

The UPLIFT Study – Lived Experience Advisory Group



Hello! You are invited to join a new lived experience advisory research group for people living with HIV and cognitive difficulties. This group will be formed of individuals who experience these types of problems, along with clinicians, researchers and advocates who work with people living with HIV.

This group represents the first of its kind in the UK and we hope it can mark the start of a programme of work aimed at maintaining or improving quality of life in people living with HIV PLWH who have cognitive difficulties . The purpose of this group will be to provide guidance and ideas for the development and delivery of new research studies in this area. This group will be initially funded with a grant from the University of Sussex’s Lived Experience Research Participatory Fund. This grant will also fund our first study which will identify the research priorities for the improvement of quality of life in people living with HIV and cognitive difficulties.

Why is quality of life in people living with HIV and cognitive difficulties so important?

Thanks to the success of antiretroviral therapy, the UK is home to a growing, ageing population of people living with HIV. However, cognitive difficulties in people living with HIV is an increasingly important health concern, and the number of people experiencing cognitive difficulties is expected to rise as the HIV population continues to age. People living with HIV are more likely to experience cognitive difficulties, than those without HIV.

To date, research has primarily focused on the underlying causes of cognitive difficulties and improving screening techniques. More recently, specialist HIV memory clinics have been developed, such as the Orange Clinic in Brighton, which have aimed to address cognitive difficulties in people living with HIV . Crucially however, research about treatments aimed at assisting people living with HIV to live well with cognitive difficulties do not currently exist. This represents an important un-met need in this group of people.

What are we planning to do?

The UPLIFT Study (**U**nderstanding **P**riorities for improving quality of **L**ife in people living with HIV and cognitive impairment**T**) was designed to begin to examine some of these needs and understand in what areas we can think about producing interventions which might improve the quality of life of this group. With this in mind, the aims of the study are:

- To establish a lived experience research advisory group for people living with HIV and cognitive difficulties
- To co-produce (i.e. with people living with HIV and cognitive difficulties, clinicians and researchers) the key research priorities for this group of people

Along with the input from the lived experience research advisory group, an understanding of the research priorities for improving quality of life will be gained from a series of focus groups with individuals experiencing these issues and from clinicians who work with people with HIV and cognitive difficulties. We plan to co-produce and reach a consensus on **ten key priorities**. We would then aim to use this information to develop future research studies which aim to improve quality of life in people living with HIV and cognitive difficulties.

What would being a member of the lived experience research advisory group involve?

Being a member of the lived experience advisory research group involves taking part in four meetings, over the course of 3/4 months. Meetings will last 1.5 hours and be held over Zoom, and we will try our best to find times which are convenient for everyone. In the meetings we will discuss the results of our previous work and the emerging findings from our focus groups. We will want to hear your views on how this information can be translated into meaningful actions and get your thoughts on how we might improve quality of life in people living with HIV and cognitive difficulties

We plan to include the lived experience research advisory group in our future ongoing research so if you would like to remain being a member and be involved in the follow-up study you can do so.

Ways of working and confidentiality

During the first meeting we will agree ways of working which will be rooted in collaboration, consultation, respect and compassion. People with HIV and cognitive impairments will be paid for their time in the form of a £20 Love2Shop voucher per meeting.

We will record the meetings so that we can remember what is said accurately, however we will keep all transcripts anonymous, so your name won't be attached to anything you say. Recordings of the meeting will be destroyed once meeting minutes have been written-up. Your personal information, such as name and contact details, will be kept by us in complete confidence. Whether or not you choose to take part in this group will not affect your treatment or the care you receive in anyway. If you have any other concerns about your personal information or how we will use your data please get in touch

If you are interested in joining the lived experience research advisory group for people living with HIV and cognitive difficulties or would like more information please contact:

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