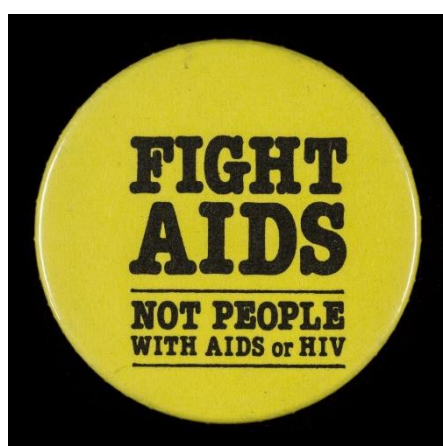


Documenting the HIV/AIDS epidemic: a survey of HIV/AIDS archives in the United Kingdom



Information sheet

January 2023-January 2025



About this document

This document provides information about the 'Documenting the HIV/AIDS epidemic: a survey of HIV/AIDS archives in United Kingdom' project. The 2-year project is based in West Sussex Records Office, in Chichester in West Sussex and funded by Annabel's Foundation, set up by the founders of the HIV/AIDS charity, AVERT.

Why preserve records relating to the history of the HIV/AIDS epidemic?

Quite simply history matters. By having a greater understanding of the past, we can have a better understanding of the present. The global pandemic continues affecting over 36 million worldwide, and many of the medical, political, and societal issues surrounding the disease remain with us today. By promoting and disseminating the history of HIV/AIDS through ongoing research, publications, and theatrical and artistic productions it helps **raise awareness** of HIV/AIDS.

By preserving the history of HIV/AIDS, it provides **evidence** of the struggle and perseverance of those affected by the pandemic, and how stigma and discrimination continue to hold back its eradication.

HIV/AIDS continues to disproportionately affect **marginalised and vulnerable communities** which often meant that they had to self-organise to provide the necessary care, support, and treatment to those living with HIV. It was also through the efforts of these communities through acts of activism and protest that increased awareness of the HIV/AIDS and pressured national and local governments to respond.

These stories and histories sadly are at the **most at risk**, as often the people and organisation who created them and lived through them are no longer around and sometimes only traces of their activity was preserved in archives operating at the time.

By contributing **your story**, whether through depositing historical records in archives or recording an oral history account about HIV, it gives us a better understanding of the past and hopefully goes some way in capturing the diversity of experiences associated with the disease.

An archive has the power to record *the good, the bad, and the ugly* of historical events, giving us fresh insights on the behaviours and attitudes of the time, and not only just record the facts associated with an event but can enrich our understanding through the personal testimony and stories of those who were there.

By contributing to this project, you will be contributing to preserving the history of HIV/AIDS and increasing our understanding of one of the most significant pandemics in the 20th and 21st centuries.

1) About the survey

Summary of proposed project

The project involves surveying HIV/AIDS records of historical value in United Kingdom; both those already held by archive services and those which are still in private hands. It will capture key information about the content and scale of these collections and where possible provide information about accessing these records to the public. Where archives are in private hands, the project archivist will offer professional support regarding collection management, preservation and storage, if requested, and can help connect owners with archive services if they are looking for a longer-term home for their records.

The project will encompass all archival material (e.g., film, digital, visual material), not just paper-based archives. It will not be limited to a specific time span but will look at material dating from the start of the AIDS epidemic up to the present day.

The project started in January 2023 and will run until January 2025. Between April 2023 and October 2024, the Project Archivist, Chris Olver, will be surveying archives in private hands and carrying out site visits.

Deliverables:

- Published detailed report of HIV/AIDS archives in the UK to be published online on the WSRO website and circulated to archives with existing collections, and organisations interested in the history of HIV/AIDS.
- Providing an online resource which provides details of both archives found in archive repositories and private hands for the first-time.
- A list of recommendations on how the understanding of the history of HIV/AIDS in the heritage sector can be strengthened.
- Advocating for the use and further study of these resources through highlighting stories and personal histories relating to these collections through presenting case-studies and blog posts for the project website and final report.
- Providing the evidence for future projects, to further improve our HIV/AIDS heritage through the cataloguing of existing collections, creating or strengthening our networks of HIV/AIDS archives, undertaking oral history projects to fill the gaps, conducting outreach activities to raise awareness of HIV/AIDS holdings.

What do archive services collect?

Archive services select material which is considered of **long-term research value** for permanent preservation. This typically understood as having a historical value relating to an organisation, individual, place or subject.

What archives decide to collect can vary but often an archivist must assess the following:

-**long-term research value** (evidential or historical value)

-**collecting policy**: all archive services have a collecting policy which outlines what archival records they will collect. There may be a geographical basis for the collecting policy (e.g. local authority record offices will collect records relating to their county or city) or a thematic one (e.g. the People's History Museum collects records relating to democracy). Archivists will assess any records offered to ensure they fit their collecting policy.

-**physical condition**: and cost associated with its preservation and making it accessible.

-**custodial and legal conditions of the records**: who owns the records, and can they legally be donated to an archive? What are the conditions of the deposit? Can these records be made publicly available or do they contain sensitive private information about living individuals.

-**size of the collection**: does the archive have the storage space or resources in order to preserve and make available this collection in future

Archives must also consider other characteristics such as authenticity, integrity, usability, and reliability.

What happens to records donated to archive repositories?



Figure 2 Image of a typical archive storage facility. National and local record offices are required to have facilities which align with the British Standard 5454.

Every archive service will have their own acquisition policy, providing details of how any donation or deposit will be processed and managed when the records are in their care. If an archive service takes in new material, it will initially be physically assessed to see what condition the material is in and whether preservation or conservation treatment is required. After the initial assessment, the material will be stored in secure, environmentally controlled strongrooms and will be repackaged in suitable storage containers to reduce the physical

deterioration of the material.



Figure 3 Conservators are highly trained professionals who can conserve, repair or restore a variety of cultural artefacts. (https://commons.wikimedia.org/wiki/File:Paper_Conservation_Department_Cieszyn_Library.jpg)

The next stage is cataloguing the collection, which is how archivists describe an archive collection. This involves listing the new records, arranging them into logical groups, assigning them a unique reference number, and surveying the records for any legal or sensitivity issues which might mean closing the record from public inspection for a certain number of years.

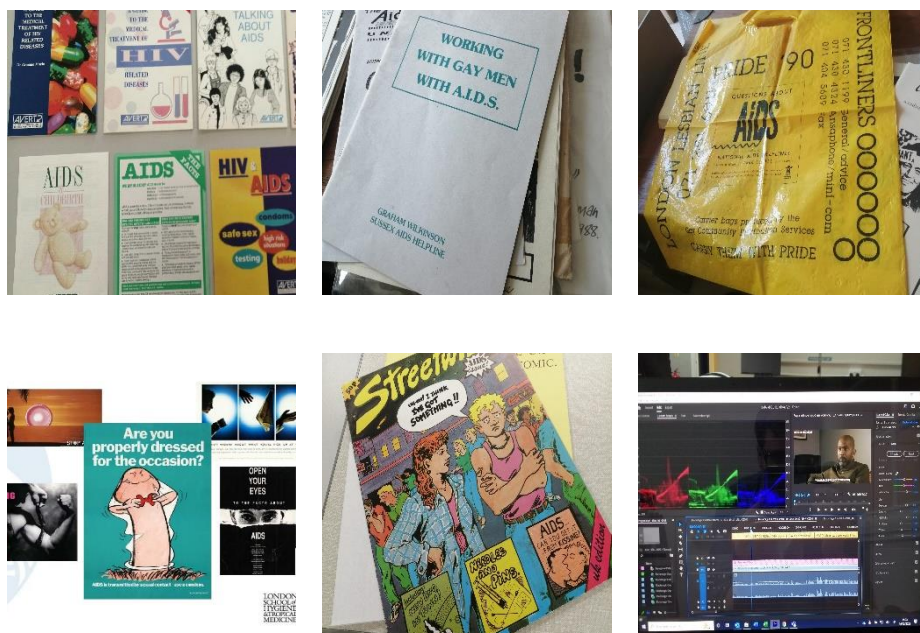


Figure 4 Digitisation of a manuscript. Digitisation of archive items often requires professional training to undertake. (https://commons.wikimedia.org/wiki/File:Dunhuang_manuscript_digitisation.jpg)

Some archive collections are selected to be digitised and available to view online although this is a relatively small sample of overall archive holdings. Primarily, this is because of the costs involved in creating digital copies of the collection and the copyright and other legal issues in publishing online. Material in the collection may occasionally be used for displays, teaching visits or promoted on social media but would be carefully supervised and handled on these occasions.

What do HIV/AIDS archives look like?

There is a great variety of records relating to HIV/AIDS found in UK archives which reflect the seismic impact that the virus had since the epidemic began in the 1980s. By 1987, the UK government amid mounting fear of the growing number of cases, launched a national HIV/AIDS public education campaign and provided financial support to health and support services across the country. Records of this activity can be found across national and local archive services.



[clockwise from top left]: selection of AVERT booklets (WSRO Archives); leaflets from Sussex AIDS Helpline (WSRO site visit); plastic bag from Brighton Pride, 1990 (WSRO site visit); booklet from selection of HIV/AIDS prevention posters (courtesy of LSHTM archives); Streetwise, a safer sex magazine for teenagers produced by the Nottingham Health Authority, 1987, (WSRO Archives); screenshot of National HIV Story Trust interview being processed at London Metropolitan Archives.

In more recent years, archive services have increasingly taken in records related to the history of groups most impacted by the virus, such as LGBTQ community, intravenous drug users, haemophiliacs, sex workers and people from the African diaspora. These records tend to show evidence of the organisations set up to support and care for people living with HIV/AIDS in the affected community, along with HIV/AIDS prevention and treatment activism.

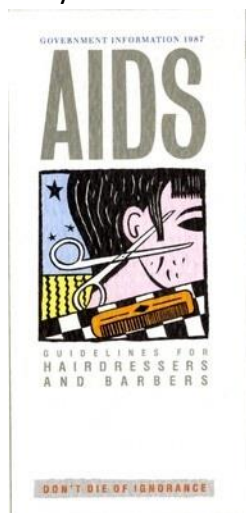
Personal testimonies of people with lived experience of HIV/AIDS epidemic have also been collected from the 1980s onwards, and is complimented by the literature, art and film and theatrical works which were produced in response to the disease.

There is extensive collections of ephemera, posters, zines, magazines, t-shirts and even safer sex paraphernalia such as condoms found across archives and museum collections.

Why collect records relating to the history of HIV/AIDS?

HIV/AIDS archives are an important cultural resource in our current understanding of the ongoing pandemic. They provide a repository of the collective memory of those with lived experience of the disease and memorialise the lives which were lost and reflect the mobilisation of affected communities for the treatment and support of those impacted by the disease. The archives document the epidemiological and public response of government, community and health professionals in preventing and treating the disease, and which continues to have relevance not just to the treatment of HIV/AIDS, but other diseases such as Covid-19 and Mpox.

They are of immense value to anyone researching the history of sexuality, science and



AIDS Information leaflet, 1987 (LSHTM archives)

medicine, as well as social and cultural change. Recognition of the importance of records documenting the HIV/AIDS epidemic in the UK and their potential for research is reflected in the award of Wellcome Trust funding to catalogue HIV/AIDS archives held at the London School of Hygiene and Tropical Medicine (2013) and to London Metropolitan Archives (2020) and the addition of the HIV/AIDS archives held by Lothian Health Services to the UNESCO UK Memory of the World Register in May 2011.

The history of HIV also contains significant personal and communal history relating to marginalised groups, which have been historically under-represented or absent in UK archive repositories. It is the aim of this project to help to promote and preserve the HIV histories and collections from the communities most impacted by the epidemic, and in doing so reflect the wide range of perspectives about HIV/AIDS.

Are HIV/AIDS archives in UK at risk?

Currently, it is difficult to know. The number of documents relating to HIV in archives is a small amount of the total which was created. Naturally, not all documents which are created should be archived for posterity. However, the 1990 report, 'HIV/AIDS services in the Contracts Culture', noted that there were "over 300 HIV-specific voluntary organisations" working towards educating people about HIV/AIDS and services for those living with HIV. While there are many HIV organisations still operating today, a lot of the earlier organisations have since ceased operating or merged with larger organisations. From the survey of HIV/AIDS records of archive institutions, I have only found records for 31 HIV voluntary and charitable organisations.

It has now been over 40 years since the epidemic began, many of the doctors, researchers, policymakers and first generation who caught the virus are retired or sadly dead. Whilst there is a significant presence of material from 1980s-1990s, there are not many personal paper collections, especially from those directly involved in the care and treatment of people with HIV.

Businesses, insurance companies and pharmaceutical companies which were heavily involved in issues surrounding HIV/AIDS, have left few visible public records of their activities during this time, raising the fear that these have not been retained. Whilst records relating to ethnic, gender and sexuality groups are under-represented despite there being many documented grassroots organisations from 1980s onwards.

All indications are from the initial survey of archive institutions is there are clear gaps in the HIV/AIDS archival landscape in the UK, and now is the time to act to locate these archives before they are lost.

3) What information will be recorded and how it will be used?

What information will be recorded?

The survey aims to collect information about collections of historical material relating to HIV found in public and private hands in the UK. The information that will be collected will provide an overview of the size, date and content of the collection, the current location and storage conditions of the collection and where possible information on whether it is publicly accessible or will be in future.

This data will be collated into a spreadsheet which will be made publicly available through the West Sussex Record Office website at the end of the project. Some data recorded from survey participants will also be quoted or featured as a case study within the report, however permission will always be sought if this is the case and can be anonymised on request.

As part of the survey other data might also be collected, such as contact details or information about participant's personal histories. This information will not be made available online and will be retained up to 6 years after the end of the project. The data may be shared internally among WSRO staff members and project funders but will not be shared with external bodies.

Sensitivity and confidentiality

All collected data will be managed in accordance with West Sussex County Council's Data Protection Policy ([Data protection policies - West Sussex County Council](#)). It will be used only for specified purposes and not be used for any other purposes. Participants might be asked if they are happy for a photo of them or their collection could be used for the purposes of social media or for the report but only if they agree to it. Participants have the right to withdraw their data or information if they request.

Considering the sensitivity of the subject, the Project Archivist will undertake a trauma-informed approach when meeting individual collectors who may have experienced trauma

due to HIV/AIDS. The Project Archivist has had significant experience in working with sensitive collections and the history of HIV/AIDS and is mindful of the personal loss and grief that some individuals would have lived through or continue to feel. They are also aware of the continued stigma and discrimination associated with HIV to the present day.

When will the results of the survey be published?

The project is due to end in January 2025 and the preceding months will see the release of the final report and datasets on the West Sussex Record Office website.

4) Other questions and contact information

Are we collecting archive material as part of the survey?

Unfortunately, no unless the archive collection relates specifically to people or organisations in West Sussex.

The project will however endeavour to assist any private individual or organisation with HIV/AIDS archival material in finding a permanent home for their collection if they wish. Assistance could be passing on contact details of local archives, arranging meetings between the two parties or providing information or assistance in listing, packaging, and storing archives.

Are there any records that are not included in the survey?

Good question! Ideally, it would be wonderful to include every historical document or artefact but due to constraints of the survey we will not (for the most part) be surveying any books or journals in the current project. This is because the sheer volume would make the task unmanageable and for the most part publications are less likely to be at risk, as copies can often be found online or within libraries.

Can I track the progress of the project?

Yes, regularly blogs and newsletters will be published throughout the duration of the project and can be found on the [project website](#). You can also follow the project on [Instagram](#).

Contact information

If you have any further questions about how your data will be used or about the wider project, please do contact the Project Archivist, Chris Olver. He can be contacted at christopher.olver@westsussex.gov.uk or by telephone on 03302226284.