INVOLVE

Supporting public involvement in NHS, public health and social care research

NHS
National Institute for Health Research

newsletter

Summer 2010

Welcome to the Summer 2010 newsletter which includes articles from groups and organisations sharing their plans and ambitions for public involvement in research.

Have you booked your place at the INVOLVE 2010 Conference? It promises to be an exciting and inspirational event and we look forward to seeing you all there!

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Developing a database for patient and public involvement in the North West

Who we are

The NIHR Research Design Service for the North West (RDSNW) has been supporting researchers in their Patient and Public Involvement (PPI) activities for several years. It has long been apparent that one of the issues researchers can find difficult is making initial contact with members of the public with a view to their involvement in research. Early in 2009 the RDSNW, along with the NW Strategic Health Authority, held a meeting of researchers, researcher managers, service users, carers and staff from voluntary organisations to explore ways in which people in the North West could work together to promote and support PPI in research.

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INVOLVE Conference 2010

Public involvement in research: innovation and impact

November 16th-17th 2010, Nottingham

To book your place or to find out more about the conference visit:

www.profbriefings.co.uk/involve2010

If you would like a copy of the newsletter in an audio or large print version, or if you would like it in another format, please contact us. Printed on recycled paper.

One suggestion was that there should be a list of groups of patients and/or members of the public involved (or interested) in health research. RDSNW therefore began to consult with local service user/carer groups to explore the kind of database that might be produced.

What we did

In the autumn of 2009 an informal scoping exercise was undertaken. Its aims were to gather:

- opinions on the willingness of groups to be involved in a database;
- any ideas on what a database might provide for both professionals and user groups;
- information on any issues and or needs identified by the groups;
- contact details of groups that could be contacted in the future.

Using prior contacts, word of mouth and web-searching, an initial list was produced that concentrated on groups which have some link with research and health issues. One-page flyers outlining the database consultation were created and distributed to the identified groups. In all, we talked with fifteen groups. A wide range of interests was represented: older people; palliative care; maternity; stroke; cancer; clinical psychology; heart disease; lung disease; mental health; primary care; research implementation; local and cultural communities. Ten of the groups either have, or are linked to, websites.

What the groups said

The majority of contacts were interested in the idea of a database that might offer opportunities for involvement and that could tie them into the NW PPI community. The main points raised were:

- Some members are more interested in research than others;
- Group members are often members of more than one group;
- Members are often very busy;
- Several groups were concerned about being overburdened with requests – a clear pathway and clear information from researchers would help them decide what to get involved with;
- Some wanted to stipulate what they would be willing to consider, such as topic, locality, payment;
- It was suggested that an explanatory leaflet for researchers would be helpful in making sure that approaches to groups were appropriate;
- Researchers need to understand that groups can be advisers and partners, but are not subjects;
- Groups want acknowledgement and information when they get involved – previous experience has been variable – a ‘thank you’ is appreciated;
- Many groups are very loyal to the organisation that supports them and would put this commitment first;
- Most groups preferred that potential involvement opportunities should be local, but a few were willing to travel within the region;
- More experienced service users may be able to contact and support new people;
- Networking and sharing among groups is seen as valuable and a possible function of the proposed database – a sense of being part of something bigger, hearing about involvement and learning opportunities;
- Rural groups can feel isolated and would value being more involved in regional activities;
- Some groups will ask for payment for involvement.

What we will do now

It is clear from our work that there is interest in setting up a contacts database, however, practical issues need to be carefully thought through to ensure benefits for both groups and researchers.

Contact: Sara Morris, Public Involvement Specialist, NIHR RDSNW, Lancaster University. Email: s.m.morris@lancaster.ac.uk

INVOLVE Coordinating Centre News

Payment for involvement: a guide to making payment to members of the public actively involved in NHS, public health and social care research

We have been working to up-date our guide about making payments for involvement in research and we are delighted to let you know that it is now available. The guide includes three sections.

- The first explains the general principles in relation to making payments for involvement, for example, why we think this is best practice; issues that need to be considered; and the need for researchers and organisations to set out their policies and procedures in detail and in advance.
- The second section provides more detailed information about specific issues, intending to help the reader think about what they need to know and do to set out their policies and procedures.
- The third section is a series of appendices which provide a wide range of different sources of information, examples and useful templates.

The revision process for the guide has taken longer than planned because we knew the Department of Work and Pensions were planning changes to state benefit regulations which would reduce the benefit barriers to involvement. We waited to see what these changes would bring. While it is good news that new benefit regulations have come into force which will make it easier for people to get involved in health and social care services, it is not yet clear if these changes apply when getting involved in research. As we explain in the guide (see page 10) we are working with the Department of Work and Pensions and the Department of Health to try to clarify this situation.

You can download the revised guide from www.invo.org.uk/INVOLVE_Publications.asp or request a copy of the guide from the INVOLVE Coordinating Centre.

Sharing innovative practice for training and support for involvement in research

In January 2010, we brought a group of people together at a workshop to think about training and support for public involvement in research. The need for the workshop had been suggested by a number of reports which identified that while many researchers and research organisations are developing public involvement strategies and practices, they have not always had the resources or capacity to develop/deliver training to the members of the public getting involved, or for researchers to develop their skills in this area. The workshop aimed to:

- share information and learn about innovative ways of providing training and support for public involvement in NHS, public health and social care research
- consider how training and support needs for public involvement in research can be better addressed.

It was attended by around 50 people – some of these had taken the lead in developing a training or support approach; others had responsibility for implementing public involvement in their organisation.

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Nine different examples of training and support were shared at the workshop. These included training courses for members of the public to develop their knowledge about research; a Masters level module for health professionals; supporting individual people (both public and professional) through action learning sets; coaching and shared learning groups; and how organisations can develop approaches to support public involvement. Details of these examples can be found in the report of the workshop – Examples of training and support for public involvement in research: Sharing innovative practice workshop. You can download it from our website www.invo.org.uk or contact the Coordinating Centre admin@invo.org.uk to request a printed copy.

Following the workshop INVOLVE is developing an on-line directory of examples and information about training. It is hoped this will enable people to access, from one location, information about different approaches which have been taken and identify models to adopt within their own practice. If you know of any examples of training or support for public involvement that could be included, please email us details at training@invo.org.uk by 1st September 2010. To find out more, please contact Lucy Simons at the INVOLVE Coordinating Centre (lsimons@invo.org.uk and 02380 651088).

**Plenary speakers at the workshop:
L to R (back row) Derek Stewart, Leanne Metcalf, Ade Adebajo (chair), Sara Morris (front row) Katrina Wyatt, Rachel Purtell**

Interesting articles and publications

- **Public Involvement in Research – How can organisations collaborate to improve involvement?**

Rosie Davies and David Evans, April 2010. This report was produced at University of West of England on behalf of fourteen stakeholder organisations in Bristol and the South West. Within the Bristol and South West area, a number of research organisations and research groups have established a steering group to look at greater collaboration around public involvement in research.

The first task of the steering group was to undertake a collaborative scoping study. This is the report of the scoping study and describes the context of involvement in the Bristol and South West regions, how public involvement is being undertaken and the key issues and challenges for developing greater co-ordination and collaboration. The study is available at http://hls.uwe.ac.uk/suci/Default.aspx?pageid=9

- **New guidance from the Mental Health Research Network to help with payments for involvement**

The Mental Health Research Network (MHRN) has commissioned a comprehensive policy to cover payments for those involved in the work of the MHRN and research in general. Two new resources are now available on the MHRN website which will be particularly helpful when managing payments to people who are receiving state benefits. The first is a comprehensive explanation of the benefit conditions and systems around paid and voluntary involvement. The second explains helpful benefit rules and benefits pitfalls to avoid. www.mhrn.info/index/ppi/SUR/Payment-information.html

• Patient and public involvement (PPI) in research groups – Guidance for Chairs
TwoCan Associates for the UK Clinical Research Collaboration and National Cancer Research Institute.
This guidance has been written to assist Chairs of Research Groups that include Patient and Public Involvement (PPI) members. It focuses on the aspects of Chairing that PPI members have identified as being important. The following general principles are outlined in the report:

- Make sure you get to know your PPI members
- Make PPI members feel welcomed, included and respected
- Make clear to all research group members that PPI perspectives are valued
- Treat PPI members as equals – equivalent to other members of your group
- Ensure PPI members are given practical support so they can meaningfully and effectively contribute to meetings
- Help other group members understand the benefits of PPI and encourage them to give the PPI perspective due consideration.

The full guidelines are available on the TwoCan website www.twocanassociates.co.uk/pubs.htm

• What difference does it make? Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients.
Steve Gillard, Rohan Borschmann, Kati Turner, Noerman Gooderich-Purnell, Kathleen Lovell and Mary Chambers
Health Expectations, volume 13, Issue 2, June 2010, pages 185-194.
This study investigated the potential to provide empirical evidence of the impact of service user researchers on the research process.

• Public involvement in health research: a case study of one NHS project over 5 years
Amanda Howe, Sarah Delaney, Jacqueline Romero, Adele Tinsley and Penny Vicary
Primary Health Care Research and Development 2010, volume 11, pages 17-28.
This study reports the evaluation of public involvement in health research in one project based within NHS and university partnerships in the Norfolk area of England.

If you have written or know of any publications or articles relevant to public involvement in research that might be of interest to readers, please contact Helen Hayes at the Coordinating Centre with details: hhayes@invo.org.uk

INVOLVE publications are available to download from our website www.invo.org.uk or you can ask us to send you the copies you need. Call us on 02380 651088 or email admin@invo.org.uk

Lay Advisory Panel for bone research

By Christine Barton

I am a member of a lay panel that has been set up to advise a Biomedical Research Unit based in Sheffield Teaching Hospitals Foundation Trust. Our panel was set up in recognition of the fact that patients and the public have different but equally valuable views about:

- what research it is most useful to fund and carry out
- how patients/public should be involved in the research
- what information should be provided for people who take part in trials
- how the results of research can be made public.

Biomedical Research Units (BRU) are partnerships between National Health Service (NHS) Foundation Trusts and Universities. Each partnership is awarded funding from the Government to carry out research in a particular disease area. The aim of a BRU is to turn laboratory discoveries into treatment for patients, known as research that is about improving 'bench to bedside' practices.

In 2008 Sheffield was awarded funding to set up two BRUs, one looking at bone disease (Bone BRU) and the other at cardiovascular disease (CVBRU). Overall funding for both units during the next four years was in the region of £7.75 million, a not inconsiderable sum. The research teams, working to INVOLVE guidelines, set up panels to make sure that patients and the public could take part in guiding their research.

Research staff from Universities and the NHS are not used to listening to what patients have to say about spending research funding and patients are not used to being asked. We are all learning together.

It wasn't difficult to apply. The opportunity was advertised in NHS newsletters, the Metabolic Bone Centre, the Cardiovascular Dept and through word-of-mouth. We were asked to describe why we were interested, if we had any experience and what we might be able to offer. We were invited to a discussion with BRU staff and two panels of people were selected. The first exploratory meeting was held in March 2009. It was an enjoyable opportunity allowing a group of nervous people, both panel members and staff, to meet each other and begin working together.

Staff have worked very hard to demystify research procedures. Our first meetings, explaining facts about research, gave us more confidence. We didn't feel 'blinded by science' and began to recognise we have a valuable role to play.

I have been impressed by the way that busy people have been prepared to give their time explaining to us what they are doing. We have been encouraged to think that our contributions are worthwhile and our views are respected. We are not paid to be panel members, but all our expenses are met. Buffet lunches have allowed us to mingle informally. We had a Christmas meeting when we worked in mixed teams with staff for a Christmas quiz and were each given a small Christmas present. The day was very good for our morale and encouraged us to look forward to 2010.

During training meetings in our first year we have:

- met staff from the BRU and had a conducted tour of the new research accommodation
- been introduced to research practices, procedures and current research proposals

- developed procedures to help us review and comment on research proposals
- suggested improvements to patient participant information sheets
- learned about the work of Ethics Committees
- established regular business meetings that we will manage, to guide how we work.

We have been encouraged to take control of our panel by developing ‘terms of reference’ and identifying members to take the minutes and chair meetings. This gives us an opportunity to discuss research proposals and procedures that have been presented and agree how we want to comment.

Now the foundation work has been done we look forward to going into a new year and playing an important role in the BRUs in Sheffield. We want to recruit new members to join us and to bring an effective voice from patients and the public into bone research.

Christine Barton on behalf of the Lay Advisory Panel for Bone Research
Sheffield Teaching Hospitals Trust
For more information please contact Dr Angela Rogers, PPI Lead, Bone BRU
Email: angela.rogers@sheffield.ac.uk

Our story

By Sue Boase and Julie Grant

As researchers at the General Practice and Primary Care Research Unit (GPPCRU) at the University of Cambridge, we have had a long-standing interest in involving patients and public in research. We welcomed therefore the opportunity in 2008 to undertake a scoping exercise of Patient and Public Involvement (PPI) in research activities in the East of England and more specifically in the Cambridgeshire area. Not only did it give us the opportunity to make contact with existing initiatives, it also provided the chance to build both awareness and action closer to home.

We conducted learning sets within our Unit, in which ideas, thoughts and beliefs about PPI in research were discussed and then presented to our group meetings. By opening up discussion in this way some of the issues and concerns researchers may have had with the idea of involving members of the public were resolved.

The scoping exercise resulted in the writing of a discussion paper for the Cambridgeshire Research Development and Support Unit and a position paper for our Unit. The discussion paper provided the evidence required to recommend appointing a regional PPI co-ordinator.
Within the GPPCRU a database has been created to log exactly who is involved with individual research studies. This will enable us to gain an overall picture of PPI activity in the Unit and also help to ensure that any training needs are addressed. We hope this work may contribute not only to the acknowledgement of the value of involving PPI members but also serve to provide feedback and support to those who have given their time and energy to helping our research.

Email Sue Boase sab72@medschl.cam.ac.uk
or Julie Grant jg274@medschl.cam.ac.uk

Deadline for contributions for our next newsletter: **6th December 2010**

If you have any questions on contributing to the newsletter, please contact Helen Hayes Tel: 02380 651088 Email: hhayes@invo.org.uk

Getting more patients and carers involved in dermatology research

By Amanda Roberts and Jason Simons, Members, Centre of Evidence Based Dermatology Patient Panel; and Carron Layfield, Patient Panel Co-ordinator.

Background

The Centre of Evidence Based Dermatology (CEBD) is part of the University of Nottingham. Its director is Professor Hywel Williams, who is both a consultant dermatologist and an academic researcher. The research carried out in the department is based around closely related cogs that work together to drive our research. As shown in our logo on our website, patients and carers are central to this process.

The three cogs of CEBD are:

- The Cochrane Skin Group (CSG)
- The UK Dermatology Clinical Trials Network (UK DCTN)
- NHS Evidence-skin disorders.

More information about CEBD can be found on our website www.nottingham.ac.uk/dermatology

At CEBD we are proud to have a strong record of involving patients and carers in our research. For example, as mentioned in the recent INVOLVE National Institute of Health Research (NIHR) Senior Investigators Report, the involvement of carers of children with eczema in the design of the Softened Water Eczema Study (SWET) led to an important change in the design of the study. This change, which led to all those taking part having access to a water softener in their home for some part of the study, made it much easier to recruit successfully. The study, investigating whether the use of a water softener will improve the eczema of young children living in hard water areas, has now recruited to target and the results will be published shortly.

Another example is our study development work with patients affected by the painful and debilitating ulcerative skin condition pyoderma gangrenosum. Having discussed the trial with patients we amended the trial design to include their feedback. For details of this study please see www.stopgaptrial.co.uk

In the past, patient and carer involvement in our work has been done on an individual or study basis. From feedback and our own observations we recognised that we needed to give those involved in our research more support and training. Also, skin disease is very diverse and we needed to increase the breadth of those involved in our work. It was felt that setting up a CEBD Patient Panel would help us to achieve these aims.

Establishing the CEBD Patient Panel

At the end of 2008, the Centre was awarded a large research grant (a National Institute for Health Research Programme Grant) to investigate reducing uncertainties for the treatment and prevention of skin disease. This meant that we needed more people to help us with our work and so we felt the time was right to set up the CEBD Patient Panel. This grant provided the resources we needed for travel expenses and to pay for meetings and training events for panel members. These funds are limited though, and all panel members provide their time and expertise on a voluntary basis.

In spring 2009 we began recruiting patients and carers into the panel by contacting those already involved in our work. We also advertised the panel on our own website. The next approach we took was to contact relevant patient support groups and charities to ask if they would help us to get people involved. All the groups we approached were extremely helpful and put links on their websites about the CEBD Patient Panel and/or articles in their newsletters. We would particularly like to thank the National Eczema Society, the Vitiligo Society, The Psoriasis Association and Skcin for their support. By autumn 2009 we had over 25 panel members (both patients and carers), affected by a wide variety of skin disorders including acne, psoriasis, eczema, vitiligo, skin cancer, hailey-hailey disease and pyoderma gangrenosum.

CEBD Patient Panel Activities

We held our first training event at Attenborough Nature Reserve in Nottingham in November. The aim of this one day meeting was to:

- Provide background information on CEBD and our activities.
- Explain what clinical research is and show the many different ways in which patients and carers can get involved.
- Explore potential roles of the panel through workshops.

Eighteen panel members attended and delegate packs with all the relevant information and presentations were made available to those who couldn't attend. Feedback from attendees revealed that most found the day extremely useful with the best aspects of the meeting for many being the enthusiasm of the group, the opportunity to have a constructive input and the workshops. It was agreed during this meeting that feedback to the panel about their input into our research was really important to them, as was regular communication. In order to try and fulfil this, we aim to produce a CEBD Patient Panel newsletter on a bi-monthly basis.

We're really pleased with the response we've had from panel members about getting involved in CEBD research development activities. Examples of involvement include:

- Reviewing and commenting on surveys to help with study development before circulation to the wider community.
- Taking part in focus group discussions to help with the development of studies.
- Joining a Trial Steering Committee to ensure that the needs of patients are considered throughout the study.
- Joining Steering and Executive Committees of the UK Dermatology Clinical Trials Network to represent the views of patients and carers in this organisation.
- Becoming involved in Cochrane Systematic Reviews.

What next for the CEBD Patient Panel?

It is important that we keep the momentum of the panel going, and with this in mind we are planning a further training day which will cover some aspects of clinical research in more detail. Due to the continued presence of the panel on the CEBD and patient support group websites we are continuing to get enquiries about the panel and membership of the group is growing.

We will continue to engage panel members via regular newsletters and e-mail updates and hope that more will become involved in our research activities with time. If you are interested in finding out more about the CEBD Patient Panel or CEBD in general, contact Carron Layfield, Patient Panel Co-ordinator, Centre of Evidence Based Dermatology, University of Nottingham, Room A103, Kings Meadow Campus, Lenton Lane, Nottingham NG7 2NR
Email carron.layfield@nottingham.ac.uk
Tel: 0115 8468625, Fax 0115 8468618
Website: www.nottingham.ac.uk/dermatology

The North West People in Research Forum – involving and engaging patients and the public

Members of the public, researchers and research funders have been working together to plan a new Forum, which will promote and support patient and public involvement (PPI) and public engagement (PE) in health research across the North West.

In February 2009, the North West Strategic Health Authority (SHA) and the National Institute for Health Research (NIHR) Research Design Service (RDS) for the North West hosted a workshop for researchers, research managers, service users, carers and staff from voluntary organisations to explore ways in which individuals and organisations in the North West could work together to promote and support PPI in health research. Those attending the workshop recommended that stakeholders should collaborate to establish and support a regional resource. Following the workshop, a survey of stakeholders was undertaken, to seek their views about PPI and how it might be supported.

A second workshop was held in November 2009 to agree what the next steps might be. Following this workshop, a new Advisory Group was set up to develop a proposal for a new PPI/PE Forum, which has been provisionally named the North West People in Research Forum. The Advisory Group is receiving financial support from the SHA and the RDS.

The Advisory Group brings together a range of people – as well as members of the public, there are representatives from the RDS, the SHA, local research networks and biomedical research centres. The Group has put together a draft plan for the Forum, which was sent out for consultation to a range of stakeholders in June. This plan includes a suggested vision for the new Forum, which is:

To contribute to the highest quality of health research in the North West by promoting effective patient and public involvement and engagement.

It also includes some suggested aims:

- To support researchers to involve and engage patients and the public in the design, conduct, analysis and dissemination of health research
- To share learning about the principles and practices of PPI and PE in research
- To support patients and members of the public who are involved in health research or who wish to become involved
- To raise awareness about health research being undertaken across the North West
- To publicise opportunities to get involved in health research in the North West.

We hope that the Forum will undertake a range of activities, including:

- Meetings where information and experience can be shared
- Conferences
- A website
- Targeted training events.

Membership will be open to organisations and individuals who are enthusiastic about PPI/PE in health research and operate/live in the North West. In its first year the Forum is likely to focus on supporting health research organisations that are supported by the NIHR, and which have an interest in a collaborative approach to PPI and PE. We hope to broaden this initial scope at the end of the first year to include other stakeholders, including organisations in the North West that are involved in social care research. The launch of this new Forum will take place in the autumn. If you would like more information about our plans, please contact us. We have benefited from learning about a parallel development in Bristol and the South West and are keen to share our experience thinking along similar lines and to remain in dialogue with other regions.

Stuart Eglin (chair) and David Britt (vice chair)
North West People in Research Forum Advisory Group. Email: stuart.eglin@northwest.nhs.uk and david.britt@freeuk.com

Funding calls update

NIHR Health Services Research/INVOLVE Themed Funding Call. The closing date for the submission of outline research proposals on public involvement in research for this funding call was 6th May 2010. There was a very good response to the call with 46 outline bids being submitted that were within the remit of the research programme. Following a meeting of the Health Services Research (HSR)/INVOLVE Commissioning Board in July 2010 a shortlist of projects will be invited to submit full research proposals. The final decision on funding will be made at the February 2011 Health Services Research Commissioning Board meeting.

The Medical Research Council Methodology Research Programme asked for proposals on ‘Methods to assess the impacts of user involvement in health and social care research’ in October 2009. Details of the award and the successful proposal are now on the website: www.mrc.ac.uk/ResearchPortfolio/Grant/Record.htm?GrantRef=G0902155&CaseId=16504

The Wessex Alcohol Research Collaboration (WARC)

The WARC is a new initiative devised by the University of Southampton; it is made up of lay expert panel members who shape the alcohol research agenda. The lay expert panel has six members, including a chairperson and a secretary, who have experience of alcohol use disorders either personally or professionally.

The WARC’s mission is to improve links with key agencies such as clinical services, public health, primary care and government agencies and work with them to encourage excellence in research.

So far, panel members have contributed to the NICE guidelines for Alcohol Dependence and Harmful Alcohol Use and to a social skills protocol by the University of Southampton. Future projects include contributing to the development of the mindfulness research plan and to liver disease protocols. During the spring, experts attended a Traumatic Brain Injury and Alcohol Research day and fourth year medical students presented their alcohol related research projects to the group.

Dates for this year’s WARC meetings have been set and members are very much looking forward to launching this exciting and new project.

For more information on the WARC, visit www.som.soton.ac.uk/research/sites/warc or contact Stacey Miller on 02380 688367.

noticeboard

This is a regular column which can be used to advertise events, initiatives and publications about public involvement in R&D. If you would like to put an article on our notice board please contact the Coordinating Centre.

Are you interested in reducing healthcare associated infections?

SURF (part of the Healthcare Associated Infection Research Network) is looking for patients, carers and people from all walks of life and areas of England to join its service user research forum. SURF members are involved in identifying issues for research; contributing to the research process; considering how best to involve patients and the public; reviewing materials and disseminating findings. No experience of healthcare associated infections or previous research involvement is required. All we ask for is a genuine interest in contributing to the reduction of healthcare associated infections.

To find out more about SURF, and becoming a member, visit www.hcaisurf.org or email the SURF Coordinator andrea.whitfield@tvu.ac.uk or call her on 020 8209 4361.

Our voices, our health: Young people in public health research – 27 October 2010 London

This is an exciting opportunity for adults and young people to attend a free conference organised by young people in the PEAR (Public health, education, awareness, research) group and staff from the National Children's Bureau (NCB) Research Centre. The conference will show how young people can be involved in public health research, and provide a unique forum for the exchange of ideas and the development of practice in this field. It's relevant to anyone interested in young people's involvement in public health and/or research, including: researchers and research funders; public health policymakers and practitioners; young people; and staff from voluntary organisations. Book online now at www.ncb.org.uk/PEAR or contact Mirit Bar for more details:

Email mbaror@ncb.org.uk Tel: 020 7843 6067.

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