

Community Discussion

Scotland's HIV History: LGBTQ+ Stories



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YEAR	2022	

The Importance of HIV History

Some initial reflections from community members on why HIV history is important brought to the forefront the sense of obligation to remember those who lost their lives to HIV and the stigma, misunderstanding and ostracisation that was experienced in the early years.

“It builds empathy and community when we tell our stories.”

“It allows everyone to see how far we have come, to acknowledge the importance of ART in the world to prolong the lives of many that have been effected.”

“We learnt so much during the 80s and 90s which is being lost and forgotten now”

“We were silenced at the time, but no more!”

“As a social worker in the 80s I visited an HIV+ guy and his partner, it was tense. He brought me a cup of tea and said “you are the first person to accept a cup of tea from us”. The many doctors visiting were too fearful to even accept a cup of tea.”

“This is prejudice within the prejudice, the minority within the minority. We have a right to be heard and to be known!”

“My uncle passed away in 1998, I was 13. He was the youngest boy on my dads’ side. I was devastated, taboos and loss.”



The importance of remembering our collective history

Contributions from community members highlighted the importance of HIV history, with most stressing the importance of discussing history to:

1 Remember those we lost

An attendee noted HIV Heritage is hugely important in order to remember the individuals we have both lost to HIV, and those living with HIV. At the time, institutional misunderstanding and prejudice flamed fear in the public and confused and obstructed the services that those with HIV desperately needed at the time. As a community we should never forget that fear, or prejudice.

2 Recognise unjust historical mistreatment

An attendee highlighted the ways in which those with HIV were often treated by medical professionals in the 1980s. *Having experienced first-hand* how services and hospitals were dealing with HIV infections and illnesses, they shared: masks, gloves, aprons and bottles of bleach were given to care staff in hospitals in the 1980s. Hospitals had limited information, and held back vital information. It took weeks to clarify people's diagnosis details, the process of which wasn't met with any kind of priority.

3 Remember the times HIV+ individuals were loved and cared for

Amongst the stigma and ostracisation, attendees highlighted the existence of true community bonds and comradery when caring for those who were HIV+ and those who later died from HIV related illnesses.

One attendee shared their experiences as a worker at **Milestone House** (a hospital where HIV+ patients were treated), stressing how honoured and privileged all staff felt, they shared:

“At Milestone House (MH) there were a diverse range of individuals living with HIV, including gay people and substance users. Patients who lived here had ensembles and cooks in their rooms, the hospital felt like an island. The hospital received lots of hate from the local community but mostly the press, in its first week the hospice received letters from the community saying they would fire-bomb it. To counteract such stigma, the hospice had open days where people could meet patients and staff. Due to the nature of the hospice the staff had very diverse roles. They acted as social workers, hotel workers and even like prison staff (sometimes substance dealers might happen upon the hospice or fights might break out amongst patients). Every day was different at MH, you'd never quite know what to expect.

The majority of people dying in MH were in their late teens or twenties. Often parents of young people were shocked their child was gay, or a substance user, but they later came to understand and be supportive of the situation. There were Artlink workers who used to attend the hospice where patients created stained glass windows and pottery. Due to the comradery in the space the lines for staff were very blurred. Staff supported patients and created an environment where they supported them. Patients knew they could turn to all staff in MH, including care staff, janitors and everyone else.”

Covid-19 and HIV

"The HIV pandemic was a lot more fun because at least I could go down to the pub during it"

Community members highlighted parallels between COVID and HIV. Lots of the language used echoes that used when talking about HIV, words such as testing, status etc.

It was also highlighted that seeing the visual of hospital staff wearing full PPE was quite triggering and traumatic for people who experienced this in the 80s due to HIV stigma and lack of understanding.

It was highlighted how quickly a Covid-19 vaccine was funded and found, but the same did not happen for HIV. HIV research was totally underfunded and experienced prejudice from the public. There were huge amounts of men dying on the African continent who experienced totally different prejudices, their experiences are often forgotten in discussions of HIV history.



The importance of safe spaces

Making safe spaces going forward

Community members mentioned safe spaces can be challenging as sometimes you aren't fully comfortable talking openly yet about experiences with HIV. It was frequently highlighted, both by those who attended the event and those who could not make it, that there are not enough spaces for people to come together and talk about HIV history and folk's experiences with it.

One community member noted:

"I booked for this but can no longer attend. Gutted because we rarely get to meet and tell our stories and I've had 2 years of isolation now."

An attendee said:

"I learned a lot and enjoyed meeting some very interesting people with real stories."

LGBT Health recognises the importance of spaces such as this and is committed to providing safer spaces for those with lived experience of HIV to share their stories and be heard".

Host Reflections

On **Thursday 17th February 2022**, *LGBT Health and Wellbeing* and *Waverley Care* joined together to host an online LGBTQ+ community discussion with the aim of providing a space for those with lived experience of HIV in Scotland. This space intended to allow attendees to share their experiences, allowing for these stories to be recorded and distributed amongst contributors and the wider community.

BSL Interpreters: **David Allan** and **Jill Gallacher**
Facilitators: **Jules Stapleton-Barnes**, **Emma Simpson** (LGBT Health) and **Francis Osis** (Waverley Care)

It was really insightful opportunity to team up with Waverley Care's oral histories project, to bring the community together to share and be heard in a supportive environment. The stories shared were so poignant and so clearly part of our individual and collective history. We heard a detailed account of somebody at the forefront of supporting people with HIV and AIDS at Milestone; the UK's first purpose-built AIDS hospice and a community-led, non-hierarchical, mutually supportive space. I was struck profoundly by how limited my perceptions of that time were and I'm so grateful people came to our event to provide first-hand reflections. LGBTQ+ history and particularly our community's HIV history is still so intrinsically linked with our present and future and I thank all the attendees and Waverley Care's Francis Osis, for the opportunity and reminder to learn and to keep paying attention."

Jules Stapleton Barnes

(she/her) Development Worker LGBT Health

the HIV Stories event was a great opportunity to be able to share some of the memories we've been collecting as part of Waverley Care's oral histories project. It's so important to preserve the stories of people who have been involved with HIV from all different perspectives, and to know that others are listening to them and learning from them. We had the opportunity to discuss things that are the same and different between HIV and COVID, which is something that has come up a lot in our interviews. People had the chance to talk about the different responses to each, including which things are funded and why, and how important testing is. The conversation highlighted how we can understand things we're going through today by thinking about what happened in the past. It was a privilege for me to hear the stories and thoughts of everyone involved.

Francis Osis

(he/him) Community Heritage Officer Waverley Care



Host Reflections

“What was clear throughout the entirety of the event was the huge value in having a held space to reflect and share on lived experiences of HIV. Many of the memories shared focused on Glasgow’s outbreaks of HIV, both past and ongoing, and the overlapping experiences of LGBTQ+ people and people using substances via injection. Other common topics that came up throughout discussions in the main space, the shared audio clips, and the feedback shared from break out rooms were:

Fear created through the media’s portrayal of HIV and those diagnosed with it, which has had a lasting impact into today.

The importance of direct commentary and story-telling from those impacted (rather than being spoken about by those without lived experience).

Joy, like found family and community connections, sometimes holding greater weight than negative experiences.

And the need to celebrate and champion the lives of folk with lived experience of HIV, including making spaces truly safe and accessible.

Emma Simpson

(they/them) Development Worker LGBT Health

Follow-up Resources

History of Milestone House:

<https://www.waverleycare.org/news/spotlight-milestone>

Support and Advice Services

Hwupenyu

A Glasgow-based health and wellbeing service principally for Black Minority Ethnic communities affected by HIV and other conditions <https://www.hwupenyuproject.org/>

LGBT Health and Wellbeing

Supports LGBTQ+ people in Scotland via a range of support services: <https://www.lgbthealth.org.uk/>

LGBT Helpline (BSL accessible): 0300 123 2523

Tues & Wed 12.00 til 21.00, Thurs & Sun 13.00 til 18.00

<https://www.lgbthealth.org.uk/services-support/lgbt-helpline-scotland/>

Live chat service: Tues & Wed from 15.00 til 21.00

<https://www.lgbthealth.org.uk/services-support/lgbt-helpline-scotland/livechat/>

Terrence Higgins Trust

Supports people living with HIV in the UK via delivery of services and amplifying voices of those with lived experience.

Support Services: <https://www.tht.org.uk/our-services/support-services/>

THT Helpline: 0808 802 1221, Mon-Fri from 9.30 til 17.30

Waverley Care

Scotland's national HIV and Hepatitis C charity. Offering support and Advice in Edinburgh (and beyond) for people affected by HIV and/or Hepatitis C: <https://www.waverleycare.org/support-and-advice/service-areas/edinburgh-sexual-health-services>

Live Chat Service: Mon-Fri from 09.00 til 17.00

<https://www.waverleycare.org/news/live-chat-service>

