

'HIV – Those Who Stayed Behind' Project and Participant Information Leaflet

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Project Introduction

HIV-Those Who Stayed Behind is an oral history project to tell the stories of the HLTS – HIV Long-Term Survivors – who are often overlooked in the dominant discussions about HIV. The project will record the personal life stories of those diagnosed with HIV and/or AIDS during the early epidemic stages and how they lived their lives, having to deal with stigma and the many changes and uncertainties over the years. Changes, such as the development of new medications and treatments to the present day, as well as life expectancy projections, have now been considered part of the long-term illness cohort.

These are stories about love, medical issues, struggles and above all, their journey. Because every human being is unique and has their own story to tell.

Further aims

The project also aims to further educate audiences about the often-hidden side of many HIV-positive individuals navigating everyday life, who have lived with the virus and its stigma for decades, bringing the past and the new generation's experiences together. Their stories can help many people understand the advances in treatments and the condition, while also offering a positive contribution to their lives and those affected by their diagnosis through a better understanding of the journeys others have experienced.

While in the UK, groups in different shapes and forms are focused on the undetectable equals untransmittable (U=U) campaigns and aiming to eradicate the virus by 2030, many countries still lack access to basic knowledge and treatment.

There is no better time to bring those stories into the conversation than now, when so many changes are happening in the international support landscape, and many patients are risking losing their treatments altogether.

Participants

Participants are required to be part of the HLTS cohort - those who contracted the virus more than 15 years ago or prior to the availability of Highly Active Antiretroviral Therapy in 1996.

Participation in this project is on a voluntary basis, and participants have the right to withdraw their participation in the project at any time during the process up until deposit at the British Library without needing to justify their decision. They can do so by directly contacting the writer/researcher using the email listed at the top and bottom of this document to express their decision. After deposit at the British Library, the oral history interview cannot be deleted but participants can negotiate changes to access conditions.

What would taking part involve?

An informal phone call or email exchange will be set up to explain the interview format and to agree on the most convenient time for the participant and researcher to conduct an oral history interview. A full interview should take at least two to three hours, but it may be longer. This interview will preferably take place in person using a Tascam DR-05XP recorder, but online interviews can also be arranged, depending on location and convenience.

Before the interview you will be asked to sign a participation agreement that signifies your agreement to take part in the project, and which allows Joaquim A. Neto and the British Library to process your personal data. After the interview you will be asked to sign a recording agreement to set the conditions under which your interview will be archived and made available at the British Library, and under which Joaquim A. Neto will use your interview to write a short story narrative.

What are the possible benefits of taking part in this study?

To contribute to the discussion with a personal story that will help many to understand the stigmas around HIV that have endured through so many years, and unfortunately, still do. Many people find reflecting on their past experiences through an oral history interview to be a positive experience. Some find it helpful to talk about past feelings and experiences which they might not have recounted before.

What are the possible disadvantages, side effects or risks of taking part in this study?

Some conversations during the interviews could trigger some individuals who have experienced constraints, stigma or other types of prejudice during their life due to their HIV status. This will be mitigated by ensuring that we can stop the recording when necessary and reinforcing the options for redaction (closure) outlined in the 'Archiving and Access at the British Library' section of this information sheet. Participants will be free to request the deletion of their interview at any point up until the files are deposited at the British Library, if they no longer wish their story to be recorded for the archive.

Archiving and access at the British Library

The full unedited audio interviews, as well as an interview summary, will be deposited at the British Library for long term archiving. After the interview, participants will sign a recording agreement to make decisions around access and copyright. You may choose to temporarily

redact all or part of the interview for a period of a time but once the interview is deposited at the British Library no part of it can be permanently deleted. The interview will be catalogued at the British Library and made available to researchers in the reading rooms in St Pancras, London and Boston Spa, Yorkshire. With your permission the full interview could also be made available online through the British Library Sounds website. It is the position of the British Library that it is not possible to anonymise an audio recording because of the amount of identifying information in an oral history interview, including the participants voice. If you are concerned about any part of the interview being made available at the British Library you should request a redaction for that part for a period of time, for example, ten years; this redaction should be noted on the Recording Agreement signed at the end of the interview. As part of the deposit Joaquim A. Neto and the British Library will also complete a review for any parts of the interview that may need to be temporarily redacted under data protection or defamation legislation.

Short story narratives

After recording, Joaquim A. Neto will use the interviews to create written short story narratives, each approximately four to five thousand words, that will be published on a dedicated website at <https://thosewhostayedbehind.com/> With participant permission, the website will also include photographs taken by Joaquim A. Neto or supplied by the interviewee. The website will include sections on best practices and resources for support. Joaquim A. Neto will share the short story narratives with you for your review and comments, and you can choose to have parts of them removed or edited. You can also choose whether the short story narrative will be published under your real name or a pseudonym. **Please note that any redactions you make to the short story narratives or pseudonyms you choose will not apply to the oral history interviews deposited at the British Library.**

The official launch of the website will be supported by a visual exhibition and promotion on regular social media channels to make those stories accessible to large audiences.

If conditions permit, a book/paper version of a diverse selection of those stories will be printed. Participants whose stories will be selected to feature in the book will then be contacted with further information to obtain their approval for or against publishing their stories in book format.

What are my rights as a participant?

- The right to withdraw from participation at any time up until deposit at the British Library.
- The right to request that any recording cease.
- The right to have any data withdrawn and destroyed, provided it can be reliably identified, and provided that so doing does not increase the risk for the participant, up until deposit at the British Library.

- After the deposit at the British Library, the right to change access restrictions in the oral history interviews.
- The right to be identified or de-identified in any photographs intended for public publication, before the point of publication, if applied and with your approval.
- The right to use your name or a pseudonym in the short story narratives – remembering that any pseudonym you choose will not apply to the oral history interviews deposited at the British Library.
- The right to have any questions answered at a convenient time for both you and the interviewer.

If you would like to learn more about the project or give an oral history interview, please email j-anew@hotmail.co.uk or fill out the Contact us form at <https://hiv-thosewhostayedbehind.com/>

Thank you for taking the time to read this document.