21st Annual Conference of the National HIV Nurses Association (NHIVNA)

27–28 June 2019 · Manchester Conference Centre
The AIDS Era: an oral history of UK healthcare workers

Sian Edwards
Northside Clinic  Melbourne Australia
Jane Bruton
Imperial College London
Declaration of interests relating to this presentation

- Nothing to declare for either speaker
The AIDS Era; an oral history of UK healthcare workers

The Project Team
Jane Bruton, Sian Edwards and Nicky Perry (manager)

The Interviewers
Wendy Rickard, Debra Hearne, Fiona Clampin, Sian Edwards, Jane Bruton

The Volunteers
Claire Bradbury, Martin Jones, Paul Mason, Julia Parr, Chris Harrington, George Leach, Barbara Hayman

The Advisory Group
Prof. Brian Gazzard (HIV Consultant), Dr. Rob Perks (British Library) Prof. Alistair Thomson (Oral Historian)
National HIV Nurses Association (NHIVNA), British HIV Association (BHIVA), Children’s HIV Association (CHIVA), National AIDS Trust (NAT)

Funded by
Heritage Lottery Fund and St. Stephen’s AIDS Trust
What is Oral history?

• In-depth, extensive, unstructured, account often using a ‘life history’ approach

• An opportunity for those ‘hidden from history’ the ‘silent voices’ to be heard

• A source of new perspectives - that may challenge/add to the traditional view of the past and formal historical accounts

• Contrast to guided interviews, where data collected is interpreted by someone else. Anonymous. Source data destroyed once data obtained.

• Preservation for use now and by future generations

• The voice will be preserved to tell the story
61 life history interviews
in The British Library Sound Archive

25 male
36 female

- 38 South East (incl London)
- 9 North/Midlands/East
- 3 South and South West
- 9 Scotland
- 2 Wales

- 24 Nurses/Midwife
- 24 Doctors
- 10 Allied health care
- 3 Other

In patient, out patient, paediatrics, family care, mental health, haemophilia, education, palliative care, drug use, pregnancy, community care & research
I think one of the attractions of the oral history project that we’re doing is that you will also hear from the north of England, you will also hear in great detail from nurses, from social workers, from other people who were involved in this epidemic, as well as the sort of, rather top-down approach that, you know, the professor of HIV medicine might have. And so I think for the future it’s very important.

[James E nurse]

a lot of the people who were originally affected by HIV were very marginalised groups whose voices weren’t heard, whether that was gay men or, people with drug problems etcetera. It’s important those voices are heard, even if it’s second-hand through my experience working in Edinburgh in the Eighties and Nineties [James E nurse]

I wanted to do it very much indeed, because Lighthouse is so important, you know, it’s important in the history of healthcare, caring for people. It was something completely new, completely innovative, unique...I am a great believer in providing information for posterity and I have got a four-year-old great-granddaughter and it’s nice, comforting to think that after, long after I’m dead, if she’s interested she can trot along to the British Library and hear her great-grandfather’s voice and that’s quite comforting [Chris B volunteer]
The Emerging themes

- Responses and attitudes
- Transmission and health promotion
- Evolution of treatment
- Healthcare worker knowledge and education
- Death and Dying
- Relationships
- Models of Care
- Impact on self
- Motivation
- Telling my story

61 Oral History Interview
The Emerging themes

61 Oral History Interview

- Impact on self
  - Responses and attitudes
- Transmission and health promotion
- Evolution of treatment
- Healthcare worker knowledge and education
- Death and Dying
- Relationships
- Models of Care
- Telling my story
- Motivation

1. Models of Care
2. Relationships
3. Impact on self
Changing models of health care
Changing models of health care

New patients

- Eileen, Nurse
- Lorna, Nurse

young, previously healthy, activists, informed stigmatised, alone, rejected chaotic, multiple social needs children, families, diverse cultures, friends, colleagues bereaved, dying

New approaches

- Jane, Nurse
- Candy, Nurse

new, innovative, patient centred, partnerships, multi-disciplinary, relaxed professional boundaries/ rules and regulation

New healthcare workers

- Geraldine, Nurse
- Simon, Doctor

responsive, gay, activists, HIV positive, invested, committed, friends, patients volunteers

Long Term impact on health care
Changing health care relationships

- Patients
- Nurses
- Doctors
- Volunteers
- Multi-disciplinary Team
- Partners, friends, and family
Changing health care relationships

Relationships between HCWs

- Flattened hierarchy
- doctors and nurses -> multidisciplinary team +++

- introduction of formal support
- emphasis on informal support -> intense personal relationships
  between staff colleagues -> patients

Relationships between patients and HCWs

- activism
- partnerships
- patient centred care

- fracturing of traditional family
- care and support from healthcare workers/volunteers/other patients

- Challenging rules and regulations
- Relaxed professional boundaries
  Patients -> friends
  Friends -> patients

- Different demographic in Scotland
- Very different narrative of relationships

Nicky P  Nurse

Tony P  Doctor

Jim K  Psychologist

Sheila M  Nurse
Impact on self

**Negative**
- Worn out
- Burn out
- Depression
- Blurred professional boundaries

**Positive**
- Close personal identification
- Relationships: intense support, fun, laughter, parties, friendships, sex
- New perspective, improved self-worth, empathy, communication
- Immersion: all-encompassing passion, privilege
-学术, 学术兴趣, 刺激
- 关怀, 护理, 人类
- 寻求额外的努力

**David O, Nurse**
**Stephen H, Nurse**
**Jane S, Nurse**
The AIDS Era: an oral history of UK healthcare workers
Website

Any other thoughts on how this project could be used?