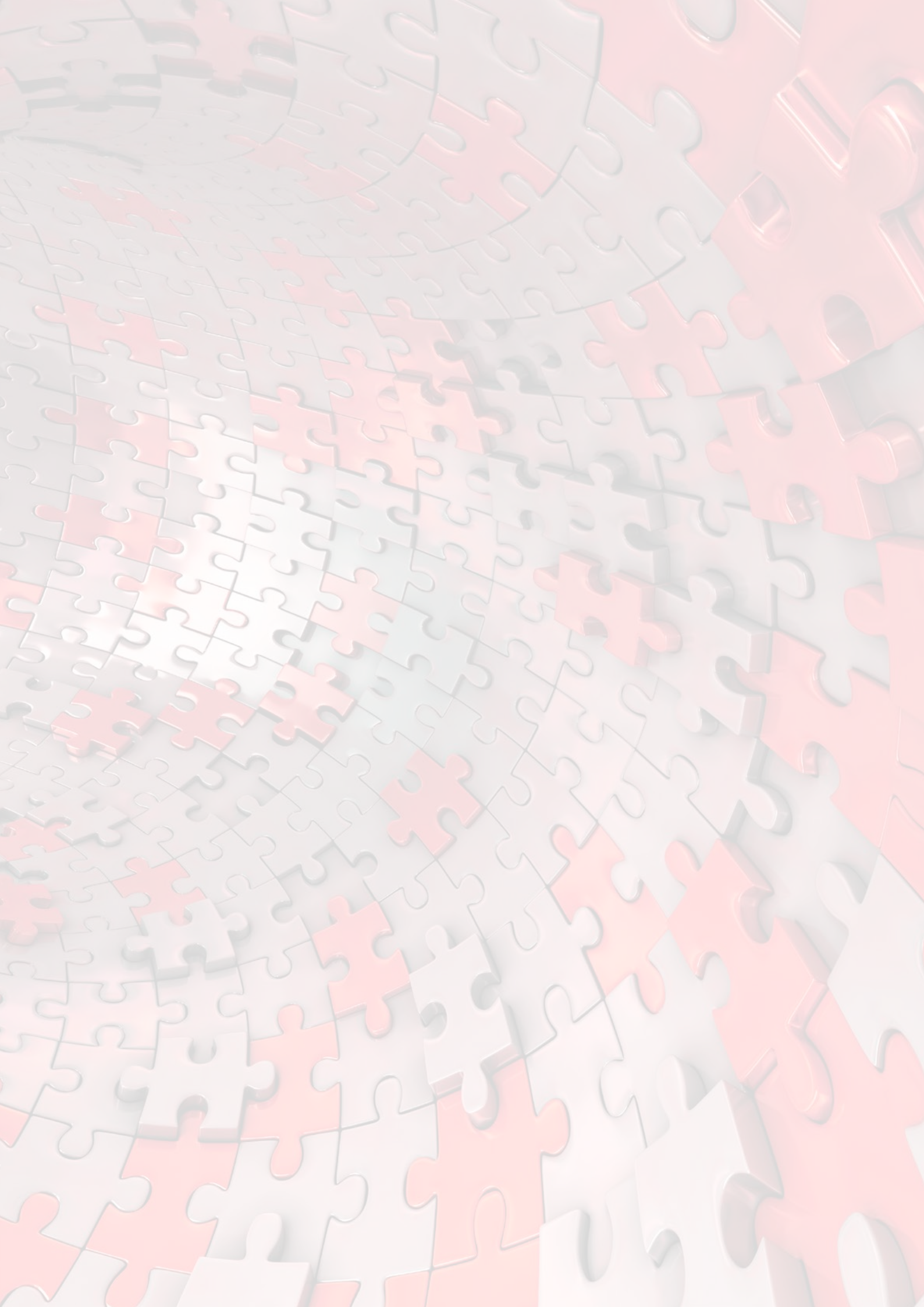


Gut Decisions

Leading change to improve the lives of
people with Crohn's and colitis





Simon, an Irish Inflammatory Bowel Disease (IBD) patient, photographed at Kilmainham Jail as part of the 'Perspectives' art exhibition.

“ Simon’s story

My disease is a prison which incarcerated me at home, turning my bedroom into a cell at a time when I was young and full of hope. Trapped physically and emotionally, I was often afraid to leave the house because of what an unexpected bowel movement would mean. I developed an interest in online genealogy and traced my family tree. I’m photographed at Kilmainham Jail, a famous place in Ireland’s history that I often visit. People who fought for freedom were held there. I even discovered an ancestor who had a short stay.

He got out. I want out too.

”



Ged Nash, Minister for Business and Employment, attending the Government

As someone both living with Inflammatory Bowel Disease (IBD) and a public representative, I welcome the development of this report which, for the first time, maps the network of IBD services in Ireland and the impact of IBD on the lives of the 20,000 people living with this debilitating condition.

It is critically important that legislators like me, health professionals and those who are charged with managing our health service have access to evidence-based information in order to properly plan services for people with IBD. There are undoubtedly serious gaps in services, facilities and supports and I have no doubt that this important report will help to shape the debate about how the resources available to us are managed in the optimum way for IBD patients.

I look forward to working with the authors of this report and experts in this field to help shape innovative policy that will lead to an improved standard of care in the years ahead.

”



Dr. Glen Doherty, Consultant Gastroenterologist, St. Vincent's University Hospital and Chair of the ISG IBD Quality Steering Committee

It is clear from the level of engagement with this first national survey of services for people with Crohn's and colitis in Ireland that there are many specialist healthcare professionals around the country with a strong commitment to caring for patients with these conditions. However, despite the efforts of those working in the field, there are clearly constraints which prevent patients from receiving timely diagnosis and equitable access to specialised care and diagnostic tests. As a result there is an over reliance on acute care services.

A renewed focus on health policy surrounding Crohn's and colitis and targeted allocation of resources would lead to a significant impact on patient outcomes whilst achieving better value for money through optimal healthcare utilisation.

”



Patricia McArdle, Chairperson of the Irish Society of Colitis & Crohn's disease (ISCC)

Crohn's disease and ulcerative colitis severely impact quality of life through ongoing debilitating symptoms; reduction in ability to work; social stigma; management of bathroom access issues; difficulty with physical intimacy; loss of leisure time; large financial burden and stress; and limited choices of career, travel and other personal options.

With the incidence of Crohn's disease and ulcerative colitis increasing in children and young people, it has never been more important to ensure that we take action to plan and develop specialist services to meet the current and growing needs of those affected. By ensuring optimal care is in place, we can enable people living with these conditions to fulfil their potential.

This report provides a benchmark of services in Ireland and outlines what is required to meet patient needs. The ISCC looks forward to working to achieve a greater understanding of Crohn's and colitis, timely diagnoses, long term illness status and a national standard of care.

”

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Executive Summary

Crohn's disease and ulcerative colitis (collectively known as Inflammatory Bowel Disease or IBD) are serious yet under-recognised health concerns affecting approximately 20,000 Irish people today¹. Often starting in early childhood, both Crohn's disease and ulcerative colitis are life-long conditions for which there is currently no cure². People living with Crohn's and colitis are at higher risk of developing colorectal cancer and dying prematurely³.

In this new report '**Gut Decisions: Leading change to improve the lives of people with Crohn's and Colitis**' the authors highlight the medical and socio-economic impact of Crohn's and colitis along with existing gaps in critical services.

The report also provides a series of policy solutions that we believe will ensure gaps in critical services are met, and that new and innovative models of care can be implemented and scaled up for use in the Irish healthcare system.

GROWING EVIDENCE

The European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) Patient IMPACT Survey described the devastating impact

these conditions can have on those affected, including complex medical and therapeutic needs, compromised emotional wellbeing, education, productivity and overall quality of life.

Key findings included:

- More than half did not get a diagnosis within the first year of onset of symptoms²
- 97% of respondents experienced one or more flare ups in the past two years²
- More than 90% of respondents had been hospitalised in the last 5 years and more than half will eventually need surgery²
- 49% say they have lost or had to leave their job because of their illness.²

INFLAMMATORY BOWEL DISEASE OVERVIEW

- Inflammatory Bowel Disease (IBD) encompasses at least two separate disorders that cause inflammation (redness and swelling) and ulcerations of the small and large intestines, namely Crohn's disease and ulcerative colitis.
- Ulcerative colitis typically affects the innermost lining of the large intestine (colon) and rectum and occurs through continuous stretches of the digestive tract.
- Crohn's disease can occur anywhere in the digestive tract. Diseased sections of the bowel are often interspersed with healthy ones.
- Both Crohn's disease and colitis can cause moderate and severe reactions such as: diarrhoea, abdominal pain, nausea and vomiting, reduced appetite, and weight loss.
- Crohn's and colitis are treated with various classes of drugs, including: aminosalicylates, corticosteroids, immunosuppressants and biologics (drugs created through biotechnology), or – if drug therapy fails – surgery.



While Ireland has a sound base of expertise and infrastructure for providing services to people with Crohn's and colitis, a recent survey conducted in Ireland by the Irish Society of Gastroenterology (ISG) illustrated several key gaps in services to patients.

These include:

- Lack of specialist IBD nurses throughout the country⁴
- Lengthy waiting times for tests⁴
- Lack of access to a gastroenterology specialist⁴

- Limited access to psychologist treatment.⁴

Building on these findings, we recognise that to improve the lives of those living with Crohn's and colitis, we must adopt a holistic policy framework that supports an increase in these vital services. This can only be achieved through the collaboration of all relevant healthcare stakeholders in creating concrete solutions that will increase access to, and improve models of care.

This report outlines in detail the policy we believe needs to be in place in order to make this happen.

KEY RECOMMENDATIONS

Gut decisions: leading change to improve the lives of people with Crohn's and Colitis

1. Develop and implement a **national strategy for Crohn's and colitis**, to deliver the highest standards of care for people living with these conditions.
2. Ensure every patient with Crohn's and colitis has **ready access to the care of a multi-disciplinary team** to allow timely referral, diagnosis and treatment.

This will require:

- increasing the number of Gastroenterologists
- providing more Specialist Nurse positions
- improving access to dietetics and psychology support
- Implementing a rapid referral pathway from primary care

3. Resource a national **Research Strategy** with specific focus on:
 - creation of a comprehensive national database
 - improved access to clinical trials
 - increased translational research activity
 - analysis of the true economic cost of Crohn's and colitis (lost work time etc.)

4. Ensure **children and adolescents with Crohn's and colitis have equal access to the care of a paediatric multi-disciplinary team** as well as appropriate mechanisms for formal transitional care to adult IBD services.
5. Promote and resource **self-management and patient empowerment approaches** using peer support mechanisms and enhanced engagement with the national patient support group.
6. Improve **public understanding** of Crohn's and colitis, especially in the workplace and in educational settings.
7. Develop specific measures to help patients and their families **deal with the financial burden** of Crohn's and colitis.

Patients with IBD and the healthcare professionals who treat them are facing a number of critical challenges here in Ireland. This will continue to grow as the prevalence increases, particularly with the number of children currently being diagnosed with this life-long condition.

We believe that if policy makers continue to increase awareness and move these recommendations forward we can drastically improve the current situation for the benefit of patients.

Understanding Crohn's Disease and Ulcerative Colitis

Crohn's disease and ulcerative colitis involve chronic inflammation of all or part of the digestive tract. They are two separate disorders that cause inflammation and ulceration of the small and large intestines. Both can be painful and debilitating, and may even lead to life-threatening complications.

CROHN'S DISEASE

Crohn's disease can cause inflammation anywhere in the digestive tract, from mouth to anus, but typically affects the lower part of the small intestine and the upper part of the colon. The ulcerations may spread deep into the affected parts of the digestive tract. Diseased sections of bowel are often interspersed with healthy ones.

Crohn's can range from mild to severe and may develop gradually or come on suddenly, without warning. Symptoms, which vary widely depending on the location(s) of disease along the digestive tract, may include:

- Abdominal pain
- Cramping
- Diarrhoea
- Nausea and vomiting
- Reduced appetite
- Weight loss

While Crohn's can occur at any age, most people are diagnosed before age 30². Risk

factors include family history, smoking, living in cities and industrialised nations.

It is not known what actually causes the disease in susceptible people, though researchers believe something triggers the immune system to mistakenly attack harmless or beneficial bacteria, foods, and even the body's own tissues.

A lifelong disease, Crohn's typically follows a pattern in which periods of acute flare-ups alternate with periods of remission.

ULCERATIVE COLITIS

Ulcerative colitis typically affects only the innermost lining of the large intestine (colon) and rectum and occurs through continuous stretches of the digestive tract.

Symptoms, which usually develop gradually, include:

- Severe and bloody diarrhoea
- False urges to have a bowel movement
- Abdominal pain and cramping

- Nausea and vomiting
- Decreased appetite and weight loss
- Mild fever
- Anaemia
- Loss of body fluids

In some patients, colitis also causes symptoms outside the digestive tract, such as arthritis, osteoporosis, and uveitis. The disease develops most frequently between the ages of 15 and 40, with a second peak in incidence between 50 and 80, and its cause is poorly understood⁵. It occurs less often than average in current smokers, but former smokers appear to be at increased risk⁶.

While colitis is a life-long disease, the inflammation tends to wax and wane. Many affected people have periods of active symptoms (flares) alternating with pain-free remission periods.

TREATING CROHN'S DISEASE AND ULCERATIVE COLITIS

The goals of therapy are to eliminate symptoms, prevent flare-ups, and restore quality of life. Medications control symptoms and promote healing in most patients.

Surgery may be warranted if medications fail to control symptoms, if precancerous changes occur in the colon, and for some serious complications.

ULCERATIVE COLITIS VS CROHN'S DISEASE: SIMILARITIES AND DIFFERENCES^{5,6}

Attribute	Ulcerative colitis	Crohn's disease
Risk Factor	Former smoker	Smoking, family history, geographical location, ethnicity
Age at onset	Two diagnosis peaks: 15-40 and 50-80	Usually before 30
Pattern of onset	Typically gradual	Gradual or sudden
Chronicity	Lifelong	Lifelong
Pattern of inflammation	Continuous along a portion of the GI tract, always involving the rectum	Alternating diseased and healthy segments
Depth of inflammation	Usually present only in the inner lining of the intestine	Ulcers can penetrate the entire thickness of the intestinal lining
Bleeding	Common during bowel movements	Uncommon
Location of pain	Typically in the lower left abdomen	Typically in the lower right abdomen

A range of medications are required to manage the symptoms of this condition:

- **Aminosalicylates:**
These drugs, which contain 5-aminosalicylic acid (5-ASA), are effective for treating mild-to-moderate IBD flare-ups as well as maintaining remission.
- **Corticosteroids:**
These fast-acting and potent anti-inflammatory drugs are a mainstay of treatment for acute flare-ups. Their side-effect profile makes long-term use or repeated short-term use inadvisable.
- **Immunomodulators:**
These drugs decrease the inflammatory response by modifying the activity of the immune system. Immunomodulators are appropriate for patients who do not respond to 5-ASA or steroids, have steroid-dependent disease, or need to maintain remission.
- **Biologics:**
Engineered through biotechnology methods and often isolated from natural sources (human, animal or microorganism), these drugs decrease inflammation by targeting specific molecular pathways that are abnormal in people with Crohn's and colitis.
- **Antibiotics:**
Antibiotics are effective in Crohn's patients with bacterial infections, abscesses and fistulas (abnormal channels between sections of intestine or between the intestine and another part of the body).



- FAST FACTS...**
- The prevalence of Crohn's disease or ulcerative colitis in Ireland is upwards of 20,000 people¹
 - Most people are diagnosed between the ages of 15 and 30²
 - In addition to digestive symptoms, many people living with IBD also frequently experience joint pain (51%)², skin problems (50%)² and eye inflammation (6%)⁷

- PAEDIATRIC IBD...**
- The incidence of new paediatric cases have increased three-fold since 2000⁸
 - An estimated 450 Irish children are living with IBD⁹
 - More than 100 new cases of IBD are diagnosed each year⁸

CROHN'S DISEASE AND ULCERATIVE COLITIS IN IRELAND

By and large, Crohn's and colitis are considered diseases of the developed world, particularly Europe and North America. As developing nations become more industrialised, the prevalence (number of reported cases) and incidence (number of new cases) of Crohn's and colitis tend to increase.

There are 19 new cases per 100,000 people in Ireland every year – seven new cases of Crohn's and 12 new cases of colitis¹⁰.

The colitis rate in Ireland is one of the highest in the world¹⁰.

Most worrisome is the substantial and sustained increase in the incidence of childhood Crohn's and colitis, which appears to be increasing at a faster rate than our neighbouring countries¹¹.

The Impact of Crohn's Disease and Ulcerative Colitis

Individuals with Crohn's and colitis have a lower quality of life than the general population across all dimensions of health¹². Not surprisingly, those with more active disease experience the greatest reductions in quality of life. However, even people without physical symptoms suffer from distress, anxiety and fear¹².

In 2011, the *European Federation of Crohn's and Ulcerative Colitis Association* (ECCA) commissioned the IMPACT survey to attempt to understand the true impact of these conditions.

The results from the Irish participants provide a startling insight into daily physical and psychosocial challenges of living with these conditions.

HEALTH AND QUALITY OF LIFE

The IMPACT report highlights the chronic and difficult nature of Crohn's and colitis with 97% of respondents having experienced one or more flare-ups* in the last two years.

During the flare up 92% were tired, weak and worn out for four days or more during this time with many experiencing symptoms such as GI bleeding (47% and abdominal cramping (76%)².

* A flare is an acute episode of symptoms of the disease which can include, diarrhoea, rectal bleeding, urgent bowel movements, abdominal cramps, pain and fever. Hospitalisation is often required to stabilise the condition.

90% of people with IBD have been hospitalised, and more than half of people with Crohn's eventually require surgery².

Almost half of the respondents say their condition has prevented them from pursuing intimate relationships².

According to the IBD Standards Group in the UK, there is an established link between disease of the large intestine and the risk of colorectal cancer¹³.

MEDICATIONS

While there is still no cure for Crohn's or colitis, advances in research have resulted in increased options for therapeutic intervention to control symptoms. In fact, the IMPACT report suggests that 74% of patients have been prescribed steroids for their condition². That is much higher than the EU average of 52%, demonstrating



THE CANCER CONNECTION

Colorectal cancer, which represents the major cause for excess morbidity and mortality in Crohn's and colitis, occurs in 5 to 13% of patients with colitis and 0.4-0.8% of patients with Crohn's. Established risk factors include long duration of the disease, large extent of disease, low disease activity, young age at onset, presence of certain complications (e.g., stenotic disease), presence of certain other diseases (e.g., primary sclerosing cholangitis), and possibly inadequate surveillance and/or drug therapy³.

increased usage of steroids in Ireland versus our European neighbours². Almost half of people regularly use pain medication to relieve their symptoms.

PRODUCTIVITY

The fluctuating nature of Crohn's and colitis means that people with these conditions have a lower rate of participation in the workforce than the general population⁶. **23% said that they are unemployed or under-employed due to the condition².** The IMPACT report shows that 77% of Irish respondents have had time off in the past year due to their condition; 59% stating that they had five or more days off².

Alarmingly, just under half of all respondents (49%) say they have lost or had to leave their job because of their illness².

Of particular and sometimes overlooked significance is that the conditions are often diagnosed in adolescence or early adulthood, which can impact educational attainment as well as career selection and thus socioeconomic status and income⁶.

As such, Crohn's and colitis affects not only patients' health but their careers, relationships, hopes and dreams.

More than half of the participants in the IMPACT study say that their disease has affected their ability to reach educational potential. Not surprisingly, this has a direct impact on their working lives, with 64% saying their career prospects have been impacted by the condition. One in four believe that they have been discriminated against in the workplace with many feeling stressed or pressured about taking time off due to their illness.

ECONOMIC BURDEN

An Italian study demonstrated that Crohn's disease may have a profound impact on an affected person's quality of life and a substantial economic impact for both them and the healthcare system¹⁴.

The cost of illness per patient with Crohn's disease in the study was estimated to be €15,521 per year, with direct costs representing 76% of total costs. Non-healthcare costs and loss of productivity accounted for 24% of total costs¹⁴.

Hospitalisation of young people due to a flare is not only disruptive to their lives in terms of work and family but leads to a significant burden on healthcare budgets.

Up to 63% of the total costs of Crohn's are comprised of hospitalisation costs including surgery¹⁵. In Ireland, 90% have been hospitalised in the last five years, this is higher than the EU average of 85%².

Thus access to appropriate follow up care and monitoring which is focused on keeping people well and out of hospital, is critical to reduce the risk of flare and further direct and non-healthcare costs.

Of note is that international evidence shows that the more severe the Crohn's disease, the higher the direct and indirect costs of its management, and that the direct costs are higher than the indirect costs¹⁵.

People with colitis experiencing a flare up can lead to 20 times increase in direct medical costs¹⁶.

This points to the urgent need to diagnose and treat individuals as early in the disease course as possible and to establish the appropriate models of care to ensure optimal patient outcomes.

PUBLIC AWARENESS

Despite the growing incidence of Crohn's and colitis in Ireland, public awareness of the symptoms of and risk factors for these conditions is low at only 50%¹⁷.

They are frequently confused with Irritable Bowel Syndrome as 79% of adults were unable to differentiate between the conditions¹⁷. Only 37% of adults in Ireland had heard of ulcerative colitis¹⁷.

Given the chronic and progressive nature of Crohn's and colitis, a broader understanding of the disease **could improve identification of symptoms and thereby earlier diagnosis and management** by the specialist team and in primary care.

Services for People with Crohn's and Colitis in Ireland

Evidence suggests that late diagnosis, inappropriate investigation, and inappropriate management are substantial problems in Crohn's and colitis⁶. While Ireland has a solid base of expertise in care for people with these conditions, a recent survey carried out by the Irish Society of Gastroenterology (ISG) identified some significant gaps in services nationally.

The National IBD Survey is the first survey to seek to understand the services and infrastructure available nationally to manage both Crohn's and colitis in the adult population. In total, 20 hospitals participated in the survey.*

The outcomes provide much needed clarity to the underlying issues facing people with these conditions, as highlighted in the IMPACT report, and their healthcare providers.

GASTROENTEROLOGISTS

Gastroenterologists are specialists in treating Crohn's disease and ulcerative colitis. These are complex medical conditions that require specialist medical attention as early as possible.

Irrespective of geographical location, patients are likely to wait a long time for specialist consultations².

Gastroenterologists are the main treaters although in some cases, patients may be treated by a consultant general

physician or surgeon. There are only 89 gastroenterologists operating across all of gastroenterology and hepatology, which is less than one for every 50,000 of the patient population.

Faced with an ageing population and bottlenecks in accessing screening and diagnostic technology, gastroenterologists are unable to meet the current demand for specialist care.

60% of centres highlighted a lack of specialist Gastroenterologists as a key barrier to optimal services⁴. The IMPACT survey highlighted that **one in three people wait longer than one year to see a specialist in Ireland and over 50% did not get a diagnosis within the first 12 months** of onset of symptoms.

It is not surprising therefore, that **24% of respondents to the IMPACT survey feel that they do not have adequate access to their specialist gastroenterologist².**

* Public hospitals only included in the survey



IBD NURSE SPECIALISTS

The specially trained IBD nurse has a critical role to play in the delivery of services and care to people with Crohn's and colitis. They are experts in the pathogenesis and presentation of the conditions, have an up-to-date knowledge of treatment options, appreciate the role of nutrition in disease management, and can draw on this knowledge to formulate and/or discuss treatment plans with patients.

In its 2013 consensus statement, N-ECCO – a European organisation devoted to improving access to nurse education in Crohn's and colitis – describes the specialist IBD nurse as:

"...an autonomous clinical expert who is responsible for the assessment and provision of evidence-based care planning and treatment evaluation, and who provides practical information, education and emotional support for patients with IBD¹⁸."

The main services provided by nurses include:

- patient education
- teaching on management of medications
- rapid access for symptomatic patients
- maintenance of databases
- research and clinical trials

The lack of a dedicated specialist nurse was identified as the most significant barrier to delivering optimal care in Ireland⁴. All centres included identified the role of the

nurse specialist as very important in enhancing patient care. Despite this, access to specialist nurses for people with Crohn's and colitis is limited in Ireland with 45% of centres having no such service. Of the nurses who currently work with people with Crohn's and colitis, only 12 work exclusively with this 20,000 patient population.

The survey clearly indicated that the role of the specialist nurse is seen as an important element of IBD services in Ireland and 70% of centres have put together a business case to request a nurse for their services.

PSYCHOLOGICAL SUPPORTS

It is well documented that Crohn's and colitis are diseases in which stress and psychosocial factors play an important role. International research demonstrates that psychosocial factors need to be recognised as important contributors to patients experience of their disease and should not be separated from biological ones¹⁹.

The Irish experience supports this with **75% of all centres viewing access to a Clinical Psychologist to be important in the care of people with Crohn's and colitis⁴.**

However, **only 10% of centres reported having access to psychological support** for their patients⁴. Where psychologists are in place, for example at Humanitas in Milan, the Gastroenterologists report having a better understanding of their patients' needs and therefore deliver a better standard of care²².

ACROSS ALL HOSPITALS, THE TOP THREE BARRIERS TO THE PROVISION OF AN OPTIMAL SERVICE WERE IDENTIFIED AS⁴:

Lack of IBD Nurses 17/20



Waiting times for tests 14/20



Lack of IBD Specialists 12/20



ACCESS TO DIAGNOSTICS

Access to endoscopy and radiology also varies significantly across regions, making it difficult for some to receive timely assessments and care⁴.

Limited access to endoscopy was reported in 75% of public voluntary hospitals⁴. The survey also highlighted that waiting times for magnetic resonance enterography (MRE) were a significant issue in the public hospitals with an average waiting time of 9.3 weeks⁴.

While almost all (95%) centres view access to a Radiologist with a special interest in treating Crohn's and colitis to be important, 30% of centres remain without this critical resource⁴.

MULTIDISCIPLINARY SUPPORT

The chronic nature of Crohn's and colitis and the need for ongoing patient monitoring align strongly with multidisciplinary team care and management.

The UK IBD Standards Group state that members of the team must establish a collaborative approach to the provision of care for people with Crohn's and colitis¹³.

Of the Irish centres surveyed, 70% have no dedicated medical clinics for Crohn's and colitis. Only 15% have combined medical/surgical clinics and 10% have a parallel surgical and medical clinic⁴.

Creating Sustainable Models of IBD Care: An International Perspective

The ISG survey and the IMPACT report demonstrate significant gaps in service delivery in the Irish healthcare system. In the context of constrained resources and the need to meet the complex needs of these patients, there exists an opportunity to evaluate and implement new, sustainable models of care that will deliver better outcomes for patients.

In this section, we are highlighting a number of international models with proven success as well as local innovations which, if applied nationally, have the potential to significantly change the course of the management of Crohn’s and colitis in this country.

THE IBD INTEGRATED MULTIDISCIPLINARY TEAM

In its 2009 report *Preventing Chronic Diseases: A Vital Investment*, The World Health Organization identified a multidisciplinary team as:

“...a highly effective approach to improving chronic disease care”²¹.

As chronic, lifelong diseases, Crohn’s and colitis require interventions at numerous points and levels of the healthcare system. Experts worldwide agree that a multidisciplinary team is the most effective structure for managing these conditions.

The first recommendation of the UK IBD Standards Group is that high-quality clinical care delivered by a multidisciplinary team that includes specialist nurses¹³.

Components of the team

The UK IBD Standards Group recommends that the multi-disciplinary team include the following members:

- Consultant gastroenterologist (physician specializing in the digestive system)¹³
- Consultant colorectal surgeon¹³
- Clinical nurse(s) with an identified role and competency in Crohn’s and colitis¹³
- Clinical nurse(s) with an identified role and competency in stoma therapy and pouch surgery¹³
- Dietician allocated to gastroenterology¹³

- GI pathologist (physician specializing in cellular abnormalities) with special interest in gastroenterology¹³
- Radiologist with special interest in gastroenterology¹³
- Pharmacist with special interest in gastroenterology¹³

Access to the following supporting services are identified as critical:

- Psychologist, Rheumatologist, Ophthalmologist, Dermatologist, Obstetrician, Nutrition Support team¹³
- Consultant Paediatrician¹³
- An established link with a GP to provide a liaison and educational role with local GPs¹³

Evidence from the IMPACT Report and the ISG survey indicate that minimum requirements in Ireland should include a **gastroenterologist, colorectal surgeon, specialist nurse, psychologist, dietician, GI pathologist, and radiologist**, all available for consults as needed^{2,4}.

THE SPECIALIST IBD NURSE

The advent of IBD nurses is a recent development. Given the chronic nature of Crohn’s and colitis, the importance of disease-specific and self-management education, the need to fine-tune therapy and encourage drug compliance, and the need to monitor patients for colorectal cancer, involvement of specialist nurses in the multidisciplinary team is a logical step.

Within the context of the Irish shortage of gastroenterologists and the regional inequities in timely access to quality care, the specialist nurse can be a resource-sparing and cost-effective member of the IBD team.

The table on the following page outlines the duties a specialist nurse might take, depending on their work setting and local clinical needs.

Increasing evidence suggests that specially trained nurses can perform as safely and effectively as doctors across a range of conditions and procedures⁶.

“Direct and indirect specialist nursing roles can include reducing referral times, the length of hospital stays and the risks of patient complications.”
Inflammatory Bowel Disease Nursing 2012, Royal College of Nursing, U.K.

A recent KPMG report states that where available, the specialist nurse provided continuity of care for patients educating them on their disease and giving them support and advice across the disease cycle²⁰.

The report highlights the three key roles performed by these nurses:

1. Care Co-ordinator

Supports patients to navigate the complex care pathway

2. Treatment Expert

Nurse led clinics manage aspects of treatment including the administration and prescription of biologics

3. Case Manager

Specialist nurses take on the role of case manager and support the patient through the medical and non-medical aspects of their disease.

At the University of Liège, Belgium, the specialist nurse links in with the primary care physician by following up each appointment with a letter to make them aware of the medications prescribed and any decisions made²⁰.

An Australian study showed that intervention with a specialist nurse leads to a reduction of hospital admission, fewer A&E presentations and clinic reviews²². The specialist nurses provided

POTENTIAL DUTIES OF A SPECIALIST IBD NURSE⁶

Clinical	Patient and Systems Management	Educational and Supportive	Research and Advocacy
<ul style="list-style-type: none">Assess patients (including history and physical exam)Order and interpret diagnostic testsPrescribe treatmentMonitor response to treatment and alter as needed to induce or maintain remissionAdminister and monitor immunomodulator or biologic therapy	<ul style="list-style-type: none">Triage community referralsManage newly-diagnosed patientsHelp run follow-up clinicsDevelop and define IBD servicesAct as a gatekeeper within the multidisciplinary teamCoordinate colorectal cancer surveillanceHelp transition adolescents to adult services	<ul style="list-style-type: none">Provide education and counsellingProvide nutritional supportProvide inpatient supportProvide telephone advice lines	<ul style="list-style-type: none">Conduct clinical IBD researchServe as a patient advocateRaise awareness of IBD in the community



MERCY UNIVERSITY HOSPITAL CORK ADVANCED NURSE PRACTITIONER IN CROHN'S AND COLITIS: CASE EXAMPLE²⁵

The Mercy University Hospital, Cork undertook an audit over a twelve week period from May to July 2013. The aim was to establish the potential impact of an Advanced Nurse Practitioner (ANP) post in working with Crohn's and colitis patients at the Gastroenterology Department.

Findings showed that 40% of patients had mild to moderate IBD and could effectively be managed by an ANP. This would result in reduced current waiting times in outpatient department, reduced A&E presentations, reduced SDU waiting lists, improved access to endoscopy as well as freeing up Consultant time to deal with more complex IBD cases.

To date more than 50 patients have been admitted through triage or out-patient review who otherwise may have been admitted through A&E. In addition, the nurse spends time with each patient to ensure that they are confident in the management of their treatment and their condition.

sustained direct cost reductions to health services. Additional benefits were accrued through better patient knowledge, earlier presentation and increased compliance.

The use of specialist nurses to carry out roles for which they have been specially trained makes obvious health-economic sense: it alleviates the burden on gastroenterologists and primary care physicians while enabling a high level of continuity,

thus streamlining the flow of care and minimising bureaucratic inefficiencies.

In a Halifax experiment, analysis demonstrated a 50% reduction in patient wait times for IBD care following the introduction of an urgent access clinic led by a specialist nurse⁶.

Patients reported that attending the nurse-led clinic enabled them to avoid a more costly visit to the emergency room⁶.

CENTRES OF EXCELLENCE

Centres of Excellence (CoE) have already proven their potency in many areas of medicine, including oncology, allergy and immunology, arthritis, stroke, and stem cell research.

As chronic, complex diseases requiring sophisticated treatment, the effective management of Crohn’s and colitis would lend itself especially well to the CoE model.

CoEs are generally organised around three pillars of healthcare excellence:

1. Patient care

2. Research

3. Education

By serving as central repositories of IBD expertise, CoEs catalyse the cross-pollination of ideas, generate efficiencies in research and data collection, and allow for consistent messaging.

We recognise that not all existing centres will have the resources to excel in all areas. As initial goals, smaller centres could focus on excellence in clinical care, while drawing from the education and research expertise of larger, more established centres.

Benefits of the Centres of Excellence Model

By centralising research capabilities and disseminating best-practice resources to avoid duplication and

THE CENTRE OF EXCELLENCE (COE) MODEL⁶

Patient Care	Research	Education
<ul style="list-style-type: none">Central triaging allows patients to be served based on needHouses multidisciplinary clinicsGenerates efficiencies in administration of biologic drug therapy	<ul style="list-style-type: none">Guiding principle: ‘every patient is a research patient’Brings together various types of research: basic science, clinical, outcomes, population healthAllows experts to collaborate to strengthen each other’s workFacilitates measurement of processes and outcomes	<ul style="list-style-type: none">Centralised dissemination of information enables ‘branded’ educationAllows for control of information

substandard care, CoEs can yield the following systemic health benefits:

- Effectiveness**
Health services are based on the most up-to-date scientific knowledge
- Efficiency**
Resources are optimally used to achieve desired outcomes
- Safety**
Standardised best practices mitigate risks and harmful effects
- Acceptability**
Health services are respectful and responsive to patient needs, preferences and expectations
- Accessibility**
Health services are provided in a suitable setting within a reasonable time and distance

For people in remote locations, the CoE could facilitate access to remote care (e.g., telehealth, patient videoconferences), thus potentially saving patients from debilitating flare ups and easing the cost burden on the healthcare system.

COMMUNITY BASED CHRONIC DISEASE MANAGEMENT

The incidence of Crohn’s and colitis has increased markedly over the last few years and primary care can be a key factor in providing early diagnosis⁸. Shared care with primary care can also play a significant role in the ongoing management of people with Crohn’s or colitis. Patients can then migrate between the Centre of Excellence and primary

care based teams according to the severity and complexity of their disease.

A system which allows for the flow of information between primary and secondary care can significantly reduce the burden on the patient, by allowing for local care while their disease is stable.

PROJECT ECHO: LINKING PRIMARY CARE AND SECONDARY CARE

A new model of care, Project ECHO, links a specialty care team to primary care teams in the community.

Regularly scheduled teleECHO clinics use a ‘bridging the gap in healthcare’ approach which allows physicians, nurse practitioners, and other clinicians to jointly manage complex illness – and promotes the use of best practices in care – while enabling patients to receive treatment in their home communities.

Project ECHO has expanded throughout New Mexico, across the country, and around the world.

As of January 2014:

- More than 300 clinical teams in 74 communities across New Mexico.
- Partner organisations have created Project ECHO hubs at a total of 32 US sites and 38 locations around the world. Hub sites include academic medical centres, a community health centre, the Veterans Health Administration, and the US Department of Defense.

ELECTRONIC DATABASE FACILITATES PATIENT ASSESSMENT THROUGH VIRTUAL CLINIC AT ST VINCENT’S UNIVERSITY HOSPITAL, DUBLIN²³

At St. Vincent’s University Hospital, an electronic database forms a valuable resource for the IBD healthcare team in clinical practice. The nurses run a daily on-demand virtual clinic during which symptomatic patients ring in for assistance and advice.

With 3,496 patients with Crohn’s or colitis attending the institution, the database is central to the rapid acquisition of a patient’s previous medical and therapeutic history. Calls are logged on the IBD database along with symptoms, advice given and prescriptions sent (the nurses are also Nurse Prescribers). A quick audit of a month’s activity shows that there are about 447 contacts.

Outcomes included immediate attendance at the Emergency Department, earlier outpatient appointments, initiation of biological therapies and, in many cases, reassurance for the patients. This virtual clinic has actually benefited all patients with Crohn’s and colitis, allowing some to be assessed and treated without actual hospital attendance while freeing up staff in actual clinics to concentrate on dealing with the more challenging cases.



VIRTUAL CLINICS

Due to the fluctuating nature of Crohn’s and colitis, a responsive and timely follow up is critical to best manage patient outcomes. In the UK, a nurse led virtual telephone follow-up clinic was trialled and questionnaires were sent to the first 50 patients reviewed¹⁸.

Of the 34 returned questionnaires, 91% were happy with the nurse led telephone clinic, stating it met their needs. Most of these patients continued under the telephone clinic which increased the clinics capacity for patients who were in need of traditional outpatient review.

This is a model that is currently being adopted locally and has the potential to deliver value to the healthcare system while improving patient outcomes.

‘BETTER HEALTH, BETTER LIVING’

At Beaumont Hospital, Dublin, The Chronic Disease Self-Management Programme (CDSMP) was identified as a leading model of psychosocial intervention. In development since 1992 at Stanford University, studies of the CDSMP demonstrate an improvement in both the behaviours and health status of patients.

The *Better Health, Better Living* programme was launched in 2013 in Beaumont. It is a course for people with Crohn’s and colitis that runs over six weeks with 9 to 18 participants and two trained leaders – one of whom must have a chronic condition.

Each session lasts 2½ hours and includes modules on:

- 1. Understanding and managing common symptoms
- 2. Cognitive strategies for managing symptoms
- 3. Exercise methods
- 4. Communication skills
- 5. Nutrition
- 6. Decision making in medical care and medication adherence.

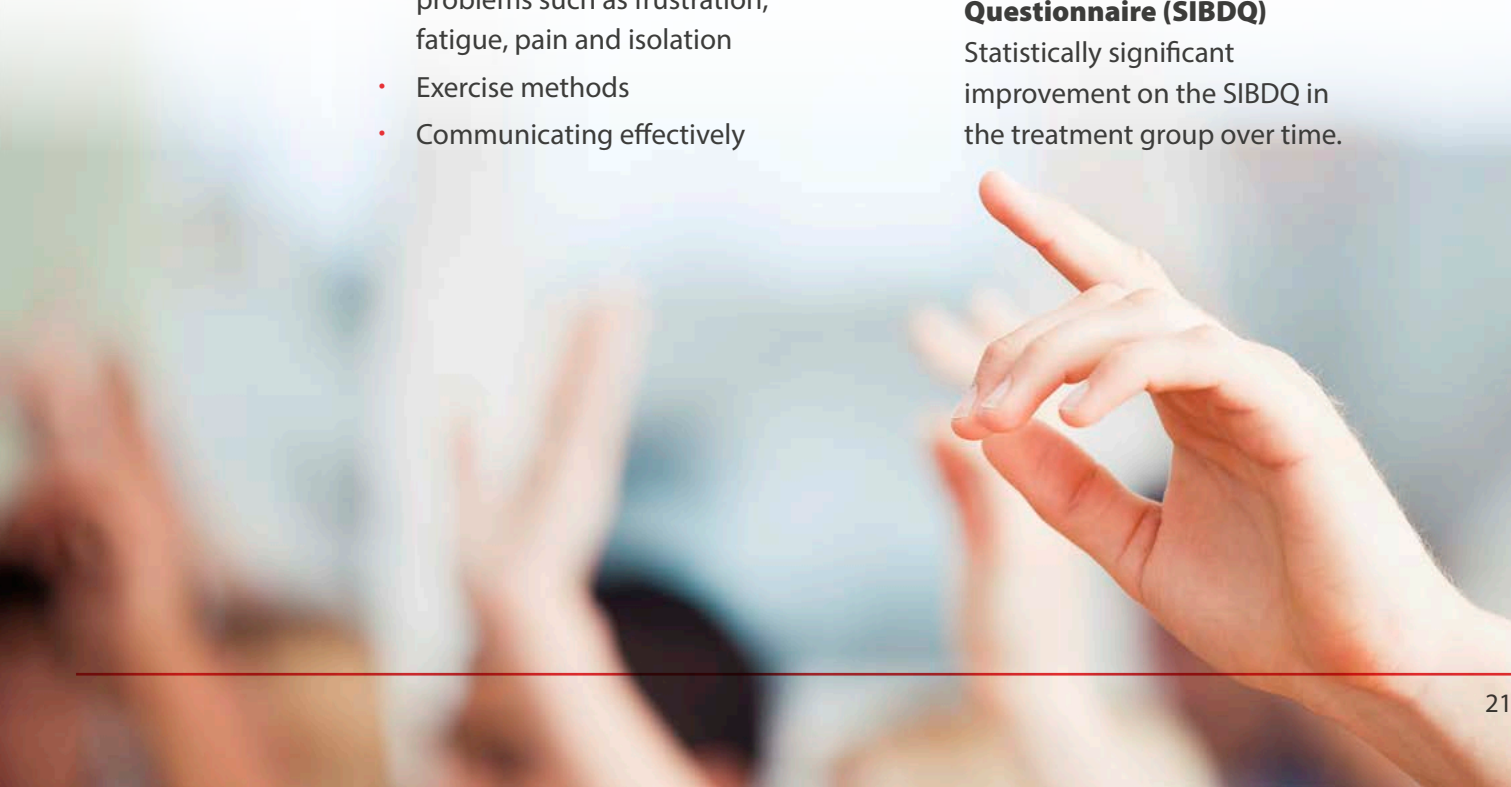
The project covers a variety of learning topics taught through action plans, group discussion and educational lecturettes. The program includes:

- Techniques to deal with problems such as frustration, fatigue, pain and isolation
- Exercise methods
- Communicating effectively

- with family, friends and medical professionals
- Nutrition
 - Relaxation
 - Appropriate use of medication
 - Decision making in medical care.

The effectiveness of the programme was assessed with pre- and post-intervention follow up assessments using questionnaires composed of three measures and a waiting-list control group²⁴.

- 1. Hospital Anxiety and Depression Scale**
Significant reduction in anxiety levels over time (treatment group 22% to 3%; control group 38% to 26%).
- 2. SF -36 Health Survey**
Significant improvement in energy/ fatigue and general health perception in treatment group over time.
- 3. Short Quality of Life in Inflammatory Bowel Disease Questionnaire (SIBDQ)**
Statistically significant improvement on the SIBDQ in the treatment group over time.



Specific Recommendations

This report outlines the need for urgent attention to the delivery of services for people with Crohn’s and colitis. National and international experience provides evidence that new and innovative models of care can achieve significant value for money for the healthcare system and most importantly for improved health outcomes for patients.

The IBD Quality Initiative Steering Group is making the following recommendations for immediate action:

1. Develop and implement a **national strategy for Crohn’s and colitis**, to deliver the highest standards of care for people living with these conditions.

2. Ensure every patient with Crohn’s and colitis has **ready access to the care of a multi-disciplinary team** to allow timely referral, diagnosis and treatment.

3. Resource a national **Research Strategy** with specific focus on:
 - creation of a comprehensive national database
- improved access to clinical trials
 - increased translational research activity
 - analysis of the true economic cost of Crohn’s and colitis (lost work time etc.)

4. Ensure **children and adolescents with Crohn’s and colitis have equal access to the care of a paediatric multi-disciplinary team** as well as appropriate mechanisms for formal transitional care to adult IBD services.

5. Promote and resource **self-management and patient empowerment approaches** using peer support mechanisms and enhanced engagement with the national patient support group.

6. Improve **public understanding** of Crohn’s and colitis, especially in the workplace and in educational settings.

7. Develop specific measures to help patients and their families **deal with the financial burden** of Crohn’s and colitis.

Appendices

THE IBD QUALITY INITIATIVE

This report seeks to highlight the results of two separate pieces of research undertaken in recent years: the ISG Physician Survey 2013 and the IMPACT Patient Survey 2010.

The IBD Quality Steering Committee

In 2014 the IBD Quality Initiative Steering Committee, comprising of healthcare professionals and patient representatives from the Irish Society of Colitis and Crohn’s disease (ISCC), came together to review the two reports on the impact of IBD on patient lives and the medical infrastructure available for the care of adults with IBD in Ireland.

The aim of the steering committee was to review the evidence from the two reports and to devise a set of prioritised recommendations to drive improvements in services for people living with IBD. The IBD Quality Steering Committee was made up of the following members:

- Dr Glen Doherty**
Consultant Gastroenterologist
St. Vincent’s University Hospital
- Professor Colm O’Morain**
Consultant Gastroenterologist
Beacon Hospital

- Dr Lucina Jackson**
Consultant Gastroenterologist
Bons Secours Hospital, Cork
- Professor Larry Egan**
Consultant Gastroenterologist
Galway University Hospital
- Dr Seamus Hussey**
Consultant Gastroenterologist
Our Lady’s Children’s Hospital, Crumlin
- Mr Dara Kavanagh**
Consultant Colorectal Surgeon,
The Adelaide and Meath Hospital,
Dublin, incorporating the
National Children’s Hospital
- Dr John Keohane**
Consultant Gastroenterologist,
Our Lady of Lourdes Hospital
- Mary Forry**
IBD Nurse, Beaumont Hospital
- Patricia McArdle**
Chairperson, Irish Society for
Colitis & Crohn’s Disease

The ISG Physician Survey

In 2013 the Irish Society of Gastroenterology carried out a survey to gather baseline information on the infrastructure for care of adults with IBD in the Republic of Ireland

and to identify and highlight current gaps that should be priority areas for development in the future.

The survey was undertaken in 20 centres (eight HSE hospitals, four public voluntary hospitals and eight private hospitals). To complete the survey physicians were asked to complete 48 questions around the infrastructure available in their individual facilities.

The results provide a benchmark of dedicated resources available for the treatment and management of IBD currently in the Irish health service.

The IMPACT Survey

The IMPACT survey was commissioned by the *European Federation of Crohn's and Ulcerative Colitis Associations* in late 2010.

Its main aim was to get an international perspective of the impact of IBD on people's lives and it was conducted in 22 countries including Ireland.

By the close of the survey, there were 4,670 responses. In total, 125 responses were received from Ireland.

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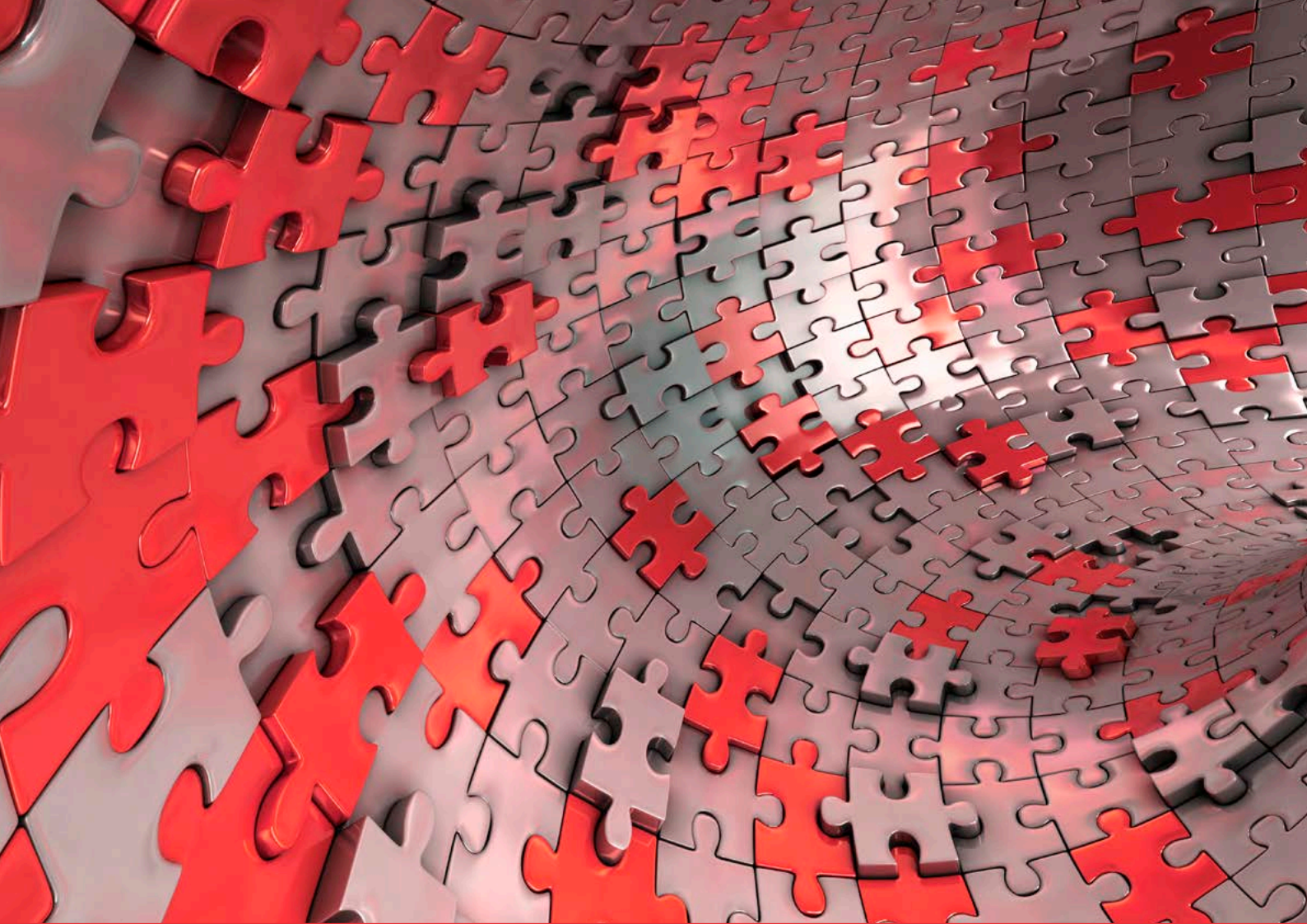
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