



People With Archives:

A survey of HIV/AIDS records in the UK

Welcome to the 2nd issue of the newsletter for the 'Documenting the HIV/AIDS epidemic: a survey of HIV/AIDS archives in United Kingdom' project. It has been a busy few months since the last newsletter and the results of the survey of HIV/AIDS records in archive institutions are now in. In this issue, I'll be reporting on some of the key findings from the survey, discussing the next steps of the project and highlighting some of the recent outreach work, such as the launch of our new Instagram page.



Handmade South African Red Ribbon badge. From AVERT collection currently being catalogued at WSRO.

Meet the funders

Last month, I was pleased to meet at WSRO, Peter and Adrian Kanabus, who are two of the trustees of Annabels Foundation who are funding the project. Peter Kanabus, along with his wife, Annabel, founded the HIV/AIDS charity, AVERT in 1986 and worked in the HIV sector for over 25 years. Peter told me many interesting stories about his many years working in the field, including an amusing anecdote about pointing out a major oversight of the 'Don't Die of Ignorance' campaign to a government minister at the time which had to be swiftly corrected. He also brought in a few more items to add to the AVERT archive, including a collection of HIV-related badges from 1980s-2000s, including some beautiful handmade South African red ribbon badges.

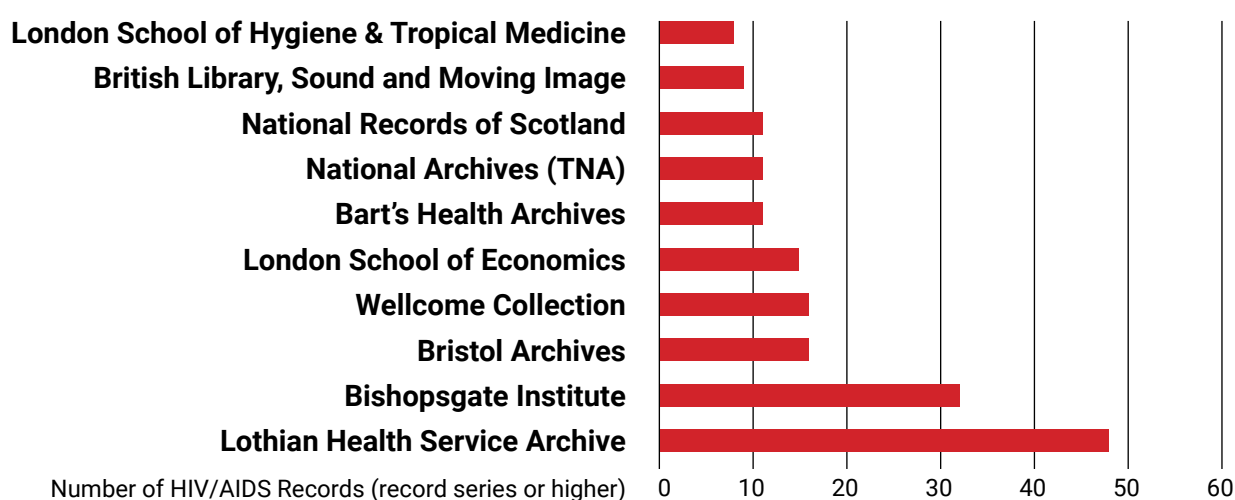
HIV/AIDS records in archive institutions in UK

Since the start of the project, over 200 archive services in the United Kingdom have been surveyed for HIV/AIDS records with 111 organisations holding some records. The majority of these organisations reported their holdings directly to me through email or via an online questionnaire which was circulated through professional archive and heritage groups and mailing lists. Catalogue information was collected or compiled from these reports and so far, 2130 archive descriptions have been recorded. The descriptions range from individual items, such as digitised television footage of news reports about HIV/AIDS in the 1980s, to large collections of business papers from national HIV charitable organisations like the Terrence Higgins Trust. Archive descriptions were also recorded of collections that may hold HIV/AIDS records but could not be directly confirmed by the reporting archive, these descriptions are listed separately.

Where to find HIV/AIDS records in UK: London

Most of the records reported in the UK are held in archive institutions in London. This reflects current and historical numbers of reported cases of HIV/AIDS which means that there are far more local initiatives and treatment centres there. It is also where the majority of UK archive services are based, and where institutions are more likely to have a long-standing interest in the subject, especially those that have collection policies with a subject interest in healthcare, LGBTQ+, political activism, charity and voluntary organisations and central government.

From the survey results, the archive services in London with the largest number of collections are Bishopsgate Institute, Wellcome Collection, London School of Economics and The National Archives. The British Library Sound Collection has the largest collection of HIV-related oral history collections, and the British Film Institute contains detailed listings of audio-visual productions relating to HIV/AIDS, with a considerable number of those accessible within their collection.



Graph showing the archive institutions with the highest reported number of HIV/AIDS records

Where to find HIV/AIDS records in UK: Rest of the UK

Other cities and regions of the UK are also well represented in the survey. By far the largest holding of material outside London (and statistically the greatest number of HIV/AIDS collections in the whole of UK) is the Lothian Health Service Archive, based at the University of Edinburgh. The HIV/AIDS collections were placed on the UNESCO UK Memory of the World Register in May 2011 and have been continually added to since that date. Other UK cities with relatively large holdings are Bristol, Brighton, Manchester and Liverpool. These areas tend to have large regional HIV charities which are still operating, and local archives often hold larger LGBTQ+ collections which hold relevant papers. A good example of this is the Our Story collection held at The Keep, in Brighton, East Sussex. This collection is from a local LGBTQ+ community history project started in 1989. Other areas with large holdings tend to be those with large charity archives like the Save the Children collection (University of Birmingham) or the Oxfam collection (Bodleian Libraries, Oxford).

Under-represented regions, such as the North East of England, Yorkshire and Humber and each region of the Midlands, do not have as many records as anticipated in comparison with other regions of similar size and HIV case numbers. This could suggest that there is a possibility that there is still a substantial number of records in private hands there, as cities such as Birmingham and Leeds had several long-standing HIV/AIDS organisations, some of which are still operating.

Subject areas found in UK HIV/AIDS holdings

There are many subject areas in the overall HIV/AIDS holdings with over 150 recorded so far. Most of the subject areas refer to the treatment, care and prevention of the disease and services provided for those living with the condition. There are a considerable number of records relating to HIV advocacy and activism; these records may be created by HIV organisations or be part of the wider political activism especially within LGBTQ+ organisations. A good example of this is the Campaign for Homosexual Equality (CHE) or the campaign against Section 28.

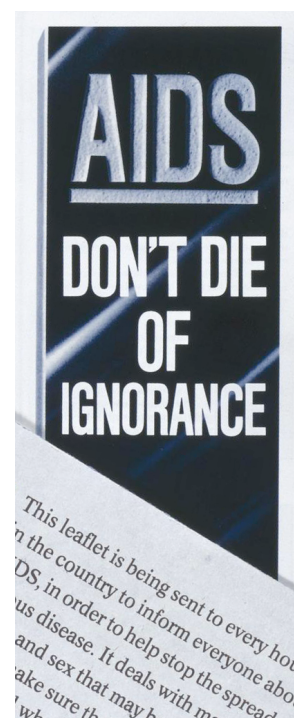
Numerous records held at the National Archives relate to HIV/AIDS policy and legislation. The majority of these records date to the late 1980s when the government ran the Don't Die of Ignorance campaign. This is mirrored in local authority archives and other national archives in Scotland and Northern Ireland. Alongside these are significant collections relating to scientific and medical research including clinical and non-clinical records. However, there are very few records relating to complementary medicine and alternative medicine.

In wider society, the media response to HIV is widely represented in film and television archives. Most of these take the form of documentaries but there are also discussion shows, magazine shows and interviews. Press cuttings in the mainstream and gay press on HIV/AIDS are found in multiple collections and archives. There are also several significant oral history collections, chiefly held at the British Library Sound Archive which began collecting HIV/AIDS stories through the Hall-Carpenter Oral History Project from 1985. Many of the more recent oral history collections have tried to bridge a perceived weakness in UK HIV/AIDS sound archives, with the current British Library project, Positively Spoken, recording interviews with current and former service users of CHIVA, the HIV/AIDS charity for young people.

There were a good number of records from religious groups in response to the AIDS crisis in the 1980s, with the Church of England archive having numerous records. There was also a good representation from other Christian organisations, especially Christian LGBTQ+ groups. However, there were limited records from other religious faiths, with no records reported or found from Buddhist, Hindu or Islamic faiths. There was some HIV material in Jewish collections at the London Metropolitan Archives but there is likely to be more, especially as the Jewish AIDS Trust (JAT) is still operating.

Areas which are potentially under-represented in the current survey include records relating to businesses, especially those involved in the creation and distribution of antiretroviral drugs and condom manufacturers. There is a handful of records relating to employment rights and guidance found in the Transport for London archive and also in trade union collections. There are also very few HIV records relating to both law and insurance records. Survey responses from archives working in these sectors were very low so it might be a case of under-reporting.

More recent developments in HIV prevention and awareness are also possibly not as well documented in the current survey. The creation and roll-out of PreP (pre-exposure prophylaxis) and PeP (post-exposure prophylaxis) is mostly evident within collected ephemera especially within museum collections. However, Bishopsgate Institute have recently catalogued the Porn4PreP UK collection, which relates to promoting the use of PreP, and may also hold the archive of PrePster, though this has not been catalogued.



AIDS: Don't Die of Ignorance leaflet produced by the UK government, 1987.

From a colour transparency in the Science Museum Group Collection. © The Board of Trustees of the Science Museum.

Bridging the gap

Overall, the findings from the survey of HIV records in institutional records were reason for optimism. Not only were there far more records held in archive services than anticipated but many of the survey participants showed a willingness to collect and preserve more records relating to the history of HIV/AIDS. The results show some areas are particularly strong in terms of subject matter or representing certain groups, such as white gay men or the national response during the AIDS crisis years in the late 1980s. Under-represented groups include black and Asian communities, the trans community and women, whilst surprisingly other historically affected communities such as IV drug users and haemophiliacs have fewer records than anticipated.

Looking for private archives

The next stage of the project is trying to identify archive collections held in private hands. This is a slightly trickier operation as unlike institutional archives there isn't a handy register of archives on the National Archives website! My method so far has been predominantly word of mouth, finding people with private archives through introduction from other contacts, and I have been fortunate to meet with 6 individuals so far to discuss their private collections. I hope to find more people with personal archives in the coming months and will be approaching HIV organisations, LGBTQ+ history groups and other networks relating to HIV/AIDS. To help document these private collections, I have created a new online questionnaire, which aims to both find out more about the contents and origin of these collections but also to ask participants what or if any practical information about archive practice or historic preservation it would be helpful to receive advice on for their current collection. The new survey can be found here and if you know anyone who might hold any historical materials, please do pass it on: <https://www.surveymonkey.co.uk/r/DT22VDC>.

📷 We're on Instagram!

To help promote the project to wider audiences, it was decided to embrace social media to help raise awareness of the stories from the archives and amazing collections currently in the UK. You can now follow the project on Instagram ([@documenting_hiv_uk](https://www.instagram.com/documenting_hiv_uk)), where I will be regularly posting stories about the project, including regular features like document of the week, HIV archive of the month and my site visits across the UK.



HIV/AIDS archive in the spotlight

Andrew Dineley is a graphic designer based in Liverpool and North Wales. He has over 20 years' experience designing HIV/AIDS awareness campaigns initially for Liverpool Health Authority and then as a freelance artist. Many of his designs were recognised nationally such as the Alter Attitudes to AIDS campaign, and he also created the logo for World AIDS Day in 1991.

◦ **What's the origin of your the archive? What made you start collecting HIV/AIDS material?**

I was working as a graphic designer at Liverpool Health Authority's Health Promotion Department from February 1987. Many of us were sceptical of the Government's approach to HIV/AIDS awareness in the 'Don't Die of Ignorance' national campaign and I was curious to see what other people were doing as an alternative. I always had my eye open for new designs and being based in a health promotional department meant we would receive material from all over the country, I just started to naturally accumulate materials. It really exploded when I started attending European HIV/AIDS conferences and seminars where there would be all sorts of stalls, South Africa, next to Sunderland... So, it just grew. It certainly wasn't like collecting records, it wasn't a hobby, but it was a very useful archive.

◦ **Can you describe the range of material in your collection?**

There is pretty much everything in terms of ephemera; badges, condom packaging, general materials, such as beer mats, window stickers, postcards, leaflets, booklets, some for specific audiences, like drug users and sex workers, and gimmicky things like a StopAIDS flipbook, things that were created to raise discussion about a subject that was often taboo.

The archive contains a mixture of local materials from small voluntary groups produced on a photocopier, to very glossy booklets from the Department of Health of the Netherlands, or New Zealand. There are about 200 to 300 things in the archive which mostly fit in one box, but there are larger items, in an A1 portfolio case, such as posters of my own and things from charities and support agencies such as the Armistead Project in Liverpool. I also still have my sketch book of designs and costings for HIV/AIDS awareness campaigns, and a framed copy of the original pencil drawing for the Alter Attitudes to AIDS main logo and flower icon



Alter Attitudes to AIDS logo and stickers (page 4), Love & Passion poster. Courtesy of Andrew Dineley.

◦ **Do you have any digital files?**

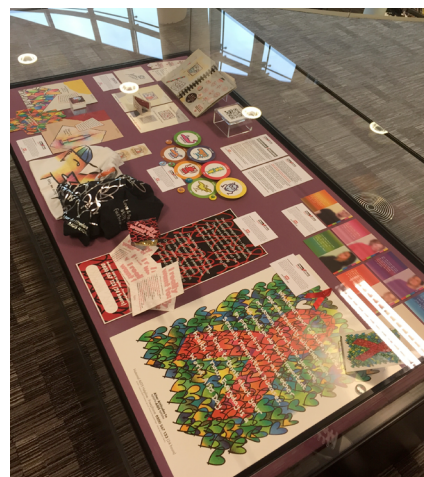
I do have digital files of my design work dating back to 1994. The problem is that the software it was created with is now largely incompatible because Adobe now dominates. If you've got things that were created prior to their software becoming the industry standard, it's not easy accessing such legacy files. There are ways around it but it would require finding specialist software. So, I do have the files, whether I can access them is a different matter.

◦ **What is the oldest item in your collection?**

The oldest item in my collection is probably from 1985, it's a leaflet, with the tagline: 'Poppers...Your Health... And A.I.D.S...Can You Afford the Risk?'. Back in the day, before HIV was identified as causing AIDS, one of the theories was that AIDS was caused by poppers and other recreational drugs. Although it is largely discredited, it's weirdly back in the news again today as Robert F Kennedy Jr, who is campaigning for the US Democratic Party nomination brought it up in a public meeting in June (<https://www.thepinknews.com/2023/06/21/robert-f-kennedy-aids-poppers-conspiracy-theory/>)

◦ **Some of your collection was displayed at the Now+then exhibition at Museum of Liverpool in 2014, can you tell me about the exhibition?**

Liverpool was one of the first cities in the UK that set up an AIDS support group in 1986. They created a helpline, which was all voluntary staffed that eventually became Sahir House, the HIV/AIDS charity which still supports people with HIV in Merseyside. The charity in 2014 wanted to commemorate their 30th anniversary and received a Heritage Lottery grant to fund the Now+then exhibitions. They wanted to show how much work had been done in those years but were acutely aware that a lot of the records were lost as much of it was on fading paper, or was the work of small grassroots initiatives, like student unions or posters that were put up in Family Planning Association waiting rooms etc.



Display cabinet from *Now+Then* exhibition at Liverpool Museum, 2014. Image courtesy of Andrew Dineley.

I was aware of Sahir House from working in this field as a graphic designer and working with all those grassroots support organisations. So, I got in touch and told them about my archive of local and national materials. Because I had designed a lot during that period I asked if I could be on board with it and they said, “yes please, would you like to do the art direction for the whole project?”

This was great for me as I was able to dig all the stuff out, raid my archive and talk about all that really important work. But it wasn't just about design. The Now+then exhibition was about broader initiatives. You know, things like setting up support groups for black and minority ethnic people, women, disabled people, gay men, there was a lot of important and impactful work that deserved to be shared and celebrated. The exhibition was designed to reflect that. I was brought on board to provide a brand for it, a name and a distinct design style that we could use across all aspects of the exhibition and its wide promotion.

◦ **What are the future plans of the archives?**

I'd be very happy to hand 99% of it over to someone who could preserve it and ensure that more people could see it. It's all still in decent condition, pretty much as it was back in the day.

If you would like to learn more about Andrew's HIV/AIDS design work, view this interview with him that was created for the Now+then exhibitions held at Museum of Liverpool and Liverpool Central Library in 2014: <https://vimeo.com/107329495>.

You can also see more of his design work on the HIV Graphic Communication website, which also has an article about his work here: <https://tinyurl.com/3uva7ph8>

For more information about the project

If you are interested in finding out more about the project, then please do feel free to contact me. I am particularly keen to hear from people who may know of or are aware of possible private HIV/AIDS archives. I can be contacted on christopher.olver@westsussex.gov.uk or by telephone on 03302226284. You can also read more about the project on the WSRO blog which can be found here: <https://westsussexrecordofficeblog.com/documenting-the-hiv-aids-epidemic/>

