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**Assessing the preferences of people living with HIV for the delivery of a health coaching and social prescribing intervention using a discrete choice experiment**

**PRIVACY INFORMATION**

About the discrete choice experiment for the design of a health coaching and social prescribing intervention for people living with HIV

This Discrete Choice Experiment study will assess people living with HIV’s preferences for the design and delivery of a health coaching and social prescribing intervention. The intervention aims to improve the health, well being and quality of life of PLHIV. Specifically, the study will assess service factors like type of practitioner delivering the intervention, session length and mode of engagement with social prescribing.

This privacy notice should be read alongside the information leaflet for participants and provides further details about the information we collect and use for the survey. It explains what your rights are and how you can find our more or raise a concern.

The UK Health Security Agency is an executive agency of the government, sponsored by the Department of Health and Social Care. The Department of Health and Social Care and University College London are the data controllers for the data collected and used for the Discrete Choice Experiment study.

You can find out more about the UK Health Security Agency at [www.gov.uk/government/organisations/uk-health-security-agency](http://www.gov.uk/government/organisations/uk-health-security-agency) and about University College London at [www.ucl.ac.uk/london](http://www.ucl.ac.uk/london).

Further information about how the UK Health Security Agency protects the information it uses to fulfil its remit can be found at <https://www.gov.uk/government/publications/dhsc-privacy-notice/dhsc-privacy-notice>. University College London has also published privacy information for participants in health and care research studies at [www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies](http://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies).

The Discrete Choice Experiment study is funded by the UK Health Security Agency and the National Institute for Health Research through a grant to University College London. The National Institute for Health Research will not have access to any information about you at any time.

The information we collect

The types of information we collect if you take part in the Discrete Choice Experiment are:

1. Service factors e.g., preferences for type of practitioner delivering the intervention, frequency of contact, number of appointments available, type of meeting (e.g., face to face or online), types of support of interest (e.g., financial help, help with housing or benefits, help with accessing social groups)
2. Mental health information asking about recent experiences of any symptoms relating to depression.

Further, these data will be linked back to your responses in the Positive Voices survey which includes information on your demographics for example your age, sex, ethnic group, sexual orientation and behaviours, religious beliefs, living arrangements, employment status, and health and treatment information, including information about your medical diagnoses, health service use, needs and satisfaction, and general health and wellbeing.

How we collect your information

We collect your information from you directly when you complete the Discrete Choice Experiment questionnaire. The information we collect is de-personalised. This means it does not directly identify you. We have your email address or telephone number because you provided this in your response to the Positive Voices survey and agreed to be contacted for further research. As stated in the Positive Voices questionnaire, your email address will only be accessible to the Positive Voices team at the UK Health Security Agency and will only be used to contact you to invite you to research initiatives such as this study.

You will be emailed directly from the UK Health Security Agency inviting you to take part in the study. The email will contain a link to the information leaflet and questionnaire. Once you have submitted your responses the Positive Voices team will link these to your Positive Voices questionnaire response using a unique identifier (a 6-letter code) that has been assigned to you. You may receive up to two reminder emails up to 14 days after initial contact.

How we collect your information

Once we have linked your Discrete Choice Experiment survey responses to your Positive Voices survey responses, we analyse this to understand more about your health and care needs and preferences for use of services.

The UK Health Security and University College London will publish information about the findings in academic journals. These papers will not contain any information that could be used to identify you.

How we store and protect your information

Your online questionnaire responses are collected using a secure website, and your information is stored on computer systems that are regularly tested to make sure they are secure and kept up to date to protect them from viruses and hacking. The survey information can only be seen by UK Health Security Agency and University College London researchers working on this study and who have been specially trained to protect your confidentiality. Strong controls are in place to make sure these staff can only see the minimum amount of information they need to do their job.

Your information is held in the UK only and will not be transferred outside of the UK.

How long we keep your information

The information we collect will be kept for as long as the Positive Voices and Discrete Choice Experiment study is running or a maximum of 20 years, whichever is less.

Your rights over your information

Under data protection law, you have several rights over your personal information. As we do not collect information that directly identifies you such as your name and NHS number, this means we may not be able to act on all your rights.

Our legal basis to use your information

The law on protecting personal information, known as the UK General Data Protection Regulation (GDPR) and the Data Protection Act 2018, allows us to use your information for this study. The sections that apply for the UK Health Security Agency are:

* GDPR Article 6(1)(e) ‘processing is necessary for the performance of a task carried out in the public interest’
* GDPR Article 9(2)(i) ‘processing is necessary for reasons of public interest in the area of public health’
* GDPR Article 9(2)(j) ‘processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes’
* Data Protection Act 2018 Schedule 1 Part 1 (3) ‘public health’
* Data Protection Act 2018 Schedule 1 Part 1 (4) ‘research’

The sections that apply for University College London are:

* GDPR Article 6(1)(e) ‘processing is necessary for the performance of a task carried out in the public interest’
* GDPR Article 9(2)(j) ‘processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes’
* Data Protection Act 2018 Schedule 1 Part 1 (4) ‘research’

The Discrete Choice Experiment study has been reviewed and approved by the London Harrow NHS Research Ethics Committee (project number 13/LO/0279).

Our legal basis to use your information

If you would like to find out more about the survey or want to speak to the research team before deciding whether to take part, you can email the NICHE study coordinator at infor@niche.ac.

If you would like to speak to someone at the UK Health Security Agency about Positive Voices you can email positive.voices@phe.gov.uk

If you have any concerns about how we use and protect your personal information, you can contact the Department of Health and Social Care’s Data Protection Officer at data\_protection@dhsc.gov.uk or by writing to:

Office of the Data Protection Officer

Department of Health and Social Care

1st Floor North

39 Victoria Street

London SW1H 0EU

You also have the right to contact the Information Commissioner’s Office if you have any concerns about how we use and protect your personal information. You can do so by calling the ICO’s helpline on 0303 123 1113 or visiting the ICO’s website at [www.ico.org.uk](http://www.ico.org.uk)

About this privacy information

In the event of changes to way we collect and use the information for the Discrete Choice Experiment survey, we may need to revise this notice. If we do, the date and version number will change.