Participation in life in advanced older age

By Dr Paul Sugarhood, Occupational Therapist, Extended Primary Care Services

Occupational therapists in Community Health Newham work in various multidisciplinary teams, where the focus is on avoiding hospital admission, preventing or delaying the need for institutional care and maximising independence in activities of daily living. With the ageing population, we increasingly receive referrals for older people, and in particular ‘older’ older people aged in their 80s and 90s.

Several years ago we were searching for outcome measures that could be used to measure the contribution of occupational therapy. This made us think more deeply than usual and ask: what are we and our clients actually trying to achieve?

Several measures that seemed promising (e.g. Impact on Participation and Autonomy, Australian Therapy Outcome Measures) were based on the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF, see figure 1). The ICF conceptualises health as the outcome of a dynamic interaction between an individual and their environment. It proposes that the components of functioning and disability are 1) body structures and functions, 2) activity and 3) participation, representing functioning successively “at the level of body or body part, the whole person, and the whole person in a social context”.

It has been argued that the participation level should be the ultimate goal of rehabilitation, and in particular occupational therapy. The concept is important for occupational therapy because of the profession’s concern with improving health and wellbeing by enabling people to overcome barriers to participation in the occupations of everyday life.

However, the ICF provides only a very basic definition of participation — “involvement in a life situation” — and a list of nine classification domains (e.g. self-care, domestic life, work and education). When we tried ICF-based outcome measures with our patients in advanced older age, they scored very poorly, often because they completed fewer activities in a typical day or were no longer involved in paid employment or education. This was despite many reporting satisfaction with their involvement in life.

So, do very old people necessarily participate less in life? Or were we missing what participation might mean in advanced older age?

My doctoral thesis therefore asked the question: “What does participation mean from the perspectives of older people aged over 80 years who experience functional decline or disability?” Using grounded theory and ethnography, the study recruited participants aged 81 to 96 years from a wide variety of ethnic, cultural and social backgrounds, home situations, medical diagnoses and levels of functional impairment.

Participation as enacting values: an adaptive process

The main finding was that participation was not experienced as an objective list of daily activities or social roles, or as frequencies that such activities or roles were performed. Rather, participation was experienced through a set of values. Values were the means through which participation was interpreted. The greater the congruence between the daily experiences of the person and their values, the greater the sense of participation.

Despite great heterogeneity, seven commonly held and enacted values were:

- Connecting with others. Almost universally, this was what mattered most and was most highly valued. Feeling linked to other people could be achieved directly in a social situation, by jointly performing an activity with others, through belonging to a family or other social group, or simply by feeling a connection to the outside world (e.g. sitting by a window watching people walk past in the street).

- Maintaining autonomy. There were two aspects to autonomy. First, the ability to act as one wished, to do the things one wanted to do. Second, the ability to make decisions for oneself without feeling overly constrained by external influences. Both types of autonomy were often referred to as being “independent”.

- Affirming abilities. Despite much discussion of physical and functional decline, and what could no longer be done or participated in, value was placed on affirming abilities that the person still had and ways moral or ethical beliefs of a person about what they perceived to be important, worthwhile, right or good.

It was through the enacting of values held by the person that he or she felt they were participating and being involved in life. Values provided the motivation for specific ways of participating, guided actions and behaviours, and were the means through which participation was interpreted. The greater the congruence between daily experiences of the person and their values, the greater the sense of participation.

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Participation in life in advanced older age

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of participating in the here and now. What was valued
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Keeping useful was achieved by doing things for or helping others, giving something in return for

Building on success - a new initiative for ELF

Researchers and clinicians from City University London, East London NHS Foundation Trust (ELFT), the Bizzard Institute Centre for Primary Care and Public Health, and Queen Mary University London have been awarded nearly £300,000 from Barts Charity to investigate diabetes care in people with severe mental illness.

People with severe mental illness (SMI) are twice as likely to develop diabetes compared with the general population. As a result, the study will seek to service users and healthcare professionals to gain a greater understanding of the views of people with SMI regarding the management of their diabetes.

Developed in consultation with clinicians, people with diabetes and severe mental illness, and members of Service User and Carer Group Advisors in Research (SUGAR), the researchers aim to interview 15 service users with diabetes and SMI, and 15 health professionals from primary, secondary and community care. This will enable the team to explore:

1. what aspect of their diabetes service users with SMI find most difficult to manage;
2. the barriers and facilitators to enabling them to manage their diabetes;
3. how healthcare professionals’ views about how best to promote self-management among service users who have diabetes and SMI.

Initial work has begun with the bulk of interviews to be conducted by 2015 and results are expected in July 2015.

Lead investigator Professor Alan Simpson, who heads the Centre for Mental Health Research at City University, said: “Self-management of diabetes is complex and the demands of managing diabetes when also living with mental illness present additional challenges for both service users and healthcare professionals.

“Increasingly, people with diabetes are being supported to self-manage their condition and treatment but very few studies include people who also have mental illness. In this study we hope that the work will inform the development of appropriate self-management education for people with diabetes and SMI. We need to better understand the difficulties people experience and what they find helpful as well as asking health professionals what they think about how best to deliver diabetes care for this population.”

The team involved in the study are Alan Simpson, Kathie Mulligan, Hayley McDermid, Mark Haddad, Chris Foxid, Julia White and Norwich. Haddad, Chris Flood, Julia Jones, Noeleen Hilton, Jackie Chapman and Sally Hull.

Upcoming Events

Research Training Sessions

The Academic Unit at the Newham Centre for Mental Health holds fortnightly training sessions on a variety of topics to those undertaking research in the NHS.

The training is held from 11:00-12:00 on a Wednesday in the Lecture Theatre; for more information, contact Hana Pavlickova by email at Hana.Pavlickova@eastlondon.nhs.uk

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<th>Date</th>
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<td>11:00</td>
<td>Early Psychiatric Rating Scale</td>
<td>Domenico Giasco</td>
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<td>18 February</td>
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<td>Twitter within research</td>
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<td>25 February</td>
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<td>Psychological testing</td>
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<td>11 March</td>
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<td>Qualitative Interviewing</td>
<td>Winnie Chow</td>
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Research Assistant Working Party

William Harvey Day is the annual research day for Barts and the London School of Medicine and Dentistry, part of Queen Mary University of London. First started in 1991, it is an opportunity to celebrate innovation and expertise in research. As well as the lecture series, posters of work carried out within the School are shown on the day and there is a competition for internal contributions. Hana Pavlickova of the Unit for Social and Community Psychiatry presented a poster on the NARSIT (Flank Financial Incentives for Adherence to Treatment: does the effect disappear over time?) which won a prize for the ‘Research Impact’ category.

USCPJOINS TWITTER

Follow the latest research from the Unit for Social and Community Psychiatry, Newham Centre for Mental Health, a WHO collaborating centre for mental health services development on twitter @LdnPsychPctELF

Study to investigate diabetes care in people with severe mental illness

By Frank Röthlich

Associate Medical Director Research & Innovation

In the NHS we are all aware of the approaches to learning from absence incident. We regularly report these incidents, develop action plans and identify learning to avoid similar events happening in the future. There is however no similar way of capturing the good practice that regularly happens apart from celebrating success in delivering statutory milestones and achieving performance targets. There are surprisingly few systematic learning methods in place that would allow us to share findings from successful clinical work related to individual patients, small groups or case series. In research terms, those scenarios feature in the literature as case studies, often providing meaningful insights into successful and creative clinical procedures, processes, engagement, innovations and treatments. Those findings are often the building blocks for hypothesis based cohort and subsequently controlled clinical trials (research cycle).

Serious Good Practice

A new initiative has been launched, aimed at sharing learning and good clinical practice across the Trust and to develop the skill base for writing about and publish case studies. All staff members are invited to share examples of good practice, clinical success stories and interesting case studies.

What was valued was a sense of mastery and pride that one was still a capable and effective actor – at least in some ways and on some occasions – and not only a spectator or person requiring care and support.

Doing the best you can. Great value was placed on doing one’s best to participate and be involved in life. There were two main aspects. First, trying or working hard to participate, which involved putting in effort (often physical or mental) to overcome obstacles or adversity and so perform valued activities. Second, participants tried to make the best of a difficult or bad situation. This involved accepting that current participation might not be ideal, and so one just had to get on with it the best one could.

Being useful. Participants wanted to be useful, to have a sense of importance by adding something to society, both within and outside their family and local community. While this was often difficult when faced with poor health or functional decline, the desire to be useful remained strong. Enacting the value of being useful was achieved by doing things for or helping others, giving something in return for help received, taking responsibility for something, or being a figure of respect.

Maintaining self-identity. The need for a sense of continuity with the past was frequently evident, with an orientation back to the past rather than forwards to the future. Value was placed on maintaining self-identity, on ways of participating in life that preserved a sense of who the person had been and still was. This could be achieved by continuing to pursue the same interests or fulfilling the same life roles as in the past (even if in an altered way), using skills and experience from the past in the present and, perhaps most commonly, interpreting the present through reflection on the past.

Pursuing interests. Interests were activities or ways of spending time that the person found stimulating, enjoyable, satisfying or fulfilling. A wide range of interests were mentioned, relating to hobbies or leisure activities, work and career, family or community roles and cultural or religious affiliations.

Participation in advanced older age was not, however, simply a continued enacting of values in the same way as had happened earlier in life. Rather, it was often challenged by deteriorating health, losses (e.g. of people, life roles) and environmental influences.

The research participants adapted (or not) to overcome these challenges by 1) interpreting their situation and thinking about things in a different way, and 2) selecting which forms of participation to engage in and how they were performed. For example, there was a tendency to move from pursuing more physically demanding forms of participation out of the home to those which were mentally stimulating, contemplative, sedentary and based in the home.

Implications for practice

To address participation, values must be considered. The patient-professional encounter should include dialogue through which an individual’s values and preferences are discovered. Interventions to promote participation might be most effective if based on these values and aimed at enabling the person to enact them in some way.

The seven values described above could act as a sensitising guide when working with very old people.

Connecting with others appears to be what matters most and is most highly valued. It might be that most attention should be paid to feelings of connection and belonging, interpersonal relationships and the social environment.

It is possible to gain access to a patient’s values – what matters to them. Values relate to particular events, people and objects and stem from resolved or repressed issues, and the challenges of everyday living. Discussion of events, people and objects therefore can enable identification of the values which, for each individual, motivate participation.

Health and social care professionals might be facilitated in gaining access to values given that 1) values tend to be recognised and articulated most commonly when challenged in some way, and 2) clinical encounters with very old people often occur during such periods of change and challenge.

There is a tendency in current occupational therapy and rehabilitation practice with very old people to focus on improving performance of activities, of optimising abilities and compensating for deficits. Less attention is paid to interpretive processes of accepting and coming to terms with challenges to participation. Rather than focusing only on changing the reality of participation for patients, might there also be a role for clinicians in helping patients to re-define their expectations?

Finally, although promoting participation might not be the stated objective of services for very old people, many do already address the issue. For example, occupational therapy interventions frequently take place in patients’ own homes and involve in-depth discussion of a person’s priorities. Such practices should be valued and expanded by building affiliation to participation is to be addressed and the goal of patients being optimally involved in life achieved.
Developing a positive psychology app for common mental health conditions

Sophie Walsh is a PhD student with the London NHS Foundation Trust to develop a new intervention for mental health nurses. This will use positive psychology which focuses on increasing life satisfaction and happiness and aims to promote wellbeing rather than fixing problems. An example is the gratitude diaries, a daily diary recording three things one is grateful for and why. This approach is quite different to symptom-focused treatments and therefore might appeal to those who do not take up current treatments. The intervention will be delivered as a smartphone application (an ‘app’) for people in primary care seeking help for anxiety, depression, so that many people can access it, where and when they want to.

The research intends to discover people’s views and opinions of positive psychology, which patients could be targeted, and how to promote the treatment.

Positive psychology will then be discussed in group interviews with 20 patients and 12 healthcare professionals from primary care. An app will then be developed and ten people will try to check if it is user-friendly. Finally, a small study with 30 people in primary care will provide evidence on information on how acceptable and useful the app is. These small studies are important, as they form the basis for future studies to test the effectiveness of the app on a larger scale. As this project is a PhD, it will be ongoing until September 2017. Sophie, the PhD student said, “I am very pleased to be working on a project which is going to try a new way of treating anxiety and depression. It will be great to get people involved in thinking about how to design the intervention and I am hoping this will result in a user-friendly, relevant intervention.” Sophie is a student at Queen Mary University London and is being supervised by Professors Stefan Pride, from the Unit for Social and Community Psychiatry, and Stephanie Taylor, from the Centre for Primary Care and Public Health.

If you are interested in finding out more about the project, such as how to get involved with the user-reference group, or would like any other details please contact Sophie on sophie.walsh@northy-london.nhs.uk.

By Dr Hugh Grant-Petekuen, General Adult Psychiatry

In 2011, following several serious concerns in the media, and a letter written to the Royal College of Psychiatrists by concerned doctors (including myself), a ‘working group on the mental health of asylum seekers’ was created to improve a longstanding interest in human rights and supporting victims of torture. I applied to the President of the College and gained a place as a member of the group. In the last three years we have written two reports, responded to Government and European level enquiries relating to refugee rights, held focus groups and advocated to improve and support asylum seekers in this area.

The most concerning area for the group was, and remains, mental health care in Immigration Removal Centres (IRCs). In November 2014 I was lead author on an editorial published in the British Medical Journal. We were prompted to write an editorial as, in late 2014, responsibility for healthcare in IRCs was transferred from the Home Office to the Department of Health. As a result there are now a large number of healthcare providers in IRCs, including one NHS Foundation trust.

Background to Immigration Removal Centres

The number of people held in IRCs in the UK has steadily increased over the last ten years, with a total of over 30,000 held in 2013. At any one time up to 3,000 people can be detained in one of thirteen IRCs. Although immigration detention is for administrative purposes (to process an asylum application or to facilitate removal from the UK), research has shown that detainees and staff both view it as punitive. The UK is one of the few countries in the world to have no time limit on the duration of detention, and detainees can remain in limbo for several years, not knowing their ultimate fate.

The standard of healthcare within centres in England is a serious cause for concern. Such evidence exists indicates that detention can harm mental health, especially for people with pre-existing mental health problems such as post-traumatic stress disorder. A systematic review of 10 studies investigating the effect of immigration detention identified high levels of mental health problems among detainees. Time spent in detention was shown to be positively associated with the severity of mental health problems, and detention has been linked to increased rates of mental health problems amongst detainees. Time spent in detention was shown to be positively associated with the severity of mental health problems, and detention has been linked to increased rates of mental health problems amongst detainees.

The needs of detainees are often not identified, and in treatment often experience interruptions in care. No effective safeguards exist to prevent vulnerable people – for example, those who have been tortured – from being detained.

System Failures

A joint inspection report by Her Majesty’s Inspectorate of Prisons and the independent inspector of borders and immigration in 2012 found ‘little evidence of the effectiveness of Detention Centre procedures, which are supposed to provide safeguards for vulnerable detainees, including those who have mental ill-treats.” This follows a report in 2011 raising concerns at Harmondsworth IRC that “Mental health needs were under identified and the inpatient department was staffed by themselves as a group of music therapists (a manual) and see if it is effective.

Mental health care today in Immigration Removal Centres

International organisations, non-governmental organisations, and the law courts have repeatedly criticized both the immigration detention of mentally ill people and the conditions in which detainees are held. The needs of detainees are often not identified, and in treatment often experience interruptions in care. No effective safeguards exist to prevent vulnerable people – for example, those who have been tortured – from being detained.

After the Immigration Removal Centres were transferred from the Home Office to the Department of Health in 2014, a joint statement issued by NHS England and the Home Office gave an assurance that “NHS England would ‘actively promote the rights and welfare of prisoners’ as ‘guaranteed by the NHS Constitution’.” As a working group we called for the Home Office to urgently make steps to ensure detainees are screened for mental health problems and that all facilities are under its umbrella to maintain the standards of care expected of the NHS. Asylum seekers are often highly vulnerable, particularly if they have mental health disorders; we have a professional duty of care to ensure that their needs are appropriately met. The evidence is overwhelming from across the globe: immigration detention can be highly detrimental to both physical and mental health.

Many alternatives to immigration detention exist, and these should be explored before vulnerable people are placed in such facilities. Given an increasingly inflammatory media debate about immigration and asylum seekers the medical profession must ensure that it does not become complicit in a system that undermines protection over refugees and asylum seekers.

Rights (the prohibition of torture). The court described the failures of the centre to apply and comply with the applicable policies ‘as willful and grossly negligent.’ There have now been six breaches of Article 3 in less than three years, all related to the provision of mental healthcare. This means that the provision of mental healthcare in detention centres has been found to, not merely be poor but to constitute inhuman and degrading treatment – an unprecedented finding for any UK institution.

In addition to these established cases of sensitive neglect and violation of human rights many former detainees have alleged physical or verbal abuse by staff. Allegations of endemic sexual abuse and exploitation of vulnerable women are currently under investigation.

Transfer of care

With the imminent transfer from the Home Office to the Department of Health a joint statement issued in November 2013 by NHS England and the Home Office would “actively promote the rights and welfare of prisoners” as “guaranteed by the NHS Constitution.” As a working group we called for the Home Office to urgently make steps to ensure detainees are screened for mental health problems and that all facilities are under its umbrella to maintain the standards of care expected of the NHS. Asylum seekers are often highly vulnerable, particularly if they have mental health disorders; we have a professional duty of care to ensure that their needs are appropriately met. The evidence is overwhelming from across the globe: immigration detention can be highly detrimental to both physical and mental health.

Many alternatives to immigration detention exist, and these should be explored before vulnerable people are placed in such facilities. Given an increasingly inflammatory media debate about immigration and asylum seekers the medical profession must ensure that it does not become complicit in a system that undermines protection over refugees and asylum seekers.

The HEE/NHS Clinical Lectureship Scheme represents the early post-doctoral element of the Programme. A Clinical Lectureship awards the holder a significant contribution to clinical practice whilst supporting their development as a clinical academic leader.

With the support of the East London NHS Foundation Trust and Queen Mary University of London, Dr Carr will develop, refine and test intensive group music therapy for acute adult psychiatric inpatients.

Music therapy can reduce mental illness symptoms and may be an important part of inpatient care. Hospital stays are short, so frequent sessions are needed to make a difference. Her previous research found how intensive group music therapy can be provided to appeal to patients and give positive experiences. To put these findings into practice, the next step will be to develop guidance for music therapists (a manual) and see if it is effective. This research will develop guidelines/training and run a small study to prepare for a larger effectiveness study. This will improve music therapy practice and care for inpatients.

Dr Catherine Carr awarded NIHR/HEE Clinical Lectureship

Music Therapist Catherine Carr has been awarded a National Institute for Health Research (NIHR) / Health Education England (HEE) Clinical Lectureship funded through the Clinical Academic Training (CAT) Programme. The CAT Programme, to be re-launched as the Integrated Clinical Academic (ICA) Programme in 2015, provides personal research training awards for non-medics/allopathic leaders who wish to develop their clinical research skills and research leadership with continued clinical practice and clinical development.

The HEE/NHS Clinical Lectureship Scheme
Are psychiatric bed removals related to increasing prison population rates?

By Adrian Mundt, Research Assistant, Unit for Social & Community Psychiatry

The 75-year-old Penrose Hypothesis

The British psychiatrist, mathematician and geneticist Lionel Sharples Penrose (1898-1972) postulated for the first time an inverse relationship between psychiatric bed numbers and increasing prison population rates in 1939. Historical background was that the number of beds in large psychiatric hospitals had reached a maximum around 1900. In the beginning of the 20th century, first psychiatric reform movements had led to the reductions of psychiatric beds numbers in Europe. Penrose analyzed data of psychiatric bed numbers and prison population rates from 18 European countries. He argued that lower numbers of psychiatric beds could mean higher numbers of crime and prisoners.

The hypothesis was forgotten for many decades and only in the 1990’s, increased interest and scientific reception had come up. Attempts had started to evaluate psychiatric reforms of the 1970’s that had led to an acceleration of psychiatric bed removals. One of the main themes of those reforms was the intent to replace institutionalized care in psychiatry with community care. Psychiatric bed removals had then become a global paradigm with community care. Psychiatric reforms was the intent to replace institutionalized care in psychiatry with community care. Psychiatric reforms was the intent to replace institutionalized care in psychiatry with community care.

Psychiatric bed removals were significantly related to increasing prison population rates. When and where more beds were removed, the prison populations increased more. This relationship on the level of an association does not yet provide any evidence for a causal link. There may be further factors mediating this relationship. We studied two such factors: the per capita Gross National Income GNI and the income distribution, the Gini-Index. Strong growth of the Gini was also associated with increasing prison population rates. The increase of the Gini explained in part but not fully the association between psychiatric bed removal and increasing prison population rates. The Gini-Index was unrelated. 75 years after the publication of the Penrose Hypothesis, this is the first study supporting this relationship in a longitudinal data set in South America.

The notion that chronically mentally ill may have been lost in mental health care institutions to criminal justice settings is worrying and raises human rights concerns. Those findings together with recent research reporting very high prevalence rates of mental health and substance use disorders in prisoners indicate that mental health care systems may need to increase engagement of people at risk for involvement with the criminal justice system.

Nine out of ten people would be willing to take part in clinical research

A new survey conducted on behalf of the NH&RI Clinical Research Network shows that 89% of people would be willing to take part in clinical research if they were diagnosed with a medical condition or disease – with an all-time low figure of just 3% saying they would not consider it at all.

The survey also revealed that 95% of people said they would be motivated if a friend or family member was seriously ill and an appropriate treatment had not yet been developed.

Patients interested in research can visit the NH&RI’s Patients carers and the public webpages to find out more about taking part and see what research is happening in their local area. http://www.crn.nihr.ac.uk/can-help/patients-carers/public/

The neuropsychological profile of early-onset Obsessive-Compulsive Disorder

The early-onset OCD study...

There is very little known about the differences between adolescent and adult Obsessive-Compulsive Disorder (OCD). The purpose of the present study is to establish a cognitive profile of adolescents with OCD by assessing a diversity of cognitive processes e.g. executive functioning, memory, decision-making, social reasoning in adolescents with OCD.

Who can take part?

• Adolescents aged 12-19
• Primary diagnosis of OCD with no additional psychiatric diagnosis
• Native or Fluent English-speaker
• Normal or corrected to normal vision
• No current or previous alcohol/drug dependence

What does it involve?

Firstly patients will have a short telephone interview with a psychiatrist. The researcher will arrange an appointment with the participant at a time and venue convenient to them. The appointment will take 4 hours and involves completing a few questionnaires and a few tasks on a touch screen computer which are like games or puzzles. Participants will be paid £40 for their time.

Studies recruiting in your trust

Upcoming Events

The S&CP regularly holds seminars to present to work of its members. These seminars are free, open to the public and held from 14:00-15:30 in the Lecture Theatre, Academic Unit, Newham Centre for Mental Health. For more information, call Caroline Ellis on 020 7540 4310.

Date Title Presented by
5 January Comparing functional and integrated systems of mental health care – management of the COTI programme Domenico Giaconia
12 January NESS – findings from the body psychotherapy for the treatment of negative symptoms trial Mark Savill
19 January EPSI – findings from the trial Eion Goldfinch
26 January Review on religious leaders involvement in mental health Victoria Bird
2 February QuESt – Quality and effectiveness of supported housing services for people with mental disorders Sima Sandhu
9 February Putting theory into practice: Developing, refining and testing intensive group music therapy for acute adult psychiatric inpatients Catherine Carr
16 February Immediate social networks for people with psychosis Domenico Giaconia
23 February VOLUME – Preferences survey design and initial findings Claudia Guia
26 March COFI – Comparing functional and integrated systems of mental health care Victoria Bird
9 March FAT – Financial incentives for adherence to medication in non-adherent patients Kate Moran
16 March Carer involvement in the mental health system Anagai Drink
23 March Development of a mobile health intervention using positive psychology for common mental health disorders Sophie Walsh
30 March Recruitment to trials and mental health Paulina Szymczynska
13 April Group processes in therapeutic groups Stavros Orfanos
20 April Built environment and mental health Nikolina Jovanovic
27 April Intimacy and wellbeing in people with mental illness: ethical challenges Ros Thompson

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If you would like to find out more or make a referral...

Contact the study team – Gorna Bastug (tel: 07984 278 678 or email gorna. bastug@eastlondon.nhs.uk) or Julia Gathwal (email jg687@cam.ac.uk).

The Local Investigator in our trust is Dr Graeme Lamb. Graeme.Lamb@ eastlondon.nhs.uk
Recent Publications

Notification of the following publications has been received since circulation of the last newsletter. Don’t be shy!! Please send copies of papers or reference details to the Research Office (ResearchOffice@eastlondon.nhs.uk) so they can be included in this list and made available to interested staff.


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