Science Ama Series: We are a team of researchers from the Universities of Manchester and Nottingham, UK, working on a 5 year program to enhance the quality of care planning in mental health services. AMA

MentalHealthService [1] and r/Science AMAs[1]

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April 17, 2023

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CORRESPONDENCE:

DATE RECEIVED:
July 14, 2017

DOI:
10.15200/winn.149995.50240

ARCHIVED:
July 13, 2017

CITATION:
MentalHealthService , r/Science , Science Ama Series: We are a team of researchers from the Universities of Manchester and Nottingham, UK, working on a 5 year program to enhance the quality of care planning in mental health services. AMA, *The Winnower* 4:e149995.50240 , 2017 , DOI: 10.15200/winn.149995.50240

What do you think needs to be done to get the general public to understand the issue of Mental Health and not disregard symptoms as a personality trait or shortcoming? I know a lot of people do not understand Mental Health being an actual illness as they cannot see physical signs like you do with traditional sickness.

granal03

Helen here - Thank for your question. I think that improving awareness of mental health issues is crucial to dealing with the misconceptions you raise. There a number of charities in the UK which are doing great work in this regard such as the Mental Health Foundation, Mind and Rethink to name just a few. The more we talk about mental health the better!

I have lived in the UK as an adult but am only treated for mental health in the US. I dont know that my pdoc made a formal plan for me when I started. It seemed more like, what are your symptoms, side effects, lets use this medication. Then we agree that it is a good idea moving forward. What is this plan that you are referring to?

ChrismCassie

Helen here - Thank for your question. A care plan is a document that describes the services and support being provided by mental health services in relation to a person's needs. UK Government policy states that service users and carers should be involved in putting this together and be given a copy. However, we know from existing evidence that service users and carers do not feel that this is happening in practice. I hope that makes it clearer.

Thanks for doing this AMA.

I have a few questions, if I may?

1. What are the primary and secondary objectives of your programme of work? Are you planning on

collecting evidence, or designing an intervention?

2. If you are designing an intervention, would this be for service users, or for healthcare professionals (HCPs) too? What are the challenges of each? Or what are your thoughts, if intervention is beyond the scope of your programme of research.

3. What are your thoughts on how we can better integrate mental and physical healthcare? The current UK government mantra is "no health without mental health", but the two systems are so disjointed that often only one or the other is acknowledged. This can be particularly problematic when either physical or mental health is particularly bad and the other is ignored while the most pressing issue is resolved.

4. What has your research taught us thus far about how best to engage service users in their mental health treatment? What challenges are posed along the continuum of mild to severe mental health issues and how will your plans reflect this?

phrenologyheadbump

Helen here - Thank for your question. I hope I have addressed them below:

1. The aim of the study is to improve user and carer involvement in care planning in mental health services. Our team will develop, evaluate, implement and disseminate a user/carer-led training package for mental health professionals. We will also develop and validate an outcome measure to assess improvements in user/carer involvement. We will assess the clinical and cost effectiveness, feasibility and acceptability of this training through a cluster randomised controlled trial design. We will also identify the individual and organisational barriers and facilitators to implementing effective user and carer involvement in care planning using a range of qualitative methods.
2. Our intervention was targeted at health professionals but we acknowledge this is only one side of the health relationship and future work may consider a service user targeted training package.
3. One of the aims of care planning is to co-ordinate care around an individual's need but I would agree with your point that this is not currently being integrated very well. The service users and carers we have spoken too have told us this too.
4. The research has demonstrated that there are a range of levels within the healthcare system that need to be targeted in order to best engage service users in their mental health treatment. These include those at the relational level (between service users and professionals), the healthcare organisation level and the wider context. You can find more information about this here: http://bjp.rcpsych.org/content/bjprcpsych/207/2/104.full.pdf

Hope this is helpful :).

Hi team, thanks for doing this AMA. I have a few questions. I have previously worked for the NHS in London on Mental Health, and this is a subject I feel passionately about. I am frustrated and saddened by the state of mental healthcare in this country, however please do not take my frustrations personally, I am wholly supportive of your goal.

1. Do you not feel like you're pushing against an open door? Multi-disciplinary care planning (between service users, carers and HCPs) is well accepted within the NHS as a gold standard, but obstacles are with funding & implementation not with buy-in. What will another study showing the benefits of care planning do?

2. I am glad to see your involvement of carers, they need to be recognised not only as an important part of the machine, but the primary source of mental health care (as reflected in the NHS' five year forward view). However, an important part of the ecosystem seems to be missing - social care. Improving national standards of mental health requires not only healthcare improvements, but integrated health and social care delivery that ensures people are able to look after themselves and

maintain good mental health - how is social care / social workers involved in your work?

3. I also think we should address the elephant in the room: funding. The quality of secondary care for mental health in the UK is generally good and helps huge numbers of people every day. However, we restrict the quantity & access to secondary care (like somehow after six months services users are expected to be 'healed'), and across the country we're cutting down secondary health teams and resources to deal with tightening budgets. This is combined with the already woeful level of underfunding which mental health care receives in the UK, and the introduction benefits caps and gutting of social care services, which may all contribute to a mental health crisis in the UK. How is this reflected in your work - are you envisaging a 'best possible world' for care planning, and if so, how do you see this benefiting service users in the UK, especially if the NHS isn't given the resources to implement?

Jbags985

Thanks so much for these interesting questions!

1). There's definitely an open door in terms of policy rhetoric, which emphasises the importance of involvement in care planning; however, the real problem is that service users consistently report being marginalised in this process. Our research not only shows the benefits of care planning, but shows what meaningful involvement looks and feels like from the service user perspective.

2). Our training intervention involved social care professionals too (47 of whom were social workers identified as 'care coordinators', and 3 who were not), so we hope to see changes around service user involvement in social care too.

3). Our work recognises the organisational constraints in which professionals are working when it comes to doing care planning. Some of the improvements are around making care planning more visible to service users, and enhancing the soft skills of professionals and we found that relationships with professionals were key to service users. But agree, more funding is much needed.

Why is it that, maybe 25+ years ago, we didn't hear about OCD, ADD, etc., but now we hear about it a lot in youth?

J916O

Helen here - Thank for your question. This isn't my area of speciality but I think there is some evidence that awareness of mental illness is increasing so people are more likely to recognise symptoms and also we are better at collecting data on the prevalence of mental health difficulties than we were 25 years ago. Interesting question and would be fascinated to get other people's take on this?

Hi!

My parents were immigrants who didn't know better and as such my mental health issues went undiagnosed until I was 21. At that point, being in uni, I was misdiagnosed with depression and anxiety and recently learned I in fact have ADHD and was probably not diagnosed due to the high incidence of seeking and selling meds in university.

What do you think can be done to firstly improve the detection of issues in children who's parents can't/won't?

Secondly how can we improve the outcome for those like me who are diagnosed in their 20s but have been suffering their whole lives? I'm 24 now and started on Dexadrine. My life has gotten much more manageable, but I have this profound sense of loss and anger that my upbringing didn't have to be so stressful, and many others diagnosed later in life have the same issue.

PM_ME_REACTJS

Hi, Claire here. I'm sorry to hear about your experiences and it is pleasing to here that things are improving for you now. The EQUIP study focussed on adults (18 years+) so your question is beyond the scope of our study but you may find the work of a colleague Professor Neil Humphrey of interest: http://blog.policy.manchester.ac.uk/posts/2017/02/childrens-mental-health-crisis/

Is peer support included as part of collaborative care planning?

villageatheist

Helen here - Thank for your question. Care plans should be focussed on recovery and promoting wellbeing so there would definitely be a role for peer support and considering how important others can contribute to recovery and wellbeing. Do you have an opinion on whether this happens in practice?

Hello

As someone with a scientific background who's also been a client of NHS MH services and subsequently volunteering as a peer mentor, also having used the services of a private psychiatrist, I think I've probably got a bit of perspective on this work.

Do you consider that consistency of care for an individual might be advantageous over having an ever changing regime dictated by the latest stats and trends from work such as yours?

Do you, collectively or individually, have views on why the current policies are, according to your work, failing to translate into practice? Is this a failure of the professionals or are the policies impractical in the views of those at ground level?

andthecircus

Helen here - thank you for your question.

Continuity of care was raised a lot by service users as being really important to build the kind of trusting relationship required to be involved in the care planning process so it would definitely seem that this was advantageous! This review we did as part of the programme of work might help answer your second question - http://bjp.rcpsych.org/content/bjprcpsych/207/2/104.full.pdf The review found that one of the reasons that policies did not translate into user experience was that service user-involved care planning was typically operationalised as a series of practice-based activities compliant with auditor standards which did not align to service users' perspectives of what constituted meaningful involvement. The review called for new patient-centred definitions of care planning quality.

Are you working with GPs for this, as well? I ask because my GP in Manchester referred me to mental health services in April 2016 and I still haven't been seen by... well... anyone, since then...

Zostarius

Helen here - Thank for your question.

We aren't unfortunately. This study only looked at secondary care so to be eligible service users had to be aged 18 and over with a severe mental illness (e.g., psychosis, bipolar disorder, schizophrenia) and be currently under the care of participating community mental health teams. It would be interesting to look at a GPs role in the care planning process though because as you suggest they are often a first port of call for people. Maybe something for the future!

I work in medical licensure testing in the United States. Do you think there are appropriate changes to be made upstream, during the education and certification phase of a clinician's career, that would be helpful to your cause? Will your 5-Year program generate any relevant academic results for inclusion in next-generation medical licensure testing?

belisaurius

The EQUIP training intervention which was developed from the qualitative data from service users, carers and professional has been delivered to community mental health teams as part of the EQUIP trial see - http://research.bmh.manchester.ac.uk/equip for more info. Student mental health practitioners had the opportunity to attend the training if they were on placement with teams participating in the trial. The feedback from students was that the content on service user involvement was extremely valuable and provided content they had not received as part of their main undergraduate degree programmes so we certainly hope this type of content can be incorporated into education programmes for mental health professionals in the future.

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belisaurius

Hello, we are in the UK and are not familiar with medical licensure testing, however the development and testing of a training package for health professionals is a large part of the EQUIP programme. Improving practitioners understanding and appreciation for the inclusion of service users and carers in mental health care is an important facet of this research, and although we cant say from this research, it may be an important component to be added to future training for professionals.

Why do you keep supporting the prescription of antidepressants even though the statistical data show them to be almost absent of efficacy.

One of many sources: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4172306/

Throwaway98709860

Thanks. This study looked at how we can improve service user and carer involvement in the care planning process to ensure that care plans are relevant to people and include all the things that are important to them.

What do you think about digitizing patient's clinical notes? I used be a VP for a mental health startup and we realised through our focus groups with patients that many chronic cases had files so thick that vital information was lost due to the case volume, or case files were lost upon transferring to other clinicians.

What do you think about seeing a clinical psychologist over online (e.g. skype)? We hypothesized that the saved time traveling to clinic and back, plus the lack of waiting time was attractive to the patient.

My assumption was that this lack of effort in making the journey to the clinician reduced the effort a patient would put into therapy- but I left before I could test this hypothesis.

[BlackRosette]

Hello, Kelly here. Dependent on the Trust, notes are now digitized (we can only speak for our locality, but the NHS Trusts I have previously worked with had digital notes systems). As for consultations over video calls etc, its a very interesting area; I am aware that via charities, people can access low intensity therapies via Skype and that this is proving successful, but I don't have any data on the effectiveness. It would be a very interesting area to explore - definitely more appealing to the younger generation it seems from my experience, but distance consultations have their pros and cons such as here isn't the opportunity to build rapport in the same way as face to face. Its an area that I expect will grow in the coming years.

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[BlackRosette]

Hello Andrew here - regarding your first point, one quote that came up in our qualitative research was "we only need one agreement of where we're headed, that's all. Not a file full of information that hardly anyone looks at. Yeah, that would be a good result for me, if there was just one sheet of paper, with aims and objectives."

Our research did not address your second point, which does sound interesting.

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[BlackRosette]

Hi, Claire here. Thanks for the questions, I will respond to your second one: the EQUIP Chief Investigator Professor Karina Lovell has explored the use of Skype/telephone CBT for managing depression - you can find more info here: https://www.bmh.manchester.ac.uk/research/impact/managing-depression/

In recent years, the NHS has accepted existential psychoanalysis as beneficial in cost and performance. It is also apparent that CBT, and other cheap para-Freudian therapies simply don't work in the long term.

With this in mind, what reconsideration are you giving to the issue of the high cost of psychoanalysis (Lacanian/Kleinian etc) balanced against the increasingly obvious reality of its effectiveness against drugs and half- measures, such as CBT?

tetsugakusei

The EQUIP research programme only considered the clinical and cost effectiveness of a training course for mental health professionals on service user and carer involved care planning, so I can't really comment on the detail of your point. However, our qualitative work with service users (the 10 Cs) found that they wanted a holistic approach to care, taking into account all of their different needs.

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tetsugakusei

Helen here - Thank for your question. This wasn't something we explored in our research unfortunately. We focussed specifically on how we could involve service users and carers in the care planning process but didn't compare different types of therapy.

Why does the UK establishment continue to ignore the massive problems with quality control in studies that fall within psychological medicine?

This is best illustrated by the case of the "PACE-Gate": http://journals.sagepub.com/doi/abs/10.1177/1359105316675213

Jonathan Edwards, a professor of medicine recently compared the situation to the Wakefield scandal because studies with fatal methodological flaws continue to be published, among others in The Lancet (which also published the Wakefield paper). In the PACE study for example, the design was so weak that it was impossible to distinguish between wishful thinking and genuine improvement (among several other problems). On the international level, the study has become the laughing stock, but somehow in the UK it's considered gold standard and reliable.

This is what international scientists say about it:

Dr. Ronald Davis, Stanford University: “I’m shocked that the Lancet published it…The PACE study has so many flaws and there are so many questions you’d want to ask about it that I don’t understand how it got through any kind of peer review.”

Dr. Arthur Reingold, University of California, Berkeley: “Under the circumstances, an independent review of the trial conducted by experts not involved in the design or conduct of the study would seem to be very much in order.”

Dr. Leonard Jason, DePaul University: “The PACE authors should have reduced the kind of blatant methodological lapses that can impugn the credibility of the research, such as having overlapping recovery and entry/disability criteria.”

What do UK researchers say about it?

Dr. Simon Wessely, King's College, London: “For those who appreciate these things, the trial is a thing of beauty, and the results confirm previous smaller studies and follow ups.”

Nihy

Hi Andrew here - you can check out our own protocol for our randomised controlled trial of our training intervention here: https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-015-0896-6

I'm not from the UK, so I won't see the implementation firsthand.

My question is, what has been the most difficult thing for you to research/solve in developing your plans thus far, and did you accomplish it yet?

dnaLlamase

Hello and welcome to the discussion. In any mental health trial recruitment can be a challenge. We needed to ensure that the trial recruited sufficient service users to ensure statistical analysis would be possible (effect size) and that the numbers recruited would be manageable from a resource perspective by the research team. We set a target of 480 service users but were delighted to enable well over this target (604 service users) to share their views.

Where do you see this research going next? Do you think it could lead to meaningful changes in the current health system?

sleepyhead246

Thanks for your question, this research was actually part of the first of four work streams, and led on to inform the development of a training package for health professionals to improve involvement in care planning. We have conducted a Trial to test the effectiveness of this training, the results will be available in the next few months :)

Where do you see this research going next? Do you think it could lead to meaningful changes in the current health system?

sleepyhead246

Helen here - We are currently analysing the results from the trial and they will be made available here when they are ready: http://research.bmh.manchester.ac.uk/equip

We are currently putting together a plan to share the knowledge we have developed over the last five years. Do you have any suggestions on how we might do this best?

Hi there,

Thank you for doing an AMA! How does your team feel about mental health labels? There is some evidence to support that labeling individuals may produce self-fulling prophecies for the diagnosed individuals and it may influence the attitude towards care individuals receive from clinicians. Will your care plan focus on a more symptomatic approach or continue to encourage labels as a means to treatment?

meyerscca

Hi there, Andrew here, thanks for an interesting question. Our research did not address your question directly, however, we did find that the service users we spoke to wanted a holistic approach to their care and were against reducing everything down to the biomedical model. We're advocating person-centred care planning, which takes the views of the service user about their own experience into account.

Hi!

I am a long term mental health patient current on antidepressants. My question is, in an academic and research capacity, how do you view the differenes in validity between medicated and non medicated trestments? For example, do you give similar levels of credibility to drug regiments as you do to cognative therapies, hypnotherapy, "lifestyle" treatments such as excercise regimes. Do you believe that treatments can be managed effectively without medication?

SwagVonYolo

Our research does not make a judgement on the effectiveness of different kinds of treatments. However, the questions you have raised are exactly the kinds of conversations we want to see service users having with their clinicians. Our qualitative work with service users (the 10Cs) emphasised that they wanted a holistic approach to their care planning, taking into account all of their different needs.

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SwagVonYolo

Hello - Helen here. I'm afraid particular therapeutic approaches were beyond the scope of this study as the specific focus was on involvement in care planning, regardless of the particular diagnosis/therapeutic approach.

Hi, your research looks really interesting. I am interested in the use of advanced care plans for people with mental health issues. As a carer and health professional I've seen these work very effectively and ensure that the care plan continues to include the patient perspective during involuntary treatment which is sometimes necessary. Do you have any thoughts or experience with this kind of care planning?

itstimeforcheesecake

Helen here - Thank for your question.

Not many of the people we spoke to had experience of an advanced directive but I would agree with you that where they had used them, they had worked really well. Do you have any sense of how often these are used in practice?

Hi! Thank you for doing this AMA.

I've recently begun visiting a GP for mental health issues (final diagnosis pending referral to the Mental Health Team). Although my GP has been very supportive, I currently have almost no idea what kind of treatment/services I can expect, time scales, etc. - which I suppose is the point of your research!

That said, my questions are:

- In what way/s do you anticipate that the mental health care system will change over, say, the next 3-5 years?
- In what ways do you think that the mental health care system *should* change over the next 3-5 years?
- As a patient, how can I help my HCPs to help me? Is there anything I can do, or extra services I can take advantage of, which will enhance the experience for both myself and e.g. my GP? For example, I only have a preliminary diagnosis at the moment - is it worth researching my (possible) condition myself, or does the risk of misinformation outweigh the benefits?

Looking forward to your response!

DanishPastry

Hello and thank you for your questions. This is not my area of expertise but I would anticipate that the 5 year forward view for mental health (published Feb 2016) would be a key document to provide you with further information: https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf You might find this blog useful: https://www.mentalhealth.org.uk/blog/what-has-2016-meant-uk-public-mental-health-policy

In terms of change which should happen, the EQUIP team would very much like to see service user and carer involvement as central in the care planning process.

As a patient, you may find it helpful to look at the 10cs animation as this is a summary of what other service users have found helpful: http://research.bmh.manchester.ac.uk/equip/10Cs

I'm a mental health nurse working in the community. What is the single biggest factor that increases the quality of a care plan and improves outcomes for clients in general?

22for2

Hi Claire here, that's a great question. We are currently analysing the results of the trial and we will share findings in the autumn. However, from our initial qualitative work we can say that the process of care planning, centred on the user-clinician relationship, is key to user involvement. Our analysis of users' definitions of meaningful involvement in care planning is summarised through a 10C framework of care planning involvement, provide clear direction for improving service users satisfaction with care planning and enhancing the culture of services.

I'm a mental health nurse working in the community. What is the single biggest factor that increases the quality of a care plan and improves outcomes for clients in general?

22for2

Hello, Kelly here. We have produced an animation on the 10 C's of care planning which you can view here: https://www.youtube.com/watch?v=6DgxFpcT1VU but in a nutshell the ethos of EQUIP is to improve involvement in care planning; people need to have a say in what goes into their care plan, be involved in the creation of the document and have ownership and a voice in their care.

This is definitely not happening. I'm an adult with fairly severe ADHD, diagnosed 3 years ago. I was referred, diagnosed, and medicated but although I made it clear I thought I needed CBT no follow up was ever done. I haven't seen a specialist in two years now. So I just wanted to say thank you for raising awareness - the NHS is great but it can definitely improve.

sepiya

Hi Andrew here - thanks so much for the encouragement. We are finding that our research chimes with service users' and carers' experiences, and hope that our research findings will be implemented to improve things.

Hi, I have a few questions. Most of them are on the edge of your area of research, so I understand if can't address them!

1. When looking at the field of mental health support in the UK as a whole (provided by both the NHS and the tangle of different charities who provide free support and private counseling and therapy paid for directly by the user) what would be the top 5 things that you think need to be done to improve the experience of people who are navigating this system?
2. I know several people who had a very long wait between talking to their GP about their mental health, and getting seen by a mental health professional - upwards of 6 months. Is this a problem that you've identified as a bottleneck in effective care planning?
3. At the same time, there seems (as far as I've seen) to be growing number of counsellors, psychotherapists, and so on, working privately to provide mental health support. While it's probably a good thing that the private sector is stepping in to fill the gaps in NHS provision, this is provided on a more ad hoc basis, and seems to have much less oversight than the NHS would provide for in-house services. Are there problems that stem from this?
4. Many people don't have a clear understanding of the difference between counselors, psychotherapists, and psychologists - despite there being a large difference in the level of training, expertise, and accreditation required for entry into these fields. Can this be better communicated to the public?
5. Is there a problem with people suffering from mental health issues (whether diagnosed or undiagnosed) that are serious, but not urgent enough for emergency care, refering themselves to private counsellors (for example) who aren't well equipped to deal with more serious conditions?
6. Is there a national system for accrediting those who provide mental health support privately? How does/should that work?
7. Are there systems in place for these private counsellors to refer clients who they believe to be at risk (and/or simply beyond their expertise) to the NHS? Is there an incentive for them not to refer people, for risk of losing that client - and, if so, how could that be addressed?
8. With the long waiting times for NHS mental health services, it would appear that there's a shortage of mental health professionals for patients to be referred to within the NHS. Is there any way of bringing in professionals who are currently working privately to ease the backlog? How would that work? Are the current budget cuts preventing this kind of thing happening?
9. Is there anything that you found out during your research (or in the broader field) that you think everyone should know - or get angry about? (An easy one to finish!)

Many thanks!

Edit: Fixed the formatting, and split a couple of long questions up into shorter ones.

CWM_93

Hello, wow lots of interesting questions! As you say most of this is a bit on the edge of our work, but the issue of people having to wait a long time to be seen my MH services is something that comes up time and again. The health professionals we refer to in our work are those working as part of CMHTs, which includes mental health nurses, social workers, occupational therapists, clinical psychologists and psychiatrists. Those you list above (counsellors and psychotherapists) would fall more under the umbrella of allied health professionals, and are not central practitioners in NHS MH services. People with serious mental illness wouldn't generally be referred for counselling and I believe most counselling services are provided outside of the NHS here in the UK. Likewise many of the professionals practising privately (such as psychiatrists) do also work within the NHS. It is true that the mental health services in the UK are underfunded and more resources are needed to provide a better service, but our work is focussed on improving those systems that are already in place, to try to make the service that is available, as effective as possible. Thank you for your interesting questions!

Did you focus in on any particular mental health conditions? And if you did, did you find any differences in the attitude/perspectives of carers and health professionals in those areas?

sleepyhead246

Hi - Helen here,

Inclusion criteria for the study was: Service users aged 18 and over with a severe mental illness (e.g., psychosis, bipolar disorder, schizophrenia) under the care of participating mental health teams. Analysis is currently on-going and results will be made public on the website soon: http://research.bmh.manchester.ac.uk/equip

Is there a requirement that patients in mental health care programs take medication?

adam_demamps_wingman

Hello, Kelly here. In UK mental health care, dependent on the situation, some people are required to take medication as part of a Community Treatment Order, but this is certainly not something which applies to everyone, and collaborative care planning aims to include the views and wishes of service users regarding medication.

Do you have a plan to tackle the issue of mental health patients who have been failed by the system and have been turned out to the streets?

farm_sauce

Hi - Helen here. This was outside the scope of the current research study and we looked only at those under the care of a secondary mental health team. I think this would be a really interesting and important population to work with in the future.

When does research turn into action?

VentusYT

Hello, Kelly here. As part of the research programme, we are providing the training we have developed to NHS Trusts who have become willing adopters, and to those who have requested the training package for their staff, so we hope this goes a little towards translating into practice.

Currently because of the waiting lists they sent out appointment letters via the post rather than let you phone them to book the appointment. I've been discharged time and time again without my knowledge because it's the one part of the NHS I never have received a single letter from. I have to find out when I have a doctors visit for a different issue to ask and chase my referral up to find out I've been yet again discharged because I didn't turn up to an appointment I was never made aware of! For me it's been a long term problem and it doesn't require urgent seeing to so for me I can wait 6 months to a year but for some people that might be too late.

VirelayVirakhian

Really sorry to hear this. I hope you manage to resolve this in the near future.

If a service user has a complaint about their care plan that has been totally ignored by their care coordinator, what should they do next? Have you found that users drop the complaint due to the opaque nature of the system?

Bulimic_Fraggle

Hello, Kelly here. Any issues with the care you receive from your care coordinator should be raised with the team manager or through PALS. We haven't investigated complaints by service users as part of our research, but one of the points raised as part of this work was the importance of communication between service users and professionals. You can find more about this in our paper: http://onlinelibrary.wiley.com/wol1/doi/10.1111/jpm.12275/full

If a service user has a complaint about their care plan that has been totally ignored by their care coordinator, what should they do next? Have you found that users drop the complaint due to the opaque nature of the system?

Bulimic_Fraggle

Hi, Andrew here - our research did not explore formal complaints processes or procedures. However, I would initially contact the Patient Advice and Liaison Service (PALS) within your NHS Trust, who can advise about how to proceed. Hope that helps.

Do you believe diet can play a role in one's mental health?

FadedFLYS

Hi Claire here. I'm not a clinician and this is not my area of expertise/nor the focus of the study but this is an increasing area of focus for research so I think we will see more on this in coming years. It is certainly very interesting.

Do you believe diet can play a role in one's mental health?

FadedFLYS

Andrew here - our research only concerns service user and carer involvement in mental health care planning. However, the service users we spoke to wanted a holistic approach to their care, which would take issues like diet into account.

Hey team! Thanks for doing this.

I've grown up with an uncle who has a mental age of 4, he isn't violent, does what he is asked to, listens to everyone and rambles on about it whenever you see him. He is clever because he recalls actors and actresses from the 1960s very well, whenever there's an old show going on and all hardly ever goes wrong with recognizing relatives. He talks with a lisp and repeats whatever he says, over three times before settling for an answer.

My question is could mental health care ever improve to a level where kids who are identified with mental health issues at an early age, can lead a normal life?

howaboutthatgod

Helen here - Thank for your question.Studies have demonstrated the resilience of those with psychiatric disabilities and that over a 20-30 year period the majority of people do recover. I hope this answers your questions and this reference might be of interest: Ciompi, L. (1980) ‘Three lectures on schizophrenia: The natural history of schizophrenia in the long-term’, British Journal of Psychiatry, 136, pp. 413-420.

I had a number of problems over several years which were referred to the local Mental Health Team, but I was never offered an appointment with a psychiatrist. Instead I went through two largely pointless rounds of cbt and tried a huge range of antidepressants which made my symptoms worse. It was only after scraping up some money to go private that I got a diagnosis of bipolar (2). I'm now on lithium and starting to stabilise.

In my case at least, this would seem like a penny-wise, pound-foolish approach from the NHS. Are you looking at providing 2nd opinions on long running cases? Or even tracking case severity through from initial presentation and taking further action if there is a decline?

m0le

Hello, Claire here. I'm sorry to hear you have had less than satisfactory support and pleased things are stabilising for you now. I'm afraid case review and tracking was beyond the scope of this particular study.

Hello, and thank you for this AMA and for what you do! I currently work with DDAs, and am curious. There are plenty of flaws with how we plan and execute care plans for DDAs at the moment, IMO. Do you feel that the enhancements you are working towards will benefit DDAs as well?

Astrobody

Hi - Helen here. That's a really interesting question and I would be fascinated to see if you think there are any applications of our work to this type of assessment. This paper may be of interest to your in making your assessment, it outlines what service users wanted from the care planning process: http://onlinelibrary.wiley.com/doi/10.1111/jpm.12275/full#references

Whats the best way for a person with dementia to remember you?

johndrake666

I'm afraid we don't know the answer to this question as it is outside our area of expertise - although I have personally been fascinated by the idea of music recognition (often playing certain songs that people associate with a person/a good time in their lives) can invoke memories and help with recognition of the person in front of them. Not something I know much about but very interesting all the same!

What would be the best way to get more people correctly diagnosed and fewer people misdiagnosed? (Specifically in the U.K.)

BluePlankton

Hello, Kelly here. I'm afraid none of us here answering questions today are practicing clinicians and this topic is outside of the area of our research - so it would be wrong for me to give an answer to this question - I'm sorry!

What implications does Brexit have on funding mental health care service and research?

EDI-Thor

Hello, Kelly here. I'm honestly not sure but I personally doubt its going to be positive; much research funding comes from the EU, as do many of the bright minds of the research world. We will have to wait and see..

What do you think about the stigma behind mental health issues? What can be done about them in your opinion? Here in Singapore, there is a lot of disliking towards being different which prevents those with disorders from getting the help that they need.

bronrg

I think that improving awareness of mental health issues is crucial to dealing with the misconceptions you raise. There a number of charities in the UK which are doing great work in this regard such as the Mental Health Foundation, Mind and Rethink to name just a few. The more we talk about mental health the better!

Can you get the word 'disabled' changed to 'disadvantaged'?

Deganawida33

Andrew here - totally agree that the language we use is really important. For example, in the EQUIP training intervention we spend some time exploring the different connotations of 'risk assessment' vs. 'safety assessment'; the former has connotations of threat, danger, and menace, which can stigmatise, whilst the latter is more nurturing.

[deleted]

[deleted]

Hi, Kelly here, mental health problems can affect anyone at any point in their lives, from the poorest to the richest, the least able to the most brilliant minds in the world, and that is all we will be responding to your question with today, thank you.

Do you consider being Transgender a mental illness? A lot of people seem to think so, but as someone who is currently transitioning, I disagree. Just wondered what the experts thought. :)

blocoftheroad

Hi, Claire here. I am not a clinician and this is not my area of research but colleagues here at Manchester do specialise in equality and diversity research and you may find their website of interest: http://www.humanities.manchester.ac.uk/connect/equality-and-diversity/research/

Do you consider being Transgender a mental illness? A lot of people seem to think so, but as someone who is currently transitioning, I disagree. Just wondered what the experts thought. :)

blocoftheroad

Hello, Kelly here, and I personally do not view being Transgender a mental illness, absolutely not!

Im a uni student with adhd in scotland and I've wanted to change my medication for a long time. However, whenever I ask my GP to refer me to the psychiatrist and he does, I am forced to call the psychiatrist's office (after waiting a few weeks for a letter) to arrange a visit far into the future. So far in the future that my exams are over and I have no use for the medication. Therefore I am forced to obtain my medication illegally. My appointment does not require a full hour and could easily be over in less than 5 minutes. 1) How are you going to address these insane waiting times especially for very quick appointments? 2) Can you give my GP the power to change my ADHD medication ?

topmage

I'm afraid this isn't something that our work covers, but would urge against obtaining medication illegally which can be very dangerous. GP's do have the ability to prescribe and make amendments to medications, and this is something you should raise with your GP.

My dad is a life care planner and I have been double checking math and errors on some reports that he is putting out this week. The patient I just reviewed had a total of 30 projected surgeries and operations that he needs to have done before he's 60, as well as 80+ likely complications with his health in the future. How much of this is reality, and how much is simply a money grab by the plaintiff?

polonuim210

Hi - Helen here. Our research looked at how we can better involve service users and carers in the mental health care planning process so your question doesn't seem like it is in the scope of our research - sorry.

How do I get my therapist to talk about what I want to talk about? I came to her with a list of things I wanted to work on - how to be more productive, how to stop mentally beating myself up, how to stop hating myself for not being as academically or economically successful as I would have liked, how to create and enforce structure in my day; and so on, but when I try to bring any of this up in sessions she brushes me off and tries to steer me onto to Freudian stuff like my relationship with my mother or my LGBT status, most of which I don't feel cause me any issues. She doesn't believe me when I tell her that I don't have strong feelings on these topics and just says "Okay, we'll put down in your file that the issues you have about this are unresolved and you're not ready to talk about them yet", and if I try to talk about what I do want to talk about she throws a fit and says she can't help me with being depressed and unproductive, or whatever, because I won't open up to her and explore the underlying issues. She throws this fit every time I see her, tells me she doubts she can help me, and we waste half the session because she starts trying to convince me to quit going to her and switch to a facility that does medication management only or life coaching, which I'm not going to do since I'm going to be back in university in six weeks and will have to see someone new anyway. The stuff I wanted to work on is in my care plan, how do I get her to stick to it?

meradorm

Hello, this must be very frustrating for you and issues of communication are something that has come up time and again in our work. It is important to speak to the service manager if you are unhappy with your treatment. It might also be worth taking your care plan with you are pointing out exactly you want to discuss in your sessions. Apologies that we cant be of more help!

Hello, i am a severely disabled individual from Manchester with a psychological illness which stumps almost every doctor i meet . Many are always facinated and airways want to hear what happens in the future... problem is, i have not been tasted or helped in the 5 years since it began with ptsd and severe depression.

I sparkly physically have the strength to walk and move, if you see me toy skulls tjink so, but i am so fearful of walking or leaning over. My arms dont even go over my head much any moreand struggle to lift them at all. My jaw locks, my eyes fatigue so quickly, i have panic attacks, wobbly legs and full body pain.

I have a phycologist who had helped narrow it down to my obsessions with my internal thoughts on every movement of my body.

My questions are; doo you gave similar people who have these issues? And are you helping inn the goal of myself and others to actually beening seen by the right help and in a quicker time frame?

Its been 5 years and i keep being told that the NHS hasnt got the budget right now and waiting for a referralto a place in mancgester which has basically been proven to give me a full recovery, if not, a close to normal life.

Pease for the love of good answer me :) !

Thank you and sorry for the long message

leonce89

Hello, I am very sorry for your situation, it sounds very difficult. I am afraid this isn't something we would be able to help you with, and urge you to continue the sessions with your psychologist.

[deleted]

[deleted]

We have used a range of outcome measures in the EQUIP trial - focussing on care planning involvement, mental health symptoms, service satisfaction, therapeutic alliance, medication side effects, quality of life, recovery & hope, health outcomes and mental well-being. These measures were chosen in conjunction with our service user and carer advisory group after being identified by this group as the key areas where change might be seen as a result of increased involvement in care planning. All the measures used are detailed in the Trial protocol paper: Bower et al (2015) http://www.trialsjournal.com/content/16/1/348

As a future pharmacist in the USA what can I do to help enhance quality and decrease the stigma?

Thank you for all of your hard work!

crashleyelora

Hello, we think that by talking about mental health we can reduce stigma, and by making people realise there is no shame in medication. Mental health problems are as valid and present as physical health problems, and taking medication for something like diabetes doesn't hold a stigma, therefore neither should taking medication for a mental health condition. Conveying that message is important in my opinion!

Thank you for doing this. Why are holistic services not automatically offered to all users of mental health services? I imagine you are going to say budget, which I can understand, but so often crises would be avoidable if the person affected had had help with managing their live-in the first place. I think an opt-out path would be better than opt-in, people who have mental health issues are not always best placed to decide or understand what they would benefit from. What do you think are the pros and cons of holistic services, by which I mean help with finances, help with housing issues, help with day to day living, as standard?

walnutwhip

Hello, great questions. People who are under a community mental health team and have the support of a care coordinator very often do get this sort of help; working with a care coordinator and often a support worker, lots of work is done to help people with things like organising housing, leisure activities and so on. The idea of a care plan is to include everything a person would like to work on/would like support with/would like to achieve, and very often theses types of things are included. I hope that answers your question :)

Hi there, great discussion so far, thank you for hosting this AMA on an area which desperately needs more support from the public and policy makers.

1. Have you made efforts to engage with third party sectors and charities? Often service users are highly dependent upon sheltered accommodation, drugs and alcohol service, etc. These organisations often have a good working relationship with service users but are 'left out of the loop' in their clinical care, therefore their potential use is limited.
2. How have policy makers responded to your efforts in service user led care planning?

mangostickyriced

Thanks for your question. One of the study co-applicants (Cree, author of the carer paper) is a carer who has close links with 3rd sector mental health services in the UK and her knowledge has greatly informed the study. The study Chief Investigator is also Patron of the National Phobic Society. The study incorporated a 'service use questionnaire' which will allow data on service use across sectors to be mapped.

Secondly, the study findings are currently been analysed so it is too early to assess impact on policy makers, however, there has been a great deal of interest across the mental health sector throughout the programme and we are hoping our forthcoming dissemination programme will have great impact.

This is all well and good, but this is far from the most pressing issue facing MH services at the moment. How do you expect patients (I loathe the term 'service users') to not feel marginalised when we can barely find beds/treatments/services for those presenting in acute crisis to A&E!?

My department is rated as outstanding, yet if anyone is going to breach (not just 4 hr, normally +12hr), it's always the psych patient (and we have a MH unit connected to my hospital, and are certainly not in the arse end of nowhere either)!

DeapVally

Hi - Helen here,

Thank you for your comments. We are running a process evaluation alongside the randomised control trial which will explore the broader contextual issues regarding the organization and delivery of care for people with mental health difficulties which may well uncover some of the issues you allude to. The results will be available here in the near future: http://research.bmh.manchester.ac.uk/equip

I would first like to say that I am not at all trying to troll or upset, it just so happens that I do believe in these things and am asking legitimate questions.

Would you ever consider including a death with dignity type program for those that have such mental deficiencies that cause them to be unfit for life? As in they wouldn't live a good life, and they'd be a burden or a danger to society at large?

Euthanasia is a great alternative I really just seek your thoughts on the matter in regards to the mentally feeble.

TheWearyBanker

I really don't think we can give an answer to your question.

I work in the health industry and often deal with mental health. Mostly anxiety and depression amongst other things too.

I've become consumed by this idea that a large portion of this can be fixed/helped by focusing on improving diet and available food choices; given that serotonin is secreted in the gut.

What is your take on this? Would you agree this is an interesting/important research area to pursue? Or do you suspect the effects might be minimal and money/time would best be spent elsewhere? Thanks!

brayn00b

Hello, Kelly here. I am certainly no expert in this area, and it does sound very interesting. As part of care planning, people often like to include information about lifestyle and health, and certainly care planning should cover all areas of a persons life, not just information around medication. I cant comment on the actual importance of diet etc myself as its not something I know about, but interesting topic!

I want to become a human Hippo hybrid and I feel that the mental health community in the US does not recognize me as a TransHippo. Dudes want to become girls, which is cool, and they are protected under the law. I do understand that as a half-human half-Hippo hybrid I represent a stomping danger to people but I feel I can control this if I am not antagonized. My question is this: should I move to England for better care and recognition as I make the transition?

jimdavis961

I am afraid Human Hippo hybrids are not something we have much expertise on nor are they covered in this research, but I do vouch for the accepting and inclusive society that we have in the UK!

So why is it, that I get reprimanded for beeing addicted to benzodiazepines by the same doctors, who gave me the medicine (and too much of it) in the first place?! And why do they not seem to know, that addiction is an illness? They treat me like someone who pops a Happy Pill at a night club to get the most out of my night dancing, when in fact, I take them, because I would not be able to withstand committing suicide otherwise.

Stundenglas

Hello, I'm very sorry for your situation and understand your position. Addiction is indeed an illness, and is something that happens to a lot of people as a result of medication. We urge you to seek help by speaking to your health team.

Are any countries, cities or organizations doing it right? Is there an example that is a guiding light? Are you researching more for younger or older patients? Are there different approaches to schizophrenia compared to dementia? If money and nationality/cooperation were unlimited what would be the ideal plan to get mental health services where they need to be? Thank you!

Davidjhyatt

Hello, thanks for your question and apologies for the delay in reply - our research hasn't targeted a specific age group or specific group in terms of diagnosis other than serious mental illness; anyone who was under the care of the community mental health team was eligible to take part in our trial (and in the original focus groups described above). I personally believe a lot more investment, staff and facilities would be the thing that would help to get services where they need to be, but we have to work with what we have and therefore the aims of our work are to improve what we have right now, to try to get the best out of what is available. Hope that kind of answers your question!

Dear Team

I am a paramedic working in England but completed my training outside of this country. As it currently stands my role (in providing care to this patient group) tends to boil down to safe guarding patient during a crisis event. I am trained and in a unique position to do more. Is there anyway you see for me to use your model in my daily practice?

Hunchie

Hello, thanks for your question, its great that you would like to incorporate care planning into your work. As it stands a persons care plan should have all of the information in there regarding the care they wish to receive, including advanced directives (so the things they would like to be done/people to be contacted etc) when they are in crisis. It would therefore be a good idea to ask to see a persons care plan in those situations, as you would be able to gain information from them which you otherwise might be unable to get from the patient.

What's the best approach for someone who is convinced they are showing the early signs of Alzheimers, even though all the tests fail to detect it? (Even to the level of MRI and PET scans). Most of the doctors put it down to an anxiety disorder, but could it be that she's noticing things the tests aren't sensitive enough to detect?

AllanfromWales1

I am afraid this is well outside of our area of expertise and therefore it would be wrong to give a speculative answer to your question - I am sorry!

I work help people who have both anxiety and depression, and have been shocked at how effetive quality, absorbable calcium and magnesium can be. There are studies that back this up. Why is this not the first thing done at the start of care?

ReasonablyConfused

Hello, interesting area but I'm afraid this is very much outside of our knowledge area.

Have you considered using the resources of the surrounding communities to encourage integration and develop the communities to accept diversity? I say this as i'm aware of the projects made by community Psychology.

neo2419912

Great question, its not something that falls into the remit of our work, but I am sure as you say there are projects out there looking at this.

I suffer from manic depression, adult attention hyperactive disorder and high functioning Aspergers, is there any med that would help me be more leveled and be more 'normal'?

Gelate98

I am afraid that none of us here are prescribing clinicians and would urge you to seek advice from your doctor.

Can I ask if there is any work towards ADHD? Or any research or schemes to reduce the stigma of having it? And maybe make doctors less reluctant at tackling it.

SoupCanVaultboy

Hello, ADHD is not something we are knowledgeable on, but there will most definitely be research out there; have a look at https://youngminds.org.uk/find-help/conditions/adhd/ which is a great resource.

Why do you think there's a problem with getting clinicians to buy into some of the recommendations of patients? It seems like they're common sense suggestions.

jimguru

Helen here - Thank for your question. In a review of the evidence we conducted as part of this programme of work, we identified a range of barriers to user involvement in care planning (http://bjp.rcpsych.org/content/bjprcpsych/207/2/104.full.pdf). These included professionals perceiving that service users lacked the capacity to be involved or might not want to be involved, poor communication between professionals and service users, organisational barriers including lack of time in meetings and high workloads and cultural barriers such as a tendency for health services to prioritise the views of professionals. The paper will give you further information if you are interested in finding out more about this.

How difficult is it to enhance this aspect of healthcare which in the UK is known to be probably the worst funded and faces further cut backs?

felizesteban

Helen here - Thank for your question. Both the professionals and service users raised the difficulties they thought the health service currently faced. More information on this can be found in these papers: http://bjp.rcpsych.org/content/bjprcpsych/207/2/104.full.pdf https://sctt.org.uk/wp-content/uploads/2016/08/Brooks-et-al.-Key-informants-perception-of-user-and-carer-involved-care-planning-2015.pdf

The results of the trial will be out soon and these will be available here: http://research.bmh.manchester.ac.uk/equip

I live with a partner with mental health problems and am acutely aware of the funding shortfall.

How bad is the problem?

MI6Observer

Hi - Helen here. We are running a process evaluation alongside the randomised control trial which will explore the broader contextual issues regarding the organization and delivery of care for people with mental health difficulties. The results will be available here in the near future: http://research.bmh.manchester.ac.uk/equip

Do you think there (still) a stigma among mental health professionals for patients with Borderline Personality Disorder?

philsown

Hello, this isn't something I am any sort of authority on, but might I refer you to the work of our former colleague who has a specialist interest in this area: http://www.seek.salford.ac.uk/user/profile/presence/viewAll.do?personId=3437

What are thoughts on DBT/CBT for long term treatment for bipolar/depression/substance abuse disorder, etc.?

LemmeSplainIt

Hello, I'm afraid particular therapeutic approaches were beyond the scope of this study as the specific focus was on involvement in care planning, regardless of the particular diagnosis/therapeutic approach.

How much of this study as the Mental Health . The aim of the projects made by community Psychology.

Doghouse144

I am not sure we understand your question I am afraid!