Early community involvement
1981-1998

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Background

Apologies: Subjective, London-based, white, gay, male perspective...

1980s were divisive. Privatisation of coal, steel, gas, water, electricity, BA, airports, rail etc. (Funded tax cuts for business and the wealthy, who donated to one political party). Four million unemployed. Social policy on “family values”.

NHS, Royal Mail and air were narrowly saved.

Community: anti-racism, anti-apartheid and the miners strike. Some local Labour councils challenged central government and supported lesbian and gay rights.
Mainstream Media: sexist, racist, homophobic - fuelled fear & discrimination

Slide: Jo Manchester and Jane Shepherd
Timeline 1 - First responses

Unless you were directly affect by HIV, the UK was behind the US by several years.

There was sex before HIV – and low awareness meant this that continued to the mid 80s.

July 1982: Terry Higgins died
Nov 1982: First article in Capital Gay
1983: early Terry Higgins Trust meeting in Conway Hall that included Jonathan Grimshaw and Dr Ian Weller.
1983: AIDS Action Group
Dec 1984 – THT safer sex leaflet included not having sex with Americans or people who were ill.
But from 1983/4 first reports in Capital Gay were in single and then double figures (compared to many thousands in the US).
Timeline 2: Community Fundraising – peer support

1984 – THT becomes a charity, first helpline.
1985 – Body Positive - later expanded to many local and regional groups - first HIV test, first candlelit vigil.
1986 - CRUSAID – (Kobler Centre and Walk for Life marches)
Early reports: prevention and treatment

Reports analysing prevention and treated included articles by Julian Meldrum and Tony Whitehead.
Body Positive – 1985 onwards

Self-help, peer support, phoneline, small grants
Youth group
Women’s group
Drop In Centre
Lunch meals

Newsletter – no. 240 (nov 1999)
Many local organisations in the UK:
Lincs, Dorset, Blackpool (94), Birmingham (89), Wear, Cheshire & N Wales, Somerset, Derbyshire, Brighton, Hertfordshire, Cardiff, Bedfordshire, Shropshire, Kent, Thames Valley, Devon, Mid Sussex, BP North East, BP North West.
London Lighthouse – 1986

Pioneering centre for respite and palliative care - when people with HIV were being turned away from existing hospice services. (Model for Bethany Trust, Sussex Beacon etc)
Timeline.3 Late 80s: Key projects for diversity

1986 – Birchgrove Group
1987 – Positively Women, Mark Ashton Trust.
1988 – Kobler Clinic
1988 – Blackliners
1988 – Food Chain
1989 – Mainliners
1989 – Frontliners
Birchgrove Group – 1986

Sept 1983 – first haemophilia cases in UK.
1985-91 – Legal action (MacFarlane Trust)
1986 – Mary Dykes supports Birchgrove meetings in Cardiff – different to Haemophilia Society.
1988 – provides peer support services and fundraising for residential support and relaxation weekends.
1993 – First conference.
1996 – First trees bought.
2004 – Woodland opens

https://www.birchgrovegroup.org

Slide: Robert James
Positively Women – 1987

By and for HIV positive women

1987 – Spare Rib interview

1991 – leaflet for women’s drop-in support service

Slide: Jo Manchester and Jane Shepherd
By and for HIV positive women 2:

Resources produced by and for women living with HIV, London 1990 and 1992

Produced by Positively Women.

Slide: Jo Manchester and Jane Shepherd
By and for HIV positive women 3:

Awareness booklet for young women, Cardiff, UK, 1990.
Cardiff AIDS Helpline.

A Positive Woman’s Survival Kit, London, UK, 1999
ICW

Slide: Jo Manchester and Jane Shepherd
BCAT 1986, Blackliners – 1988

HIV prevention and support for African, Caribbean and Asian communities.

Developed from the Black Communities AIDS Team (BCAT, 1986):
mixed group mainly for black and Asian gay/bi men.
Red, Hot and Blue (1990)
Tribute fundraiser, Simon Watney.

Reach Out and Touch (1991)
Community concert – ft Whitney Houston
Largest HIV march and vigil, Vernal Scott.

Photographs: Vernal Scott
Mainliners – 1989
Specialist support for people who inject drugs
1987: 32 UK AIDS helplines

AIDS: A guide to survival, Peter Tatchell, 1987
Timeline.4 1990s

1990 - Black HIV/AIDS Forum (Manchester)
1991 – LEAN (London East AIDS Network)
    – now Positive East.
1992 – Naz foundation & NAM updates
1993 – UK Coalition of People Living with HIV
    (Published Positive Nation and Back to Work project )
1994 - Scottish Voluntary HIV and AIDS Forum (HIV Scotland)
1996 - Body & soul.

*Plus numerous African support groups (see next slide).*
1997 – First BHIVA guidelines.
African support groups

Many African support groups included
• Africa Advocacy Foundation
• African Community Involvement Association (ACIA)
• African HIV Policy Network (AHPN)
• BHAF (Black HIV/AIDS Forum)
• Black Health Agency
• HIV/AIDS Association of Zambia
• Ugandan AIDS Advocacy Foundation
• Uganda Community Relief Association
• Vanguard
Naz – 1992

Support group and services for HIV positive people from BAME communities.
Publications 1996 –

ATP DrFax #11 – (Nov 1996)
Body Positive #226 (Sep 1998)
Positive Nation #40 (March 1999)
Positive Times #39 (July 1998)
Publications

EQ#11 (John Stevens) 1999, ATU from 1992 , Continuum (Denialist) 1996
AIDS Treatment Project (ATP)

Peer organisation of people who personally benefited form combination therapy.

DrFax – compilation of latest treatment news faxed to doctors every two weeks.

Volunteer-based treatment information phoneline. Could say treatment worked – at a time when many other HIV organisation were at-best cautious of treatment and at worst were actively hostile.
Summary 1998

By 1998 – when HAART was widely available, hundreds of community organisations had been set up across the UK. Apologies to the many who I have not been able to include.

More than 50 African support groups in London.

More than 30 branches of Body Positive across the UK.


Many of these have no internet history (please keep your archives).
In Memory

Simon Mwendapole, Uganda AIDS Action Foundation (UAAF)

and

Paul Blanchard, Founded the Chapman Clinic. First editor of ATP’s Dr Fax and i-Base’s HIV Treatment Bulletin (HTB)
Thanks

Robert James, Hope Mhereza, Badru Male, Graham McKerrow, Simon Watney, Ash Kotak, Vernal Scott, Kate Thompson, Jo Manchester and Jane Shepherd, Polly Clayden, UK CAB. Wellcome Trust (for some images).

Questions…

Flyposting 1987, S Collins
Back-up slides
AIDS: A guide to survival, Peter Tatchell, 1987

Mental imagery: Imagining sharks chasing infections.
Early events

Community activism included getting information from the US (3 years ahead), prevention work in different communities (safer sex) and fundraising events.

1981 – first cases reported in the US and the UK.
1982 - Terry Higgins died in July.
1983 – First THT meeting at Conway Hall,
1983 - Panorama and Horizon “Killer in the village”.

Horizon 1983: Bobbi Campbell, HIV positive nurse, coauthor of Denver Principles
Early safer sex: THT 1984

1. Have sex with fewer men.
2. Avoid anal sex, except possibly with your regular partner.
3. Have sex only with men whom you know to be in good health and who have had few other sexual partners.
4. Avoid sex with men who have been sexually active in North America in the last three years.
5. Since the virus has been found even in saliva, perhaps the only safe sex is mutual masturbation, body rubbing and dry kissing.