

Culturally-adapted Family Intervention RAG Information Sheet

What is Culturally-adapted Family Intervention?

Culturally-adapted Family Intervention (or CaFI) is the name of a study which is researching the effectiveness of culturally-sensitive Family Intervention for people from African and Caribbean backgrounds with psychosis, and those close to them.

Family Intervention (FI) is a key therapy used to help treat people with psychosis and provide support for those who care for service users. FI should be offered to all service users across the country, but it is rarely offered to or taken up by people from Black backgrounds.

We believe standard FI is not culturally sensitive enough to be helpful for people from Black backgrounds, so we have made changes to the model to make it more relevant to the unique experiences of people of Black ethnic groups in England. CaFI has been formulated with the help of service users and carers across the country.

Some examples of the changes we have made include (but are not limited to):

- Making resources more relevant by adding in cultural beliefs around mental illness;
- Using representative imagery and language;
- Enabling service users who have lost contact with family to take part with a volunteer, known as a Family Support Member (FSM), who might be someone they know, such as a friend or a religious leader, or a volunteer recruited by CaFI.

We have already tested CaFI with a small group of 26 service users and carers from Caribbean backgrounds in a feasibility study in Manchester, which showed promising results. We are now testing CaFI with African and Caribbean people, on a larger scale.

We have been given more money by the National Institute of Health Research, or NIHR (the research arm of the NHS) to trial CaFI with 202 service users across the country as part of a Randomised Controlled Trial (RCT). We will recruit 404 service

users overall, and 202 will be randomly allocated by a computer to receive CaFI, whilst the other 202 will have their normal care. We will be recruiting people from Greater Manchester, the West Midlands and Warwickshire, London, and Southampton, to test CaFI.

All service users and their family or FSM will take the same measures at 0, 6, and 12 months, which will be analysed to let us know whether CaFI helps improve outcomes for the people who receive it. The findings will then be used to inform funding and policy in the NHS.

To find out more about CaFI, please see our webpage -

<https://sites.manchester.ac.uk/cafi/>

On this webpage there is also a video featuring some people who participated in the feasibility study, including the Research Advisory Group, talking about their experiences of being involved.

Who will be in the Research Advisory Group?

The CaFI Research Advisory Group (or RAG) is a group of people with different lived experience of psychosis as a member of the African or Caribbean Community. The RAG group will help guide the study throughout the trial acting as representatives for service users, carers, and members of communities.

Members of the RAG will be:

- Service users, carers, family members, friends, or with significant experience of supporting people with psychosis in a professional capacity, for example a faith leader.
- African or Caribbean heritage. Members can be born in England and identify as Black British, or Mixed for example, as long as they have at least one grandparent or parent from an African or Caribbean Country.
- Of another heritage with experience supporting someone who is from an African or Caribbean background with psychosis – for example, a White British mum who has a Mixed child with psychosis.

We are not looking for any other specific experience or characteristics. We want the RAG to represent a wide range of demographics and backgrounds.

What will the RAG do?

The RAG will help us over the next three years of the study by giving us feedback and support.

Examples of the activities we may ask people to do:

- Promoting CaFI, by sending emails to your contacts, handing out flyers to churches, etc.
- Engaging communities and organisations, for example, by introducing us to organisations in your area that you think will be interested in our work.
- Advising our team, such as helping us edit resources, so they are more appealing
- Supporting communication of findings, such as editing language to make it easier to read, speaking at events on our behalf.

RAG members will meet at least twice yearly, via video call and once a year in person. More meetings will happen during the pilot phase of CaFI, which will be over the next 12 months. Members will not be expected to attend all meetings – we understand that you have lives outside of our work and scheduling may not always be perfect. We will work around availability of the majority of members, by sending out polls. The location of face-to-face meetings will be confirmed when they are being scheduled, but it is likely some people will have to travel long distance to attend these.

Members may also be asked to do ad-hoc tasks. We will ask people to volunteer for these, by giving a summary of what is required, the payment for this, and timescales to complete these in.

What do RAG members get from CaFI?

Members will receive payment, expenses, and opportunities to develop skills, training, and experience.

Payment

Members will be paid £25 an hour for each meeting attended and task completed (excluding travel time). This is in line with recommended rates for PPI activities by NIHR.

Meetings and tasks will be given time frames and payment rates, to make it clear how long we expect you to spend on them. You are more than welcome to spend extra time on a task if you want to, however we will not be able to pay extra for this, due to budget constraints.

Payments for PPI are no longer considered protected and now affect benefits. It is your responsibility to research into how payments may affect your benefits if you claim any. Please follow this link for more information -

<https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392> and select 6. Welfare Benefits from the contents bar on the right hand of the page. We also recommend you seek independent guidance from the Benefits Advice Service and your local job centre.

When it is clear to you how ad-hoc work on CaFI will affect your benefits, please let us know whether you would like to proceed with working on the project, and if there are any adjustments we can make to prevent issues. This might mean paying you less than the payment threshold for your type of benefits, or not making any financial payments to you at all but reimbursing you in alternative ways, for example, paying for you to attend a training course or conference.

Expenses

Any reasonable expenses will be paid for by the CaFI team. This includes travel costs (standard train fares, mileage) and food costs (max £25 per day) when attending face-to-face meetings. We will pay for a hotel room ONLY in cases where travel will exceed 4 hours each way (i.e. 8h of travel to attend a 6h meeting). In most cases, we will pay expenses for you in advance (e.g. by booking train tickets), so there will be limited out of pocket costs for you.

Opportunities to develop skills, training, and experience

Being part of the RAG will give you an insight into the world of health research and academia. We hope you will find it useful and that it will help you develop skills and

knowledge. We'd also like to enable people identify opportunities to develop these further in their spare time outside of the RAG.

We can do this by:

- Helping you access free training, such as Good Clinical Practice online training.
- Enabling access to university libraries and resources, by issuing honorary contracts.
- Connecting you with other researchers and PPI projects to find new opportunities.

How to contact us

If you are interested in taking part or have any questions about the study, please contact:

cafi@gmmh.nhs.uk