



Improving life for
people affected
by Colitis and
Crohn's Disease

NACC Plan 2010-12

Meeting The Challenge of Colitis and Crohn's Disease



Almost a quarter of a million people across the UK have Colitis or Crohn's Disease

Many are diagnosed in their teens or early twenties - facing a lifetime of living with these conditions

What are Colitis and Crohn's?

Ulcerative Colitis and Crohn's Disease are inflammatory bowel diseases (often shortened to IBD) which last a lifetime and for which there is no known cure. This is not the same as IBS, Irritable Bowel Syndrome, which some people with IBD may also suffer with. IBD can strike at any age, but begins most commonly in teenagers or young adults - at a time in life when it is vital for them and their families to have information and support to help cope with these conditions.

Around 240,000 people in the UK are estimated to have IBD.

Symptoms can include:

- relentless diarrhoea
- bleeding
- severe pain
- extreme fatigue
- eye, skin and joint problems
- Impaired growth in childhood

Family life, education, work and social activities can be significantly impaired as people struggle to cope with their symptoms and live with the effects of IBD.

What is NACC?

The National Association for Colitis and Crohn's Disease, or NACC as we are often called, is made up of more than 30,000 members across the UK - people who have either been diagnosed with IBD or who have family, friends or work colleagues who have become members to support the charity and its work.

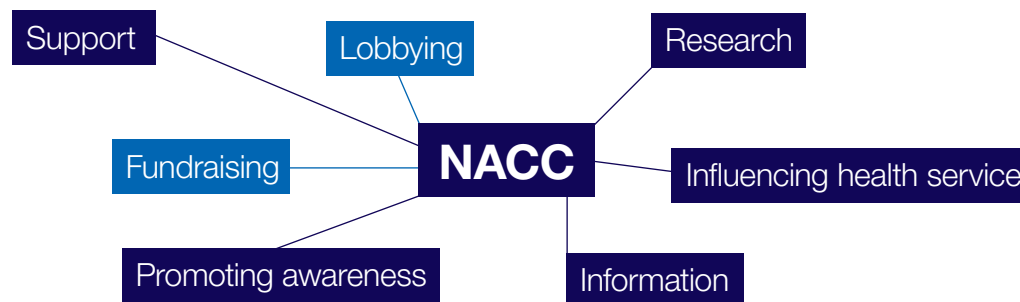
NACC is the major UK charity offering information and support to people affected by IBD.

Established in 1979 as a partnership between patients, their families, friends and the health professionals charged with their care, NACC's services have grown to include helplines, regular newsletters, and a comprehensive website with downloadable resources such as information sheets.

NACC's main activities are to provide information to all IBD patients and their families, support its members, raise IBD awareness across the UK, campaign for improved IBD health care and fund vital research.

[For more information about IBD see page 15.](#)

NACC's Vision is to be a well-known and active organisation recognised for excellence



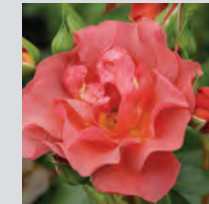
NACC's Aim

Improving life for people affected by Colitis and Crohn's Disease

NACC's Principles

- NACC aims to be an active organisation both in the sense that members and volunteers will take an active role in achieving the objectives that have been agreed and in the sense that NACC will take a leading role in championing the needs and concerns of people affected by Inflammatory Bowel Diseases.
- NACC aims for excellence by adopting recognised standards of quality in its services and by basing its policies and plans on objective evidence wherever possible.
- NACC expects Trustees, members, volunteers and staff to observe the principles of compassion, equality and inclusion and to act with respect and integrity in their work for the Association.
- The Trustees aim to forward NACC's objectives in research, development and service activities in partnership both with the health service, health professional and patient organisations and also the pharmaceutical industry, in line with NACC's policies.

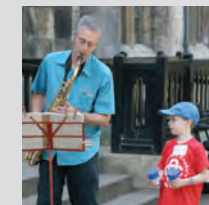
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Meeting the Challenge of Colitis and Crohn's - Step Up and Be Counted in 2010 (Freepost) insert

Introduction

Elaine Steven, Chairman, and Richard Driscoll, Chief Executive, set out the thinking behind the NACC Plan for 2010-2012

Whilst not losing sight of the ultimate goal for everyone involved with IBD, finding the cause and a cure, the Trustees established a simple comprehensive aim for NACC - to improve life for everyone affected by Ulcerative Colitis and Crohn's Disease. They also set out key principles underpinning NACC's approach to its work and broad objectives in the NACC Plan 2005-2008.

The great majority of these objectives have been achieved. NACC has developed significantly as an organisation and is now widely recognised for providing high-quality services, maintaining strong member and 'user' involvement and for effective campaigning and leadership in the drive to improve NHS Services for Inflammatory Bowel Disease. Over 2008-2009, NACC's internal governance, management and staffing structures have been reviewed and reshaped to provide the platform for continued development across all of the charity's areas of activity.

These periodic cycles of review, redefinition and change are necessary for the continued successful development of the association, for meeting the needs of people who have

IBD more effectively and for adapting our work to fit changes in the external environment. These include growing public expectations of charities, developments in government policy and services, the world economic situation etc. The Trustees recognise that the pace of change requires strategic and operational plans to be flexible, and that almost constant change places great demand on the understanding and commitment of volunteers, staff, members and supporters who together are 'NACC'.

Formulating this Strategic Plan 2010-2012, the Trustees decided that the overall Aim and Principles of NACC remain almost unchanged. NACC's Vision is carried forward and developed into the Vision laid out in each of the Areas of Work for 2010-2012. The Association's day-to-day work continues, with regular cycles of review and development. This continuing work is included within the Objectives set out in the Areas of Work. For each area the Trustees have identified the Challenges NACC faces, our Vision of the outcomes we would like to achieve and key Objectives that we have set for the next three years.

Running through the Challenges, Visions and Objectives for each area of NACC, you will see that there are recurring themes, for example objectives that focus on young people or the better use of IT. There were eight such themes that the Trustees identified as areas for priority attention within NACC and which have ramifications across most or all of the areas of NACC's work. These are set out in the next two pages of this document and they represent the areas to which NACC will give greater priority and focus over the next three years.

This is an ambitious plan which can only be fully realised if we can successfully increase both the active involvement of our members, volunteers and supporters and our fundraising income. The Trustees and Senior Management Team will together balance and manage the resources available and the more detailed operational plans year by year with the aim of achieving as many of these objectives as possible. We hope that everyone reading this plan will turn to the insert in the final page, and think about how to support and join with us in improving life for everyone affected by IBD.

Elaine Steven
Chairman

Richard Driscoll
Chief Executive



Public awareness of Colitis and Crohn's

In May 2009 the NACC Trustees commissioned Ipsos Mori to undertake a survey of public awareness of IBD. Face-to-face interviews were conducted with a sample of 2,023 people which was weighted to be representative of the UK population. [The full report can be found at www.nacc.org.uk/research/reports](http://www.nacc.org.uk/research/reports)

As can be seen from the bar chart below, the survey confirmed a much lower awareness and understanding of Inflammatory Bowel Disease than other equally or less prevalent conditions such as Parkinson's Disease and Multiple Sclerosis. Awareness of Ulcerative Colitis was significantly lower than for Crohn's Disease.

Of the three possible names - Ulcerative Colitis, Crohn's Disease and Inflammatory Bowel Disease - the analysis of all responses reveals that 33% of people had heard of all three names, 26% knew of two, 23% knew just one and 18% of people had not heard of any of the three possible names.

Unlike the more well-known illnesses which show a sustained level of awareness across all age-groups, the survey found that awareness of Crohn's, Ulcerative Colitis and Inflammatory Bowel Disease was much lower among people under 25 years of age. This is very concerning because many young people will be diagnosed with IBD in their teens and twenties at a time when school, college and social relationships are being developed.

More awareness and understanding of what it means to have IBD among their peers would be of great assistance in all aspects of their lives.

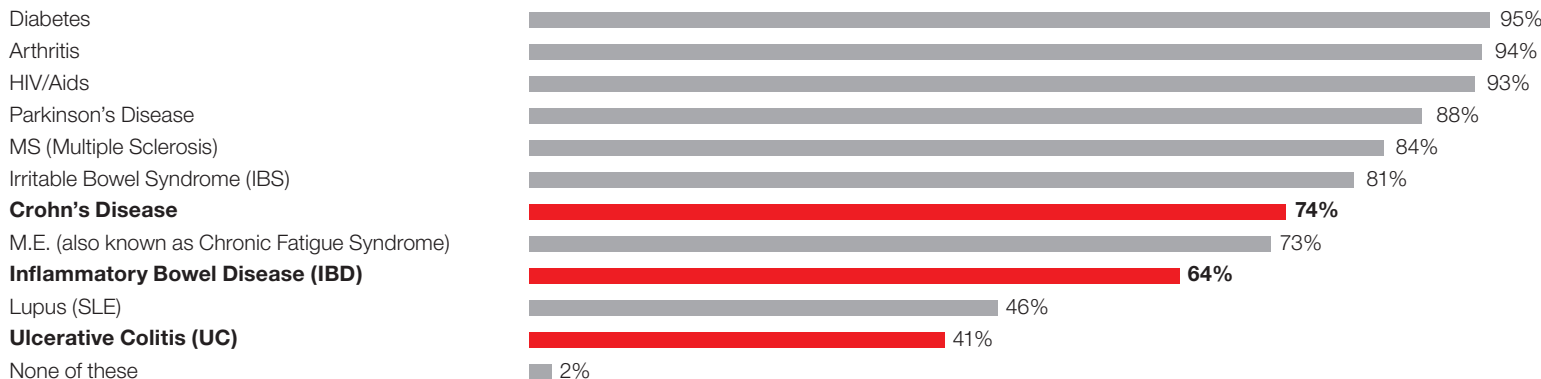
54% of the sample said they knew someone diagnosed with IBD, Crohn's or Colitis. 21% of those who did know someone could not name a single symptom of the condition.

These findings provide us with a benchmark for assessing whether NACC is successful in raising awareness over the three years covered by this Plan, and also guide us in developing more specific publicity objectives, suggesting we should focus particularly on younger age groups.

Ulcerative Colitis and Crohn's Disease are more prevalent in the UK than Multiple Sclerosis or Parkinson's Disease and yet are less well-known

Awareness of chronic illnesses

Which of the following chronic (i.e. ongoing) illnesses have you heard of?



Awareness of IBD, Ulcerative Colitis and Crohn's Disease, is particularly low in young people at the age that they are most likely to be diagnosed

NACC's Themes 2010-2012

In developing this plan, several themes emerged as important priorities for NACC in the immediate future. These are not entirely new areas of work, but represent a new or specific emphasis that the Trustees believe should be taken into account across all areas of NACC activity during the next three years.

Awareness of IBD

The Trustees have decided that increasing awareness should be an important objective in all NACC services and activities and have a pre-eminent place in this NACC Plan. Greater understanding of Ulcerative Colitis and Crohn's Disease and what it means to live with the conditions would help every person who is affected by IBD in their daily life and would assist every area of NACC's work.

Young People who have IBD

Half the 10,000 people diagnosed with IBD each year are under 29 years of age at the time of diagnosis, many in their teens or early twenties, on the threshold of adult life. NACC's 'IBD and Me' research project identified many important issues that young people can face: impaired growth and self-image, interrupted education, separation from peer groups, personal relationships, first job, transition to independence from family and transition to adult health services. Some of these difficulties are not unique to young people, but have a more intense and perhaps cumulative impact at that time of life. The Trustees believe that an

increased focus on supporting young people through these stages may significantly improve their chance of leading a more complete life within the constraints of their IBD.

A focus on 'Living with IBD'

NACC should consider the non-medical aspects of living with IBD in a systematic way, identifying priorities, considering how NACC can best intervene, and developing plans for research, campaigning or NACC services accordingly.

Key areas will be:

- The psychological impact of IBD at all ages on the individual person and their relationships.
- The impact on the close family of someone having IBD.
- How education and employment are affected and how disadvantages caused by IBD can be minimised.
- The financial impact of IBD - direct and indirect costs, such as prescription charges, loss of earnings, statutory benefits related to Sickness, Disability and Work

- Disadvantage in obtaining insurance cover
- Availability of toilets, travel and parking issues

Meeting everyone's needs - developing inclusiveness in NACC

NACC has developed a good range of generic support and information for people living with IBD, including a wide range of more specific publications providing detailed information about particular issues such as fertility, pregnancy, smoking etc. There are groups of people who have IBD and who have shared identifiable concerns and issues, for example people from ethnic minorities, the gay community, people in prison, people with IBD who also have particular visual or hearing needs. The Trustees intend that NACC should now begin to reach out in a more planned and comprehensive way to any such groups who have been under-represented within NACC in the past.

'Empowering' people who have IBD

Empowering is a concept frequently used in relation to people living with long-term illness, but is not one that NACC has hitherto adopted. The concept underpins initiatives such as the Expert Patients Programme which seeks to give people the confidence to participate effectively in the management of their condition. Having IBD can lead to loss of self-esteem and self-confidence, and NACC has developed services and activities to support people individually and collectively to meet the challenges that IBD presents: individually through direct telephone or email support, through the



solidarity of being a NACC member or through the positive experience of becoming a NACC volunteer or supporter, and collectively through the campaigning and awareness activities that seek to change public perceptions, attitudes and services.

In this plan NACC will increase the range of formally organised opportunities for people to explore these issues together through shared activities and online communities, building on the concepts of mutual support and collaboration that have been at the heart of NACC's approach through all its 30 years.

iNACC

Although NACC is always conscious that there are many people who do not have access to or use the internet routinely, an increasing number of people of all ages do. The internet offers opportunities for people to come together and be involved in NACC through sharing information and

giving mutual support in new, flexible and economic ways. This is an area that NACC is keen to develop across all its activities and services.

Adapting to the impact of devolved government in the UK

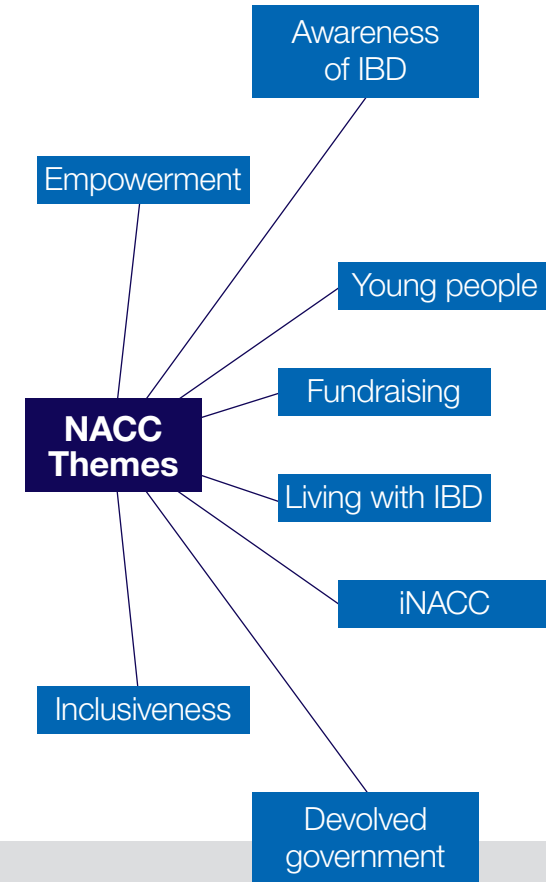
Particularly in NHS services, but increasingly in other aspects of public policy and provision, there is a growing divergence as a result of government being devolved within the four UK countries. For example, the Scottish Government has already set up a separate system of regulation for charities active in Scotland.

Across all NACC activities, awareness of the potential impact of these changes needs to be taken into account. There may be a need or an opportunity for NACC to develop aspects of its work in different ways in the different countries.

Raising funds to maintain and develop NACC's work

NACC cannot sustain and improve its range of activities and support for people with IBD without also increasing its income. NACC has traditionally relied almost entirely on voluntary income and in 2009 to support all activities NACC needed to raise about £35,000 every week. Our plans for 2010-2012 aim to improve and extend how NACC meets the needs of people affected by IBD.

The Trustees recognise that fundraising will need to become a more prominent part of NACC's activities to enable us to meet the challenges and achieve the vision set out in the following pages. NACC will need the help of everyone to support our fundraising as well as being involved in the service and campaigning aspects of NACC's work.



The Challenge, Vision and Objectives

The NACC Plan 2010-2012

Areas of Work



NACC's campaign for 2010 calls for everyone with IBD to "Step Up and Be Counted"

Raising Awareness of IBD

The Challenge:

People who have been diagnosed with IBD often feel that other people do not understand what it means to live with IBD and therefore feel very alone. Crohn's and Colitis can seem almost invisible as illnesses with the primary symptoms being diarrhoea, weight loss, pain and fatigue. Patients commonly find it difficult and embarrassing to explain their illness to their friends, colleagues and employers.

As the Ipsos Mori survey for NACC showed, the public, which includes teachers, employers and NHS managers, generally don't understand the real day-to-day impact of the condition on people's lives and that lack of understanding affects the decisions they make, for example about the priority to be given to IBD care in the NHS.

Our Vision Is:

IBD becomes as well known as other long-term conditions such as Parkinson's Disease and young people particularly are more aware of Crohn's Disease and Ulcerative Colitis.

People understand both that IBD is a serious illness and that many of those affected do succeed in adapting to life with IBD and lead productive and fulfilling lives.

The benefit of greater awareness and understanding will be to lessen the social embarrassment and stigma of having IBD. People who have IBD will find it easier to be open about their illness, the impact it has on their life and the support that could help them achieve a better quality of life.

Objectives For 2010-2012

- Place raising awareness and increasing understanding of IBD at the centre of all that we do in NACC.
- Consider changing the name by which the Association is known to make the words Colitis and Crohn's more prominent.
- Plan awareness campaigns annually to target selected key audiences including health professionals and managers, politicians, schools and colleges, businesses and employers, the media, young people and the general public.
- Hold an awareness month in May each year, commencing in 2010, to focus on proposed themes - in 2010 this will be "Step Up and Be Counted", in 2011 IBD and Employment, and in 2012 Sport, Exercise and IBD.
- Raise awareness among IBD patients of NACC and the support the charity offers, and encourage them, their families and friends to support and join NACC.
- Raise awareness within and outside of NACC of people affected by IBD who have particular needs, for example people from ethnic minorities or those living with IBD in prison.
- Seek funding support to develop a major campaign to increase public awareness.



Over 7,000 enquiries to its information and support services are handled by NACC's staff and trained volunteers each year

Meeting needs for information and support

The Challenge:

All patients need to be made aware of and have access to good quality information and emotional support provided through a variety of channels and in an accessible way. All patients need to be aware of support services and be able to access them easily both early in their illness and at critical stages in their lifelong experience of IBD.

Our Vision Is:

People with IBD will have the information and education they need to understand and manage their illness confidently and the support to help them achieve their individual potential so far as possible within the constraints imposed by their illness.

Access to helpline services for individual patients and the opportunity to take part in group activities will help patients and their families feel less alone and will enable them to benefit from sharing experiences, comparing approaches and exchanging practical ideas on how best to live with IBD. Information, education and support will help to increase people's confidence and mitigate the impact of the disease on them and their family.

Objectives For 2010-2012

- Continue to provide high-quality one-to-one information and support services by telephone and email, with ongoing processes for review and improvement.
- Provide a range of high-quality information publications covering the medical and non-medical aspects of living with IBD.
- Provide information and education about strategies for living with IBD through a variety of audio-visual media and using IT developments creatively.
- Consider how to provide information and support to people who find traditional publications inaccessible or need information in other formats or languages.
- Publicise and provide personal grants to assist those affected by IBD who are on low incomes, and increase vocational support for young people.
- Develop a NACC programme providing opportunities for lay-led education in groups adapting models for long-term conditions.
- Work with IBD health professionals to improve awareness to information, education and support within health services and promote awareness of the services that NACC offers.



Changing society's attitudes and campaigning for better provision for people living with IBD

The Challenge:

Changing attitudes to IBD among the public is made more difficult by the continuing social taboos that surround bowels, bodily functions and faecal incontinence. This widespread social embarrassment creates barriers to open and helpful communication between patients, their families and friends, work colleagues, teachers and employers. Many patients decide to keep their IBD to themselves and say as little as possible. This lack of discussion, together with the perception that IBD is an illness that affects relatively few people, has meant that the real needs of people with IBD are often overlooked.

Our Vision Is:

People will know that IBD is a lifelong condition affecting 1 in 250 of the UK population and appreciate that the symptoms of urgency, diarrhoea, pain and fatigue are real, at times severe and may still affect people when the illness is in remission.

People will not shy away from talking about the impact of urgent diarrhoea on the daily activities of an IBD patient, but will acknowledge the reality and the distress it can cause and, where possible, will support the patient with any practical steps or emotional support that seems helpful. Those providing services will recognise that there are genuine continuing needs for assistance even though IBD naturally and repeatedly fluctuates in severity.

In 2009 NACC presented the needs of those with IBD to all four of the UK's devolved Parliaments and Assemblies

Objectives For 2010-2012

- Continue ongoing public awareness and education activities through the media to change attitudes to bowel problems and gradually reduce the social taboos, working with other organisations where this will be more effective.
- Seek opportunities for bringing IBD to the attention of politicians, organisations and the public to promote understanding of the illness, its impact on people's lives and what specific support would be helpful.
- Translate the learning from NACC-funded 'Living with IBD' Research into practical recommendations and action that will benefit people living with IBD.
- Inform relevant organisations how their activities and services could more effectively meet the needs of people who have IBD.
- Campaign for better provision to meet the needs of young people with IBD, and other specific groups whose needs are not being met by existing mainstream services.



Improving health services for people who have IBD

The Challenge:

Two national IBD Audits in 2006 and 2008, have shown that whilst services and care may be of high quality in some areas, there is considerable local variation in the resources, organisation and clinical quality of healthcare for people who have Colitis or Crohn's Disease. This situation has developed because the NHS has not had specific national plans or standards for these illnesses. The result has often been an inability to secure funding and management support for IBD because NHS attention has focused on other political priorities. Although the IBD community has now published national standards for IBD Services these have yet to be implemented systematically in the NHS.

Our Vision Is:

Across the UK there are defined IBD Services with well-trained staff who understand IBD and its impact on people's lives, offering safe, high quality care with a patient-centred approach. IBD Services will provide integrated care across paediatric, adolescent and adult services and across tertiary, secondary and primary care organisational systems.

Patients with suspected IBD will be referred for specialist investigation quickly. Patients will be able to choose between different approaches to ongoing outpatient care at different stages in their illness, depending on their confidence and ability to self-manage, and will receive the necessary information, education and support to do so. IBD Services will involve patients in reviewing services and planning changes.

One third of UK hospitals lack a dedicated gastroenterology ward and/or a specialist IBD nurse

Objectives For 2010-2012

- To work with health professional groups at national and local level to put in place an overall strategy for the improvement of IBD Services.
- To campaign for NHS implementation of the IBD Standards throughout the UK.
- To contribute to a support programme for IBD service development and regular audit of IBD services in all four UK countries.
- To support the development of service quality measures that reflect patients' experience of their IBD care and the outcomes of IBD treatment that matter to them.
- To create opportunities for education of health professionals, including those in primary care, about the experiences and needs of people affected by IBD.
- To encourage greater involvement of IBD patients in the design and improvement of services and to support the development of good practice for patient involvement.
- To promote the concept of IBD Patient Panels and provide support, training and opportunities for sharing experiences and knowledge between Panel members.
- To promote and support the involvement of NACC volunteer patient representatives in NHS services and IBD research projects.



Supporting IBD Research

The Challenge:

The ultimate goal shared by all IBD researchers and the other IBD patient organisations around the world is to find a cure for Inflammatory Bowel Disease. Until that happens IBD Research needs to cover not only the search for causes, cure and better treatments for the physical aspects of Ulcerative Colitis and Crohn's Disease, but also the social and psychological impact of the illnesses on patients and their families, the health and economic impact on society and the most effective approaches in providing health services. This is a very wide remit and NACC needs both to increase significantly the money it raises for direct funding of IBD research and to compete with other disease areas to influence public, commercial and charitable funds to invest in IBD.

Our Vision Is:

Progress in medical research within a few years that will enable a more certain prognosis to be given to patients about the type and severity of their disease and its longer term implications, and enable treatment to become more personalised with genetic profiling identifying which medical treatments are more likely to be effective.

In addition, there will be greater investment in 'Living with IBD' and research into IBD Health Services to identify how we can improve life for people and provide the evidence base for better services. By 2012 that NACC will have developed a more strategic approach to research, identifying where NACC funds can be most effectively used and creating opportunities to work collaboratively with other researchers and organisations to secure more external funding for IBD.

Almost £5,000,000 in research funding has been raised by NACC's members, Groups, volunteers, supporters and staff

Objectives For 2010-2012

- To increase the income available for NACC Research grants without detriment to NACC's other activities.
- To maintain three NACC-funded research grant programmes:
 - Medical Research,
 - Living with IBD Research
 - IBD Health Services Research
- To maintain high standards for assessment and decision-making on NACC-funded research.
- To establish a Research Strategy Advisory Panel representative of all areas of IBD Research to provide expert guidance to the Trustees.
- To seek opportunities for partnership applications for external funding for IBD research.
- To support others' research applications and projects where these meet NACC's research objectives.
- To encourage and support the involvement of IBD patients in developing ideas and priorities for IBD research and in giving patient perspectives on the involvement of patients in individual research projects.
- To support the development of a web-based resource to increase IBD patients' access to relevant clinical trials.



Members, Volunteers and Supporters

The Challenge:

NACC needs to build on the success of our present membership of 30,600 people to encourage the remaining 210,000 IBD patients to join NACC. This will involve conveying the intangible benefits of being part of NACC whilst at the same time fulfilling NACC's charitable objects of providing support to all who have IBD irrespective of membership. We have a firm belief that being a member of NACC is valuable for individuals and their families as well as being important for NACC both in terms of its authority as the national representative of IBD patients and a significant element in NACC's income.

We also need to manage our volunteer roles and supporter activities to make them attractive, meaningful and rewarding whilst at the same time meeting our responsibilities as a public organisation.

A key aim must be to encourage people who have IBD, but who are now well, to continue as active members, volunteers or supporters, helping NACC to achieve the vision set out in this plan.

Our Vision Is:

Everyone is encouraged to join NACC when diagnosed and finds it valuable to continue as a member. Their families and friends also join NACC as members, volunteers or supporters. People continue to be part of NACC even when they have sustained periods of remission.

Through volunteering and supporting NACC, people who have IBD develop their skills and personal confidence which then helps them to overcome the barriers or disadvantages that IBD has imposed and to fulfil or even increase their potential achievement in their education, employment or daily activities. (Examples are a volunteer NACC-in-Contact moving on to a new career as a counsellor and a volunteer fundraiser to a career in marketing.)

Membership of NACC costs only £12 per year, and is waived in the case of hardship

Objectives For 2010-2012

- Ensure all newly-diagnosed patients are told about membership and encouraged to join.
- Explore whether NACC membership can be provided free to new patients as part of the education and support offered by IBD Services.
- Develop NACC's membership structure and benefits to encourage as many people as possible to join.
- Increase membership numbers substantially to add to NACC's authority as the leading UK organisation representing IBD patients, families and professionals.
- Assist existing NACC members to encourage other IBD patients, family and friends to join NACC.
- Encourage members to be active within NACC and to support NACC.
- Encourage people to become volunteers and/or active members of NACC.
- Develop volunteer activities within NACC and provide high quality training and support.
- Increase the numbers of people supporting NACC through fundraising.



IBD and Me, NACC's online discussion board for 16 - 29 years olds, has over 1,000 young adults participating

NACC Groups, Networks and Communities

The Challenge:

Many people remain quite isolated after being diagnosed with Ulcerative Colitis or Crohn's Disease. The illnesses can be complicated and embarrassing to explain and NACC surveys have shown that many patients choose only to tell close family and friends. One consequence is that it can be quite difficult for people to identify other patients with similar interests and share experiences.

Our traditional volunteer-run NACC Groups have provided a great service to people over NACC's 30 years as the local face of NACC, but there are constraints imposed by volunteer time and by the fact that people naturally have a greater desire to talk with other patients and families when their disease is more active and tend to 'get on with life' when it isn't. We wish to create sustainable communities of people with shared interests or life experiences so that, when people wish to, they can network and make contact.

Our Vision Is:

Strong local NACC Groups provide the opportunity for local members to come together for education, support or fundraising and provide an effective local face for NACC in their community and for health professionals locally. Alongside these geographical NACC Groups there are vibrant web-based communities enabling sharing of experiences and mutual support through online communities or virtual networks.

Objectives For 2010-2012

- Continue and develop an effective network of NACC Groups across the whole of the UK providing educational meetings and social opportunities for IBD patients and their families to meet other people affected by IBD, and to develop awareness and fundraising activities as the local face of NACC.
- Develop web-based communities and networks to enable people to share experiences, interact and support each other in living with IBD or helping NACC.
- Promote and develop increased membership and Group activities in Scotland which has the highest incidence of IBD in the UK.
- Develop a network of young people with IBD who are selected and trained to lead group education and activity programmes for teenagers and young adults who have IBD.
- Promote Smilie's Network and arrange activity days and educational meetings for families who have a child diagnosed with IBD.



Marketing and Fundraising for NACC

The Challenge:

People who have IBD look to NACC to constantly review and improve upon the quality and scale of its services and activities. Their expectations are influenced in part by what other health-related charities, often much larger and better-funded than NACC, offer to their members and supporters. This Plan sets out how NACC wishes to maintain, extend and raise awareness of the services and activities that it offers. This cannot happen without continual, increasing and successful fundraising

15% of NACC's funding needs are currently met by membership subscriptions, which are kept low in order to achieve universal access and inclusion. The remainder comes through the enthusiasm and generosity of its supporters, solicitation to external funding bodies, and small income streams from merchandise and publications.

For a secure future NACC will need to be able to rely on continuing streams of income from a variety of sources. New funding sources need to be identified and developed to replace those affected adversely by donor fatigue or economic downturn.

Our Vision Is:

Fundraising will be developed as a strategic and integrated activity across the whole of NACC, valued and supported equally alongside NACC's traditional membership, service and campaigning activities. Our vision is that successful fundraising will support the re-positioning of NACC as an increasingly viable recipient of major funding.

Fundraising is recognised as an activity that has value over and above the money raised, by enabling those who participate as volunteers to do something positive and active in response to the diagnosis of IBD for themselves or their family. With support, people can develop skills and achieve goals that they might not have achieved without taking up the challenge of helping NACC.

Fundraising also offers the opportunity to meet and talk to others, and to enjoy a sense of participation and owning a stake in the charity. NACC is committed to providing the online and publication media tools to help those who wish to participate in fundraising activities.

NACC needs to raise over £5,000 per day to deliver its service, campaigns and research. Only 14p in every pound is spent on administration and governance.

Objectives For 2010-2012

- Grow income from events and challenge activities (walks, runs, cycling etc).
- Develop corporate awareness and fundraising income, including increasing support from pharmaceutical companies up to the 10% limit set by the Trustees.
- Develop Trust, Legacies and In Memoriam income.
- Develop individual giving and explore the potential for key supporters to make significant personal donations and 'open doors' for NACC.
- Reinforce awareness of fundraising needs across the organisation and provide support and guidance to maximise the effectiveness of individual and NACC Group fundraising.
- Reinforce and develop NACC 'brand' awareness through the website, digital and print media activity, NACC-branded merchandise and charity awards opportunities.

Information about IBD

What are Ulcerative Colitis and Crohn's Disease?

Ulcerative Colitis and Crohn's Disease are both forms of Inflammatory Bowel Disease (IBD); in both conditions a part of the intestines becomes swollen, inflamed and ulcerated. Symptoms include pain in the abdomen (tummy area), weight loss, diarrhoea and tiredness. Some people also get swollen joints, mouth ulcers, inflamed eyes or rashes on their body. Symptoms vary from person to person and they may flare up or improve at different times. They are not infectious.

What are the differences between Ulcerative Colitis and Crohn's Disease?

Crohn's Disease can affect any part of the digestive system from the mouth to the anus (back passage) and all the layers of the lining of the intestine may be inflamed.

Ulcerative Colitis affects the colon (the large intestine) and only the inner lining of the intestine is inflamed. Ulcerative Colitis affecting only the rectum is known as proctitis.

Who is affected by these illnesses?

About 1 in 250 people in the UK have either Ulcerative Colitis or Crohn's Disease, with Ulcerative Colitis being more common. The conditions affect men and women equally and most often diagnosed in younger people (between 10 and 40 years of age). There is greater likelihood of developing IBD if you have a close relative who has it.

What causes Ulcerative Colitis and Crohn's Disease?

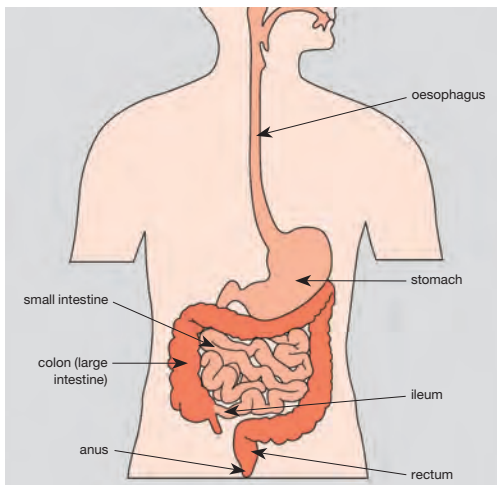
We do not know the cause although research has advanced our understanding of the illnesses and improved treatments.

The general view at present is that specific genes may make some people more likely to develop IBD than others, and that there are one or more 'triggers' which set off a reaction by the body's immune system. Possible triggers that are being researched include particular bacteria, viruses, some elements in our diet, plus many other factors in our modern environment. A great deal of research is looking at how the immune system works and how the inflammatory reaction can be better controlled.

The need for IBD Service Standards

As well as funding clinical and social research, NACC leads the way for a consortium of organisations who are pressing the four devolved UK Health Authorities to adopt and promote recommended standards for NHS services across the UK which will support an improved experience for patients and encourage best practice and clinical care.

NACC's largest research grant, made in conjunction with a grant from The Wellcome Trust, helped to identify the first genes for Ulcerative Colitis in 2008



NACC is collaborating with University College Hospital and King's College, London, to investigate the problem of fatigue in IBD, funded by The Big Lottery



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