Leeds and York Partnership NHS
NHS Foundation Trust

R & D

Innovation

Research and Development Newsletter

www.leedsandyorkpft.nhs.uk/professionals/RD
October 2016 Issue 26

Contents

Editorial

Welcome to the autumn edition of Innovation.

I am looking forward to our tenth Annual Research Forum on 15 November at Horizon Leeds, 2 Brewery Wharf, Kendall Street, Leeds, LS10 1JR. I hope to see you there. I want to thank all our presenters, workshop leaders and poster contributors for making the programme so interesting. Unfortunately we will not have Dr Jim Isherwood as Chair this year as he will have left his role as Medical Director by then. The Research and Development team and I thank Jim for his support throughout his time as Medical Director. The Forum would not happen without a lot of work over a number of months by the Research and Development and the Library and Knowledge Services teams, and I appreciate their efforts. There are still a few places remaining – visit **www.rdforum16.eventbrite.co.uk** to book and tweet using **#RDForum16**.

This newsletter, as usual, contains summaries of completed projects - ten in total. These range across a number of clinical specialties and areas of research in the Trust. They also demonstrate the collaborative nature of research, referencing other trusts and universities we have worked with to achieve these research outcomes. In addition, you can read about how to ‘Join Dementia Research’ (you don’t need to have dementia) and about the list of research publications by Trust staff that the R&D department maintains. There are also training dates and links to funding opportunities.

Correction: I apologise for an omission in Innovation July 2016, Issue 25. The article ‘A survey of burnout and support systems for staff in the CAS’ on pages 6-7 should have stated the researcher and author as Dr Anuradha Menon (ST8 in Psychotherapy and Adult Psychiatry), supervised by Dr Claire Flannigan (Consultant Psychiatrist and Lead, CAS) and Dr James Johnston (Consultant Psychiatrist in Psychotherapy).

If you have any feedback about this newsletter, wish to contribute an article, or would like to visit the R&D department to find out more about what we do, please contact me at **athompson11@nhs.net** or **0113 855 2360**.

Alison Thompson
Head of Research and Development

Completed Research Projects

Articles about recently completed research projects are marked with this symbol.

Completed Project

An evaluation of **Leeds Autism Diagnostic Service**

Leeds Autism Diagnostic Service (LADS) is an adult autism diagnostic service for people of any intellectual ability which also offers consultancy to service users/carers or professionals, as well as a wide range of autism training.

In 2014, medical students from the University of Leeds conducted detailed service evaluations, which included prospective and retrospective questionnaires. Both questionnaires were created with the help of a Service User Involvement Facilitator within our Trust working as part of the 'easy on the i' team. This information design team specialise in producing easy-to-understand information for service users. They also provided us with service user feedback around the practicalities of filling out the questionnaire. Both questionnaires were available in paper and online formats.

We sent the retrospective survey to 117 service users who LADS had diagnosed with autism, receiving 29 responses to the postal survey and two to the online version. Unfortunately the response rate was only 26%. The majority of respondents had an intellectual disability (73%) and in most of these cases the questionnaire was filled in with the help of a carer. It was notable that 38% of respondents rated our pre-pack questionnaire as 'hard to understand', a finding which has prompted us to review the readability of our paperwork.

The other most interesting finding was that when asked 'has having a diagnosis of autism made your life better?', only 44% said 'yes' (33% said 'not sure' and 23% said 'no'). Perhaps this can be explained by the fact that over half the respondents reported getting no extra support post-diagnosis. The most prominent example of this was one written response saying they required "help with a complete mental breakdown". Others reported wanting help with tasks related to day-to-day living and finances. On the other hand, some people told us they have received additional support since diagnosis. The types of support described were wide-ranging, including local charities, brain in hand (assistive digital technology), specialist counselling, peer support groups, finance and housing. The questionnaire was not designed to explore what factors led to only some people receiving extra support, but it seems to us that this is a key issue worthy of further research. Perhaps having highly motivated and able family members, a sympathetic and understanding GP or greater financial resources can explain why some patients are able to access more support post-diagnosis.

The prospective survey garnered 57 responses. Of these, 28 (49%) had received a diagnosis of autism and 19 (33%) had an intellectual disability. Results showed that those referred by GPs were less likely to be diagnosed with autism than those who self-referred: 24% vs 62%. This appears to contradict the hypothesis that our relatively low diagnosis rates are in part due to allowing self-referrals who are less likely to be autistic than people screened by GPs (see figure 3).

The results of the prospective survey also showed that there was generally more dissatisfaction with the service amongst people who were not diagnosed with autism (figure 3). This backs up our own clinical observations, that if patients are told they do not in fact have autism, they are more likely to be unhappy (in some cases angry) and are also more likely to make a complaint. We are not aware of any studies looking at the emotional reaction to an autism diagnosis, but there is such a study looking at ADHD diagnosis (Young S. et al 2008). The authors suggest there are several stages:

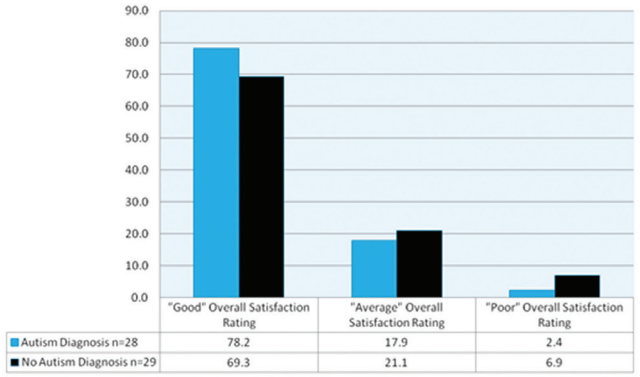
1. Initial relief and elation
2. Confusion and emotional turmoil
3. Anger
4. Sadness and grief
5. Anxiety
6. Accommodation and acceptance

It may be that not receiving an expected diagnosis leaves the person stuck with feelings of anger and confusion, without necessarily progressing to the acceptance stage. It is not uncommon for us to be asked 'well if it's not autism, what is the reason for the problems I have?' Many of the people we have diagnosed report a strong emotional reaction, including relief, but also in some cases a sense of grief and loss of identity. An example is James McGrath, lecturer at Leeds Beckett University, who was recently diagnosed with autism by LADS. He writes powerfully of his experience of receiving the diagnosis (see below). We believe this topic warrants further study.

The elements of the service with most dissatisfaction were the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1989) activities, and accessibility of information about the service. The ADOS was originally designed for children, although the module we use has been adapted for adolescents and young adults, and we advise patients of this beforehand. However perhaps this warning in fact primes them to consider the ADOS tasks 'childish'. A few service users described these activities with comments such as "awkward… patronising…childlike toys". Regarding accessibility of information, we have made efforts to ensure our literature is easy-read and we are improving our website and online information.

Going forward, the team is trying hard to empower people with autism to embrace their specific skills and integrate into the neurotypical world. We're incredibly grateful to all our service users who have assisted in improving our service. We continue to learn from them on a daily basis as we constantly strive to provide a world-class autism diagnostic service.

Figure 3: Overall satisfaction with the service from prospective survey



	"Good" Overall Satisfaction Rating	"Average" Overall Satisfaction Rating	"Poor" Overall Satisfaction Rating
🟦 Autism Diagnosis n=28	78.2	17.9	2.4
■ No Autism Diagnosis n=29	69.3	21.1	6.9

'World is suddener than we fancy it': Imagination, Change and Autism Diagnosis

I underwent assessment assuming diagnosis would be little more than an abstract formality, confirming something I had in some way known all my life. I had expected it would feel like little other than a more clinical definition of my 'eccentricity', 'oddness' and 'Jamesness' as observed to me from teachers, peers and friends. But You clearly have Autism. We are all in agreement. Diagnosis brought a weird mix of shock and relief; but first and greatest was the shock. The previous sentence might have specified that diagnosis brought shock to me. Yet for some weeks after, the very state of 'me' felt almost absent. I had, however, known something very like this physical and emotional state before: it was grief. What was I mourning now? What had been lost? A small corner of uncertainty. Until that point, I hadn't had to know for certain I was Autistic, even if many around me had seemed sure. For me, the medical diagnosis, at 36, brought an unprecedented collision between a changed self-perception, and a fear of how others might view me... The constant question of diagnostic aftermath is: am I feeling, remembering, or fearing in this way because I am Autistic - or is it just because I'm human? In other words: if even science does not yet understand quite what Autism actually is, how do I begin to understand who I am?

Edited extract reproduced with permission from the author: McGrath (2017, forthcoming)

References

1. Young, S., Bramham, J., Gray, K., Rose, E. (2008). The experience of receiving a diagnosis and treatment of ADHD in adulthood: A qualitative study of clinically referred patients using Interpretative Phenomenological Analysis. Journal of Attention Disorders 11(4), 493-503.
2. Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L. and Schopler, E.J. (1989), "Autism Diagnostic Observation Schedule: a standardized observation of communicative and social behavior", Autism Dev Disord. Jun, Vol. 19 No. 2, pp. 185-212.

Dr Conor Davidson, Tees, Esk and Wear Valleys NHS Foundation Trust, **conor.davidson@nhs.net**

Completed Project

Effect of weight gain on re-admission in anorexic patients

Anorexia is relatively young in terms of research as a complex mental health condition. The purpose of this study was to explore relationships between the rate of weight gain and factors influencing re-admission to a specialist eating disorders unit.

Methods

The study used a quantitative retrospective cohort design using a 'convenience sample' based in one specialist eating disorders unit. Participants included those who were admitted to the Yorkshire Centre for Eating Disorders (YCED) during 2015 who had previously been inpatients. The medical records and weight charts of participants were examined to collect data which was then entered into SPSS (statistical package for social sciences) for analysis.

Findings

No correlation between the rate of weight gain and variables such as age, area, admission and discharge body mass indexes (BMIs) and Eating Disorder Evaluation Questionnaire (EDEQ) scores was apparent. There were significant differences (p=0.004) suggesting participants who self-discharged regain weight quicker than those discharged in other circumstances. There were also significant findings (p=0.24) suggesting participants who opt for a 'risk reduction' programme are more likely to complete treatment.

Conclusions

The small sample size (n=26) prevented robust statistical analysis; however the study provided valuable information about recommendations during treatment. These included supporting patients to opt for a realistic BMI based on their previous admission history, noting that there is no difference between the rate of weight gain based on age or other variables and highlighting this to the patient group.

Admission and discharge BMIs tend to decrease as number of admissions increase, informing clinicians about treatment expectations i.e. patients being repeatedly admitted may not be in a psychological position to achieve a healthy body mass index and aiming for a low BMI and risk management may be more realistic. Further research is necessary to consolidate the results.

Elinor Campbell, LYPFT, **elinor.campbell@nhs.net**

Supervised by: Dr Helen White, Leeds Beckett University

Completed Project

Use of club and prescription drugs in people with eating disorders

Patterns of substance use are changing with the emergence of novel psychoactive substances, prescription drug abuse, and internet drug purchasing; however the impact of these changes on individuals with eating disorders is unclear. To our knowledge this is the first study to examine these changing trends in individuals with eating disorders.

Method

72 participants recruited from two eating disorder services completed measures for substance use and eating disorder psychopathology. Additional clinical information was gathered via a thorough review of participant case notes.

Results

Novel psychoactive substance use was reported in 22% (n=16) of participants, with Ketamine and Mephedrone being the most frequently used. 56% (n=40) had a history of prescription drug abuse whilst 28% (n=19/68) of those who had used substances had bought them online. Novel psychoactive substance use, prescription drug abuse, and internet drug purchasing were more common in individuals who engaged in binge-purge behaviours and in those who had a history of deliberate self-harm.

Discussion

The use of novel psychoactive substances, prescription drug abuse, and internet drug purchasing appear to be common in individuals with eating disorders and clinicians should be aware of their physical and psychological complications so that they can educate patients about their risks.

Dr William Rhys Jones, LYPFT, **r.jones9@nhs.net**

Completed Project

Going Smokefree: A service user survey

On 4 April this year, Leeds and York Partnership NHS Foundation Trust (LYPFT) became smoke free, as part of a commitment to provide a healthy environment for everyone who uses our sites, based on guidance from the National Institute of Care and Excellence (NICE).

The Trust engaged with and provided information to service users, carers, staff and visitors about going smoke free in various ways. In March this year members of the Trust, who use or have used services, were asked to complete a short survey about implementing a Smokefree policy. The survey was part of a regional CLAHRC (Collaboration for Leadership in Applied Health Research and Care) research and development programme and also took place in Sheffield Health and Social Care NHS Foundation Trust.

Members who had access to email were asked to take part by completing an electronic survey and paper copies were made available across a number of services. The questions mirrored the ones asked in the LYPFT staff survey.

Responses and key findings

87 responses were received, which were analysed by an independent researcher. 38% of respondents were current smokers, 29% were ex-smokers and 33% had never smoked. Of those that did smoke, 60% wanted to cut down or quit smoking. There were mixed views about the Trust's plans to go smoke free. Some people supported being a Smokefree Trust, while others had some concerns or queries about how this would work in practice.

SMOKEFREE

Using the findings

The findings from the survey will be, or have been, used in the following ways:

1. They were used to prepare for going smoke free.
2. They will act as a baseline to compare with a further survey later in the year. These will be used to advise on the impact of being a Smokefree Trust.

A "frequently asked questions" (FAQ) document has been developed which summarises the questions and concerns of service users, staff and carers with an evidence based response. The FAQ is available on the Trust's intranet site, Staffnet, and the Trust's website. A full report and FAQ document have also been distributed to our service user membership database.

The CLAHRC will be used to support the Trust's continued collaboration with colleagues in Sheffield, and at other neighbouring trusts who have implemented a Smokefree policy, to support and learn from each other as the Smokefree journeys progress.

Further information

If you would like further information about the survey or to find out more about how the results are being used, please email: **lypft.smokefree@nhs.net**.

You can get more information about research supported by the CLAHRC in Yorkshire and Humber at: **http://clahrc-yh.nihr.ac.uk/**

If you work for the Trust or Interserve and would like support to stop smoking, the Healthy Living Service can provide one-to-one support and two weeks of Nicotine Replacement Therapy products for free. Email **stopsmokingsupport.lypft@nhs.net** or call Matthew Osborne on **0113 855 6631**.

Completed Project

Evaluating the BSL4Kids group

It is understood that effective communication is essential to positive mental health. By enhancing communication, a person's mental health can be improved, raising self-esteem and providing the opportunity to achieve and enable engagement with peers who have shared experiences.

In September 2014, the York Deaf Child and Adolescent Mental Health Service (CAMHS) started a 'BSL (British Sign Language) Kids' course for deaf children and their siblings. It took place on Saturday afternoons, once a month for 12 months. The main aim was to give deaf children and their siblings an opportunity to learn and communicate in BSL, providing 'confidence in communication'.

Whilst teaching BSL to deaf children is not a new concept, this is the first time a course of this kind has been evaluated. The evaluation included qualitative semi-structured interviews, questionnaires and the Strengths and Difficulties Questionnaire (SDQ) which took place at two time points to capture the impact of the course.

A cross thematic analysis found that the course positively impacted upon deaf children, their siblings and families; notably in terms of friendships, exposure to other deaf people, confidence, self-esteem, attitude towards communication, and fostering a positive identity. The SDQ showed definite improvement in pro-social and peer relationships, and a slight improvement in emotional and conduct scores.

In summary, the headline defined themes are:

- From deficit to empowerment
- From participation to social networks
- From an individual focus, to greater awareness and shared experience.

The findings of the evaluation were presented at the British Society for Mental Health and Deafness (BSMHD) conference in June 2016 and will be submitted for inclusion in a journal article.

Victoria Ackroyd, **v.ackroyd@nhs.net** and Gillian Nowell, **gnowell@nhs.net**, LYPFT

Completed Project

Challenges to staff compassion for patients detained under the MHA

Background

In recent years, grave malpractice and care failings, that jeopardise the lives of patients, the integrity of staff and the reputation of healthcare organisations, have been exposed both within the NHS and the private sector. Subsequently, the construct of 'compassion' and the apparent lack of kindness within the healthcare system has received mounting academic, clinical and legislative consideration. Contemporary literature increasingly acknowledges the growing challenges to the delivery of compassionate care within mental health services, which exist across individual, interpersonal, organisational and societal levels. However research has yet to explore this.

Objectives

This study aimed to investigate the relationship between individual differences in direct-care staff and challenges to compassion they experience towards patients who are detained under the Mental Health Act (MHA). Furthermore, as the existing measure of challenges to compassion was deemed to have shortcomings within clinical relationship contexts, the study also aimed to develop a more appropriate measure of the challenges staff experience in displaying compassionate care to patients. This incorporates client, team and service-level challenges that may be encountered.

Method

In total, 104 support workers, nurses and clinical managers were recruited anonymously from a range of inpatient mental health services across the country (both NHS and private) including Leeds and York Partnership NHS Foundation Trust. Participants completed an online questionnaire comprising measures of challenges to compassion, attachment, emotional intelligence, professional quality of life and explicit attitudes towards detained patients. A self-selecting subsample of participants completed an online test of implicit attitudes towards displaying compassion for detained vs. general hospital patients.

Findings

High levels of compassion were found within the sample. Statistical analyses revealed that higher rates of intrapersonal emotional intelligence (i.e. the capacity to recognise, reflect on and manage our own emotional states) and compassion satisfaction (i.e. the pleasure and gratification obtained from caregiving) predicted fewer challenges to compassion towards detained patients. Increased challenges to compassionate care were associated with attachment-related anxiety, the support worker role and compassion fatigue (i.e. vicarious stress caused by caring for individuals in distress). The age, gender and length of clinical experience of participants were unrelated to challenges to delivering compassionate care. Burnout scores suggested experiences of work-related stress in some participants due to environmental and organisational factors. The new Challenges to Compassion Questionnaire demonstrated good internal reliability and validity.

Implications

Compassionate care can provide a 'corrective' emotional and interpersonal experience for patients with mental health difficulties and can contribute greatly to their psychological wellbeing and recovery. Mental health services are able to enhance the provision of compassionate care by promoting health and wellbeing, self-compassion, intrapersonal emotional intelligence and mentalising capacities in their staff. Interventions that may support this, include:

- Supporting staff to develop a repertoire of personal self-care resources and coping mechanisms to enable them to work effectively with patients with severe and complex mental health difficulties
- Providing education around identifying signs of burnout and compassion fatigue and ways in which this can be addressed promptly
- Ensuring that all staff have access to regular clinical supervision in order to process the emotional responses to their work
- Using the Challenges to Compassion Questionnaire formally or as a framework to guide discussions with individual staff members or teams to openly acknowledge the existence of barriers and to identify appropriate measures to overcome these
- Promoting kinship, communication and agency within teams and encouraging staff to support the professional welfare of their colleagues
- Creating opportunities for group supervision and reflective meetings to allow staff to consider the psychological impact of both clinical and non-clinical work (e.g. Schwartz rounds)
- Developing team formulations to allow staff to 'tune in' to a patient's world and to increase the psychological understanding of their presentation
- Investing in the professional development of staff by supporting training attendance, CPD and networking
- Fostering a compassionate, secure and nurturing psychologically-informed environment that promotes patient-staff relationships and emotional wellbeing (e.g. 'PIEs')

Mirella Hopper, Lancashire Care NHS Foundation Trust and Lancaster University,
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Supervised by: Dr Ian Fletcher, Lancaster University

Completed Project

Therapeutic Engagement Questionnaire (TEQ)

It is important to be as explicit as possible about the contribution registered mental health nurses make to service user recovery. The development of a mental health nursing metric that measures the nurse–patient relationship and therapeutic engagement is vital and long overdue.

To mark the achievements of mental health nursing it is important to capture the contribution of the profession to the quality care agenda and acknowledge the way it enhances the experience of service users. The metric, which takes the form of a twenty-item, multidimensional questionnaire measures both the atmosphere and environment of the acute clinical setting and 1:1 sessions with registered mental health nurses.

The metric has been designed to produce data that will identify the nature of nursing interactions and the impact on service user recovery. It also indicates how service users are involved in the decision-making and monitoring of their care and treatment. Information gathered by the Therapeutic Engagement Questionnaire (TEQ) will help to advise mental health nursing staff at all levels of seniority about the nature of therapeutic engagement experienced by service users. In addition, the data will be in a form that can be integrated into the key performance indicator (KPI) data bank of healthcare trusts, thus enabling trusts to identify areas of good practice and to support those facing challenges.

The metric has been developed and initially authenticated in collaboration with four NHS trusts across England; Leeds and York Partnership NHS Foundation Trust was one of these, successfully recruiting 45 participants on to the study. The study has brought together service users and registered mental health nurses who have co-produced this metric with the study team. We are currently authenticating the metric in a further 25 trusts across England with wide geographical spread. The study has been adopted by the UKCRN Portfolio.

Mary Chambers, Kingston University and St George's, **M.Chambers@sgul.kingston.ac.uk**

Co-Investigators: Sue McAndrew, University of Salford, Fiona Nolan, Camden and Islington NHS Foundation Trust, Ben Thomas, Department of Health, Paul Watts, Somerset Partnership NHS Foundation Trust, and Xenya Kantaris, Kingston University and St George's.

Local collaborator: Linda Rose, LYPFT, **lrose1@nhs.net**

Completed Project

Growing up with a parent with psychosis

The aim of this study was to find out how adults who grew up with a parent with psychosis made sense of these experiences, both as a child and during adulthood.

Method

Five people, who grew up with a parent with psychosis, were interviewed using a semi-structured interview approach.

Results

Four major themes were identified. These were: "people don't want to care for me", "I'm different", "what if people find out?" and "finding my identity". The findings indicated that, as children, participants felt uncared for and neglected by the parent with psychosis and by others.

They described feeling different from their peers and made attempts to increase their sense of belonging by finding people similar to them. They also felt shame and feared humiliation if people found out about their parents' condition. However, participants reported positive growth as an adult as a result of their experiences, such as being more caring or independent.

Discussion

The findings highlighted the benefits of services being more aware of the family around someone experiencing psychosis. An increased awareness would enable services to support parents to help their children make sense of what is happening in the family. This may involve helping parents to make sense of their own unusual experiences, so they in turn can help their children to understand. In addition, it might be useful for services to involve schools more closely in support of these families.

Finally, although participants reported some difficulties in childhood, in adulthood they were functioning well. This research shows how having parents who experience psychosis may provide an opportunity for positive growth in adulthood.

Melanie Parkins, formerly LYPFT

Supervised by: Dr Anjula Gupta, LYPFT

Research publications

Leeds and York Partnership NHS Foundation Trust is committed to conducting and promoting research to improve the current and future health and care of the population.

The Trust is proud to not only actively conduct research, but also work in collaboration with other organisations to complete research projects. Current lists of outcomes from research projects carried out through the Trust, and details of where they have been publicised, can be found on the Research and Development (R&D) pages of the Trust's website: **http://www.leedsandyorkpft.nhs.uk/professionals/RD/Publications.**

The publications list consists of studies including House, Allan 'Non-suicidal reasons for self-harm: A systematic review of self-reported accounts', Burke, Louise 'Pharmacological treatments for managing eating disorders', and Hughes, Tom 'Unrecognised bipolar disorder among UK primary care patients prescribed antidepressants: An observational study'.

If you have been involved in a publication that could be added to the publications list, please contact us on **0113 85 52387** or email **research.lypft@nhs.net**.

Alternatively if you have not yet published a study and are looking for support, you can attend the free 'Writing for publications' course delivered by the National Institute of Health Research (NIHR) or our in-house course delivered jointly by the Trust's R&D and Library and Knowledge Services departments. Please contact **research.lypft@nhs.net** for details.

Completed Project

Conceptualisation of psychosis in people of a Muslim faith

Research shows religion is an important issue for some people with psychosis. Although there has been interest in the interpretative frameworks of people experiencing psychosis, there have been few studies that have focused on religion, and more specifically on experiences of psychosis in people from a particular religion.

Aims

This investigation aimed to explore how people of a Muslim faith conceptualise their psychotic experiences and the role of religion in this conceptualisation.

Methods

Seven men of a Muslim faith, who have experienced psychotic experiences, took part in the study. They were interviewed individually using a semi-structured interview schedule. Interpretative phenomenological analysis was used as the method of analysis.

Results

Four super-ordinate themes emerged. These were: ‘The self in relation to others’, ‘getting help and moving on’, ‘the unseen’, and ‘the mind in the wider world’.

Conclusion and clinical implications

The results of this study support the existing literature, in that participants utilised a variety of interpretative frameworks, with religion being important in making sense of their psychotic experiences. The findings demonstrated the multifaceted nature of the rebuilding of the self and relationships, highlighting the importance of being listened to and understood in the process of recovery and use of services. The study can help clinicians to appreciate the complex interaction of a variety of interpretive frameworks that people of a Muslim faith use in making sense of their unusual experiences, thereby helping them to appreciate these in a therapeutic context.

The study highlights the importance of therapists developing competency in working with explanatory models for people from diverse ethnic and cultural backgrounds, in the provision of psychological therapy. The process of psychological formulation may seek to help the individual to make sense of different interpretative frameworks and develop a shared understanding of their difficulties. The study highlights how greater collaboration between statutory and a variety of non-statutory services is required in the provision of services within a biopsychosocial-spiritual model.

Dissemination

The findings of this study were presented as part of a symposium of four papers titled ‘Religious, cultural and ethnic considerations for engaging people with lived experience of psychosis in the UK’ at the International Society for Psychological and Social Approaches to Psychosis (ISPS) Residential Conference on 7 September 2016.

Dr Mahbub Khan, LYPFT, **mahbubkhan1@nhs.net**

Co-Investigators: Dr Georgina Rowse and Prof Gillian Hardy, University of Sheffield and Prof Rasjid Skinner, Ihsaan Therapeutic services, Sharing Voices, Bradford.

Join Dementia Research

Dementia affects 850,000 people in the UK and this figure is set to double over the next three decades. Research offers us the opportunity to gain an understanding of the processes that cause dementia and to develop effective treatments.

The progression of dementia research is dependent upon the number of people willing to take part. One of the difficulties that researchers currently face is recruiting an adequate number of participants for their studies. Usually, this reflects a lack of communication with people about the ways in which they are able to get involved with research, rather than unwillingness to participate. It is for this reason that Join Dementia Research has been initiated.

Join Dementia Research is a service set up by the National Institute for Health Research in collaboration with Alzheimer’s Research UK, Alzheimer’s Society and Alzheimer’s Scotland. It aims to remove the barriers to participation in research and give everybody the opportunity to participate in dementia research in order to significantly improve patient outcomes in the coming years.

Anyone aged 18 years or over can sign up themselves or on behalf of someone else with their consent. The service welcomes individuals living with dementia, their carers and anyone else interested in participating in dementia research. You can express your interest online or by calling Alzheimer’s Research UK on **0300 111 5 111** or Alzheimer’s Society on **0300 222 1122**. Once participants have signed up, researchers may contact them with details of studies that match their profile. This gives people the opportunity to read about the available studies and make a decision about whether they would like to get involved. There is no obligation to participate in any studies; it just allows potential participants to hear about the wide range of studies open to them.

Since 2013 the number of drug trials to treat Alzheimer’s has almost doubled and in the UK there are currently 19 drug studies investigating new treatments for Alzheimer’s. Given this increase, now is a critical time to ensure that sufficient numbers of participants are recruited into dementia research.

Leeds and York Partnership NHS Foundation Trust is engaged with Join Dementia Research to maximise recruitment to dementia studies. Current dementia research in this Trust includes studies looking at medication, lifestyle interventions and people’s experiences of living with dementia.

For a full list of current projects contact the R&D team or visit: **http://www.leedsandyorkpft.nhs.uk/professionals/RD/Current_Projects**

Rebecca Hargate, LYPFT, **rebecca.hargate@nhs.net**

NIHR funding deadlines

The NIHR Clinical Research Network Portfolio is a database of clinical research studies showing the clinical research activity nationally. Clinical trials and other well-designed studies involving the NHS, funded by the NIHR, other areas of government and non-commercial partners are automatically eligible for portfolio adoption. Studies that are adopted on to the portfolio can access infrastructure support and NHS service support costs to aid with study promotion, set-up, recruitment, and follow-up.

Funding streams

1. **Efficacy and Mechanism Evaluation (EME)**
   Researcher-led and aims to improve health/patient care. Its remit includes clinical trials and evaluative studies.
2. **Health Services and Delivery Research (HS&DR)**
   Funding research to improve the quality, effectiveness and accessibility of the NHS, including evaluations of how the NHS might improve delivery of services. It has two work streams, researcher-led and commissioned.
3. **Health Technology Assessment (HTA)**
   Funds research to ensure that health professionals, NHS managers, the public, and patients have the best and up-to-date information on the costs, effectiveness, and impacts of developments in health technology.
4. **NIHR Fellowships**
   Support outstanding individuals to become the health research leaders of the future by contributing to research costs needed to complete an identified research project.
5. **Programme Grants for Applied Research**
   To produce independent research findings that will have practical application for the benefit of patients and the NHS in the relatively near future.
6. **Programme Development Grants**
   Intended to meet the further development needs of those intending to apply for a Programme Grant for Applied Research.
7. **Public Health Research (PHR) Programme**
   Funds research to evaluate non-NHS interventions intended to improve the health of the public and reduce inequalities in health.

For further details, see: **http://www.nihr.ac.uk/funding/programme-grants-for-applied-research.htm**

Funding stream	Deadline
Efficacy and Mechanism Evaluation (EME)	Commissioned – 1 November 2016, 1pm
	Researcher-led – 1 November 2016, 1pm
Health Services and Delivery Research	Researcher-led – 19 January 2017, 1pm
Programme Grants for Applied Research (PGfAR)	Competition 21: Stage 2 – 29 November 2016, 1pm
	Competition 22: Stage 1 – 29 November 2016, 1pm
Programme Development Grants	Competition 17: 17 November 2016, 1pm
Public Health Research (PHR) Programme	Commissioned – 5 December 2016, 1pm
Research for Patient Benefit (RfPB)	Competition 30: Stage 2 – (Date TBC)
	Competition 31: Stage 1 – 23 November 2016, 1pm

Completed Project

Outcome measure: ReQoL latest news

The Recovering Quality of Life (ReQoL) survey, developed by a research team based at the University of Sheffield and led by Professor John Brazier, was created to assess the Quality of Life for people aged 16 years and over with mental health conditions. This short generic patient reported outcome measure (PROM) is now available for use.

From March 2015, over 6500 service users, including 247 from LYPFT, were recruited to respond to the ReQoL survey of 61 questions, which were then refined and tested as a survey of 40 questions between September and December 2015. Recruitment took place across England in 20 NHS trusts, six GP practices and a number of voluntary sector organisations. The measure was assessed psychometrically using a robust psychometric methodology.

A short version of ReQoL was created, containing ten mental health questions and one physical health question, taking less than five minutes to complete. The long version contains 20-30 questions. Both are scored using a simple summative score. Initial validation of ReQoL shows that the measures perform well in the mental health populations. The measures are available free of charge to the NHS simply by submitting a request. A link to the distributor's page is available on the ReQoL website: **www.reqol.org.uk**

There are no reports for the project but there are four main manuscripts that are in preparation for submission to peer-reviewed journals.

The next step involves generating preference weights for the calculation of Quality Adjusted Life Years to conduct economic evaluation. ReQoL will be an instrument for routine use to assess the outcomes of interventions in clinical practice, audit, and monitoring.

ReQoL is commissioned and funded by the Department of Health Policy Research Programme (PRP). The work was undertaken by a research team at the University of Sheffield. ReQoL is also part-funded by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Yorkshire & Humber.

Acknowledgements: Thank you to all participants; staff at various NHS trusts, GP surgeries, charities; NIHR Clinical Research Network Mental Health; expert users and members of ReQoL governance groups.

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Assisted by: Alice Locker and Carla Girling, LYPFT, and Emma Fleming, formerly LYPFT

Finding the Evidence Training Dates: Courses free to Leeds and York NHS staff

Cochrane Library training

This course focuses on the skills required to search the Cochrane Library effectively to retrieve high quality evidence to support work and study.

Critical appraisal

This course focuses on why it is important to appraise journal articles, how to go about doing this, and how to obtain further help.

Current awareness (On request)

Aimed at all Leeds and York NHS staff who wish to set up and use email and RSS alerts and feeds to support their practice or professional development.

Healthcare databases

This course focuses on searching healthcare databases.

E-journals and e-books

Aimed at all Leeds and York NHS staff who wish to use e-journals and e-books to support their practice or professional development.

Google training (On request)

Aimed at all Leeds and York NHS staff who wish to gain skills in searching Google for information to support their work, practice or professional development.

Making the most of your Athens account (On request)

This course is aimed at all Leeds and York NHS staff who wish to better understand their Athens account and learn about the e-resources that are available to them.

OCTOBER				
25	Tue	10:00-12:00	HDAS Conversion Course	IT Suite, Mount Annexe
27	Thur	14:00-15:00	HDAS Conversion Course	IT Suite, Mount Annexe
31	Mon	11:00-12:00	HDAS Conversion Course	BEX

NOVEMBER				
02	Wed	09:00-16:30	Finding & Appraising the Evidence	BEX
04	Fri	10:00-11:00	HDAS Conversion Course	BEX
09	Wed	14:00-15:00	HDAS Conversion Course	IT Suite, Mount Annexe
10	Thur	09:00-16:30	Return to Study	Mount
11	Fri	14:30-15:30	HDAS Conversion Course	LGI
11	Fri	10:00-12:00	Google & Beyond	LGI
14	Mon	11:00-12:00	HDAS Conversion Course	Stockdale House Library
16	Weds	14:00-16:00	Critical Appraisal	MR1, Stockdale House
18	Fri	14:00-15:00	HDAS Conversion Course	IT Suite, Mount Annexe
24	Thur	10:00-11.:00	HDAS Conversion Course	LGI
25	Fri	14:00-15:00	HDAS Conversion Course	LGI
30	Wed	09:30-10:00	HDAS Conversion Course	Mount

DECEMBER				
01	Thur	10:00-11:00	HDAS Conversion Course	IT Suite, Mount Annexe
01	Thur	09:00-16:30	Finding & Appraising the Evidence	LGI
05	Mon	11:00-12:00	HDAS Conversion Course	BEX
08	Thur	10:30-12:30	Google & Beyond	BEX
09	Fri	12:00-13:00	HDAS Conversion Course	BEX
15	Thur	13:00-14:00	HDAS Conversion Course	LGI
12	Mon	15:00-16:00	HDAS Conversion Course	Mount
13	Tue	TBC	Critical Appraisal	LGI
19	Mon	14:00-15:00	HDAS Conversion Course	LGI
w/c 19/12/16		TBC	HDAS Conversion Course	TBC

If the course you are interested in is listed as being on request, please contact **libraryandknowledgeservices.lypft@nhs.net** for more details.

Full details and online booking information can be found at: **http://www.leedslibraries.nhs.uk/Training/bookingForm.php**

R & D

Contact us R&D

Innovation is a newsletter for sharing and learning about research. This includes information about projects being carried out in your area. We welcome any articles or suggestions for future editions.

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Annual Research Forum 2016

Date: 15 November 2016

Venue: Horizon, Leeds, LS10 1JR.

The Annual Research Forum is an all-day event hosted by Leeds and York Partnership NHS Foundation Trust's Research and Development and Library and Knowledge Services Teams. Its purpose is to showcase some of the research and evaluation work that our Trust and academic staff have completed in the past year.

The Forum is held in November, in part to coincide with the completion of the projects from the Doctorate in Clinical Psychology course at the University of Leeds. Around 90 delegates attend, including service users, carers, nurses, allied health professionals, psychologists, academics, researchers, and psychiatrists.

The projects are presented either in plenary or workshop sessions by the researchers or in poster form. There are typically 15-20 posters and these will be judged by delegates attending the event, with prizes awarded for 1st and 2nd places.

Registration and poster submission details will be available shortly and a full programme of the event will be advertised in the autumn.

The latest information about the event can be found on the Research and Development pages of the Trust's website.

This is a free all-day event, including lunch.