

Mental Health Carers Workshop: The Way Forward

Event Programme



9th July 2019, Friends' Meeting House, Manchester

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Introduction and Welcome

This event aims to bring together people from different backgrounds with different experiences to discuss how we can work together to make real change happen.

Despite policies, clinical guidelines, and evidence based interventions, relatives and carers of people with severe mental health problems still feel excluded from services and struggle to get the support they need.

We want this to be a space for carers, relatives, friends, family and other stakeholders to discuss what is needed for real change to happen. We will hear from a range of experts including carers, relatives, charities, clinicians, and researchers, who will outline innovative approaches currently underway and their likely impacts.

In the afternoon, there will be discussions around the following six questions developed with carers. The focus will be on how we can make real change happen:

1. What needs to change in creating and delivering policy?
2. How can we use networks and organisations to facilitate change?
3. What research should we be doing?
4. How can digital interventions support change?
5. What needs to change in the NHS?
6. What involvement and outcomes need to be improved?

Plan for the day

10:30am – Welcome

Join us for tea, coffee and pastries and give us your thoughts on what you are hoping to get out of the day.

11am – Morning Presentations Part 1

Hear from carers, relatives, charities, clinicians, and researchers about; where we are now, and an update on carers' support.

12pm – Tea, Coffee and Biscuit Break

Have a break and the opportunity to ask speakers questions about their talks.

12:20pm - Morning Presentations Part 2

Hear about innovative developments, carers studies and the new Relatives Education and Coping Toolkit (REACT).

1:15pm – Lunch Time

Please join us for lunch and the chance to talk informally about the morning's presentations.

2:15pm – Discussion Workshop 1

Join us in the main hall for a brief explanation of how the discussion workshops will run, then find your discussion workshop and enjoy.

3pm – Discussion Workshop 2

Grab a tea or coffee and work your way around the other discussion workshops, add your thoughts to the boards and build on the first discussion.

3:50pm – Panel Discussion

Join us back in the main hall for a panel discussion, where questions from the day will be explored.

4:30pm – Thank You and What Happens Now

Five minute final wrap up to conclude the day and potential next steps.

Meet the Speakers

Jo Smith



Jo Smith is Professor of Early Intervention and Psychosis at the University of Worcester. She is a Chartered Clinical Psychologist who worked in adult mental health services during a 34 year NHS career. For 16 years, she was the Early Intervention in Psychosis (EIP) Lead for Worcestershire Health and Care NHS Trust and a Joint National EIP Programme Lead for England from 2004-2010. Her clinical and research work has largely focused on the

development, evaluation and delivery of psychosocial interventions to individuals with psychosis and their families. She is involved with IMPART (IMPlimentation of A Relatives' Toolkit) and EFFIP (e-support for Families and Friends of Individuals affected by Psychosis) research trials. In March 2018, Jo was appointed as National Clinical Audit of Psychosis (NCAP) Joint Clinical Advisor to the EIP Audit in England and Wales.

Talk:

'How well are Early Intervention in Psychosis (EIP) services in England doing in relation to providing Carers Education and Family Intervention to families coping with first episode psychosis?'

Within an international context, England has arguably had the most uniform EIP service implementation driven by national mental health reforms. For almost 20 years, EIP has remained a policy and commissioning priority and EIP services are seen as a key element of specialist mental health service provision for people with first episode psychosis. From April 2016, EIP teams were required to meet a 2 week Access and Waiting Time (AWT) standard and deliver on NICE QS80 Quality Standards for psychosis (NICE 2015). A national EIP baseline audit to measure performance and progress against these standards was instituted in 2015/16, with repeat audits carried out annually. This presentation will review national audit data in relation to providing Family Intervention and Carer Education and Support for families supporting a relative with first episode psychosis in line with national AWT standards for England.

Meet the Speakers

Chris Lodge



Chris is the service user researcher with the Spectrum centre, and helps co-ordinate the involvement of people with lived experience in our research. He has lived experience himself, having been diagnosed with Manic Depression, Psychosis, and Schizophrenia in 1993/4. Having spent a long time with secondary mental health services, in and out of the community, and

having lived rough for many years, Chris likes to use his experiences positively to benefit others. He worked as a Mental Health Support Worker in Lancashire Care Foundation Trust, before joining the Spectrum Centre. He was nominated for the 2018 Outstanding Contribution to Public Patient Involvement in Research at the North West Coast Research and Innovation Awards, and has recently taken up a role on the Board of Trustees of the McPin Foundation, which promotes and guides lived experience in Mental Health Research. He lives in St Anne's, by the seaside, with his wife and two dogs, and is returning to Manchester for this event, where he gained his First Degree from Manchester University in 1988. Chris is also a practicing Horticultural Therapist and an Institute of Leadership and Management Coach.

Talk:

'You can't get lost if you don't know where you're going.'

Chris's presentation will try and explain the feelings associated with the early experiences of severe mental health conditions, and especially how that relates to any understanding of what was happening to the world and life in general. Looking at how the onset of illness affected support networks and family and friends, Chris will explain some of the emotions and fears and challenges to relationships that others have described. Chris will examine how the services available then, were much less than today, but try and find the positive aspects of them. Chris hopes to

show how we must look to the future together and use shared experiences to provide, genuinely useful information, and support to overcome the breakdown of supportive relationships.

Meet the Speakers

Alison Brabban



Although Dr Alison Brabban is a clinical psychologist by profession she now has a number of roles within the NHS, each concerned with trying to improve carers' and services' experience of mental health services. She is the Recovery Lead within Tees, Esk and Wear Valleys NHS Trust, which has the aim of ensuring services meet the individual needs of service users. In her role as Expert Advisor to the Adult Mental

Health team within NHS England her focus is on improving access to psychological therapies for people diagnosed with psychosis, bipolar disorder and personality disorders, on the promotion of values based care as well as measuring outcomes (looking at what difference interventions and services are making). Over the last few years she has also been involved in the development of the NICE Guideline for Psychosis & Schizophrenia and the related NICE Quality Standards and was part of the Schizophrenia Commission.

Talk:

The Vision for Community Mental Health Provision - What does it mean for carers?

The ambition of the Long Term Plan is to transform Community Mental Health provision. The plan recognises that services need to address the wide and diverse needs of the local community, going beyond treating illnesses, offering choice and promoting the wellbeing of the local population. In her talk Alison will consider the implications of these plans for carers.

Meet the Speakers

Philippa Lowe



Philippa Lowe is a carer for her son who has experienced schizophrenia for over 20 years. Her career was spent as a psychologist in the Prison Service, where she worked in four London prisons and then in the Service's headquarters on staff projects. Having discovered Rethink Mental Illness through contacting its Advice and Information Service, she became involved in its governance about 15 years ago and has been Chair of Trustees since 2015.

Talk:

"Rethink Mental Illness: how campaigns, groups and services can change the experience of carers".

Rethink Mental Illness provides advice support and a strong voice for people severely affected by mental illness, which includes carers as well as service users. As the Chair of Trustees, Philippa will give a personal perspective on the lessons that she has drawn from her experience as a carer for her son, who has a diagnosis of schizophrenia, and how these relate to the approach taken by Rethink Mental Illness

Alex Kennedy



Alex Kennedy is the Head of Campaigns and Public Affairs for Rethink Mental Illness. In that role he has campaigned on issues including funding for supported housing, the use of restraint in mental health units and out of area placements. He was a member of the Working Group of the Independent Review of the Mental Health Act as the lead on the involvement of families and carers as well as on advocacy. Alongside the Royal

College of Psychiatrists, his team provides the secretariat to the APPG on Mental Health, which last year conducted an inquiry into progress on the Five Year Forward View for Mental Health. Before joining Rethink Mental Illness, Alex worked for the homelessness charity Crisis where he managed the campaign that led to the Homelessness Reduction Act

Talk:

"Rethink Mental Illness: how campaigns, groups and services can change the experience of carers".

Alex will explore the significance for carers, friends and relatives of people with mental illness of policy developments such as the Independent Review of the Mental Health Act and the new approach to community services set out in the NHS Long Term plan.

Meet the Speakers

Julie Billsborough



Julie Billsborough is a researcher with The McPin Foundation. She has recently been working on a mini-evaluation of the Triangle of Care and on IMPART (IMplementation of A Relatives' Toolkit). She started her research career with Rethink Mental Illness on a project about recovery from severe mental illness. Since then, she has worked on a variety of projects for The McPin Foundation, including a project about peer support, an evaluation

of Local Mind Associations and a directory of involvement. Julie has experience of supporting a friend with mental health difficulties and has a particular interest in using these experiences within research. She is passionate about improving mental health services for the benefit of both carers and for those using these services

Talk:

How can initiatives like Triangle of Care drive change?

The 'Triangle of Care' approach was developed by carers and staff to improve carer engagement in acute inpatient wards. Implementing the Triangle of Care involves a collaboration between the service user, professionals and carers. Carers Trust currently hosts the Triangle of Care and has developed a scheme for Trusts that wish to implement it locally. The McPin Foundation was commissioned by the Carers Trust to carry out a small-scale evaluation of the Triangle of Care. The aims were to look at the impact of the Triangle of Care on carers and staff; how to embed the Triangle of Care as a cultural change; and how the self-assessment process is working and whether it can be improved.

Julie Billsborough (The McPin Foundation) and Donna Bradford (Carers Trust) will be talking about the results of the evaluation and how initiatives like Triangle of Care can drive change.

Meet the Speakers

Donna Bradford



Donna is a Registered Mental Health Nurse after qualifying in 1991 has worked in acute mental health settings, rehab and forensic services over her career. She is particularly interested in supporting carers and has for the past year been looking after carers within Lincolnshire Partnership NHS Foundation Trust. She has been heavily involved in and led on work on the Triangle of Care within her Trust. Donna is a Meriden Behavioural Family

Therapy trainer and also sits on the Advisory Board for Rehab for the Royal College of Psychiatry. Donna has been instrumental in setting up carer education groups and support groups for carers of people with mental health problems. Donna is currently the Interim Project Manager for the Triangle of care for Carers Trust two days a week. Donna is a cat lover and enjoys gardening, reading and sunny holidays.

Talk:

Donna will speak with Julie about 'How can initiatives like Triangle of Care drive change?'

Sheena Foster



Sheena Foster is a carer and was involved with the development of the Secure Carers Toolkit and is now working with the National Secure Programme. She is a Family and Friends Representative for the Forensic Quality Network and also sits on the Advisory Committee for the Network at the Royal College of Psychiatry(RCPsych). More recently she was appointed by NHS England to the Adult Secure Clinical Reference Group. Sheena

was also involved with the IMPART study looking at how REACT was implemented across 6 NHS Trusts.

Talk:

Doing things differently -the Secure Carers Toolkit.

In March 2018 NHS England and the University of Central Lancashire, in partnership with the RCPsych, launched "Carer support and involvement in secure mental health services – a toolkit". This is an online toolkit but hard copies were also produced and sent round to all Secure Services in the Country.

Sheena's presentation will look at previous attempts to involve Mental Health Carers and the factors that influenced the development of the toolkit. It will look at what we aimed to do and where the toolkit needed to 'sit' in order to give leverage to its implementation. While there is still a long way to go in engaging with carers in secure services there have been some successes as a result of the toolkit.

Meet the Speakers

Heather Robinson



Dr Heather Robinson is a Lecturer in Mental Health at Lancaster University and former REACT Trial Manager. Heather was involved in the day-to-day management of the REACT trial including ethical approvals; initiating and maintaining contact with NHS patient identification centres; participant recruitment; and participant retention to follow-up. Heather has a general research interest in the development of psychological interventions,

particularly digital interventions, for people with severe mental illness and their relatives/close friends. She is also interested in understanding the psychological processes, such as illness beliefs and coping styles, that underlie mood management in bipolar disorder in order to enhance mood management skills through intervention.

Talk: **The REACT Trial**

Relatives and friends of people with bipolar and psychosis provide a large amount of vital unpaid support, but this can come at a cost in terms of high levels of distress and increased use of healthcare services. Despite UK government commitments to provide relatives with the information and support they need, there is still a challenge with access to clinical services and support for relatives. The Relatives Education and Coping Toolkit (REACT) is a digital, peer-supported, self-management toolkit for relatives of people with psychosis or bipolar disorder, which provides NICE recommended information and support. REACT includes 12 psychoeducation modules, a peer supported group forum, private messaging to a trained relative (REACT Supporter), and a resource directory – a comprehensive list of existing support for relatives.

The clinical and cost effectiveness of REACT plus treatment as usual (TAU) compared to a Resource Directory plus TAU was evaluated in a primarily online single-blind national definitive randomised controlled trial (RCT). Eight hundred UK-based, help-seeking relatives, aged 16 or over, with high levels of distress (primary outcome) and access to the

internet took part in the RCT. Findings from the REACT Trial will be presented.

Meet the Speakers

Naomi Fisher



Dr Naomi Fisher is an implementation researcher who works to understand how learning and interventions can be used to improve services and support carers. To do this she brings together people from each of the groups who are involved in getting research into routine use. Together through workshops and feedback cycles they problem solve together and share what works across different settings. Naomi is also a lecturer in

mental health in the Division of health Research and a member of the Spectrum centre for mental health research.

Talk:

Implementation of the online Relatives Education And Coping Toolkit: Key learning and update

We conducted an implementation study to understand the factors that influence implementation of REACT in six NHS Trusts across the UK. Challenges for staff included concern around clinical responsibility for online risk, managing competing priorities and high caseloads. The plan involved strategies to raise awareness of REACT and identifying how offering REACT could fit into routine practice.

Carers felt that REACT should be offered as soon as possible as part of support offered by Early Intervention Services and not replace face to face contact. Carers saw additional benefits to being offered REACT by other carer who were viewed as offering potentially greater levels of understanding than clinical staff, which has implications in terms of involving carers to introduce REACT in future. Participants were positive about REACT's use of video illustrating situations faced by other carers and how they dealt with them. Watching the videos reduced feelings of isolation, as they identified with people in similar situations. Factors discouraging use or returning to REACT included technical problems accessing REACT, lack of forum activity, and omission of important areas of content.

Meet the Speakers

Sue Flowers



Sue Flowers is an artist and project manager. She established the third sector organisation Green Close in 1996, which specialises in using the arts to address social concerns and empower individuals www.greenclose.org. Between 2014-15 she was commissioned to work as an artist on the Arts and Health programme for Lancashire Care NHS Foundation Trust; developing new artworks with service users and staff for the acute wards and café at their new mental health facility, The Harbour in

Blackpool. In 2015 she joined the Spectrum Centre for Mental Health Research at Lancaster University to work part-time as a peer supporter on the online study REACT. Here, she brought her lived experience of supporting two close relatives with bipolar disorder to the role of supporting others who help their friends and relatives manage complex mental health conditions. She has recently used her skills to successfully lead the two-year arts, heritage and mental health project: Whittingham Lives www.whittinghamlives.org. She is a member of the mental health charity Rethink. Contact sue@greenclose.org Studio 015242 21233

Talk:

Peer Support –getting it right?!

Sue will talk about her experiences of working as a peer supporter on REACT the Relatives Education And Coping Toolkit for the last four years, from the beginning of the research study through to its conclusion and a period where Lancashire Care NHS Foundation Trust explored implementing the project into their services. She will speak about what she has learnt by being involved in this process, exploring some of the benefits and challenges of working in this way. Her key focus will be the utilisation of peer supporters in research projects; what does this mean for individuals who choose to bring lived experience

Meet the Speakers

Steven Jones



Steven Jones is Professor of Clinical Psychology at Lancaster University. Steve has expertise in managing multi-site research including an NIHR Programme Grant in Bipolar Disorder, is part of the IAPT Expert Group for Implementation, and with Fiona Lobban co-directs the Spectrum Centre hosting several online trials for Bipolar Disorder.

Talk:

Steve will speak with Sue Flowers about Peer Support in the REACT Trial.

Sonia Johnson

Professor Sonia will give a talk titled

“Implementing digital for patient and carer self-management in the NHS: what we know so far and what we need to know next”

Resources Available

The REACT Toolkit

<https://reacttoolkit.uk/>

The REACT toolkit is the Relatives Education And Coping Toolkit, an online self-help package or toolkit for relatives and friends of people with mental health problems associated with psychosis or bipolar. It was put together by a team of people with expertise in this area, including clinicians, researchers and relatives of people with psychosis or bipolar.

Carer Support and Involvement in secure mental health services. A toolkit.

<https://www.england.nhs.uk/publication/carers-support-and-involvement-in-secure-mental-health-services/>

This toolkit aims to provide clear information for carers, service users, service providers and commissioners about how carers of people who use secure mental health services should be engaged with, supported, involved and empowered.

Outputs from the Day

Following the event recordings of the presentations and a report summarising the outcomes day will be made available here

<https://www.lancaster.ac.uk/react/>

Contacts

For any questions or comments about the event, please contact Bethany Gill on 01524592910 or at b.gill2@lancaster.ac.uk

If you have any questions about REACT and how to offer it as part of what you do please contact Dr Naomi Fisher on 01524593009 or at n.r.fisher@lancaster.ac.uk

