3 Public Information Pack (PIP)

How to get actively involved in NHS, public health and social care research

Finding out more

INVOLVE

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

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National In

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National Institute for Health Research.

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Using this Public Information Pack

This booklet is one of a series of four booklets that make up the Public Information Pack. If you only have this booklet (Booklet 3) and would like the whole Pack, then please get in touch with us at

2 Organisations

2.1 Introduction

This is by no means a comprehensive list of all organisations within England that either have **public involvement** in their **research** or who will provide relevant information. However we hope that these will be a starting point for you to find out the information you require. Please also be aware that this information becomes out of date very quickly. If you are unable to find the organisations through the contact details in this booklet then please do contact the INVOLVE Support Unit, and we will try to find the current information for you.

The organisations are in alphabetical order and they have been included in this booklet because either they have been mentioned in the text of one of the booklets or because they have information that might be of interest. Organisations included in the text will have been highlighted in blue in the booklets.

Public involvement in research is still a developing area and some organisations and areas are doing more than others. It isn't always easy to find exactly what you are looking for and it might take some time. You may need to make several enquiries, some of which could turn out to be dead ends. But don't be put off!

In order to make it easier for you to identify the broad focus of the organisation, in relation to public involvement in research, we have developed a very simple key structure.

Key

Organisations which are sources of information

VO Voluntary Organisations

RF Organisations that fund research

PI Organisations who sometimes have opportunities for members of the public to get involved in research

Part of the National Institute for Health Research

Disabled Living

VO

A charity offering a comprehensive range of services to improve the quality of life of disabled people, their families and carers. The centre is based in Manchester.

Contact details:

Redbank House,
4 St Chad's Street, Cheetham
Manchester M8 8QA

Telephone: **08707 601580**

Email: **info@disabledliving.co.uk**

Website: **www.disabledliving.co.uk/disabledliving.shtml**

Economic and Social Research Council

RF I

The Economic and Social Research Council (ESRC) funds research and training in social and economic issues.

They aim to provide high quality research on issues of importance to business, the public sector and government.

Contact details:

Economic and Social Research Council
Polaris House, North Star Avenue
Swindon SN2 1UJ

Telephone: **01793 413000**

Website: **www.esrcsocietytoday.ac.uk/ESRCInfoCentre/index.aspx**

Folk.us

PI I

Folk.us is a Department of Health funded initiative which was established to facilitate and promote meaningful and effective service user, patient and carer involvement, in all types of research relating to health and social care in North and East Devon.

Contact details:

Rachel Purtell
Folk.us Co-ordinator
Room 407, Noy Scott House
Royal Devon & Exeter Hospital
Barrack Road, Exeter EX2 5DW

Telephone: **01392 403049**

Email: **folk.us@exeter.ac.uk**

Website: **www.projects.ex.ac.uk/folk.us/findex.htm**

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2 Organisations

Health R&D North West

PI I

Health R & D North West is a collaboration between three research-led Universities: Lancaster, Liverpool, and Salford. They have a Research and Development Manager with a specific remit of supporting and developing user involvement in their research and have developed the North West Users Research Advisory Group (NWURAG).

Contact details:

Dr Sara Morris
R&D Manager for User Involvement, Health R&D NoW
Bowland Tower East
Lancaster University
Lancaster LA1 4YT

Telephone: **01524 592656**

Email: **s.m.morris@lancaster.ac.uk**

Website: **www.lancs.ac.uk/fass/organisations/hrdn/userinvolvement.htm**

Health Technology Assessment (HTA) Programme

PI NI HR RF

This is one of the programmes funded by the National Institute for Health Research. The purpose of the HTA programme is to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most effective way for those who use, manage and provide care in the NHS.

The HTA programme has been actively involving 'service users' in all stages of its processes since 1997. There are a variety of ways that you can get involved in the programme. Further details are on the public involvement section of their website.

Contact details:

Mailpoint 728
Boldrewood
University of Southampton
Bassett Crescent East
Southampton SO16 7PX

Telephone: **023 8059 5586**

Email: **hta@hta.ac.uk**

Website: **www.hta.nhsweb.nhs.uk**

Public involvement page: **www.hta.nhsweb.nhs.uk/consumers/index.htm**

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INVOLVE

PI I

INVOLVE is a National Advisory Group funded by the Department of Health to promote and support public involvement in NHS, public health and social care research and development.

We advertise for new members to join the sub-groups of INVOLVE every two years but there are other opportunities to get involved in our work such as by commenting on documents and participating in events, workshops and our conference.

Find out about opportunities for involvement either in the work of INVOLVE or others by:

- Viewing the news and notice board section of the website
- Signing up for email alerts
- joining the INVOLVE discussion forum

To learn more about research projects that are involving members of the public:

- join our mailing list to receive our quarterly newsletter
- view the database of research projects on our website
- view the abstracts and presentations from the INVOLVE conference on our website

All of our publications can be downloaded from our website.

Contact details:

Wessex House
Upper Market Street
Eastleigh
Hampshire SO50 9FD

Telephone: **02380 651088**

Textphone: **02380 626239**

Email: **admin@invo.org.uk**

Website: **www.invo.org.uk**

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2 Organisations

James Lind Alliance

I

The James Lind Alliance has been established to bring patients and clinicians together in 'Working Partnerships' to identify and prioritise the unanswered questions that they agree are most important. This information will help ensure that those who fund health research are aware of what matters to patients and clinicians.

Contact details:

Patricia Atkinson
Administrator
James Lind Initiative
Summertown Pavilion
Middle Way
Oxford OX2 7LG

Email: **patkinson@lindalliance.org**

Website: **www.lindalliance.org**

Joseph Rowntree Foundation

PI RF I

The Joseph Rowntree Foundation is one of the largest social policy research and development charities in the UK. Their research and development programme seeks to better understand the causes of social difficulties and explore ways of overcoming them. They have a bookshop and put the findings of their research on their website.

They do not carry out research in-house, but work in partnership with a large variety of academic and other institutions to achieve their aims.

The Joseph Rowntree Foundation has panels for each of their current themes, and these often include people who use services. Sometimes they may be able to suggest research that they are funding in which you might want to get involved.

Contact details:

Alex O'Neil
Principal Research Manager
Independent Living Programme and Older People's Programme
The Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP

Telephone: **01904 615 913**

Email: **aon@jrf.org.uk**

Website: **www.jrf.org.uk**

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Macmillan Cancer Support

PI VO I

Macmillan is a registered charity which works to improve the lives of people affected by cancer.

Cancer Voices is a UK-wide network of people who have experience of cancer and sign up to actively use their experience of cancer to improve cancer care. There is an opportunity exchange where organisations seeking the involvement and views of people who have experience of cancer can post messages.

Contact details:

Macmillan Cancer Support
89 Albert Embankment
London SE1 7UQ

Telephone for general enquiries: **020 7840 7840**

Textphone: **0808 808 0121**

Website: **www.macmillan.org.uk/Get_Involved/cancerVoices/Home.aspx**

Medical Research Council (MRC)

PI RF

The MRC is a publicly funded organisation; they support research across health and the medical sciences. They have an Advisory Group for Public Involvement (AGPI) who advise the MRC on ways of promoting effective and appropriate consumer involvement in their activities.

Contact details:

Simon Wilde
Patient and Public Involvement Lead
20 Park Crescent
London W1B 1AL

Telephone: **0207 636 5422**

Email: **simon.wilde@headoffice.mrc.ac.uk**

Website: **www.mrc.ac.uk**

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2 Organisations

Mental Health Foundation

I RF VO

This is a major UK mental health organisation providing information and carrying out research. You can find out about the research they have funded in the research section of **'our work'**.

Contact details:

Mental Health Foundation
London Office, 9th Floor
Sea Containers House
20 Upper Ground
London SE1 9QB

Telephone: **020 7803 1101**

Website: **www.mentalhealth.org.uk**

They also have an online discussion forum on user-led research – the **Us as Experts Forum**. This forum brings together mental health service users and survivors who are undertaking research into mental health issues. It provides access to examples of good practice, the latest research, and other expertise.

Website: **www.mentalhealth.org.uk/information/have-your-say/forums**

Multiple Sclerosis (MS) Society Research Network

PI RF VO

The MS Society Research Network was launched in 2002. It has 140 members all of whom have experience of living with multiple sclerosis or caring for a person with multiple sclerosis.

The mission statement of the Research Network is:

'To be actively involved in all aspects of the MS Society research programme in order to make a difference to the quality of MS research.'

Contact details:

MS Society
The Research Network
372 Edgware Road
London NW2 6ND

Telephone: **020 8438 0700**

Email: **online form on website**

Website: **www.mssociety.org.uk**

Research Network webpage: **www.mssociety.org.uk/research/research_network**

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National Childbirth Trust (NCT)

VO

A charity for pregnancy, birth and parenting in the UK.

Contact details:

Alexandra House
Oldham Terrace
Acton
London W3 6NH

Telephone: **0870 770 3236**

Textphone: **020 8993 6714**

Enquiries Line: **0870 444 8707** (9am to 5pm, Monday to Thursday; 9am to 4pm on Friday)

Email: **enquiries@nct.org.uk**

Website: **www.nct.org.uk**

National Children's Bureau (NCB)

PI I VO

The NCB promotes the voices, interests and well-being of all children and young people across every aspect of their lives. They have a research department and a Participation Unit which facilitates the involvement of children and young people in NCB projects and in the running of NCB itself via its support of young people on the NCB's board of management. It also assists external agencies in involving children and young people in their work.

Contact details:

8 Wakley Street
London EC1V 7QE

Telephone: **020 7843 6000**

Enquiry line: **020 7843 6008**

The Enquiry Line is available from Monday to Friday:
10am to 12pm and 2pm to 4pm

Email: **library@ncb.org.uk**

Website: **www.ncb.org.uk**

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2 Organisations

National Institute for Health and Clinical Excellence (NICE)

PI I

NICE makes recommendations on treatments and care using the best available evidence. NICE is committed to producing guidance for the NHS that meets the needs of patients, carers and the public and that involves patients, carers and the public in its development. There are a number of different opportunities for patient, carer and public involvement. Vacancies are advertised on their website.

Contact details:

Patient and Public Involvement Programme for NICE
National Institute for Health and Clinical Excellence
Mid City Place
71 High Holborn
London WC1V 6NA

Telephone: **020 7067 5800**

E-mail: **PPIP@nice.org.uk**

Website: **www.nice.org.uk**

National Institute for Health Research (NIHR)

I PI NI HR RF

As part of '**Best Research for Best Health: a new national research strategy**' 2006, the Government established the National Institute for Health Research (NIHR) to oversee the direction for NHS research in England.

Contact details:

Room 132
Richmond House
79 Whitehall
London SW1A 2NL

Email: **enquiries@nihr.ac.uk**

Website: **www.nihr.ac.uk**

National Institute for Health Research Central Commissioning Facility (CCF)

PI NI HR RF

The Central Commissioning Facility (CCF) was set up in 2006 to manage and administer the NHS National Research and Development (R&D) Programme. The national NHS R&D programme investigates a range of healthcare matters and assists how research-based knowledge is applied across all healthcare sectors.

Visit the CCF website to find the links to the individual programmes and information about public involvement in the programmes.

Website: **www.nihr-ccf.org.uk**

The programmes administered by the CCF are all part of the National Institute for Health Research:

- **Research for Patient Benefit (RfPB)**

The aim of the Research for Patient Benefit programme, is to commission research to improve the day to day practices of NHS staff. There are ten funding committees, one for each of the Strategic Health Authority regions in England, who will decide on which projects will be funded in their regions.

- **Research for Innovation, Speculation and Creativity (RISC)**

These awards are intended particularly for speculative, novel proposals that are likely to have a low chance of success but a potential for high impact.

- **Programme Grants for Applied Research**

The Programme Grants for Applied Research programme, is designed to encourage health services research in areas of importance for patients and also make sure that the research funding support is available for the entire length of the project.

Programme Grants are to be awarded for work in areas of greatest need and/or innovation (eg introduction of new technologies), where there is potential gain for patients within the relatively near future. This means whatever comes out of the work should be able to be applied in the NHS within a 3-5 year time-scale. It is important that the patient community, their families and their support networks, should have a say in what will be funded under this programme. Each team applying for funding is asked to provide information about the relevance and application of their work to patients in the areas they work in, and also to describe how they have included patients and the public in their project planning.

- **Invention for Innovation Research Programme**

This fund is for innovative research in the area of medical technologies and devices. This new programme will incorporate two existing programmes, New and Emerging Applications of Technology (NEAT) and Health Technology Devices (HTD) and will be combined with the new challenge fund.

- **Policy Research Programme (PRP)**

The Policy Research Programme commissions research to support a wide range of policy development and evaluation in health, public health and social care.

- **Biomedical Research Centres**

The National Institute for Health Research has established eleven new Biomedical Research Centres which will be based in leading NHS/University partnerships. These partnerships will be funded for a five year period; funding will be awarded on the basis of previous excellence in biomedical research and the quality, scale and nature of the research proposed.

- **NIHR Research Centres for NHS Patient Safety & Service Quality**

Planned as centres of international expertise, the NIHR Research Centres for NHS Patient Safety & Service Quality will bring together NHS professionals with a wide range of research disciplines. Their focus will be to drive forward improvements in the quality, effectiveness and safety of NHS services.

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2 Organisations

National Library for Health – Patient and Public Involvement Specialist Library

I

This is a web based Library which aims to support patient, user, carer and public involvement in healthcare. It contains articles and reports on public involvement as well as information on organisations that support public involvement in health.

Website: **www.library.nhs.uk/ppi**

National Patient Safety Agency (NPSA)

I

The National Patient Safety Agency (NPSA) – improving the safety and quality of care through reporting, analysing and learning from adverse incidents and 'near misses' involving NHS patients.

Website: **www.npsa.nhs.uk**

National Research Ethics Service (Formerly Central Office for Research Ethics Committees)

PI I

The National Research Ethics Service is part of the **National Patient Safety Agency** and provides help, leadership and support for **Research Ethics Committees**.

All Research Ethics Committees have members of the public on them. You can find out if there are any vacancies on your local ethics committee by contacting your local health authority. You will find these contact details in your phone book or on the **NHS England** website.

Contact details:

National Patient Safety Agency (NPSA)
2nd Floor, A Block
50 Eastbourne Terrace
London W2 6LG

Telephone: **020 7725 3431**

Email: **queries@corec.org.uk**

Website: **www.corec.org.uk/public/index.htm**

National Research Register (NRR)

I

The National Research Register (NRR) is an online database of ongoing and recently completed research projects funded by, or of interest to, the United Kingdom's National Health Service (NHS).

Website: **www.nrr.nhs.uk**

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Open University

I

The Open University is dedicated to distance learning, visit their website for further information on their courses.

Website: **http://www.open.ac.uk**

Patient UK

I

Is a website whose aim is to be a reliable and comprehensive source of health and disease information. It is mainly aimed at the UK general public, but is of interest to all.

It contains health information and details of patient support organisations and self-help groups.

Website: **www.patient.co.uk**

Patient and Public Involvement (PPI) Forum

I PI

There is a Patient and Public Involvement (PPI) Forum for every NHS Trust and Primary Care Trust (PCT) in England.

The PPI Forums are made up of local volunteers who are enthusiastic about influencing and improving the way that local healthcare is delivered. You can search on the Commission for Patient and Public Involvement in Health website below to find out details of your local forum.

Website: **www.cppih.org/ppi_new.html**

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2 Organisations

People in Research

I PI

People in Research is a website which aims to help members of the public make contact with organisations that want to actively involve people in clinical research. It is a UK Clinical Research Collaboration project that has been led by INVOLVE.

The original idea behind People in Research came from two frequently asked questions. Members of the public asking 'How can I get involved?' and research organisations or projects asking 'How do we find people who want to get involved?'

The website contains a directory of organisations that sometimes offer opportunities for public involvement in their work.

All of these organisations:

- undertake, fund or support clinical research
- involve the public in their work
- sometimes advertise for members of the public to get involved and
- have a page on their website that focuses on public involvement.

Contact details:

Philippa Yeeles
UK Clinical Research Collaboration
20 Park Crescent
London W1B 1AL

Telephone: **0207 670 5153**

Email: **philippa.yeeles@ukcrc.org**

Website: **www.peopleinresearch.org**

Primary Care Trust (PCT)

I

Primary Care is the care provided by people you normally see when you first have a health problem. It might be a visit to a doctor or dentist, an optician for an eye test, or just a trip to a pharmacist to buy cough mixture. NHS Walk-in Centres, and the phone line service NHS Direct, are also part of primary care. All of these services are managed for you by your local Primary Care Trust (PCT).

To find contact details of your local Primary Care Trust visit the **NHS England** website.

Website: **www.nhs.uk/England**

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Race Equality Foundation (REF)

I

The Race Equality Foundation promotes race equality in social support (what families and friends do for each other) and social care (what 'workers' do for people who need support). They do this by exploring what is known about discrimination and disadvantage. They then develop interventions that will overcome barriers and promote equality, and disseminate good practice through training, conferences and written material.

Contact details:

Unit 35 Kings Exchange
Tileyard Rd
London N7 9AH

Telephone: **0207 619 6220**

Website: **www.reu.org.uk**

RDInfo

I

This is a Department of Health funded project and its website has three sections:

Website: **www.rdinfo.org.uk**

For information on research funding visit RDFunding
Website: **www.rdfunding.org.uk**

For information on training in research visit RDLearning:
Website: **www.rdlearning.org.uk**

For advice on a research project visit RDDirect
Website: **www.rddirect.org.uk**

or telephone their advice line: 0113 295 1122 (Monday – Friday 8.30am – 5pm)

Email: **info@rddirect.org.uk**

Research and Development Support Unit (RDSU)

I

There are Research and Development Support Units (RDSUs) in many areas of England. They offer information, advice and support for researchers carrying out health and social care research. To find out the contact details of your nearest RDSU visit the National Network of Research and Development Support Unit's website.

Website: **www.national-rdsu.org.uk**

If your area is not covered by an RDSU please contact **RDDirect** – see above

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2 Organisations

Royal College of Physicians

I PI

The Royal College of Physicians sets standards of medical practice and provide education, training and support to physicians. They have a Patient Involvement Unit to encourage and promote patient, carer and public involvement in College activities including research. This unit supports their Patient and Carer Involvement Steering Group and Patient and Carer Network.

Contact details:

Nicole Barlow
The Royal College of Physicians
11 St Andrews Place
Regent's Park
London NW1 4LE

Telephone: **0207 935 1174**

Email: **nicole.barlow@rcplondon.ac.uk**

Website: **www.rcplondon.ac.uk/patientcarer.asp**

Service Delivery and Organisation (SDO) programme

PI NI HR RF

This is one of the programmes funded by the National Institute for Health Research. The SDO programme was established to consolidate and develop the evidence base on the organisation, management and delivery of healthcare services to increase the quality of patient care, ensure better patient outcomes and contribute to improved population health.

Further information on the way you can get involved in the programme is available on the Patient and Public Involvement section of their website.

Contact details:

London School of Hygiene & Tropical Medicine
99 Gower Street
London WC1E 6AA

Telephone: **020 7612 7980**

Email: **sdo@lshtm.ac.uk**

Website: **www.sdo.lshtm.ac.uk**

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Service User Research Group in England (SURGE)

I PI

SURGE is the service user arm of the UK-Mental Health Research Network (MHRN). SURGE is a national network set up to support mental health service users and people from universities and NHS trusts, as they work together on mental health research. SURGE plays an important part in making sure research across the MHRN is valuable for and makes sense to service users. SURGE supports service user input to the MHRN through service user involvement in local hub committees, research project teams and at a national level.

Contact details:

Jan Wallcraft
Sainsbury Centre for Mental Health
134-138 Borough High Street
London SE1 1LB

Telephone: **020 7716 6778**

Email: **info@surge.scmh.org.uk**

Website: **www.ukmhrn.info/dnn**

Shaping Our Lives

I PI

Shaping Our Lives National User Network is an independent user controlled organisation. Shaping Our Lives works with a diverse range of service users and other key stakeholders to build towards a society which is equal and fair where all people have the same opportunities, choices, rights and responsibilities. A society where people have choice and control over the way they live and the support services they use.

Contact details:

BM Box 4845
London WC1N 3XX

Telephone: **0845 241 0383**

Text users please use TYPE TALK: **18001 0845 241 0383**

Email: **information@shapingourlives.org.uk**

Website: **www.shapingourlives.org.uk**

Shaping Our Lives networking website

This website has been designed by service users as a way of finding out about what service user organisations are doing and also what non-service user organisations are doing for service users.

Website: **www.solnetwork.org.uk**

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2 Organisations

Social Care Institute for Excellence (SCIE)

I PI

SCIE's role is to develop and promote knowledge about good practice in social care. In order to do this they work with people and organisations throughout the social care sector to identify useful information, research and examples of good practice.

SCIE's work covers the breadth of social care including services for adults, children and families, participation, human resource development, social work education, e-learning and the use of knowledge in social care.

SCIE is committed to involving service users and carers in its work and ensuring that their experiences and knowledge influence their resources. This is done in a number of ways including through the Partners' Council, reference groups, and quality assurance groups.

Contact details:

Goldings House
2 Hay's Lane
London SE1 2HB

Telephone: **020 7089 6840**

Textphone: **020 7089 6893**

Website: **www.scie.org.uk**

Social Care Online

I

An online database of resources on all aspects of social care including journal articles, websites, research reviews, legislation and government documents, and service user knowledge. Updated daily by SCIE's (Social Care Institute for Excellence) information managers.

Website: **www.scie-socialcareonline.org.uk**

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Social Services Research Group

I

The Social Services Research Group (SSRG) is a non-profit making organisation, the purpose of which is to provide a network for research, providing a range of research information, planning and evaluation in social care and health services. SSRG members are drawn from a wide range of professional groups and organisations sharing a common interest in the work of the caring services. They are interested in increasing the active presence of people who use services and people who are carers in social care research.

Contact details:

Membership Secretary
Brighton and Hove Social Care and Health
Kings House
Grand Avenue
Hove BN3 2SS

Telephone: **01273 295 739** Fax: **01273 295 041**

Email: **margaret.cooney@brighton-hove.gov.uk**

Website: **www.ssrg.org.uk/about/join.asp**

Strategic Health Authority

I

Created by the Government in 2002 to manage the local NHS on behalf of the Secretary of State, there were originally 28 Strategic Health Authorities (SHAs). On 1 July 2006, this number was reduced to 10.

Strategic Health Authorities are responsible for:

- Developing plans for improving health services in their local area
- Making sure local health services are of a high quality and are performing well
- Increasing the capacity of local health services – so they can provide more services
- Making sure national priorities – for example, programmes for improving cancer services – are integrated into local health service plans

Strategic Health Authorities manage the NHS locally and are a key link between the Department of Health and the NHS.

Contact details:

To find contact details for your local Strategic Health Authority view the **NHS England** website.

Website: **www.nhs.uk/England**

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2 Organisations

Suresearch

PI

Suresearch is a network of Mental Health service users in Research and Education based at the University of Birmingham. It welcomes as members users and survivors of mental health services and their allies who have experience and/or have an interest in mental health research and education. It undertakes commissioned research and professional and user education and training.

Contact details:

Centre of Excellence in Interdisciplinary Mental Health
Watson Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT

Telephone: **0121 414 5734**

Website: **www.suresearch.org.uk**

Sure Start

PI

Sure Start is a Government programme which aims to achieve better outcomes for children, parents and communities by:

- increasing the availability of childcare for all children
- improving health and emotional development for young children
- supporting parents as parents and in their aspirations towards employment.

In the research section, you will find details of the research programme, including consultations, evaluations, pilot projects, surveys and key research, along with other useful links and downloadable research documents.

Contact details:

Telephone Public Enquiry Unit: **0870 0002288**

Email: **info@dfes.gsi.gov.uk**

Website: **www.surestart.gov.uk**

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UK Clinical Research Collaboration (UKCRC)

I PI

The UK Clinical Research Collaboration (UKCRC) was established in 2004. It is a partnership of organisations working to establish the UK as a world leader in clinical research. INVOLVE is one of the partners of the collaboration which brings together the NHS, research funders, industry, regulatory bodies, Royal Colleges, patient groups and academia.

For further information about opportunities for public involvement in the UKCRC please see the patient and public section of their website: http://www.ukcrc.org/patientsandpublic/patientandpublicinvolvement.aspx

Contact details:

Philippa Yeeles
Patient and Public Involvement Lead
UK Clinical Research Collaboration
20 Park Crescent
London W1B 1AL

Telephone: **020 7670 5452**

Email: **info@ukcrc.org**

Website: **www.ukcrc.org**

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2 Organisations

UK Clinical Research Networks (UKCRN)

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The UKCRN was established to provide support for clinical research. There are a range of opportunities for patients and the public to get involved with the work of UKCRN which is committed to supporting patient and public involvement within their work.

Each individual topic specific clinical research network is developing its own programme of patient and public involvement activities. The specific topic networks are cancer, diabetes, dementias and neurodegenerative diseases, medicines for children, mental health, stroke and primary care. There is also a comprehensive network which includes all other disease topics.

The UKCRN is developing a range of resources to support public involvement in research and these are available on their website. For further information on patient and public involvement within the UKCRN please contact the Patient and Public Involvement lead or visit their website.

Contact details:

Marianne Miles
Patient and Public Involvement Lead
UKCRN Co-ordinating Centre
Arthington House
Cookridge Hospital
Hospital Lane
Leeds LS16 6QB

Telephone: **0113 392 4345**

Email: **info@ukcrn.org.uk**

Website: **www.ukcrn.org.uk**

All of the individual UKCRN research networks (see below) are involving patients and the public in their work. Please contact the individual networks to find out further information. Information on further networks developed after this publication went to print will be available from the UKCRN.

Comprehensive Research Network

The Comprehensive Research Network will be implemented over a two-year period beginning in April 2007.

See UKCRN website for further information: **www.ukcrn.org.uk**

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Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)

Contact details:

Terry McGrath
Patient and Public Involvement Co-ordinator
Box 16
Institute of Neurology
8-11 Queen Square
London WC1N 3BG

Telephone: **020 7676 2121**

Email: **info@dendron.org.uk**

Website: **www.dendron.org.uk**

Diabetes Research Network

Contact details:

Martin Lodemore
Patient and Public Liaison Officer
The Diabetes Research Network Co-ordinating Centre
ICCH Building, Imperial College
59 – 61 North Wharf Road
London W2 1LA

Telephone: **0207 594 3377**

Email: **drninfo@ukdrn.org**

Website: **www.ukdrn.org**

Medicines for Children Research Network

Contact details:

Jenny Preston
Consumer Liaison Officer
Medicines for Children Research Network
Institute of Child Health
University of Liverpool
Royal Liverpool Children's NHS Trust
Eaton Road
Liverpool L12 2AP

Telephone: **0151 252 5067**

Email: **info@mcrn.org.uk**

Website: **www.mcrn.org.uk**

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2 Organisations

Mental Health Research Network

SURGE (Service User Research Group in England) is the service user arm of the Mental Health Research Network (MHRN)

Contact details:

Jan Wallcraft
SURGE Operational Manager
Sainsbury Centre for Mental Health
134-138 Borough High Street
London SE1 1LB

Telephone: **020 7716 6778**

Email: **info@surge.scmh.org.uk**

Website SURGE: **www.ukmhrn.info/dnn/ServiceUserInvolvement/tabid/98/Default.aspx**

Website MHRN: **www.ukmhrn.info**

National Cancer Research Network

Contact details:

Karen Inns
National Cancer Research Network Co-ordinating Centre
Arthington House
Cookridge Hospital
Hospital Lane
Leeds LS16 6QB

Telephone: **0113 392 4093**

Email: **enquiries@ncrn.org.uk**

Website: **www.ncrn.org.uk/About/centre.htm**

Primary Care Research Network

See UKCRN website for further information: **www.ukcrn.org.uk**

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Stroke Research Network

Contact details:

Zena Lethbridge
Patient and Carer Involvement Manager
4th Floor Leazes Wing
Royal Victoria Infirmary
Queen Victoria Rd
Newcastle upon Tyne NE1 4LP

Telephone: **0191 246 4659**

Email: **uksrn@ncl.ac.uk**

Website: **www.uksrn.ac.uk**

Warwick Diabetes Care – Research User Group

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The Warwick Diabetes Care Research User Group is a group of lay people who have an active interest in the diabetes control and care of people living with diabetes. Its main purpose is to assist the Warwick Diabetes Care Research Team in all aspects of diabetes research. The Group covers the West Midlands.

Website: **www2.warwick.ac.uk/fac/med/study/cpd/subject_index/diabetes/wdc/usergroup**

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3 References

3.1 Introduction

References in the text are highlighted in **blue**. When we refer to books, reports or articles in the text, we give the name of the main author, followed by the year when it was written. For example, (**Faulkner, Alison 2004**) refers to an article written by Alison Faulkner in 2004.

The references are in alphabetical order, however they are divided into two sections:

- Department of Health reports and publications
- Other reports, guides and journal articles

Reports and guides

Details of where these publications can be obtained from have been included in the reference. This information was correct when the booklets went to print, however websites do change. If you are unable to find the report, many of the contact details for the information will be found in **Chapter 2, 'Organisations'**.

3.2 Department of Health (DH) publications

Department of Health (January 2006)

Best Research for Best Health, NHS R&D Strategy

A new national health research strategy.

Available to download from the publications section of the Department of Health website www.dh.gov.uk

To order a hard copy, telephone: **0870 155 54 55**

Department of Health (March 2006)

Let me in – I'm a researcher: Getting involved in research

This report is about how to involve people with learning difficulties in research. The report was produced by a team of people with learning difficulties.

Available to download from the publications section of the Department of Health website **www.dh.gov.uk**

To order a hard copy, telephone: **0870 155 54 55**

Department of Health (August 2006)

Reward and Recognition: the principles and practice of service user payment and reimbursement in health and social care Second Edition

Available to download from the publications section of the Department of Health website: **www.dh.gov.uk**

To order a hard copy telephone: **0870 155 54 55**

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3.3 Reports, guides and journal articles

Beresford, Peter and Turner, Michael (2005)

User Controlled Research: Its meanings and potential

Shaping Our Lives and the Centre for Citizen Participation, Brunel University. Commissioned by INVOLVE

Available to download from the publications section of the INVOLVE website **www.invo.org.uk** or by contacting the INVOLVE Support Unit:

Telephone: **02380 651088**

Email: **admin@invo.org.uk**

Beresford, Peter and Turner, Michael (2005)

User Controlled Research: Its meanings and potential. Report Summary

Shaping Our Lives and the Centre for Citizen Participation, Brunel University. Commissioned by INVOLVE.

Available to download from the publications section of the INVOLVE website **www.invo.org.uk** or by contacting the INVOLVE Support Unit:

Telephone: **02380 651088**

Email: **admin@invo.org.uk**

Faulkner, Alison (January 2004)

Capturing the experiences of those involved in the TRUE project: A story of colliding worlds

Commissioned by INVOLVE.

Available to download from the publications section of the INVOLVE website: **www.invo.org.uk** or by contacting the INVOLVE Support Unit.

Telephone: **02380 651088**

Email: **admin@invo.org.uk**

Faulkner, Alison (November 2004)

The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors

This is available from the Joseph Rowntree Foundation (JRF) bookshop where it can either be downloaded free of charge from the website or hard copies can be purchased.

Bookshop web address: **www.jrf.org.uk/bookshop**

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3 References

Hanley, Bec and others (2004)

Involving the public in NHS, public health and social care research: Briefing notes for researchers

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Available to download from the publications section of the INVOLVE website **www.invo.org.uk** or by contacting the INVOLVE Support Unit:

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INVOLVE (2006)

Commissioning Guidelines

A set of seven guidelines. Three of these are written for members of the public who are interested in getting involved in the commissioning of research.

Written by Jane Royle and Maryrose Tarpey

INVOLVE Support Unit

Getting involved in research grant applications: guidelines for members of the public. P1

Peer reviewing research proposals: Guidelines for members of the public. P2

Being a member of a Commissioning Board: Guidelines for members of the public. P3

Available to download from the publications section of the INVOLVE website **www.invo.org.uk** or by contacting the INVOLVE Support Unit.

Telephone: **02380 651088**

Email: **admin@invo.org.uk**

Lockey, Rachael and others (2004)

Training for consumer involvement in health and social care research – a study of training provision and participants' experiences

Commissioned by INVOLVE

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Royle, Jane and others (2001)

Getting involved in research: A Guide For Consumers

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This is now out of print and hard copies are no longer available but it can be downloaded from the publications section of our website **www.invo.org.uk**

The Public Information Pack (PIP) 2007 replaces this publication.

Steel, Roger (2006)

Guide to reimbursing and paying members of the public actively involved in research. Revised August 2006

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Available to download from the publications section of the INVOLVE website **www.invo.org.uk** or by contacting the INVOLVE Support Unit:

Telephone: **02380 651088**

Email: **admin@invo.org.uk**

SURGE (Service User Research Group England) (2005)

Guidance for good practice: Service User Involvement in the UK Mental Health Research Network

These guidelines were developed with the aim of providing guidance to researchers and service users who wish to develop collaborative research projects and programmes involving service users within the UK Mental Health Research Network. The guidelines contain a literature review and guidance for good practice.

The guidance can be downloaded from the service user involvement section of the **UK Mental Health Research Network**

website: **www.ukmhrn.info/dnn**

Tarpey, Maryrose (2006)

Why people get involved in health and social care research: a working paper

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Notes

INVOLVE

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

INVOLVE is a national advisory body that is funded by the Department of Health to promote and support public involvement in NHS, public health and social care research and development.

If you would like to know more about what we do, please contact us:

INVOLVE
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD

Web: www.invo.org.uk
Email: admin@invo.org.uk
Telephone: 02380 651088
Textphone: 02380 626239

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Textphone: 02380 626239

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