



Summary of the Mental Health Carers Workshop: The Way Forward

Tuesday 9th July 2019



Short summary

The aim of this report is to summarise our Mental Health Carers Workshop which we ran to talk about the REACT research findings and carers interests and concerns more generally. It is provided for people who were not able to join us and for everyone who was involved in the day. We have described each of the talks, discussions and the feedback on the day.

What was the aim of the day?

To bring together carers, health professionals, people with experiences of providing or using mental health services and researchers to share ideas about how we can work together to make real change happen to improve the lives of carers and those they support.

Who attended and what did they think of the day?

95 people, including speakers and delegates from a range of backgrounds.

What were the key messages from the day?

- More opportunities need to be created for carers to be heard. Innovative ways to encourage open dialogue and peer to peer forums (face to face and online) should be explored.
- In services, there should be peer worker roles for carers, and carers should be involved in training staff how to work with families so they feel heard, valued, and supported.
- Existing policies that support carers are not being effectively implemented. We need to identify who is accountable for what – and hold them to account.
- The focus of policy, funding and services needs to be on long term continuity of care, not just early intervention.
- Carer concerns have remained pretty constant for the last 20 years –they want better support and treatment for their relatives and for their voices to be heard and valued. Many carers are frustrated as they don't see a system listening to them and they are experiencing extreme pain and anguish watching their relatives suffer.
- The Triangle of Care offers a good framework, but why is it not used everywhere? It was designed with carers, has evolved over the years but still it's not widespread and this frustrates and angers carers. Triangle of Care should be further tested, and is appropriate, mandated.
- A key concern for carers is "What will happen when I am gone (dead)? Who will support my son/daughter then?". This is often not addressed by support services.
- Black And Minority Ethnic Carers feel their specific problems are not understood, and their needs are still not being met. The healthcare system needs to work to become more culturally aware and adapted.

What next?

- At the event, individual pledges were made to take action which would support change for mental health carers, and Spectrum pledged to write the report and circulate it.
- This report will now be circulated to relevant organisations including, NHS England, Mental Health Policy Implementation Unit, Leading Charities including McPin and Rethink and to local NHS Trusts.

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Aims and overview of the Day

The Mental Health Carers Workshop: The Way Forward event took place on the 9th July at the Friends Meeting House, Manchester. The event brought together people of different backgrounds and experiences to discuss how we can work together to make real change happen.

The reason for having this event was the recognition that 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 created a space for carers, relatives, friends, family and other stakeholders to discuss what is needed for real change to happen.

Overview of the day

Talks to inform and inspire discussions

We heard from a range of experts including carers, relatives, charities, clinicians and researchers who outlined innovative approaches from different areas. The speakers were invited to give brief presentations to inform and inspire the afternoon interactive discussion workshops.

Discussion workshops

In the afternoon, there were interactive discussion workshops, which explored how we can make change happen in: delivering policy, by using networks and organisations, doing research, using digital interventions, in the NHS and for carer involvement and outcomes.

Panel Discussion, pledges and take away messages

We finished the day with a panel discussion with some of our speakers from the morning, and then asked the audience and speakers to make pledges on what action they would take after this event.

Who attended the Mental Health Carers Workshop

Naomi Fisher and Chris Lodge set the scene for the day and André Tomilin from 'The Mental Elf' described how he was using Twitter to invite people to join in our discussion online.

The day was attended by 95 people, including speakers and delegates.

The morning presentations were delivered by people speaking from the perspective of carers, service users, chairs or employees of charities, NHS staff and academics.

Of the people who attended 42 people completed feedback forms on the day. Of the 42 people described themselves as:

- Carer, Relative or Friend (25)
- Supporter of Carers (1)
- Carer, Relative or Friend and a Service User and Other (1)
- Carer, Relative or Friend and a Service User (3)
- Carer, Relative or Friend and a Clinician or Health Related Professional (2)
- An Academic (1)
- A Service User (1)
- Clinician or Health Related Professional (6)
- 'Other' (including Third Sector Care Support Worker and Programme Development Lead at a Charity) (2)

The day was also covered by The Mental elf on Twitter which involved even more people.



The Mental Elf @Mental_Elf · Jul 9

Big thanks to all of the #MentalHealthCarers tweeters!

>450 tweets

Sent by >130 people

>8 million Twitter impressions



Talks to inform and inspire discussions

We have summarised the talks delivered by each of our speakers below. To watch recordings of the morning talks we were permitted to film see <https://www.lancaster.ac.uk/react/carers-event/>

Talk 1: '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?' Jo Smith



Jo began her talk by discussing the robust evidence base, cost effectiveness, positive outcomes and value for carers and service users of Family Intervention (FI) in early intervention services. Jo discussed the reality of having an efficacious intervention that is evidence based, that is not being translated into routine practice.

Jo talked about what is happening in relation to early intervention in psychosis services and reviewed national audit data from 2018/2019 in relation to providing Family Intervention and Carer Education and Support for families supporting a relative with first episode psychosis in line with national Access and Waiting Time (AWT) standards for England.

For Family Intervention, 22% of families took up the intervention, which is an improvement on the previous year. Around 50 % of the Trusts who took part in the audit are performing well in regards to family intervention, there are some Trusts which need improvement. For Carer Education and Support, on average 55% took up or were referred to a Carer Education and Support programme which is an improvement on the previous year.

Jo discussed that although there has been a national improvement on these two standards, it is important to understand why there is variation between teams. Sufficient staffing numbers and access to family intervention training and supervision have been important factors, but we need to understand what other factors influence this variation. We need to campaign at commissions to provide funding, so teams can have trained staff who can deliver Family Intervention and Carer Education and Support to everyone who wants it to a high standard.

The National Clinical Audit of Psychosis 2018/2019 is available here https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/ncap-library/ncap-eip-national-report---final-online-20190807.pdf?sfvrsn=166d7fe7_2

Talk 2: 'You can't get lost if you don't know where you're going.' Chris Lodge



Chris introduced himself and explained that he had been living with mental health conditions since 1993, and presented what it feels like to be part of a caring team, with family and friends, is trying to cope whilst he himself was also trying to cope.

Chris explained the title of his talk, saying that he chose this to reflect that in the early 1990s, himself and the people around him did not understand what they should be doing, what it meant and what it should feel like. Chris then discussed other examples of this type of experience by referring to the 2014 NICE Guidelines 178 (<https://www.nice.org.uk/guidance/cg178>) which highlights important parts of the relationships between service users and

carers.

Chris talked about how the lack of positive references and information about psychosis available to those around him led to a hindrance in his recovery. Expressed emotion also caused difficulties, as did the lack of information provided by services. Chris talked about how his mum felt that both she and Chris had been ignored, and that she had to get very angry to be heard. Chris described how once he gained insight, and his friends and family began to understand more, they were able as a unit, to strongly help him recover.

Chris concluded by saying that the key thing is insight, and that when going through these experiences you need clear understanding as it is a complex process. Once there is insight and information available for everyone, recovery can start.

Chris also made a podcast with The Mental Elf which you can listen to here:

<https://soundcloud.com/national-elf-service/chris-lodge?in=national-elf-service/sets/mentalhealthcarers-mental>

Talk 3: The Vision for Community Mental Health Provision - What does it mean for carers? Alison Brabban



Alison presented the NHS vision for community mental health, and what this will mean for carers. She started by explaining that over the next 10 years we should experience a transformational change in mental health services. Alison compared the traditional model of illness services, which includes waiting for people to become ill, having specialist care in hospital and being discharged to the community to the new vision, which includes a population community focus on mental wellbeing. This will include looking at the health of the population and thinking about prevention.

Alison posed the question of, what do we need to do to stay well? She said that in general we all need the same basic needs to thrive, including decent housing, money, safety and

connections rather than isolation. She went on to say this won't be enough for everyone, and some will go on to need specialist treatment, which is not just about medication as psychological therapies can make a huge difference. Alison explained that although not everyone will want these interventions, the important thing is that there is a choice and they are available if wanted.

Alison discussed NHS England current work, which is going beyond early intervention services to make sure everyone has access to psychological interventions. For community services, the drive is to have a community that works together rather than in silos. This includes primary and secondary care working together, mental and physical health, social care, public services, social prescribers and local assets including recovery colleges. The aim is to bring people together so that they feel connected to their community.

To conclude, Alison talked about the importance of co-production with communities and carers for NHS England's plan and that the buzz words we will be hearing are: shared decision making and choice, supported self-management, personalised care planning, personalised health planning and social prescribing.

Talk: "Rethink Mental Illness: how campaigns, groups and services can change the experience of carers" Philippa Lowe & Alex Kennedy



Phillipa began by outlining the main thrust of their talk, which is how Rethink Mental Illness (<https://www.rethink.org/>) changes the experiences of carers. Philippa introduced herself as Chair of Rethink and a carer, and that she was going to use her time to talk about her journey, and Rethink's involvement in that journey. Philippa explained that she has cared for her son who has a diagnosis of schizophrenia for 22 years, and found Rethink's advice line enormously helpful early on. The advice line advised her to join a carers group, of which Rethink provides 150 peer supported groups for carers, service users and both. Philippa discussed how, on joining a carers' group she became more aware of the injustices and stigma that individuals with severe mental illness face and wanted to help campaign about this. Rethink is noted for its campaigning and influencing. She also became more aware of the services needed for individuals with mental illness, and Rethink provides over 150 of these services including crisis houses and



supporting houses. Philippa then handed over to Alex who is head of campaigns for Rethink.

Alex explained how Rethink works through different ways including services, groups and campaigning. He explained that even though things have been done well, there is still a long

way to go for carers and people with mental illness, but that his talk would focus on two particular issues. The first was the new NHS long term plan, which Rethink as an organisation did a lot to shape debate, bring together evidence and the views of carers and those with mental illness. Alex explained that the next step is now to shape the services outlined by the long term plan which needs to have co-production the whole way through. The next issue Alex discussed was The Mental health Act, which is always on Rethink's agenda, and the large survey Rethink conducted to get the Act reviewed. Alex talked about the recommendations for family and friends that had come from this review which includes: a move away from a nearest relative model, to information sharing and advance decisions, more involvement in treatment decisions and better advice and support for carers and nominated people. Alex finished by saying that campaigning, although frustrating, is important and he encourages everyone to get involved.

Philippa concluded their talk by asking the question, 'what happens when we are gone?' and how are services and Rethink placed to help this. She said this is a question which hangs in the air and that is the way that we will judge the success of what we are doing.

Talk 5 : How can initiatives like Triangle of Care drive change? Julie Billsborough and Donna Bradford



Julie and Donna talked about the 'Triangle of Care' approach (<https://carers.org/article/triangle-care>), which was developed by carers and staff to improve carer engagement in acute inpatient wards. They discussed how implementing the Triangle of Care involves a collaboration between the service user, professionals and carers. Donna explained that Carers Trust currently hosts the Triangle of Care and has developed a scheme for Trusts that wish to implement it locally, and that the McPin Foundation (<https://mcpin.org/>) 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 talked about the results of the evaluation and how initiatives like Triangle of Care can drive change.



Talk 6: Doing things differently -the Secure Carers Toolkit. Sheena Foster



Sheena began her talk by saying she once thought there was hope for mental health carers when the National Service Framework for Mental Health was introduced over 15 years ago (<https://www.gov.uk/government/publications/quality-standards-for-mental-health-services>). This included Standard 6 advising that carers should be identified but this was not always helpful as mental health carers usually were in secondary services and the Local Authority was given the responsibility for carers. Sheena explained there had some progress with Developing Services for Carers and Families of People with

mental illness, and the Triangle of Care but that there were large gaps of time between these initiatives. Sheena explained that for her the Triangle of Care had raised questions as to whether it promoted itself beyond its capabilities when it focussed on all services when it's primary aim had been in-patient care.

Sheena then went on to talk about the secure services carers' toolkit. She explained that secure services are services for people with mental illness who have also been involved with the criminal justice service. Both the Five Year Forward View (<https://www.england.nhs.uk/five-year-forward-view/>) and the language it uses such as empower, navigate, peer support, and the research done by UCLAN (University of Central Lancashire) about the needs of carers in secure services were used to inform the development of the toolkit. Sheena explained how over 100 carers were involved and the most important thing for them was that their emotional needs were met.

Sheena explained the toolkit has been created as a pathway so the chapters show the journey through the system for carers. Each chapter includes key issues faced for carers, what they should expect from services, good practice examples and further reading. Understanding where the toolkit needs to be placed for impact was important so it was adopted by the Royal College of Psychiatrists in their Standards for the Forensic Quality Network, College Centre for Quality Improvement (CCQI) and NHS England has included it in the Service Specifications for all secure services across the country. The toolkit aims to create a dialogue between commissioners, providers, carers and service user. It is available as a hard copy or on line here <https://www.england.nhs.uk/publication/carers-support-and-involvement-in-secure-mental-health-services/>.

Talk 7: The REACT Trial Heather Robinson



Heather started her talk with some background to why REACT had been developed, explaining that 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. She described how 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.

She explained about the randomised controlled trial that had been carried out to assess REACT and presented the outcomes of this trial. She explained that the trial results will be made available soon.

The REACT Toolkit is now freely available to everyone. You can register to use the site here <https://reacttoolkit.uk/>.

Talk 8 Peer Support –getting it right?! Sue Flowers and Steven Jones



Steven introduced the intention in REACT was to work with relatives as REACT supporters from the outset, and having people with lived experience was crucial to deliver appropriate support and empathy to people. In the trial, there were 400 people accessing the REACT site and for this 1.2 full time equivalent REACT supporters were employed, but having more to cover sick leave and holidays would have been useful. The supporters had a crucial role in the study, providing empathy and authenticity, but it was important that they themselves have support for the role for dealing with scenarios that may have triggered personal emotional responses. There was peer-to-peer support which was organised into the working week and clinical supervision which occurred fortnightly. Key issues were supporter wellbeing, clinical issues coming up through the site, managing site practicalities and having flexibility to discuss traumatic posts and identifying risks and their subsequent impact on individuals. Steven highlighted learning from the trial including, offering text based support which meant that the supporters had to hone messages with fewer cues, there was a tension for what could be offered within the time available, offering

support rather than giving specific advice and being aware of what it is possible to do remotely.

Sue began her talk by explaining the challenge of having the desire to help people, but also remembering that REACT supporters were not offering a crisis service. Sue introduced that she had worked as a REACT supporter for three years and had personal experience of supporting close relatives. Sue explained that the job involved drawing on their own experiences, but this wasn't always simple, especially when having to draw upon previous traumatic experiences.

The REACT team kept a reflective learning log about the study which included records from the supporters highlighting the importance of needing clinical supervision and having peer support. Sue discussed the learning of being a REACT supporter suggesting training and supported adjustment to working in a research context is vital, the confidentiality of supporter's own stories and the friends and family members they support are considered at the outset of a study, ensuring that supporters are recruited who have genuine lived experience to ensure parity in the role, that peer support work is effective and reduce a possible sense of isolation, flexibility of approach and location for work for people who are in a caring role needs careful consideration and planning, and understanding the complexity of acronyms for those coming from outside the research and health care sectors.

Sue presented some reflections about what it can feel like being a REACT supporter which included, complex feelings, speaking from personal experience so not wanting people to take offence and being over sensitive to being left out of discussions. Sue concluded that despite the issues and challenges it has been a worthwhile process, and that the feedback from participants had made it exceptionally worthwhile.

Steven also made a podcast with The Mental Elf which you can listen to here <https://soundcloud.com/national-elf-service/steven-jones?in=national-elf-service/sets/mentalhealthcarers-mental>

Talk 9: "Implementing digital for patient and carer self-management in the NHS: what we know so far and what we need to know next" Sonia Johnson



Sonia introduced the focus of her talk, which is research that may be relevant to the implementation of REACT. Sonia first discussed supporting self-management, as research has shown that helping people with their own strategies is important. It is particularly helpful when it is supported by those around them including professionals peer support, family and friends and professionals, not when people are left to their own devices. Sonia next discussed approaches to family and friends, including psychoeducation which has benefits for carer outcomes and also for service users. However, there are implementation problems which limits access to support for family and friends. Sonia then discussed how widely digital tools are being used in the NHS, which are doing well comparatively to previous

attempts, but there is still widespread non-adoption and primary services seem to have more success than secondary services. The main barriers to digital implementation include: scepticism amongst staff, service users and carers, lack of digital skills and lack of staff support and time. Other barriers include complexity in new systems, which may be hard to set up or require a change to services. Sonia concluded with some thoughts on what this might mean for REACT, in relation to it being digital, it's roll out and funding.

Sonia also took part in a podcast with The Mental Elf to explore developments in digital interventions and what needs to be done to support change. You can listen to the podcast here <https://soundcloud.com/national-elf-service/sonia-johnson-2?in=national-elf-service/sets/mentalhealthcarers-mental>

Talk 10: Implementation of the online Relatives Education And Coping Toolkit: Key learning and update. Naomi Fisher



The final talk was delivered by Naomi who explained that she would be wrapping up the REACT talks and sharing what is being done to try and get REACT adopted and is made widely available. Naomi started by explaining that they had looked at the use and offering of REACT in early intervention services in six NHS trusts. Naomi explained that there was variation in the number of relatives that created accounts across the six trust, and they wanted to explore what in the implementation process had impacted on this. actors that helped including: identifying individuals already working in the service who were digitally competent and it should be offered as part of face to face contact, and factors which didn't help: interacting and managing risk online, large staff turnover and competing priorities including audits. Naomi explained that the learning from this is to develop things as part of trusts and services rather than badging it as research. Naomi explained that relatives, staff and the digital team were all involved in problem solving rather than just looking at what was not working.

What worked well for staff was knowing that carers had appreciated REACT and found it useful. What worked well for carers, was having the information available for them themselves to choose when they wanted to access it, to have REACT alongside face to face and for it not being another leaflet but having videos and having all the information in one place. What did not help carers was technical problems, lack of activity on the forum and wanting more information about different things.

Naomi finished her talk by explaining that now they are looking for ways to make REACT available and sustainable beyond the research.

You can find out more about the REACT studies here <https://www.lancaster.ac.uk/react/>

Discussion Workshops

The afternoon of the Mental health Carers Workshop began with interactive discussion workshops. People chose what area of change they wanted to discuss in depth and then moved to other discussions to find out what others had said and to add their thoughts or questions if they wanted. Below are brief summaries of the discussions

[Discussion Workshop 1: How can we make real change happen: what needs to change in creating and delivering policy?](#)

[Facilitated by Alison Brabban and Philippa Lowe](#)

The discussion centred around the following points:

- Co-production was repeatedly raised as a factor that needs to be improved. Co-production was seen an important part of future research consultations, involvement with pilot schemes, having open dialogue, and understanding what matters to carers and service users.
- The barriers for carers around policy, which centred around complexities and lack of transparency in systems and services.
- The lack of integration and information sharing at service, local and national levels. Organisations who work alongside NHS multidisciplinary teams are not meeting together to improve service and quality although they often have the same goals, they were described as 'working in silos'.
The need for changes in where the 'power' is held between services, local authority and charities.

[Key messages and recommendations from this workshop](#)

- Co-production with carers should be considered throughout policy creation and delivery and integrated throughout all aspects. Individuals responsible for creating and delivering policy need to review how carers are involved and increase opportunities for co-production.
- We can all make change happen in policy, through making individuals accountable, challenging opinions and meeting the 'who' are responsible to voice experiences and what needs to change. The system needs to be simplified so that this is easier to accomplish for Mental Health Carers.
- Third sector organisations, local authorities and the NHS need to work more closely to provide more integrated services for carers and service users.

Discussion Workshop 2: How can we make change happen: how can we use networks and organisations to facilitate change?

Facilitated by Chris Lodge and Julie Billsborough

The discussion centred around the following points:

- Commissioning for Quality and Innovation (CQUIN) Targets could be used to help facilitate change. This would have capacity to create change at a broad level in the NHS which would impact on Trust and Carers.
- Engagement with Mental Health Carers needs to be improved. There are barriers to engagement with mental health carers which networks and organisations need to be aware of and overcome including; geographic issues, support issues and lack of information. There should be more involvement opportunities for carers, including capacity to have peer supporters, hold carer support groups conferences such and have a carers point where information can be passed on in a more co-ordinated way.
- The Triangle of Care (<https://carers.org/article/triangle-care>) is an effective tool, but could it's use be improved? Clinicians should have to intent to engage with carers, and this engagement with carer relationships should be measured. This should be mandatory in NHS Trusts. Triangle of Care is more likely to be effective if it has the support of all staff, particularly senior management. Also, Trusts need to be more pro-active in engaging with a wide variety of carers - co-production is helpful.
- External networks and organisations should be advertised through NHS Trusts. Carer's Trusts, Carer's Assessments and Counselling should all be signposted to and how to access the support explained. Improvements need to be made to the REACT site (<https://reacttoolkit.uk/>), including content and how it is used. REACT should contain information on educating carers on how to get what they want out of services and organisations. REACT should be used to enable better carer involvement and also to support the volume of assessments clinicians and teams have to complete.

Key messages and recommendations from this workshop

- Networks and organisations need to facilitate engagement with and involvement of mental health carers in a capacity to make change in the NHS. To do this, they need to acknowledge and provide solutions to the barriers mental health carers face around involvement.
- Networks and Organisations need to create opportunities to bring Mental Health Carers together to share experiences and information and explore involvement opportunities.
- There needs to be an increase in the recognition and uptake of the Triangle of Care. This could be achieved by making it a mandatory requirement that NHS Trusts have to sign up to it.
- REACT should include information about services, and how to navigate them, this would help carers learn how they can get the most out of them

Discussion Workshop 3: How can we make real change happen: what research should we be doing?

Facilitated by Vanessa Pinfold and Steven Jones

The research discussion group looked at what topics people in the group were interested in and the challenge of getting research findings into practice. Like a lot of research conversations the problems carers encounter themselves were the focus of the discussion mainly, not research practices per se. We heard how carers felt that they were always on a “roller coaster”, “waiting for the show to drop” (next crisis), “on a roundabout that never stops”, and the experience is like “wading through mud” (exhausting).

Challenges for current research included:

- General concepts presented by researchers such as ‘recovery’ and ‘treatment resistant’ can have very different individual meanings to carers supporting a person with mental health problems. This can lead to frustration with a research system.
- What does research achieve? Where is all the implementation of research studies to benefit individual service users and their relatives. Research must do more to change actual practices on the ground, particularly among psychiatrists.
- Developing new treatment choices for people with mental health problems. There is a lack of options (unlike cancer) and research should strive to develop new treatments and support including use of virtual reality.
- How to interest NHS staff in research – doesn’t seem like a priority for them.

Future research should consider:

- The link between different conditions such as autism and mental health issues, Multiple Sclerosis (MS) and Schizophrenia. We need to know how different conditions linked particularly genetically.
- More work on prevention of relapse as this would lessen everyone’s distress. Additionally, better signposting to available sources of help, so access to services is quicker when needed.
- Concerns of carers, especially, ‘what will happen when we are gone?’
- We need new treatments thus research needs to focus on simple, accessible solutions that improve lives in the everyday plus we need new interventions developed.
- Exploring new explanations do how mental health problems develop such as Immunology
- We also need to focus upon personalised medication – how can this be achieved in mental health? Can it create better outcomes?
- The silos of the life course need to be studied longitudinally so we better understand the transfer between systems particularly children and adolescents to adult services.

There were also concerns raised about attitudes towards research and mental health more generally. For carers research was about generating hope and in this group it was felt to be valuable in the 'making change happen' agenda with caveats. Including the need for a greater interest in research amongst staff (in services), which could be supported by linking to their continued professional development. There is felt to be a lack of optimism in mental health research, which is an attitude so different to that of cancer research. However, one member of the group explained how she wanted to do research from a carer perspective as a 'peer' and how the conversation motivated her further.

Key messages and recommendations from this workshop

- Future research including investments, grants and programmes should consider the ideas outlined above as areas of priority and implementation of what we already know.
- Create opportunities for carers to have their voice heard and shape research agendas in a setting where they can feel confident and listened to.
- The lack of research interest amongst NHS staff needs to be addressed, and greater involvement needs to be encouraged.

Discussion Workshop 4: How can we make change happen: how can digital interventions support change?

Due to only one attendee signing up to the workshop it was not run. The following are thoughts and suggestions about digital interventions people gave during the day

Feedback on the discussion page in the main hall had three points listed:

- Have method of postal service as well as email to communicate with carers
- CMHT and inpatient services should signpost to digital services
Can digital services address needs for face to face support? Would a regular carer support taking place over video conference allow participation by those whose location or caring responsibilities prevent attendance at physical groups? Could more expert consultations take place this way? Avoid travelling etc.

Key messages and recommendations about digital interventions

- The limited interest in the digital interventions workshop may possibly reflect the interest of digital interventions more generally.
- Can digital be used to support face to face services rather than being stand alone interventions?

Sonia Johnson took part in a podcast with The Mental Elf to explore developments in digital interventions and what needs to be done to support change. You can listen to the podcast [here](#)

<https://soundcloud.com/national-elf-service/sonia-johnson-2?in=national-elf-service/sets/mentalhealthcarers-mental>

Discussion Workshop 5: How can we make change happen: what needs to change in the NHS?

Facilitated by Jo Smith and Fiona Lobban

The output from this workshop has been summarised into four key themes where change needs to happen in the NHS which includes; culture change, financial change, service change and change in support that this is available for carers.

The discussion centred around the following points:

Culture change

Mental Health teams should be about helping service users and their families achieve the best they can. Mental health services need to be more innovative with family work, including spaces for open dialogue better advice for carers around identifying and supporting risk. There needs to be more respect towards individuals and carers cultures, for instance involving religious beliefs in care plans. The culture and attitudes of some staff towards carers also needs to change. Some carers feel stigmatised, stereotyped and excluded, when they should be listened to and involved as carers know the person best and staff should use the carers experience.

Financial Change

Changes which had a financial aspect were raised in this workshop. Financial constraints are preventing services being properly staffed, some services are being left without psychiatrists and others are struggling to retain staff. Staff are also not being trained and there are concerns around stopping staff bursaries. It was also raised that funding should not just be put in to early intervention services but should also go into services to support people with long term conditions and serious mental health problems.

Service Change

Mental health services need to change to provide a better service for Mental health Carers and Service Users. There needs to be an improved and extended Child and adolescent mental health services (CAMHS), as brains continue to mature until the age of 25, 17/18 is too early to be cut off. Learning disability services already do lots of things that carers of people with serious mental illness want, other services should learn from the examples set including, being person centred, care planning, and involve family. There should be carers awareness training for all mental health professionals, which should train staff how to identify carers and signpost them for relevant support to look after their own wellbeing so that they are able to continue caring. There is concern that there is 'Short term services for long term illness', services need to look at how they can provide long term care.

Support that should be offered

There should be more forums for carers to share their stories. This could be done with face to face care forums or online such as through REACT. There should be more carers groups and transport and sitting service, and funding so carers can attend these.

Key messages and recommendations from this workshop

- Involvement of carers needs to be at every level of the NHS including, teams, trusts, commissioning groups and NHS England.
- Change needs to occur at several levels within the NHS including culture, finance, service and the support that is offered to carers.
- The changes raised by this workshop need to be brought to the attention of those identified who can make change including: NHS England policy makers, Psychiatrists and health professionals, Trusts, Health Education England, Care quality Commission (CQC), Royal College of Psychiatrists, Third sector and GPs.

Discussion Workshop 6: How can we make real change happen: what involvement and outcomes need to be improved?

Facilitated by Sue Flowers and Sheena Foster

The areas identified where involvement and outcomes need to be improved include, more opportunities for peer support networks, service change to include more carer involvement and listening to carer voices and more support and information for carers.

The discussion centred around the following points:

Peer Support

There should be informal peer to peer support in community settings, with close access and links to commissioning. Facilitated peer groups for service users / carers would allow for discussion of shared experiences and considering each other's views. Peer supporters should be employed on permanent roles within trusts, should be valued, have role consistency and should be paid at a suitable banding or level.

Service Change

Services should include consistent, national standards of practice when working with carers that are measurable. Everyone, including carers, should have a Wellness Recovery Action Plan (WRAP). Family work should be at the top of the hierarchy and there should be a commitment to family work. There should be opportunities for shared learning opportunities for carers, service users and staff.

Support and Information for Carers

To provide carers with more information and support there should be a resource centre (library, leaflets, online resources) and a person in every mental health team where carers can get information and support. When a service user declines and is in crisis, carer needs extra support and this needs to be recognised and responded to. Carers also need to be supported to manage their own wellbeing, which could be done by social prescribing, having an advance statement for when carers themselves become unwell and having a respite or personal budget.

Listening to the Carer's Voice

Carers should have the opportunity to be a part of the service user's appointments, staff may find it helpful to have carers in interviews/ appointments/ counselling sessions with service users. Service providers need to listen and take into account the carers observations and knowledge of the service users 'We know best we see them deteriorate and flag this up – but are told to go away and if it gets back contact again'. Carers need to feel that they are being believed and being valued.

Key messages and recommendations from this workshop

- Involvement and outcomes for carers need improvements in all aspects of services, but a lot could be addressed by providing better information and support for carers and listening to the carers voice for their own care and the care of the service user.
- Services need to include carers more, by supporting them and having peer support workers who understand their needs.

Panel Discussion

After the discussion workshops we held a panel event which was hosted by Naomi Fisher and included, Sheena Foster, Alison Brabban, Jo Smith, Steven Jones and Phillipa Lowe.

Naomi asked the panel questions which had been written down by attendees on question cards, The Mental Elf asked questions that had been asked on Twitter, and finished with a talk from Phillipa.

You can watch the panel discussion here <https://www.lancaster.ac.uk/react/carers-event/>

Some of the questions asked to the panel included

- ‘How can we encourage all mental health professionals and teams to look towards long term outcomes rather than short term outcomes?’
- ‘With the grants for central government and funding being slashed is there anything we can do to address this and build momentum in the north of the country? In response to service need and getting carers groups together’.
- ‘We often tell mental health carers how important it is to look after themselves too, but this can be hard. What practical advice would you give to carers who might feel stressed, tired, angry, scared, confused, who are finding it hard to prioritise their own needs?’
- ‘Have we had experiences of diverse groups mentioned today, if not, why not?’
- ‘What informed support can professionals give for working age people with treatment resistant psychosis?’

Take Aways and Pledges

After the Panel Event Jo Smith led a session, asking what messages people will take away from the day and share with others, and for pledges, statements of what people will pledge to do following the event.

Jo invited everyone to share their thoughts, and also encouraged everyone to make a silent pledge or to think about what can be taken away from the day that they might share with someone, whether on the train or as part of a conversation with services.

Some of the take away statements and pledges given on the day and written on the feedback forms are listed below.

- 'I am going to actively join a charity in my area or somewhere that has carers interaction and help to make positive change'
- 'I'm pledging that I will continue to roll out, collaboratively with our carers, families and friends psychoeducation, information and support. It's something we have done at high secure for a number of years and carers have been amazing but we would like to roll out in more divisions and from today the secure carers toolkit will be rolled out'
- 'After seeing so many caring mothers today, having bipolar and with having a mother who has been a carer, I'm pledging to see things from her point of view a lot more'
- 'My pledge to take away is to leave no stone unturned and to work tirelessly to get better treatment and service for my 39 year old bipolar son from local trust in South Yorkshire and "my take away" is that if I fail to do this there were people in the event with sufficient authority and clout and drive, motivation and empathy to do what is possible nationally and locally to help complete my pledge to my son.'
- 'I pledge as do the group the rest of us are in, we pledge to continue holding the CCG, CEN, adult social care manager and CCG commissioner to have some money specifically spent on serious mental illness in the community so that it's no longer unsafe and not effective and if not we will have a judicial review..... and I will be reaching out where I haven't in the past'
- 'I'll take away hope. And that hope is that communication between medical staff and carers is opened up'
- 'We're going to put our heads together and think about how we can support parents in the psychosis team in our area, from the bottom up, about what they need, what will it look like and what we can do'
- 'I am going to make a pledge on behalf of Spectrum we've heard some brilliant ideas from so many people today so we pledge to make sure we capture them all and circulate them all back to you and then make sure that this kind of information gets in front of the people who can actually change things at every level'

Feedback on the day and Reflections

When we asked how you would describe the content of the event....'

16 people said it was Excellent, 18 that it was good and 7 satisfactory – no one said it was poor.

- *'Good variety of speakers but some of the information seemed rushed and was hard to follow'*
- *'The event was extremely useful. It would be great if it could be an annual event.'*
- *'Very disappointed re NHS England self-care and digital is not appropriate for the majority of the long term seriously mentally ill.'*

When we asked how you would describe the combination of presentations and interactive discussion workshops.....'

13 people said it was Excellent, 21 that it was good and 8 satisfactory – no one said it was poor.

- *'All information shared was extremely interesting and useful.'*
- *'I would have liked to hear more from carers, presentations were very short.'*
- *'Good opportunity to network and share good practice.'*

When we asked if there was enough opportunity to have your voice heard?

38 people said yes and 2 people said no

- *'would like more time for conversation with the interesting people'*
- *'I would have liked more opportunity to hear other carers. Maybe give carers a different coloured badge so we could easily identify and network with each other during the day.'*
- *'Just right'*

When we asked which aspect of the day did you find most interesting and relevant?

You said

- *'All of it, discussion workshop and meeting speakers'*
- *'Talking with other carers - many of whom were bubbling with ideas generated by their lived experience'*
- *'Hearing other carers stories and particularly their advice on how they had accessed support and also how they were pushing or campaigning for positive change for carers.'*
- *'All good. Carers are overlooked and ignored - but I felt valued today'*
- *'So many different people from across NHS / academia/ relatives coming together interested in change'*
- *'All of it was extremely relevant. Opportunity for me to network with others. Panel questions at the end were very welcome and was a good idea.'*

We asked 'What are you thinking about doing following this event?'

You said

- *'Reflecting on this conference in a productive way, sharing information as necessary.'*
- *'Appreciate myself more! Giving myself more self-respect. A carer and proud.'*
- *'Have a rest and then regroup to get a better NHS treatment for my bipolar son'*
- *'Looking at the requirement for a care plan which is a legal requirement not a paper exercise taking up a clinicians time unnecessarily.'*
- *'Trying again to find a mental health carers support group (not online but face to face). Try campaigning to drive change for carers.'*
- *'Joining a group to campaign for mental health. Rethink.'*
- *'Having a conversation with my son regarding hope for his future.'*

We asked 'Was there anything else you would like to say about the day?'

You said

- *'I feel the research isn't taking the right approach. Carers need the system to work and the system doesn't work. It would be good to look at carers views of where the system is broken and trial interventions aimed at fixing these in the NHS/stakeholders rather than educating carers as they are already the experts by experience and battle and battle but don't get listened to.'*
- *'These conversations need to be ongoing until we achieve the outcomes in mental health that is needed.'*
- *'Great to see people who want change coming together. Where there is a will there is a way.'*
- *'Good idea and valuable for me as a carer in terms of validation of my experience - hope for the future.'*
- *'Self-help won't help someone with psychosis and paranoia. They will not attend groups and talk about their feelings.'*
- *'Very useful. Encouraging. Informative. Inclusive. Positive. Hopeful.'*
- *'The event was 'comforting' knowing I'm not the only one. Thank you.'*

Reflections: What we will do differently next time?

Following feedback about the day we will do some things differently in our future events.

We are sharing these for people who might also be thinking about putting on carers events in the future:

- We will consider the number of speakers and timings of presentations. There was mixed feedback about the timings of the morning presentation, with some people enjoying the several brief presentations and others having said they would have preferred fewer speakers and longer presentations so information would not be rushed.

- Although there was a lot of positive feedback about the venue there were some issues that we need to consider for future events including parking and layout of tables. A venue with better parking would have made the day more accessible. In the main hall there were only six round tables for people to sit at, and once these were full, others had to sit in the theatre style seats at the sides. This meant that in the breaks and during the presentations, there was not as much opportunity to network with others. The next event should have space for all round tables so that discussions can take place.
- The day focused mainly on adult carers, and in future we will include discussions of young carers who have a parent with mental illness, and is an area that is often overlooked. Future carers events should consider all different types of mental health carers, including young carers, carers from Black and Ethnic Minority backgrounds and hold this in mind during the planning and running of events.