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**“Speaking out in a silenced society.”** Some reasons for the silenced voices of people living with HIV and the usefulness of life histories as an educational tool for the wider community



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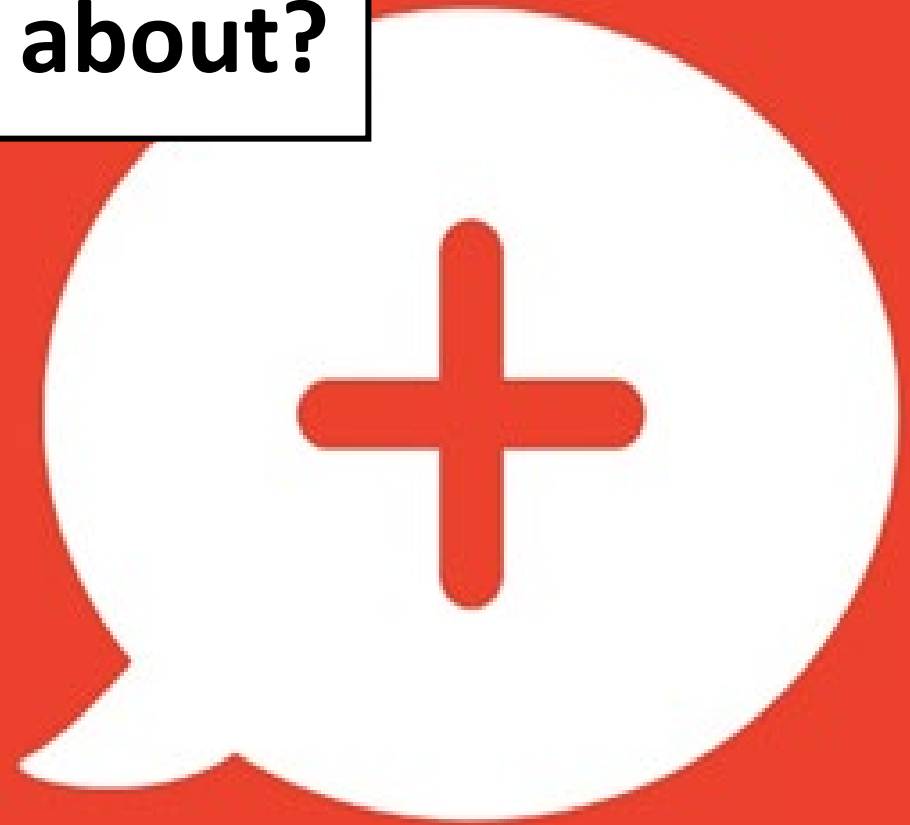
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## Some context to HIV in the UK...

- UK Nationwide figures. **National AIDS Trust** survey (2014)...
- **1 in 10 people have 'no sympathy'** for those who are living with HIV.
- **1/3 of people 'simply do not know'** about the realities of the HIV epidemic.
- **64% of people believe there is stigma** toward HIV (NAT, 2014). **87% more people feel more needs to be done** to tackle stigma in NE (Dalton, 2014).
- “Ignorance of how to prevent HIV is still vast and in the absence of public health education campaigns it has increased over the last twenty years” (Fowler, 2013: x).
- No **nationwide campaign since 1987** on a national level. Fragmented.
- Schools and sex education **is poor around HIV** (NAT, 2014).
- “HIV may have slipped out of the headlines, but we should avoid any false assurances that the battle is almost won or HIV is no longer a problem” (Fowler, 2013: 253). **Bio-medical causes have been dominant.**

# What is this research project about?

- **Practitioner collaboration.**
- **Methodology:** “I have a story to tell and I need to somehow help others by telling it.”
- **Life histories** (Plummer, 2008).
- **Sample.** BPNE service users.
- **14 life history** interviews.
- **Access.** Volunteering at BPNE.
- **Practitioner report.**
- **Eventual** book/journal article.



BodyPositive  
North East

# Using visual methods alongside life histories...

- **Inspiration!**
- **'AIDS Quilt'** started in 1987.
- Three-by-six foot panels. Each one **memorialises a person** who had died from AIDS.
- Got me **thinking about imagery and biography** and using them with vulnerable people.
- **Cameras!** Explore their personal geography and lives. Photovoice.
- **Theoretical principle** is that it makes a difference to communities.





# Theoretical background...a model to use...

- **Ghaziani (2014) 'There Goes the Gaybourhood?'**
- 'Gaybourhoods' (e.g. Castro, Soho, NE Pink Triangle) have gone **through three transitions** in regards to identity and reactions to that identity. These are also situated within a physical and geographical space which is changing.
  1. **An insular stage** (people not 'out' and public uninformed about LGBT issues – regarded with shock or disgust in limited communities that do exist).
  2. **A protection/security stage** (live together and share experiences within the gaybourhood, campaigns).
  3. **A post-gay stage** (a mixing of straight/LGBT people within the gaybourhood, changing legal landscapes – no need to inhabit gay bars as part of LGBT identity and slow dissolution of strictly LGBT spaces as it becomes more 'accepted'). **Largely a positive step forward for the LGBT community...**





# How is this reflected in HIV in the UK?

However, **in order to tackle HIV related stigma through education**, we can recognise three stages of how UK society has reacted to HIV 'communities' using Ghaziani's (2014) model:

1. **An insular stage** (only gays or deviant groups have it. Ignore it or attack the groups. Panic toward those living with HIV).
2. **A protection/security stage** (everyone could get it now transmission campaigns and sexual health, medical advances).
3. **A post-HIV stage?** (It is not a huge thing anymore, you can live your life like anyone else, it is the same as diabetes, one tablet is all that is needed, etc.) **This is dominated by bio-medical dialogue and takes little into account around HIV 'communities' affected by HIV-related stigma.**

**In post-HIV stage geographical communities are changing: HIV 'flight' and funding cuts under austerity (Dalton, 2015) has led to funding for HIV organisations being cut or changed...a stagnation of HIV discourse.**



**“I think because originally it was the tombstone adverts, as you know, which frightened the shite out of everybody, and that it was a plague basically; that’s the way it was perceived, that was the way it was shown on the television. It was to frighten people, to stop them, to, well I think what they were trying to do was frighten people from having sex, unsafe sex anyway. But then there was nothing for years, so the medication and everything progressed but the actual understanding of it didn’t. So people still remember those adverts from the 80s and there’s been no awareness really since. I can’t remember any anyway.”**

**Respondent 13**

# Emerging themes from the stories...

1. **Structural/political factors:** School and sexual health; or lack of it. **Stigma from health care** and the HIV education of health professionals.
2. **Work:** employment experiences of living with HIV.
3. **Personal, lived and emotional:** coping methods of living with HIV: identities and their complexities in telling others (stigma and mental health).
4. **Campaigns:** invisibility of HIV in long lasting public dialogue.
5. **Education:** as a way of combating HIV stigma **“nobody talks about it anymore.”**

**All of these themes contained HIV related stigma** and the need to break it down. Expressed by **all respondents powerfully**, as well as the ‘silencing’ of the subject.

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Silent Scream? The Life Histories of  
People Living with HIV in the North East  
of England (2015)

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## Executive Summary

Author: Andrew Dalton  
October 2015

**“I would like to see the gay scene be much more supportive and I think its incredible cause I think the general public think that the gay scene would probably be really supportive with people with HIV who were suffering and who were. Yet I’ve found that that group of people have been the most stigmatic of the lot.”**

**Respondent 6**

**“In London there is a much higher rate of men being HIV positive. It is more accepted. People don’t really freak out if tell them your HIV positive. It is just another guy who has HIV. Up here it doesn’t really get discussed that much, it’s not really accepted that much.”**

**“I don’t think it had ever been mentioned while I was there [former workplace], and there must’ve been people, there’s fifteen hundred people work in that call centre. There’s got to have been somebody with HIV. Just nothing, nothing at all, not mentioned or anything, and I think there should be training on it in all workplaces.”**

**Respondents 2 and 13**

# Usefulness of life histories as an educational tool...

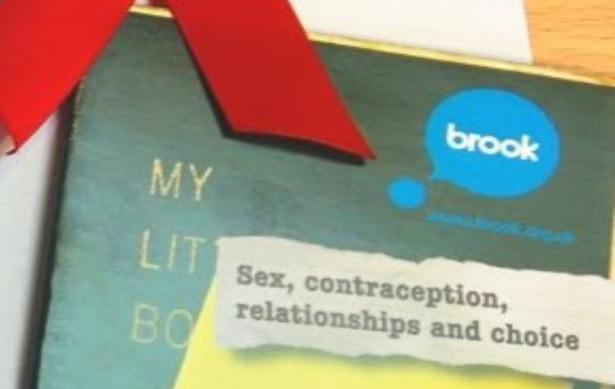
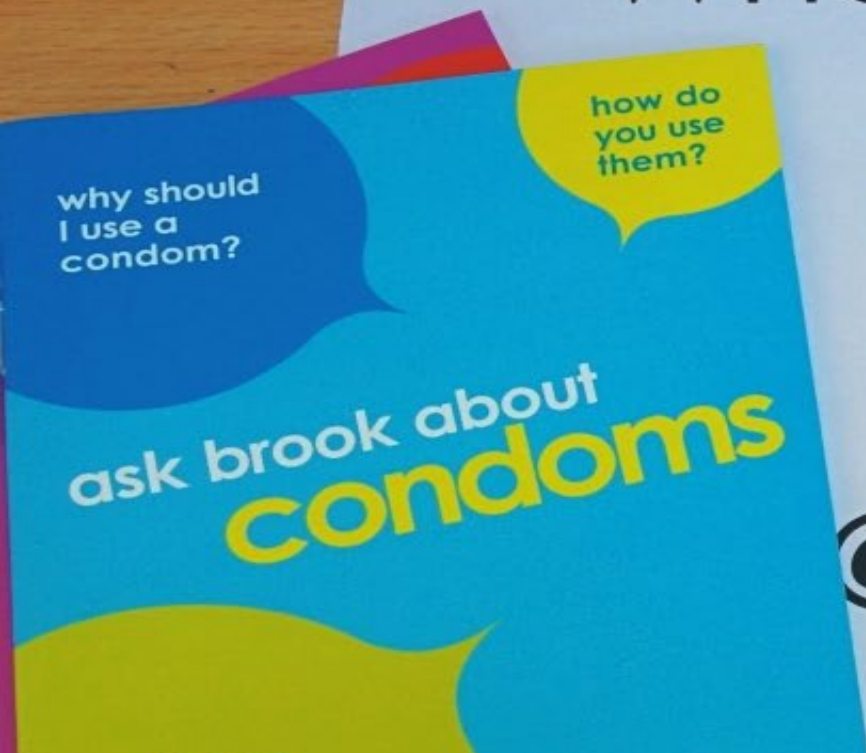
- How can we use life histories to break down stigma and to push past this apparent 'post-HIV' stage? Ideas suggested and moving forward with...
- **Art gallery exhibition of the Photovoice images** and the launch of the stories.
- **'HIV Voices Project'** – a digital storytelling project to highlight the life histories.
- **HIV Chartermark** for employers: Equalities Act (2010).
- Based on Disability 'Two Ticks Scheme.' **"Positive about People"**
- ***Logo, Policy and Standards: Level 1 (four strands) and Level 2 (two extra strands).***
- ***Online Training Module (free) – national and then international.***
- **'Live HIV Neutral Campaign'** started in the UK in 2015. First of its kind on this level. Target wider population about HIV stigma. This research helped develop the campaign.
- ***Pledge and HIV stigma projects in each region of the UK.***
- ***Supporting 'Positive about People' as a key partner.***

What #LiveHIVneutral  
means to us:

Education!

@BrookCharity

#WAD2015



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