

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

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‘HIV positive and treated for Cancer: the evolution of a video project to translate research findings about patient experiences into improved clinical care’

Abstract

Background: People living with HIV are at an increased risk of developing cancer. Cancer healthcare professionals could benefit from improving and updating their knowledge on HIV and their understanding of experiences to deliver good patient-centred care. **Aims:** To detail the process for the identification and development of co-produced, evidence-based educational resources to improve patient care. **Methods:** Two stages: 1. Workshop discussion to reach consensus on priority intervention. 2. Co-production of video content ‘Life with HIV & Cancer’. **Findings:** Consensus of the key expert group that video content featuring first person accounts would be the most impactful intervention to address the gap in knowledge. Development of three co-produced, and professionally produced video resources. **Conclusion:** The videos provide insight into the impact of stigma and current information on HIV today. Their use can improve the knowledge of oncology clinical staff and better equip them to provide patient-centred care.

Keywords

HIV, Cancer, Patient and public involvement, HIV stigma, Co-production, Co-creation

Keypoints

Healthcare professionals working in cancer could benefit from improving and updating their knowledge on HIV. Gaining an understanding of the experiences of those people living with HIV will help them to deliver good patient-centred care. These co-produced videos act as useful educational tools providing oncology healthcare professionals with first hand insight into the unique experiences of this group. Themes include 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.

Background and rationale

People living with HIV are at an increased risk of developing certain cancers. The pattern of cancer incidence has changed with the introduction of highly active antiretroviral therapy (HAART) in 1996. Cancers which had previously been considered as AIDS-defining (Kaposi Sarcoma, Non-Hodgkins Lymphoma and cervical cancer) occur less frequently in the era of effective HIV treatment, but their incidence still remains more common in those living with HIV compared to 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 cancer, 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 healthcare professionals who understand their needs.

The National AIDS Trust recently conducted a research programme to understand public perceptions and knowledge of HIV in the UK (National AIDS Trust, 2021). This found that most of the public do not hear or think about HIV much but 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 U equals U.

‘Undetectable=Untransmittable’ (U=U) is a campaign launched by Prevention Access which promotes the finding that people infected with HIV who are virally suppressed cannot sexually transmit the virus to others (Prevention Access Campaign, 2019). This message is now accepted because of accumulating evidence since the early 2000s including 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 due to 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, Stephney, & Prosalendis, 2005; Flowers, 2010; Mazanderani & Paparini, 2015; Hsieh et al, 2022). Against this backdrop of wider societal views, recent work which focused on the

area of cancer care, revealed that the experience of both a HIV and cancer diagnosis 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, they 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 healthcare professionals working in cancer could benefit from improving and updating their knowledge on HIV and their understanding of the experiences of those people living with it in order to deliver good patient-centred care. This paper describes a two-stage project, firstly to identify a priority intervention which could bridge this gap in healthcare professional knowledge and improve these cancer experiences, and then the subsequent process of developing it.

Aim

To detail the process for the identification and development of a set of co-produced, evidence-based educational resources to improve patient care

Methods

Stage 1 The workshop discussion 'Reaching consensus on a priority intervention'

The literature showed that cancer healthcare professionals could benefit from updating their knowledge about people living with HIV and better understand their experiences of care. The first stage of our work brought key experts together to seek their opinions on the most effective interventions for bridging this gap in healthcare professional knowledge and to develop consensus between them. The expert group included nursing experts from both HIV and cancer disciplines and two patient representatives with lived experience, see Table 1.

Table 1 Workshop participants

	Role
1	Lymphoma clinical nurse specialist
2	Advanced nurse practitioner in haematology
3	HIV Community nurse specialist
4	Clinical skills facilitator HIV unit
5	Patient representative one
6	Patient representative two
7	Senior academic researcher (specialist area sexual health and HIV)
8	Nurse researcher (author)

The consensus work was conducted flexibly using a modified nominal group technique method. This method was originally developed in the 1950's and has been widely used to capture views and opinions from a group of skilled and experienced individuals, to then put them together and develop consensus between them (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 the contributions of all members of a group and to promote the generation of ideas through discussion and debate.

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

interviews were listed and the list was circulated to all ahead of our group discussion which was conducted online. Individuals were asked to consider ranking the themes listed in terms of preference; the initial intention being 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. The group 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, as part of online or face to face training and could also be promoted via social media.

Stage 2 The 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 a 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 diagnosis and confident to speak 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 varied 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 which is based around a set of key principles. Those principles are power-sharing, building trusted relationships, reciprocity and shared learning (NIHR, 2021, Hickey et al, 2018; Staley et al, 2017). 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 which 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 (Papoulis and Callard, 2021; Ocloo and Matthews, 2016). We wanted to conduct our involvement activity with a more equal power balance between researchers and the experts by experience so that the output was framed in the terms of the people concerned.

The three participants were provided with a summary of the findings of the author's earlier work conducted as part of a PhD (Hainsworth et al, 2020). The researcher held initial one to one discussion with participants to discuss the findings and to ask them to reflect upon and consider these in the context of their own experience. Flexible contact was maintained, back and forth to agree a loose script which reflected the evidence and their own experiences. Guidance around appropriate length and technical advice on filming video content was 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 to include. Participants filmed the videos themselves using smartphones and sent unedited clips to the researcher.

The content of the video scripts that the participants had developed was 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 was 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 finalised content.

Ethical considerations

Ethics approval for Stage 1 (consultation with key experts) was obtained on 30th September 2019 from UCL Research Ethics Committee. Project ID 16343/001. The video participants provided their consent to participate in the project by responding to the advertisement circulated by the HIV advocacy group, UK CAB. They provided written consent for the final videos to be published on the NHIVNA website. All video participants received reimbursement for their time according to the NIHR National Standards for Public Involvement (NIHR 2020).

Results

Stage one:

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 the gap in knowledge and understanding about HIV amongst oncology healthcare professionals. The group agreed that this resource featuring the voice of lived experience would be accessible, credible and have an immediate impact on the viewer. It could also be used in a variety of different settings for different audiences.

Stage 2: The 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 to coordinate information about HIV and cancer medication between the two healthcare services. This video serves to remind cancer healthcare professionals of the potential complexity of medication regimes 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 upon 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 the misjudged conversation and providing education as to how handle this better, but they 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 own Spanish language 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 facts that people living with HIV on effective treatment can expect to live a normal life expectancy and an explanation of the 'Undetectable=Untransmittable' (U=U) message.

Dissemination

The videos are housed on the National HIV Nurses Association website <https://www.nhivna.org/life-with-HIV-and-cancer> They have been circulated amongst Macmillan Engagement Leads who work with communities to enable Macmillan to understand the needs of everyone affected by cancer; they will decide upon the appropriate platform for signposting. The work has been presented at the annual NHIVNA conference and signposted via social media by the charity Live Through This (who

support LGBTQIA+ people living with cancer). It has 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 consisted of three separate short films which were co-created in partnership with people of relevant lived experiences. They were aimed to act as educational tools to provide oncology healthcare professionals with first hand 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 which update oncology staff on HIV as it is today, challenging those dated misconceptions from the past which have persisted to 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 healthcare professionals which described a variety of approaches including those that were information based for example delivered through a brochure or classroom presentation, and those involving contact with and sharing with the 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 providing first person testimonial and evidence-based information. They can be used within an educational setting in such a way that allows for reflection upon and discussion of the content and therefore facilitates the building of skills. They therefore provide resources which can address gaps in knowledge about HIV amongst healthcare professionals and can help staff avoid misjudged communication or behaviour which may be perceived by patients as stigmatising.

May et al (2014) described a situation within some areas of health services in which 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 social networks to share the work. Lack of healthcare professional knowledge about HIV and its management can create a situation where patients are being given work as 'expert patients' which 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 themselves.

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 and 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

Conclusions

The three co-produced videos, featuring the first-person accounts of being treated for cancer and living with HIV, can be utilised by cancer healthcare 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 gap in knowledge about HIV as it is today by clearly presenting the U equals U message. It is hoped that their use will improve knowledge amongst oncology clinical staff and facilitate better patient centred care for people living with HIV.

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