

# R&Dnewsletter

Spring 2014

East London **NHS**  
NHS Foundation Trust

## SUGAR coated: Service user and carer collaboration in mental health nursing research

By [Alan Simpson](#),  
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Patient and public involvement (PPI) in health research is increasingly advocated due to its perceived beneficial impact on the research and for those who participate. A recent review of 89 published studies that actively involved the public identified a number of impacts, including improving the research design and relevancy of research questions; helping researchers develop ethically acceptable research; improving recruitment and response rates; enhancing the collection and analysis of data; and enhancing dissemination of findings in an accessible way to the general public.

Numerous challenges remain. These include ensuring that any involvement is meaningful and not tokenistic; researchers needing to give up/share power in the research process; researchers accepting that the research will often take a slower pace; and ensuring there are adequate resources, in terms of time, people and money, for additional training and support required for the user and carer researchers.

Our own programme of mental health nursing research had a reasonable record of PPI with service users often on project steering groups and contributing advice and increasingly employed to undertake data collection. However, we were keen to move away from a reliance on one or two service users in order to obtain wider representation and a greater range of voices, including that of carers.

In 2009, SUGAR (Service User Group Advising

on Research) was established. (The name was recently appended to explicitly acknowledge the involvement of carers). Funding awarded for five years as part of a National Institute of Health Research programme grant led by Professor Len Bowers allowed the development, involvement and collaboration of mental health service users and carers in a programme of mental health nursing research.

SUGAR currently consists of 13 members: 11 service users and two carers recruited through the East London NHS Foundation Trust (ELFT) using a 'job description' and person specification designed for the

role. The group reflects the rich diversity of London in terms of age, gender, sexuality and ethnic mix and includes people with a range of mental and physical illness and life experiences. It meets once a month, facilitated and supported by Professor

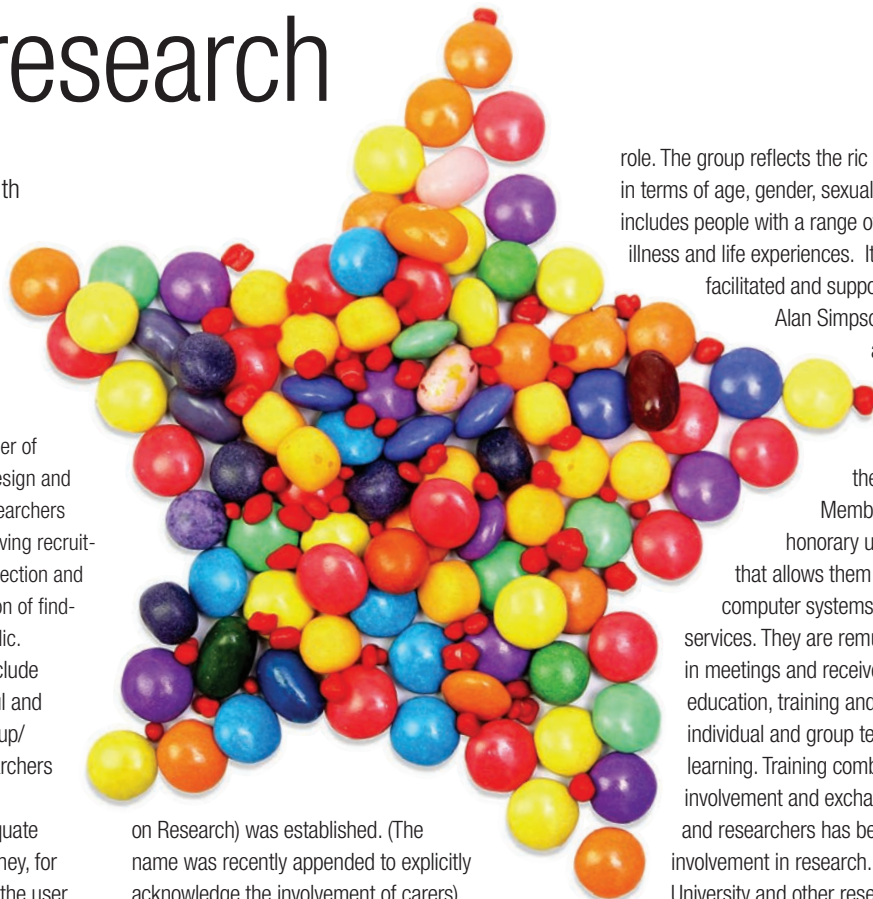
Alan Simpson and his colleagues at City University London, to discuss and collaborate on all aspects of the research process.

Members are provided with honorary university contracts that allows them access to the library, computer systems and other university services. They are remunerated for involvement in meetings and receive on-going support, education, training and development with individual and group teaching and self-directed learning. Training combined with genuine involvement and exchange with research issues and researchers has been linked with continued involvement in research. Members also attend University and other research events.

### Active involvement in research

Over the last four years, members of the mental health nursing research team, research students and external collaborators have discussed aspects of research projects with SUGAR on 46 occasions. On average, 11 SUGAR members and at least three members of the research team attend each meeting. Usually, two research topics are discussed and a range of methods

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# SUGAR coated: Service user and carer collaboration in mental health nursing research

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are used to maximise service user and carer input, including large and small group work, written exercises, mind mapping, discussions and presentations.

Research projects have included reducing conflict and containment in acute settings; peer support in mental health and haemodialysis settings; protected engagement time; care planning and coordination; suicidal behaviour and self-harm; measuring health utilities; substance use and intoxication; using technologies; carers in crisis and acute care; seclusion, observation, and sensory rooms; medication information; acceptance and commitment therapy; self-stigma; staff attitudes; mental health of mental health professionals; HIV screening in mental health settings and supporting parents on acute wards.

Additionally, SUGAR members have been recruited as members of study steering groups and lived-experience advisory groups by core and external research staff and contributed to educational programmes at the University. Joint presentations and workshops have been given at a number of international and national mental health nursing research conferences and events including a poster presentation and workshop delivered to the International Network of Psychiatric Nursing Research (NPNR) conference in Oxford, England in 2012. In 2013, SUGAR received the Highly Commended Award (and £2,500) for innovation in healthcare education and training from the Health Education North Central and East London (HENCEL) Quality Awards.

From the academic and clinical researchers' perspective, collaboration with SUGAR has been a great success. Consultation with the service users and carers has seen changes and improvements in research funding applications, with the level of PPI commended by reviewers. SUGAR members have also helped us address ethical issues and applications to research



■ Dr Chris Flood discussing health utilities research with SUGAR members

purposeful activities focused on generating high quality research designed to improve mental health services is a winning formulae. As was pointed out by one member, participation with SUGAR meets all the five criteria that have been identified for

ethics committees; develop, refine and test research instruments such as questionnaires and interview schedules; refine interventions; recruit staff; analyse and interpret findings; and help disseminate results. The group also provides a fantastic opportunity for our PhD and Masters' degree students to discuss their projects with people with lived experience of mental distress and service use.

## Reflective evaluation

Over the last year, members of the group were supported to take part in a reflective evaluation of their involvement with SUGAR. Members wrote about their experiences and these texts were then analysed by the group members using constant comparison analysis. The findings of this process have now been published in the *Journal of Psychosocial Nursing and Health Services*, an open access journal published in the USA and can be downloaded at <http://tinyurl.com/p7ojxna>

The members identify a range of personal gains, growth, opportunities, inclusion and empowerment that has come about through their extended involvement with SUGAR and academic research colleagues. One person summarised it this way:

I learn about different things, for example, how the stages of research are processed, how to ask research questions, how to collect data in research, and most of all funding and how that works in research. I also learn from other members in the group because we all have different experiences as service users and carers.

The combination of a friendly, supportive group environment and the opportunity to engage with

maintaining wellbeing: connect, be active, take notice, keep learning, and give.

The deliberate shift away from relying on one or two individual service users or carers for specific projects has undoubtedly been successful and reduces the risk of placing too much pressure on lone participants, widens representation and provides opportunities for group teaching and learning of research processes and methods. Additionally, there is a synthesis of learning that takes place as the various contributions and perspectives feed discussions leading to new ideas and approaches.

For most of us involved in the SUGAR experience over the last four years it has been a rewarding, friendly, thought-provoking and sometimes challenging place to be. Occasionally it has been frustrating and there has never been enough time to do everything we would like to in the way that we would like. Undoubtedly, friendships have been created and views have been changed. Importantly, the perspectives of service users and carers have influenced and shaped a large number of research studies conducted by a group of mental health nurse researchers and their colleagues. Hopefully, there is much more to come.

## Acknowledgements/Disclaimer

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## Upcoming Events

### Research Training Sessions

The Academic Unit at the Newham Centre for Mental Health holds fortnightly training sessions on a variety of topics of interest 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 Husnara Khanom at [husnara.khanom@eastlondon.nhs.uk](mailto:husnara.khanom@eastlondon.nhs.uk)

Date	Title	Presented by
19 March	<b>Statistics Refresher</b>	Stephen Bremner
2 April	<b>Systematic Reviews</b>	Erica Eassom
16 April	<b>Thematic Analysis</b>	Ciara Banks
7 May	<b>Introduction to STATA</b>	Stephen Bremner
21 May	<b>Meta-Analysis</b>	Mark Savill
4 June	<b>Sample size and Power Calculations</b>	Stephen Bremner
18 June	<b>Interpretative Phenomenological Analysis</b>	Mathew Colahan



# Duration of untreated psychosis in adolescents: Ethnic differences and clinical profiles

By **Karl Marlowe**,  
Consultant Psychiatrist

An article on the duration of untreated psychosis in adolescents was published in *Schizophrenia Research* in November 2013, and subsequently taken up by the *London Evening Standard*, based on research which included a number of collaborators from ELFT from both the Tower Hamlets and Hackney Early Intervention Services. The important message is to families and those professionals working with young people, that when there is an index of suspicion that someone is developing a psychotic illness, this should not be automatically explained away, but there is need to have an expert assessment as soon as possible.

In this study of 940 patients who presented with a first episode of psychosis to London services up to 2009, 136 were under the age of 18 years old. This group of adolescents has a delay to medication being started after overt psychosis of 6 months, which is more than twice the time for the delay in medication starting (2 ¾ months)



for the adult group. In addition, this delay in treatment for adolescents was significant associated with those from a white ethnicity and who had been using cannabis at the time of the development of the psychosis.

This research leads to practical advice for all those with adolescent

children, and has a health and wellbeing message in the prevention and early intervention for those with a developing psychotic disorder.

## New research planned in diabetes self-management

Dr Kathleen Mulligan and Hayley McBain are health services researchers co-funded by City University London and ELFT to undertake research into long-term conditions in Community Health Newham. We are working both with Professor Alan Simpson and his team from the Centre for Mental Health Research at City University London and ELFT's community diabetes team to undertake a series of studies exploring how best to support diabetes self-management in people who also have a severe mental illness.

Type 2 diabetes mellitus is one of the most common chronic illnesses in the UK affecting 3 million people. Rates of diabetes in East London are above the national average and in Newham they are amongst the highest in the country. Other research has shown that the risk of developing type 2 diabetes is almost doubled in people living with a severe mental illness such as schizophrenia and the mortality rate is higher in people who have both severe mental illness and diabetes compared with diabetes alone.

Research conducted in primary care in East London found that people with severe mental illness were more likely to smoke, be obese and less likely to have had retinopathy screening than those without severe mental illness. Although they were more likely to have an HbA1c of less than

7.5%, more than 50% of the sample was outside of this target. Improving outcomes for people with these conditions is a local priority, evidenced in the 2013/14 operating plan for Newham Clinical Commissioning Group which establishes improvement in glycaemic control among patients with diabetes and severe mental illness as a key priority.

The demands of managing diabetes and comorbid severe mental illness present additional challenges for both service users and health professionals. In spite of this, research has so far failed to ask service users about what they find most challenging when trying to manage their diabetes and what they would find helpful. Similarly there is also very little research from the perspective of health professionals.

To gain a better understanding of the challenges to effective diabetes management, we are working on a series of studies in this area. Firstly we are reviewing the literature on diabetes self-management for people with severe mental illness. We also aim to carry out in-depth interviews with a number of service



users to find out about their understanding of diabetes and how they manage it on a day-to-day basis. We will also interview health professionals, including GPs, practice nurses, diabetes specialist nurses, community mental health nurses and psychiatrists to obtain their views about the difficulties of implementing diabetes guidelines for people with severe mental illness and about how best to deliver support for self-management. The findings from this work will help us to identify the most important components to address when planning services to help improve self-management for this population.

For further information please contact Dr Kathleen Mulligan at Kathleen.Mulligan.1@city.ac.uk

### OTHER NEWS

#### NEW NAME UNVEILED: VIOLENCE PREVENTION RESEARCH UNIT

The Forensic Psychiatry Research Unit, one of the Queen Mary, University of London, research units that the Trust is affiliated with and jointly funds, has changed its name to better reflect the current focus of their research and acknowledge the multidisciplinary nature of the team.

Henceforth, Professor Jeremy Coid's team, formerly the Forensic Psychiatry Research Unit, will be known as the Violence Prevention Research Unit.

#### NEW RESEARCH DEVELOPMENTS WITH INVOLVEMENT4ACCESS PROJECT

The Involvement4Access project encourages patients, carers and the public to help improve opportunities for patients to participate in research in their local NHS Services, whether that's in GP surgeries or local hospitals. They are calling patients, carers and the public who help bring this about 'Patient Research Ambassadors'. For more information, see [www.crnc.nihr.ac.uk/ppi](http://www.crnc.nihr.ac.uk/ppi) or write to [crnc.ppi@nihr.ac.uk](mailto:crnc.ppi@nihr.ac.uk)

# The role of social class in the associations of intelligence and violence in the population

By **Dr Rafael Alberto Gonzalez**,  
Post-doctoral research fellow, Violence  
Prevention Research Unit

The Trust's Violence Prevention Research Unit led by Professor Jeremy Coid recently published an important paper in the journal *Personality and Individual Differences* (Gonzalez et al. 2014) on the essential role of socio-economic position in the association between higher intellectual functioning with population violence.

Literature shows that intelligence, often measured by IQ, is inversely related to indices of morbidity and mortality in the population. Low IQ and intellectual disability have been consistently linked with delinquency and violent crime, with several authors reporting that this relationship is not explained by socio-demographic factors, such as age, ethnicity or socio-economic status. Because a significant proportion of violent incidents go unreported, and therefore do not result in conviction, we set out to test the role of social class in the associations of IQ with violence at the population level.

For this study we drew all relevant data from two British national surveys of psychiatric morbidity among adults aged 16 years and older: the ONS survey of psychiatric morbidity among adults in Great Britain (2000) and the Adult Psychiatry Morbidity survey (2007). The total sample drawn for this study was 14, 738.

We were particularly interested in estimating the extent to which belonging to a particular social class group would have an effect in the associations between general intelligence with violence. Social class was based on the UK Registrar General's Classification, which uses most recent occupation of the head of household. This is generally considered a good indicator of income, education and level of

responsibility at work.

Meanwhile, the violence assessment questions included any violence in the past years, its severity, injuries related to the incidents, violence repetition and violent events during episodes of intoxication, as well as violence in the family (e.g., intimate partner violence). IQ was estimated via a standardized adult reading test. These scores were corrected to adjust for the effects of age.

Intellectual categories groups were distributed in our sample as follows: above average IQ (26.6%), average IQ (58.6%), below average IQ (12.9%) and intellectual disability (1.9%). Of total respondents, 10.5% reported any violence incidents in the last 5 years.



In this study above average IQ had a clear and significant protective effect on all outcomes, even after considering the confounding effects of socio-economic circumstances. On the other hand, we observed an increased risk of violence among persons of below average IQ. However this finding was explained by social class. A critical finding from our study was that the protection gained from having an above average IQ depended on the social class group. Specifically, amongst those in the lower social classes, intelligence conveys no protection for violence. In summary, social class has both an explanatory and a moderating role in associations of

intelligence with violence.

That the above average intelligence association with violence seems independent of socio-demographic factors in contrast with below average IQ is a novel finding, which may suggest increased vulnerability to environmental factors among those with lower IQ. We are aware of one previous study reporting a protective effect of IQ on violent crime, but the association was only tested for a subgroup of subjects identified 'at risk' for offending, whereas our findings are the only ones based on the general population.

Our findings suggest that high intelligence may exert a protective effect via better development of communication skills and through the ability to achieve conflict resolution by using verbal mediation. Persons with higher intellectual functioning are likely to anticipate consequences and regulate affective responses to social situations requiring complex social and moral assessments, have greater understanding of other's emotions, therefore, reduced likelihood of recourse to violence.

Other factors such as location, general area deprivation and wealth inheritance may have a tacit role in the complex associations between socio-economic position and violence. Since our findings are based on cross-sectional data, there may be unobserved explanatory variables which may impact both cognitive capacity and a proclivity to engage in aggressive acts.

Our findings may inform programs aiming to identify those individuals at risk in the population and support their transition through the educational system. Since the sample is representative of the household population and social class was based on the head of family, our findings have the potential of advising the development of family-level interventions to prevent violence.

## East London joins the noclor partnership

In March 2014, the East London NHS Foundation Trust became the newest partner in the noclor (north and central london research) consortium. Noclor represents a group of NHS trusts across north, central and east London. The aim of the partnership is to promote and support high quality research in primary care, community health and mental health in this geographical area.

The noclor partnership consists of 13 former PCTs (including NHS City & Hackney, NHS Newham, NHS Tower Hamlets), four Foundation Trusts (including Camden & Islington, Central and North West London, East London, and the Tavistock and Portman) and one Mental Health Trust (Barnet Enfield & Haringey). They also have an alliance with West London Mental Health Trust and provide a governance service to the North East London Foundation Trust.

The noclor team includes specialists on research funding, research management and governance and research training who will support the research at ELFT by

- Managing the research governance process; a small team of governance experts aim to support all researchers through the legal requirements of project registration, and in their accountability for public funds, in the most straightforward and time-efficient manner possible.
- Assisting researchers and managers on the accurate costing of research projects.
- Working alongside academic and service partners to ensure research activity is aligned with service priorities and to maximise advantages of sharing good practice.
- Helping researchers develop their skills in bidding for, managing and disseminating successful research by running training and development workshops and

**noclor** 

### Research Support Service

providing networking opportunities at their annual conference and other events.

- Supporting research site and participant recruitment through various schemes across the noclor area; offering practical support and intelligence about local research-friendly primary care organisations as well as advice and input designed to facilitate participant enrolment into studies.

We are very excited about the opportunities this partnership will bring to research in East London and across the region.

For more information about noclor or to contact the team, see [www.noclor.nhs.uk](http://www.noclor.nhs.uk)



# Involving Service Users and Carers in Research

## OTHER NEWS

Involving service users and carers in research that takes place in our Trust is of mutual benefit to both and a priority, but investigators are sometimes unclear about what meaningful involvement means and how to achieve it.

'Involvement' in research is when research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants. 'Involvement' does not mean simply participating in a research study, such as taking part in a clinical trial (although participation is undoubtedly critical to success).

The National Institute for Health Research (NIHR) Patient and Public Involvement (PPI) organisation, INVOLVE, defines three distinct levels of involvement:

**Consultation** is where the views of service users, carers, and others are either formally or informally sought. There is no sharing of power in any decision making process at this level of involvement. Examples of opportunities to consult with service users and carers include:

- Asking service users or carers to **review a funding application** and involve them in its development; applications with significant PPI elements are more likely to be successful.
- Service users and carers can help considerably in **developing patient information sheets, consent forms, and other patient- or carer-orientated materials** for your study. A report from INVOLVE suggests that service user and carer involvement can help improve the ethical acceptability of research.

**Collaboration** is where there is an active on-going partnership between researchers, service users, and carers in the research process. Examples of opportunities to collaborate with service users and carers include:

- Involvement of service users and carers on trial **steering committees or study management groups** or establishing a dedicated service user

and carer steering group for your study. Such a group can help troubleshoot any practical problems that may arise during the course of your study and assist in the production of study publications. If you are going to involve service users or carers in this way then it is important that they are supported.

- **Publicising the study** It is worthwhile considering involving service users and carers to write a clear, plain English 'lay summary' of your research study which can be used to advertise the study when you start and then publicise the



findings when you are finished. Service users and carers can also assist in the production of study newsletters. They can be involved in the presentation of study findings at conferences and patient/carer organisation meetings. Consider inviting service users and carers that have been involved in your study to be co-authors of research papers and other publications that arise.

- **Undertaking the research** There are a growing number of studies that involve service users and carers as members of the study team (carrying out interviews, recruiting participants, facilitating focus groups, and so forth).

- **Data Analysis** Service users and carers often provide invaluable assistance in analysing and interpreting study data. They can identify themes that researchers might miss, help in checking the validity of the conclusions from a public perspective, and highlight findings that are more relevant to the public.

**Control** is where research is actively controlled, directed and managed by

service users, carers, or service user and carer organizations.

Successful involvement requires appropriate planning and funding; it is advisable to set aside a specific budget for involvement activities.

Consider paying service users and carers for their work; as a minimum cover the travel/out of pocket expenses. If you are going to involve 'lay people' on trial management groups or other committees that oversee the conduct of your study consider carefully the support that they might need.

Take time to give them a clear

introduction to the research study (preferably both verbally and in writing) without which people may be left struggling to understand what your research is about let alone make a contribution as to how it might be done better. Always provide people with the contact details of a member of your study team who can answer any questions.

The INVOLVE website has a number of resources at [www.invo.org.uk/resource-centre](http://www.invo.org.uk/resource-centre) including case studies and briefing notes for researchers; useful documents such as template job descriptions and terms of reference for committees and steering groups; an involvement cost calculator to help you plan your budget; and advice and guidance on developing training and support packages, and writing a plain English summary.

"No matter how complicated the research, or how brilliant the researcher" said Dame Sally Davies, Department of Health's Chief Medical Officer and Chief Scientific Adviser, "patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well."

## EAST LONDON RECRUITMENT INTO RESEARCH

At month 10 (January), we were slightly behind our recruitment goal having only achieved 63% of our 13/14 target. In numbers, we have recruited 378 participants against a target of 594.

This target is 2.5 times the recruitment we had in 2008/9 – more even than the government's challenge to double recruitment in five years (which we are on target to meet).

Few of the 23 organisations in our region have been set such ambitious targets (in terms of multiples of 2008/9 recruitment), they include BEH, C&I, and ELFT (in mental health); NHS Outer NE London (a grouping of Waltham Forest, Barking and Dagenham, Redbridge, and Havering) and Camden PCT (in primary care); and Homerton and Royal Free Hampstead (in acute, tertiary or speciality trusts).



## NEW DECLARATION OF HELSINKI

In October the WMA Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects, was revised and reissued. A full copy of the Declaration can be found online at <http://www.wma.net/en/30publications/10policies/b3/>

## SITE SPECIFIC ASSESSMENTS – NON-NHS SITES

Further clarification has been requested regarding the change of process for conducting SSAs for non-NHS sites.

From 1st November 2013, SSAs for non-NHS sites have been undertaken by the REC who reviewed the full application regardless of the location of the site.

Consequently some RECs who did not previously review SSAs for particular sites, will now be responsible for reviewing them.

# After Cancer: Surviving or Living?

By **Ania Korszun**,  
Professor of Psychiatry and Education,  
Queen Mary University of London

More than 1 in 3 people in the UK will develop some form of cancer during their lifetime and being diagnosed with cancer remains the British public's number one fear. But, in the last 40 years, survival rates for cancer have doubled and are continuing to improve. There are currently 2 million cancer survivors in the UK and the number is projected to rise to 3 million by 2040, when nearly a quarter of those over 65 years will be cancer survivors. So, it is of great importance that the needs of long-term cancer survivors are properly identified to enable them to have the best possible quality of life.

For survivors, cancer is a chronic life-altering condition and several psychosocial factors can have a profoundly negative impact on their quality of life: in particular, psychological problems such as depression, excessive anxiety about cancer recurrence, and social aspects, such as unemployment and social isolation. These need to be adequately understood and addressed in the healthcare of long-term cancer survivors.

The Bart's Study (Korszun et al *Br J Haematol*. 2013) is the first large British study of long-term haematological cancer survivors that looks at the combined association of several disease-related, social and psychological factors with quality of life. The participants were 718 patients (5-40 years since diagnosis) who had been treated for Hodgkin and Non-Hodgkin Lymphomas and Acute Leukaemia at St. Bartholomew's Hospital. The illness course and treatments for these different disorders vary widely, depending on cancer subtypes, and long-term survivors can experience a variety of late adverse physical effects, including cardiovascular and thyroid disease, infertility and second cancers.

Participants completed a series of questionnaires that included psychosocial, functional and quality of life scales. Most quality of life measures consist of a generic list of physical symptoms, with or without some cancer site-specific symptoms and one or two items for psychological distress. These do not necessarily capture the experiences and subtle needs of long-term cancer survivors, including how current conditions in their lives may be attributed, related to or influenced by having had cancer. The Bart's study used the Impact of Cancer (IOC) Scale, which is a quality of life measure that was developed to measure both positive (Altruism/Empathy', 'Health Awareness', 'Meaning of Cancer' and 'Positive Self-Evaluation') and negative ('Appearance Concerns', 'Body Change Concerns', 'Life Interferences' and 'Worry') aspects of cancer impact. Levels of psychological distress, depression and fatigue were also measured to examine how these were interrelated with the type and severity of cancer, levels of functioning and social support.

In this group of survivors, 24.3% reported a previous history of depression, which is higher than the

lifetime prevalence of depressive disorders reported for the general population both in Europe (6.7%) and in USA (16.2%) and 15% of respondents also reported clinically significant levels of psychological distress (three times higher than in the general UK population). High fatigue levels of fatigue were reported by 18% of participants. Those who had high distress and fatigue also showed poorer quality of life. Interestingly, however, there were no significant differences in depression, fatigue or functional impairment across the different haematological cancer subtypes and it is not the cancer type, stage and extent of treatment that determine the subsequent quality of life of survivors.

Both positive and negative impacts of cancer



■ High scores in the positive IOC domain may reflect optimistic personality traits with "the ability to turn lemons into lemonade"

were associated with different sets of factors. Greater negative impact of cancer was associated with depression, fatigue, functional impairment and less social support. Also, those who were diagnosed at an earlier age (<21 years) had significantly higher negative impact of cancer than those diagnosed as adults. This suggests that patients diagnosed at a young age may need developmentally appropriate interventions at the time of diagnosis to address their specific concerns to improve long-term outcome. Factors such as sex, ethnicity, education, and relationship status were not associated with negative impact scores.

On the other hand, lower positive impact of cancer was associated with white ethnicity, higher level of education, and a lower level of social support. Age at diagnosis, sex, history of depression, and fatigue had no association with positive impact scores.

Clearly, negative and positive impacts of cancer are not just the obverse of each other and the role of psychosocial factors is complex. Although we need a greater understanding of their interaction, these findings demonstrate that application of simple

screening tools may help identify those most in need of intervention soon after their cancer diagnosis. Targeted treatment with pharmacotherapy, cognitive behavioural therapy, exercise therapies or a combination could then be delivered in a resource-effective manner appropriately to improve quality of life and promote well-being in those diagnosed with cancer.

But interventions for cancer survivors could go beyond this by learning from those reporting a positive impact of cancer. The positive and negative impact IOC measures measure different constructs as shown by the different patterns of associations with positive and negative IOC domains.

There were some intriguing differences between

white and other ethnic groups with the former showing lower positive impact scores. Education also had a significant effect on positive outcome perhaps reflecting that those with higher levels of education have a greater understanding of the implications of living with cancer, or that the cancer affects their functional capacity and ability to achieve their life goals and aspirations to a greater extent. Survivors' quality of life and function may be significantly improved by early interventions addressing vocational rehabilitation.

Being without a partner and having lower levels of social support were also significant factors associated with lower positive IOC scores. Although it is not possible to draw conclusions on causality in this study, it may be that those cancer

survivors showing high levels of positive impact are more likely to join support groups and be active in their communities.

High scores in the positive IOC domain may reflect optimistic personality traits with "the ability to turn lemons into lemonade". Importantly, this ability could be taught to those who don't know how "to make lemonade". Therapies are available that focus on engaging cancer patients and facilitating change by encouraging patients' flexibility and acceptance of what cannot be altered and committing themselves to what can be achieved e.g. "Acceptance and Commitment Therapy". Although a higher positive IOC score may not translate into a better functional level, improving the score through intervention may improve an individual cancer survivor's quality of life.

These findings show that whilst quality of life amongst the majority of cancer survivors is good, there is a distinct subgroup that reports poor quality of life. There are several psychosocial factors that are associated with this but most striking is the consistent association of depression, psychological distress and fatigue with greater negative impact of cancer. Recognition and treatment of depression and anxiety are a high priority for improving quality of life in long-term cancer survivors as well as the development of modular interventions to improve well-being.

## Upcoming Events

# Spring/Summer Research Seminars in the Unit for Social & Community Psychiatry

The USCP regularly holds seminars to present the work of its members. These seminars are free, open to the public and held from 14:00-15:00 in the Lecture Theatre, Academic Unit, Newham Centre for Mental Health. For more information, call Carolanne Ellis on 020 7540 4210.

Date	Title	Presented by
17 March	<b>FIAT – The follow-up on financial incentives for adherence to medication in non-adherent patients</b>	Hana Pavlickova
24 March	<b>Carers' engagement in mental health care</b>	Domenico Giacco
31 March	<b>Reciprocity in social networks</b>	Eleanora Arcidiacono
7 April	<b>QuEST – Quality and effectiveness of supported housing services for people with mental disorders</b>	Sima Sandhu
14 April	<b>Negative symptoms in schizophrenia</b>	Mark Savill
21 April	BANK HOLIDAY	
28 April	<b>FIAT – Financial incentives for adherence to medication in non-adherent patients</b>	Katie Moran
5 May	BANK HOLIDAY	
12 May	<b>Comparing functional and integrated systems of mental health care – management of the COFI programme</b>	Domenico Giacco
19 May	<b>NESS – findings from the body psychotherapy for the treatment of negative symptoms trial</b>	Ciara Banks
26 May	BANK HOLIDAY	
2 June	<b>EPOS-findings from the trial</b>	Lauren Kelley
9 June	<b>Video clip study</b>	Husnara Khanom
16 June	<b>EPOS – findings from clinical and patient focus groups</b>	Eoin Golden
23 June	<b>Helping relationships</b>	Paula John
30 June	<b>Ethics of befriending</b>	Rose Thompson

## New template for attributing costs in a grant application being piloted

The Department of Health (DH) is piloting an Activity Capture and Attribution Template (ACAT) and related services designed to help researchers and funders identify and appropriately attribute the activities (research, service support, or excess treatment) in research studies.

The ACAT is designed to be added as an addendum to a grant application form. Completion of the ACAT will be required for any application to funders participating in the pilot programme, including the NIHR RfPB, HSDR (formerly known as SDO), and HTA funding streams.

It is recognised that researchers will require support

to complete the ACAT. The NIHR CRN will provide a pre-application support service for researchers applying to research programmes participating in the pilot. To support the research community we have developed a number of resources e.g. an attribution e-learning tool and an ACAT tutorial which can be accessed at: [http://www.crncc.nihr.ac.uk/researchers/planning\\_your\\_study/AcoRD/Learning+resources.htm](http://www.crncc.nihr.ac.uk/researchers/planning_your_study/AcoRD/Learning+resources.htm)

In addition, the NIHR has established a network of AcoRD Specialists to:

- Provide specialist advice to researchers on the CRN related AcoRD implementation processes i.e. pre-

application support service, completion of the ACAT and the ACAT Review

- Assist researchers to use and independently complete the ACAT
- Carry out the ACAT Review for AMRC member funded studies
- Resolve any queries as a result of the ACAT Review working closely with the Funders and researchers

If you wish to seek support from an AcoRD Specialist on how to correctly identify and attribute these activities contact [CRNCC.Acord@nihr.ac.uk](mailto:CRNCC.Acord@nihr.ac.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](mailto:ResearchOffice@eastlondon.nhs.uk)) so they can be included in this list and made available to interested staff.

- Ajdukovic D, Ajdukovic D, Bogic M, Franciskovic T, Galeazzi GM, Kucukalic A, Lecic-Tosevski D, Schutzwohl M & Priebe S (2013) *Recovery from posttraumatic stress symptoms: a qualitative study of attributions in survivors of war*, **PloS One** 8(8):e70579.

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- Basner M, Babisch W, Davis A, Brink M, Clark C, Janssen S & Stansfeld S (2013) *Auditory and non-auditory effects of*

*noise on health*, **Lancet**, [Epub ahead of print] doi:10.1016/S0140-6736(13)61613-X

- Bowers L, Alexander J, Bilgin H, Botha M, Dack C, James K, Jarrett M, Jeffery D, Nijman H, Owiti J A, Papadopoulos C, Ross J, Wright S & Stewart D (2014) *Safewards: the empirical basis of the model and a critical appraisal*, **Journal of Psychiatric Mental Health Nursing**, [Epub ahead of print]. doi: 10.1111/jpm.12085.

- Brunner EJ, Shipley MJ, Britton AR, Stansfeld SA, Heuschmann PU, Rudd AG, Wolfe CD, Singh-Manoux A & Kivimaki M (2014) *Depressive disorder, coronary heart disease, and stroke: dose-response and reverse causation effects in the Whitehall II cohort study*, **European Journal of Preventative Cardiology**, 21(3): 340-346. doi: 10.1177/2047487314520785

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- Curtis D (2013), *Consider factors that are important to patients when quantifying harms*, **British Medical Journal**, 347: f6614. doi: <http://dx.doi.org/10.1136/bmj.f6614>

- Das-Munshi J, Clark C, Dewey ME, Leavey G, Stansfeld SA & Prince MJ (2014) *Born into adversity: psychological distress in two birth cohorts of second-generation Irish children growing up in Britain*, **Journal of Public Health**, 36(1):92-103. doi: 10.1093/pubmed/ftd034.

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## Recent Publications Continued

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- Dominquez M, Fisher HL, Major B, Chisolm B, Rahaman N, Joyce J, Lawrence J, Hinton M, Marlowe K, Aitchison K, Johnson S & Hodes M (2013) *Duration of untreated psychosis in adolescents: Ethnic differences and clinical profiles*, **Schizophrenia Research**, 150(2): 526-532. doi:10.1016/j.schres.2013.08.018
- Ferentinos P, Rivera M, Ising M, Spain SL, Cohen-Woods S, Butler AW, Craddock N, Owen MJ, Korszun A, Jones L, Jones I, Gill M, Rice JP, Maier W, More O, Rietschel M, Lucae S, Binder EB, Preisig M, Tozzi F, Muglia P, Breen G, Craig IW, Farmer AE, Muller-Myhsok B, McGuffin P & Lewis CM (2014) *Investigating the genetic variation underlying episodicity in major depressive disorder: Suggestive evidence for a bipolar contribution*, **Journal of Affective Disorders**, 155: 81-89. doi: 10.1016/j.jad.2013.10.027.
- Giacco D, Bartoli F, Di PC, Palumbo C, Piras S, Rubinacci A & Aguglia A (2014) *[Can psychiatric trainees have a role in the improvement of training? The first 20 years of European Federation of Psychiatric Trainees]*, **Rivista di Psichiatria**, 49(1):50-55. doi: 10.1708/1407.15625.(In press)
- González RA, Kallis C, Ullrich S, Zhang T & Coid JW (2014) *The protective role of higher intellectual functioning on violence in the household population of Great Britain*, **Personality and Individual Differences**, 61-62(0):80-85. doi: http://dx.doi.org/10.1016/j.paid.2014.01.012
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- Gould RL, Coulson MC, Patel N, Highton-Williamson E & Howard RJ (2014) *Interventions for reducing benzodiazepine use in older people: meta-analysis of randomised controlled trials*, **British Journal of Psychiatry**, 204:98-107. doi: 10.1192/bjp.bp.113.126003.
- Greaves P, Sarker SJ, Chowdhury K, Johnson R, Matthews J, Matthews R, Smith M, Korszun A, Gribben JG & Lister TA (2014), *Fertility and sexual function in long-term survivors of haematological malignancy: using patient-reported outcome measures to assess a neglected area of need in the late effects clinic*, **British Journal of Haematology**, 164(4): 526-535. doi: 10.1111/bjh.12651.
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- Humm R & Simpson A (2014) *Guest Editorial: Users of Mental Health Services as Peer Support Providers and Research Collaborators*, **Journal of Psychosocial Nursing and Mental Health Services**, 52(1):3-4. doi: 10.3928/02793695-20131126-0.
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- Kirkbride JB, Jones PB, Ullrich S & Coid JW (2014) *Social deprivation, inequality, and the neighborhood-level incidence of psychotic syndromes in East London*, **Schizophrenia Bulletin**, 40(1): 169-180. doi: 10.1093/schbul/sbs151.
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- Lecic-Tosevski D, Pejuskovic B, Miladinovic T, Toskovic O & Priebe S (2013) *Post traumatic stress disorder in a Serbian community: seven years after trauma exposure*, **Journal of Nervous and Mental Diseases**, 201(12):1040-1044. doi: 10.1097/NMD.0000000000000051
- Lee SH, Ripke S, Neale BM, Faraone SV, Purcell SM, Perlis RH, Mowry BJ, Thapar A, Goddard ME, Witte JS, et al (2013) *Genetic relationship between five psychiatric disorders estimated from genome-wide SNPs*, **Nature Genetics**, 45(9):984-994. doi: 10.1038/ng.2711.
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- Xenitidis K, Campbell C, Coid J, Ullrich S & Kallis C (2014) *Authors' reply*, **British Journal of Psychiatry**, 204:240-241. doi: 10.1192/bjp.204.3.240a
- Yang M, Wong SCP & Coid J (2013) *Violence, mental health and violence risk factors among women in the general population: an epidemiology study based on two national household surveys in the UK*, **BMC Public Health** 13:1020. doi: 10.1186/1471-2458-13-1020.

