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Using a co-creation approach to share the cancer experiences of patients living with HIV: Translating research findings into practice

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Life with HIV and Cancer

Translating research findings into practice

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Conflict of Interest

In relation to this presentation I declare that I have no conflict of interest

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BACKGROUND TO THE PROJECT

- Cancer likely to affect growing numbers
- 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:** extra infection control, GP, exclusion from clinical trials, feeling responsible for HIV care

IMPLICATIONS FOR IMPROVING CARE

- Standardised pathways of cancer treatment don't recognise vulnerability
- Oncology services need more knowledge about HIV to deliver good patient centred care
- Future improvement should include acknowledgement of HIV stigma so that the patient does not bear this alone
- NHIVNA research award 2019





TRANSLATING RESEARCH INTO PRACTICE

‘Oncology services need more knowledge about HIV and a better understanding of experiences to deliver good patient centred care’

- NHIVNA Research Award to identify priority areas for intervention to improve patient experiences. Mentor Dr Hilary Piercy SHU
- Workshop of healthcare professionals & patient representatives July 2020
- Consensus that video an impactful, versatile output - to educate and inform in a wide variety of settings



CO-CREATION CO-PRODUCTION APPROACH



Five co-production principles

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

#CoProWeek

Principles Driven

Emphasis on **power-sharing**, building trust, reciprocity & **shared learning**

Individual experiences are at the centre & ensure that research is framed in the terms of the people concerned

THE VIDEO PROJECT RECRUITMENT

- Challenge finding people willing to share their HIV status & experience on camera
- Help to advertise opportunity by UK CAB
- Mid Covid-19 pandemic, all interaction remote





THE PARTICIPANTS

- **Susan** *Community engagement manager HIV information charity Nam Aidsmap*
- **Gordon** *non-executive director of Terrence Higgins Trust & Positive Voices speaker*
- **Virginia** *horticulturalist who works with charities that help people living with HIV overcome isolation & loneliness*

THE CO-CREATION PROCESS

- Participants considered PhD findings in context of own experience
- Flexible contact to agree a loose script
- Advice on technical issues provided by Russ Maher of SHU

Principles

- Individual experience at the centre
 - Power sharing relationships, respect & reciprocity
 - Open to challenge
-
- 3 videos with 3 main themes





1. CARING FOR THE WHOLE PERSON

- *'So right now I feel as though I am on so many different drugs, that I don't really know where to turn, I'm undergoing chemotherapy and I'm on HIV medication and it doesn't feel at any time that any of the clinicians are looking at me holistically....*
- *there's no-one really coordinating, and sometimes I just feel so unwell that I'm unable to advocate for myself'*

2. CHALLENGING STIGMA

‘very often when people experience stigma in healthcare settings it’s at the point when we are at our most vulnerable. It can be difficult to challenge that type of behaviour’





3. HIV GET UP TO SPEED

- *'I think it's really important that healthcare professionals working in cancer need to understand the reality of HIV today and know that people with HIV on effective treatment can expect to live as long as everyone else.....*
- *it's impossible to pass on HIV to our sexual partners much less within social settings, so you know, just get up to speed'*

DISSEMINATION

Housed on NHIVNA website

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

Conversations with Macmillan – signpost on Learning & Communication Hub

Social media promotion by Live Through This (charity supporting LGBTQIA+ people living with cancer)

Presentation at Royal Marsden educational forums



THANK YOU

- To Virginia, Susan and Gordon for sharing their experiences so candidly
- To NHIVNA for funding & hosting the videos
- To Dr Hilary Piercy for her expert mentorship & support
- Russ Meyer for technical expertise
- Emma.hainsworth@rmh.nhs.uk

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

