



# Oral History Project

30 years of HIV Healthcare

Sian Edwards and Jane Bruton on behalf of the Project Team  
'The AIDS Era: an oral history of UK healthcare workers'

# Why this project now?

- ▶ The 80s and 90s in HIV were a unique and profound era of British healthcare history
- ▶ The lived experience of HIV healthcare workers are stories that need to be told to both preserve those past experiences and to help inform future care, education and research
- ▶ Time is pressing we can't afford to lose that lived experience
- ▶ And lastly we successfully secured funding!

# Some thoughts from HIV health workers

“It will enable healthcare workers to understand the experiences and context of the needs of long term survivors living with HIV for whom they are currently providing care”

“The impact of how we changed how nursing was delivered - the patient was truly the center of their care, what they wanted, how, when.....How we started to work more closely with the Voluntary Sector and address stigma and discrimination”

Survey Monkey 2016

# The AIDS Era; an oral history of UK healthcare workers

## Project Team

Jane Bruton, Sian Edwards and Nicky Perry (manager)

## Supported by

Heritage Lottery Fund and St. Stephen's AIDS Trust

## Advisory Group

Prof. Brian Gazzard (HIV Consultant), Dr. Rob Perks (British Library Sound Archive)

Prof. Alistair Thomson (Oral historian)

National HIV Nurses Association (NHIVNA), British HIV Association (BHIVA),

Children's HIV Association (CHIVA), National AIDS Trust (NAT)



**UK directory of helplines offering HIV/AIDS and sexual health advice**

**National helplines**

**British HIV Association**  
 100, St Andrew's Place, London, W1G 0ET  
 Tel: 020 7462 5555  
 Fax: 020 7462 5555  
 Email: info@bhiva.org.uk  
 Website: www.bhiva.org.uk

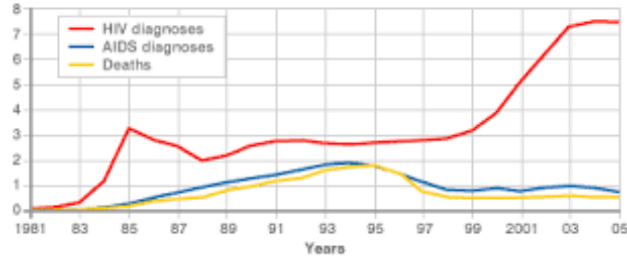
**Terrence Higgins Trust**  
 110, Tottenham Court Road, London, W1P 0LP  
 Tel: 020 7713 3333  
 Fax: 020 7713 3333  
 Email: info@terrencehiggins.org.uk  
 Website: www.terrencehiggins.org.uk

**Sexual Health Helpline**  
 100, St Andrew's Place, London, W1G 0ET  
 Tel: 020 7462 5555  
 Fax: 020 7462 5555  
 Email: info@sexhelpline.org.uk  
 Website: www.sexhelpline.org.uk

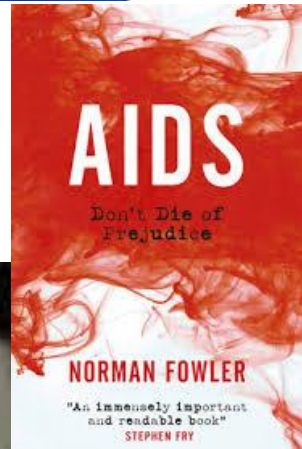


**HIV AND AIDS IN THE UK**

Number of diagnoses and deaths (thousands)



SOURCE: Health Protection Agency



# Oral history approach

- ▶ Contrast to anonymous, guided interview, destroyed once data obtained
- ▶ In-depth, free talking account using a 'life history' approach
- ▶ An opportunity for those people who have been 'hidden from history' to have their voices heard. Verbal account, the voice will tell the story in their own words - not interpreted by someone else
- ▶ A source of new insights and perspectives that may challenge the traditional view of the past and formal historical accounts
- ▶ The ordinary/extraordinary story
- ▶ Preservation for use by future generations

# The HIV/AIDS - oral history collections

- ▶ **The HIV/AIDS Testimonies 1995-2000** 30 interviews and 2005-2008 revisited plus 10 more
- ▶ **Invisible Women - Positively Women Oral History Project**  
2007/8, a collection of 16 oral history interviews with women living with HIV.
- ▶ **The Haemophilia and HIV Life History Project**  
30 oral history interviews patients with Haemophilia and HIV
- ▶ **HIV in the Family**  
36 oral history interviews with parents, partners and children of those with haemophilia and HIV  
Extracts from both projects feature on the 'Living Stories' website

<https://www.bl.uk/collection-guides/oral-histories-of-personal-and-mental-health-and-disability#sthash.LPxySF9j.dpuf>



# LIVING STORIES

EXPERIENCES OF PEOPLE LIVING WITH HAEMOPHILIA AND HIV

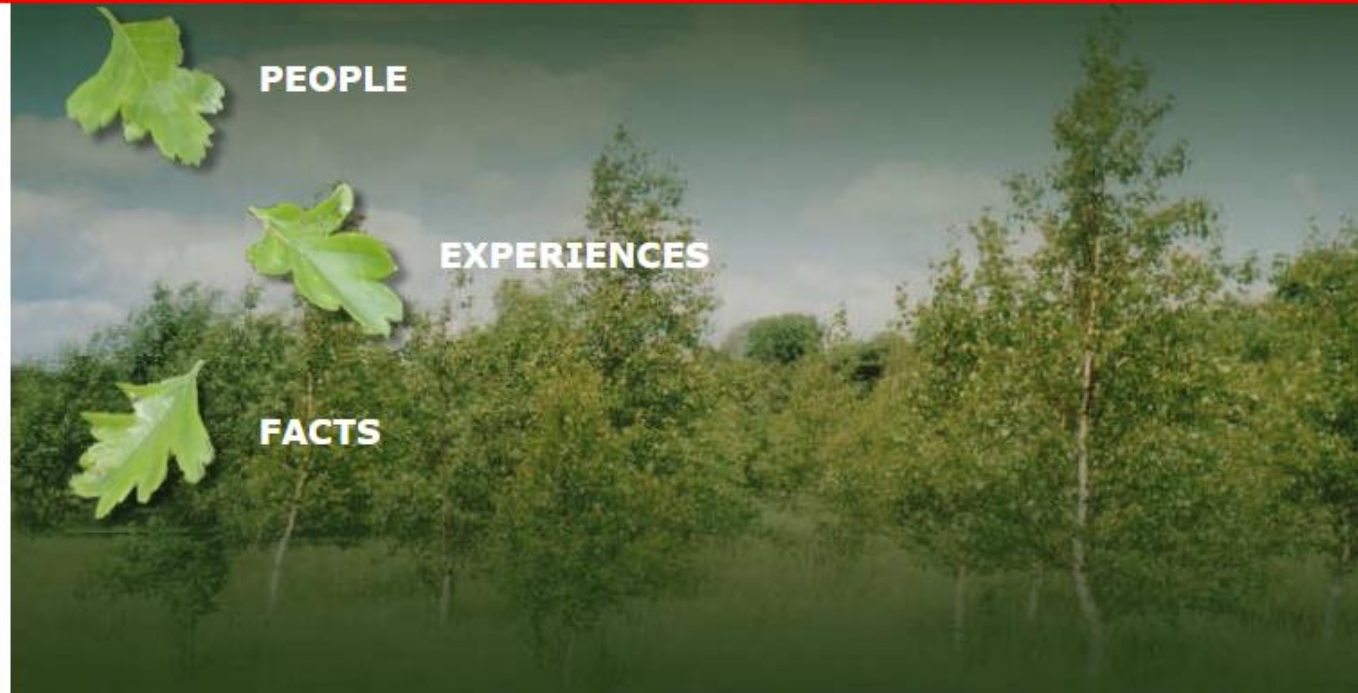
PEOPLE • EXPERIENCES • FACTS

In 1985, 1246 people with haemophilia in the UK were diagnosed with HIV. Of these, over 800 people have died.

There are extraordinary stories to tell from the individuals and families affected.

On this audio website, you can hear their stories, gain an insight into their experiences and learn the facts behind their history.

[About this life history PROJECT](#)



PEOPLE

EXPERIENCES

FACTS

The photo above shows Stratton Wood in Wiltshire. 1200 trees were planted in tribute to the lives of people with Haemophilia and HIV.

Website by **COMMUNITY SITES**



# Extract from the Living Stories website

## Dave on diagnosis of HTLV3

[http://www.livingstories.org.uk/pageaudio\\_id\\_5\\_aid\\_58.html](http://www.livingstories.org.uk/pageaudio_id_5_aid_58.html)

## Mary on death of her son Colin

[http://www.livingstories.org.uk/pageaudio\\_id\\_69\\_aid\\_229.html](http://www.livingstories.org.uk/pageaudio_id_69_aid_229.html)

## Mick on Birchgrove (peer support)

[http://www.livingstories.org.uk/pageaudio\\_id\\_4\\_aid\\_106.html](http://www.livingstories.org.uk/pageaudio_id_4_aid_106.html)

# The AIDS Era: an oral history of UK healthcare workers

- ▶ Interviews commence July 17<sup>th</sup> 2017 60 4-hour interviews over 12 months by 5 trained oral historians
- ▶ Healthcare professions - doctors (20)/nurses (20)/allied HCWs(15)/'others' (5)
- ▶ HIV specialities - adult/MSM/children/pregnancy/women/haemophiliac/drug use/black and ethnic minorities
- ▶ Geographical spread
- ▶ Known figures and hidden stories
  
- ▶ Timed summary (searchable) and written transcript
  
- ▶ Archived British Library Sound Archive according to participants instructions (recording agreement and consent form) with on-line access
  
- ▶ Website/radio broadcast/theatre production by project group

# What next?

- ▶ Press release via NHIVNA, BHIVA, CHIVA, NAT, SSAT,
- ▶ Seeking 'Expressions of Interest' (EOI) from people want to take part/or suggestions of who to approach for an interview.
- ▶ An EOI on-line form will be available via NHIVNA, BHIVA, CHIVA or SSAT websites
- ▶ If invited to interview you will be contacted by the interviewer to make arrangements and sent Participant Information Sheet and Consent Form
- ▶ Sian and Jane keen to discuss project further and answer any questions
- ▶ Contact Nicky Perry, Project Manager on [N.perry@bsms.ac.uk](mailto:N.perry@bsms.ac.uk)

# Extracts from Living Stories website

- ▶ **Mick on ‘telling my story’** (and the Birchgrove memorial Stone)
- ▶ [http://www.livingstories.org.uk/pageaudio\\_id\\_4\\_aid\\_108.html](http://www.livingstories.org.uk/pageaudio_id_4_aid_108.html)