



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

The NACC Plan for 2005 – 2008



Developing an active and caring organisation

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Acknowledgements:

The Trustees wish to thank Marianne Purdie and Karen Petticrew of NOP World Health and David Cotterell of Apex Consulting Ltd for their significant contributions to the research and discussions that helped prepare for the development of this Plan.

NACC was founded in November 1979 as a partnership of patients, their families and friends and the health professionals who care for them. The charity was created as a voluntary association of members working at the national level and through local groups to provide mutual support and to help all those affected by Colitis and Crohn's Disease, which are Inflammatory Bowel Diseases (IBD). The charity is now served by a staff team of 18 based at the NACC Office in St Albans, but it retains a very strong emphasis on volunteer involvement in all areas of NACC activity, from service provision to fundraising.

Now in its 25th year, NACC is a well-established and creative patient organisation which can demonstrate significant achievements:

- NACC has nearly 30,000 members (about 1 in 8 of the IBD patients in the UK)
- 70 local Groups covering much of England, Wales, Scotland and Northern Ireland.
- An Information Service responding to 7,000 enquiries a year and incorporating a support service for patients applying for Disability Living Allowance.
- A comprehensive range of publications
- NACC-in-Contact – an evening support line staffed by volunteers
- A successful quarterly newsletter (NACC News) and a website visited by an average of 800 users every day.
- Grants totalling £3.5 million for medical research and for social & psychological research.
- Respect and support from health professionals throughout gastroenterology.

Developing a plan for NACC for 2005 - 2008

Having achieved many of the goals set out in previous years, the question for NACC was what should the objectives be for beyond 2004? The NACC Trustees commissioned a large market research study into perceptions of NACC from NOP World Health and Apex Consulting Ltd. The findings from this research informed the Trustees' discussions at a Planning Day held in June 2004 from which this strategic plan for NACC has been developed.

Market Research Findings

The market research for NACC was undertaken independently by NOP World Health, who surveyed a range of people including patients with Colitis or Crohn's Disease attending 20 different hospitals, healthcare professionals and NACC members, current, past and potential. The primary aims of the research were to establish what level of knowledge people had about NACC, their views of the organisation and what activities the charity should be undertaking. The findings are summarised below.

Knowledge of NACC

All groups had a good understanding of what NACC offers, identifying NACC as providing information through publications, website, local Groups, raising awareness and fundraising for research.

Opinions about NACC

Respondents valued all the existing services. Information, support with day-to-day living and helping people feel less alone were seen as important roles for NACC. Raising awareness and funding research were also considered to be valuable activities by all groups. 70% of the ex-members who responded were satisfied or very satisfied with their membership. Respondents generally wanted NACC to do more in some areas, but not at the risk of current services. Health professionals wished to hear regularly from NACC.

Where NACC should aim to do more

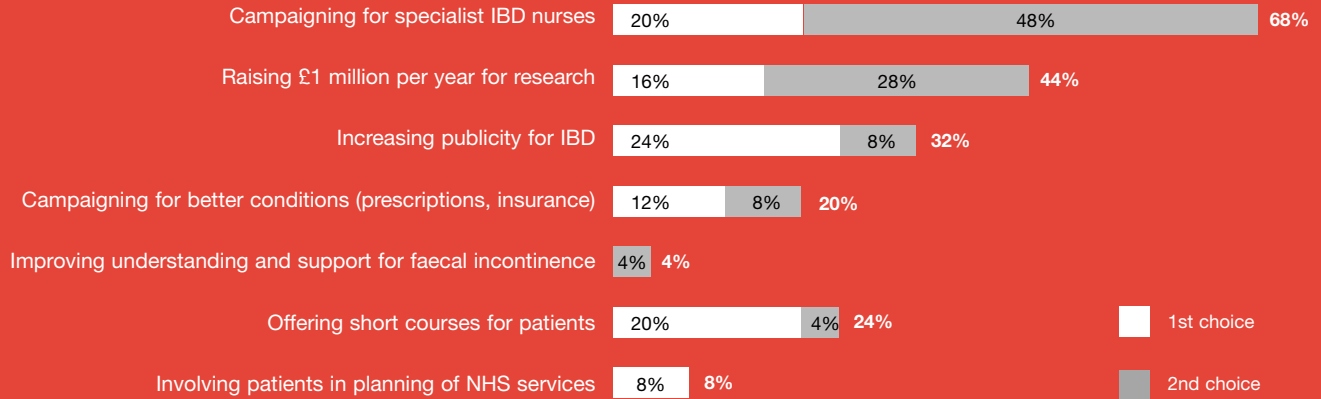
Members, Chairpersons of NACC Groups and healthcare professionals all identified similar areas:

- More awareness of Colitis and Crohn's Disease and of NACC
- Raising more money for research
- Campaigning on issues that affect the lives of patients and their families
- Campaigning for more specialist nurses

The full report 'Perceptions of NACC in 2004' is to be published on the NACC website.

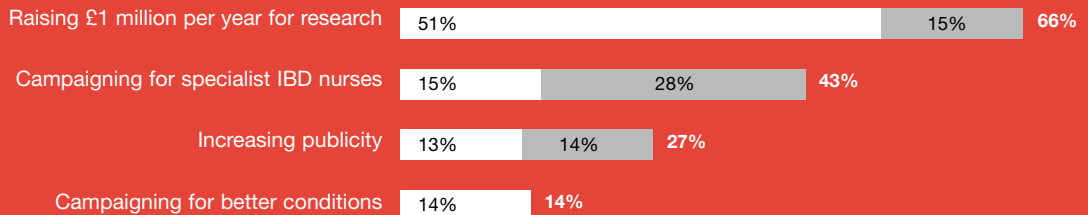
Future development of NACC – the top two choices

Base: all healthcare professionals (25)

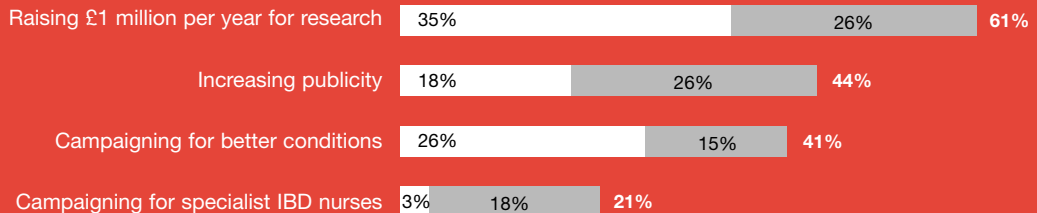


Future projects for NACC to develop – current members and chairpersons

Current members (287)



Chairpersons (34)



NACC's Aim,

As part of the process of developing a plan for NACC the Trustees agreed the following statements of NACC's Aim, Vision and Principles.

NACC's Aim

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

NACC's Vision

NACC should be a well-known and active organisation recognised for excellence in:

- providing support & information for IBD patients & their families.
- raising public & political awareness of Inflammatory Bowel Diseases.
- striving to improve healthcare services & provision for IBD.
- influencing the attitudes of society to achieve positive change for those affected by Inflammatory Bowel Diseases.
- promoting research into all aspects of Inflammatory Bowel Diseases & how they affect people's lives.

Vision and Principles

Principles underpinning NACC's Vision

NACC will be an active organisation with both members and volunteers taking an active role in achieving the objectives that have been agreed and with NACC taking a leading role in championing the needs and concerns of people affected by Inflammatory Bowel Diseases.

NACC will aim for excellence by basing its policies and plans on objective evidence wherever possible and by adopting recognised standards of quality in its services and practices.

NACC Trustees, members, volunteers and staff will observe the principles of compassion, equality and inclusion and to act with respect and integrity in their work for the Association.

Whenever possible the Trustees will forward NACC's objectives through research, development and service activities in partnership with Health Service, professional and other patient organisations and with the pharmaceutical industry.

The NACC Plan – Information and support

We will

Continue to develop the Information Service, recruiting a Benefits Specialist and improving our systems for monitoring and evaluation.

Explore how access to NACC's Information and Support Services can be effectively developed and promoted to meet the needs of callers in the most appropriate way.

Review the current 'positioning' of NACC's written information in relation to other information available to IBD patients and health professionals and consider how best to make NACC information more widely available.

Produce a booklet on Surgery for Ulcerative Colitis, a Guide to Incapacity Benefit and information in other languages for ethnic minority communities that are affected by Inflammatory Bowel Diseases.

Consider what new publications are required and how NACC can meet this need whilst also meeting the need to review and update existing publications at appropriate intervals.

Consider the potential value of short courses in Living with IBD in the overall development of NHS services for people living with long-term medical conditions.

Provide opportunities for interaction and mutual support between members through the NACC website.

Support for Young People

Develop more services and activities both nationally and through local Groups for younger members within the age range 16-29.

Support for Families

Continue NACC's existing policies to help families where a child has IBD, which are to work with CICRA and health professionals to increase awareness of the information and support currently available; encourage sharing of good practice in the transition from paediatric to adult care, organise 'family days' with NACC Groups in different parts of the UK and fund research into the experience of teenagers in living with IBD, particularly at school.

Consider ways of providing opportunities for parents of young people to share their feelings and support each other.

Consider how support might be developed for children in families where a parent has IBD.

The NACC Plan - Raising awareness

We will

Develop a major campaign or series of campaigns to raise awareness of Colitis and Crohn's Disease and of NACC with the aim of achieving much higher recognition by the public that Colitis and Crohn's Disease are serious illnesses. This work will begin in 2005 with a campaign focused on the need for more specialist nursing for people affected by Colitis and Crohn's Disease.

Increase awareness of Colitis and Crohn's Disease among those who have political influence or management responsibility for funding and specifying Gastroenterology services.

Encourage and support patients who have Colitis or Crohn's Disease in becoming patient representatives at national or local level in response to the Public Involvement opportunities within the NHS and related bodies.

Ensure through regular communication that health professionals have a good understanding of NACC's services and that they have access to NACC information materials for their patients.

The Trustees considered whether a general renaming or re-branding of the charity was necessary to achieve greater awareness, but decided that this would be unwise at this point because of the potential time and cost involved in this and the risk of losing the recognition that NACC has within the world of Gastroenterology. Instead, it was agreed that we should review and over time improve our communications materials in ways that emphasise NACC as a dynamic, active and personal organisation.

The NACC Plan - **Improving healthcare services**

We will

Undertake a campaign for more specialist nursing for people affected by Colitis or Crohn's Disease. This need may be met by IBD Nurses or by Gastrointestinal Nurses (GI nurses) with a broader remit but properly trained in IBD nursing. The aim is for each Primary Care Trust to fund a minimum of one GI Nurse.

Support the development of specialist nursing and underpin the campaign for more funded posts by commissioning research to review the evidence for the purpose and value of specialist nurses in Gastroenterology.

Work with the professional nursing bodies to assist in defining good nursing input for IBD and the specialist nursing role and to help build training capacity for the role within the framework set by Agenda for Change.

Work with the British Society of Gastroenterology and other professional associations and with the other Gastroenterology charities to establish a Strategic Framework for the future funding and development of services for Gastroenterology patients.

Assist in developing an independent document outlining good practice in the care of patients who have Colitis and Crohn's Disease.

Provide NACC training days on patients' experience of living with IBD and their perspectives on how health professionals can help, perhaps with accreditation for Continuing Professional Development programmes.

Support the development of patient panels or other initiatives through which people affected by Colitis and Crohn's Disease and the professionals involved in their care can exchange ideas on how local services for IBD can best be developed.

Consider funding research involving health professionals and IBD patients in working together to define what makes a good IBD service. The aim would be to identify both what is good service and models of how professionals and patients can implement 'user involvement' effectively.

The NACC Plan - **Influencing the attitudes of society**

We will

Develop actions based on the findings of our Social and Psychological Research projects, for example the recently-completed research on Managing IBD at Work.

Identify members who are willing to work as individuals or in teams on specific projects or campaigns, for example on eligibility for the Blue Parking Badge. Projects or campaigns may have a local or national focus and will be undertaken within a framework of accountability and support established by NACC's Group and Member Activities Committee.

The NACC Plan - Promoting research

We will

Increase NACC's fundraising target for research from £300,000 pa in 2004 to £500,000 pa by 2007, whilst continuing to encourage those who fundraise to support NACC's research and non-research activities equally.

Provide equal funding each year to *medical research*, which improves our understanding of the causes, mechanisms and possible treatments for Colitis and Crohn's Disease, and to *social, psychological and health services research*, which improves our understanding of the impact of the illnesses on people's lives and how services can best be developed to provide care and support. NACC will apply the same standards of quality assessment and monitoring to both programmes in accordance with peer-review principles approved by the Association of Medical Research Charities.

Undertake a formal review of NACC's research funding policy and processes to determine whether responsive mode funding continues to be the most appropriate way for NACC to obtain the best value from Research Funds and how NACC can make the most worthwhile contribution to IBD research.

Work with other organisations that fund research in Gastroenterology to coordinate funding activities where this would be beneficial.

The NACC Plan - Developing our Organisation

Governance

The Trustees have reviewed and approved changes to the structure, remit and membership of the committees through which the major areas of NACC's work are developed and managed. These changes ensure that the governance structure will appropriately support the development and implementation of the NACC Plan for 2005-2008.

Membership

We will

Review what NACC offers as the categories and benefits of membership and consider whether it would be appropriate to introduce a new form of relationship for those who do not wish to become or remain members, but who wish to continue their support of NACC.

Review all membership communications to ensure they express clearly the value of NACC membership and encourage people to consider how continuing their membership could help NACC and other people who have Colitis and Crohn's Disease.

Aim to increase the number of members through better marketing of NACC in hospitals and by following-up those who enquire but do not join and those who allow their subscription to lapse.

Encourage members to be active within the Association by extending and publicising the range of opportunities for people to become involved.

Consider how we can increase the range of opportunities for interaction and mutual support between members through national action, particularly the NACC website, and through local Groups.

NACC Groups

We will

Provide a clearer statement of the purpose of NACC Groups as the local face of NACC explaining the range of core, optional or nationally-supported activities that Groups can undertake.

Provide Group Organising Teams with good practice guidance and support to help them in undertaking or coordinating the range of NACC activities locally.

Introduce the use of 0845 number technology to provide call management capabilities throughout the country, ensuring consistent access to Groups whilst also providing privacy and protection for Group volunteers.

Introduce a framework for young adults to work within NACC Groups.

Improve how we communicate the role of local Groups to new members of NACC.

Make members aware that they can if they wish receive information about and take part in other NACC Groups beyond their local one.

Encourage the development of new Groups within the limitations of current resources.

Volunteers

We will

Develop a new, more coordinated approach to how we respond to offers of help from members and how we encourage more volunteers to assist in NACC's work.

Integrate our volunteer policies and training opportunities to ensure greater consistency and to enable volunteers to see how they and their role fit alongside others as part of the National Association.

Consider how NACC's volunteer policies and practices may need to change to meet commonly accepted good practice standards.

Introduce a framework for volunteers to work on Projects or Campaigns.

Encourage more people with a personal interest or involvement in IBD to consider helping NACC in some voluntary way.

Staffing

We will

Discuss with key staff how their roles may need to change to meet the needs of the NACC Plan, for example the Group Development Officer has become the Group and Volunteer Development Manager.

Review regularly the progress made in achieving the objectives of this plan and consider whether changes to staff roles or the staffing establishment are needed.

Funding and fundraising

The Trustees recognise that this Plan will require more funds to sustain the work envisaged, but believe this can be achieved without the essential nature of NACC changing so that it comes to be perceived as primarily a fundraising charity.

The Trustees appreciate the support given by members, their families and friends and will continue to encourage fundraising by groups and individuals that raises awareness, provides opportunities for mutual support in an informal and enjoyable context and enables people to show their support for NACC and for all those who have IBD.

Monitoring and reporting progress

Progress towards these objectives will be regularly reviewed by Trustees and senior staff at Council and Committee meetings in order to ensure that the necessary operational plans are developed and implemented and to manage resource issues and conflicting priorities. The Plan will be updated each year in the light of changes within or external to NACC and progress towards the objectives in the Plan will be reported to members annually.

NACC's Vision

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- raising public & political awareness of Inflammatory Bowel Diseases.
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- influencing the attitudes of society to achieve positive change for those affected by Inflammatory Bowel Diseases.
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