ARE YOU OK?

A participatory animation project to imagine a better world for young people with HIV

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What research tells us

Over the past 20 years, people living with HIV in the UK have gained access to better treatment, increased survival rates and improved quality of life[1]. At the same time, young people responding to a survey in 2017 are still experiencing stigma and worries related to their HIV[2]. Compared to a survey of adults with HIV[3], young people report far fewer direct experiences of stigma or discrimination and much more supportive relationships with both peers and health care professionals. However, young people's worries about stigma were still significant, with many young people agreeing that they avoided attending social events and even seeking medical help when necessary. Half of all young people who responded avoided intimate relationships and sex, while more than half of respondents worried about the possibility of being rejected by a sexual partner.

Qualitative research into the experiences of young people living with HIV reveals similar issues. The potential for stigma and rejection at a time when young people are developing identity, independence and a sense of belonging are significant barriers to talking about their HIV[4] to peers[5]. For 97% of young people with HIV in the UK, vertical transmission (mother to child) was the route of infection[6]. As HIV status may only be known amongst close family, fear and shame can also be passed down from parents to young people. Some parents actively discourage young people from being open about their HIV with peers in order to protect the confidentiality of other family members[7]. The burdens of secrecy and silence can lead to self-isolation. At a life stage when peer relationships are becoming more important than family[8], this can have a particularly negative impact on young people's mental health and wellbeing.

What we wanted to find out

As with most stigmatised conditions, young people with HIV face additional challenges beyond the common difficulties of early adolescence. Rather than just focus on problems, The Association for Young People's Health (AYPH) wanted to find out what young women with HIV thought could help with these challenges and how formal and informal structures could better meet their physical and emotional wellbeing needs.

Our process

We worked in partnership with Children's HIV Association (CHIVA) to find this out directly from young people with HIV. We used science fiction and animation as a means to imagine a world free from stigma, discrimination and limitations and where support came from a variety of sources. Building on AYPH's previous work about early adolescence and using the same science fiction method, we supported eight girls and young women aged 8-14 to create characters and stories that take place on an ideal planet for young people with HIV. Using fictional characters in an imagined world allowed participants to explore highly

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[1] Kirwan PD, Chau C, Brown AE, Gill ON, Delpech VC and contributors. HIV in the UK - 2016 report. December 2016. Public Health England, London.

[2] The Young People Living With HIV Stigma Survey UK: National findings 2017.

[3] HIV in the UK: Changes and Challenges; Actions and Answers. The People Living With HIV Stigma Survey UK 2015 National findings.

[4] 'Naming HIV' or 'talking about HIV' are terms preferred by CHIVA because of the negative connotations associated with the concept of disclosure. We have chosen to use these terms in this report.

[5] Grainger C. Understanding disclosure behaviours in HIV-positive young people. J Infect Prev. 2017 Jan;18(1):35-39.

[6] Collaborative HIV Paediatric Study (CHIPS) (2011) Annual Report 2010/11 (June 2011) and CHIPS UK & Ireland Slide Set 2010–11 [online], Available from: http://www.chipscohort.ac.uk/summary_data.asp [Accessed: 4.11.2011].

[7] Hamblin E (2011) Just normal young people; Supporting young people living with HIV in their transition to adulthood: A report from the Children and Young People HIV Network.

[8] Hagell A, Shah R, Viner R, Hargreaves D, Varnes L and Heys M (2018*) The social determinants of young people's health: Identifying the key issues and assessing how young people are doing in the 2010s*. Health Foundation Working Paper. London: Health Foundation

sensitive issues in a safer, depersonalised way. We ran this project as a full day workshop at a CHIVA residential in November 2018. We used the following working definition of wellbeing:

1. **Feeling physically and mentally well**
2. **Feeling prepared for and supported through difficult changes in life**
3. **Feeling fully included in society and having a sense of belonging**

What the young people told us

We asked participants to identify the unmet health and support needs of young people with HIV, highlight what barriers currently exist and suggest what support might help them overcome these barriers. Participants raised a number of concerns including:

- confidentiality and the fear of involuntary naming of their condition
- difficultly adhering to medications and how they limit their freedom
- difficulty of being the only person/only sibling in their family with HIV
- difficulty talking to anyone about their problems if HIV is kept secret
- being defined by HIV – this was seen as both negative and positive with one young person explaining how her involvement with CHIVA gave her a stronger sense of identity

These ideas were fed into the development of a story focused on a young woman growing up with HIV. The young people were split into three groups and each was tasked with developing a character and their back story: the main character, a character who provides informal support and a character who provides formal support to the main character. We encouraged the young women to use their imaginations and incorporate magical and science fiction elements into both the characters and the storylines. The three characters developed by the groups were:

Main character	**Misty Lilac – 13 years old, wears a duvet at all times, her eyes change colour depending on her mood, she is very independent**
Informal support character	**Unnamed – an empathic talking unicorn who appears for Misty whenever she needs it and feels exactly what she is feeling so Misty doesn't have to explain anything**
Formal support character	**Dr. Duck – an anthropomorphic duck who is caring and supportive, asks Misty what she wants to do and supports her to make her own informed decisions**

Themes

A number of themes emerged from the young people's stories. Some of them are specific to growing up with HIV and others reflect similar concerns young people have raised with us in other group settings. When developing their stories, we encouraged the participants to think of a variety of ways these problems could be solved if services and society were organised differently.

Balancing protection and independence in adolescence

The main character Misty walks around wrapped in a duvet to feel warm and safe at all times. The participants highlighted how much emotions can affect day to day life and the importance of having people you trust who can support you at all times. At the same time, Misty is a female character who is fiercely independent and navigates the world either on her own or through her informal support network. Despite the difficulties she faces, Misty enjoys a degree of freedom far beyond what is the reality for most 13 year old girls. This was the first way the young people were able to distinguish Misty's world from their own.

Communicating emotions in non-verbal ways

Misty's eyes change colour depending on her mood. She is also directly connected to an empathic unicorn to whom she does not have to explain anything because it feels the same emotions. In informal conversations, participants explained that silence around HIV can exist even within their own households. This creates extra barriers to seeking both formal and informal support. Misty having a visible representation of her emotions that could not be ignored placed the onus on others to recognise and address her feelings. Silence or ignoring negative emotions was not an option in Misty's world.

Feeling understood

Beyond having someone to talk to, young people need to feel like they are understood. The unicorn character in this story is a literal representation of this need. Dr. Duck also responds empathetically to Misty's concerns and reassures her that it is common for young people to experience similar side effects with HIV medication. It's important to note that he does this in a way that does not diminish or belittle her feelings. Misty feels believed and taken seriously by her doctor, an important outcome when a young person seeks formal support. The fact that Misty and her doctor can communicate clearly even though they speak different languages is another sci-fi clue that indicates how well they can understand each other.

Being trusted to make informed choices about my own health

Although Misty is only 13 years old, she initiates contact and attends her doctor's appointment on her own. There was never any specific discussion amongst participants about this but nor did anyone question her independence or suggest that a parent or carer should be supporting her. She is trusted by her doctor to be involved in decisions about her medication during this visit.

Access to respite and escaping reality

An important science fiction element of the story is revealed at the end when Misty disappears into the painting of a beach she keeps on her wall. Young people with HIV have to take daily medication and deal with a lifelong health condition from a relatively young age. Participants talked about the difficulty of doing 'normal' adolescent things like attending sleepovers because of the fear that taking medication in front of friends would mean having to talk about their HIV. The opportunity to spontaneously visit exciting places or go on adventures like those in books without being limited by her condition was a powerful and liberating aspect of Misty's world.

What young people can teach us

Considering the stigma and discrimination people with HIV continue to face over 30 years after the first diagnosis[9], change can be protracted. Although young people with HIV report fewer direct experiences of stigma than adults, they worry about it and as a result, avoid seeking support from peers and professionals[10]. Anyone working to improve young people's health should take these worries very seriously. Using science fiction with young people may not produce hard data from which professionals and policy makers can adapt or reform services but that is not the point. Science fiction allows young people the opportunity to imagine completely new ways of living that conform neither to the systems and structures adults have created nor

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[9] The People Living With HIV Stigma Survey UK: National findings. 2015.

[10] The Young People Living With HIV Stigma Survey UK: National findings. 2017

are hindered by the barriers to change. It just requires a bit of imagination on the part of adults to decipher how these fantasy worlds can influence and improve our real world.

Five recommendations for supporting young people with HIV[11]

As a starting point, we suggest everyone working with young people familiarise themselves with the concerns and realities of young people with HIV. We have provided a list of resources created by young people in the box below. The young people who made this film are asking us to:

1. **Recognise that many issues affecting young people are structural that they have no control over** – stigma, discrimination and the accompanying silence and burden are issues young people with HIV experience and worry about. Expecting them to overcome these in order to access support is unreasonable. It should be the responsibility of professionals to proactively reach out to young people with HIV.
2. **Look out for non-verbal clues about emotions** – whilst they may not be as obvious as Misty's, young people give non-verbal clues all the time that communicate their emotions.
3. **Ask 'are you ok?' regularly** – this simple question acknowledges and validates how much day to day emotions can affect a young person and allows space for them to talk if they want.
4. **Encourage creativity and escapes from reality** – adolescence is a time when responsibility and stress are increasing anyway. For young people with stigmatised conditions that create further limitations, moments of freedom are especially important.
5. **Support independence when young people are ready** – young people with HIV and other long term conditions may be ready to take responsibility for their own care earlier than other young people.

Resources created by young people with HIV

Are you OK?: animated science fiction film about a better world for young people with HIV

Treat Me Like This: a series of clinical guides for practitioners

Video Resources: short films created by young people about growing up with HIV in the UK

Communication Infographic: guidance about effective communication with young patients

Schools Guidance: a series of documents for schools

Acute care flowchart: poster about effective support for young people in acute care settings

AYPH is the UK's leading independent voice for young people's health. We work to improve the health and wellbeing of all 10-24 year olds. To see more of our work with young people visit our website.

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[11] See also AYPH's Early Adolescence project report for more general recommendations for this age group and references to broader studies on adolescence.