



# Attitudes to HIV among 12-18 year olds in London

Report to Body and Soul

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## Executive summary

Body and Soul is a London-based charity that supports children, teenagers and families living with or closely affected by HIV. It also works to tackle the widespread stigma and prejudice, which forces many people who are HIV positive to live in isolation. To find out more about current levels of knowledge and attitudes to HIV among young people, Body and Soul commissioned OPM, an independent public interest company, to undertake primary research with young people aged 12 to 18 in London. This included a questionnaire-based survey of 508 young people and six focus groups with young people aged 13 to 15.

The following findings were highlighted by the research:

### 1. Knowledge about how HIV can be transmitted

Overall the majority of young people surveyed correctly identified the ways in which a person *can* get HIV:

- Over 9 in 10 young people knew that HIV could be transmitted through **unsafe sex**.
- 85 per cent of young people knew that HIV could be transmitted by receiving an infected **blood transfusion** and 84 per cent identified **unsterilised needles** as a means of transmission.
- But fewer young people – 76 per cent – correctly identified HIV being passed from a **mother to her baby** as a means of transmission. Importantly, girls were significantly more likely than boys to be *unsure* as to whether HIV could be passed from a mother to her baby.

### 2. Knowledge about how HIV cannot be transmitted

The majority of young people correctly identified ways it is *not* possible to get HIV. But a significant minority incorrectly believed that it is either possible to get HIV in ways you can't, or were unsure:

- While 69 per cent of young people knew they couldn't get HIV by **kissing** someone who was HIV positive, 31 per cent either believed kissing was a means of transmission or were unsure.
- 81 per cent knew that they could not get HIV by **sharing a cup** with someone who was HIV positive. However, just under one in five of the young people consulted either believed it was possible to get HIV this way, or were not sure.
- 85 per cent were aware that it is not possible to get HIV through **sharing a meal** and 91 per cent knew that **shaking hands** with someone who is HIV positive is not a possible means of transmission.

### 3. Behaviour towards people who are HIV positive

Despite the majority of young people knowing that HIV cannot be transmitted through kissing or sharing a cup, this knowledge was not consistently reflected in their intended behaviours towards people who are HIV positive. The research highlighted a contradiction between what young people knew and how they said they would behave.

- While 81 per cent of young people knew that HIV could not be transmitted by **sharing a cup**, only 27 per cent of them went on to say that they would drink from the same cup as someone who they knew was HIV positive.
- Likewise, while 69 per cent of young people knew they could not get HIV by **kissing**, only 24 per cent of them went on to say they would kiss someone who they knew was HIV positive.
- Even some of the youngest people in the sample – 12 and 13 year olds – said they would not share a cup with, shake hands with or kiss someone who they knew was HIV positive, even if they knew it was not possible to get HIV that way. Crucially, this shows that HIV-related stigma starts at an **early age**.
- However, the research also suggests that the occurrence of contradictions between knowledge and behaviour **increases with age**: the older the person, the more likely the contradiction between their knowledge and behaviour. For example, while 46 per cent of 12 to 13 year olds would not share a cup with someone who has HIV despite knowing that HIV cannot be transmitted in this way, 54 per cent of 14 to 15 year olds and 61 per cent of 17 to 18 year olds demonstrate this same contradiction.
- 76 per cent of young people said they would **remain friends** with someone who was HIV positive compared to only 11 per cent who would not. Girls were significantly *more likely* than boys to say that they *would* remain friends with someone with HIV. However, remaining friends with someone who was HIV positive was accompanied by the perceived need for strict conditions to be imposed on the friendship – including no sleepovers or sharing of personal belongings.

#### 4. Explaining the difference between knowledge and behaviours

These contradictions between knowledge and intended behaviour appear to stem from the fact that although young people tended to know the ‘headline’ facts about HIV transmission, they imagined situations where these facts might not apply.

- While knowledge of the ‘headline’ facts, for example that you can’t get HIV by shaking hands, encouraged young people to feel that HIV transmission in this way was *unlikely*, it did not seem to convince them that it was *impossible*. Therefore, many continued to believe that there was still an **element of risk**.
- As such, young people tended to develop imaginary scenarios based on a series of ‘**what ifs...**’ which they believed might heighten the risk of transmission. For example, ‘what if both people have cuts on their hands when they shake hands?’, or ‘what if you kiss someone every day and there is a build up of saliva over a period of time?’
- Coupled with the tendency of the young people consulted to view HIV as a **death sentence**, young people seemed in many cases to have decided that the risk associated with physical contact with someone who was HIV positive – however small – was not worth taking.

In addition to the perceived risk of getting HIV themselves, young people were also concerned that there would be an emotional strain associated with being close to someone who has HIV, as well as a risk of stigma by association. These concerns again appeared to affect the young people’s intended behaviour with people who are HIV positive.

- Partly due to the strict conditions young people felt they would need to impose on a friendship with someone with HIV, they were concerned that time with that person would

**not be much fun** and could actually be a burden. This was compounded by the belief that they would need to treat a friend with HIV more ‘delicately’ due to their perceived vulnerability, which would also limit the things they could do together. Young people said they would also be worried about the other person dying and the distress this would cause.

- Some young people also said they would feel **embarrassed and awkward** if they found out that a friend had HIV, with these feelings stemming from an uncertainty over how best to approach the subject with their friend and concern that they might annoy their friend if they treated them differently.
- Young people were also conscious of what they perceived to be the social risks of associating themselves with people who have HIV. As well as being treated differently just by dint of having HIV and the fear of getting HIV that this engenders, young people were also well aware that both themselves and other people may make **moral judgements** about people with HIV, specifically around the lifestyles they associated with HIV, including drug use and promiscuity. Importantly, when talking about their own moral judgements about people who are HIV positive, young people were clear that it is not HIV itself that invites moral judgement but rather the way in which the person contracted HIV. In other words, stigma through association is not only about stigma related directly to HIV but also stigma related to other aspects of identity such as lifestyle choice.
- As such, findings also suggest that young people tend to equate physical distance with protection, both literally and figuratively. As well as being cautious about physical contact they also appeared to distance themselves mentally from people with HIV through a process of ‘**othering**’ them, imagining they are very different to themselves. In particular that they either live in developing countries and are therefore far away, or have got HIV through ‘bad’ lifestyle choices – doing things which they would never choose to do themselves.

## 5. Appetite for more information

Importantly, this study has revealed a strong appetite for more information about HIV among young people and recognition by many that they do not currently know enough.

- While 57 per cent of the young people felt that they had already been given enough information, 41 per cent felt they had received **too little information** on HIV. Girls were more likely than boys to say that they had not received enough information. Hardly any respondents felt that they had received too much information about HIV.
- Whether or not young people felt they knew enough about HIV was also dependent on whether they had been **taught about HIV at school**. 79 per cent of those who said they had *not* been taught about HIV in school said they knew too little compared to 27 per cent of those who said they had been taught about HIV. However, this still means that of those who said they had been taught about HIV, over a quarter still felt they had been given too little information.
- Young people tended to feel that teachers were the most trustworthy source of information on HIV, suggesting that schools are a good route of communicating with young people on the topic. Communication by teachers also appears to have the **potential to have an effect**: those who said they had been taught about HIV in school not only had higher levels of knowledge about how HIV is transmitted but also – to some extent – appeared to be less prejudiced towards people with HIV. For example,

respondents who said they *had* been taught about HIV in school were more likely to say they would stay friends with someone who was HIV positive and drink from the same cup as them. But they were just as likely as other young people to not want to kiss someone who was HIV positive.

- Importantly, almost 1 in 3 of the young people consulted said they had either **not been taught** about HIV in their school, or did not know if they had.
- However, while respondents who said they had been taught about HIV in school were more likely to say they would behave positively towards someone with HIV compared to those who said they had not been taught about HIV, a larger proportion still gave negative rather than positive responses. For example, 56 per cent of young people who said they had been taught about HIV in school still said they would *not* drink from the same cup as someone who was HIV positive. This suggests that while being taught about HIV in school certainly seems to reduce prejudiced attitudes, it **currently only goes some way** in achieving this.

## Acknowledgements

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## Acronyms

<b>AIDS</b>	Acquired immune deficiency syndrome
<b>HIV</b>	Human immunodeficiency virus
<b>NHS</b>	National Health Service
<b>OPM</b>	Office for Public Management
<b>PSHE</b>	Personal, social, health and economic education
<b>SRE</b>	Sex and relationships education
<b>STD</b>	Sexually transmitted disease
<b>STI</b>	Sexually transmitted infection
<b>UK</b>	United Kingdom

# 1. Introduction

## 1.1 Aims of this report

Body and Soul is a London-based charity that supports children, teenagers and families living with or closely affected by HIV. It also works to tackle the widespread stigma and prejudice which forces many people who are HIV positive to live in isolation. As part of this work, Body and Soul are planning to develop a campaign targeted at young people to counter the myths and misconceptions that fuel stigma. To find out more about current levels of knowledge and attitudes to HIV among young people, Body and Soul commissioned OPM to undertake primary research with young people aged 12 to 18 in London, with the specific aims of:

- Generating evidence of levels of knowledge among young people about basic facts relating to HIV.
- Exploring the attitudes of young people to people who are HIV positive.
- Exploring the relationships between knowledge, attitudes and behaviours towards HIV and how these interact.

This report presents the findings from this research, which was conducted between January and June 2010.

## 1.2 Methodology

The research involved six main stages:

- **Initial consultation with young people at Body and Soul.** As a starting point in designing this study, we ran a short session with young people who attend Body and Soul to explore their perceptions of what other young people know about HIV and what their attitudes are to people who are HIV positive. We also asked them what they would most like to change about other young people's attitudes to HIV. A summary of the issues raised by young people at this session is outlined in Appendix 1.
- **Rapid literature review.** We also gathered evidence of what is already known about levels of knowledge and attitudes to HIV from recent studies involving young adults, as well as research with younger groups conducted in the 1980s and early 1990s. Through internet searches we identified a total of 35 reports, journal articles, and press and website articles, with the majority based on research conducted in the UK and published between 1990 and 2010. However, only a small number of these examined younger teenagers' attitudes to HIV. This therefore steered the focus of our primary research towards this group. The evidence gathered in the literature review also served as a basis for creating research tools to be used in our primary research. A summary of findings from existing literature is presented in Section 2.
- **Review of existing materials.** As this study was intended to inform future campaigns and teaching materials developed by Body and Soul, it was important to examine what materials have already been produced. A list of existing materials previously identified by Body and Soul were supplemented by those we identified through further internet searches. A total of 50 items, including leaflets, books and DVDs were analysed with the aim of determining the range of resources currently available to young people and

teachers in the UK. For each item, we attempted to establish its target audience, purpose and the HIV-related issues it addressed. An overview of the materials identified is attached in Appendix 3.

- **Questionnaire-based survey of young people.** The quantitative element of the primary research was based on a questionnaire completed by 508 secondary school pupils across London in April and May 2010. The survey relied on a convenience sample and the seven secondary schools and colleges that participated in the survey did so voluntarily. The profile of the sample used, broken down by gender, age and school type can be found in Appendix 4. The primary purpose of the questionnaire was to gather evidence of young people's knowledge of basic facts relating to HIV, for example, modes of transmission, as well as their attitudes to people with HIV and their opinions on how they would behave around someone who was HIV positive. The questionnaire also asked respondents about their appetite for more information about HIV. A copy of the questionnaire can be found in Appendix 7.
- **Focus groups with young people.** The main qualitative element of the primary research involved six focus groups held in May and June 2010. These focus groups involved young people aged 13 to 15 who were attending schools in London. The purpose of the focus groups was to develop a more detailed understanding of young people's attitudes and opinions to explore the questions raised in the questionnaires in greater depth. A copy of the topic guide can be found in Appendix 5.
- **Interviews with teachers.** The second qualitative element of the research involved carrying out structured telephone interviews with six teachers in six separate schools in London. These teachers were biology teachers or personal, social, health and economic education (PSHE) teachers or citizenship teachers who again participated voluntarily and were recruited through the schools that took part in either the questionnaires or the focus groups. The purpose of the interviews with teachers was to explore how HIV is currently taught in their school, teachers' perceptions about how well HIV issues are currently covered, as well as their understanding of what young people think about HIV and their reactions to HIV lessons. A copy of the interview schedule can be found in Appendix 6. Findings from these interviews are reflected in the conclusions in Section 6.

### 1.2.1 Limitations to the research

While the approach to the study is influenced by the quality standards associated with academic research, the primary purpose of this study was not simply to produce new academic research evidence for an academic and policy audience. Instead the primary aim of this study is to generate evidence that can be used to inform future campaigns and materials developed by Body and Soul. This practical focus is reflected in the presentation of findings in this report.

While efforts have been made to ensure a rigorous approach to data collection and analysis in this study, it is important to recognise the limitations of the methodology used and to be clear on what the size and scope of the study allowed in terms of analysis.

- Given the use of convenience sampling, this research does not claim to be representative of the population of young people aged between 12 and 18 years old in London. We would therefore advise caution in generalising the findings of this report to all young people in London. While effort was taken to collect a diverse sample in terms of age, gender and school type, our spread was limited by the level of access schools granted. It

is not possible to say with certainty why schools that were initially contacted chose not to take part, but it is possible that some may have done so because they either regard HIV as a controversial topic, or something that is not a priority for their school. Conversely, some of the schools that did agree to take part may have a tendency to be more proactive than most schools in teaching their students about HIV-related issues. This could be reflected in the study findings.

- Furthermore, teachers had significant discretion over the pupils selected to take part in the focus-group discussions and questionnaires. While teachers were asked to choose a diverse sample, it is possible that teachers may have used other methods to select pupils, for example, those who they thought would most enjoy taking part.
- Even though a survey sample size of 508 is large enough to be able to conduct significance testing, it has already been noted that the survey sample is unlikely to be representative of all young people in London. Therefore the age and gender differences highlighted in this report may be subject to sample bias, and should be seen as indications only of possible differences between gender and age. These differences could be tested using a representative sample in further research.
- Finally, the limited resources available for this study mean that only a selection of variables could be considered in the collection and subsequent analysis of data. We are conscious that a broader range of variables may have a bearing on the attitudes and behaviours of young people towards people with HIV, including their ethnic, religious and socio-economic backgrounds.

## 2. Context

It is important to situate the findings from this study in the context of existing evidence. Two types of evidence are particularly important to consider: research conducted with younger age groups in the 1980s and early 1990s and more recent evidence from research conducted with older teenagers and adults.

The literature review found that most of the evidence of young people's attitudes to HIV is based on studies conducted in the late 1980s and early 1990s. Research at that time found that educational efforts in the 1980s had had positive effects in increasing knowledge and awareness of HIV/AIDS. For example, Memon (1990) reports that following government campaigns in the late 1980s there were high levels of awareness among young people of basic facts, for example, that sexual intercourse without a condom may lead to HIV transmission<sup>1</sup>.

However, the Memon report concluded that while educational efforts in the 1980s had the effect of increasing knowledge and awareness, HIV/AIDS-related stigma remained prevalent. The report highlighted an 'innocent' versus 'guilty' construct at work when judgements were being made by young people. For example, babies and haemophiliacs were seen by young people as 'innocent' victims while gay men and drug users 'have themselves to blame' (Memon, 1990: 333).

Young people today have not been exposed to the government campaigns of the 1980s and research for the Staying Alive Foundation in 2009 found that 35 per cent of the young people they surveyed could not recall ever having seen an advertising campaign about HIV/AIDS<sup>2</sup>. This same research also found that knowledge about HIV and how it is transmitted actually appears to be decreasing among young people aged between 16 and 24<sup>3</sup>. For example, they found that 79 per cent of their respondents knew that HIV could be passed on by unprotected heterosexual sex, which compared unfavourably with 91 per cent reported in 2000.<sup>4</sup> In addition it was found that 60 per cent of the respondents aged 16 to 24 thought that they were not at risk of contracting the infection after having unprotected sex.<sup>5</sup> Moreover, 14 per cent believed that the fact they were not gay ensured they could not get infected and eight per cent thought that taking a contraceptive pill offered protection against HIV.<sup>6</sup> As a result those working for organisations such as the Staying Alive Foundation have suggested that young people are being 'lulled into a false sense of security'<sup>7</sup>.

The majority of studies published since the 1990s have focused on young adults' sexual health practices rather than on their attitudes to HIV. However, the evidence on attitudes that is available paints a picture in which people still have misconceptions about HIV and people

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<sup>1</sup> Memon, A. (1990), 'Young people's knowledge, beliefs and attitudes about HIV/AIDS: A review of research', *Health Education Research*, Vol. 5, No. 3, 327-335, 1990

<sup>2</sup> 'Concern over young people's risky sex', *The Guardian*, 4 June 2009

<sup>3</sup> *ibid*

<sup>4</sup> *ibid*

<sup>5</sup> *ibid*

<sup>6</sup> *ibid.*

<sup>7</sup> *ibid.*

who are HIV positive. For example, recent research by the British Red Cross in 2009 looking at the attitudes of 16 to 25 year olds found that stigma still persists, even though they have found (in contrast to the Staying Alive Foundation's research) that there has been progress made in educating young people about how HIV is transmitted<sup>8</sup>. For example, the British Red Cross survey found even though 85 per cent of respondents aged 16 to 25 knew that HIV could not be transmitted through kissing, more than two-thirds would not kiss someone with the virus. It was also reported that 44 per cent of respondents would not buy food from an HIV-positive shopkeeper despite 96 per cent agreeing that HIV could not be contracted by sharing a meal with an infected person.

Not only does this research highlight an apparent contradiction between increased levels of knowledge on the one hand, and increased stigma on the other, when compared to the research by the Staying Alive Foundation, it also presents conflicting evidence about whether or not levels of knowledge are actually increasing.

The Red Cross research suggests that organisations and individuals involved in HIV education and campaigning today face similar challenges to those in the late 1980s and 1990s. Even if levels of knowledge about HIV have improved among certain groups of young people, it is clear from the research that there are still people who are unaware of how HIV can be transmitted and stigma about HIV is still as much as an issue as ever.

In the 1990s it was highlighted that there was a particular need for further research looking at attitudes to HIV/AIDS among younger age groups. They were seen as a particularly important group to target as they are likely to be developing new beliefs and forming new relationships (Memon, 1990). But in the intervening period there has been little focus on young people below the age of 16. Even though the findings from recent surveys by the British Red Cross and the Staying Alive Foundation provide new insights into the attitudes of young adults to HIV, they tell us nothing about the knowledge, beliefs and attitudes of younger teenagers. This research aims to begin the process of filling part of this gap.

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<sup>8</sup> 'World AIDS Day 2009 Survey', British Red Cross, November 2009

### 3. Young people's knowledge about HIV

This chapter presents findings from our primary research, in particular from the questionnaires and focus groups with young people. It examines young people's knowledge about HIV looking specifically at what words they associate with HIV, their knowledge about HIV as a medical condition, what they know about how HIV is transmitted and their perceptions about which groups of people are more likely to get HIV and why this is the case. It also looks at the current sources of information on HIV identified by young people, as well as their appetite for more information.

At the start of the focus groups, young people were asked to write down any words they associated with HIV. The most common response was that they **associated HIV with negative concepts**.

*These are very negative words. Because there's nothing positive comes out of catching HIV. (Year 10 focus group participant)*

When prompted whether there was anything positive that they associated with either HIV itself or living with HIV, the majority of young people struggled to identify any positive attributes. Where positive attributes were identified, these centred on the possibility of making new friends through joining HIV community groups and on the scope to affect positive social change through campaigning on HIV issues and raising awareness of HIV among other people.

*There could be a social element to having HIV ... you can meet other people with HIV and join a new community. And you can educate other people as well. You could start up charities that you believe should be there because you have HIV. You can help other people and raise awareness about it. (Year 10 focus group participant)*

In the following sub-sections the specific words chosen by young people in the focus groups are listed and analysed along with data from the questionnaires.

#### 3.1 Knowledge about HIV as a medical condition

All the young people we spoke to in the focus groups had heard of HIV before. But even within a small group of young people in the same year group at the same school, there were significant **variations in levels of knowledge** between individuals, illustrated by the following conversation from a focus group with Year 9s at a non-religious state school:

*Young person 1: I don't have a clue [what HIV is]; well I do know that's it a disease to do with bodily fluids but I don't really know what it is.*

*Young person 2: I don't really know what it is either. I would want to know about symptoms and cures.*

*Young person 3: What are you talking about? There's no cure.*

*Young person 2: Oh.*

*Young person 3: There are no symptoms either.*

*Young person 1: Can you die from HIV?*

*Young person 2: Oh my god!*

*Young person 4: You don't die from HIV or AIDS you die from [things like] pneumonia – it gets into your immune system ... it removes your natural defences so stuff like a cold can kill you.*

As we will be showing later when we examine the questionnaire findings, there do appear to be trends in young people's knowledge about HIV, linked in particular to whether or not they have been taught about HIV at school. However, as the above extract demonstrates, even within the same class there can be significant variation in levels of knowledge.

### 3.1.1 What is HIV?

When young people in the focus groups were asked what words they associated with HIV, the most frequent responses were 'AIDS', 'STD', 'virus', 'disease', 'immune system', 'mutations', 'cancer' and 'infectious'. At the most basic level of awareness, almost all young people knew HIV to be linked somehow to AIDS and that it is a disease that is transmitted from one person to another through bodily fluid. Blood was the most readily identified type of bodily fluid and sex was the most commonly identified means of transmission.

At a more specific level, many young people demonstrated more nuanced understandings of HIV, identifying the weakening of the immune system as the primary effect of HIV on the body. However, the **difference between HIV and AIDS was less clear** to them, although in each focus group there were usually at least several people who were able to explain to the others that HIV can lead to AIDS. Other areas of uncertainty included where HIV came from originally and what the symptoms (if any) of HIV are.

### 3.1.2 Consequences of HIV

The young people in the focus groups identified two types of potential consequences that arise as a result of having HIV: health and social.

#### Health consequences

In terms of what young people saw as the health consequences of HIV, there were often strong **associations between HIV and death**, with some young people in the focus groups perceived it to be an extremely negative, life-changing disease that causes protracted suffering, pain and in many cases death due to the lack of cure. For example, many focus group participants associated HIV with words such as 'no cure', 'dangerous', 'sometimes fatal', 'death', 'slow', 'suffering', 'life-changing', 'dying', 'pain', 'deadly', 'hospital', 'illness'. However, this strong association with death and suffering highlighted in the focus groups does, to some extent, contradict the findings from the questionnaire where just over half (53 per cent) of respondents agreed that it *is* possible for people with HIV to live long and happy lives. However, one-third (33 per cent) disagreed that this was possible and a further 14 per cent did not know.

These findings from the questionnaire could be explained by the perception expressed in the focus groups that while it is possible for people with HIV to live longer and happier lives **compared to 20 years** ago due to medical advances, it is still not possible for people with HIV to live as long as - and be as happy as - people without HIV. This perception of relativity may help to explain the questionnaire findings in light of the associations between HIV and death that came out in the focus groups.

When young people were aware of the **availability of treatment**, they were more likely to agree that people with HIV can live long and happy lives. In the questionnaire, 45 per cent of respondents agreed that there is treatment for HIV, as did some focus group participants.

*Yeah, I agree [that people with HIV can live long and happy lives]. I've seen on the news that there's drugs to help it - there's stuff to help you out. But they haven't been able to find a cure because the virus changes shape, it constantly mutates. (Year 10 focus group participant)*

However, in other cases this agreement was mitigated by their knowledge that it is not possible to rid the body of the virus and that therefore the 'health problems never really go away'.

### **Social consequences**

HIV is seen as having negative consequences for future **family relationships** such as getting married and having children. When this issue was raised in the focus groups, it became apparent that young people viewed long-term relationships and having children as problematic for people with HIV.

*Getting married is a problem because they can't have kids. (Year 9 focus group participant)*

However, it is unclear what this belief is based on. It could be due to awareness among young people of the risk of HIV transmission from mother to baby but low awareness that this risk can be considerably lowered through things such as appropriate use of drugs during pregnancy. This issue is explored in greater depth in section 4.3.

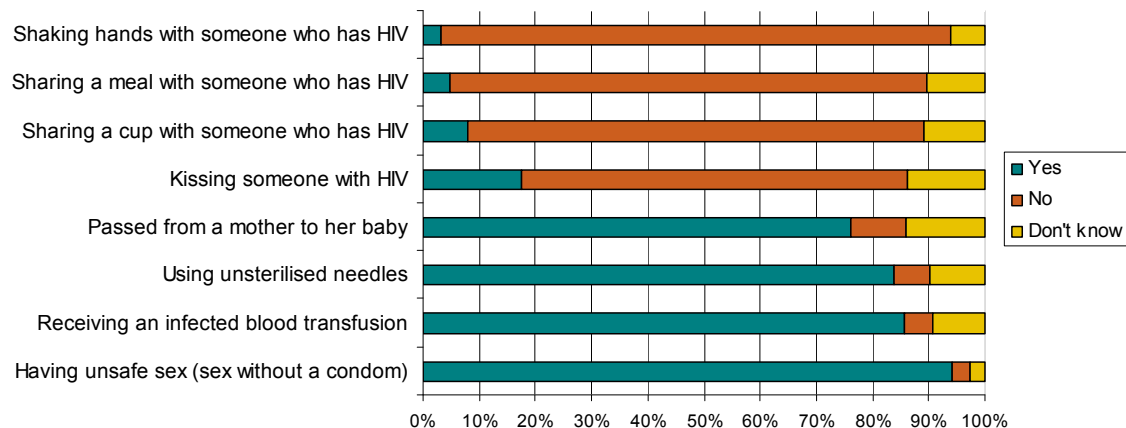
In addition, in one focus group negative consequences of HIV were also identified in terms of future **employment opportunities**.

*I disagree [that people with HIV can live a long and happy life] because they have a lot of limitations on which jobs they can get and because of things like getting life insurance. (Year 9 focus group participant)*

This appears to be based both on some awareness about HIV-related discrimination among employers and also a perception that some people with HIV may not be able to or allowed to work in some professions. This issue is explored in greater depth in Section 4.5.

## **3.2 Knowledge about how HIV is transmitted**

In the questionnaire, young people were given a list of possible ways through which HIV can and cannot be transmitted. For every activity they were asked to respond 'yes', 'no' or 'don't know' according to whether they thought HIV could be transmitted through that activity. The findings are presented in Figure 1 below.

**Figure 1 - How can a person get HIV?**

Base: 508

### 3.2.1 Understanding of how HIV can be transmitted

This data shows that **overall, the majority of young people surveyed were able to identify the correct ways in which a person can get HIV:**

- Having **unsafe sex** was the most readily identified way that HIV can be transmitted, with over nine in ten of all respondents (94 per cent) giving the correct answer (three per cent answered incorrectly and three per cent did not know).
- The next most correctly identified way that HIV can be transmitted was receiving an infected **blood transfusion**, correctly identified by 85 per cent of all respondents (five per cent answered incorrectly and nine per cent did not know).
- A similar percentage were also able to correctly identify use of **unsterilised needles** as a means of transmission (84 per cent answered correctly, seven per cent answered incorrectly and ten per cent did not know).
- However, a slightly lower proportion of young people were able to correctly identify HIV being passed from a **mother to her baby** as a means of transmission (76 per cent answered correctly, ten per cent answered incorrectly and 14 per cent did not know). Importantly, girls were significantly more likely than boys to be *unsure* as to whether HIV can be passed from a mother to her baby.

This confidence in knowing how HIV *can* be transmitted was also reflected in the focus group discussions, in which the young people we spoke to displayed a good understanding of the basic facts about how HIV is transmitted through bodily fluid. This is illustrated in the types of words participants associated with HIV, such as 'needles', 'body fluid', 'unprotected sex', 'sex', 'condoms', 'protection', 'blood' and 'rape'. Based on both the questionnaire results and the focus group discussions, young people appeared to have relatively high levels of awareness about the ways in which HIV *can* be transmitted.

Importantly, when analysing for any differences between those who responded correctly and those who did not, in nearly every case **young people who said they had been taught about HIV in school demonstrated higher levels of knowledge than those who said they had not**. For example, those who said they *had* been taught about HIV were

significantly more likely to know that HIV can be transmitted through receiving an infected blood transfusion and through using unsterilised needles.

### 3.2.2 Understanding of how HIV *cannot* be transmitted

Although the majority of questionnaire respondents also answered correctly in terms of knowing the ways it is *not* possible to get HIV, the questionnaire data also revealed that a significant minority either incorrectly believed it is possible to get HIV in ways you can't, or were unsure and therefore responded that they did not know.

- While 69 per cent of respondents knew they could not get HIV by **kissing** someone who is HIV positive, it is also the activity that young people appear to have the greatest misconception and uncertainty about, with just under one in three of all respondents (31 per cent) failing to correctly identify this as a way in which HIV cannot be transmitted (18 per cent thought they could and 14 per cent did not know).
- A larger percentage of respondents – 81 per cent – knew that they could not get HIV by **sharing a cup** with someone who is HIV positive. However, just under a fifth of all respondents (19 per cent) failed to correctly identify this as a way in which HIV cannot be transmitted (eight per cent thought they could and 11 per cent did not know).
- Slightly more young people were aware that it is not possible to get HIV through **sharing a meal** (85 per cent answered correctly, although 5 per cent still thought they could and ten per cent did not know).
- Far more respondents were confident that **shaking hands** with someone who is HIV positive is not a possible means of transmission, with 91 per cent answering correctly. However, just under one in ten respondents still failed to answer correctly (three per cent thought they could and six per cent did not know).

This apparent confusion among a number of young people in terms of how HIV *cannot* be transmitted is demonstrated in the questionnaire responses by the greater number of incorrect and 'don't know' answers. This is also reflected in the focus group discussions, in which participants displayed far less confidence in explaining how HIV *could not* be transmitted compared to their explanations about how it could.

Again, it is clear from analysis of the questionnaires that there are **significant differences according to whether or not HIV had been taught in school**, with respondents who said they had been taught about HIV being significantly *more likely* than those who said they had not, to know that HIV cannot be transmitted through kissing, shaking hands with or sharing a cup or meal with someone who is HIV positive.

Focus group discussions revealed that the confusion about the ways in which HIV *cannot* be transmitted appears to stem from uncertainty regarding the specific details of the role of bodily fluids in HIV transmission. In the focus groups it became apparent that while almost all young people were aware that HIV is transmitted through the exchange of bodily fluid, there remain **four areas of uncertainty in relation to bodily fluid**. These areas of uncertainty lead to confusion about the ways in which HIV cannot be transmitted by creating misperceptions over which circumstances heighten the risk of transmission. The four areas of uncertainty around bodily fluid are:

1. **Type of bodily fluid:** while blood was the primary bodily fluid associated with HIV by the young people we spoke to, saliva was also readily identified as a means of transmission. In both cases there appears to be uncertainty over the quantity of these fluids needed to

transmit the virus. This therefore seems to lead to young people collapsing the distinction between the various types of bodily fluid leading to the perception that any presence of either blood or saliva heightens the risk of transmission. Similarly while sex is an activity highly associated by young people with HIV, there is less awareness over the role of vaginal and seminal fluid and how these can enter into the bloodstream.

2. **Quantity of bodily fluid:** a significant minority of the young people we spoke to incorrectly thought that a small amount of saliva could transmit HIV, indicating that there could be a perception that the concentration of the HIV virus in saliva is similar to that in blood. Other young people cited facts they had heard, for example, that HIV can only be transmitted through saliva in large amounts, such as swallowing 'bucketfuls' or 'gallons' of saliva.

*You can't catch HIV through saliva – only if you have a bucket of it. They told us, I think it was in sex education, that you can't catch it through saliva unless you have buckets of saliva. (Year 10 focus group participant)*

However, it seems that there is a perception that to be 'on the safe side' activities involving possible exchange of saliva should be avoided because there is a risk that larger than 'normal' amounts of saliva could be present, for example, 'backwash' of saliva when sharing a drink or 'dribble' on food when sharing a meal. Even though these amounts of saliva still fall far short of the 'bucketfuls' or 'gallons' needed, the fact that they are possibly larger than average is perceived to heighten risk.

3. **Cumulative effects of exposure to bodily fluid:** this uncertainty was raised by young people specifically with regards to saliva and in particular in relation to kissing. In the focus groups (even in groups where knowledge levels were generally high) there were several instances where young people thought that HIV could be contracted through kissing depending on how long the kiss lasted and the number of times you kissed a person with HIV. This suggests that for some young people at least, there is a perception that even if HIV cannot be transmitted through a single kiss, the accumulation of 'infected' saliva may increase the risk of transmission.

*Yeah but it depends how long you kiss ... what if you kissed for hours? If you kissed them for ages I think you could get it [HIV]. (Year 9 focus group participant)*

*You have to get 80 gallons of saliva to get HIV. So in theory you could get it through kissing. It depends on how much you kiss them. (Year 10 focus group participant)*

4. **Exchange of bodily fluid through the body:** there appears to be uncertainty about how exactly the HIV virus is able to enter into the bloodstream and what is meant by 'exchange'. For example, the young people we spoke to explained that bleeding gums, ulcers or cuts in the mouth or on the body were a means through which the virus could enter the bloodstream. However, they were less certain about whether there are different levels of risk associated with various types of bodily fluid entering their mouth or other body part from a person with HIV. In addition it is also less clear what size cut is needed to facilitate exchange. This lack of certainty around the specific details of bodily fluid and exchange can lead to the perception that HIV can be easily transmitted:

*[HIV] is basically sharing what's inside you ... I think it can happen quite easily (Year 9 focus group participant)*

These four areas of uncertainty regarding bodily fluid (type, quantity, cumulative effects and exchange) means that when young people assess risk in terms of which activities can or

cannot result in HIV transmission, they imagine specific situations or circumstances in which everyday activities take place that could potentially heighten the risk of transmission.

For example, even if they know that as a general rule HIV cannot be transmitted through sharing a cup, due to uncertainty regarding bodily fluid, young people imagine circumstances that could lead to the presence of blood or a larger than usual amounts of saliva on a cup or in food. This could either be through backwash of saliva in a single instance, or the accumulation of the other person's saliva in their body over time, for example, by sharing a cup on multiple occasions. Due to their uncertainty over the specific details, these imagined situations of potentially heightened risk discredit in their eyes the validity of general rules, for example, that HIV cannot be transmitted by sharing a cup or a meal with someone.

In other words, while they may know that you generally cannot get HIV by sharing a cup or meal with someone who is HIV positive (and therefore the majority answered correctly in the questionnaire), they are not confident that it is *impossible* – so there is still some element of risk (reflected in some incorrect questionnaire responses and by a large number of participants in focus group discussions). This may therefore explain our findings from both the quantitative survey and focus groups where there are generally high levels of certainty about the correct ways in which HIV can be transmitted, but lower levels of certainty about the ways in which HIV cannot be transmitted.

The sections below examine in greater depth the situations and circumstances of potentially heightened risk that young people in the focus groups identified in relation to the 'incorrect' ways of getting HIV: simply being around someone with HIV (asked in the focus groups but not in the questionnaire), shaking hands, sharing a meal or cup, or kissing someone who is HIV positive.

### **Simply being around someone who has HIV**

Young people in the focus groups were asked whether they thought HIV could be transmitted through simply being around someone with HIV. On the face of it, there were very high levels of awareness among young people that it is not possible to catch HIV this way. Indeed when asked about this in the focus groups, many laughed at the question or tutted.

There appears to be some uncertainty at a deeper, subconscious level that manifests itself when young people talk about how they imagine they would behave around someone with HIV. For example, in one group there was uncertainty about whether the HIV virus can survive in the air, with the group drawing **parallels with colds and flu** and the way these can be passed from one person to another even without physical contact, such as touching a doorknob that someone with a cold has already touched.

This confusion may explain how in another group, one boy joked that if he found out a teacher had HIV he would not want to sit at the front of the class. While there are several ways of interpreting such a statement, such as physical distancing to avoid association with the teacher, the idea of using **physical space as a barrier** to infection is implicit.

However, on the whole there were very few instances of young people in the focus groups either explicitly or implicitly identifying being around someone with HIV as a possible means of transmission and most of the young people we spoke to appeared confident about the impossibility.

### **Shaking hands with someone who has HIV**

There were generally high levels of awareness among the young people surveyed and those we spoke to in the focus groups that HIV cannot be transmitted through shaking hands with someone who has HIV. Using this as a proxy for whether young people believe touch is a possible means of transmission shows confidence among young people that **touching someone with HIV is 'safe'**, with only one young person in all the groups who expressed uncertainty about touch.

However, in terms of specific circumstances, there was greater uncertainty about shaking someone's hand if there was the possibility of this touch resulting in exchange of bodily fluid, for example, situations where blood is present on the hand or other part of the body.

*[I would shake the hand of someone with HIV] unless their hand is covered in their blood, which is unlikely. (Year 10 focus group participant)*

*If you've got a cut on your hand and they've got a cut on their hand then maybe you could get HIV – like blood brothers. (Year 10 focus group participant)*

### **Sharing a cup or meal with someone who has HIV**

As previously mentioned, unlike shaking someone's hand or simply being around someone with HIV, there were greater levels of uncertainty among the young people surveyed and in the focus groups as to whether HIV can be transmitted through sharing a cup or sharing a meal with someone. This is due to the uncertainty about how bodily fluid, specifically **blood and saliva**, transmit the virus. For example, the following extract from a focus group with Year 10s at a non-religious state school highlights disagreement as to whether the perceived risk of sharing a cup is due to the possibility of blood or saliva being present:

*Facilitator: Can you get HIV through sharing a cup with someone?*

*Young person 1: Maybe. If you backwash.*

*Young person 2: No maybe if you drank her blood you would. Like a vampire.*

*Young person 3: It's transferred through blood so if you got a cut in your lips you might get it from sharing a cup.*

This example demonstrates that while the young people believed HIV could be transmitted through blood and saliva in some circumstances, they were not always confident about in which specific circumstances this could actually happen.

Similar issues and uncertainties in relation to blood and saliva were raised when the young people were asked whether they thought HIV could be transmitted through sharing a meal, as highlighted by the following extract from a focus group with Year 9s at a non-religious state school:

*Facilitator: Can you get HIV through sharing a meal with someone who has HIV?*

*Young person 1: No.*

*Young person 2: Yeah, because of the saliva. Actually I'm not sure. But what if they accidentally dribble on the food then their saliva is on the food and you eat it then their saliva is going in your mouth? Or if you shared a fork?*

*Young person 1: I don't think it can be passed by saliva because that's like saying if someone sneezed, you could catch HIV and that's not right. Everyone on the bus would get it. That's not true.*

*Young person 3: It depends on if you have bleeding gums.*

### **Kissing someone with HIV**

Kissing is the activity with the highest levels of misperception and uncertainty attached to it, suggesting that young people may be identifying more circumstances involving potentially heightened risk for kissing than for the other activities. As with sharing a meal or a cup, the four areas of uncertainty are applicable to kissing due to the perceived possibility of risks such as cuts, bleedings gums and braces causing tearing in the mouth, and exchange of saliva during kissing, with kissing on the lips seen as more risky than kissing on the cheek. This is demonstrated by the following extract from a focus group with Year 10s at a non-religious state school:

*Young person 1: I wasn't sure about kissing because like it is possible if you've got a cut in your mouth.*

*Young person 2: But I swear that you're not going to kiss someone if you've just cut your mouth.*

*Young person 1: But it might be a small cut that you don't even notice. You can get HIV from blood so maybe you can get it from a small cut.*

However, unlike sharing a meal or a cup, kissing was associated by the young people with **sexual intimacy**. The association of HIV with both sex and sexually transmitted diseases means that because kissing itself is associated with sexual intimacy, young people perceive kissing to be taking place within a riskier set of circumstances than other activities. This may help to explain the higher levels of misperception and uncertainty attached to kissing as a means of transmitting HIV.

On the other hand, a minority of young people in the focus groups felt more confident that they knew kissing is not a means of transmission because they had heard this to be a common myth.

*I think that's [kissing] one I know about more as it's such a classic example of one that people are always saying you can get HIV from ... so I knew it as not being true. I heard about it at citizenship class. (Year 9 focus group participant)*

To summarise, it is clear that while young people are generally knowledgeable about the ways in which HIV can be transmitted, there are greater levels of uncertainty about how HIV *cannot* be transmitted. Given the **everyday nature** of these activities, for example, sharing a meal or shaking a hand as opposed to the more exceptional activities such as using unsterilised needles or having a blood transfusion, the high levels of uncertainty about how HIV cannot be transmitted may be particularly problematic as they could lead to young people behaving differently towards people with HIV in everyday situations. This issue is examined further in Section 4.5.

## **3.3 Perceptions about who gets HIV**

The questionnaire and focus groups both asked young people whether they thought that certain groups of people are more likely to get HIV. Overall, the questionnaires show that there were more young people who believe there are certain groups of people who are more likely to get HIV (41 per cent of those surveyed) than those who disagree (28 per cent of those surveyed). The groups that young people identified as being more likely to get HIV

were people from developing countries, people who engage in risky sexual behaviour, people who are homosexual, people who are substance abusers and people from certain religious groups.

### 3.3.1 Risky sexual behaviour

In the UK, people engaging in perceived risky sexual behaviour were identified by young people in both the questionnaire and focus groups as more likely to get HIV. In the survey 34 per cent of those who believe there are certain groups who are more likely to get HIV identified sexually promiscuous people, making them the **most identified group of people**. These respondents usually mentioned people who engage in unsafe sex, not using condoms or contraception; also promiscuous people (and various offensive terms referring to it); prostitutes; some respondents also specifically mentioned anal sex or pointed to the frequency of having sex.

In the focus groups promiscuity was generally defined as 'people who sleep around a lot', which included particular groups such as prostitutes and porn stars. There were several reasons given by young people as to why sexually promiscuous people are more likely to get HIV. Firstly, it was felt that they have increased chances of unprotected sex, for example, by forgetting to use a condom. Secondly, it was felt that they are less likely to know the other person or to be planning on forming a long-term relationship, both of which were seen as having implications for commitment and openness. The young people in the focus groups felt that if there is little commitment between two people, then usual precautions may not be taken.

*[Prostitutes are more likely to get HIV] because they have sex with someone for money and don't ask them if they HIV or not. They don't know the person. And even if they did the person may not tell them. So if they don't know the person they are less likely to have that conversation. (Year 9 focus group participant)*

### 3.3.2 Sexual orientation

In much of this research there is little difference between the findings from the focus groups and the questionnaire responses. However, there are significant differences when it comes to identifying gay people as a group more likely to get HIV. In the questionnaire, 22 per cent of respondents who felt certain groups were more likely to get HIV than others identified specific groups because of their sexual orientation. Responses included 'gay people' (22 responses), 'homosexuals' (17 responses) and 'bisexual people' (six responses). A minority of young people chose offensive terms.

However, in the focus groups, young people were more reticent to talk about the relationship between HIV and gay people. It was apparent that while some believed that HIV is more prevalent among gay men, there was much uncertainty as to why this is the case and whether this is actually still true. This uncertainty meant that in the focus groups when asked to name which, if any, groups they thought were more likely to get HIV, if an individual said 'gay men' others in the group would question this immediately. Those who felt that it was not true that gay men are more likely to get HIV often disputed it by saying that anyone, heterosexual or homosexual, can get HIV and that labelling it as a 'gay disease' is inaccurate as well as stigmatising.

*I used to think that gay people were more likely to get [HIV] although I know it's not necessarily true. It's one of those things that people say but it's not necessarily true. (Year 10 focus group participant)*

Those who did identify gay people as a group more likely to get HIV were generally unable to give any reasons as to why this might be the case, although one individual did say that she felt gay people were more likely to get HIV because they were less likely to use condoms.

There were mixed opinions in the focus groups about whether heterosexual people were less likely to get HIV. While the majority of those who were asked knew that heterosexual people could get HIV, there was a perception among a minority of young people that heterosexual people were less likely to get HIV. When asked to explain why, most were unable to give a reason and there was some discomfort on this topic due to the lack of certainty about what is fact and what is prejudice. This uncertainty is demonstrated from an extract of conversation in a focus group with Year 10s at a non-religious state school:

*Young person 1: Are gay people more likely to get HIV?*

*Young person 2: No because anyone can get it.*

*Young person 1: Well I'm just saying this because that's what I've heard.*

*Young person 2: It doesn't matter; anyone can get it.*

*Young person 1: I heard you can get it from anal fluid.*

*Young person 3: I've heard that too.*

*Facilitator: What about heterosexual people? Do you think they are less likely to get HIV?*

*Young person 3: They can get it but I'm sure I've heard that gay people are more likely. I've heard stuff that anal fluid carries it.*

*Young person 2: A lot of people make stuff up.*

In the questionnaire, however, young people were not asked to explain why they thought gay men were more likely to get HIV under the scrutiny of their peers. It may have therefore been more difficult in the focus groups for people to feel that they could bring the issue up, particularly if they could not explain their answer. This may be why in the anonymous questionnaire gay men were identified more frequently as a group more likely to get HIV than in the focus groups discussions.

### 3.3.3 Developing countries

In the focus groups there was believed to be a strong association between HIV and poverty, in particular people from developing countries in Africa and Asia. In the questionnaire only 18 per cent of those who felt certain groups were more at risk of getting HIV made this link to poorer countries; 23 respondents specifically identified people from Africa, and 20 people identified people from 'third world countries'.

*I think of India when I think of HIV because it has poverty and people in poverty are more likely to get HIV. (Year 9 focus group participant)*

The reasons given for why people from developing countries are more likely to get HIV include **poor access** to healthcare, contraception and education about HIV.

*A lot of people in Africa don't use contraception because they can't afford it and because there's no place to buy it. (Year 10 focus group participant)*

*Poorer countries might not have as much information as we do – how to prevent it, what causes it, what do if you have it, symptoms. (Year 9 focus group participant)*

When probed in the focus groups on whether there were any **groups in the UK** more likely to get HIV, poverty was less readily identified. This seems to be because of the knowledge that there is access to free healthcare services through the NHS, although with regards to contraception it was felt that while free condoms can be accessed through the NHS, they can be difficult to obtain and that condoms in shops are quite expensive – as demonstrated by the following extract from a focus group with Year 9s at a private school:

*Young person 1: But you can get condoms on the NHS for free can't you?*

*Young person 2: Some people might not know and might not actively seek them as you have to go there to get them.*

None of the focus groups identified specific racial or ethnic groups in the UK as more or less likely to get HIV. Instead, responses for which groups in the UK are more likely to get HIV generally centred on promiscuity and drug use. However, **'people who are less educated'** was a frequently identified category for both developing countries and the UK. In the case of 'people who are less educated' it was not always clear whether it was because they have not received education about HIV or whether it is because of perceived behavioural differences between educated and less-educated groups. **Conversely, people who had been educated specifically about HIV were seen by young people as much less likely to get it.**

### 3.3.4 Substance abuse

Unsurprisingly, given the high percentage of young people who were aware that HIV can be transmitted through the use of unsterilised needles, drug users were commonly identified as a group of people more likely to get HIV. In the questionnaire, 14 per cent of respondents who felt certain groups were more likely to get HIV identified people who use drugs. Responses included 'drug users' (19 responses) and people who use 'drugs with needles' (13 responses). Six respondents also mentioned alcohol users as being more likely to get HIV.

In addition, in one focus group there appeared to be an association between drug use and a particular **type of lifestyle** adding to the risk of getting HIV, suggesting that there may be a perception that drug users are not only seen as at higher risk due to the possibility of sharing needles but also because of lifestyle choices.

*Groups of people who sleep around and do drugs together [are more likely to get HIV].  
(Year 9 focus group participant)*

### 3.3.5 Religion

In two of the focus groups, Catholics were identified as more likely to get HIV due to the Church and Pope's stance on **contraception**, as were evangelical Christians for the same reason. Conversely, one group felt that devout religious people, including Catholics and evangelical Christians, may actually be less likely to get HIV as they do not have sex before marriage and are more likely to be in long-term relationships.

## 3.4 Sources of information about HIV

The questionnaire asked young people whether they had been taught about HIV in school and the focus groups asked young people to recall the various sources where they had heard information about HIV. The overall findings indicate that **schools/teachers and television** are the main sources of information on HIV for the young people we spoke to. Other sources include friends and family, the internet, books, magazines, posters and song lyrics. The following subsections outline in more depth these sources and the types of information young people have learnt from them.

### 3.4.1 School and teachers

Overall, just over two thirds (69 per cent) of questionnaire respondents said they had been taught about HIV in school. However, this means that almost one in three of the respondents said they had either not been taught about HIV in their school, or did not know if they had.

The focus groups identified biology, English, life skills, sex education, citizenship and sociology are the main subject lessons that had covered HIV. There appears to be considerable variation in what young people had been taught about. For example, in English lessons one group had studied a novel in Year 7 that included a character who found out he had HIV, and in citizenship lessons another group had learnt about poverty and HIV in developing countries. In a couple of instances young people remembered doing exercises in sex education about the various ways in which HIV can be transmitted. However, there is a general perception that they had been taught more about what it is like to live with HIV rather than medical information about what HIV is and how it links to AIDS.

*The book we studied didn't really tell you about HIV and it was more about how HIV was affecting and destroying his [the character's] life – the emotional impact of having HIV. I think we've learnt more about the impacts than the science thing. (Year 10 focus group participant)*

Importantly, when asked what sources of information they would most trust, **teachers were identified as the most trustworthy**.

### 3.4.2 Television

Television was the second most frequently identified source of information about HIV. Specific types of programmes include news programmes, documentaries such as *Embarrassing Bodies*, charity appeals such as Red Nose Day and Children in Need, and soap operas such as *Hollyoaks*, *Eastenders*, *ER* and *House*. Out of all these programmes, *Hollyoaks* was the most frequently mentioned.

*In Hollyoaks they had a storyline about HIV - I can't really remember what it was about as I've stopped watching it, but I think a male character got HIV but it didn't get passed on to his girlfriend, he'd been having sex with his girlfriend but she doesn't have it. That would be telling people you don't always catch it. (Year 9 focus group participant)*

When recalling the *Hollyoaks* storyline young people focused on how HIV had made the character reassess his lifestyle choices, which he began to regret upon finding out that he was HIV positive.

*In things like Hollyoaks, they wish they had never done what made them get HIV. (Year 9 focus group participant)*

While it was often difficult for the young people to remember exactly what the various TV programmes had said about HIV, the most frequently mentioned things related to the difficulty of being able to tell who has HIV, the fact that HIV is a more serious problem than many suspect it to be due to underestimations of its prevalence and that there have been cases where people with HIV have consciously passed on the virus to others.

*They've told us that it's bad – that it's serious and real, because a lot of people don't think it's real until they get it or someone close to them gets it. (Year 9 focus group participant)*

*It shows there's a fear that you can never really know who has it. (Year 10 focus group participant)*

Again this suggests that young people are learning more about the 'consequences' of HIV rather than medical knowledge.

### 3.4.3 Other sources

A number of other sources were also identified by young people. These included entertainment mediums such as popular **song lyrics**, for example, one boy remembered that Eminem mentioned HIV in one his lyrics, although he could not remember what exactly the lyric was about.

Other sources included **family and friends**, both through general conversation and through hearing about 'friends of friends' who have HIV. For example, one girl remembered hearing about her family's cleaner's niece who had contracted HIV after being raped, although the girl said that she did not feel comfortable bringing the subject up with the cleaner. In another group one young person had a family member who works at the Terence Higgins Trust and had learnt a great deal about HIV from his relative.

Friends were identified as a potential source of '**false information**' about HIV, with several young people saying that they had heard jokes being told about people with HIV. Again, it was difficult for them to remember the actual jokes.

*I'm sure I have heard some jokes about HIV ... I think people are scared about it that's why they make the jokes. (Year 10 focus group participant)*

Similarly, other young people recalled playground conversations about how it is possible to get HIV off toilet seats and how in lessons when HIV was talked about other young people would sometimes talk among themselves and that this is a possible means for false information to be circulated. It is interesting that this example of how false information about HIV could be communicated takes place within the context of a lesson about HIV suggesting that it is important for any myths about HIV to be clarified before the pupils leave the classroom.

*In citizenship people might be like, oh yeah, you can get it from this ... they think the wrong things and spread it around. (Year 9 focus group participant)*

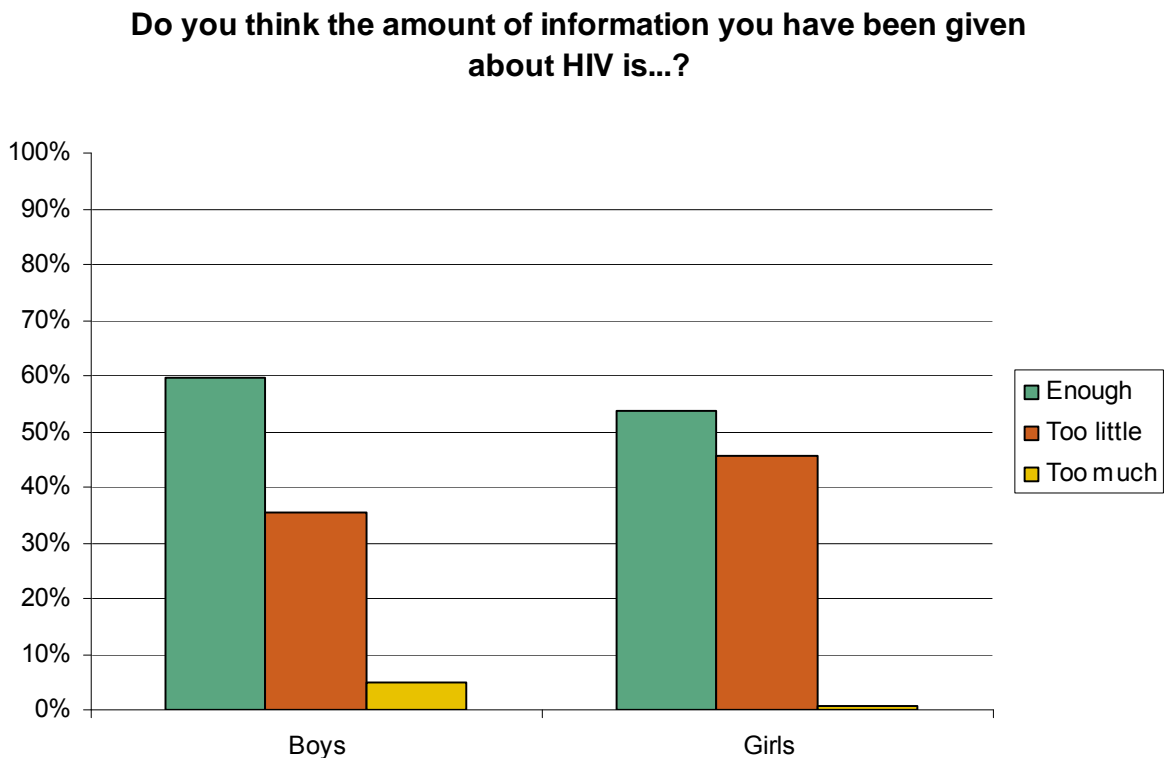
Finally, other sources of information included seeing **posters** around school, in doctors' waiting rooms and in the streets, but again, the young people could not recount any specific campaigns.

## 3.5 Young people's appetite for more information about HIV

### 3.5.1 Amount of information already received

The questionnaire asked young people to state whether they felt they had received enough, too little or too much information about HIV. Over half of all respondents (57 per cent) felt that they had already been given enough information. Importantly, however, 41 per cent said they felt they had received too little information on HIV. When looking at whether there are any statistical differences to people's responses according to their gender, it becomes apparent that **girls are more likely than boys to say that they have not received enough information about HIV**, with 35 per cent of boys saying they had received too little information compared to 46 per cent of girls. Figure 2 below illustrates views on the amount of information already received, broken down by gender.

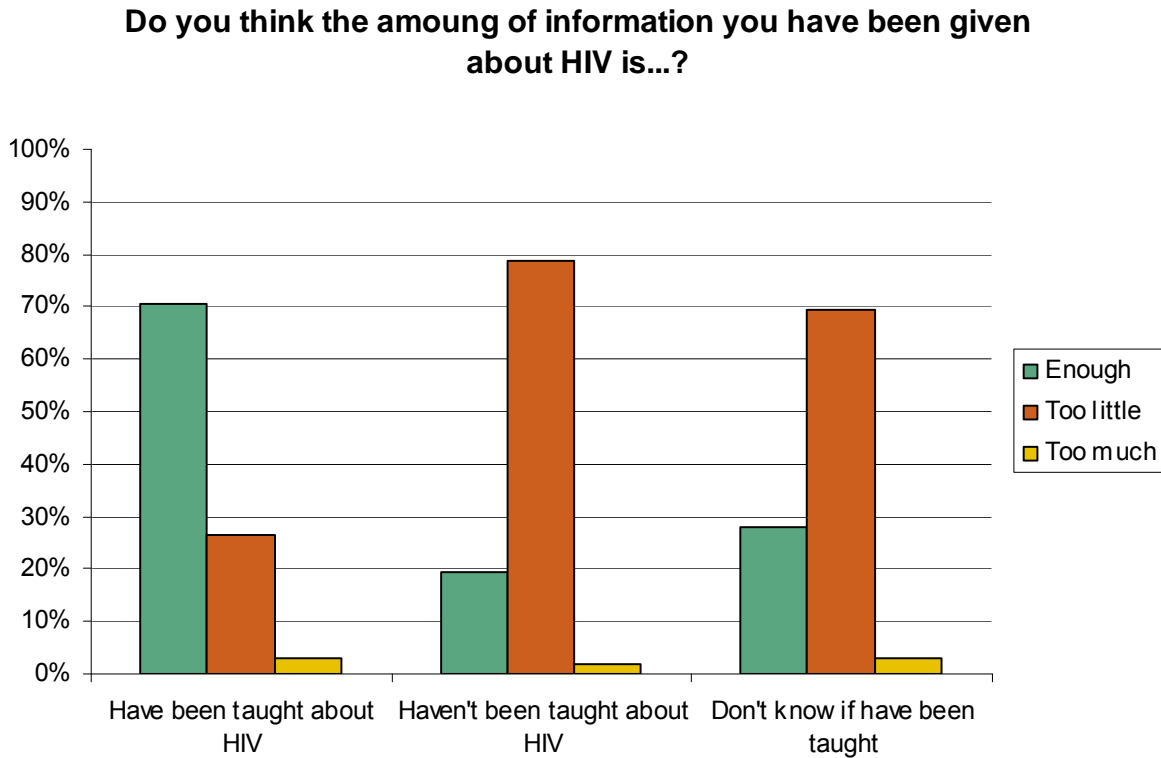
Figure 2 – Amount of information already received, by gender



Base: 485

Unsurprisingly, the responses to the question on whether the amount of information received is enough, too little or too much also vary depending on whether the respondents have **learnt about HIV in school**, with 79 per cent of those who said they had *not* been taught about HIV in school saying they had received too little information compared to 27 per cent of those who said they *had* been taught about HIV (Figure 3 below). However, it is important to reflect on the fact that this means that of those who have been taught about HIV at school, over a quarter still felt they had been given too little information. It is also worth noting that hardly any respondents felt they had received too much information about HIV.

Figure 3 - Amount of information already received, by whether been taught about HIV in school



Base: 484

### 3.5.2 Appetite for more information

In the questionnaire, respondents were also asked whether they would like more information about HIV. **Over half (54 per cent) of those who gave an answer said that they would like more information**, compared to only 21 per cent who said they would not. The remaining respondents either answered 'don't know' or did not give any response.

In addition, the questions that young people asked about HIV in the focus groups were recorded as these give a helpful idea about the specific questions young people have. These questions are listed in Box 1 below.

### Box 1: Questions asked by young people in the focus groups

#### What HIV is

- What do HIV and AIDS stand for?
- What is the difference between HIV and AIDS?
- What are the symptoms of HIV?
- Where did HIV come from?
- Can you get rid of HIV once you have got it?
- Can you inherit HIV?
- Can you die from HIV or is it just AIDS that you die from?
- Does the virus die in the air?

#### How people get HIV

- Is it certain that you'll get HIV through unprotected sex?
- Can you get HIV through small cuts?
- Does kissing someone over a long period of time build up HIV?
- Can you get HIV through oral sex?
- Can you get HIV through saliva?
- How much blood and saliva does it take to pass on HIV?
- How do you get tested for HIV?

#### Legal rights and duties

- Do you have to tell your employer that you have HIV?
- Is it illegal to pass on HIV if you know you have it?

### 3.5.3 Most interesting types of information

When asked what they thought would be the most interesting way of giving young people information about HIV, focus group participants agreed that the two best ways would be **true or false exercises** done in school lessons and **real life stories** presented by people living with HIV.

*True and false games is a good way, as it's better than writing and it's not boring, it's kind of fun. If we watched some videos about people living with HIV – it's more personal, better, more interesting, so like actual stories would be good. (Year 9 focus group participant)*

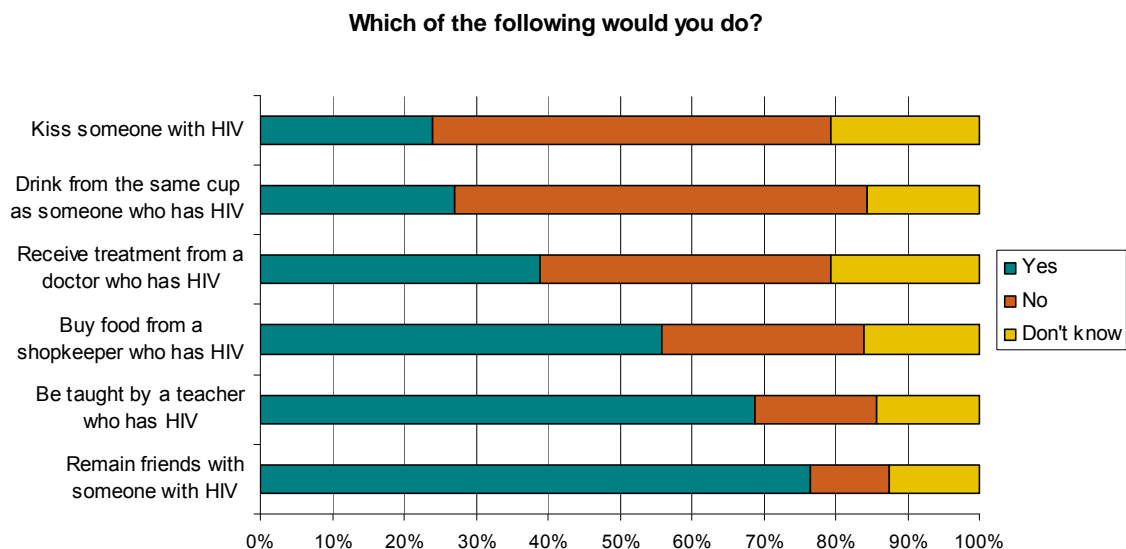
## 4. Attitudes and behaviours towards people with HIV

Having considered findings about the knowledge of young people in relation to HIV, we now move on to examine their attitudes and behaviours towards people who are HIV positive. It should be noted that in the vast majority of cases this is based on hypothetical and imagined situations as the vast majority of young people we spoke to did not know anyone with HIV (or were not aware that they knew someone with HIV); for example, in the questionnaire, only eight per cent of respondents reported knowing someone who was HIV positive.

### 4.1 Behaviours in different situations

This section examines the questionnaire findings relating to the behaviours respondents said they would demonstrate when interacting with people who are HIV positive. The behaviours they were asked about were whether they would remain friends with or drink from the same cup as someone who was HIV positive. They were also asked whether they would buy food from a shopkeeper, receive treatment from a doctor or be taught by a teacher who was HIV positive. These findings are presented in Figure 4 below.

Figure 4 - Behaviours in different situations



Base: 508

- Data from the questionnaires show that more young people said they would not **kiss** someone with HIV or drink from the **same cup** as someone with HIV than those who said they would (only 24 per cent of young people said they would kiss someone with HIV compared to 55 per cent who said they would not, and only 27 per cent said they would share a cup compared to 57 per cent who would not).
- Roughly equal numbers of young people said they would receive **treatment from a doctor** with HIV as those who said they would not (39 per cent say they would compared to 40 per cent who said they would not receive treatment).

- Over half of the young people surveyed said they would buy food from a **shopkeeper** with HIV (56 per cent said they would buy food compared to 28 per cent who would not).
- The majority of respondents also said they would be **taught by a teacher** with HIV (with 69 per cent saying they would be taught by a teacher who was HIV positive compared to only 17 per cent who would not).
- However, more young people said they would **remain friends** with someone who was HIV positive (76 per cent of young people say they would compared to only 11 per cent who would not). Girls are significantly *more likely* than boys to say that they would remain friends with someone with HIV. On the other hand, boys are more likely than girls to say they 'don't know' whether they would remain friends.

Importantly, **whether respondents said they had been taught about HIV in school appears to significantly influence how young people say they would behave towards people who are HIV positive.** For example, respondents who said they had been taught about HIV in school were more likely to say they would stay friends with someone who has HIV and drink from the same cup, more likely to say they would buy food from a shopkeeper with HIV and more likely to receive treatment from a doctor and be taught by a teacher who was HIV positive. But they are just as likely as other young people to not want to kiss someone with HIV.

In addition, it should also be remembered that while respondents who said they had been taught about HIV in school were more likely to say they would behave positively towards someone with HIV, even in this group there were more young people who gave negative responses than positive responses. For example, while 31 per cent of young people who said they had been taught about HIV at school said they *would* drink from the same cup as someone with HIV (compared to 19 per cent of those who said they had not been taught about HIV) there were still a majority (56 per cent) of young people who said they had been taught about HIV in school saying that they would *not* drink from the same cup as someone who was HIV positive. This suggests that while being taught about HIV in school certainly seems to reduce prejudiced attitudes, it currently only goes some way to doing this.

The reasons given in the focus groups as to why young people would or would not want to engage in these behaviours are explored in Section 4.2 onwards.

## 4.2 Contradiction between knowledge and behaviours

Perhaps the most puzzling finding in this research is the contradiction between young people's knowledge about how they think it is possible to get HIV and the way they expect themselves to behave towards someone who is HIV positive. For example, even if they know it is not possible to get HIV through sharing a cup, they are still less likely to want to drink from the same cup as someone who has HIV.

*I don't think I would kiss someone with HIV, even though you told me that I couldn't get it through their spit and stuff I still wouldn't do it. (Year 10 focus group participant)*

This contradiction has arisen in previous research, such as the Red Cross' World AIDS Day 2009 Survey with 16 to 25 year olds. As we expected that this contradiction might arise in this research, the questions asked in the focus groups were designed to explore this contradiction in greater depth.

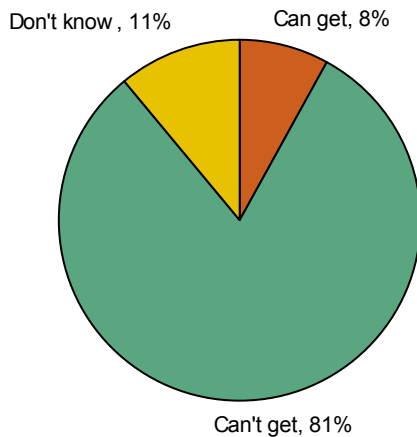
### 4.2.1 Demonstration of the contradiction

The two activities listed in the survey that we can directly compare knowledge and behaviour against are sharing a cup with someone with HIV and kissing someone with HIV. These activities are therefore used now to demonstrate the contradiction between knowledge about HIV and behaviour towards people who are HIV positive.

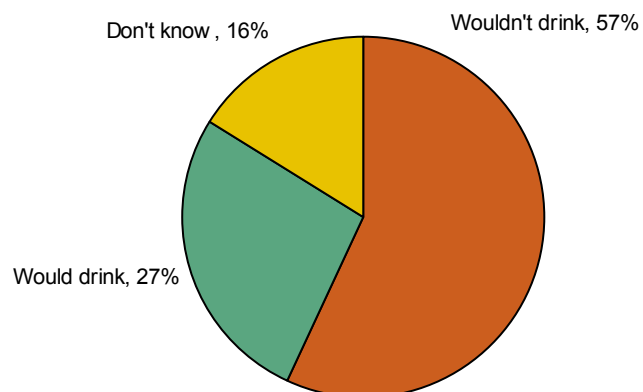
Figure 5 below compares the knowledge and behaviours relating to **sharing a cup** with someone who has HIV. It shows that while 81 per cent of the young people surveyed knew that HIV cannot be transmitted via sharing a cup, only 27 per cent went on to say that they would drink from the same cup as someone with HIV.

**Figure 5 - Knowledge and behaviour on sharing a cup**

#### You can get HIV by sharing a cup with someone who has HIV

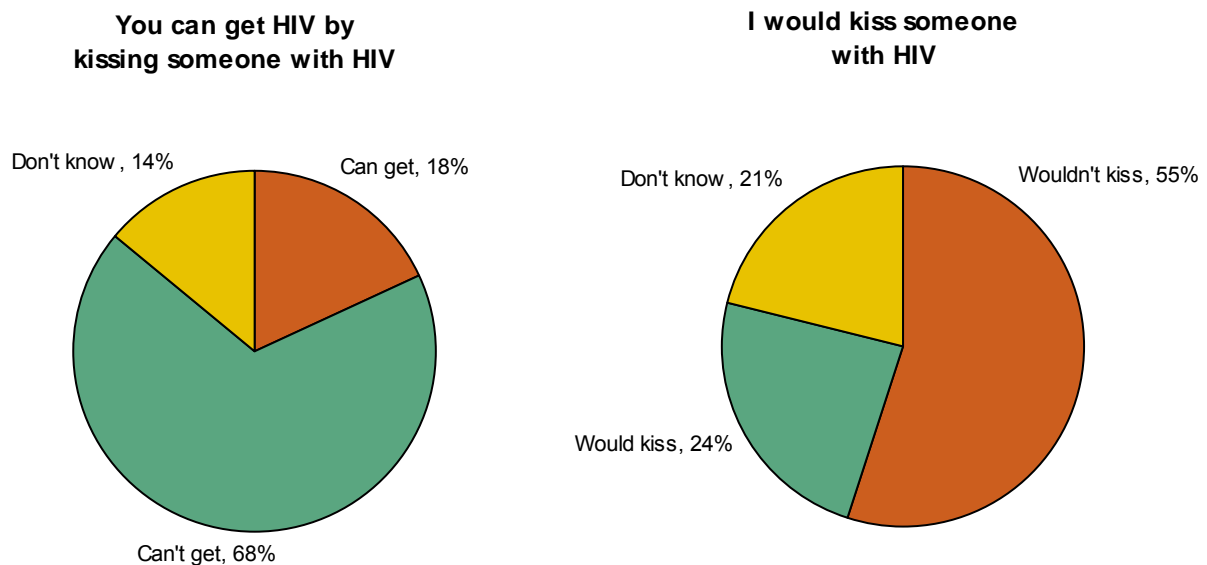


#### I would drink from the same cup as someone with HIV



A similar picture is presented with regards to **kissing**. Figure 6 below compares the knowledge and behaviours towards kissing someone who is HIV positive. It shows that while 68 per cent of the young people surveyed knew they could not get HIV by kissing someone who has it, only 24 per cent said that they would actually kiss someone with HIV.

Figure 6 - Knowledge and behaviour towards kissing



Our findings suggest that the **older the person, the greater the contradiction between their knowledge and behaviour**. While 46 per cent of 12 to 13 year olds would not share a cup with someone who has HIV despite knowing that HIV cannot be transmitted in this way, 54 per cent of 14 to 15 year olds and 61 per cent of 17 to 18 year olds demonstrate this same contradiction. Similarly, while 32 per cent of 12 to 13 year olds would not kiss someone with HIV despite knowing that this does not lead to HIV transmission; 46 per cent of 14 to 15 year olds and 49 per cent of 16 to 18 year olds show the contradiction in their knowledge and behaviour with regards to kissing. Although it is important to note that these differences could be attributed to other factors that this study has been unable to consider (for example, religion or socioeconomic background).

The contradiction between knowledge about HIV and behaviour towards people with HIV described in the section above appears to depend on the way that young people carry out **assessments of risk**. When a young person considers whether or not they would stay friends with someone or whether or not they would kiss someone with HIV, they weigh up the perceived risks that this may have for them individually. Their assessment of these potential risks then informs their judgement of how they think they would behave in a given situation.

From the focus group discussions, we have identified three types of risk that young people consider: health risks, emotional risks and social risks.

### 4.3 Health risks

The perceived health risks associated with interacting with people who have HIV focus on the **risk of getting HIV themselves**. For example, when young people in the focus groups were probed about why they would not want to be friends with or kiss someone who was HIV positive, fear of getting HIV was the most readily identified reason. They often acknowledged that this presented a difficult situation because on the one hand they would want to be a good friend but on the other hand the fear of getting HIV may cause them to act 'selfishly' by

putting their own interests first. This **dilemma** is exemplified in the following extract of conversation from a focus group with Year 10 pupils at a non-religious state school:

*Facilitator: If you found out that a friend of yours had HIV, would you stay friends with them?*

*Young person 1: If you are a true friend you wouldn't leave them.*

*Young person 2: But even though you say that you won't leave them, when it comes down to it you just don't know, even though you know you can't catch it through just holding their hand or being around them, you would still feel a bit uneasy.*

*Young person 3: Yeah it's a bit hard to tolerate them knowing that.*

*Young person 1: But shouldn't your friendship be stronger than that?*

*Young person 3: Yeah but I'm just saying that you don't know. It'd be hard to tolerate the paranoia of being able to get it.*

This 'paranoia' around the possibility of getting HIV can be explained by two factors. The first factor is linked to the uncertainty over how HIV can be transmitted, particularly with regards to the role of bodily fluid. In Section 3.2 we described the four areas of uncertainty that young people have about bodily fluid, namely type of bodily fluid, quantity of bodily fluid, cumulative effects of bodily fluid and exchange of bodily fluid. Uncertainty over the specific details in these four areas mean that young people imagine situations or circumstances that could be associated with heightened risk.

*I know that HIV can't be transmitted by like sharing bottles or sharing things, but I would, in a way be reluctant – I know it sounds horrible – but I would be quite reluctant in that sense. I wouldn't be like, 'No, don't touch my water', but I'd be like, 'Yeah', and then make sure I'd clean it, properly. But I'd do that even if a friend had a cold, it's not because it's HIV, but it's because I'd be reluctant, like automatic reactions. (Year 9 focus group participant)*

The second factor that explains the 'paranoia' of getting HIV is the perception that HIV is a '**death sentence**', or at the very least has extremely negative medical and social consequences. It is therefore seen as not being *worth* the risk, no matter how small the perceived risk might be. For example, even though just over half (53 per cent) of survey respondents agreed with the statement that people with HIV 'can live long and happy lives' and 45 per cent knew that treatment for HIV is available, there were still strong associations between HIV and death. This is partly due to awareness that although treatment is available, currently there is no cure for HIV.

The belief that the negative medical and social consequences of HIV mean that 'it's not worth the risk', is highlighted by an extract from a focus group with Year 9 at a non-religious state school:

*Facilitator: If you know you can't HIV through kissing someone – would you still not want to kiss them?*

*Young person 1: A little bit yeah. I'd be scared. It's not worth it. I'd still worry about getting it.*

*Young person 2: Not at this age, it's not worth the risk.*

*Young person 3: Can you die from HIV as well as from AIDS?*

This extract highlights a relationship between age and willingness to take risks. This will be discussed in further depth in the section on sexual relationships and perceived health risks below.

These two factors, namely the four areas of uncertainty and the perception of HIV as a 'death sentence' underpin young people's perceptions of health risks and play out in certain ways across three types of relationships: friendships, sexual relationships and professional relationships. Each of these is explored below.

### 4.3.1 Friendships and perceived health risks

The majority of young people surveyed (76 per cent) said they would remain friends with someone with HIV. But it became apparent in the focus group discussions that because of the perceived possibility of getting HIV by remaining friends, they would seek to limit these health risks by attaching **strict conditions** to the friendship.

*If I had a friend with HIV I wouldn't really care – I'd still be friends with them, although he's not going to be sharing my drink or nothing! [Group laugh] I'd be careful. I'd worry about catching it. But I'd be worried about them too actually. (Year 10 focus group participant)*

Certain behaviours were perceived to be particularly risky and therefore to be avoided. Examples of these behaviours mentioned in the focus groups included things like sharing razors, water bottles and lollipops and going for sleepovers with friends who have HIV. These suggest that young people would be particularly wary about **sharing personal belongings** with a friend who has HIV, due to the potential exchange of bodily fluid. This could have negative implications for the friendship as willingness to share personal belongings is often seen as an important symbol of friendship.

*I think I'd also be like, it sounds like weird, but say they cut themselves or something, like with most friends I'd just like help and put a plaster on or something, but I think I'd be more careful, or like say with like a razor, like with some of my friends are, 'Oh, can I borrow your razor?', I'd be like, 'Yeah', but then if they did, I'd be like, 'Well ... no'. I think I'd be more cautious with that sort of sight like if they hurt themselves then I'd be more careful, if there was blood. (Year 9 focus group participant)*

*I'd be worried about catching it and having sleepovers, you wouldn't really want to [have sleepovers]; you would be like 'urgh'. (Year 10 focus group participant)*

But although fear of getting HIV themselves led some young people to say they would remain friends with someone who had HIV but would attach conditions to that particular friendship, other young people were keen to say that they would treat their friend with HIV in the same way they would treat other friends as this was the **morally right** thing to do. This was generally underpinned by the idea of what it is to be 'a good friend'.

*If you're a good friend ... you should really support them, because obviously there are going to be people who are going to be like, 'No, don't come near me', and if you're one of those people who are, then like it's not worth it. It kinda tells you who your true friends are and who are not. (Year 9 focus group participant)*

Similarly, other young people felt that if they got HIV themselves, they would want their friends to treat them the same way as they did before. This means that they would be careful to treat a friend with HIV in the same way.

*You can't catch it just by sitting next to them, if you had it you would want other people to treat you the same. (Year 9 focus group participant)*

Finally, a minority of young people saw friendship and health risks in a different way, focusing instead on the potential health risks to their friend with HIV rather than health risks to themselves resulting from friendship. This is due to an awareness that HIV can lead to people being more vulnerable to common illnesses:

*But also doesn't HIV, I don't really know, but like doesn't it weaken your immune system and stuff? So like they're more vulnerable to getting stuff, so like if I was ill, maybe I wouldn't want to spend as much time with them, for their own health risk. (Year 9 focus group participant)*

### 4.3.2 Sexual relationships and perceived health risks

Unlike remaining friends with someone who has HIV, where the majority of young people responded favourably, kissing someone with HIV was viewed as much more risky behaviour. This is demonstrated by the fact that only 24 per cent of young people surveyed said they would kiss someone with HIV compared to 76 per cent who said they would remain friends. As kissing is associated with **sexual intimacy**, the common view held by young people was that it was therefore not worth the risk of getting HIV by kissing and then possibly having sex with someone who has it because of the perception that 'you're done for life' if you do get HIV. The following extract from a focus group with Year 9 at a non-religious state school introduces many of the concerns that were shared across almost all of the groups that we spoke to:

*Young person 1: It depends on whether you have a crush on them or if you really love them ... a crush doesn't last forever so what if you get HIV [from your crush] and then give it to other people later on - you wouldn't want to do that.*

*Facilitator: If you knew that you definitely couldn't get HIV through kissing someone, would that change anything?*

*Young person 1: I'd still be scared because they've still got HIV. If you get HIV yeah and you get into a relationship you might want kids and then you might give it to your children. If you're going out with someone yeah and if you get married seven years down the line, your kids are going to get it. I would be weird about it because your crushes and your boyfriends don't last forever yeah but like afterwards if you have it, if you get it, you're done for life, everyone you go out with is going to get it.*

*Young person 2: You wouldn't want to ruin their life but you would want to tell them but if you tell them they wouldn't want to go out with you. And if you have a child you might die before them, and your child might have HIV.*

Furthermore, it was assumed by other young people that you would not be able to safely have sex with someone who was HIV positive even if using a condom, as they had heard that condoms are not always 100 per cent effective:

*I'd worry about meeting up with them [person with HIV] and then like being there and maybe wanting to have sex with them, but then afterwards thinking 'oh no'. I suppose there's an element of the relationship that's gone as well, there's no intimate relationships anymore. I'm not sure whether I could have sex with them. Even protected sex because there's still that idea that maybe it wouldn't work. It could break. And condoms are only 99% efficient. It is possible. (Year 9 focus group participant)*

A contradiction emerged on the **issue of age and willingness to take risks** when having sexually intimate relationships with people who are HIV positive. In the focus groups, young people expressed two opposite views in relation to this issue. On the one hand, some young people in one focus group thought that it was okay to take the risk while you were young and not wanting to have a long-term relationship or children because the risk of getting HIV can be minimised through condom use. Therefore, it was thought that **older people** might find the risk harder to take:

*It depends – if you are older and want to be in a relationship, it might be harder, but it would depend on who it was ... in the long term it might be different. You would have to trust them to tell you that they have HIV beforehand. (Year 9 focus group participant)*

*If you were older, you'd have to consider it. What protection you would use etc, whether you are willing to take the risk. It's kind of an age issue. I think when you are older if you love someone you shouldn't not be with them; if you love them you should stay with them. (Year 9 focus group participant)*

On the other hand, other young people in two of the focus groups felt that it was only worth the risk if you really loved someone with HIV and saw a long-term future with them, and that therefore, for **younger people**, it was probably not worth the risk.

*I think it's different with our age, if you were older – say if you are like 30 and married and in love with them then you probably would [be sexually intimate] but not if you're this age. It's not worth the risk. (Year 10 focus group participant)*

*If it's just a crush I wouldn't bother. (Year 9 focus group participant)*

Therefore when young people make risk assessments over whether they would engage in sexually intimate behaviour such as kissing and sex, they consider the long-term prospects of the relationship. For some young people, there is less risk associated with short-term sexually intimate relationships with either they have a crush on. Whereas for others, the risk is only worth taking if they love the person and want to commit to a long-term relationship with them.

### 4.3.3 Professional relationships and perceived health risks

Whether professional relationships with teachers and doctors who have HIV might be affected by perceived health risks appear to depend on the **risk of bodily contact** and potential for exchange of bodily fluid. Professional relationships involving more bodily contact are deemed riskier than those where there is minimal bodily contact. Therefore going to the **doctor** is seen as more likely to involve some bodily contact, for example, during physical examinations, and hence be more risky than being in a classroom with a **teacher** where there are already strict rules discouraging bodily contact between teachers and pupils.

*I don't think I'd mind with someone like a teacher, but with something more like a doctor or a dentist or something like that I mean I know they're not bleeding on you but I still think I'd be a bit iffy about it. (Year 9 focus group participant)*

Therefore this may explain why in our survey findings only 39 per cent of the young people surveyed said that they would receive treatment from a doctor with HIV, compared to the 69 per cent who said that they would be taught by a teacher with HIV. It was occasionally expressed that this could be a subconscious judgement about the heightened risk of transmission.

*The thing is I think like even if most of us wouldn't do it consciously, I think if most people were having like an operation and they got a choice of having a doctor with HIV and without, most people would choose the doctor without HIV. (Year 9 focus group participant)*

In the case of receiving treatment by doctors, young people generally felt that they would be more confident if they knew that protective measures were being taken by the doctor to prevent transmission of HIV. They therefore often attached certain **caveats** to being treated by a doctor who was HIV positive, such as that the doctor should wear gloves when touching a patient, and not take blood samples or operate.

*With a role like a doctor, I'd be fine with it, as long as I was completely reassured that precautions have been taken and stuff like that, like if I knew that everything was safe, then I would be completely fine with it. But like if there is something where like blood can pass or whatever, anything like that, then I would definitely want to be reassured that like precautions have been taken. (Year 9 focus group participant)*

*I'd want dentists to wear gloves. (Year 9 focus group participant)*

For some young people, if they were confident that all precautions had been taken to minimise the possibility of HIV transmission from doctors to patients, then they would rather make their judgement about which doctor to go to for treatment on the basis of their **skills**, rather than HIV status.

*If I had a choice of like an incredibly highly-skilled doctor with HIV or a doctor who wasn't very skilled who didn't have it, I would rather go for the one with HIV, but ... it's easy for me to say that, if I actually was in the situation, I don't know, I could change my views, but I think that generally, as long as I was completely reassured that all the precautions have been taken, I would be pretty, like not comfortable, but understanding. (Year 9 focus group participant)*

However, in some cases it was apparent that young people would still question the **professional integrity** of professionals who were HIV positive due to moral judgements as to how the teacher or doctor contracted HIV. This issue is explored in further depth in Section 4.3.

Finally, as with friendships, in a minority of conversations about professional relationships, some young people highlighted that there could be **health risks for doctors with HIV** due to their weakened immune system and exposure to their patients' illnesses. It was felt that this may make it harder for people with HIV to carry on in their profession. This is demonstrated in the following extract from a Year 10 focus group at a private school:

*Young person 1: But I don't think a doctor with HIV would want to be a doctor, because when you have HIV your immune system is slow, and if you're working with people who are sick, then you're more likely to get something.*

*Young person 2: But they might think that that's just a risk they have to take. I suppose maybe if you like if you have HIV especially, like you want to help other people more, and I don't think they should be stopped from doing that.*

## 4.4 Emotional risks

Having considered the perceived health risks of HIV that young people associate with various behaviours, we now move on to examine the second type of risk underpinning the

contradiction between young people's knowledge about HIV and their behaviours towards people who are HIV positive. The emotional risks associated with HIV centre on young people's perceptions that there is a **risk of damage to their relationships** with people who are HIV positive and that these relationships could fundamentally change if they found out the other person had HIV. This risk is primarily identified with friendships and sexually intimate relationships.

Many of the young people we spoke to felt that it should not be the case that their relationships with people with HIV would alter, saying that if someone they knew got HIV then they would still be the same person:

*You've known them before they had HIV so they'll be the same person; they haven't changed so why should HIV change them. They'll need you to support them. (Year 10 focus group participant)*

Despite this, the majority of young people felt that their relationships would nevertheless be altered. Young people in the focus groups identified three possible ways in which their relationships could change after finding out that their friend or partner had HIV:

- **Feeling burdened:** Some young people said they would worry that having a friend or sexual partner with HIV would place a burden on them. It was generally felt that while they would want to spend more time with that person to provide support, spending more time with them might affect other areas of their life and they could feel guilty if they did not spend enough time with them. Similarly on one occasion the burden of taking on a caring responsibility, particularly if in a long-term relationship was identified as a concern. In addition, young people said that they would worry about the other person dying and that this would be upsetting and stressful.

*I would be worried that I might have it because if they have it then so might I. I'd also be worried about making sure I spend time with them because they might die. (Year 10 focus group participant)*

*You can't marry someone who is so illness dependent. (Year 9 focus group participant)*

- **Not being able to have as much fun as before:** Because of the anxiety over getting HIV that leads to young people to imagine that they would have to place strict conditions on their friendship (for example, not sharing belongings and not going for sleepovers), it seemed that young people were concerned that they would not be able to have as much fun with them. When asked how they might treat someone with HIV, a common response was that they would treat them more 'delicately' due to perceived vulnerability. This may be seen as limiting the scope of activities that they could do with a friend who has HIV.

*The thing is though I think like even though all of us would stay friends with them, I think there are some people that would still find it difficult to act like they did before. Not because they're scared of like catching it but maybe because they feel sorry for them or that sort of thing. I mean some people would have no problem, but I think some people might find it difficult to act exactly the same around them as before. (Year 9 focus group participant)*

- **Feeling embarrassed and awkward:** Several young people said they would feel embarrassed and awkward on finding out that a friend had HIV, with these feelings stemming from an uncertainty over how best to approach the subject with their friend and concern that they might annoy their friend if they treated them differently.

*I would treat someone not in a horrible way; I would be nicer to them because it must be a hard time. But then they might get frustrated because I am not treating them like normal person. You could end up treating them too much like say someone who has no legs; you might try and help them even if they didn't need it. (Year 10 focus group participant)*

*It wouldn't be normal anymore – I'd find it embarrassing to talk about it with them. (Year 9 focus group participant)*

While these are fairly negative ways in which relationships could potentially be altered, other young people were keen to point out that actually finding out that a friend had HIV could change the relationship **positively** and that the process of going through something together could help strengthen the friendship.

*Your relationship would quite possibly change though if they got it when you were friends with them already, just because then you would've gone through something together kind of thing like you would've been friends with them as it was happening and so like your relationship might become stronger or weaker or whatever like due to that. (Year 9 focus group participant)*

## 4.5 Social risks

This section moves on to consider the third type of risk underpinning the contradiction between young people's knowledge about HIV and their behaviours towards people who are HIV positive, namely the social risk. This risk is characterised by the **perceived risk of stigma by association** with people who have HIV.

Young people appeared to be well aware that people who have HIV are likely to be treated differently. For example, when asked to imagine how they think their friends would treat them if they as individuals got HIV, young people felt that they would be treated differently because their friends would always have the fact that they are HIV positive in the back of their minds, as described by one young person:

*If I had HIV I think my friends would still be my friends but I would know that in the back of their mind there would be something there telling them – you would just feel that it's different. It wouldn't be the same like it was before. Even if they say they love you there might still be something in the back of their minds that you have HIV, that they have to be a bit careful around you. They might be a bit iffy with you. (Year 9 focus group participant)*

As well as being treated differently just by dint of having HIV and the fear of getting HIV that this engenders, young people were also well aware that both themselves and other people may make **moral judgements** about HIV, specifically on the lifestyles associated with HIV and the types of people who are perceived as getting HIV.

In the questionnaire young people were asked to either agree or disagree with the statement that 'there's nothing to be ashamed of if you have HIV'. Just under two-thirds (63 per cent) agreed that there was **nothing to be ashamed of** about having HIV, with far fewer (24 per cent) feeling that there was something to be ashamed of. It could therefore be the case that some young people are hesitant about either forming or expressing moral judgements about people with HIV, but are aware that other people make moral judgements. Alternatively moral judgements could be taking place at a more subconscious level and it is only when discussing these issues, as in the focus groups, that moral judgements about HIV or people who have HIV come to the surface.

The words that young people used to describe HIV in the exercise at the beginning of the focus groups gives some indication of both the moral judgements made by young people themselves as well as the way in which they know other people make moral judgements. These include: 'irresponsible', 'choices', 'embarrassing', 'prejudice' and 'misunderstood'.

Importantly, when talking about their own moral judgements about people who have HIV, young people were clear that it is **not HIV itself that invites moral judgement** but rather the way in which the person contracted HIV.

*I don't think there is anything to be ashamed of if you have the disease itself – but I think it's how you got it that matters and that you should be ashamed of. (Year 9 focus group participant)*

However, it appears that in some circumstances, moral judgements about lifestyle choices are more likely to be made only **after a person has contracted HIV**, not before. For example, in the focus groups while there was an awareness that many young people have unsafe sex when drunk or otherwise and that in the majority of cases this does not lead to HIV transmission, people who do contract HIV through unsafe sex seemed to attract more moral judgements about their choice to have unprotected sex. In other words, those who have unsafe sex and get HIV as a result are seen as 'stupid'; whereas those who have unsafe sex but do not get HIV are seen as 'lucky'.

*I think if one of my friends told me, 'I have got HIV', I'd ask, 'why? when? how?', and if they said they'd had unprotected sex then I think, to be honest, my respect would drop for them because we've been told so many times to have protected sex. But it's not like the disease should control who they are, I wouldn't do that because they had HIV, but because they were stupid enough to have unprotected sex. It's nothing to do with like the disease. It's more about like how they got it. (Year 9 focus group participant)*

#### 4.5.1 'It depends on how they got HIV'

When talking about hypothetical situations in the focus groups, young people were often keen to know how the person became HIV positive. This is because they saw people with HIV as falling into two categories: '**innocent victims**' who contracted HIV through no fault of their own and those who '**bought it upon themselves**' by engaging in risky behaviour. Having put someone with HIV in one of these two categories, the young people then tended to adjust their judgements and therefore behaviours accordingly. Several young people said that this categorisation often appeared to happen subconsciously and was difficult to control:

*Subconsciously you'd be judging them even though you know you shouldn't. (Year 9 focus group participant)*

However, other young people felt more comfortable with making their moral judgements explicit, as suggested by the following extract from a focus group with Year 10 at a non-religious state school:

*Young person 1: It depends how you caught it, it might be your fault.*

*Young person 2: It might be your fault but you shouldn't feel ashamed that you caught it - you should just feel sad.*

*Young person 3: Are you telling me that someone who took drugs the whole time everyday would be the same as someone who got it through no fault of their own?*

### Innocent victims

The groups of people most likely to be categorised as ‘innocent victims’ in the eyes of the young people we spoke to include people in **developing countries** with high levels of poverty and low levels of access to healthcare and treatment, people who have contracted HIV through receiving infected **blood transfusions** in hospital, people who were **born with HIV** and people who were forced into unprotected sex such as **rape victims**. With the exception of the latter, innocent victims are therefore seen as mainly being people overseas.

*If it's passed from your mother it's not your fault but if you share needles or have unprotected sex – you'd think what kind of person are they? But the other one you don't really have a choice. (Year 9 focus group participant)*

*I would like to know how they got it possibly. Say someone gave it to them deliberately. There's a lot of people out there who do that, like if they're angry they might give other people HIV. I've heard stuff like that. I'd be more sympathetic towards someone if they didn't know – but I'd be mad at them if they knew that whoever they slept with had it. I would think it's their fault. You have to take some responsibility but I'd still be there to support them. (Year 10 focus group participant)*

As these two quotes show, there is a clear distinction in young people's minds between those who get HIV through no fault of their own and those who have made risky choices. ‘Innocent victims’ who get HIV through no fault of their own are seen as deserving **sympathy**, unlike those who bought it on themselves.

### Those who bought it on themselves

The groups of people most likely to be categorised as ‘those who bought it on themselves’ because of bad lifestyle choices were considered to be **promiscuous people**, those engaging in **unsafe sex** and **drug users**. The young people appear to make a distinction between people they know and people they do not know or know less well, with moral judgements cast more easily upon those they know less well.

*Maybe if there was someone who wasn't a good friend and they got it from unprotected sex, I might think of them more negatively, that it's a bit of a silly thing to do. (Year 9 focus group participant)*

But in both cases, it was generally felt that if they found out that someone contracted HIV as a result of poor lifestyle choices they would **lose respect** for that person.

*You'd probably lose respect for them if you found out they'd been taking loads of drugs or sleeping around. (Year 9 focus group participant)*

### 4.5.2 Impact on professional relationships

Losing respect has particular implications for professional relationships. Young people generally felt that if they found out that a teacher or a doctor contracted HIV through poor lifestyle choices, even if in the past, they would **question the individual's professional integrity**. For example, in the following quote, the young person notes that finding out that a teacher has HIV as a result of poor lifestyle choices would have implications for that teacher's standing as an authoritative figure:

*I would be a bit reluctant, like, you never know how they've got it, so say they were young and they were like, you know, wild at the time, had unprotected sex and injected lots of*

*drugs, obviously I wouldn't know it, if I didn't know it, then I'd be fine, if I knew that, obviously there are rumours in a girls school, I would lose respect for them, quite a lot. If they told me off, I'd be like, 'Well, you can't talk', or comments like that. Because I feel like it would be wrong for someone to lecture me if they hadn't done the right thing themselves. (Year 9 focus group participant)*

The perception that a teacher or doctor who had contracted HIV through poor lifestyle choices would have less respect afforded to them and **diminished authority** as a result may help explain how social risks associated with HIV affect young people's assessment about whether they would be taught by a teacher who has HIV or receive treatment from a doctor with HIV.

### 4.5.3 Impact on friendships and sexually intimate relationships

Some young people felt that they simply would not be friends or have sexually intimate relationships with the 'types' of people likely to get HIV in the first place, and as such, there was **little chance** that they would ever be in a situation where they would have to make an assessment over whether to remain friends with or kiss someone with HIV. This may partially explain why some young people in the survey responded that they would not remain friends with or kiss someone who has HIV – they would not do it because they felt it was so unlikely that they would have contact with someone 'like that'.

*I wouldn't be friends with them because, like if they'd been like serious drug users or whatever, I wouldn't be friends with them because of that and not because they had HIV. (Year 9 focus group participant)*

This perception that they would not be friends or have sexually intimate relationships with people who have HIV in the first place may be due to two factors:

- **Lack of anything in common:** many young people saw themselves as unlikely to come into contact with someone who has HIV because they do not share the same lifestyles or friendship groups:

*The people I hang around with are kind of anti those sorts of things [drugs and unsafe sex] so I think it's a silly thing to do. It depends on the people around you. (Year 9 focus group participant)*

- **Less likely to fancy or like that 'type' of person:** while rarely explicitly stated, on some occasions young people indicated that they would be less likely to fancy or want to be friends with the 'type' of person who they felt was at risk of contracting HIV. Bearing in mind that many young people were clear that their judgements about people who contracted HIV through 'risky lifestyle choices' were more judgements about the lifestyle than the disease itself, we could assume that they are less likely to fancy or like people with lifestyles that are seen as less appealing.

*I wouldn't fancy anyone with HIV. I may have fancied people who have HIV without knowing that they did. But if I knew before then I don't think I would fancy them. (Year 9 focus group participant)*

These two factors may also help explain why over one third (38 per cent) of young people surveyed agreed with the statement that **they are less likely to get HIV than other people**. If they believe that they are unlikely to have contact with people who have HIV they may therefore assume that they are less likely to get HIV than people who have 'risky' lifestyles. Other reasons given by young people as to why they felt they were less likely to get HIV

included that they had been educated about safe sex, could access information and because they did not live in a developing country. A slightly lower percentage of young people (35 per cent) disagreed with the statement that they were less likely to get HIV and 28 per cent said they did not know.

But when young people imagined that they were in a situation where they found out that a friend or sexual partner had HIV, they highlighted two social risks that could have potentially negative impacts for themselves as individuals. First was the risk of becoming socially isolated or bullied and second was the risk of becoming associated with a specific type of lifestyle that has negative connotations. Both risks are caused through the stigma of being associated with HIV.

- **Risk of social isolation and bullying:** the main impact of stigma by association that the young people were concerned about was being bullied and becoming socially isolated. For example, when asked to imagine how they thought their peers would treat them if they had HIV, one young person felt that even being marked out as **'different' from other young people** would heighten the risk of bullying. This could then be compounded by the moral judgements and misconceptions about who gets HIV and why:

*A lot of people if they don't know about it could think that they could get it just from being around you. I wouldn't tell people if I didn't know them or if I didn't trust them. You could get bullied. Anyone who is different gets bullied. Even if they didn't say anything about it you might be having an argument with them later and they could just bring it up and say 'yeah well you've got HIV' so they'd use it against you. (Year 10 focus group participant)*

Importantly, the perceived risk of bullying resulting from being marked out as 'different' was seen as a risk for both the person with HIV and those closely associated with them. It is therefore one reason why young people may be wary about remaining – or becoming – friends with someone who is HIV positive.

- **Risk of becoming associated with a lifestyle that has negative connotations:** when young people talked about lifestyles with negative connotations, such as injecting drugs, promiscuity and unprotected sex, there was an assumption that they were 'dirty', 'disgusting' and 'unhygienic' lifestyles. This could lead to people who have HIV also being seen as having those traits. Some young people therefore expressed a concern that **other people** could judge them as having these negative traits if they saw them being friends with or having a sexually intimate relationship with someone who was HIV positive.

*I think you would be worried about what would your friends think about you because people might think you're dirty if you hang around with people with HIV, because HIV seen as unclean. (Year 9 focus group participant)*

*Because I think people associate disease with dirty and unhygienic people, they don't want to hang out with people who have those kinds of diseases, they'd think 'what's that person doing going round having unprotected sex, I don't want to be seen with her.' (Year 9 focus group participant)*

In addition to the risk of being seen as 'dirty' and 'unhygienic' through hanging around someone with HIV, other young people identified the risk that they could be simply associated with derogatory terms such 'slag' or 'addict'. Importantly, it was felt that this could happen to be people who contracted HIV through no fault of their own as well as those who 'bought it upon themselves'.

*There also might be misconceptions about how you've got it – they might start saying that because you've got HIV you're gay or you're a drug addict. They might think that. Other people would probably think it's their fault, like they're a slag or something. (Year 10 focus group participant)*

It was recognised by young people that **peer pressure** may therefore mean that someone might be less willing to stay friends or kiss someone with HIV as it is not worth the risk of being bullied or called derogatory names. However, several young people were defiant that if this happened they would not bow down to peer pressure as it was important to them to be a 'good friend'.

*Maybe because someone would be really superficial and think about what other people think more they would not want to be friends with someone who has HIV. It'd be down to peer pressure. (Year 9 focus group participant)*

*I wouldn't care what people think about me. (Year 9 focus group participant)*

Beyond the moral judgements that young people themselves make about people with HIV and the decisions that they make based upon these judgements, young people were also aware that **other people would be making moral judgements** and that these may be more harsh than their own. Therefore even if they personally would feel comfortable remaining or becoming friends with someone who has HIV, they worry that they would end up suffering from the stigma and negative attitudes associated with HIV themselves. Therefore when young people assess the social risks of having friendships and sexually intimate relationships with people who are HIV positive, they can question whether it is worth the risk. This may go some way to explaining the contradiction between young people's knowledge about HIV and their behaviours towards people who are HIV positive.

## 5. Conclusions

The following section provides a set of conclusions based on the findings outlined above. Where possible, ideas and opinions expressed by the six PSHE/science teachers we interviewed are also reflected.

### Young people need more information – and they know it

Importantly, our research has revealed a strong appetite for more information about HIV among the young people we consulted. Even more widespread was the recognition that they knew too little, felt particularly by girls and by those who said they had not been taught about HIV at school. Almost four out of five of the young people who said they had not been taught about HIV at school felt they knew too little. This appears to be an encouraging starting point for future campaigns targeted at young people, and a strong case to present to schools.

The young people we spoke to also had clear ideas about how information about HIV should be communicated to them, in particular, through true/false quiz-like exercises and through hearing about real life stories. They also tended to feel that teachers were the most trustworthy sources of information on HIV, suggesting that schools are a good route of communicating with young people. Communication by teachers also appears to have the potential to achieve impact: those who said they had been taught about HIV in school not only had higher levels of knowledge about how HIV is transmitted but also, to some extent, appeared to be less prejudiced towards people with HIV.

But there are challenges in working with schools to educate young people about HIV. The teachers we spoke to stressed their lack of access to HIV-related resources, not necessarily because the resources weren't out there, but because they didn't have time to look for them and didn't know what sources to trust. The teachers we spoke to, although confident in teaching about HIV, worried that other teachers may struggle to teach about HIV effectively. There was a particular concern that where teachers lack confidence in issues relating to HIV, they could unintentionally pass this uncertainty on to their students. Some of the teachers felt that a DVD that covers all of the issues should be used in schools so that information about HIV is not dependent on levels of knowledge among individual teachers.

### Young people need to know the details about transmission and answers to the 'what ifs ...'

Although many of the young people were aware of the headline facts – especially about the ways HIV *can* be transmitted – they were far less sure about how HIV *cannot* be transmitted. This lack of clarity appears to manifest itself as contradictions between knowledge and behaviours. In line with recent research with older age groups, young people who participated in this study displayed contradictions between their knowledge about how HIV can be transmitted and the way they would behave around someone who was HIV positive.

These contradictions appear to stem from the fact that although young people tended to know the headline facts about HIV transmission, they imagined situations where these facts might not apply. In other words, the facts were seen to be generally – but not always – true. Coupled with the tendency of the young people to view HIV as a death sentence, they seemed in many cases to have decided that the risk associated with physical contact with someone who is HIV positive – however small – was not worth taking. The crucial point here

is that although young people tended to recognise that it was not *likely* that they would get HIV by touching or sharing things with someone who is HIV positive, they also felt that it was not *impossible*.

Future campaigns and other efforts to raise awareness among young people need to address the types of ‘what ifs’ that young people tend to think of, not just the headline facts. For example, the issue to be addressed if young people are to feel confident about knowing that HIV cannot be transmitted through sharing a cup is not *if* HIV can be transmitted through sharing a cup, but rather clarifying whether specific circumstances such as ‘backwash’ or small cuts in the mouth *heighten the risk* of transmission.

### **Stigma starts at a young age and needs to be tackled early**

In this study, apparent contradictions between knowledge and behaviour have been articulated by a much younger age group than previous studies have focused on. Even some of the youngest people in the sample – 12 and 13 year olds – said they would not share a cup with, shake hands with or kiss someone who they knew was HIV positive, even if they knew it was not possible to get HIV that way. Crucially, this shows that HIV-related stigma starts at an early age. This chimes with the views of the teachers we spoke to, who tended to feel that HIV lessons needed to happen earlier – around years eight and nine, rather than around years ten and 11. Some teachers firmly believed that misconceptions are formed at a young age and are harder to break the longer they remain unchallenged. This emphasises the need to ensure that young teenagers are included in future campaigns to raise awareness about HIV and challenge stigma.

However, the teachers we spoke to highlighted particular challenges, including resistance among some schools – particularly faith schools – to allow space for HIV to be taught about in any depth. While some teachers had personally decided to teach their students about HIV, they were concerned about the inconsistency associated with relying on lone teachers to address the topic in the absence of a statutory requirement to teach about HIV in schools. Furthermore, some of the teachers felt that where schools only teach about HIV as part of sex education, it encourages HIV to be viewed in terms of ‘safety’, ‘protection’ and ‘managing risk’. Some of the teachers we spoke to felt that schools often use scare tactics to teach their students about HIV, which reinforce negative stereotypes and stigma.

### **There is a need to tackle the sense of distance young people tend to feel from people with HIV**

The findings from this study suggest that young people tended to equate physical distance with protection, both literally and figuratively. In other words, while on a practical level many would not want to touch, share something with or kiss someone who was HIV positive because they would worry either about the risks of getting HIV or stigma by association, they also tended to distance mentally from people with HIV through a process of ‘othering’ them by imagining people with HIV are very different to themselves. In other words, stigma through association is not only about stigma related directly to HIV but also stigma related to other aspects of identity such as lifestyle choice. There are young people who think that they are less at risk than others of getting HIV because they believe they are less likely to come into contact with the ‘types’ of people who have it. This belief appears to result from a perception that people who have HIV through no fault of their own (the ‘innocent victims’) live overseas and that they have little in common with people who have HIV as a result of ‘bad’ lifestyle

choices in the UK (those who have 'bought it upon themselves'). This appears to be a process of 'othering' whereby young people put people with HIV into categories that they themselves do not fall into as this helps them to feel safer. While future campaigns need to take care not to reinforce stereotypes of people with HIV as either 'innocent victims' or those 'who brought it upon themselves', there is a need for future campaigns to show that young people who are HIV positive are no different to other young people.

## Appendix 1: Initial consultation with young people at Body and Soul

### Summary of the feedback provided in a group exercise with members of Teen Spirit at Body and Soul, December 2009

Participants were given colourful cards. Each had two questions with some space to provide a short answer. The first question was 'What do you think people your age think about HIV?' and the second question was 'What would you most like to change their minds about?' A total of 45 participants completed the exercise, with 44 answering the first question and 39 giving an answer to the second question.

The general theme emerging from participants' answers was the perceived **lack of knowledge about HIV or limited understanding of it**. Seven participants emphasised this in general terms in their answers to Question 1, saying that either people of their age don't know what HIV is, they don't know much about it or they don't know enough. One participant also indicated that their peers think HIV is a disease. For many, this perceived lack of knowledge was at the root of negative attitudes and discrimination in relation to HIV. In terms of participants' desire to change their peers' understanding of HIV, seven participants said that people of their age should generally know more facts about HIV. For example, they should know 'about the what and how to do with HIV'. One answer also suggested that people should have a better understanding of how medication currently available to HIV-positive individuals can help them. According to one of the participants, HIV should be discussed more with young people 'so they'll learn about it'.

Answers to the two questions also provided insights into more specific problems associated with young people's limited understanding of HIV. A number of participants pointed to specific gaps in their peers' knowledge about the virus, namely the distorted information regarding **who can be infected with HIV and how it can happen**.

Three participants said that their peers tend to think of HIV as an issue concerning gay people only. Interestingly, all three participants used the term 'people' as opposed to 'men', which suggests that young individuals continue to associate HIV with sexual orientation and not with a particular kind of sex. One of these three participants pointed to another group associated with HIV – people from Africa. Two other participants suggested that their peers are likely to think that people only get HIV if they are 'loose' or 'sleep around'. In terms of the answers to the second question, only one participant highlighted the importance of educating young people on who can be infected with HIV, saying that 'HIV has no favourites, only victims.'

As far as the ways though which HIV can be contracted are concerned, two participants said that a common misunderstanding among their peers is that unprotected sex is the only way of getting HIV. One of these participants said that this was something they would most like to change their peers' minds about. Another participant suggested that some young people might still think that one can get HIV merely through being around HIV-positive individuals and this needs to be changed. Yet another participant highlighted other myths present among their peers that have to be challenged: 'You can't catch it from a drink or on the toilet.'

One of the most prevalent themes across participants' answers to the two questions was **HIV as a life and death issue**. When asked about what people of their age thought about HIV, it was stated that common misunderstandings were that 'HIV kills' (two participants) and that

'people with HIV die' (two participants). One participant said that young people 'believe it's a death sentence'. Other participants indicated their peers thought that 'HIV could kill', that 'it can shorten your life' and that 'you can't live with HIV'. As regards participants' ideas for change, four thought it should be articulated more clearly that one can live a normal life with HIV or that 'living with HIV is not that bad'. Two others said that for people with HIV 'life goes on.'

On 16 cards, on which participants provided their answers, **negative feelings towards people with HIV** could be identified as common among their peers. **Disgust** was the most prevalent feeling as six participants indicated it was common for people of their age to think of HIV, or HIV-positive individuals, as 'dirty', 'disgusting', 'nasty' or 'butters'. For two participants, other young people view HIV as 'scary' and they believed that stereotypes about HIV encourage this **fear**. **Moral judgement** emerged as a common sub-theme from participants' answers with some saying HIV is seen as 'bad' or 'horrible' and others suggesting the message to young individuals be that 'there's nothing wrong with people with HIV' and that they shouldn't be judged.

Five participants provided answers, which demonstrated the prevalence of **ignorant attitudes to HIV** among their peers who often 'feel quite far removed from it' or think there is nothing they can do. One participant said that people of their age should know that 'HIV shouldn't be dismissed if it isn't impacting directly on them', while another wanted their peers to be aware that 'there are millions of people living around the world with it.'

Seven participants touched on the **avoidance of and stigma attached to people with HIV**. Answers to the first question included perceptions that people with HIV 'are to be avoided' and that 'it is bad for people which are around others which have HIV'. Five participants suggested this issue should be tackled. The messages to their peers said that people with HIV should be treated equally to others, that feelings should be considered and that they are not the 'other'.

Despite the overall agreement that the knowledge and understanding of HIV among young people is very limited, six participants provided answers that were not all negative. Three of them showed that, in fact, there is some awareness of HIV. This included recognition by participants' peers that HIV is a growing problem and that it is no longer 'someone else's problem'. According to one participant's answer, young people think how HIV might affect them, while based on another response they might wonder if there will be a cure for HIV.

## Appendix 2: Analysis of teacher interviews

### Summary of findings from six telephone interviews with the following secondary school teachers in London:

- History teacher – also PHSE coordinator (including Citizenship)
  - Biology teacher
  - Biology teacher – also head of PHSE (including Citizenship)
  - History teacher – also teaching PHSE and Citizenship
  - Health and Social Care teacher – also lead for PSHE
  - Science teacher – also teaching PHSE and Citizenship
- The **amount of time schools spent teaching about HIV varied considerably**, ranging from just a one-off 40-minute lesson to one or two hours every year. A number of teachers felt that HIV tended to be given more or less attention based on personal decisions by teachers about whether or not to address it. As one teacher explained:

*HIV is not on the curriculum, but I always teach about HIV/AIDS on World Aids Day. This is my personal choice and I chose to do this because I felt there was a gap in syllabus.*
  - While some teachers had personally decided to teach their students about HIV, they were concerned about the **inconsistency associated with relying on lone teachers** to address the topic in the absence of a statutory requirement to teach about HIV in schools. But despite the limited time spent teaching about HIV, all of the teachers we spoke to believed the HIV lessons they currently provide were very beneficial to students.
  - HIV tended to be addressed in relation to sexual health issues, in particular safe sex and the use of contraception. Some teachers also taught about HIV in science classes and had provided more scientific explanations about the means of transmission to their students. A minority of teachers had also explored issues of discrimination in relation to HIV. However, some of the **teachers expressed concern about the way HIV was being framed in relation to sex education, with a focus on protection and safety**. One teacher explained that she thought some teachers were using 'scare tactics' to teach about HIV, with negative consequences such as fuelling stigma and discrimination and a fear of people with HIV. One teacher emphasised the need for students to be taught about the 'realistic risks' relating to transmission. Most of the teachers felt there was a need to go into greater depth in terms of the facts relating to HIV transmission and that schools needed to spend more time exploring the social issues relating to HIV.
  - While many of the teachers felt more time should be spent on teaching about HIV-related issues, they were mindful of the practical constraints to doing this, in particular that there is **not enough time to available to focus on HIV and that there can be resistance from parents and other teachers, especially in faith schools**. However, teachers generally agreed that young people would be interested in learning more about HIV, in particular how to protect themselves from HIV and what it is like living with the virus.
  - The fact that HIV is often addressed only when students reach GCSE and A-level, when their timetables are particularly full was highlighted as a particular barrier to spending more time teaching about HIV. For this reason, **the teachers we spoke to tended to feel that HIV lessons needed to happen earlier – around years eight and nine**, rather

than just at years ten and 11. In addition, some of the teachers firmly believed that misconceptions about HIV are formed at a young age and are harder to break the longer they remain unchallenged. This strengthened their view that HIV should be addressed at a younger age, in particular because school can't allocate the amount of time needed to break down negative attitudes at an older age. However, some teachers felt that HIV should not be raised earlier than year eight.

- Some of the teachers **questioned how confident and comfortable other teachers might be about teaching about what they saw as a controversial topic**. There was some concern that if teachers were not qualified to teach about HIV they could pass on some of their own misconceptions to their students. At the very least, a lack of confidence about the facts relating to HIV could lead to doubt in some students' minds about their validity. As one teacher explained 'adults need to be educated before children'.
- The teachers we spoke to stressed their **lack of access to HIV-related resources – not necessarily because the resources weren't out there - but because they didn't have time to look for them** – and didn't know what sources of information to trust. In addition to science textbooks, the teachers we spoke to tended to rely on their own internet research to develop materials on HIV for their lessons. Given the limited time available to teach about HIV in schools, teachers tended to feel unable to spend significant amounts of time searching for materials to use in their classes. One of the specific frustrations expressed was that many of the resources they came across on the internet were not 'student-friendly' and that time had to be spent tailoring materials targeted at adults for use with their students. Some of the teachers felt that more specific guidance about what should and should not be covered in relation HIV would be helpful and that a statutory requirement to teach about HIV education would make it less of a taboo subject.

## Appendix 3: Educational materials on HIV in the UK: Overview of available resources

We have identified 50 materials that touch on HIV in relation to educating children and young people. In this overview, we summarise the form and content of available resources as a whole and with respect to particular age groups.

The majority of materials are suitable for children and young people of both genders, apart from gender-specific leaflets on safe sex and one illustrated booklet on sexual health intended particularly for teenage boys. One publication is targeted specifically at young people with learning difficulties.

Types of materials vary widely and include DVDs, CD-ROMs, factsheets, comic books, illustrated booklets, TV programmes, leaflets and an audio diary. There are also some teaching packs or activity kits/manuals, mainly for PSHE and SRE teachers, which include worksheets and lesson plans. Most resources are intended for use by teachers during appropriate lessons. However, some materials are meant to be used by children and young people, while others are targeted at parents. Many materials are available for free and others can be ordered from publishers or other websites. Their cost ranges from £5 to £60.

Generally, the materials can be divided into those that talk of HIV as a social issue, often in relation to prejudice and stigma, and those that mention HIV exclusively or predominantly in connection with sexual health. The three organisations that have published the greatest number of HIV-related educational resources targeted at children and young people are Children With AIDS Charity (ten materials), the Chalkface Project (seven materials) and FPA (six materials). While the first organisation is a charity supporting families infected and affected by HIV/AIDS and, as a result, provides resources talking of HIV in a 'social' context, the other two are publishers for secondary education and a sexual health charity, respectively, and have published materials touching on HIV in relation to sexually transmitted infections (STIs).

Other organisations whose materials we have reviewed include UK and international organisations promoting health and well-being of children, HIV charities, educational publishers and providers of online educational resources. The full list of materials, by organisation, is presented towards the end of this section.

### Key Stage 1-2 / Years 1-6 / Age 5-11

There are relatively few HIV-related educational materials targeted at children in Key Stage 1 and 2. Out of 50 materials, six (n=6) were identified to be suitable for children in Key Stage 1 (ages 5-7). These six materials, along with three additional resources (n=9), were also deemed appropriate for children in Key Stage 2 (ages 7-11).

Materials in this age group cover a range of topics, but focus mainly on social rather than sexual aspects of HIV. They include worksheets explaining what blood consists of and how it functions, a DVD telling a story of a girl with HIV who experiences discrimination at school, an educational storybook explaining what HIV and AIDS are, with an emphasis on the fact that most social situations are not risky and an activity kit that aims to raise awareness in young people of the damage stigma can make to people living with HIV.

## List of materials for Key Stage 1 and 2

**Children With Aids Charity (CWAC)**, *'Your Body, Your Blood'* - basic colourful worksheets for younger children about what blood is composed of and how we fight off germs. Available at [http://www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**19 – Children With Aids Charity (CWAC)**, *'Problem?'* - DVD intended for children 7-10 years old about a girl with HIV who experiences discrimination at school. Available at [http://www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Women's Press (1990)**, *'Come sit by me'* - educational storybook for children aged 4 to 8 that explains what HIV and AIDS are and how a person can and cannot get infected

**National Children's Bureau (NCB)**, *'Teaching and Learning about HIV: a resource for key stages 1-4'* - teaching resource that deals solely with HIV and addresses other aspects of the curriculum where HIV can be discussed apart from sexual health. Available at [www.ncb.org.uk](http://www.ncb.org.uk)

**Red Cross**, *'HIV and AIDS Activity kit'* - teacher briefing on facts and major issues surrounding HIV including an assembly kit covering stigma and HIV as a global problem. Covers ages 7 to 16. Available at [www.redcross.org.uk](http://www.redcross.org.uk)

**Tacade**, *'Skills for the Primary School Child Part 2: Current Issues in Personal and Social Education'* – 32 lessons on PSHE and Citizenship including two lessons on HIV/AIDS. First lesson 'myths and misconceptions,' and second lesson looks at prejudice and identifies ways that to help and support those with HIV. Provides guidance for teachers on key issues that should be discussed and how. Aimed at ages 5 to 11. Available at [www.tacade.com/publications\\_sex.php](http://www.tacade.com/publications_sex.php)

**Medikidz**, *'What's up with Matt? Medikidz explain HIV'* – Comic book that explains the immune system and how HIV affects it. Available at <http://medikidz.myshopify.com/products/whats-up-with-matt-medikidz-explain-hiv>.

**Red Cross**, *'HIV and AIDS Activity kit'* - teacher briefing on facts and major issues surrounding HIV including an assembly kit covering stigma and HIV as a global problem. Covers ages 7 to 16. Available at [www.redcross.org.uk](http://www.redcross.org.uk)

**Sense Interactive**, *'Growing Up and Keeping Safe for KS2'* - Interactive CD-ROM developed for teachers and parents to use as a tool in SRE. Available at [www.sensecds.com](http://www.sensecds.com). Costs £12

**Walker Books**, *'Let's talk about sex: Growing up, changing bodies, sex and sexual health'* – book that provides accurate and up-to-date answers to questions ranging from conception and puberty to birth control and AIDS

## Key Stage 3 / Years 7-9 / Age 11-14

More than twice as many (n=20) materials were identified as suitable for children in Key Stage 3. About half of the materials deal with HIV exclusively or predominantly in relation to sexual health. HIV is usually mentioned along with other sexually transmitted infections (STIs) in the context of sex and relationships. The materials discuss HIV prevention and how to protect oneself from HIV through safe-sex practices as well as symptoms and long effects

that HIV may have. Resources include a comic book telling a story of a boy who decides to have a sexual health check.

However, a number of materials concern also or mainly people with HIV and their experiences. They touch on issues such as how children and young people may feel when they experience discrimination and what people's reactions to HIV tend to be. There are some materials aimed at raising general awareness, some of which provide facts and statistics about HIV. Resources also include a DVD targeted at people who are likely to work with HIV-positive individuals, providing suggestions on how to talk about HIV.

### List of materials for Key Stage 3

**Channel 4 Learning**, 'KNTV Sex' – Ten-part animated series aimed at 14-19 year olds for Sex and Relationships Education. Ideas for activities for each program available online. Some discussion of HIV in STIs lesson and mention of World AIDS day. Available at [www.channel4learning.net/support/programnotes/micro/kntvsex/index.html](http://www.channel4learning.net/support/programnotes/micro/kntvsex/index.html)

**Chalkface Project**, 'Developing a Healthy, Safer Lifestyle at KS3: Sexual Awareness' - one lesson on HIV - discussed in the context of high-risk sexual behaviours and STIs Available at [www.chalkface.com](http://www.chalkface.com)

**Children With Aids Charity (CWAC)**, 'The Cloakroom' - DVD aimed to encourage talking about worrying issues e.g. keeping HIV a secret, being affected by HIV, family members with HIV. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm).

**Children With Aids Charity (CWAC)**, 'Voices of Young People' - booklet compiled mostly of quotes from children and young people living with or affected by HIV on different topics. Topics include: finding out, secrecy and isolation. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, 'HIV Risky Business' - DVD aimed at 12-15 year olds. Follows a teenager walking through different parts of London talking about HIV. He goes through three case studies of young people putting themselves at risk. At the end the boy reveals he is HIV positive following unprotected sex with a girl he met at a party. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Christopher Winter Project (CWP)**, 'Teaching SRE with Confidence in Secondary Schools' - CD-ROM provides secondary teachers with the tools to teach SRE with confidence. Available at [www.tcwp.co.uk/index.php?m=resources](http://www.tcwp.co.uk/index.php?m=resources)

**Family Planning Association (FPA)**, '4 Boys: a below-the-belt guide to the male body'/'4 Girls: a below-the-bra guide to the female body' - among other issues covers sexually transmitted infection and safer sex. Aimed at young people age 12 and above. Meets curriculum guidance for key stages 3 and 4. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, 'Is everybody doing it? Your guide to contraception' - discusses issues about going to sexual health clinics, contraception and sexually transmitted infections. Aimed at young people 12 and above. Meets curriculum guidance for key stages 3 and 4. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, 'Love S.T.I.ngs: a beginners guide to sexually transmitted infections' - Written in a comic strip style, looks at symptoms and long-term effects of STIs and how they are treated and avoided. Aimed at 12 and above. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, *'Talking together...about sex and relationships'* - activity sheet titled 'Can you get rid of HIV virus?' Demonstration: blue dye added to red water representing the blood. Discussion topics fairly vague: 'both sexes are liable to catch HIV from unprotected sex,' 'the infection rate for heterosexuals is rising. Why might this be?' Opportunity to explain about HIV infection and treatment' (limited information for the teachers on how these topics should be discussed and what the treatment for HIV actually is. Aimed at young people aged 13 and above with learning difficulties. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Hodder Education**, *'PSHE Education: Teachers resource book'* - lesson plans for each year of key stage 3. Complete programme of study to support current PSHE framework. Pupil booklet, teacher's resource book and CD-ROM available for each year group. HIV looked at in year 8. Available at [www.hoddereducation.co.uk](http://www.hoddereducation.co.uk)

**National AIDS Trust**, *'HIV in Schools'* - resources aimed at teachers including assembly ideas, lesson plans for teaching HIV in PSHE, ideas for activism and displays. Available at: <http://www.nat.org.uk/Information-and-Resources/Schools.aspx>

**National AIDS Trust /Lyric Creative Learning**, *'Angels in America Education Pack'* – 'aims to provide teachers and students with numerous ways to engage directly with some of the most innovative and imaginative practitioners in theatre. They aim to stimulate creativity, offering dynamic learning opportunities and insights into the techniques and processes used to create the Lyric's unique style of theatre.' Available at [www.nat.org.uk/HIV-Facts/School-Packs.aspx](http://www.nat.org.uk/HIV-Facts/School-Packs.aspx)

**National Children's Bureau (NCB)**, *'Teaching and Learning about HIV: a resource for key stages 1-4'* - teaching resource that deals solely with HIV and addresses other aspects of the curriculum where HIV can be discussed in apart from sexual health. Available at [www.ncb.org.uk](http://www.ncb.org.uk)

**Red Cross**, *'HIV and AIDS Activity kit'* - teacher briefing on facts and major issues surrounding HIV including an assembly kit covering stigma and HIV as a global problem. Covers ages 7 to 16. Available at [www.redcross.org.uk](http://www.redcross.org.uk)

**Sense Interactive**, *'Sex and relationships'* - Interactive CD-ROM developed for teachers and parents to use as a tool in SRE, suitable for ages 12-16. Available at [www.sensecds.com](http://www.sensecds.com)

**UNICEF**, *'Hannah's Story - My Sister Too'* - cartoon strip and activity sheet. Cartoon follows a young girl and her father to Africa looking for her missing sister. Aims to raise young people's awareness of children infected with HIV, the problems they face and rights that protect them. Available at [www.unicef.org.uk/tz/resources/assets/pdf/aidscomic\\_5pages.pdf](http://www.unicef.org.uk/tz/resources/assets/pdf/aidscomic_5pages.pdf)

**Cable Educational**, *'PHSE: Personal Wellbeing Sex and Relationship KS3: Sexual Activity'* - seven lessons covering sexual activity, love and relationships, STIs and HIV/AIDS. Available at [www.cableeducational.com](http://www.cableeducational.com)

**Walker Books**, *'Let's talk about sex: Growing up, changing bodies, sex and sexual health'* – book that provides accurate and up-to-date answers to questions ranging from conception and puberty to birth control and AIDS.

## Key Stage 4 / Years 10-11 / Age 14-16

The greatest number of educational materials covering HIV (n=29) is targeted at young people in Key Stage 4. Many of them meet curriculum guidance at this level and are intended

for use by PSHE teachers. Some of the materials are also suggested for use by those teaching SRE (sex and relationships education), RE (religious education), Citizenship and life skills. Most of the materials discuss HIV in connection with sexual health, often providing more detailed information than some of the resources targeted at younger age groups. A number of materials consider what constitutes HIV risks, sometimes showing specific sexual activities that may lead to infection in the form of a diagram. Resources tend to aim at developing young people's understanding of and ability to cope with sexual issues.

Some materials consider HIV as a social issue, exploring the impact of HIV and AIDS on people's lives in the UK and around the world. They tend to consider what problems and responsibilities people who have HIV face.

#### **List of materials for Key Stage 4**

**Channel 4 Learning**, '*Off Limits: Living with AIDS*' - Channel 4 learning program along with guidance literature and lesson plan on the internet. Available at [www.channel4learning.com/support/programnotes/netnotes/sersec/sersecid609.htm](http://www.channel4learning.com/support/programnotes/netnotes/sersec/sersecid609.htm).

**Channel 4 Learning**, '*KNTV Sex*' – Ten-part animated series aimed at 14-19 year olds for Sex and Relationships Education. Ideas for activities for each program available online. Some discussion of HIV in STIs lesson and mention of World AIDS day. Available at [www.channel4learning.net/support/programnotes/micro/kntvsex/index.html](http://www.channel4learning.net/support/programnotes/micro/kntvsex/index.html).

**Chalkface Project**, '*Developing a Healthy, Safer Lifestyle at KS4: Sexual Awareness*', two lessons on HIV - one discussed in the context of high-risk sexual behaviours and STI's and one on living with HIV/AIDS. Available at [www.chalkface.com](http://www.chalkface.com).

**Chalkface Project**, '*Coping with Problems at work*', This resource includes a chapter on HIV - gives children a case study about what would happen if someone they worked with was diagnosed with HIV, asks about precautions (description of exercise given over the phone by sales rep). Available at [www.chalkface.com](http://www.chalkface.com).

**Chalkface Project**, '*Sex Education*' - Has a chapter in the relationships section called 'be aware: Attitudes Towards HIV', aged 11-16; info related to HIV aimed at KS4. Available at [www.chalkface.com](http://www.chalkface.com)

**Chalkface Project**, '*Sexual Health*' - two lessons on HIV - one HIV and AIDS (students explore issues surrounding HIV and AIDS) and one 'Kelly's story' (students explore the problems and responsibilities of being HIV positive) aimed at 14 to 16 year olds. Available at [www.chalkface.com](http://www.chalkface.com)

**Children With Aids Charity (CWAC)**, '*The Cloakroom*' - DVD aimed to encourage talking about worrying issues e.g. keeping HIV a secret; being affected by HIV, family members with HIV. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*Voices of Young People*' - booklet compiled mostly of quotes from children and young people living with or affected by HIV on different topics. Topics include: finding out, secrecy and isolation. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*Young men's safer sex leaflet*' - aimed at promoting HIV awareness in young men (no ages specified, but it's aimed at those who have or might soon become sexually active). Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm).

**Children With Aids Charity (CWAC)**, '*Young women's safer sex leaflet*' - aimed at promoting HIV awareness in young women (no ages specified, but it's aimed at those who have or might soon become sexually active). Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*Safer sex leaflet*'- Leaflet encouraging condom use among teenagers (no ages specified, but it's aimed at those who have or might soon become sexually active); what constitutes HIV risks (shows a diagram of sexual activities that might or do not lead to infection). Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*HIV Risky Business*' - DVD aimed at 12-15 year olds. Follows a teenager walking through different parts of London talking about HIV. He goes through three case studies of young people putting themselves at risk. At the end the boy reveals he is HIV positive following unprotected sex with a girl he met at a party. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Christopher Winter Project (CWP)**, '*Teaching SRE with Confidence in Secondary Schools*' - CD-ROM provides secondary teachers with the tools to teach SRE with confidence. Available at [www.tcwp.co.uk/index.php?m=resources](http://www.tcwp.co.uk/index.php?m=resources)

**Family Planning Association (FPA)**, '*4 Boys: a below-the-belt guide to the male body*'/'*4 Girls: a below-the-bra guide to the female body*' - among other issues covers sexually transmitted infection and safer sex. Aimed at young people age 12 and above. Meets curriculum guidance for key stages 3 and 4. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, '*Is everybody doing it? Your guide to contraception*'- discusses issues about going to sexual health clinics, contraception and sexually transmitted infections. Aimed at young people 12 and above. Meets curriculum guidance for key stages 3 and 4. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, '*Love S.T.I.ngs: a beginners guide to sexually transmitted infections*' - Written in a comic-strip style, looks at symptoms and long-term effects of STIs and how they are treated and avoided. Aimed at 12 and above. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, '*4 Boys/4 Girls: talking to young people about sex and relationships*'. Accompanies other FPA publications. Incorporates learning methods to develop themes of booklets. Couple of activities relate to 'Love S.T.I.ngs' booklet- no real discussion of HIV despite reference to AIDS in cartoon. Aimed at 12 and above. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, '*Talking together...about sex and relationships*' - activity sheet titled 'Can you get rid of HIV virus?' Demonstration: blue dye added to red water representing the blood. Discussion topics fairly vague: 'both sexes are liable to catch HIV from unprotected sex,' 'the infection rate for heterosexuals is rising. Why might this be?'. Opportunity to explain about HIV infection and treatment' (limited information for the teachers on how these topics should be discussed and what the treatment for HIV actually is. Aimed at young people aged 13 and above with learning difficulties. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, '*HIV: Looking after your sexual health*' - booklet to provide information about HIV, what you can do if you are worried that you might have the infection and advice on how to protect yourself, medical issues: causes of HIV; ways of transmission; symptoms; testing; treatment. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**National AIDS Trust**, '*HIV in Schools*' - resources aimed at teachers including assembly ideas, lesson plans for teaching HIV in PSHE, ideas for activism and displays. Available at: <http://www.nat.org.uk/Information-and-Resources/Schools.aspx>

**National AIDS Trust /Lyric Creative Learning**, '*Angels in America Education Pack*' – 'aims to provide both teachers and students with numerous ways to engage directly with some of the most innovative and imaginative practitioners in theatre. They aim to stimulate creativity, offering dynamic learning opportunities and insights into the techniques and processes used to create the Lyric's unique style of theatre.' Available at [www.nat.org.uk/HIV-Facts/School-Packs.aspx](http://www.nat.org.uk/HIV-Facts/School-Packs.aspx)

**National Children's Bureau (NCB)**, '*Teaching and Learning about HIV: a resource for key stages 1-4*' - teaching resource that deals solely with HIV and addresses other aspects of the curriculum where HIV can be discussed in apart from sexual health. Available at [www.ncb.org.uk](http://www.ncb.org.uk)

**Red Cross**, '*HIV and AIDS Activity kit*' - teacher briefing on facts and major issues surrounding HIV including an assembly kit covering stigma and HIV as a global problem. Covers ages 7 to 16. Available at [www.redcross.org.uk](http://www.redcross.org.uk)

**Sense Interactive**, '*Sex and relationships*' - Interactive CD-ROM developed for teachers and parents to use as a tool in SRE, suitable for ages 12-16. Available at [www.sensecds.com](http://www.sensecds.com)

**Terrence Higgins Trust**, '*Out in School*' - Key stage 4 pack for teachers helping them to talk about issues relating to relationships and homophobia. HIV mentioned in myths section. Good comprehensive resource for relationships education. Available at [www.tht.org.uk/informationresources/publications](http://www.tht.org.uk/informationresources/publications)

**UNICEF**, '*Hannah's Story - My Sister Too*' - cartoon strip and activity sheet. Cartoon follows a young girl and her father to Africa looking for her missing sister. Aims to raise young people's awareness of children infected with HIV, the problems they face and rights that protect them. Available at [www.unicef.org/tz/resources/assets/pdf/aidscomic\\_5pages.pdf](http://www.unicef.org/tz/resources/assets/pdf/aidscomic_5pages.pdf)

**Radio Diaries**, '*The AIDS Diaries Project*' - A series of audio diaries from South Africa. Available at <http://radiodiaries.org/aidsdiary/story.html>

**Brook**, '*Protect yourself!*' - this teaching resource consists of eight ready-made teaching packages on contraception and sexually transmitted infections, complete with teachers' notes, lesson plans, photocopiable handouts and evaluation sheets. Each lesson lasts an hour – or each can be divided into smaller teaching segments. Aimed at children 14 and above. Available at [www.brook.org.uk](http://www.brook.org.uk)

## Key Stage 5 / Years 12-13 / Age 16-18

Fifteen materials were identified as suitable for young people in Key Stage 5 or sixth form. The vast majority of these materials overlap with those suitable for Key Stage 4, where they are more likely to be included in the curriculum. The educational purpose of the resources is often to develop social and emotional skills to handle potentially difficult situations to help young people make considered decisions about their sexual health.

**Channel 4 Learning**, '*Off Limits: Living with AIDS*' - Channel 4 learning program along with guidance literature and lesson plan on the internet. Available at [www.channel4learning.com/support/programnotes/netnotes/sersec/sersecid609.htm](http://www.channel4learning.com/support/programnotes/netnotes/sersec/sersecid609.htm)

**Channel 4 Learning**, '*KNTV Sex*' – Ten-part animated series aimed at 14-19 year olds for Sex and Relationships Education. Ideas for activities for each program available online. Some discussion of HIV in STIs lesson and mention of World AIDS day. Available at [www.channel4learning.net/support/programmenotes/micro/kntvsex/index.html](http://www.channel4learning.net/support/programmenotes/micro/kntvsex/index.html)

**Chalkface Project**, '*Morals and Values: Sixth Form Tutorial Materials*' - This resource looks at prejudice and human rights and has a section on HIV; addresses key contemporary moral issues. It is intended to challenge, provoke further exploration and to widen debate and the scope for reason – one lesson on HIV/AIDS. Available at [www.chalkface.com](http://www.chalkface.com)

**Chalkface Project**, '*PSE 16+: Sex and Drugs Issues*' - This resource includes an exercise where young people prepare a television item on attitudes towards HIV among teenagers. Aimed at advanced-level students (those on AS, A and Advanced Level GNVQ courses). Series of illustrated worksheets. Available at [www.chalkface.com](http://www.chalkface.com)

**Children With Aids Charity (CWAC)**, '*Voices of Young People*' - booklet compiled mostly of quotes from children and young people living with or affected by HIV on different topics including finding out, secrecy and isolation. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*Young men's safer sex leaflet*' - aimed at promoting HIV awareness in young men (no ages specified, but it's aimed at those who have or might soon become sexually active). Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*Young women's safer sex leaflet*' - aimed at promoting HIV awareness in young women (no ages specified, but it's aimed at those who have or might soon become sexually active). Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Children With Aids Charity (CWAC)**, '*Safer sex leaflet*'- Leaflet encouraging condom use among teenagers (no ages specified, but it's aimed at those who have or might soon become sexually active); what constitutes HIV risks (shows a diagram of sexual activities that might or do not lead to infection). Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Family Planning Association (FPA)**, '*Talking together...about sex and relationships*' - activity sheet titled 'Can you get rid of HIV virus?' Demonstration: blue dye added to red water representing the blood. Discussion topics fairly vague: 'both sexes are liable to catch HIV from unprotected sex,' 'the infection rate for heterosexuals is rising. Why might this be?'. Opportunity to explain about HIV infection and treatment' (limited information for the teachers on how these topics should be discussed and what the treatment for HIV actually is. Aimed at young people aged 13 and above with learning difficulties. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Family Planning Association (FPA)**, '*HIV: Looking after your sexual health*' - booklet to provide information about HIV, what you can do if you are worried that you might have the infection and advice on how to protect yourself, medical issues: causes of HIV, ways of transmission, symptoms, testing, treatment. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**National AIDS Trust /Lyric Creative Learning**, '*Angels in America Education Pack*' – 'aims to provide both teachers and students with numerous ways to engage directly with some of the most innovative and imaginative practitioners in theatre. They aim to stimulate creativity, offering dynamic learning opportunities and insights into the techniques and processes used to create the Lyric's unique style of theatre.' Available at [www.nat.org.uk/HIV-Facts/School-Packs.aspx](http://www.nat.org.uk/HIV-Facts/School-Packs.aspx)

**Tacade**, '*Sex, Drugs and Alcohol: HIV Transmission Activity*' – Interactive resource for young adults 16+. Cartoon style illustrations and discussion questions. Activity has been recommended for use with 16+ because the illustrations are quite explicit, but it has been used with younger adolescents. Designed to have an emotional focus as well as addressing practical issues. The game is about identifying risks in HIV transmission; it has been used in colleges and YOT teams.' Has to be bought with 'Sex, Drugs and Alcohol' materials. Available at [www.tacade.com/publications\\_sex.php](http://www.tacade.com/publications_sex.php)

**UNICEF**, '*Hannah's Story - My Sister Too*' - cartoon strip and activity sheet. Cartoon follows a young girl and her father to Africa looking for her missing sister. Aims to raise young people's awareness of children infected with HIV, the problems they face and rights that protect them. Available at [www.unicef.org.uk/tz/resources/assets/pdf/aidscomic\\_5pages.pdf](http://www.unicef.org.uk/tz/resources/assets/pdf/aidscomic_5pages.pdf)

**Radio Diaries**, '*The AIDS Diaries Project*' - A series of audio diaries from South Africa. Available at <http://radiodiaries.org/aidsdiary/story.html>

## Materials targeted at parents

Three resources were identified for use by parents. These include a workshop plan, a booklet and an information sheet which all address the issue of how to talk with children about HIV. The resources offer suggestions and practical ideas for answering specific questions. One of the materials discusses revealing parents' HIV status to their children.

**Children With Aids Charity (CWAC)**, '*Talking with Children about Illness and HIV*' – booklet offering suggestions and practical ideas as to how to talk to children about HIV. Aimed at parents and those caring for children in families where someone has HIV. Available at [www.cwac.org/education\\_resources.htm](http://www.cwac.org/education_resources.htm)

**Family Planning Association (FPA)**, '*Talking together...about sex and relationships*' - activity sheet titled 'Can you get rid of HIV virus?' Demonstration: blue dye added to red water representing the blood. Discussion topics fairly vague: 'both sexes are liable to catch HIV from unprotected sex,' 'the infection rate for heterosexuals is rising. Why might this be?'. Opportunity to explain about HIV infection and treatment' (limited information for the teachers on how these topics should be discussed and what the treatment for HIV actually is. Aimed at young people aged 13 and above with learning difficulties. Also has pages for parents/carers so that home and school can work in partnership; to explore how much the young people already know about HIV and AIDS. Available at [www.fpa.org.uk](http://www.fpa.org.uk)

**Sense Interactive**, '*Sex and relationships*' - Interactive CD-ROM developed for teachers and parents to use as a tool in SRE, suitable for ages 12-16. [www.sensecds.com](http://www.sensecds.com)

## Appendix 4: Primary research: methodology and sample profile

### Questionnaire-based survey of young people

#### Approach

The quantitative element of this research is based on a questionnaire completed by 508 secondary school pupils across London in April and May 2010. The survey relied on a convenience sample. The seven secondary schools and colleges that participated in the

survey did so voluntarily. Questionnaire responses were anonymous but respondents were asked their age, gender and the name of their school to facilitate analysis of responses according to these variables.

The primary purpose of the questionnaire was to gather evidence of young people's knowledge of basic facts relating to HIV, for example, modes of transmission, as well as their attitudes to people with HIV and their opinions on how they would behave around someone who was HIV positive. The questionnaire also asked respondents about their appetite for more information about HIV.

The questionnaire, developed by OPM in consultation with staff at Body and Soul, included seven closed questions (three of which contained multiple items already pre-coded) and one open-ended question that asked respondents to indicate which groups of people, if any, they thought were more likely to get HIV. A copy of the questionnaire is available in Appendix 2.

However, care was taken to ensure that asking students to complete the questionnaires was not a purely extractive process. We were also conscious that we did not want the exercise of completing the questionnaire – and potentially discussing it with other students afterwards – to confirm any negative myths and misconceptions. As such, teachers were provided with a factsheet covering basic information on HIV, which was compiled by the OPM team in consultation with staff at Body and Soul. Teachers were asked to go through the factsheet with students once they had completed the questionnaire. We also provided teachers with copies of information leaflets published by the National AIDS Trust (NAT) as well as a reflections sheet so they could record any discussion among students immediately after they had completed their questionnaires.

## **Sampling**

Secondary schools and sixth-form colleges in Greater London were identified online using the 'schoolsfinder' function available on the DirectGov website<sup>9</sup>. Schools were divided into three categories based on school type: non-religious state schools, religious state schools and private schools. Through consultation with staff at Body and Soul, we removed all schools from the list, which Body and Soul had previously provided HIV awareness sessions with, as this could potentially skew the findings.

A total of 82 schools, were initially contacted via email to take part in the research. Follow-up telephone calls were made to schools to identify six that agreed to take part: two from each of the three types of school.

Teachers at these six schools were asked to distribute paper copies of the questionnaires to randomly-selected classrooms of students. Teachers were asked to ask students to complete the questionnaires without providing any information about HIV beforehand and to ensure the questionnaires were completed in test-style conditions as far as possible. This was to minimise any external influences on responses.

All respondents were aged between 12 and 18 years old. In error, a number of surveys were completed by 11 year olds but these have been excluded from the analysis.

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<sup>9</sup> <http://schoolsfinder.direct.gov.uk/>

Table 1 below shows the number and percentage of respondents by gender, age and school type.

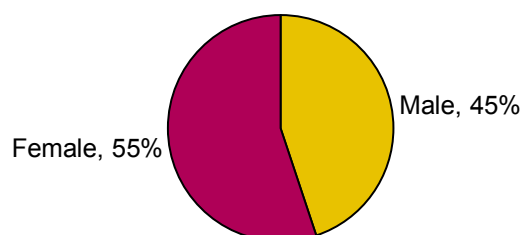
**Table 1 - Survey demographics**

	Number of respondents N	Sample profile %
<b>Gender</b>		
Male	226	45%
Female	280	55%
Missing	2	(0.7%)
<b>Age</b>		
12-13	134	27%
14-15	257	51%
16-18	66	13%
Missing	4	(0.8%)
<b>Type of School</b>		
State non-religious	129	25%
State- religious	218	43%
Private	126	25%
Missing	35	(7%)

**Gender of survey respondents**

Two respondents did not give details of their gender. Based on the 506 respondents that did, the sample gender profile is more heavily weighted to female respondents as 55 per cent of the sample is female and 45 per cent is male.

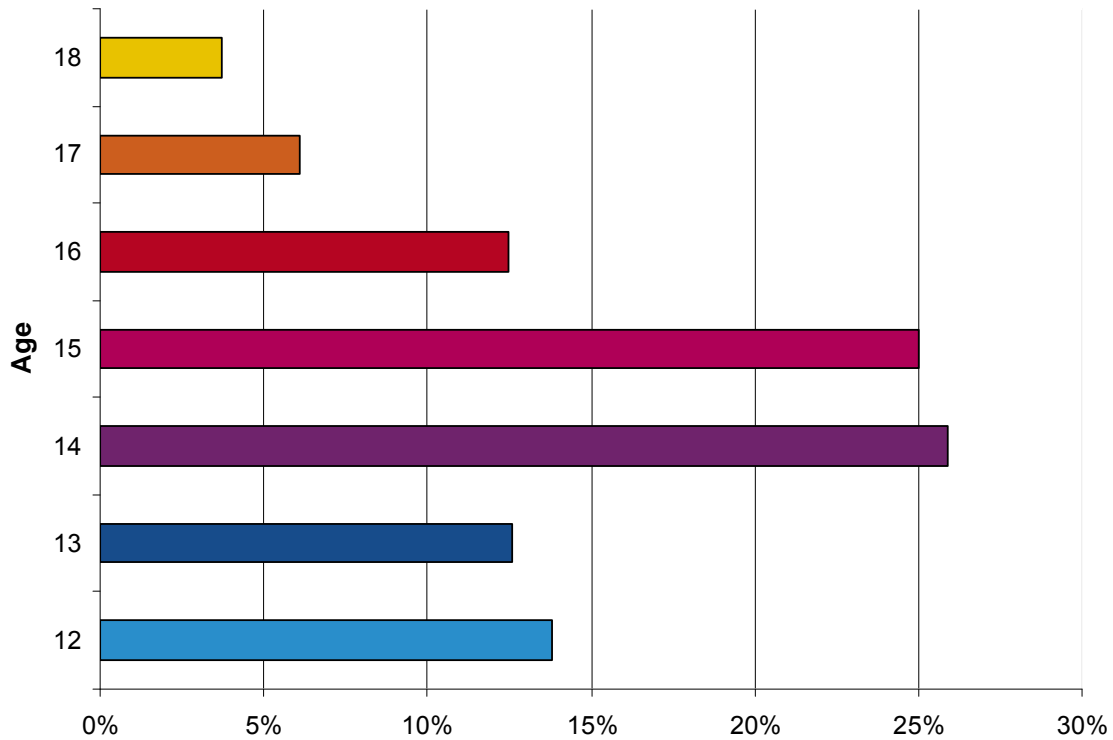
**Figure 1 - Gender of survey respondents**



### Age of survey respondents

Four respondents did not give details of their age. Based on the 504 respondents that did, the sample is more heavily weighted towards the 14 to 15 age category.

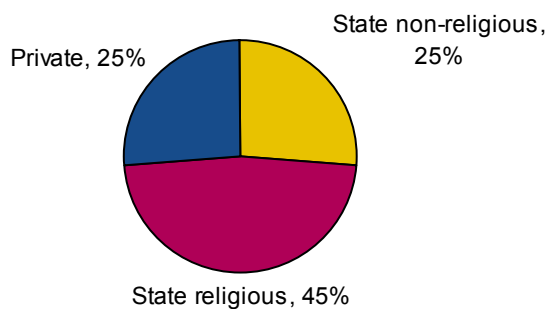
**Figure 2 - Age of survey respondents (as percentage of total sample)**



### Type of school

Six schools in London distributed questionnaires to their pupils, two of which are state non-religious schools, two of which are state religious schools (Catholic and Church of England) and two of which are private schools. The two state-religious schools returned a larger number of completed questionnaires, which explains why a larger proportion of respondents come from this type of school.

**Figure 3 - School type of survey respondents**



## Analysis

The quantitative data generated by the questionnaires was analysed using SPSS software. As the survey sample size was over 500, we have undertaken statistical significance testing to explore any differences in young people's knowledge and attitudes according to key variables such as age and gender. If a difference is statistically significant it means that it is unlikely to have occurred by chance, for example, if the difference between the answers to a question given by males and females meets the significance test then it is likely that people's answers are influenced by their gender. Only differences that are found to be statistically significant at the levels of  $p < 0.05$  and below (e.g.  $p < 0.01$  and  $p < 0.001$ ) are reported, where 'p' is the estimate of probability that the result has occurred by statistical accident. The smaller the 'p' number, the more significant the finding is. Therefore when reporting on differences that reach the  $p < 0.001$  level, we have highlighted these in the report as 'highly significant'.

## Focus groups with young people

### Approach

The main qualitative element of this study involved conducting six focus groups in May and June 2010. These focus groups involved young people aged between 13 and 15 attending schools in London. The purpose of the focus groups was to develop a more detailed understanding of young people's attitudes and opinions to explore the questions raised in the questionnaires in greater depth.

The focus groups each lasted approximately one hour and were facilitated by two members of the OPM research team. Interactive voting exercises based on questions in the questionnaire were used as an entry point into different topics of discussion. Hypothetical scenarios were presented to the groups by the researchers to seek the views of students about how they would act in different situations, for example, if one of their best friends told them they were HIV positive.

Following each focus group, the OPM research team revised the basic focus group topic guide to 'drill down' and explore particular issues in greater depth. A copy of the basic topic guide can be found in Appendix 3.

Again, care was taken to ensure that the focus group discussions were not purely extractive and did not reinforce negative myths or misconceptions about HIV. As such, a fact-giving question and answer session was run at the end of each focus group with a member of staff from Body and Soul. Students were also given copies of the leaflets produced by the NAT.

### Sampling

The recruitment of schools for the focus groups was again based on a convenience sample. Using the same method of recruitment as we did for the questionnaires, schools were contacted by email and telephone and asked if they wanted to take part in the focus groups. Again, schools that had previous contact with Body and Soul were removed from the list, as were schools which had taken part in completing the questionnaires. This was so that we could ensure that no pupils who had completed the questionnaire – and therefore received information from their teacher via the factsheet and NAT leaflet – went on to take part in the focus groups as this could potentially skew the findings. Four schools agreed for their

students to take part, including four focus groups in two non-religious state schools, one focus group in a private school and one focus group in a Church of England state school.

Teachers were asked to select a representative group of students in terms of age, gender and educational attainment. The majority of focus groups had between eight to ten students attending each group, however, in two focus groups the number of students was higher than 15.

In total, 66 students from four schools took part in the six focus groups. Half of the focus groups were with Year 9s and half with Year 10s. Two schools were state non-religious co-educational schools, one was a private school for girls and one was a state-religious (Church of England) school for girls.

**Table 2 - Focus group demographics**

Group	School	Year	School type	Number of participants	Gender
1	School 1	Year 9	State non-religious	8	Mixed
2	School 1	Year 10	State non-religious	8	Mixed
3	School 2	Year 9	State non-religious	5	Mixed
4	School 2	Year 10	State non-religious	18	Mixed
5	School 3	Year 10	Private	18	Female
6	School 4	Year 9	State - religious	9	Female

### Analysis

Consent was gained from the focus group participants to record the discussions. These recordings were then transcribed with participant details anonymised, and the words that focus group participants identified in the word-association exercise logged. While records have been kept of the interactive voting sessions, these were not analysed separately due to the sample numbers being too small.

The qualitative findings from the focus groups were thematically analysed, a method used to analyse primary qualitative research. This method involved coding each of the themes arising in the focus group transcripts against the following coding schemes:

- 1) Knowledge – what do young people associate with HIV and why, what do they know and not know about how HIV is transmitted and why, which groups of young people do young people perceive to be at more risk of transmitting HIV and why and where they get information about HIV from

- 2) Attitudes and behaviours – why do young people say they would behave in certain ways towards people with HIV in the various hypothetical situations and what are the risks that they perceive on interacting with people who have HIV

Particular emphasis was given to thematically analysing the reasons behind young people's knowledge and attitudes/behaviours as given by them in the focus groups, to 'explain' the quantitative survey findings.

## Appendix 5: Focus group topic guide

(Note – this topic guide is an amalgamated version of the two guides used in the focus groups.)

### Introduction and ground rules

#### Ground rules

- *This is not a test!*
- *So, don't feel bad if you don't know whether what you are saying is right or wrong. We just want to know what you think*
- *Ask questions if you are unsure about anything*
- *Respect each other's views and listen to what other people have to say*
- *Everything you say will be confidential*
- *Switch off mobile phones*

Are there any other ground rules you would like to add?

### Exploring attitudes with interactive voting and discussion (45 minutes)

(Questions using PPVote are underlined; open-ended discussion questions are bullet pointed)

#### **PPVote test question (test that keypads are working)**

Where did Hackney-born Leona Lewis work before she became famous?

- Pizza Hut (right answer)
- Nandos
- KFC

1. Have you heard about HIV before today?

*Yes/no/not sure*

#### **Section 1: Icebreaker question - What do you know about HIV?**

2. Please write down any words – on these post-it notes – which come to mind when you think of HIV

*[Put post it notes on wall.]*

- Why do you think these words are linked to HIV?
- What were you thinking about when you wrote these words down?
- Do you think these words are positive/ negative?
- Why are they positive/negative?
- Do you think there are any other words which other young people would write down? If so, why would they think of these words when they think of HIV?

#### **Section 2: Where do you get information from?**

3. Where have you heard/learned about HIV before today? (Remember, this isn't asking you about where you would go if you wanted to find out about HIV- it's where you've already heard about HIV from)

*Teacher/TV/ internet/Friend/Other/ Not heard anything about HIV*

- If you voted 'other' – where else have you heard about HIV from?
- Try and remember where you've heard about HIV specifically – are there any TV programmes? Any internet sites? Magazines?
- What have these sources told you about HIV?
  - For example, has it been medical information? Stories about people who have HIV?

4. Do you think that the amount of information you have been given about HIV is enough?

*Yes/No/Don't Know*

- [If no] What else would you like to know? What would be the best/most interesting way to be given more information?
- What sources of information about HIV do you most trust? Why?

5. Would you like to know more about HIV?

*Yes/no/not sure*

- What questions do you have about HIV?

*[Note down any questions and if Emily is at session, have a Q&A session afterwards]*

**Section 3: How do you get HIV?**

6. How do you think a person can get HIV? By:

6a. Sharing a meal with someone who has HIV– *Yes/No/Don't Know*

6b. Kissing someone who has HIV – *Yes/No/Don't Know*

6c. Passed from a mother to her baby– *Yes/No/Don't Know*

6d. Simply being around someone who has HIV – *Yes/No/Don't Know*

6e. Sharing a cup with someone who has HIV– *Yes/No/Don't Know*

6f. By injecting drugs using unsterilized needles – *Yes/No/Don't Know*

6g. Having unsafe sex (sex without a condom)– *Yes/No/Don't Know*

6h. Shaking hands with someone who has HIV– *Yes/No/Don't Know*

6i. Receiving an infected blood transfusion (when people are given someone else's blood in hospital)– *Yes/No/Don't Know*

- Which of these are most likely? Why
- Which of these are least likely? Why?
- Are there any of these you were unsure about? Which ones? Why?

**Section 4: Who gets HIV?**

7. Do you think some groups of people are more likely to get HIV than others?

*Yes/No/Don't Know*

- Why do you think you would / would not want to stay friends with someone if you found out they had HIV?
- Would it depend if you knew them and were already friends before you found out they had HIV? What else might it depend on?
- Would it matter how your friend had got HIV? How would it affect things?

- Do you think your view of a friend would change if you found out they had HIV?
  - Probe - If yes, how would it change?
  - Probe – do you think you might treat them differently depending on how they got HIV?
  - Probe – do you think you might change your behaviour around them? If yes, how might you behave differently?
  - Probe - Do you think you would see them more positively or more negatively?
- If you found out that a friend had HIV – is there anything that you might be worried about?
  - Probe – would you be worried about getting HIV yourselves?
  - Probe – are there any activities that you imagine you could be worried about doing with your friend if you found out they had HIV?
    - Sharing a meal / sharing a drink?
    - Touching them?
    - Any other activities?
  - Probe - would you worry about what other people would think about you if they saw you being friends with that person? Why is this?
  - Probe – would you worry about what having HIV might be like for them – how it might affect their lives?
- Why do you think it is that for some people, even if they know they can't get HIV through any of the things that they normally do with their friends, they still might be less likely to stay friends with someone who has HIV?
- Do you think other young people would feel the same as you? If not, why not?

### **Section 5: Would you....?**

#### 8. Would you stay friends with someone with HIV? Yes/No/Don't Know

- Why do you think you would / would not want to stay friends with someone if you found out they had HIV?
- Would it depend if you knew them and were already friends before you found out they had HIV?
- If you found out that a friend had HIV – is there anything that you might be worried about? [Probe – would they be worried about getting HIV themselves? Would they worry about what other people would think about them?]
- Do you think other young people would feel the same as you? If not, why not?

#### 9. Would you kiss someone who has HIV? Yes/No/Don't know

- Why do you think you would / would not want to stay friends with someone if you found out they had HIV?
- Would it depend if you knew them and were already friends before you found out they had HIV? What else might it depend on?
- Would it matter how your friend had got HIV? How would it affect things?
- Do you think your view of a friend would change if you found out they had HIV?

- Probe - If yes, how would it change?
- Probe – do you think you might treat them differently depending on how they got HIV?
- Probe – do you think you might change your behaviour around them? If yes, how might you behave differently?
- Probe - Do you think you would see them more positively or more negatively?
- If you found out that a friend had HIV – is there anything that you might be worried about?
  - Probe – would you be worried about getting HIV yourselves?
  - Probe – are there any activities that you imagine you could be worried about doing with your friend if you found out they had HIV?
    - Sharing a meal / sharing a drink?
    - Touching them?
    - Any other activities?
  - Probe - would you worry about what other people would think about you if they saw you being friends with that person? Why is this?
  - Probe – would you worry about what having HIV might be like for them – how it might affect their lives?
- Why do you think it is that for some people, even if they know they can't get HIV through any of the things that they normally do with their friends, they still might be less likely to stay friends with someone who has HIV?
- Do you think other young people would feel the same as you? If not, why not?

9. Would you kiss someone who has HIV? Yes/No/Don't know

- Why did you answer as you did?
- What if you were going out with them already and then found out that they had HIV? How do you think you might react?
- What about if you found out that they had HIV before you'd already kissed them – might that change anything on how you felt about them?
- Do you think there would be any differences in how you'd react depending on whether they were 'just a crush' or someone that you were actually in love with? What might these differences be?
- Do you think your view of someone you fancied would change if you found out they had HIV? What about if it was someone you loved, would that change?
  - Probe - If yes, how would it change?
  - Probe – do you think you might treat them differently depending on how they got HIV?
  - Probe – do you think you might change your behaviour around them? If yes, how might you behave differently?
  - Probe - Do you think you would see them more positively or more negatively?
- Are there any places on the body where you might be less sure about kissing someone with HIV?

- If you found out that a person you fancied had HIV – is there anything that you might be worried about? What if your relationship was more than just fancying them – i.e. you were already going out with them?
  - Probe – would you be worried about getting HIV yourselves?
  - Probe – are there any activities that you imagine you could be worried about doing with someone you fancied if you found out they had HIV? Which activities would you most worry about?
  - Probe - would you worry about what other people would think about you if they saw you kissing that person?
  - Probe - What do you think other people might think about you if they saw you kissing someone who they knew had HIV? What do you think other people might think about you if they knew you were going out with someone who has HIV?
  - Probe – would you worry about what having HIV might be like for them – how it might affect their lives?
- Why do you think it is that for some people, even if they know they can't get HIV through kissing someone, they still might be less likely to kiss someone who has HIV?

So we've talked about friends and/or about boyfriends/girlfriends, what about people who are in professional roles, for example teachers?

- How would you feel if you found out that one of your teachers had HIV?
- If you found out that a teacher had HIV, do you think it might change the way you saw them? If yes, how?
- If you found out that a teacher had HIV, is there anything that you would want to know about?
- Do you think you would do anything differently when you were around the teacher in class? If yes, what might you do differently?
- Would you worry about getting HIV from a teacher who had it? Are there any types of contact with the teacher that you would worry about?
- Do you think a teacher with HIV would be as good at their job as a teacher without HIV? Would it depend on anything?

What about other professional roles, for example – doctors and nurses?

- How would you feel if you found out that your doctor or nurse had HIV?
- Do you think it might change the way you saw them? If yes, how?
- Are there any differences between finding out whether your teacher had HIV and whether your doctor had HIV? If yes, what are these differences?
- If you found out that a doctor had HIV, is there anything that you would want to know about?
- Do you think you would do anything differently when you were around the doctor when having a consultation? If yes, what might you do differently?
- Would you worry about getting HIV from a doctor who had it? Are there any types of contact with the doctor that you would worry about?

- Do you think a doctor with HIV would be as good at their job as a doctor without HIV? Would it depend on anything?

### **Section 6: What is it like to live with HIV?**

10. Do you agree or disagree that:

10a. There's nothing to be ashamed of if you have HIV

*Strongly Agree/Agree/Disagree /Strongly Disagree/Don't Know*

- Why did you answer as you did?
- Do you think it matters how someone got HIV?
- Do you think other young people would feel the same as you? If not, why not?

10b. Even with HIV, you can live a long and happy life

*Strongly Agree/Agree/Disagree/ Strongly Disagree/Don't Know*

- Why did you answer as you did?
- Do you think there is treatment for HIV? What do you think this treatment does?
- What are the symptoms of HIV?
- Do you think other young people would feel the same as you? If not, why not?

10c. I am less likely than most people to get HIV one day

*Strongly Agree/Agree/Disagree/ Strongly Disagree/Don't Know*

- Why did you answer as you did?
- Are you worried about getting HIV? Why?
- How do you think other people might treat you if you had HIV?
- Do you think other young people would feel the same as you? If not, why not?

### **Q&A session**

### **Thanks and Close**

Is there anything else you would like to discuss about any of the topics we have raised today?

**NAT Leaflets to be given out at the end.**

## Appendix 6: Teacher interview guide

### Introduction

Thank you for helping us carry out this research project. OPM is a research organisation and we are working together with Body and Soul, a London-based charity which supports young people with HIV. The purpose of this study is to understand levels of awareness and attitudes to HIV among young people in London. There has been very little research in this area, and the findings will help inform Body and Soul how to raise awareness and reduce stigma.

We would like to conduct a short interview with you now over the phone to gain a teacher's perspective. It shouldn't take more than 20 minutes and the data collected will be completely anonymous.

### **These first questions are aimed at understanding how HIV lessons are taught in your school...**

1. What is the main subject you teach?
  - a) Do you also teach PHSE or Citizenship – or something similar (in case they call it something different)?
  - b) Which lessons do you teach about HIV in?
2. How much time is spent teaching about HIV? [Prompt: how many hours per school year? Also, is it raised a number of times during their time at school, or just as a one-off?]
3. What are the main issues covered in HIV lessons? [Prompt: sexual health/ social/ scientific issues]
4. Do you think HIV is also addressed in other lessons which other teachers cover [e.g. biology]

### **The next questions are aimed at understanding what you think about HIV lessons...**

5. Do you think enough time is spent teaching about HIV?
6. Do you think all of the issues which need to be communicated to young people about HIV are currently covered?
7. [If not] What other issues do you think should be communicated?
8. Do you think that HIV lessons currently provided are beneficial to young people?
9. Is there anything that would make them more useful?

### **The next questions are aimed at understanding what materials you are currently using to teach young people about HIV...**

10. What resources do you use when teaching about HIV? [Prompt: Videos, books, presentations...]

11. How useful are they? [Prompt: Which is the most useful resource? We will send over a Resource List with the questionnaires for you to tick which ones you have used and add any different titles to the bottom of the page]
12. What issues do they cover?
13. Are there any other resources that would be useful?
14. Would you know where to get hold of further resources on HIV if you needed them?

**The next questions are aimed at understanding how much support you have in teaching lessons about HIV...**

15. Do you think you have enough information and guidance to teach lessons about HIV?
16. [If not] What additional types of information and guidance would be useful?
17. Are there any particular issues relating to HIV that you find difficult to address?
18. [ Return to responses on time/issues covered] Do you think there's scope for more time to be spent on HIV lessons and more issues to be covered? [if not, why not? If yes, should/ could this be in a PSHE lesson?]

**The next questions are aimed at understanding what you think young people think about HIV...**

19. What reaction do you tend to get from students when you talk about HIV?
20. What do you think explains this reaction? [Prompt: e.g., If negative, are there any common misconceptions? If positive, is it because they already have a certain level of knowledge?]
21. Do you think young people would be interested to learn more about HIV?
22. [If not] Why not? [If yes] Why?
23. Overall, what views do you think young people tend to have about HIV?

**That's the end of the questions we have for you. Are there any further comments about anything we have already discussed that you would like to add?**

Thank you for your time.

## Appendix 7: Questionnaire

We are asking lots of young people these questions - it's not a test so don't worry about getting them right or wrong – we just want to know what you think. It should take you between 5 and 10 minutes. Please tick the boxes to answer the questions. You do not need to put your name on this paper.




**Thank you!**

Let's start with the basics...




1. Which school do you go to?			
Name of school 1	<input type="checkbox"/>	Name of school 6	<input type="checkbox"/>
Name of school 2	<input type="checkbox"/>	Name of school 7	<input type="checkbox"/>
Name of school 3	<input type="checkbox"/>	Name of school 8	<input type="checkbox"/>
Name of school 4	<input type="checkbox"/>	Name of school 9	<input type="checkbox"/>
Name of school 5	<input type="checkbox"/>		




2. And are you ...	
Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

3. And how old are you?	
-------------------------	--




	 Yes	 No	 Don't know
4. Have you been taught about HIV in school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>




	Enough	Too little	Too much
5. Do you think the amount of information you have been given about HIV is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	 Yes	 No	 Don't know
6. Do you know anyone with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>






7. How do you think a person can get HIV?	 Yes	 No	 Don't know
Sharing a cup with someone who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receiving an infected blood transfusion (please ask your teacher if you are not sure what this is)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Passed from a mother to her baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sharing a meal with someone who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kissing someone with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shaking hands with someone who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having unsafe sex (sex without a condom)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using unsterilised needles (please ask your teacher if you are not sure what this is)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Just a few more questions...

8. And which of the following would YOU do?	 Yes	 No	 Don't know
Remain friends with someone with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kiss someone who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Buy food from a shopkeeper who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drink from the same cup as someone who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receive treatment from a doctor who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Be taught by a teacher who has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	 Yes	 No	 Don't know
9. Do you think some groups of people are more likely to get HIV than others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If you ticked yes, who do you think these groups of people are (if you ticked 'no' or 'don't know' then you don't need to write anything here)			

This is the last set of questions now...nearly there!

10. Do you agree or disagree with these?	<b>Strongly agree</b> 	<b>Agree</b> 	<b>Disagree</b> 	<b>Strongly disagree</b> 	<b>Don't know</b> 
You can tell by looking at someone if they have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There's nothing to be ashamed of if you have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Even with HIV, you can live a long and happy life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anyone can get HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'd like more information about HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am less likely than most people to get HIV one day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is treatment for HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thanks again for answering these questions! Please give this back to your teacher.