



GROWING TOGETHER FOR
HEALTH AND HAPPINESS

EMPOWER STUDENTS: END HIV STIGMA EDUCATION TOOLKIT



A practical resource for education settings to empower students with HIV knowledge to end HIV stigma

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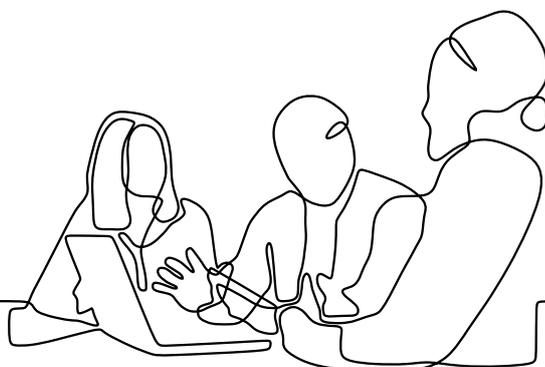
INTRODUCTION

This toolkit is designed to work hand in hand with the short film Life Growing Up. The toolkit contains information for teachers and education settings to better understand HIV and includes a number of activities designed for classes to complete. Students will learn about HIV, stigma and what it is like to be a young person growing up with HIV in the UK.

All secondary schools in England are required to be delivering the Relationships and Sex Education guidance, and HIV should be included in that. This toolkit helps teachers to fulfill that requirement.

The toolkit can help education settings to empower the students of today to be better educated on HIV and be the generation that ends HIV stigma. There is also a separate publication, HIV in Schools, which is a guide to help schools support any children living with and affected by HIV.

We know that different schools have different length lessons, tutor times and priorities, so teachers can adapt this resource in a way that suits them and their students. The content could be delivered in 2 x 1 hour lessons or across four or five 20 minute tutor time sessions. The activities are designed for key stages 3 and 4 but could be useful for older age groups and wider education settings. World Aids Day is on the 1st December every year so teachers may want to schedule sessions around that.



LIFE GROWING UP

A group of young people living with HIV from across the UK participated in an arts engagement programme in 2018. This was delivered by Chiva in partnership with the Lyric Hammersmith and Turtle Key Arts, who co-facilitated the workshop development stage. The young people worked with musicians, spoken word artists and performance art facilitators to express and examine their personal experiences, challenges and successes. The project writing, production and direction team, Danny Scheinman and

Sarah Sutcliffe, also conducted in-depth interviews with participants. Danny and Sarah used this material to develop a script from which a physical performance piece was devised for three actors. The piece was then developed into the film directed by Simon Baker and produced by Tamsin Herbert. The film stars actors Alistair Nwachukwu, Jack James Ryan and Maia Watkins. Music was composed by Aga Serugo-Lugo and performed by Aga and Simon Edwards.



**GETTING
READY TO
RUN THESE
SESSIONS
WITH YOUR
STUDENTS**

www.chiva.org.uk/lifegrowingup



It's important that before you begin running these sessions you check your own knowledge and reflect on what you know.

PREFERRED LANGUAGE ABOUT HIV



Language is really important when we talk about HIV.

It's important to model the use of appropriate language.

Below is a list of some problematic phrases and what they can be replaced with.

Don't Say	Say	Don't Say	Say
HIV-infected person/ HIV or AIDS patient	First person language such as: Person living with HIV	Became infected/ To catch HIV	Contracted or acquired HIV/ Diagnosed with HIV
AIDS (when referring to the virus, HIV)	HIV is not the same thing as AIDS. AIDS means a group of illnesses you get when your immune system hasn't been working properly for a long time. Use HIV and AIDS (when referring to both.)	To catch AIDS/ To contract AIDS/ Transmit AIDS	AIDS is a diagnosis and cannot be passed from one person to the next Use An AIDS diagnosis/ Developed AIDS
Full-blown AIDS	There is no medical definition for this phrase. Use the term AIDS/ Stage 3 HIV	Died of AIDS/ To die of AIDS	Died of AIDS-related illness/ AIDS-related complications/ End-stage HIV
		"Tainted" blood/ "Dirty" needles	Blood containing HIV/ Shared needles



For a longer language checklist visit: www.thewellproject.org/hiv-information/why-language-matters-facing-hiv-stigma-our-own-words

WHAT IS HIV?

HIV stands for Human Immunodeficiency Virus.

Unlike flu, HIV is a 'blood-borne virus', which means it can only live inside fluids within the body.

Everyone's body has an immune system (this is what fights off illnesses). The HIV virus attacks the immune system cells, and makes copies of itself which kill off the helpful immune system cells, and so, after a while, the immune system cannot fight off colds and other illnesses as easily anymore.

There are very good medicines that people living with HIV take, called anti-retroviral therapies (ART). The medicines can't get rid of the HIV virus completely, but they stop the HIV from attacking the immune system. People living with HIV who are on effective HIV treatment can live a long, healthy life. They may never get what is termed, an AIDS defining illness.

It is important to know that HIV is not the same thing as AIDS. AIDS means a group of illnesses you get when your immune system hasn't been working properly for a long time.

HOW CAN HIV BE PASSED FROM ONE PERSON TO ANOTHER?

You CANNOT get HIV from kissing, cuddling, or sharing drinks, plates or toilet seats.

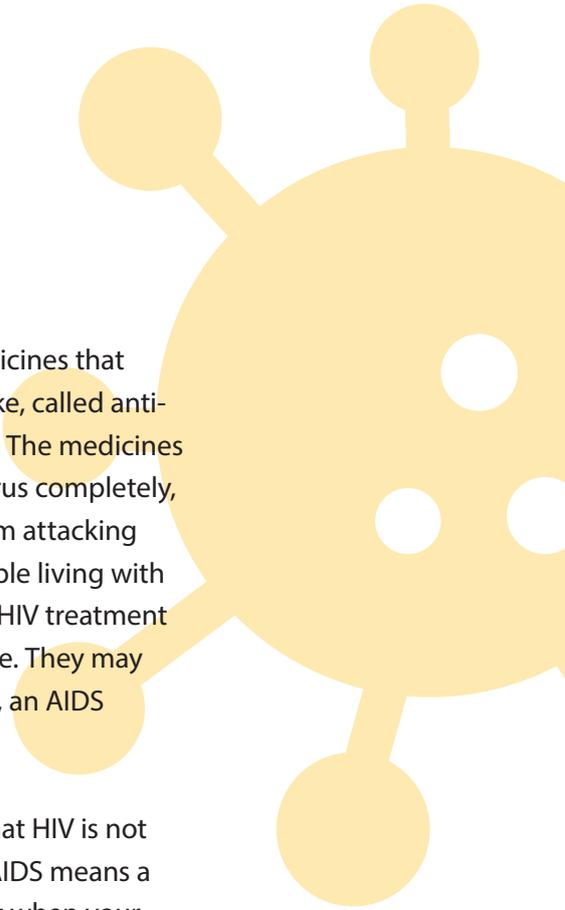
There are only a few ways HIV can be passed between people:

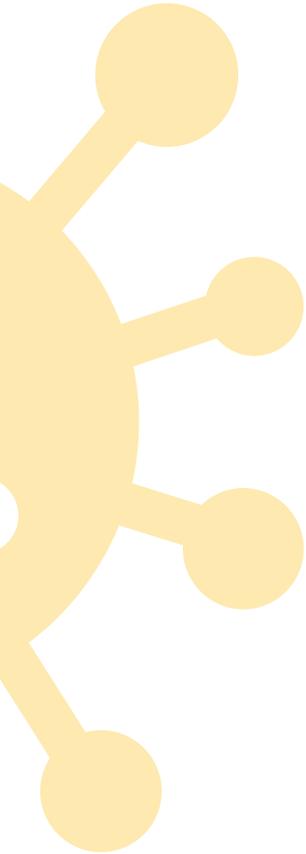
Semen, vaginal fluids and anal mucus

If a person living with HIV has sex without a condom, and they do not have an 'undetectable viral load'*, HIV

can get into the other person's blood because it lives in the semen, vaginal fluid and anal mucus. There does need to be a tear or graze in the other person for the HIV to enter into their body. A condom stops any fluid being passed to the other person, and it also stops unwanted pregnancy and getting other sexually transmitted infections.

*However, a person living with HIV who is taking ART may have an 'undetectable





HIV viral load'. This means they still have HIV but ART has reduced the amount of HIV in their blood to such low quantities that it can no longer be detected by a standard blood test. If their HIV is undetectable, there is zero risk of transmitting the virus to sexual partners. The phrase U=U (undetectable = untransmittable) is now widely used.

Blood

In the past lots of people got HIV through blood transfusions but this was before it was known how the virus was passed on. In most places in the world now, blood is checked before it is given to other people.

Outside of the body, HIV can't survive for very long. Even if a person living with HIV cuts themselves, there is a very low risk for HIV transmission if someone else comes into contact with their blood. The skin is a protective layer. Unless the other person has a cut or broken skin at the same time, there is no risk of transmitting the virus between them.

Needles

If one person has HIV and they inject themselves with a needle, and then another person injects themselves with

the same needle directly after, HIV can be passed on.

Vertical transmission

HIV can be passed on to a baby whilst they are growing in the womb or during childbirth if the mother is living with HIV. However, there are now steps that are taken that help stop their baby being born with HIV, including:

- ▶ Women living with HIV taking HIV medication during her pregnancy
- ▶ Additional care and support for the mother during labour
- ▶ The baby is given HIV medication in the first few weeks after birth

These steps work so well that in the UK now, there is less than a 1 in 100 chance of HIV being passed from a mother living with HIV to her baby.

Breast milk

HIV can be found in breast milk, so if a mother is living with HIV, in the UK it is recommended she shouldn't breastfeed her baby unless it has been advised as safe to do so by a medical professional. For a mother with an undetectable HIV viral load she may choose to breastfeed with support from medical teams.

SOME USEFUL STRATEGIES FOR RUNNING THESE SESSIONS

SET SOME GROUND RULES

It's important to consider that you may have a young person living with HIV in your classroom or someone may know someone living with HIV. In collaboration with your students, set some ground rules for the sessions to help people understand what's ok and what's not ok, and ensure that conversations remain respectful.

Some things you might include:

▶ Be kind - You don't know what other people in the room have experienced so be kind to each other

▶ It's ok not to know everything - If you get something wrong, that's ok and it's good chance to learn something new

▶ If you aren't sure just ask - It can be hard to ask questions but if we don't ask we won't know what's right

▶ Be respectful - Use language and words that are respectful of others who might have a different experience to us

▶ Humour isn't always fun - Sometimes words are used to make fun of people. That's not kind and won't be accepted.

Question car park

As a teacher, you might be asked questions that you can't answer. You can be honest about this, as it helps to model to the students that it's ok not to know everything. You can put these questions up on the board and either do some research while they are working or reach out to one of the organisations listed to get answers.

If you want to find out more you can visit:

- ▶ Chiva: chiva.org.uk
- ▶ I-base: I-base.info
- ▶ Avert: avert.org
- ▶ Terrence Higgins Trust: ttht.org.uk
- ▶ National Aids Trust: nat.org.uk (See HIV Schools Pack as a supplementary resource for teaching students the facts about HIV.)



PART 1 – UNDERSTANDING THE BASICS

The purpose of this session is to understand the facts about HIV and start busting myths. There are often myths that persist about HIV. Some of these are because of stigma and some are things that used to be true but with advances in medicine are no longer true. You will begin by watching the short film Life Growing Up with the group. It would be useful to watch this in advance so you are aware of what the video is about and preempt any particular questions the students might have.



Play Life Growing Up (12 minutes):
<https://www.chiva.org.uk/lifegrowingup>

DISCUSSION (10 MINUTES)



Ask the students if there was anything that surprised them or anything they learnt from the film?

ACTIVITY ONE – FACTS AND MYTHS CARD SORT (20 MINUTES)

1. Print off packs of the cards in Appendix A and cut them up so they are in packs with one pack per 2-3 students.
2. Ask the students to sort them into facts and myths. (5 minutes)
3. Once they are complete go through each one and ask them to put their hands up if they thought it was either a myth or a fact. Use the teacher answers sheet in Appendix A, and the HIV information at the beginning of this toolkit, to help manage the conversation and explore each one a little further. (15 minutes)



PART 2 – UNDERSTANDING STIGMA

The purpose of this session is to understand what stigma is and how it affects many people in different ways, not just those living with HIV.

ACTIVITY ONE – WHAT IS STIGMA? (15 MINUTES)



- ▶ Ask the group if they have heard of the word 'stigma' before.
- ▶ Ask what they think the word means

Explain the definition:

Stigma is when a person is seen or treated in a negative way, based on a particular experience (like a health condition) or because of something that makes up their identity (like their gender, age, sexuality, race etc.)

There are two types of stigma we see when talking about HIV; social stigma and self (or internalised) stigma.

Social stigma

HIV stigma is when a person is treated badly because they are living with HIV or are thought to be living with HIV. Stigma is a negative public attitude, often based on the wrong information and stereotypes. HIV-related stigma can lead to people thinking it's unwise or even unsafe to talk about their HIV status.

Self-stigma

Self-stigma (also known as internalised stigma) happens when a person from a stigmatised group, for example a person living with HIV, internalises negative public attitudes and believes them to be true. This can have a range of impacts on a person's mental and emotional health and what they feel comfortable doing (e.g. starting a relationship or applying for a particular job). Self-stigma can even occur if a person has not directly experienced stigma or discrimination themselves.



Besides HIV stigma, can anyone think of other examples of stigma?

Conversations to draw out:

- ▶ Self-stigma is caused by social stigma
- ▶ Stigma affects everyone in different ways and it's important to recognise it and challenge it
- ▶ Stigma is not based on fact. Often it is caused by misinformation and stereotypes



ACTIVITY TWO – EXPLORING CASE STUDIES (15 MINUTES)

Break the class into small groups and give each group one of the case studies found in Appendix A. Ask them to read through the case studies and highlight anything they think might be related to stigma.

DISCUSSION (15 MINUTES):



Ask them to share the examples of stigma they find. Ask the following questions and write down what they say about each case study on a piece of flip chart paper. Keep these as they will be used in the next session.

- ▶ Which of the stigmas listed by the group fall into each category (social stigma or self-stigma)?
- ▶ Try and draw out the root cause of the stigma.
- ▶ Who is perpetuating the stigma?
- ▶ What harm is being done by stigma?

Examples:

Malakai has heard a lot of misinformation about HIV from other people who are not educated about it. Other people's ignorance affects his self-confidence. This is an example of self-stigma because negative public attitudes are causing him to believe his HIV is something to be ashamed of.

When Dylan's friend's mum hears that he is living with HIV she calls Dylan's mum and asks questions that make her feel very uncomfortable and ashamed. This is an example of social stigma because his mum is treated badly when her family is thought to be living with HIV.

PART 3 – MAKING CHANGE

So far you have covered some of the basics around HIV and also some of the challenges that stigma brings for people, and in particular young people living with HIV. This session looks at what actions can be taken to change and challenge some of this.

ACTIVITY ONE – CHALLENGING STIGMA (20 MINUTES)

Put up the list of examples of stigma from the case studies session on the wall and ask the class to read them through.



Ask the students to break into groups and see if they can think of an action that could be taken in that situation to address the stigma.

Examples:

Malakai has heard a lot of misinformation about HIV from other people who are not educated about it. Other people's ignorance affects his self-confidence. This is an example of self-stigma because negative public attitudes are causing him to believe his HIV is something to be ashamed of. We should look for information on topics we are unsure of and make sure that it's from a reputable source e.g. a charity website or NHS website.

When Dylan's friend's mum hears that he is living with HIV she calls Dylan's mum and asks questions that make her feel very uncomfortable and ashamed. This is an example of social stigma because his mum is treated badly when her family is thought to be living with HIV. If we hear someone expressing stigma we can say that it's not ok, or ask them why they believe that person should be treated badly.



- ▶ Ask each group to share some examples of what they were talking about.
- ▶ After each one, ask the class to raise their hands to show whether they think the action would be EASY or HARD to do. The purpose of this is to recognise that while it's easy to come

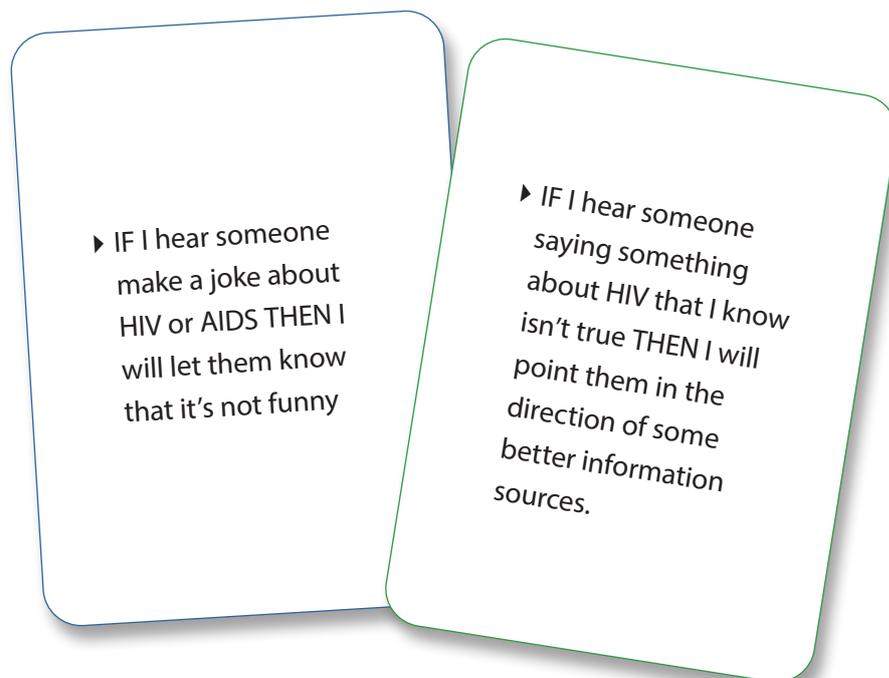
up with ideas, they aren't always easy to do in practice.

When someone suggests something the group thinks might be hard to take action on, ask them if they can come up with any strategies that might make it easier.

ACTIVITY TWO – COMMIT TO ACTION (15 MINUTES)

Ask each student to write down three If/Then statements, these are statements that will help them lay out what they can do in situations they might find themselves in.

Examples:



Ask if any students would like to share one of their IF/THEN statements.

APPENDIX A – RESOURCES FOR PRINTING

FACTS AND MYTHS CARDS FOR STUDENTS

Photocopy these pages and cut up into packs, with one pack for 2-3 students.

 <p>HIV stigma is often based on misinformation</p>	 <p>HIV is a 'gay' disease</p>
 <p>You can get HIV from kissing or sharing a cup with someone</p>	 <p>Some people are born with HIV</p>
 <p>If you get HIV you will die young</p>	 <p>If a person's viral load (amount of HIV in their blood) is undetectable they cannot pass it on</p>



HIV stands for Human Immunodeficiency Virus



There is no cure for HIV



You can't be a surgeon, medical professional or member of the armed forces if you live with HIV



It's dangerous to be near a person living with HIV



HIV is a manageable long term health condition like diabetes



HIV stigma is often based on misinformation

TEACHER'S ANSWER SHEET

HIV stigma is often based on misinformation	HIV is a 'gay' disease
FACT	MYTH
HIV carries a lot of stigma, mainly because people who are not educated about it make moral judgements about how someone has contracted HIV.	While some groups of people are disproportionately affected by HIV, it can affect anyone.
You can get HIV from kissing or sharing a cup with someone	Some people are born with HIV
MYTH	FACT
You cannot get HIV from kissing or sharing cups or cutlery.	This is a fact many people are not aware of. Around 500 children currently access children's HIV care in the UK and Ireland.
If you get HIV you will die young	If a person's viral load (amount of HIV in their blood) is undetectable they cannot pass it on
MYTH	FACT
Most people living with HIV who are on effective medication will have the same life expectancy as a person not living with HIV.	This is Undetectable = Untransmittable (U=U).

HIV stands for Human Immunodeficiency Virus	There is no cure for HIV
FACT	FACT
	This is true, but scientists are working towards a cure. Treatments available are so effective in controlling HIV that it is essentially like a cure.
You can't be a surgeon, medical professional or member of the armed forces if you live with HIV	It's dangerous to be near a person living with HIV
MYTH	MYTH
In some professions you may need more support from your doctor, but there are no jobs you are unable to do because of HIV.	There is nothing dangerous about being near a person living with a long term health condition.
HIV is a manageable long term health condition like diabetes	HIV stigma is often based on misinformation
FACT	FACT
HIV is a long term health condition that is well managed by medication.	HIV carries a lot of stigma, mainly because people who are not educated about it make moral judgements about how someone has contracted HIV.

CASE STUDIES



MALAKAI, 15

Malakai has heard a lot of misinformation about HIV from other people who are not educated about it. He gets frustrated that people are stuck in the past and think HIV is contagious and think it is the same as AIDS. He knows about U=U and he wants to correct people but doesn't want them to suspect he is growing up living with HIV. Other people's ignorance affects his self-confidence. He knows HIV is a manageable medical disease, like asthma or diabetes, but for some reason it's not the same. Diabetics don't hide away in shame. They take medication just like he does. He feels isolated and is disappointed because he believes he can't join the military while living with HIV.



JANE, 17

Jane is a keen football player who is currently in college. She goes on a lot of away games and hides her HIV medication in a paracetamol box. She worries that if her teammates find out she is growing up living with HIV that they might drop her from their friendship group. She recently met a girl who she really liked and had great chemistry with, but she was scared to tell her about her HIV so she just stopped talking to her. She worries that she will always struggle to commit to long-term relationships because she doesn't want to open up about her HIV.



CHARLIE, 14

Charlie is in secondary school. She has a difficult home life because she is growing up living with HIV while her brothers are not. Her mum never talks to her about their HIV and she keeps it secret from her brothers. Charlie feels like she is living a lie. The secrecy at home makes her feel like she can't tell anyone outside of her family about her HIV either. Sometimes the secrecy makes her feel frustrated and angry. She wishes her mum didn't fear other people's judgement. She would prefer to talk about HIV as a family so she didn't have to keep it secret or feel ashamed.



DYLAN, 16

Dylan is at secondary school and has a good group of friends. He once decided to tell his closest friend about his HIV - against his mum's wishes. The friend then told his mum, who then called Dylan's mum and asked all sorts of questions about whether Dylan could pass on the virus to his friends or her son. Dylan felt terrible because his mum was made to feel ashamed. He knows it's not his mum's fault that she has HIV or that she passed it to Dylan.

EVALUATION

An evaluation form for students can be downloaded from chiva.org.uk/education. This can help teachers understand how much their students have learned. On the same website page you will also find a link to a short evaluation form for teachers. We would welcome your feedback on this resource.

If you would like to discuss facilitation support with delivering these sessions, or for any other information, please contact Chiva on 0117 905 5149 or message@chiva.org.uk.

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