



# Innovation

Research and Development Newsletter



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

# Editorial

## Welcome to the 34th edition of Innovation, our Trust's Research and Development newsletter.

**BOOK NOW:** Annual Research Forum 15 November, Horizon, Leeds.  
Book here: <https://goo.gl/ZcgZKj>

The R&D team has moved to Willow House, St Mary's Hospital. Email addresses and telephone numbers remain the same.

In this bumper edition, we have reports from 14 completed projects as follows:

- Consanguinity, cognition and connectivity in psychosis
- Understanding the impact of caring for a family member with Dementia
- EQUIP: Enhancing the Quality of User Involved Care Planning in Mental Health Services
- Upbeat: An evaluation of a mobile application for eating disorders
- What Works? in dementia training and education
- Lithium and hyperparathyroidism
- Sexual health service provision for people with serious mental illness
- Evaluation of psychological formulation meetings in R&R service
- Systemic family therapy vs treatment as usual for young people after self-harm
- National investigation into suicide in children and young people
- Exploring the experience of living with young onset dementia
- Evaluating the use of a collaborative dynamic risk assessment tool
- A service user and staff led evaluation of PD inpatient secure services
- Dynamic risk assessment within an inpatient forensic team

You can also read introductions from Satti Saggu and Diane Langthorne who joined the R&D team this year. Satti replaces Rebecca Hargate who is starting medical training and Diane replaces Damian Reynolds who took a promotion opportunity in primary care.

Additionally, Helen Phillips explains how work continues after the final research report, to implement and make more widely known, an assessment tool that was translated into British Sign Language. We also have the usual library training dates and research funding information.

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# Consanguinity, cognition and connectivity in psychosis

This study is based on families with multiple cases of schizophrenia whose parents are first cousins. Our assumption (hypothesis) is that such families increase the chances of finding single genes that can cause psychosis. They also provide the opportunity of exploring the links between genes, cognitive changes such as working memory deficits and associated brain circuits.

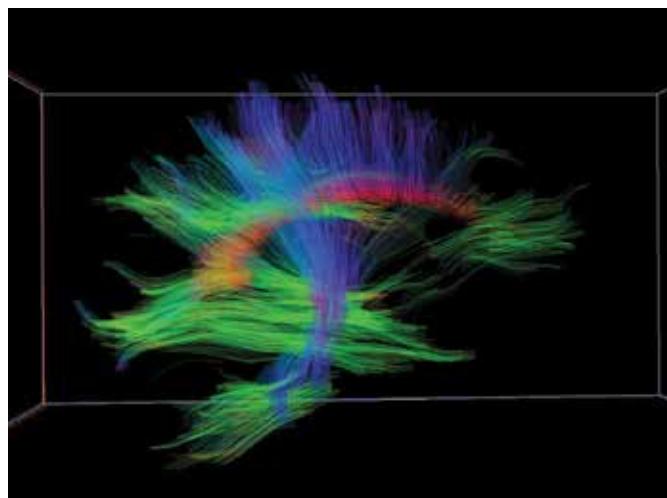
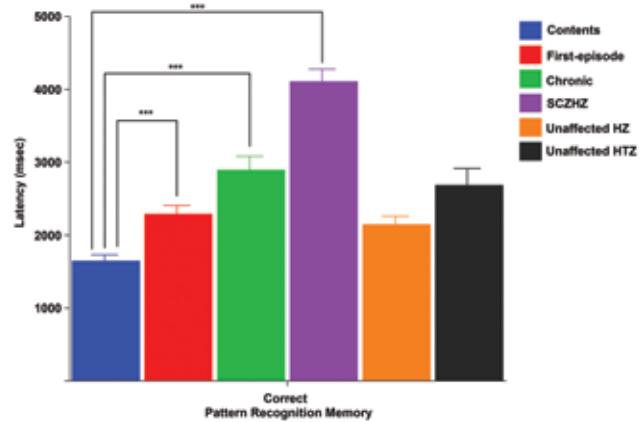
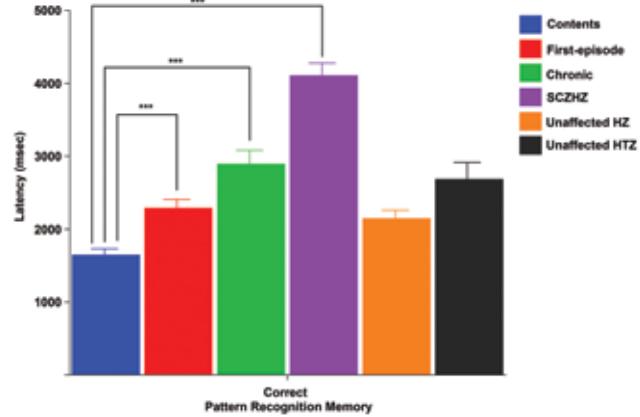
Members of an extended family with multiple cousin marriages and six cases of schizophrenia in one generation were included in this study and were investigated clinically, gene sequencing, neuropsychological testing and functional magnetic resonance imaging (fMRI). In this study our aim was to see if the brain areas serving the working memory activate differently in those carrying two copies (homozygous) of a set of genes on chromosome 13 and those with one copy (heterozygous), when they are performing working memory tasks and undergoing fMRI scanning.

We hypothesized that with increasing genetic loading, neural activation in dorsolateral – prefrontal parts of the brain would reduce in patients and homozygous unaffected relatives compared with heterozygous unaffected relatives and healthy controls.

On fMRI we found lower neural activation in dorsolateral prefrontal cortex and cingulate regions in patients and their unaffected homozygous relatives.

Diffusion tensor imaging, which studies the movement of water in nerve fibres, showed reduced connectivity in anterior cingulate regions of patients.

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# Understanding the impact of caring for a family member with Dementia

## Background and Objectives

Approximately half the care for people with dementia is provided by families. It is therefore imperative that research informs ways of maintaining such care. In this study, we propose that a needs-led approach can provide a useful, novel means of conceptualizing the impact of caring on the lives of family carers. Our aim was to develop and present a needs-led framework for understanding how providing care impacts on carers' fulfilment of needs.

## Design and Methods

In this qualitative study, we conducted 42 semi-structured interviews with a purposively diverse sample of family carers to generate nuanced contextualized accounts of how caring impacted on carers' lives. Our inductive thematic analysis focused upon asking: "What need is being impacted here?" in order to generate a needs-led framework for understanding.

## Results

Nine themes were widely endorsed. Each completed the sentence: "Being a carer impacts on fulfilling my need to/for....":

Freedom; feel close to my relative; feel in control of my life; be my own person; protect my relative; share/express my thoughts and feelings; take care of myself; feel connected to the people around me; get things done.

## Discussion and Implications

These needs echo those from other research areas, with relational needs emerging as particularly central. The needs-led approach offers a perspective that is able to capture both stresses and positive aspects of caregiving. We recommend that clinical interviewing using Socratic questioning to discover human needs that are being impacted by caring would provide a valuable starting point for care planning.

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### Other Researchers

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**Linda Clare, University of Exeter.**



# EQUIP: Enhancing the Quality of User Involvement in Mental Health Services

## Summary of Results

### Why did we do this research?

- Mental health service users and their carers want to be more involved in decisions about their care. Guidance tells us that user and carer involvement is important for improving care quality, satisfaction with health and care outcomes, and promoting recovery. However, research has shown that this involvement does not always happen, and people report feeling excluded and unsupported by services.
- The EQUIP programme of research aimed to address this by working with service users, carers and professionals to design and deliver a training programme for staff to improve service user and carer involvement in mental health care planning.

### What did we do during this project?

- A two-day training course was co-developed and co-delivered with service users and carers to improve service user and carer involvement in care planning. 350 health professionals, from 18 community mental health teams in 10 NHS Trusts in England received the training.
- We tested how well the training worked by measuring how involved people felt in their care before and after staff were trained. We compared these findings to feedback from people cared for by staff in 18 different community mental health teams who had not received the training.
- A total of 1286 service users and 90 carers took part in this study and shared their views on user and carer involvement in care planning.

- A further 54 participants (21 mental health professionals, 29 service users and 4 carers from 7 Mental Health Trusts in England) were interviewed to explore the organisational context in which care planning takes place.

## Our Key Messages

- The health professionals who took part told us that they liked the training they received, especially because it was jointly delivered by professionals, service users and carers.
- Although professionals were positive about the training, the results showed there was no difference in how involved people felt in their care 6 months after staff had received the training and no difference between people cared for by the trained and untrained teams.
- Interviews with staff about their experiences of receiving the training found that they recognised the importance of involvement and wanted to do this better. However, it was difficult for them to use the training in day-to-day practice due to organisational limitations. Examples included limited time to spend with service users and a lack of resources with which to help people.
- In order to successfully improve service user and carer involvement in mental health care planning we may need to focus on more than trying to change professional behaviours through training. It is likely that more resources and time and organisational commitment will be required to fully involve users and carers in care planning.

# Involved Care Planning

## EQUIP care planning resources

- We have worked with service users and carers to design a tool for NHS trusts to measure involvement in care planning. More information is available via the following link: [www.click2go.umip.com/i/coa/EQUIP.html](http://www.click2go.umip.com/i/coa/EQUIP.html)
- We have created animations and a leaflet to communicate information about care planning and being involved in care decisions. The animations are available via the EQUIP website [www.research.bmh.manchester.ac.uk/equip](http://www.research.bmh.manchester.ac.uk/equip)
- We have produced an accessible animated summary of our research findings and a video, co-produced with

our Service User and Carer Advisory Group, about co-production. You can view these on the EQUIP website and via our YouTube channel: [www.youtube.com/watch?v=PEjI3zq5FcQ](https://www.youtube.com/watch?v=PEjI3zq5FcQ)

The EQUIP team would like to thank all the service users, carers, professionals and NHS Trusts who dedicated their time to the study.

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# Upbeat: An evaluation of a mobile application for eating disorders

**This project was an evaluation of a mobile application 'Upbeat' developed by service users and staff of Yorkshire Centre for Eating Disorders.**

Clinicians considered themselves at least fairly experienced or confident, and most used apps quite often in their day to day lives. At work, WhatsApp was most popular, being seen as quick and easy, offering an advantage for patient communication. The majority of respondents did not worry about trusting an app with their data. While most respondents would be happy to find an app by searching the app stores or getting recommendations from a friend, when it comes to health apps some do search recommendations from a trusted knowledgeable source, including the NHS.

In terms of negative aspects of mHealth, respondents mentioned it can present a skewed view and an overwhelming amount of information, some of which is not written by experts or underpinned by evidence. People have changed expectations on how to communicate, and may be quicker and more likely to share private information. On the other hand they also expect more of the clinicians and may become reliant on technology, fuelling obsessive behaviours. Furthermore, some people may not want to or be able to use smart devices.

Regarding positive aspects of mHealth, foremost was its potential to be used anytime and anywhere, without being confined to office hours or spaces. This includes the ability to motivate and support as well as the ease to find, share and keep information. Other advantages include the ability to learn new information or views, self-monitor health and enjoy increased confidentiality.

Specific barriers for clinicians to use Upbeat included lack of confidence due to lack of knowledge and use. A related factor was perceived lack of user-friendliness of

the clinician portal, not being intuitive or mobile friendly, particularly compared to alternatives such as WhatsApp. Most respondents worried about the potential impact on their way of working, including how to use it optimally with patients, how to manage patient expectations and the resulting impact on caseload.

Advantages of Upbeat to clinicians comprised the ability to monitor and motivate as often as needed. Patient data can potentially be tracked in more detail and more reliably in between clinical sessions. This data would be useful to clinicians to help prepare and focus in a session, and discuss with colleagues. Respondents hoped Upbeat could free up time and allow them to offer additional continuous support.

Patients may encounter barriers to start using the app, and may require training and/or help from a clinician, not just for technical reasons but also to get them motivated and alleviate any concerns about reducing face to face contact. To ensure a patient's continued engagement, clinicians may need to monitor and motivate them. The app may not be suitable for all patients or may need personalisation, which would depend on the clinician's judgement. Two specific issues were brought up: inability to enter forgotten meals the next day and text-heavy not very engaging resources.

Potential benefits to patients include giving them more ownership, as they can self-monitor in an easier way than tracking in paper format, and offering an alternative way to communicate about thoughts and emotions. Patients may be more comfortable with digital communication in general, as this is seen as more relevant and normal, which hopefully encourages them to use it more.

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# What Works? in dementia training and education

Supporting health and care staff to have the right knowledge and skills to provide good quality care for people with dementia is a government priority. A number of policies and programmes over recent years have helped to increase awareness of the need for and the availability of dementia training, however little was known about what high quality, effective training looks like.

The What Works in dementia education and training? study was commissioned by the National Institute for Health Research Policy Research Programme on behalf of Health Education England, in order to explore the components of dementia education and training that leads to better outcomes.

We used Kirkpatrick's four level model for evaluating training which looks at learner reaction, learning, behaviour change, and the resultant outcomes for people with dementia and those who support them. The whole study involved four components including: 1) a systematic review of existing international literature 2) a national audit of dementia training currently being provided or commissioned, 3) a survey of staff who had undertaken dementia training to assess knowledge, attitudes and barriers and facilitators to implementation and 4) in-depth, mixed-methods case studies in health and social care organisations who responded to the national audit and demonstrated hallmarks of good practice.

We found that training that led to positive outcomes across the four Kirkpatrick levels was delivered face-to-face, was interactive, tailored to the service setting and role of learners and delivered by an experienced

training facilitator with clinical dementia experience. It was also at least half a day in length, with programmes that were longer producing better outcomes. There were a range of barriers to training implementation including a lack of time and resources, poor staff attitudes towards training and poor planning in terms of release of staff to attend training. Facilitators for training implementation included a supportive organisational culture and management, clear and strong leadership for dementia training and a whole systems approach that connected managers, trainers and learners.

We are sharing the results of the study at a number of national and international conferences, we are writing up papers for journals, we have produced a good practice audit tool for training providers and commissioners to use and we plan to produce a range of other ways of sharing the findings with people with dementia, carers, the general public and staff who are working in health and care services.

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# Lithium and hyperparathyroidism

A patient with high calcium levels, when it's a consequence of having a high level of the parathyroid hormone (or hyperparathyroidism), may present with a variety of symptoms.

This can include abnormal bone remodelling\* as a result of the increased parathyroid hormone, kidney stones secondary to high calcium levels, abdominal pain and constipation due to a calcium-induced slowing of the intestines, and depression as a result of persistently elevated calcium levels. As the mnemonic goes, "(painful) bones, (renal) stones, (abdominal) groans and (psychic) moans."

It is known that up to 15% of patients on lithium can develop a high calcium level. It is therefore important to monitor calcium levels in patients who have been taking lithium for Bipolar Affective Disorder long-term.

In a Swedish epidemiological cross-sectional study of patients who have been on lithium for 15 years or more, there was a point prevalence of 3.6% for persistent high calcium levels, surgically-verified increased parathyroid hormone of 2.7% and an observed incidence of high parathyroid hormone of 6.3%. Thirteen patients had their lithium stopped in this study to see if their calcium levels returned to normal, but all continued to have significantly increased calcium levels after a mean of 8.5 weeks.

It is suggested that lithium antagonises the body's calcium-sensing receptor, resulting in a higher calcium level being needed to suppress the extra parathyroid hormone coming from the parathyroid gland. It also acts directly on the renal tubules and bowel to increase calcium resorption independent

of parathyroid hormone effects on the kidneys.

There are case reports that show that the drug Cinacalcet has been used to treat patients with lithium-induced high parathyroid hormone levels successfully. Here, symptoms may be different to other forms of this condition, including normal serum phosphate, raised magnesium and mild bone loss/normal bone density.

The NICE guidance for Bipolar Affective Disorder states that when a person is taking lithium, their calcium levels should be monitored at baseline then every six months, along with the urea and electrolytes. An audit of lithium at the Trust showed that out of 47 patients on lithium, five

(11%) had not had a calcium level recorded in the last year. The remaining patients had calcium levels recorded within the normal range.

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Other Researchers:

**Dr Vikram Luthra, LYPFT, and Christopher Todd, Bradford District Care NHS Foundation Trust.**

\*Bone remodelling is a lifelong process where old bone is replaced with new bone.



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# Sexual health service provision for people with serious mental illness

## Background

Nurses in mental health settings avoid talking to consumers about sexual health concerns. It is unclear whether this avoidance prevents the provision of sexual health care.

## Objectives

To gather information about how mental health nurses respond to sexual health issues within their routine practice, what issues they address, and their view on their role in promoting sexual health for consumers.

## Design

A cross sectional study using an electronic survey questionnaire.

## Settings

The study occurred in four National Health Service Trusts in England and a national call for participants in Australia. Participants: Participants were nurse clinicians (n=303) who self-selected by completing surveys available via email and newsletters containing links to the survey.

## Methods

This is a cross sectional study consisting of an electronic survey questionnaire which was distributed to staff in the Trust and three other NHS mental health providers in Yorkshire. The results confirmed that mental health staff do not routinely include sexual health in their practice, are poorly prepared in knowing what to do with a sexual health issue, or what services to assist service users to access to. Mental health consumers experience high sexual health needs that potentially impact on health and recovery. Mental health staff are ideally placed to promote sexual health and refer service users to sexual health and family planning services. Training to improve the confidence and responsiveness of mental health staff regarding sexual health is an urgent need.

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# Evaluation of psychological formulation meetings

## Introduction

The Leeds Rehabilitation and Recovery Service (R&R) Integrated Care Pathway (ICP) stipulates that, in line with best practice guidelines regarding compassionate and psychologically informed care for people with a diagnosis of psychosis, a formulation meeting should take place within 4-6 weeks of each service-users' admission (JCP-MH, 2016; UK Schizophrenia Commission, 2012). The meetings are based on a cognitive interpersonal model, which involves exploration of how the service-user's life experiences may have shaped their core beliefs, interpersonal relationships and attempts to cope with their distress (Berry et al., 2009).

## Aim

This service evaluation was undertaken to evaluate the implementation and impact of psychological formulation\* meetings.

## Background

Preliminary research suggest that team psychological formulation meetings have a positive impact on therapeutic relationships\*\* (Berry et al., 2016a; Berry et al., 2016b; Cole et al., 2015; Hollingworth & Johnstone, 2014).

## Method

Three audio-recorded focus groups of approximately one hour each were conducted with staff from Asket Croft, Asket House and the Recovery Centre between August-September 2017. There were 18 participants in total; three psychologists and 15 nursing staff. The psychologists who facilitate the meetings were interviewed separately from the wider

team. The focus group data was analysed using Thematic Analysis\*\*\* (Braun & Clarke, 2006).

## Results

### A valued resource

Experiences of attending the meetings were "positive" due to the "welcoming" atmosphere and impact on their ability to engage with service-users therapeutically, such as by enhancing their "compassion, empathy and patience".

### Challenges to the usefulness of meetings

Challenges included the absence of the "key players" that know the service-user well, "last minute cancellations" and meetings not always being "timely" in the admission. Service-user perspectives were not always included in the development of the formulation and did not always have the resulting formulation feedback to them due to staff feeling "unclear" about how best to do this and "anxious" about managing any resulting distress.

### Lack of centrality to care

Participants discussed that formulation meetings tend to exist "in isolation" from day-to-day clinical practice, due to uncertainty about how to feedback formulations to service-users and integrate them with care plans.

### Wanting to make more of formulations

Participants wanted formulations to have a "greater impact on care", such as through feedback to the service-user, inclusion in care plans, longer meetings and introduction of "re-formulation" sessions later in the admission.

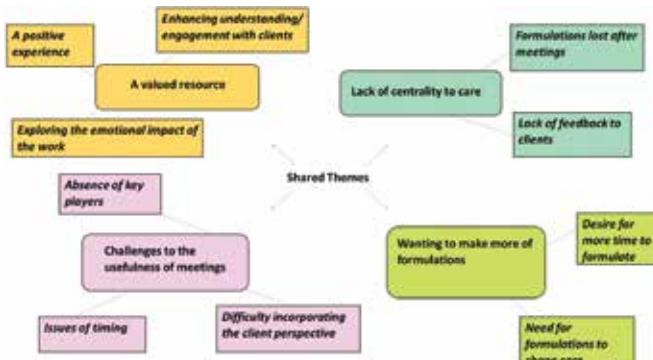
# on meetings in R&R service

## Conclusion

The findings suggest that the implementation of formulation meetings has been successful, as staff experience them as a valuable and beneficial resource. Some barriers to maximising the impact of formulations and potential solutions were also identified.

## Recommendations

- Team discussions and training to increase service-user involvement and embed formulations into routine clinical practice (e.g. use in supervision and review meetings).
- Clarify administrative procedures to make them timelier and avoid cancellations.
- Consider 1.5 hour meetings and introduction of re-formulation meetings.



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\* Psychological formulation is a hypothesis about a person's difficulties, which links theory with practice and guides the intervention

\*\* Therapeutic relationships refers to the relationship between a healthcare professional and a client (or patient).

\*\*\* Thematic analysis is a widely-used qualitative data analysis method that focuses on identifying patterned meaning across a dataset.



# Systemic family therapy vs treatment as usual for young people after self-harm

## Background

Self-harm in adolescents is common and repetition occurs in a high proportion of these cases. Scarce evidence exists for effectiveness of interventions to reduce self-harm.

## Methods

This pragmatic, multicentre, randomised controlled trial of family therapy versus treatment as usual was done at 40 UK Child and Adolescent Mental Health Services (CAMHS) centres. We recruited young people aged 11–17 years who had self-harmed at least twice and presented to CAMHS after self-harm. Participants were randomly assigned (1:1) to receive manualised family therapy delivered by trained and supervised family therapists or treatment as usual by local CAMHS. Participants and therapists were aware of treatment allocation; researchers were masked. The primary outcome was hospital attendance for repetition of self-harm in the 18 months after group assignment. Primary and safety analyses were done in the intention-to-treat population.

## Findings

Between Nov 23, 2009, and Dec 31, 2013, 3554 young people were screened and 832 eligible young people consented to participation and were randomly assigned to receive family therapy ( $n=415$ ) or treatment as usual ( $n=417$ ). Primary outcome data were available for 795 (96%) participants. Numbers of hospital attendances for repeat self-harm events were not significantly different between the groups (118 [28%] in the family therapy group vs 103 [25%] in the treatment as usual group; hazard ratio 1·14 [95% CI 0·87–1·49]  $p=0·33$ ). Similar numbers of

adverse events occurred in both groups (787 in the family therapy group vs 847 in the treatment as usual group).

## Interpretation

For adolescents referred to CAMHS after self-harm, having self-harmed at least once before, our family therapy intervention conferred no benefits over treatment as usual in reducing subsequent hospital attendance for self-harm. Clinicians are therefore still unable to recommend a clear, evidence-based intervention to reduce repeated self-harm in adolescents.

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### Other Researchers

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† Prof Kerfoot died in June, 2013.

The trial is registered at the ISRCTN registry, number ISRCTN59793150.



# Engaging with the Deaf Community

## Raising awareness of the British Sign Language Translation of the Strengths and Difficulties Questionnaire

During 2002 to 2003 the COMIC team translated the Strengths and Difficulties Questionnaire (SDQ) into British Sign Language (BSL) and successfully tested it in order to validate its use with the Deaf Community. The SDQ is the most widely used mental health screening questionnaire in the world (translated into 60 languages to date). The aim of this research was to give Deaf parents/carers and Deaf young people access to this questionnaire in their first language, British Sign Language, thus ensuring accurate reporting.

Prof Richard Ogden from the Department of Language and Linguistic Science at the University of York was a linguistic consultant on the original team. With Prof Barry Wright and Helen Phillips, he successfully applied for funding to enable the SDQ report to be translated into BSL to share within the Deaf community. The report had previously been written in English; however in this form it is inaccessible to the Deaf Community. Now funding has been secured, a summary of the report will be translated into BSL and publicised throughout the Deaf community and amongst practitioners allowing full access to the findings and increased awareness of this tool. The team have been awarded a grant from the Centre for Future Health – Knowledge exchange, impact and translation (KIT). The aims of this project are:

- Increasing awareness of BSL SDQ resources within the Deaf community, including teachers, parents and carers as well as Deaf children and young people themselves.

- Increased confidence among the Deaf community about the quality and reliability of the BSL SDQ resource.
- Increasing uptake of mental health services as a result of access to the BSL SDQ.
- Ongoing enhanced collaboration between the University and both the Deaf community and the providers of health services for the Deaf community.

The team are in the process of appointing a project officer who will be based in the COMIC team for six months, though employed through the University of York. The Project Officer will be working alongside a media company to produce the SDQ report into a BSL video then promoting this version amongst professionals and the Deaf community. We are hoping they will organise and attend events to share the BSL SDQ version and increase its profile. One such event we are hoping to organise is a 'Question Time' format event inviting MPs, Professionals and the Deaf community to discuss the SDQ and Deaf children and young people's mental health.

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# National investigation into suicide in children and young people

## Background

Suicide is the second leading cause of death among 15- 29 year olds worldwide accounting for 8% of all deaths. We established a national study combining multiple sources of information to investigate the frequency with which suicide is preceded by young person-specific antecedents of public concern.

## Method

A descriptive examination of suicide in a national sample of under 25s who died by suicide or undetermined death in England and Wales between January 2014 and December 2015. We obtained general population mortality data from the Office for National Statistics. We collected information about antecedents considered relevant to suicide from investigations by official bodies— coroner inquest hearings, child death investigations, criminal justice system reports, and serious untoward incident reports.

## Findings

We obtained antecedent information for 391 people aged under 25 who died by suicide during the study period. The number of suicides at each age rose steadily in the late teens and early 20s. Although under 20s and 20-24 year olds shared many antecedents, there was a changing pattern, reflecting the stresses experienced at different ages. Academic pressures and bullying were more common before suicide in under 20s, while workplace, housing and financial problems occurred more often in 20-24 year olds.

## Discussion

The circumstances that lead to suicide in young people often appear to follow a pattern of cumulative risk, with traumatic experiences in early life, a build up of adversity and high risk behaviours in adolescence and early adulthood, and a “final straw” event. Suicide prevention in children and young people is a role shared by front-line

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# Exploring the experience of living with young onset dementia

Research into the experiences of those with a diagnosis of young onset dementia is extremely limited and the research that does exist tends to be loss orientated. The current study aimed to explore the full spectrum of lived experience of those with young onset dementia, whilst considering the unique impact of diagnosis at a younger age and the possibility of personal growth.

Five individuals took part in semi-structured interviews within which they were invited to bring along anything that helped them to share their experiences. Each participants' transcribed interviews were then analysed using Interpretative Phenomenological Analysis\* (IPA). A group level analysis was conducted and superordinate and subordinate themes were identified.

Four superordinate themes emerged: 'Fear', 'Anger', 'Sadness', 'Contentment' from which a further thirteen subordinate themes were identified. The findings indicated that participants experienced feelings of fear and vulnerability in response to their diagnosis. Participants felt angry that they did not have a voice, not enough was being done for those with dementia and they were being stereotyped. Participants also spoke of a more depressive state of mind in which they grieved for their past self, experienced isolation and loneliness, and feelings of hopelessness and despair. Finally, participant's spoke of a sense of contentment in relation to a preserved self, a sense of living alongside their dementia and an desire to live in the present; making the most of the here and now.

The findings of the study were explored in relation to existing literature and psychological theory. This research highlighted the transitory nature of participants experiences as a result of multiple and repeated challenges to one's psychological equanimity. A critical appraisal of the strengths and limitations of this study were explored along with clinical implications. Future areas of research were also considered.

\* Interpretative Phenomenological Analysis  
- is an approach to psychological qualitative research with an idiographic focus, which means that it aims to offer insights into how a given person, in a given context, makes sense of a given phenomenon.

**Charlotte Berry, University of Leeds**

Supervised by:

**Carol Martin, University of Leeds and Jan Oyebode, Bradford University.**

## EXPLORING THE EXPERIENCE OF LIVING WITH YOUNG ONSET DEMENTIA

### SUMMARY

- This study shows some common experiences of people who are living with young onset dementia.
- We now know more about the anxieties people feel. These include fear of the diagnosis and fear of being vulnerable.
- We also know that some people with dementia, at times, feel angry about the situation they find themselves in and with others for not helping in the right way.
- One of the important things we discovered is that, even with dementia, people can enjoy life, living in the moment, and continuing with activities and relationships.
- It is hoped that these findings will be published in the near future and will go on to help people understand more about what it is really like to live with young onset dementia.

### METHOD

- Five people were interviewed about their experiences of living with young onset dementia.
- They were aged from their 40s to their 60s and had different types of dementia.
- I invited the people interviewed to bring along photos or objects to help tell their stories.
- The experiences that they spoke about were sorted into groups or 'themes'.

### RESULTS

The four main feelings that people spoke about were: fear, anger, sadness and contentment.

#### FEAR

- For some time before diagnosis, people felt confused and scared and wanted to know what was going on.
- After the diagnosis, people felt vulnerable around others in case they were taken advantage of. They sometimes felt they had to 'put on a mask' to keep themselves safe.
- People were scared about the future and wished they could get clear answers about what it would hold.
- People spoke about managing fear by trying to keep the symptoms of dementia at bay as much as possible.

#### SADNESS

- People felt the loss of their old selves, memories or roles. Some people felt nostalgic and spent time reminiscing about the time before they received their diagnosis.
- After their diagnosis, some people found that others stopped including them in social events as much as before. This made people feel isolated.
- Some people also felt very alone with their diagnosis as they felt others did not understand what it was like for them.
- People said that, on some days, living with dementia made them feel overwhelmed and hopeless.

#### CONTENTMENT

- People felt at peace when they realised that, despite the diagnosis, they were still themselves. They were still able to fill roles they had always filled and were valued by others around them.
- Some people reached a point where they were able to accept their diagnosis. They started finding new ways to manage their symptoms and learn to live alongside their dementia.
- People spoke about activities they did that allowed them to be 'in the moment' and forget about their dementia. Some examples included gardening, drawing, making music, and spending time with grandchildren.
- People had a strong desire to make the most of the here-and-now and found that they started to appreciate the present moment more than they had done before.

#### ANGER

- Some people were frustrated because they felt that sometimes they were not listened to by health professionals. They also felt that people in general didn't want to talk to them about their dementia.
- Some people were angry because they thought that not enough was being done to find a cure or to support people with their diagnosis.
- Some people felt angry that other people expected them to be less capable than they are. They felt annoyed that people expected them to fit an old-fashioned stereotype of someone with dementia.
- Some people were angry that others judged them for living well with dementia.



# Evaluating the use of a collaborative dynamic risk assessment tool

## Background

Forensic services have a responsibility to manage the risk of violence by their service users. This is typically done using structured professional judgement tools such as the HCR-20 and FACE risk assessment. These tools are primarily based on historical (static) risk factors and ultimately produce a categorical risk rating. Douglas and Skeem (2005) introduced the idea of risk state (opposed to risk status) and collated a number of dynamic (changeable) risk factors. The team at the Newsam Centre have used this model to develop a conversational tool to use with service users to facilitate a collaborative risk assessment. They also developed a framework to be used as part of community multidisciplinary team meetings to support the formulation of risk management plans.

### Aims:

To evaluate the service users' experience of the tool in terms of:

1. A comparison to previous experiences of risk assessment
2. Informing an understanding of risk
3. Linking to personal experience and meaning
4. Contributing to an understanding of staff-led risk management

## Methodology

The project recruited eight inpatient staff, seven community staff and six inpatient service users, who engaged in semi-structured interviews which were then subject to thematic analysis (Braun and Clark, 2006)

### Main Themes:

- Task-focused: a risk assessment is an obligatory service-led task to be completed through information gathering on multiple occasions.

- "To monitor my position, you know, mentally, emotionally and physically. To see what stage I'm at." – Participant 1
- Relationship-focused: the conversational style (communication and setting) of the discussion contributed to a positive experience.
- "Just to be upfront with the patient, that's all we are asking for" – Participant 5
- The Past: a focus on previous offending can elicit feelings of vulnerability but allows for reflection on repeating patterns of behaviour
- "Keep digging into my past ... they're attacking me with my past" – Participant 6
- Outcome: risk assessment can inform personal decision making but has no effect at a staff/service level.
- "I didn't see no difference [after the risk discussion]" – Participant 6

## Recommendations

1. Self-efficacy: Consider ways of reducing a sense of 'service demand'
2. Personalisation: To include blanks circles
3. Linking to management: to connect to discussions to decision making

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Supervised by:

**Kerry Hinsby and Alex Brooks,  
LYPFT**

### References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.
- Douglas, K. S., & Skeem, J. L. (2005). Violence risk assessment: getting specific about being dynamic. Psychology, Public Policy, and Law, 11(3), 347.

# Hello my name is ...

Satbir (Satti) Saggu, I joined the trust in February 2018 as a research programme manager. I previously worked in an acute setting for Bradford Teaching Hospitals NHS Foundation Trust as a research project manager. During the 3 years spent in this role I managed two National Institute for Health Research (NIHR) funded grants.

The first NIHR study examined the utility of a Delirium Observational Screening Scale in a care home setting. Research evidence demonstrates that the early recognition and therefore treatment of patients with delirium improves health outcomes and secondary care use.

The second project set out to determine the drivers for cost efficiencies in a UK community hospital setting. This proposal consisted of four inter-related sub studies which included: a health economics analysis, a national survey of community hospitals, a qualitative study, and the implementation of a toolkit for commissioners.

I have over 10 years' experience of clinical research in the NHS, and have a particular interest in the mobilisation of research knowledge. This is when research evidence is used to shape and change clinical practice. Whilst working for the West Yorkshire Commissioning Support Unit in 2013, I developed a series of fora that facilitated the use of research evidence in primary care commissioning decisions.

I also feel very strongly about addressing local health care and clinical priorities through high quality locally developed research.

**Satbir Saggu, LYPFT,**  
[satbir.saggu1@nhs.net](mailto:satbir.saggu1@nhs.net)

Diane Langthorne, I was recently appointed as a Research Assistant in the Trust's research and development team.

I completed an undergraduate degree in psychology then went on to work as a health care assistant and an assistant psychologist. I supported patients in a secure hospital with personality disorders and psychosis through facilitating group psycho education and mindfulness.

I then trained as a Psychological Wellbeing Practitioner. I learnt to use guided self-help based on the principles of cognitive behavioural therapy to support people with anxiety and depression.

Following this I wanted to improve my research skills, so I am currently finishing my master's degree in research in psychology. My research throughout the degree focussed on how sleep can affect different types of memory. I chose this topic as sleep disturbances and the problems that this can cause are often closely linked with mental health difficulties.

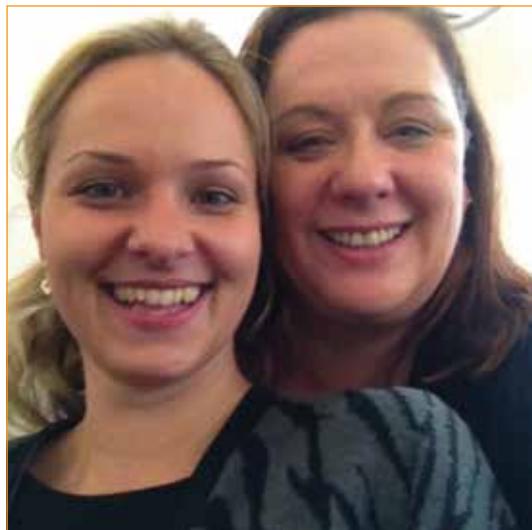
I am looking forward to starting the Research Assistant post full time once my degree is finished as it combines my previous experience of working in mental health with the skills I gained in my research degree. I am also looking forward to the diverse range of people that I will work with, and the opportunity to be involved in research that will hopefully contribute towards the development of future mental health services offered by the NHS.

**Diane Langthorne, LYPFT,**  
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# A service user and staff led evaluation

NHS England have commissioned a strategic review of personality disorder (PD) specific low and medium secure inpatient services for men and women within the Yorkshire and Humber region as well as a mapping of available community provision. The key task of the strategic review will be make key recommendations as part of a



3-5 year strategic implementation plan with the aim to help develop best practice inpatient care and the development of community pathways that better meet the needs of service users. Crucial to the success of the strategic review is that we consult and gather views, and better understand the experiences, of all key stakeholders including service users, staff and senior clinical leaders within such services.

We were tasked with gaining a better understanding of current practices and pathways through engagement and discussion with service users and staff, as well as to better understand the needs of service users and the workforce.

## Initial themes from service user included:

- **Experiences in the community:** Vast majority of people felt they had little or no support in the community prior to hospital admission.

- **Experience of different types of wards:** Main theme was that people had often been moved to a PD specific ward due to a lack of progress on mixed diagnosis wards
- **Differences between PD specific and mixed diagnosis wards:** People generally found mixed diagnosis wards to be busy, unsettled and unpredictable compared to PD specific wards. Majority of people expressed that they would rather be cared for on PD specific wards.
- **Needs at point of admission to hospital:** People were often not understanding of their own needs at point of admission and described as often feeling chaotic, living chaotic lifestyles and needing help although difficult to identify at the time.
- **How useful was hospital:** People described development of relationships and working collaboratively with their clinical team as important as well as learning skills to manage emotions.
- **Contact with community whilst in hospital:** Inconsistent contact with care coordinators and case managers highlighted.
- **Helpful experiences in PD specific wards:** Need for structure and boundaries with high levels of activities.
- **Unhelpful experiences in PD specific wards:** In general people struggled with unpredictable behaviour and staff shortages which led to inconsistencies in approach.
- **Planning a successful discharge:** People identified requiring placements in the community that were stable and safe.

## Main themes for staff included:

- Mixed staff group in terms of experience of PD specific work.
- More demand on staff time in PD specific wards and the importance of structure,

# Inpatient secure services

boundaries and constancy highlighted. More opportunities for staff training felt to be available on PD specific wards.

- Often staff had not chosen to work on PD specific wards and noted difficulties in recruitment and retention.
- Staff highlighted service user's apparent fluctuating engagement and motivation as challenging alongside maintaining consistent interpersonal boundaries.
- Staff described that PD specific wards were 'specialist' due to the type of psychological interventions available.
- Importance of identifying a clinical pathway on admission and planning for

the required interventions as important considerations.

- Staff support varied within the different services.
- Need for informed and accurate Access assessments prior to admission noted.
- Collaborative risk and safety management required

**Mark Naylor, LYPFT,**  
[marknaylor@nhs.net](mailto:marknaylor@nhs.net)

Other Researchers:

**Holly Cade and Jo Harris, LYPFT (pictured)**

## Dynamic risk assessment within an inpatient forensic team

This service evaluation project was commissioned and supervised by Dr. Alex Brooks and Dr. Kerry Hinsby, who are Clinical Psychologists and both work within the adult forensic service at the Newsam Centre, in Leeds.

The psychology team at the Newsam Centre have created a collaborative risk assessment process and 'circles' tool based on dynamic risk factors. Service requirements are that every individual must have a risk assessment and the Leeds service currently uses a structured professional judgement tool to do this. However, several of the inpatient staff have also been using the collaborative dynamic risk assessment process and the circles tool that has been created, in addition to the structured tool.

The aim of the project was to gather staff's opinions and experiences of participating in the collaborative dynamic risk assessment process and to get suggestions for how it could be improved. Eight clinicians from across the inpatient wards were interviewed regarding the experiences of conducting

collaborative risk assessments using the circles tool.

The results highlighted the strengths and limitations of the collaborative dynamic risk assessment process. Overall, clinicians recounted positive experiences and opinions of the process and circles tool. Their experiences reflected those in the current literature, where there is a draw to move towards risk formulation. Recommendations for improvements were put forward, such as increased training and a peer supervision space, for clinicians to discuss their experiences and learn from each other.

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# Finding the Evidence - training dates for your diary

The following courses are free to all Trust staff.

Alongside the schedule of courses below, the library runs a number of sessions on request. These include:

**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 get further help.

**Current awareness** – Aimed at staff who wish to set up and use email and RSS alerts and feeds to support their practice or professional development.

**E-journals and e-books** – Aimed at staff who wish to use e-journals and e-books to support their practice or professional development.

**Google and beyond** – Aimed at staff who wish to gain skills in searching Google for information to support their work, practice or professional development.

**Healthcare databases** – This course focuses on searching healthcare databases.

**NHS OpenAthens account** – Aimed at staff who wish to better understand their Athens account and learn about the e-resources that are available to them.

NOV				
5	Mon	10.00-12.00	Google and Beyond	IT Suite, Mount Annexe
14	Wed	13.30-15.30	Critical Appraisal	IT Suite, Mount Annexe
15	Thur	09:00-16.30	Finding and Appraising the evidence	Library and Evidence Research Centre, LGI
20	Tues	10.00-12.00	Google and Beyond	Library and Evidence Research Centre, LGI
28	Wed	13.30-16.00	Healthcare databases	Morley Health Centre
29	Thur	09:30-12:00	Healthcare databases	Library & Evidence Research Centre, LGI

DEC				
05	Wed	14.00-16.00	Critical Appraisal	Stockdale House, MR1
06	Thur	13:00-15:00	Google and Beyond	Library and Evidence Research Centre, LGI
07	Fri	09:00-16.30	Finding and Appraising the evidence	Library & Evidence Research Centre, LGI
13	Thur	10.00-12.00	Google & Beyond	IT Suite, Mount Annexe
17	Mon	10.00-12.30	Healthcare databases	IT Suite, Mount Annexe
19	Wed	10:00-12:30	Healthcare databases	Library & Evidence Research Centre, LGI

The 'Current awareness' and 'Making the most of your Athens account' courses are now offered on request as a tutorial. Please contact [libraryandknowledgeservices.lypft@nhs.net](mailto:libraryandknowledgeservices.lypft@nhs.net) for more details.

For more information about any of our library courses and to book your place, visit [www.leedslibraries.nhs.uk/home/](http://www.leedslibraries.nhs.uk/home/).

# National Institute for Health Research (NIHR) funding opportunities

The NIHR Clinical Research Network Portfolio is a database of studies that shows national clinical research study activity. 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 help with study promotion, set-up, recruitment, and follow-up.

Funding stream	Deadline
Efficacy and Mechanism Evaluation (EME)	Primary Research (Stage 1) - 06 Nov, 1pm
Health Services and Delivery Research (HS&DR)	Primary Research - 06 Nov, 1pm
	Commissioned Research - 06 Nov, 1pm
	Primary Research (Stage 1) - 06 Nov, 1pm
	Primary Research (Stage 1) - 05 Dec, 1pm
Health Technology Assessment (HTA)	Researcher-led: Evidence synthesis and Primary Research (Stage 1) - 29 Aug, 1pm
	Mental health themed call: Evidence synthesis and Primary Research - 29 Aug, 1pm
Programme Grants for Applied Research	Competition 27 (Stage 2) - 28 Nov, 1pm
Programme Development Grants	Competition 23 - 28 Nov, 1pm
Public Health Research (PHR)	Commissioned: Primary Research 06 Nov, 1pm
	Rapid Funding Scheme 31 Dec, 1pm
Research for Patient Benefit (RfPB)	Competition 36 (Stage 2) - TBC Nov

## 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. Invention for innovation (i4i): Funds research into advanced healthcare technologies and interventions for increased patient benefit in areas of existing or emerging clinical need.
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. 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.
7. Research for Patient Benefit (RfPB): Generates research evidence to improve, expand and strengthen the way that healthcare is delivered for patients, the public and the NHS.

For further details about funding opportunities through the NIHR, visit: [www.nihr.ac.uk/about-us/how-we-are-managed/boards-and-panels/programme-boards-and-panels/](http://www.nihr.ac.uk/about-us/how-we-are-managed/boards-and-panels/programme-boards-and-panels/)

# 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. As such we welcome any articles or suggestions for future editions.

## For more information please contact:

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# Research Forum 2018

You are invited to join us for the annual Research Forum on  
**Thursday 15th November 2018\***  
**Horizon Leeds, 2 Brewery Wharf, Kendall Street, Leeds LS10 1JR**

The Research Forum is an annual 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 previous year.

**TO BOOK A PLACE:** Please book online at the following address:  
<https://goo.gl/ZcgZKj>

**CALL FOR POSTERS:** Have you been running a research project within the Trust? Showcase it at the forum - poster prizes available! Complete the online form at the following address: <https://goo.gl/AEYbd9>

Follow the event on twitter using the hashtag #LYPFTResearch18

\*All-day event – buffet lunch provided