

## Exploring strategies to support the health and well-being of people living with HIV

Thank you for taking part in our study. We are pleased to share the findings of this research and the next steps for our project.

### Background to the project

People living with HIV in the UK on treatment have normal life expectancy and receive excellent HIV clinical care. However, this care does not necessarily help with some social or psychological issues that people may face (for example, housing, employment or mental health problems).

The NHS Long Term Plan (<https://www.longtermplan.nhs.uk>) aims for people with long-term health conditions, like HIV, to be fully involved in decisions about their health and wellbeing. It recognises that ‘what matters to someone’ is not just ‘what’s the matter with someone’. Health and wellbeing coaching, social prescribing and community-based support could help people to better manage their own health and improve well-being but have not been tested yet in people with HIV in the UK.

The Needs Informed model of Care for people living with HIV (NICHE) ([www.niche.ac](http://www.niche.ac)) is a five-year NIHR funded research programme aiming to design a new, person-centred model of care to improve the health and well-being of people living with HIV. This includes the design and testing of a health coaching and social prescribing intervention in a trial.

### What did we do and who took part?

Last year, we conducted focus groups with people living with HIV and interviews with clinical and non-clinical workers who support people living with HIV. We spoke with 37 people living with HIV and 20 clinical/non-clinical workers.

We wanted to understand the challenges and concerns of people living with HIV in England and what ‘living well’ means.

We also asked for feedback to help us design a health and well-being coaching intervention. This intervention is being tested in a randomised controlled trial called SPHERE within the NICHE programme. The aim of the trial is to see whether the intervention improves health and well-being in people with HIV.

### What did we find?

People with HIV described living well to include:

- living in an unrestricted way (for example, experiencing life in the same way as other people)
- a desire to live fulfilled and satisfying sex lives without fear of stigma
- aspirations of choice (or autonomy) in health and healthcare (for example, having the self-confidence to advocate for the services you need)

We found that stigma and discrimination continue to affect the health and well-being of people with HIV. Living well means living beyond an HIV status and having good social support (from friends, family and loved ones) and supportive intimate relationships so people age well with HIV and live long, fulfilled and happy lives. The feedback from the focus groups and interviews was also used to design our intervention (see examples in Table below).

You said...

We did...

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| <ul style="list-style-type: none"> <li>• <b>People should have a choice with how (format) the intervention is delivered</b></li> </ul>   | <ul style="list-style-type: none"> <li>• The first two sessions will be face-to-face to build rapport with a health coach.</li> <li>• Further sessions will be in the format preferred by the person being coached (e.g. in person, online, by phone).</li> </ul>  |
| <ul style="list-style-type: none"> <li>• <b>There was no consensus on the number of coaching sessions to be delivered</b></li> </ul>   | <ul style="list-style-type: none"> <li>• Each person will receive a maximum of eight coaching sessions over 3-months.</li> </ul>   |
| <ul style="list-style-type: none"> <li>• <b>It was undecided who would be best placed to deliver coaching sessions. Some people working in HIV services felt a peer with lived experience would be best, but people with HIV preferred a trained health professional who works in HIV services.</b></li> </ul> | <ul style="list-style-type: none"> <li>• Experienced HIV healthcare professionals have been trained as coaches across seven sites. This includes HIV nurses, health advisors, an HIV pharmacist and a social worker.</li> </ul>  |
| <ul style="list-style-type: none"> <li>• <b>Staff delivering the intervention need training and support</b></li> </ul>   | <ul style="list-style-type: none"> <li>• Health and well-being coaches will receive monthly supervision from a trained behavioural psychologist and monthly drop-in sessions from the social prescribing training team.</li> <li>• All have received training and will complete a diary to reflect on sessions and have access to online support and self-directed learning.</li> </ul>  |
| <ul style="list-style-type: none"> <li>• <b>People may face barriers accessing support services</b></li> </ul>   | <ul style="list-style-type: none"> <li>• Coaches will have direct contact with a social prescribing lead who works closely with local authority social prescribing link workers, Third Sector organisations and primary care local networks.</li> <li>• Coaches will receive a social prescribing directory that outlines local community resources. This should mean nobody is missed from receiving the support they need and information on services is kept up-to-date.</li> </ul> |

- **Reaching the end of sessions may be difficult**
- The coaches' training covered topics including boundaries, expectation setting and closure planning.

### What happens next?

- The findings about the concerns and ongoing challenges being faced by people with HIV in England have been written up into a journal article. We can share this once it is published.
- Recruitment to the SPHERE trial will open this summer across seven HIV clinics in England.
- We will be interviewing trial participants and staff throughout the duration of the SPHERE trial to understand their views and experiences of coaching sessions, including how they might be improved. Interviews will form part of a process evaluation sub-study.

### Where can I learn more?

- For more information on the NICHE research programme, please visit: [www.niche.ac](http://www.niche.ac)
- For more information on the SPHERE trial, please visit: <https://www.birmingham.ac.uk/research/bctu/trials/pd/sphere>
- If you would like to be kept updated on the study, please email: [info@niche.ac](mailto:info@niche.ac)

### Study details

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- Ethical approval: Health Research Authority (REC ref: 23/IEC08/0008)

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The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.