

# Living with HIV & Treated for Cancer

## Research focusing on person-centred care

Annual Cancer Nurse & Allied Health Professional Conference

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Life demands excellence

# BACKGROUND

## Researcher biography

- Nurse who has worked in both HIV and Cancer
- Worked in HIV care in the 1990's at a time without effective treatment
- Interest in experience of people coming into contact with both services

Gideon Mendel The Ward



# HIV Progress - The good news

**U=U\***

UNDETECTABLE  
**viral load** means **HIV IS**  
UNTRANSMITTABLE

[www.i-Base.info/u-equals-u](http://www.i-Base.info/u-equals-u)

\* Undetectable = Untransmittable

PEOPLE ON EFFECTIVE  
HIV TREATMENT  
CANNOT PASS  
ON THE VIRUS.

FACT.

CAN'T  
PASS  
IT ON

## Increasingly likely to encounter cancer services

**People living with HIV have greater risk for certain cancers**

Cancers with viral cause:

Anal cancer, cervical cancer, some head & neck (HPV)

Liver cancer (Hepatitis B or C)

Hodgkins (EBV)

Higher rates of modifiable cancer risk due to smoking, alcohol intake



**BY 2030, UP TO  
70% OF PEOPLE  
WITH HIV WILL BE  
OVER THE AGE OF 50.**



HIVAGE  
POSITIVELY

GILEAD

# Intersecting Challenges

- experience of HIV-related isolation and stigma
- receiving care from more than one speciality
- toxicity of cancer treatment
- being part of the LGBTQ+ community
- being a migrant, being from a racially minoritised group
- increased risk of frailty/comorbidity in the older population



**STIGMA IS MORE HARMFUL THAN HIV**

Common misconceptions about HIV have a devastating impact on people living with the virus. But HIV is now treatable, and just one pill a day means it can't be passed on.

Stigma and self-stigma

at [HIVstigma.scot](http://HIVstigma.scot)

Terrence HIGGINS TRUST

in Trust is a registered charity in Scotland Reg. no. SC038862

The graphic features a man with glasses in the background. The text 'STIGMA IS MORE HARMFUL THAN HIV' is in large yellow letters. Below it is a graphic with a woman's face and a couple walking. The text 'Stigma and self-stigma' is in a black box. The website 'at HIVstigma.scot' is in yellow. The Terrence Higgins Trust logo is in the bottom right. A small note at the bottom left says 'in Trust is a registered charity in Scotland Reg. no. SC038862'.



**RESEARCH  
ON  
EXPERIENCES**

# Convergence of pressures “invisible” in HIV and “visible” in cancer

PhD 2019 explored experiences of people with this dual diagnosis

## Findings:

- HIV treatment easy but kept secret
- Emotional burden of managing information
- **Lack of fit & feeling isolation in cancer services:** self stigma, extra infection control, GP, exclusion from clinical trials, feeling responsible for HIV care



Hainsworth, EG, Shahmanesh, M and Stevenson, F. (2020). HIV positive and treated for cancer: The convergence of pressures “invisible” in HIV and “visible” in cancer. *European Journal of Cancer Care* 5 January 2020

# Implications for improving care



- Standardised pathways of cancer treatment don't always recognise vulnerability (the invisible pressures)
- Oncology services may need more knowledge about HIV to deliver person centred care
- Future improvement should include acknowledgement of HIV stigma (nature of self-stigma as well as actual)





# Developing Person-centred Care

## Co-Production Research Methodology



**Five co-production principles**

1. Share power
2. Include all perspectives & skills
3. Respect everyone's knowledge
4. Reciprocity
5. Build relationships

*#CoProWeek*



# Caring for the Whole Person: Gordon



Videos housed on NHIVNA website

<https://www.nhivna.org/life-with-HIV-and-cancer>



# Research Journey



Writing research protocols  
Ethics submissions

Cancer clinical trial delivery

Research governance knowledge

PhD Exploring experiences of people living with HIV & treated for Cancer

- Co –production of videos featuring first person accounts
- Publications
- Wider Applied Health research experience
- Relationship-building with charities/advocates
- RMH Service evaluation HIV & Anal cancer treatment experience
- NIHR grant application



Thank You

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