

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.

Please note, a glossary of specific terms used in this summary can be found on page 3.

Background to the project

People living with HIV in the UK can expect a normal life expectancy and receive excellent HIV 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 England in people with HIV.

The Needs Informed model of Care for people living with HIV (NICHE) (www.niche.ac) is a five-year 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 will include the design and testing of a health coaching and social prescribing intervention.

What did we do and who took part?

Last year, we conducted focus groups (small group discussions) 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 will be 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"> • People should have a choice with how (format) the intervention is delivered | <ul style="list-style-type: none"> • The first two health coaching sessions will be face-to-face to build rapport with a coach. • Further sessions will be in the format preferred by the person being coached (e.g. in person, online, by phone). |
| <ul style="list-style-type: none"> • There was no consensus on the number of coaching sessions to be delivered | <ul style="list-style-type: none"> • Each person will receive a maximum of eight coaching sessions over 3-months. |
| <ul style="list-style-type: none"> • It was undecided who would be best placed to deliver coaching sessions. Some people working in HIV services felt a peer with lived experience of HIV would be best, but people with HIV preferred a trained health professional who works in HIV services. | <ul style="list-style-type: none"> • 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. |

What happens next?

- The findings about the concerns and ongoing challenges being faced by people with HIV 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 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
- 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

Study details

- Sponsor: UCL Joint Research Office
- Funder: National Institute for Health and Care Research [NIHR202038]
- Ethical approval: Health Research Authority (REC ref: 23/IEC08/0008)

Glossary

Some definitions taken from NIHR (<https://www.nihr.ac.uk/glossary/>)

- **Focus group:** a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.
- **Intervention:** the process of intervening on people, groups, entities or objects in an experimental study. In controlled trials, the word is sometimes used to describe the regimens in all comparison groups, including placebo and no-treatment arms.
- **Interviews:** in research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the person (or people) being interviewed. Interviews can be carried out in person (face-to-face) or over the phone.
- **Process evaluation:** this 'aims to explain how complex interventions work', or 'how an intervention results in an outcome'. More here: <https://www.gov.uk/guidance/evaluation-in-health-and-wellbeing-process>
- **Randomised Controlled Trial (RCT):** an experiment in which two or more interventions, possibly including a control intervention or no intervention, are compared by being randomly allocated to participants. In most trials one intervention is assigned to each individual but sometimes assignment is to defined groups of individuals (for example, in a household) or interventions are assigned within individuals (for example, in different orders or to different parts of the body).
- **Social prescribing:** is a 'way which connected people to activities, groups, and services in their community to meet the practical, social and emotional needs that affect their health and well-being.' More here: <https://www.england.nhs.uk/personalisedcare/social-prescribing/>
- **Sub-study:** this is a 'study within a study'. In other words, people involved in an existing study are invited to take part in another study which may ask a slightly different research question which relates to the work of the main study.

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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.

