Young People ReThinking Mental Health Research

Involving young people in mental health research

29th January 2015, The British Library
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10:00 - 10:30  Registration and refreshments
10:30 - 10:45  Welcome address and keynote by Charles Walker MP
10:45 - 11:00  Quiz: What do you know about young people's mental health?
11:00 - 11:15  Closing the gap: why we need more research in to mental health by Cynthia Joyce
11:15 - 12:15  Debate: Boys don't cry Are men psychologically tougher than women?
12:15 - 13:15  Lunch
13:15 - 13:45  Young People ReThinking Mental Health Research by the national Young People’s Mental Health Advisory Group
13:45 - 13:50  A message from Dame Sally Davies
13:50 - 14:30  The Psychiatrist's Couch: Interviews with Sir Iain Chalmers, Professor Til Wykes, Professor Janet Treasure and Dr Jonathan Sheffield
14:30 - 15:00  Afternoon refreshments
15.00 - 15.10  Newfound Theatre Production: On The Edge
15:10 - 15:30  Stigma, Mental Health and Young People by Professor Graham Thornicroft
15:30 - 16:00  Transitioning from Child and Adolescent Mental Health Services by Professor Swaran Singh
16:00 - 16:20  Panel discussion
16:20 - 16:30  Pledges and close
Speaker Biographies

Charles Walker MP

Charles is the Member of Parliament for Broxbourne and is currently Vice-Chairman of the 1922 Committee and sits on the Conservative Party Board.

Since entering Parliament in 2005, he has campaigned in the area of mental health and more recently has focused attention on deaths in custody, with a particular emphasis on the experiences of the African/Caribbean community.

In 2013 he was a recipient of the Royal College of Psychiatry’s President’s Medal, awarded to those deemed to have advanced the cause of mental health.

Joanne Ashcroft

Joanne Ashcroft is Divisional Research Delivery Director at the National Institute for Health Research Clinical Research Network.

Joanne has worked for the Clinical Research Network for ten years. She was part of the central team who established the Mental Health Research Network and has an interest in working with researchers to plan recruitment to clinical studies. An advocate for service user and carer involvement in research Joanne has overseen an active programme of Patient and Public Involvement work for mental health.

Before joining the CRN Joanne worked as a research nurse for the Intensive Care Audit and Research Centre (ICNARC) working on the first large non-commercial RCT in critical care in England. Prior to this she work in the NHS in a variety of nursing roles since qualifying in 1984.
Cynthia Joyce

Cynthia Joyce is the Chief Executive of the major new research charity MQ: Transforming Mental Health. In addition to supporting research to improve the diagnosis, treatment or prevention of mental illness, the charity also advocates for improved awareness and understanding of the importance of mental health in our society.

In past years, Cynthia has served as Executive Director of the SMA Foundation and Executive Director of the American Academy of Neurology Foundation; she has also held positions at Ciba-Geigy (now Novartis; 1987-1995) and Cephalon (1995-1999).

She holds a BA from the University of Chicago and an MS from the University of Minnesota.

Professor George Szmukler

George Szmukler is Professor of Psychiatry and Society at the Institute of Psychiatry, Psychology & Neuroscience, King’s College London, and an honorary consultant psychiatrist at the South London and Maudsley NHS Foundation Trust.

He is an Associate Director of NIHR – Mental Health specialty with responsibility for patient and public involvement in research. He was Dean of the Institute of Psychiatry (2001-2006), Medical Director of the Maudsley and Bethlem NHS Trust, later the South London and Maudsley NHS Trust (1997-2001), and a Visiting Professor in the BIOS Centre, Department of Sociology, at the London School of Economics (2005-2013).

His major research interests are in health services research; decision-making capacity; mental health law; methods for reducing the use of ‘coercive’ interventions in psychiatry; and the role of service users and carers as collaborators in the conduct of research.
**Dr Paul Galdas**

Paul is a senior lecturer, NMC approved teacher, and a leading researcher in the field of men’s health. His PhD, examining the influence of masculinity on men’s help-seeking behaviour for cardiac chest pain, was awarded in 2006 from the University of Leeds. Since this time he has developed a programme of research investigating men’s help-seeking behaviour and engagement with health services in a variety of issues including coronary heart disease, depression, and chronic illness, and has published widely on these topics.

His current research focuses on self-management support for men living with long term conditions and this is reflected in his teaching activities, which involve contributions to pre- and post-registration nursing programmes and post-graduate health sciences courses.

He held academic positions at the University of British Columbia, University of Sheffield, and Sheffield Hallam University before joining the University of York in 2011.

**Dr Tania Gergel**

Tania Gergel joined Kings College London in 1996, where she completed a PhD on Plato’s Phaedo, and then became a lecturer. Tania has also taught at Birkbeck College, the Open University and Cambridge. Following an extended career break, Tania returned to King’s in 2011 and has re-joined Classics in a visiting capacity, as well as developing new research interests in philosophy of medicine and psychiatry, in collaboration with clinicians from the Institute of Psychiatry and committees such as those within CRN: Mental Health.
Iain Chalmers, Coordinator, James Lind Initiative

Iain Chalmers practised as a clinician for seven years in the UK and the Gaza Strip before becoming a full time health services researcher. Between 1978 and 1992 he was founding director of the National Perinatal Epidemiology Unit (www.npeu.ox.ac.uk).

Between 1992 and 2002, he was founding director of the UK Cochrane Centre, which convened the meeting at which the Cochrane Collaboration (www.cochrane.org) was inaugurated. Since 2003, he has coordinated the James Lind Initiative to promote public and professional acknowledgement of the need to address uncertainties about the effects of treatments.

Between 2003 and 2013 the James Lind Initiative established the UK Database of Uncertainties about the Effects of Treatments (http://www.library.nhs.uk/duets/) and the James Lind Alliance (http://www.lindalliance.org/), a framework to enable patients and clinicians to identify shared priorities for research. The James Lind Initiative is currently responsible for editing Testing Treatments interactive – English (www.testingtreatments.org) and The James Lind Library (www.jameslindlibrary.org).

Iain Chalmers was knighted in 2000 for services to health care.

Professor Janet Treasure

Janet is Director of the Eating Disorder Unit and Professor of Psychiatry at Kings College London. She has more than 30 years’ experience in the treatment and study of eating disorders. She is currently director of the Eating Disorders Service, which is at the epicenter for clinical management of eating disorders and training.

As well as this, Professor Treasure is Chief Medical advisor for Beat and a fellow for the Academy of Eating Disorders. In 2007, Professor Treasure received an Eating Disorders National Award from national eating disorder charity Beat. During her illustrious career, she has edited seven academic texts on eating disorders and authored three self-help books, including Getting Better Bite by Bite, Anorexia Nervosa and A Survival Guide for Families, Friends and Sufferers.

Professor Treasure has been active in a number of research projects and has over 300 peer reviewed papers in print. In 1984, she was awarded the Gaskell medal from the Royal College of Psychiatrists and has numerous other awards for her work. In 2004, she was awarded the Academy for Eating Disorders (AED) Leadership Award in Research.
Professor Til Wykes

Til Wykes is Professor of Clinical Psychology and Rehabilitation and Vice Dean Psychology and Systems Sciences at the Institute of Psychiatry, Psychology & Neuroscience, King’s College London. She has been involved in research on rehabilitation for many years both in the development of services and the evaluation of innovative psychological treatments. She is the director of the Centre for Recovery in Severe Psychosis (CRiSP) which has carried out a number of RCTs into the efficacy of Cognitive Remediation Therapy (CRT), Group Cognitive Behaviour Therapy for voices as well as motivational interviewing techniques in compliance and therapy to reduce the effects of stigmatization. She is also Co-Director in a new collaborative venture, the Service User Research Enterprise (SURE), which encourages consumers of mental health services to become more involved in all the aspects of research from the priorities for funding to the actual design and execution of the study.

Til Wykes is the editor of the Journal of Mental Health and the first director, NIHR Clinical Research Network: Mental Health which is a Department of Health funded research network responsible for providing the national NHS infrastructure for RCTs and other high quality research studies in mental health.

Dr Jonathan Sheffield

Dr Jonathan Sheffield is Chief Executive of the National Institute for Health Research, Clinical Research Network. This organisation is funded by the Department of Health to support the practical delivery of both academic and commercial clinical research in the NHS, and was responsible for recruiting more than half a million patients into clinical studies last year.

Jonathan trained as a doctor at Dundee University, before following a career as a histopathologist at Yeovil District Hospital, where he was instrumental in developing its research capabilities. In 2003 he became Medical Director for the Trust, before moving on to University Hospitals Bristol – again as Medical Director.

In 2009, Jonathan was awarded an OBE for services to the NHS. In 2011 he was elected an Honorary Fellow of the Royal College of Physicians’ Faculty of Pharmaceutical Medicine – its highest honour – for his contribution in the area of clinical research delivery.

A passionate advocate for clinical research, Jonathan’s ambition is for participation in a suitable research study to be a standard treatment option, open to all NHS patients.
**Professor Graham Thornicroft**

Graham Thornicroft is Professor of Community Psychiatry at the Institute of Psychiatry, King’s College London (KCL) and is a member of the Health Service and Population Research Department at KCL, and the Centre for Global Mental Health, a joint centre between King’s Health Partners and the London School of Hygiene and Tropical Medicine. He also works as a Consultant Psychiatrist at South London & Maudsley NHS Foundation Trust in a local community mental health early intervention team in Lambeth. He is a Fellow of the Academy of Medical Sciences and is a National Institute of Health Research Senior Investigator.

Graham has made significant contributions to the development of mental health policy in England, including Chairing the External Reference Group for the National Service Framework for Mental Health, the national mental health plan for England for 1999-2009.

His areas of research expertise include: stigma and discrimination, mental health needs assessment, cost-effectiveness evaluations of mental health treatments, service user led research, implementation science, and global mental health. Graham has authored or edited 29 books and 365 peer-reviewed papers in Pubmed.

**Professor Swaran Singh**

Swaran Singh is Head of Mental Health and Wellbeing at Warwick University and consultant psychiatrist in the early intervention service; Birmingham and Solihull Mental Health Foundation Trust; and Commissioner, Equality and Human Rights Commission, UK.

Swaran has led a number of large studies relating to transitioning from child to adult mental health services. Findings from studies such as the TRACK study have to date been far-reaching and focused attention on transition amongst policy makers, commissioners, providers and clinicians nationally and internationally. Transition of care is now prominent in the UK government’s mental health strategy (No Health Without Mental Health and the earlier New Horizons). NICE has recently set up a Guidelines Development Group on Transition from children’s to adult services for young people using health or social care services with a special focus on mental health services. The Deputy Prime Minister Nick Clegg launched the coalition government’s action plan Mental Health: Priorities for Change on 20th Jan 2014 with transitions seen as a key priority for service reform. The European Union FP7 Programme has recently funded an eight-country five year study (MILESTONE Project) to improve transitions across the EU.
The national Young People’s Mental Health Advisory Group

The first national Young People’s Mental Health Advisory Group was established in January 2014 and is facilitated by the NIHR Clinical Research Network: Mental Health.

Background - why the national Young People’s Mental Health Advisory Group formed?

Over the past 10 years, CRN: Mental Health (formerly the Mental Health Research Network) has supported the delivery of over 1200 mental health research studies. The studies we support all aim to improve NHS services and treatments – and we believe the people who use those services and potentially benefit from the treatments, can give invaluable advice to researchers.

In order to ensure that our research benefits from service user and carer involvement, we support a community of over 2000 mental health service users and carers interested in getting involved in research. Through their involvement with the Network, our service user and carer members have been integral to ensuring the delivery of high quality research.

Despite our success, the Network has historically found it difficult to reach out to young adults. In 2012, a scoping exercise was undertaken confirming that, at the time, there no organisations actively supported involvement of young people in mental health research. This had resulted in a lack of involvement opportunities for young service users and carers, as well as making it challenging for researchers to gain appropriate and meaningful PPI input into studies relating to young people and mental health.

Who are we? About the national Young People’s Mental Health Advisory Group

The Young People’s Mental Health Advisory Group was established in January 2014 to act as the main point of contact for researchers seeking patient and public involvement in young people’s mental health research.

The Group itself is made up of fourteen 16-24 year olds with either direct or indirect (friends/family members) experience of mental health issues. Members come from across England and have a wide range of experiences and interests. Meetings are held approximately once every 6 weeks in London. All travel expenses and payment for time are covered by the CRN: Mental Health.
How can we help?

The main objectives of the Group are to:

• Provide a point of contact for researchers seeking advice on studies relating to young people’s mental health
• Promote the young service user/carer perspective in mental health research
• Identify and share good practice in service user and carer involvement
• Collaborate with the wider NIHR family and charities on specific projects

What do researchers say about the group?

Since forming, the Group have been visited by twelve researchers investigating children’s and young people’s mental health. The Group have received fantastic feedback from the researchers and research teams.

Comments have included:

‘It was an exciting and worthwhile opportunity to work with a group of bright, articulate and reflective young people.’

‘The group worked hard and were very focused and articulate, which meant we had a good discussion about the data and new ideas to feed into our study.’

‘The group met our research project with enthusiasm, inquisitiveness and a genuine desire to contribute constructively to the research, and we would be keen to benefit from their insight again in the future.’

‘I was really grateful to the group for their thought, consideration and positive approach which helped me develop and improve the research proposal’

The Group’s excellent achievements have been recognised by the CRN: Mental Health Executive Committee. They will be presented with an award by the Committee next month at the National Scientific meeting.

About today’s event - ‘Young People ReThinking Mental Health Research’

After reading an article in The Times discussing the need for more up-to-date research on the prevalence of mental health conditions amongst young people, the group decided to write to Dame Sally Davies to express their enthusiasm for the project. Upon receiving the group’s letter, Dame Sally invited the group to meet with her in April 2014. Since then, Dame Sally Davies has been hugely supportive of the group and the group have been involved with a Department of Health initiative to collect up to date national statistics on the prevalence of mental health issues amongst young people in the UK.

Today’s event aims to:

• Highlight the important role that young people with experience of mental health services or supporting someone who has, can play in improving research into young people’s mental health research
• To raise awareness of the need for more relevant research in to young people’s mental health
• To promote the Group to researchers and funders
• To celebrate the achievements of the Group to date
Are you conducting research into young people’s mental health?

Need Patient and Public Involvement?

Visit the first national...

Young People’s Mental Health Advisory Group

16 - 24 year olds with personal experience of having used mental health services or caring for someone who has.

We help to:

- Identify important research topics for young people
- Improve accessibility of patient information and consent forms
- Identify useful outcome measures for young people
- Identify barriers to recruitment and suggest ways to overcoming them
- Develop study protocols
- Develop dissemination materials and strategies

If you would like to visit the group for support on your study or for more information please contact: megan.rees@kcl.ac.uk or lisa.doughty@kcl.ac.uk
Telephone: 02078480660