



Service Users in Research
Mental Health Research Network



**National Institute for
Health Research**

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Service Users in Research Bulletin

Issue Twelve: April 2011

This is the twelve edition of the bulletin that we send out to members via post or email. In these bulletins we provide news about user involvement in the NIHR Mental Health Research Network (MHRN) and advertise opportunities for people to get involved in the MHRN and mental health research generally.

If anyone has anything that they would like to be in the bulletin or if you would like to join Service Users in Research then please let us know. You can email us at: mhrnppi@kcl.ac.uk.

To join Service Users in Research please fill out the membership form which is sent out alongside this email. You can also join online at:

<http://www.mhrn.info/pages/join-service-users-in-research-online.html>

These bulletins are additionally placed online at www.mhrn.info



We are on Facebook! To find the Service Users in Research page type in 'Service Users in Research' in the search box at www.facebook.com

Contents

- MHRN Magazine now available **p3**
- MHRN North London Hub Seminar: Recovery and Nidotherapy **p4**
- NIHR MHRN East Midlands Hub in Partnership with South Yorkshire CLRN Art and Mental Health Event **p5**
- The 2011 Budget: Implications for Research **p6**
- The British National Formulary **p6**
- Wellcome Collection Events **p7**
- Book Reviews **p7**
- Sussex Partnership NHS Foundation Trust Annual Research & Development Conference **p9**
- Lay Members wanted for Research Ethics Committees in London **p10**
- Mental Health in the News **p11**
- Findings of MHRN Supported Research Studies **p13**

Please note that for events organised by MHRN hubs or local NHS trusts, travel expenses are usually only able to be offered to people living in the area covered by that hub or NHS trust. Please always check beforehand.

MHRN Magazine Available

Why personal experience makes research better

“Research need not be an esoteric exercise. You don’t need to have a degree to get involved and there is no substitute for experience. Unless you’ve walked in those shoes, day in and day out, you simply don’t have full insight into a particular mental health problem.” So says Tim Flavell, whose job it is to encourage people with experience of mental health problems to work with researchers – and vice versa.

This is a service user development officer for the North West regional office covering the north west of England. It is to identify research and promote opportunities for service users. There are many ways of being involved, regardless of your background, and the experience of having a mental health problem gives you a particular insight that can complement the work of an academic researcher who has no personal experience, he says. I also work with research teams to highlight the benefits. I think service user involvement can bring, and make them work out meaningful ways to involve people.”

“Research, even funding bodies – and indeed the Mental Health Research Network itself – demand evidence of ‘involvement’ before support is offered. However, for some research teams, this can often seem to be an ‘oh thought through, coherent’ but easier than other routes, far from meaningful, he says. “It’s a bit of a mixed bag. Some research teams are very committed to service user involvement and to one of their first considerations when putting together a research proposal. Some teams specifically employ service user researchers and involvement is embedded in their research design. But other researchers sometimes have it far too late in the day.”

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“Research, even funding bodies – and indeed the Mental Health Research Network itself – demand evidence of ‘involvement’ before support is offered. However, for some research teams, this can often seem to be an ‘oh thought through, coherent’ but easier than other routes, far from meaningful, he says. “It’s a bit of a mixed bag. Some research teams are very committed to service user involvement and to one of their first considerations when putting together a research proposal. Some teams specifically employ service user researchers and involvement is embedded in their research design. But other researchers sometimes have it far too late in the day.”

“My gut feeling is that service user involvement can also benefit researchers. By commenting on the design, for example, service users can make sure the tasks asked of individuals who agree to participate are not too onerous. An academic with no experience won’t necessarily know if the step is really undertaken and planned making it a bit more difficult for the individual who agrees to take part in it. In the real world, doing for two hours and presenting very personal questions may be an unrealistic thing to ask for someone who is unwell and feeling vulnerable. It can leave people feeling pretty raw, and people with no personal experience don’t necessarily know that. By getting service users involved with developing, designing and delivering questionnaires, researchers can get advice about the right way to do things of people, about what is realistic and reasonable.”

Tim has worked at the MHRN North West hub as a paid employee since 2006 but before that was involved in his work as a service user representative member of a research team.

Course teaches communication skills – and boosts confidence



A new course has been created to help people with experience of mental health problems to get involved in research, understand agreements produced for studies and trials and contribute at meetings. The Communication Skills course has been designed by Jackie Barnett and David Armes, both of whom have experience of mental health problems and are involved with the work of the Mental Health Research Network’s North London Hub.

“In terms of getting on with their everyday lives, they said. The packs suggest questionnaires about social functioning should be designed to find out whether people are happy in certain areas of their life, rather than just asking if they are. It also takes into account of individual problems and can be used as a professional’s judgment of ‘normality’. Some of the questions included in these materials were considered by the panels to be not only relevant but also intrusive – questions about people’s sex lives, for example. They also expressed concern that some of the questionnaires were far too long, that others were far too short to be comprehensive, and that there was a focus on mental ill health rather than mental good health. The questionnaires should also ask about the negative effects of treatments and packages of care, instead of just concentrating on potential improvements, they said. Some questionnaires have been developed from recently in collaboration with people who have experience of mental health problems, but these were not included in the pack.”

“The Communication Skills course has been designed by Jackie Barnett and David Armes, both of whom have experience of mental health problems and are involved with the work of the Mental Health Research Network’s North London Hub.”

“The course is also suitable for newly recruited hub staff who will be working with people who use mental health services to both recruit them to, and involve them in, research projects. We think it’s important to get service users involved in research, but we also need to think about their training needs, and give them confidence to get more involved. Going to research meetings can be very intimidating if you’re not used to it. You need to be able to read people body language, know when to speak and when to listen, and to understand the points of action. Many people do have the confidence to take part in meetings associated with research projects, but others don’t.”

“The plan is to make the course available across England via all eight MHRN regional offices. David and Jackie are among a team of service users who regularly work with the North London hub on projects that aim to get people with experience of mental health problems more involved in research. They have been working on a book for research teams that get service users and have been developed from their projects, and this includes practical resources like job descriptions. Service users who work with North London hub also maintain www.unwell.org.uk, a website that provides information about the health research being carried out in the area.”

The Mental Health Research Network (MHRN) has produced a magazine about its work, the research that we support, and the people that we work with. It’s all in completely plain English and there is a two page article about user involvement in the North West on p16-17.

The full magazine can be downloaded from:

http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/MHRN_magazine_2011.pdf

If you would like a printed copy then please email mhrnppi@kcl.ac.uk or phone 0207 848 0644

MHRN North London Hub Seminar



27th May 2011

MHRN North London Hub Seminar: Recovery and Nidotherapy

This seminar, on 27 May 2011, features Professor Peter Tyrer from Imperial College London. He will be talking about nidotherapy (nido, meaning nest), a new therapy for people with severe mental illness that focuses on changing a person's environment, not the individual. Dr Mary Leamy from the REFOCUS research team, based at the Institute of Psychiatry, King's College London, and exploring ways of making mental health services more recovery-focused, will also be speaking. The discussion will focus on whether nidotherapy can help people on their recovery journeys.

For more information and to register a place, contact hub administrator Jemma Reilly-Ayton, 020 7386 1156, j.reilly-ayton@imperial.ac.uk

This is the third in the 2011 series of 'Sunlows seminars' organised by people with experience of mental health problems who work with the MHRN's North London Hub. The seminars aim to inform people living within the hub's boundaries about MHRN-supported research.

www.sunlows.org.uk contains information about mental health research being carried out in the North London area and is maintained by people with experience of mental health problems who work with the hub.

Event details

Location: North London Hub offices, The Claybrook Centre, St Dunstan's Road
London W6 8RP

Date and Time: 27th May 2011, 2pm to 4.30pm

NIHR MHRN East Midlands Hub in Partnership with South Yorkshire CLRN Event



 **East Midlands Hub**
Mental Health Research Network

In partnership with  **South Yorkshire**
NIHR Comprehensive Local Research Network

 **NHS**
National Institute for Health Research

Invitation to attend a session on Art and Mental Health.

April the 19th
1.30pm - 4.00pm

Geospatial Building
Room A19

Jubilee Campus
Triumph Road,
Nottingham, NG7 2TU.

■ **Lunch and refreshments will be provided.**

■ **A map of Jubilee Campus can be found at:**

<http://www.nottingham.ac.uk/sharedresources/documents/mapjubileecampus.pdf>

A workshop for service users and carers to help understand this fascinating subject.

We have invited Dr Victoria Tischler from the University of Nottingham to come and talk to us about the subject.

If you would like to book a place please contact Rebecca Ellis.

Please also let Rebecca know of any dietary needs or access requirements.

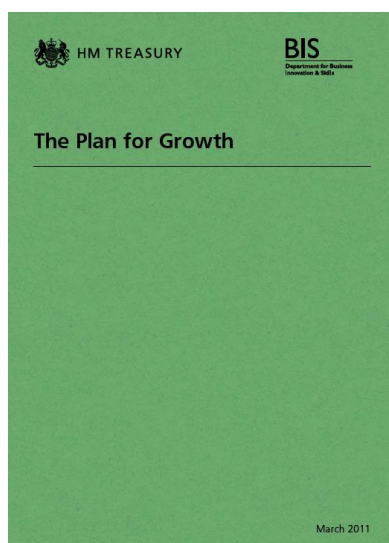
To book your place contact :

Rebecca Ellis
0115 823 1302
Rebecca.Ellis@nottshc.nhs.uk

NIHR Mental Health Research Network
East Midlands Hub in partnership with South Yorkshire CLRN
The NIHR Mental Health Research Network is part of the NIHR Clinical Research Network



The 2011 Budget: Implications for Medical Research



The 2011 budget was delivered by the Chancellor on March 23rd. The budget contains significant news about the government's plans for medical research over the coming years. The section entitled 'Healthcare and the Life Sciences' on p91-98 is the bit of the document that is relevant to medical research. There is a useful summary of all the key points in this section on p98. One of these points is:

'The Government will open up information about clinical trials to enable the public to get involved. The Government is committed to opening up information about clinical trials so that patients can find out about trials that may be relevant to their condition.'

The NIHR is developing a web-based UK Clinical Trials Gateway. It will present, in accessible form, information about trials conducted in the UK. By 2012, the Gateway will make it easy for patients, their doctors and carers, friends and families to see what a trial is about, where it is taking place, and who is running it. It will help patients to join in clinical trials if they are suitable and choose to do so with full information and advice'

The budget can be read in full at: http://cdn.hm-treasury.gov.uk/2011budget_growth.pdf

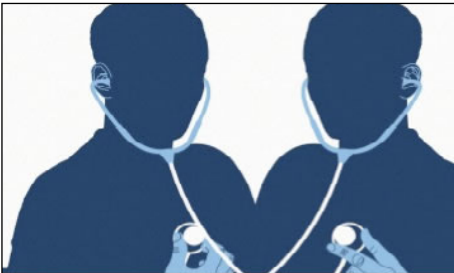
The British National Formulary



The British National Formulary (commonly known as the 'BNF') is the pharmacists 'bible'. It contains details of every drug that is licensed for use in the UK together with its known side effects, interactions with other drugs, information regarding doses, etc. The chances are that you have seen this book many times on the shelf of your GP's office, in your psychiatrist's consulting room or behind the counter of your local Boots. The BNF is the standard reference book for healthcare professionals regarding medication.

The book is updated twice a year, but it is freely available online. You do have to register online at www.bnf.org but aside from that access is free. Most drugs that are prescribed for mental health conditions are in the 'central nervous system' section of the British National Formulary.

Wellcome Collection Events



TELL IT TO YOUR DOCTOR
These events offer a rare opportunity to hear how the doctor-patient relationship works behind closed doors.

FREE
book now

The Expert Patient
Saturday 16 April, 15.00-16.00
When Andrew Chapman, who had been a busy GP all his life, concluded he was too depressed to continue practising medicine, he turned to psychiatrist Peter Agulnik for help. This event re-creates the variety of communication between the two doctors. [> BOOK NOW](#)

The Empowered Patient
Thursday 21 April, 19.00-20.00
Susan Pike was born with osteogenesis imperfecta (brittle bone disease). She spent the first five years of her life in hospitals and was then reclaimed by her parents. Almost miraculously, she has lived into her 50s, in part owing to the efforts of the rheumatologist who made heroic strides to keep her healthy. [> BOOK NOW](#)

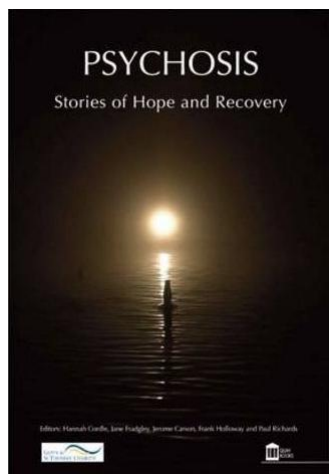
The Wellcome Trust is the UK's largest biomedical charity. The Wellcome Trust is a major funder of medical research in the UK. It also funds some research abroad. The Wellcome Trust has a large building right next to its headquarters on Euston Rd in London called the Wellcome Collection.

The Wellcome Collection has a museum, library, bookshop and a number of permanent and temporary exhibitions. The Wellcome Collection also organise a large number of events each year. And almost all of these are completely free.

The image to the left is a screenshot of the Wellcome Collection website: www.wellcomecollection.org

The Wellcome Collection is having a really good event on April 16th which is a re-creation of the sessions that a depressed GP had with his psychiatrist. The GP in question will be present at the event. You can book tickets for this event and find out more about all the other events and exhibitions at the Wellcome Collection via their website at: www.wellcomecollection.org

Book Reviews



Psychosis Stories of Hope and Recovery

Edited by Hannah Cordle and Jerome Carson

Published by Quay Books, RRP £19.99

ISBN: 1856424200

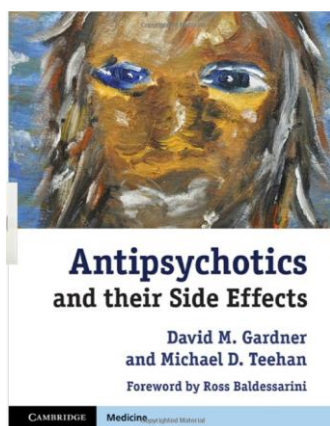
I found this book to be a bit like a TARDIS. It's rather bigger on the inside than it is on the outside. I thought that the cover of the book could have been a bit better (to be fair this is probably down to budget reasons) but that the content of the book is golden. It's one of those books where the more you read it the more you get out of it. The book has a really good plain English introduction to psychosis, its definition, how it is diagnosed, its causes and treatments.

The bulk of the book is made up of a range of individuals telling their own stories (in a structured way) of how psychosis has affected their lives and how they recovered. Quite a range of people give their stories in this book including a psychologist working in south London, a film maker, a poet, and a dancer. Their stories of recovery are of course, as individual as the people they come from. I think that this is one of the over points the book is trying to make. Everyone's definition of recovery is similarly unique.

The book ends with a section of quotes from the people that have contributed to the book split into different headings. I particularly like the section entitled 'development of a positive sense of identity'.

The book as a whole (I think) is intended to inform people about psychosis and to demonstrate that people with serious mental health problems not only **can** but **do** lead full and important lives. We need more of these stories and I would recommend this book to anyone.

By Thomas Kabir



Antipsychotics and their Side Effects

By David Gardner and Michael Teehan

Published by Cambridge University Press, RRP £35
ISBN: 0521132088

This book is **not** for beginners. It's very technical and squarely aimed at people that actually prescribe antipsychotic medication. However the author's hearts are clearly in the right place and the book is dedication is a generous one: "we dedicate this book first and foremost to people, patients, and families affected by mental illness..." The introduction is well written and reasonably accessible. It also contains an interesting section on the 'history of side effects [of antipsychotic-medication]'. The main part of the book contains sections on the side effects of antipsychotics by theme (diabetes, sedation and sleep disturbance, sexual dysfunction, etc). One thing I like about this book is that it is quite clear not just on what is known, but on what **is not** known regarding the side-effects of antipsychotics. All the chapters contain a good set of references. The last section of the book contains many monitoring forms for prescribers to use to check the health of people on different anti-psychotics.

I found this to be a useful and up to date authoritative reference book on the side effects of quite a problematic class of medication. A weakness of this book is that information is given on the side-effects of anti-psychotics but not on any treatments for them.

If anyone tries to deny to you that a certain anti-antipsychotic has a certain side effect then this book can be used as rather an effective rebuttal. If you do use this book though, I would use Google to unravel the meanings of many of the technical terms used in this book. This is first and foremost a textbook for psychiatrists and other doctors and it is highly technical. But it is useful.

By Thomas Kabir

Would you like to review a book for us?

If you would like to review a book for us then please let us know. The book needs to be on a mental health topic (ideally vaguely related to research, mental health services etc). If you do have any ideas of a book that you would like to review for the Bulletin then please let us know. If you write a review for us, we will buy the book for you, and we will give you a £25 Amazon voucher as a token of our appreciation. Please email mhrnppi@kcl.ac.uk if you have any suggestions.

Sussex Partnership NHS Foundation Trust Annual Research & Development Conference

Sussex Partnership 
NHS Foundation Trust

Research & Development Annual Conference

**A one day conference,
showcasing the
collaborative research
activities of the Trust
and its academic partners**

**9.00am - 4.00pm
Thursday 23 June 2011**

The Conference Centre,
Bramber House, University of Sussex


US
University of Sussex


University of Brighton


brighton and sussex
medical school

www.sussexpartnership.nhs.uk

Enhancing understandings and improving practice

Keynote speaker:
Professor Tom Burns CBE
Professor of Social Psychiatry at the
University of Oxford.

Speakers, workshops and a poster
session will present studies related
to the collaborative research themes.

Service users and carers are welcome
and all out of pocket expenses will
be reimbursed in cash on the day.

CPD points are available for attendees.

For further details please contact:
research@sussexpartnership.nhs.uk
or: 01273 265928

Lay Members wanted for Research Ethics Committees in London


National Patient Safety Agency
National Research Ethics Service

Research Ethics Committee Lay Members

The National Research Ethics Service is trying to recruit lay members to Research Ethics Committees in the London area.

Lay members are non-health care professionals, perhaps patients, ex-patients or their relatives, who are interested in scrutinising the ethical aspects of research proposals.

Committee members receive training in ethical review and have opportunities to debate challenging issues in the life sciences to help protect the rights and well-being of research participants and promote ethical research.

Positions are voluntary but expenses are paid, including travel and childcare costs if applicable. Committees meet on average for half a day per month and applicants will need to be able to attend at least two thirds of meetings.

Please note there is no deadline for applications – the recruitment process is ongoing.

To find out more please contact:

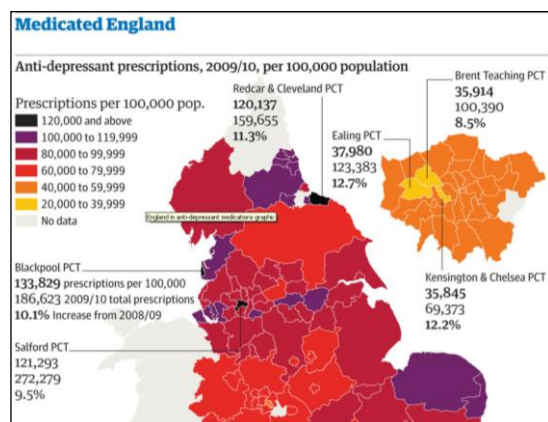
Michael Fox on 020 7794 0500 ext - 31342
michael.fox1@nhs.net

Research & Ethics Dept
South House
Royal Free Hospital
Pond Street
London, NW3 2QG

<http://www.nres.npsa.nhs.uk/aboutus/>

Mental Health in the News

Antidepressants in England and Wales: a map of GP prescriptions



This is a really good piece from the Guardian. The Guardian has managed to get hold of the numbers of anti-depressant prescriptions for every PCT in England and Wales in 2009/2010. Surprisingly, the numbers of prescriptions for anti-depressants in London is relatively low. This is despite certain parts of London having quite high levels of poverty. According to the data obtained by the Guardian, Blackpool PCT had the highest number of anti-depressant prescriptions in 2009/2010.

The Guardian has produced a map of all of this which can be accessed at:

<http://www.guardian.co.uk/news/datablog/2011/mar/05/data-store-pharmaceuticals-industry>

There are three other articles relating to this story:

1. Depression: Why pills are likely to be the first resort in northern England

<http://www.guardian.co.uk/society/2011/mar/04/depression-why-pills-first-resort>

2. Northern doctors prescribe more antidepressants, study reveals

Patients in areas such as Blackpool are prescribed up to three times as many antidepressants as those in parts of London

<http://www.guardian.co.uk/society/2011/mar/04/northern-gps-prescribe-more-antidepressants>

3. Blackpool: England's antidepressant capital

Fading seaside resort of Blackpool has highest rate of anti-depressant prescribing in England and Wales

<http://www.guardian.co.uk/society/2011/mar/04/blackpool-englands-antidepressant-capital>

Cannabis use 'raises psychosis'

“Using cannabis as a teenager or young adult increases the risk of psychosis, a report suggests”

See: <http://www.bbc.co.uk/news/uk-12616543>

The full text of the original research paper can be downloaded freely at:

<http://www.bmj.com/content/342/bmj.d738>

Male depression 'set to increase'



“Psychiatrists have warned that the number of men with depression could rise because of changes in Western society”

See:

<http://www.bbc.co.uk/news/health-12582292>

The original research paper was published in the British Journal of Psychiatry and can be accessed online at:

<http://bjp.rcpsych.org/cgi/content/abstract/198/3/167>

Life Expectancy of Severely Mentally ill Dramatically Reduced Due To Poor Physical Health

“Physical ill-health is rife among the severely mentally ill in Britain, according to new research published today by the University of East Anglia (UEA)”

See: <http://www.medicalnewstoday.com/articles/219330.php>

The full text of the original research paper can be downloaded freely at:

<http://www.biomedcentral.com/1471-244X/11/46/abstract>

Protein found in brain cells may be key to autism

“Scientists have shown how a single protein may trigger autistic spectrum disorders by stopping effective communication between brain cells”

See: <http://www.bbc.co.uk/news/health-12759587>

Findings of MHRN Supported Research Studies

This is a new section of the Bulletin. Every month we are going to have a section in the Bulletin dedicated to disseminating the findings of research projects that the MHRN has supported. We will also put links in this section to any research papers that have been published for these papers. The first project in this section is the Midas study:

MANCHESTER
1824

The University of Manchester

MIDAS Trial Results Summary

MIDAS
Motivational Interventions for
Drugs & Alcohol misuse in
Schizophrenia

Aim

The MIDAS trial compared a psychological therapy (integrated motivational interviewing and cognitive behavioural therapy, MI-CBT) with usual care provided by mental health services.

We wanted to test whether the therapy helped people to reduce their substance use. We also wanted to know whether it improved people's symptoms and functioning and helped to reduce hospital admissions and relapse rates.

Results

All the assessments have now been completed and the results have been analysed. These are the main findings of the study.

The psychological therapy helped to:

- engage people in treatment
- increase their motivation to change substance use habits
- reduce the *amount* of drugs or alcohol that they use

However, the therapy did not help to:

- reduce the *frequency* of people's drug or alcohol use
- prevent them being admitted to hospital
- reduce their symptoms
- prevent relapses (increases in symptoms lasting more than 2 weeks)
- improve their day to day functioning

Retention of participants in the MIDAS trial was excellent, greatly improving on previous studies.

Participants

Between 2004 and 2007, we recruited 327 participants from 6 NHS Trusts in Greater Manchester, Lancashire and South London. These were all people who had been diagnosed with schizophrenia (or a similar condition) and who had high levels of alcohol or drug use.

Treatments

Half of the participants continued with their usual treatment. The other half were offered the psychological therapy for 12 months as well as their usual treatment. We used random allocation to decide who was in each group (i.e. it was decided by chance).

Assessments

We contacted all the participants every 6 months to ask about their drug or alcohol use. We also asked about their symptoms every 12 months. Participants gave us permission to look at their case notes to find out if they had been admitted to hospital or experienced any relapses (increases in symptoms lasting more than 2 weeks).

The assessments continued for 2 years in total, with the final assessments completed in 2009.

Acknowledgements

We want to warmly thank everyone who took part in the trial. We are also grateful to all the NHS staff who helped us to recruit participants and to the trial therapists and research assistants.

For further info: 0161 275 8485
www.midastrial.ac.uk

Manchester Mental Health **NHS**
and Social Care Trust

Greater Manchester West **NHS**
Mental Health NHS Foundation Trust

Lancashire Care **NHS**
NHS Trust

Pennine Care **NHS**
NHS Trust

The full results of the MIDAS trial have been published in the British Medical Journal (BMJ) and can be accessed here:

<http://www.bmj.com/content/341/bmj.c6325.abstract?sid=00d9b407-42bf-4fd0-aa87-b44d352d0097>

The MIDAS trial also has a website: <http://www.midastrial.ac.uk/>