

Consent for Contact (C4C) Newsletter

Issue 2

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Welcome

to the second edition of our quarterly C4C newsletter where we provide a recruitment update, a roundup of recent activity and a look ahead at upcoming events.

In this edition, we report on, why join the C4C register, recent publications, service user involvement and other important updates.

We hope you enjoy this issue of the C4C Newsletter and wish for you to please let us know your thoughts for its future content.

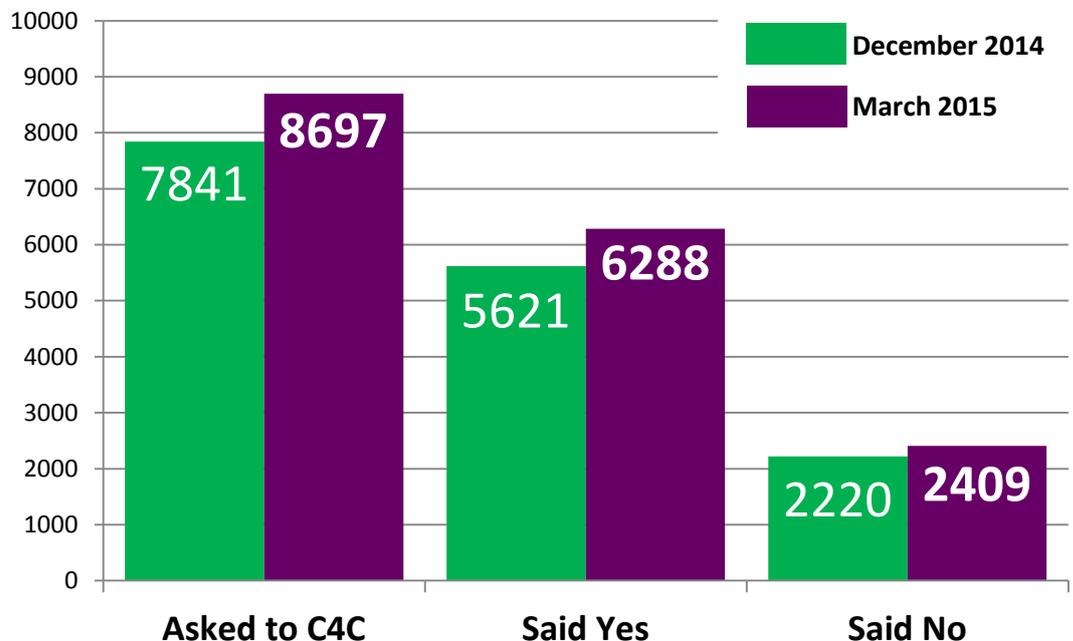
Consent for Contact growth - C4C hits 6K+

We are delighted to see C4C recruitment grow and service engagement increase.

Service engagement is at the heart of C4C implementation objectives and we are pleased to report that C4C engagement in all Clinical Academic Groups (CAGs) is growing steadily - 209/219 services have asked their service users about C4C. This is translated in the latest recruitment figures presented in Fig.1 below where there has been around a 10% increase in recruitment.

This is great news and we hope services keep up the excellent work in enabling involvement in much needed research into mental health conditions.

Fig 1. Number of Patients asked about C4C and number of those who have joined the register



To find out about your team's C4C activity and performance, or if you would like a member of the C4C team to come along to your service and give a brief introduction and run through of the C4C process, Please contact us - details below. For further information, PDF copies of leaflets, FAQ for staff, and more, please visit our website.

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Why join the C4C register?

Mental health research plays a vital role in improving the lives of people affected by mental health conditions. It is one of the best known ways to develop better treatments and nearly all mental health research needs the help of those affected by mental health conditions in order to improve treatment outcomes.

South London and Maudsley (SLaM) NHS Foundation Trust is one of the most 'research productive' Trusts in the whole of the NHS – Mitchell and Gill (2014)¹. This is due to its partnership with the Institute of Psychiatry, Psychology and Neuroscience (IOPPN) at King's College London. Together, they form Europe's largest research centre for Psychiatry, Psychology and Neuroscience. This is also due to its openness to pioneering innovation and Consent for Contact (C4C) is an example of this.

SLaM patients can volunteer to take part in the latest mental health research by signing up to SLaM's research participation register – Consent for Contact (C4C). This register is exclusively for service users of SLaM only.

The C4C register is easy to join. Service users who are interested in being involved in research related to their mental health condition, experience of therapy, medication taken or even a general interest in leading edge research, can give consent to be contacted for research. Currently, the C4C register consist of service users who are receiving care from a wide range of therapeutic settings and conditions such as depression, anxiety, psychosis, affective conditions etc. When new research about these conditions take place, the service users who have consented to be contacted, will be invited to take part in the latest research.

Participating in research could involve any of the following:

Interviews	Brain scans	Giving a small blood sample
Questionnaires	Completing a week-long diary	New or alternative medication
New or alternative psychological therapy		
New health technologies such as smart watches that monitor sleep, physical activity and alert to improve medication compliance and/or therapy attendance		
It could even simply involve just giving some useful feedback about experiences with SLaM services		

Patients who provide such invaluable research involvement may be paid for their time in participating, but ultimately help others in similar positions as well as researchers to develop and improve treatments.

Participants will always be fully informed about what is involved before they take part in any research and can always say no to taking part. They can also withdraw from a research study at any time without giving any reason. Participation is completely voluntary.

England's NHS Constitution pledges 'to inform [patients] of research studies in which [they] may be eligible to participate'² SLaM aims to follow this pledge and expects all clinicians to discuss and offer C4C to their service users. It is important to note that the consent patients give is only to be contacted about research they may want to participate in.

Some benefits of participating in research:

- Patients can help others as well as themselves by participating in research
- Patients could be paid for taking part in some research studies
- Patients could have access to new treatments faster than waiting lists – e.g. when taking part in a Randomised Clinical Trial where the latest treatments are tested against the more traditionally/currently used ones

Common reassurances for participating in research:

- Patient data is protected as it is held within SLaM electronic clinical records
- Patients can always say no to research if they do not wish to participate
- Patients are not 'guinea-pigs' to test on; research is more like 'product' or 'service' testing for improvement
- By simply being on the C4C research register, patients can influence the demand for further research on their condition - i.e. having more potential participants means a higher likelihood for research studies to be granted the necessary funding to proceed

1) Mitchell, A. J., & Gill, J. (2014). Research productivity of staff in NHS mental health trusts: comparison using the Leiden method. *The psychiatric bulletin*. 38(1), 19-23.

Recent publications about C4C

- Callard, F., Broadbent, M., Denis, M., Hotopf, M., Soncul, M., Wykes, T., & Stewart, R. (2014). Developing a new model for patient recruitment in mental health services: a cohort study using Electronic Health Records. *BMJ open*, 4(12)
- Papoulias, C., Robotham, D., Drake, G., Rose, D., & Wykes, T. (2014). Staff and service users' views on a 'Consent for Contact' research register within psychosis services: a qualitative study. *BMC Psychiatry*, 14, [377].
- Robotham, D., Evans, J., Watson, A., Perdue, I., Craig, T., Rose, D., & Wykes, T. (2015). Linking a research register to clinical records in older adults' mental health services: a mixed-methods study. *Alzheimer's Research and Therapy*, 12/2015; 7(1).

Leavers and Joiners



Caroline Morris

Victor Dangare

Barbra Davison

Amos Omerri

Caroline Morris – C4C Project officer, has left C4C after working for over 3 years from its inception: building its foundations and leaving it in good stead for the future.

Victor Dangare – Secondment C4C Project worker, supporting C4C in the Mental Health of Older Adults Clinical Academic Group: promoted and implemented C4C in many services for Older Adults, across the Trust.

Thank you both for your endeavours, you will be dearly missed but not forgotten.

We welcome **Barbra Davison** and **Amos Omerri** in their capacity as C4C Service User Ambassadors. They will contribute to the work of promoting C4C to service users and staff across the Trust.

We also welcome **Rob van der Waal**, Lead nurse in the Addictions Clinical Academic Group, as a new C4C Champion.

C4C from a Care Coordinator's perspective

by Victor Dangare

In the last four months I have worked as C4C Project Worker for the Mental Health of Older Adults Clinical Academic Group, on secondment from Croydon Community Mental Health Services.

The role involved promotion of C4C to teams as well as support with increasing service user recruitment into the C4C research register. The experience highlighted varying levels of team and individuals' engagement with C4C as observed from meetings held with teams and from the recruitment data. In most teams, Care Coordinators were familiar with C4C and were routinely asking service users about research participation. In some teams, Care Coordinators were unfamiliar with C4C and a few had not heard about it.

Those teams recruiting consistently well into the C4C register had embedded C4C within their clinical assessments and processes. This ensured that each service user was offered an opportunity to participate in research by their Care Coordinator from initial contact right through to discharge. Interestingly, clinical teams that did not embed C4C within their clinical processes also had consistently low recruitment figures.

I enjoyed working with the C4C team and increasing research participation within SLAM. I would just urge all Care Coordinators to continue asking for C4C with all their service users.

Upcoming events

Save the date: International Clinical Trials Day – Wednesday, the 20th of May 2015

International Clinical Trials Day is celebrated around the world on or near the 20th of May each year, to commemorate the day that James Lind started his famous trial on the deadly disease scurvy. It provides a focal point to raise awareness of the importance of research to health care, and highlights how partnerships between patients and healthcare practitioners are vital to high-quality, relevant research.

Last year, the C4C team were stationed in canteens across the Trust: Maudsley, Bethlem, Lambeth and Lewisham – Handing out promotional materials such as Pens and T-shirts. This was done to celebrate the day and encourage staff and patients to get involved in research by using SLAM's very own research participation register – Consent for Contact: C4C.

This year we are looking forward to do more of the same so save the date to celebrate the day with us.

Wednesday, 20th May, 2015 - from 11am to 2pm in a Trust canteen/café near you.



YouTube video update

Our C4C YouTube video has now been updated to include subtitles.



Research studies using C4C for recruitment

There are currently 49 research studies (including clinical trials) using the C4C register to recruit participants. Types of research studies range across all Clinical Academic Groups (CAGS) within the Trust: Addictions, Behavioural and Developmental, Child and Adolescent, Older Adults and Dementia, Mood, Anxiety and Personality, Psychosis and Psychological medicines.

If you would like to find out more about how to use the C4C register to recruit potential research participants – Please contact the R&D Manager, Jenny Liebscher in the first instance – Jennifer.liebscher@kcl.ac.uk or call 0207 848 0251. Subsequently, a CRIS (Clinical Records Interactive Search) project application will need to be completed. Please contact cris.administrator@slam.nhs.uk for more information.

Thanks for reading!

Enjoy the May Bank Holidays: Monday 4th and Monday 25th

Acknowledgements: The C4C register is part funded by the National Institute for Health Research (NIHR) Biomedical Research Centre and Dementia Unit at South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry, Psychology and Neuroscience (IoPPN) at Kings College London.

Thank you for your continued support and contributions to the C4C register