Evolution of a video project to translate research findings about patient experiences into improved clinical care

Emma Hainsworth and Hilary Piercy

ABSTRACT

Background: People living with HIV are at an increased risk of developing cancer. Cancer health professionals could benefit from improving and updating their knowledge of HIV and their understanding of patient experiences to deliver high-quality, patient-centred care. Aims: Evidence-based educational resources to improve patient care were identified and developed using a co-production approach. Methods: There were two stages: a workshop discussion by experts to reach consensus on a priority intervention; and co-production of video content *Life with HIV and Cancer*. Findings: The consensus of the expert group was that video content featuring first-person accounts would be the most impactful intervention to address the gap in knowledge. Three co-produced and professionally made video resources were developed and disseminated. Conclusion: The videos provide insight into the impact of stigma as well as current information on HIV. Their use can improve oncology clinical staff knowledge and better equip them to provide patient-centred care.

Key words: HIV ■ Cancer ■ Patient and public involvement ■ HIV stigma ■ Co-production ■ Co-creation

People living with HIV are at an increased risk of developing certain cancers. Their pattern of cancer incidence changed with the introduction of highly active antiretroviral therapy in 1996. Cancers that had previously been considered as AIDS defining (Kaposi sarcoma, non-Hodgkin's lymphoma and cervical cancer) occur less frequently in the era of effective HIV treatment but remain more common in those living with HIV than those without (Franceschi et al, 2010). Shiels et al (2018) have projected that cancers such as lung (currently higher in people living with HIV) and prostate will become more common in the next 10 years as this population ages. This means that people living with HIV will continue to engage with cancer services and should expect to receive good, patient-centred care from oncology health professionals who understand their needs.

The National AIDS Trust (2021) recently conducted a research programme to gain an understanding of public perceptions and knowledge of HIV in the UK. This found that most of the public do not hear or think about HIV much, that many of their reference points are dated (from the 1980s and 1990s) and they are not aware of current knowledge and messaging such as Undetectable=Untransmittable (U=U). This is a campaign run by the Prevention Access Campaign (2023) promoting the finding that people infected with HIV who are virally suppressed cannot sexually transmit the virus to others. This message is now accepted because of evidence accumulated since the early 2000s, including that from the Partners of People on ART—a New Evaluation of the Risks (PARTNER) study (Rodger et al, 2016).

HIV-related stigma continues to exist in part because of this lack of knowledge and is often experienced by people living with HIV in combination with social and economic stressors and intersecting stigmas such as being gay or a migrant (Deacon et al, 2005; Flowers, 2010; Mazanderani and Paparini, 2015; Hsieh et al, 2022). Against this backdrop of wider societal views, recent work focused on cancer care revealed that the experience of being diagnosed with both HIV and cancer can have a powerful combined impact on individuals (Hainsworth et al, 2020).

Cancer care experiences can be poorly matched to patients' needs in several areas. Patients report experiencing a feeling of difference from others in the cancer setting and feel responsible for liaising between the two services, and both they and staff encounter difficulties around the management of information in relation to HIV (Hainsworth et al, 2020). This work suggests that health professionals working in the field of cancer could benefit from improving and updating their knowledge of HIV and their understanding of the experiences of people living with it in order to deliver good, patient-centred care.

This article describes a two-stage project: first; identifying a priority intervention that could bridge this gap in health professionals' knowledge and improve these experiences of cancer care; second, the subsequent process of developing it.

Emma Hainsworth, Nurse researcher, Applied Health Research Group, Royal Marsden NHS Foundation Trust, London, emma.hainsworth@rmh.nhs.uk

Hilary Piercy, Associate Professor, Department of Nursing and Midwifery, College of Health, Wellbeing and Life Sciences, Sheffield Hallam University, Sheffield

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Aim

This article details the processes of identifying and developing a set of co-produced, evidence-based educational resources to improve patient care.

Methods

Stage 1. Workshop discussion: reaching consensus on a priority intervention

The literature showed that cancer health professionals could benefit from updating their knowledge about people living with HIV in order to better understand their experiences of care. The first stage of this work involved bringing together key experts to seek their opinions on the most effective interventions for bridging the gap in practitioner knowledge and to reach a consensus. The expert group included nursing experts from both HIV and cancer disciplines and two patient representatives with lived experience (*Box 1*).

The consensus work was conducted flexibly using a modified nominal group technique method. This method was developed in the 1950s and has been used widely to capture views and opinions of skilled and experienced individuals and then bring them together where they develop a consensus as a group (Murphy et al, 1998; Foth et al, 2016). The technique uses an ordered procedure involving a series of individual and group processes to obtain and manage qualitative information. It aims to elicit contributions from all members of a group and to promote the generation of ideas through discussion and debate.

For this project, the individuals within the group were provided with a summary of existing evidence relating to the experiences of people living with HIV and being treated for cancer. One-to-one interviews were then conducted with them; this allowed individual group members to express their ideas about proposed interventions independently and privately.

Themes from these interviews were listed and the list was circulated to all ahead of the group discussion, which was conducted online. Individuals were asked to consider ranking the themes listed in terms of preference; the initial intention was to aggregate the group decision statistically. However, the group quickly achieved consensus through a rich and fruitful discussion and reached a collective agreement that video materials featuring first-person accounts of experiences would be the most effective approach. Participants agreed that video content featuring patient voices would be immediately credible and engaging. It would also have the potential to reach a wide and diverse audience and could be used flexibly on different platforms, for example at conferences and as part of online or face-to-face training, and could be promoted via social media.

Box 1. Expert group members

- Lymphoma clinical nurse specialist
- Advanced nurse practitioner in haematology
- HIV community nurse specialist
- Clinical skills facilitator HIV unit
- Patient representative 1
- Patient representative 2
- Senior academic researcher (specialist area sexual health and HIV)
- Nurse researcher (author)

Stage 2. Co-production of video content: life with HIV and cancer

The development of the video content adopted a different methodological approach. Three participants were recruited through an HIV advocacy network advertisement. Two women and one man came forward to participate; all worked in different capacities as HIV advocates within the third sector and all had personal experience of living with HIV and being treated for cancer. They were open about their HIV diagnoses and confident about speaking about their experiences on camera. Although just three voices, they represented a diversity of experience in that they had been treated for different cancers and came from a variety of ethnic and cultural backgrounds.

A co-production approach was adopted to develop the video content. The term co-production or co-creation can be difficult to define. Some use it to describe a particular set of methods; others use it more loosely to mean consulting the public. Here, it is used to describe an approach that is based around a set of key principles. Those principles are power-sharing, building trusted relationships, reciprocity and shared learning (Staley et al, 2017; Hickey et al, 2018; National Institute for Health and Care Research (NIHR), 2021). The approach has been described as collaborative knowledge generation by researchers alongside stakeholders rather than top-down knowledge 'translation' (Greenhalgh et al, 2016). It goes beyond the consultation or collaboration models of patient involvement that are commonly adopted and which can reproduce imbalances of power when they retain professionally dominated approaches with a business meeting or committee format with the agenda led by researchers (Ocloo and Matthews, 2016; Papoulias and Callard, 2021).

The authors wanted to conduct the involvement activity with a more equal power balance between researchers and the experts by experience so that the output would be framed in the terms of the people concerned.

The three participants were provided with a summary of the findings of the first author's earlier work conducted as part of a PhD (Hainsworth et al, 2020). The researcher (EH) held initial one-to-one discussions with the participants to discuss the findings and to ask them to reflect on and consider these in the context of their own experience. Flexible contact was maintained between the researcher and the three participants, and they went back and forth to agree a loose script that reflected the evidence and their own experiences. Guidance around appropriate length and technical advice on filming video content were provided by a technical officer who supported the project.

The key principles of co-creation were adopted, placing individuals' experiences at the centre and ensuring that they played an equal role in deciding what should be included. Participants filmed the videos themselves using smartphones and sent unedited clips to the researcher.

The contents of the video scripts that the participants had developed were transcribed and a thematic analysis performed. The key themes they discussed related to: the impact of HIV-related stigma; cancer clinicians having inadequate knowledge about HIV; and their perceived need to carry the burden of coordinating care and communication between the HIV and cancer clinical teams.

The content was grouped under three titles in collaboration and continual negotiation with the participants and technical officer, ensuring that there were three short, coherent and impactful narratives of appropriate length. Once the content had been agreed by all, the three videos were put together with a unique logo and title page designed by the technical officer. The participants had input into the design of the logo and title pages and reviewed edits of the video clips before agreeing the final content.

Ethical considerations

Ethics approval for stage 1 (consultation with key experts) was obtained on 30 September 2019 from the UCL research ethics committee (project ID 16343/001). The video participants gave consent to take part in the project by responding to the advertisement circulated by HIV advocacy group UK CAB. They provided written consent for the final videos to be published on the National HIV Nurses Association (NHIVNA) website. All video participants received reimbursement for their time according to the NIHR (2022) National Standards for Public Involvement.

Results

Stage 1

The result of stage 1 of this project was the consensus of the key expert group, who agreed that video content featuring first-person accounts would be the most effective, impactful and versatile intervention to address gaps in knowledge and understanding about HIV among oncology health professionals. The group agreed that this resource, featuring voices of lived experience, would be accessible, credible and have an immediate impact on the viewer. It could also be used in a variety of settings for different audiences.

Stage 2. Development of three co-produced and professionally produced video resources

The first video, *Caring for the Whole Person*, featured a topic that one of the participants felt was a current and immediate concern for them. It was recorded in the middle of their cancer treatment when they were feeling unsafe and vulnerable, and it conveys with great impact their perception of carrying the sole responsibility of coordinating information about HIV and cancer medication between the two healthcare services. This video serves to remind cancer health professionals of the potential complexity of medication regimens for people living with HIV and receiving cancer treatment and to be aware that extra efforts might need to be made to coordinate care. Communication between cancer and HIV healthcare teams has the potential to be disjointed, with the onus placed on the patient to drive the liaison at a time when they are likely to be feeling the most unwell and vulnerable.

In the second video, *Challenging Stigma*, all three participants spoke about their experiences and perceptions of HIV-related stigma within the cancer clinical setting. These included examples of clumsy and misjudged communication, and some described instances of staff failing to note the sensitivity around discussing HIV status in situations where they may be overheard. In these examples, the participants described challenging misjudged conversations and providing education on to how handle this better, and reiterated that it took considerable strength to do so at a time when they were feeling particularly vulnerable and unwell. One participant spoke a short section about this vulnerability in their native language (Spanish) with subtitles. This was included to convey the additional impact of stigma for people living with HIV who do not find it easy to speak and articulate their needs.

In the third video, *HIV Get up to Speed*, two of the participants reiterated important messages about HIV today. These included the fact that people living with HIV on effective treatment can expect to have a normal life expectancy and an explanation of the U=U message.

Dissemination

The videos are hosted on the NHIVNA website (https://www.nhivna.org/life-with-HIV-and-cancer). They have been circulated among Macmillan Cancer Support engagement leads, who work with communities to enable Macmillan to understand the needs of everyone affected by cancer; they will decide on the appropriate platform for signposting. The work has been presented at the annual NHIVNA conference and promoted via social media by the Live Through This charity (which supports LGBTQI+ people living with cancer). The videos have also been shared within staff educational forums at the Royal Marsden Hospital and circulated to nurse leaders at cancer centres nationally to allow onward sharing with their staff. It is envisaged that they will be used most effectively within educational forums where they can be played in their entirety to create opportunities for discussion and reflection and to generate thoughts about potential improvements to services.

Discussion

The video project developed three separate short films that were co-created in partnership with people who had relevant lived experiences. They were intended to act as educational tools to give oncology health professionals firsthand insight into the unique experiences of this group, including: an appreciation of the impact of HIV-related stigma; the perceived burden of liaising between different healthcare services; and the provision of up-to-date HIV knowledge.

The videos, in particular *HIV Get up to Speed*, act as educational tools that update oncology staff on HIV as it is today, challenging dated misconceptions from the past that have persisted and frame the virus in a stigmatising way as a highly infectious and lethal killer (Flowers, 2010).

Ma and Loke (2020) performed a review of HIV-related stigma-reduction interventions for health professionals, and described a variety of approaches including those based on information, for example being delivered through a brochure

KEY POINTS

- Health professionals often have an outdated knowledge of HIV
- Gaining an understanding of the experiences of people living with HIV will help cancer practitioners deliver high-quality, patient-centred care
- Videos featuring patients with HIV and cancer can give oncology health professionals an insight into their unique experiences
- Co-production ensures projects give true weight to patients' perspectives and priorities
- The themes in videos co-produced with patients include: the impact of HIV-related stigma; the burden of liaising between different healthcare services; and the provision of up-to-date HIV knowledge

or classroom presentation, and those involving contact with and sharing with an affected group. The review concluded that multiple approaches should be adopted in interventions to reduce stigma. The videos, particularly *HIV Challenging Stigma*, provide this effective combination by including both first-person testimonials and evidence-based information. They can be used in educational settings in a way that allows for reflection on and discussion of the content, so facilitate the building of skills. In addition, they provide resources to close gaps in knowledge about HIV among health professionals and can help staff avoid misjudged communication or behaviour that may be perceived by patients as stigmatising.

May et al (2014) described a situation in some areas of health services where, in response to growing populations with long-term conditions, 'work'—such as that aimed at managing symptoms—has been delegated to patients, founded on ideas of self-care and self-empowerment. Some of this work can place demands on patients that they experience as burdens and which have the potential to overwhelm them, particularly if they do not have their own supportive social networks. A lack of health professional knowledge about HIV and its management can create a situation where patients are given work as 'expert patients' that they do not welcome, and which adds to the mounting pressures they experience during the period of cancer treatment. The video *Caring for the Whole Person* conveys this pressure with the participant talking powerfully about the responsibility of ensuring that their HIV was appropriately managed at a time when they were feeling overwhelmed, unwell and unable to advocate for themself.

Strengths and limitations

The greatest strength of the project is its genuine adherence to the principles of co-production and the centring of the participants' experiences spoken in their own words. The videos feature the diverse experiences of three participants, two women and one man from different ethnic and cultural backgrounds and with different cancers. However, these voices cannot be said to represent the huge diversity of experiences of people living with HIV who are being treated for cancer.

Although the videos provide information and share the voices of those affected to help combat stigma, they cannot address the wider social and structural determinants of HIV-related stigma, which remain and continue to impact people living with HIV.

Conclusion

The three co-produced videos, featuring first-person accounts of being treated for cancer and living with HIV, can be used by cancer health professionals as impactful educational tools. They provide insight into the burden that patients experience when they feel responsible for the liaison between oncology and other healthcare services and the impact of HIV-related stigma. They also address the gaps in current knowledge about HIV by clearly presenting the U=U message. It is hoped that the videos will improve knowledge among oncology clinical staff and facilitate better patient-centred care for people living with HIV. **BJN**

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Deacon H, Stephney I, Prosalendis S. Understanding HIV/AIDS stigma: a theoretical and methodological analysis. Cape Town, South Africa: HSRC Press; 2005

Flowers P. HIV transitions: consequences for self in an era of medicalization. In: Davis M, Squire C (eds). HIV treatment and prevention technologies in international perspective. Basingstoke. Palgrave Macmillan; 2010:109-125

Foth T, Efstathiou N, Vanderspank-Wright B et al. The use of Delphi and nominal group technique in nursing education: a review. Int J Nurs Stud. 2016;60:112–120. https:/doi.org/10.1016/j.ijnurstu.2016.04.015

Franceschi S, Lise M, Clifford GM et al. Changing patterns of cancer incidence in the early- and late-HAART periods: the Swiss HIV Cohort Study. Br J Cancer. 2010;103(3):416–422. https:/doi.org/10.1038/sj.bjc.6605756

Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving research impact through co-creation in community-based health services: literature review and case study. Milbank Q. 2016;94(2):392–429. https:/doi.org/10.1111/1468-0009.12197

Hainsworth EG, Shahmanesh M, Stevenson F. HIV positive and treated for cancer: the convergence of pressures 'invisible' in HIV and 'visible' in cancer. Eur J Cancer Care (Engl). 2020;29(3):e13222. https:/doi.org/10.1111/ecc.13222

Hickey G, Brearley S, Coldham T et al. Guidance on coproducing a research project. Southampton: Involve; 2018

Hsieh E, Polo R, Qian HZ, Fuster-RuizdeApodaca MJ, Del Amo J. Intersectionality of stigmas and health-related quality of life in people ageing with HIV in China, Europe, and Latin America. Lancet Healthy Longev. 2022;3(3):e206–e215. https:/doi.org/10.1016/S2666-7568(22)00003-4

Ma H, Loke AY. A scoping review of an HIV/AIDS-related stigma-reduction intervention for professionals and students from health-related disciplines. Int J Sex Health. 2020;32(2):94–129. https:/doi.org/10.1080/19317611.2020.1754317

May CR, Eton DT, Boehmer K et al. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. BMC Health Serv Res. 2014;14(1):281. https:/doi.org/10.1186/1472-6963-14-281

Mazanderani F, Paparini S. The stories we tell: qualitative research interviews, talking technologies and the 'normalisation' of life with HIV. Soc Sci Med. 2015;131:66–73. https:/doi.org/10.1016/j.socscimed.2015.02.041

Murphy MK, Black NA, Lamping DL et al. Consensus development methods, and their use in clinical guideline development. Health Technol Assess. 1998;2(3):i–iv, 1–88. https:/doi.org/10.3310/hta2030

National AIDS Trust. HIV: public knowledge and attitudes. 2021. https://tinyurl.com/49dywcsn (accessed 9 May 2023)

National Institute for Health and Care Research. Guidance on co-producing a research project. 2021. https://tinyurl.com/329w62vc (accessed 9 May 2022)

National Institute for Health and Care Research. Payment guidance for researchers and professionals. Version 1.3—July 2022. 2022. https://tinyurl.com/3cuzehz8 (accessed 9 May 2022)

Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Qual Saf. 2016;25(8):626–632. https:/doi.org/10.1136/bmjqs-2015-004839

Papoulias SC, Callard F. 'A limpet on a ship': spatio-temporal dynamics of patient and public involvement in research. Health Expect. 2021;24(3):810–818. https:/doi.org/10.1111/hex.13215

Prevention Access Campaign. The U=U global community. 2023. https://www.preventionaccess.org/community (accessed 9 May 2023)

Rodger AJ, Cambiano V, Bruun T et al. Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV positive partner is using suppressive antiretroviral therapy. JAMA. 2016;316(2):171–181. https:/doi.org/10.1001/jama.2016.5148

Shiels MS, Islam JY, Rosenberg PS, Hall HI, Jacobson E, Engels EA. Projected cancer incidence rates and burden of incident cancer cases in HIV-infected adults in the United States through 2030. Ann Intern Med. 2018;168(12):866–873. https:/doi.org/10.7326/M17-2499

Staley K, Abbey-Vital I, Nolan C. The impact of involvement on researchers: a learning experience. Res Involv Engagem. 2017;3(1):20. https:/doi.org/10.1186/s40900-017-0071-1

CPD reflective questions

- Consider the U=U message: how might this help to reduce stigma for people living with HIV?
- How might the content of the videos be best used within your team to update knowledge about the experiences of people living with HIV?
- Are there features of your clinical setting that give patients an extra burden of liaising between services? How could this be improved?