

National Ambulance
LGBT Network



Supporting Lesbian, Gay,
Bisexual, Trans staff,
patients and communities

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Providing Good Care to People Living with HIV

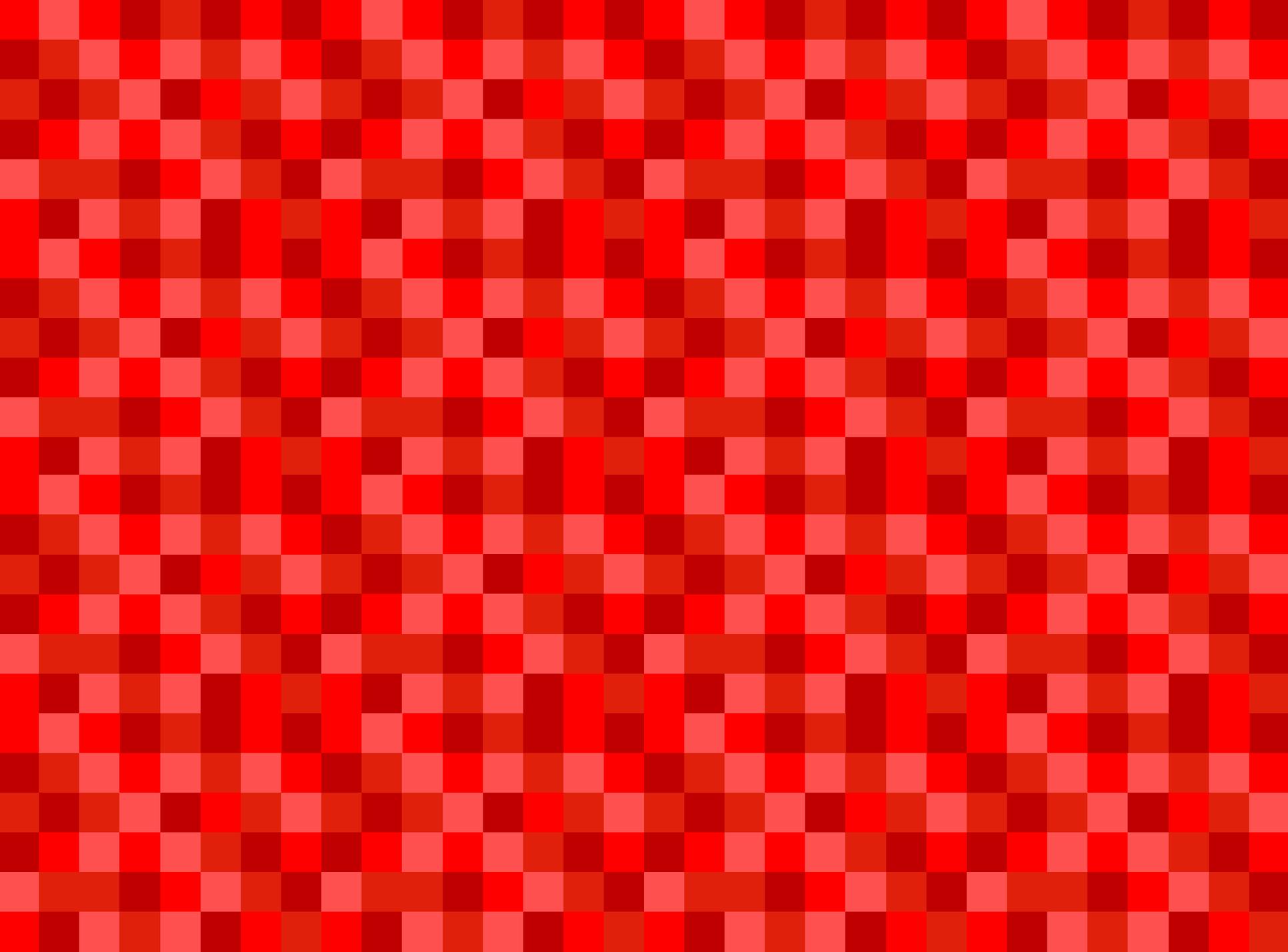
An Ambulance Service Resource Pack

Tony Faraway, Alistair Gunn,
Kat Smithson and Adam Williams
25 November 2019

This resource pack has
been put together with NAT
(National AIDS Trust)

TRANSFORMING
THE UK'S
RESPONSE
TO HIV





Introduction



We are very proud to launch a newly expanded pack which looks at the experiences of people living with HIV and how, as ambulance professionals, we can provide the best care.

HIV infections amongst the LGBT community still present one of the biggest health inequalities today and you will soon discover, in the new part of this resource, that the experience of people with HIV is not always as good as it should be.

Training about HIV and many other diseases is often confined to initial training programmes. For some of our colleagues this may be some considerable time ago. Times change and so the range of treatments available, along with their effectiveness.

We can all help to keep people informed and also wear a red ribbon on World AIDS Day to show our support for people around the world who live with HIV.

Alistair Gunn, Chair, National Ambulance LGBT Network





Report on the Survey into Patient Experience and Staff Knowledge

In 2019 Adam Williams (pictured right), a Paramedic from North West Ambulance Service, and Chair of the North West Ambulance Service LGBT Network, carried out a survey of patient experiences. Having completed this Adam then surveyed ambulance staff to assess the confidence people have in dealing with people with HIV and how up-to-date their knowledge is.



Adam joined forces with Tony Faraway (pictured left) from South East Coast Ambulance Service to present the findings at the National Ambulance LGBT Network conference 2019.

Attitudes [1]



A Starting Point

Some notable examples of poor patient experience prompted this survey – this raised the question of how people living with HIV have experienced the ambulance service, and specifically how staff attitudes and level of knowledge contribute to this.

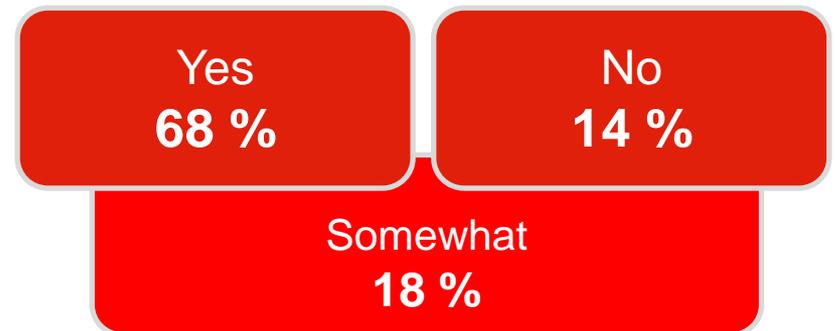
All good ambulance clinicians recognise that establishing a rapport and gaining the trust of our patients is essential. It is the bedrock upon which all assessment and treatment is built. Therefore, our approach to our patients, formed by the attitudes we take, directly influences both the quality of assessment and treatment, and therefore the experience of our patients.

However, even the most exemplary attitude will not compensate for a lack of appropriate

knowledge. So, in order to assess the extent to which we are fully supporting (or letting down!) our HIV positive patients, we also need to consider our level of knowledge and understanding.

Worryingly, nearly a third of patients indicated a lack of care and compassion:

Did the crew show care and compassion throughout your experience with them?

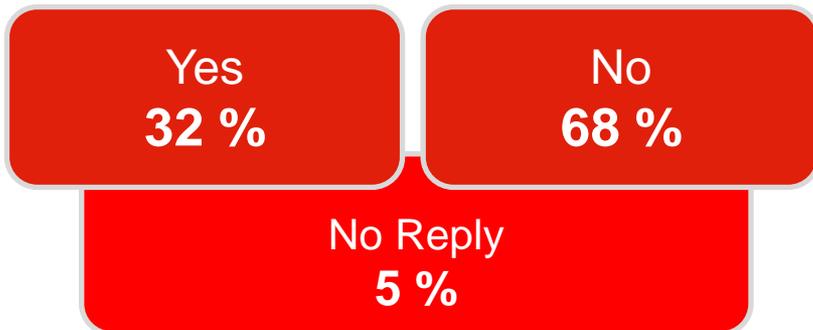




Was this linked to HIV status?

The extent to which the perceived lack of care and compassion might be linked to a patient's HIV status is suggested by how the crew's attitude was seen to change. Again, almost a third of patients stated it did.

Did the attitude of the ambulance crew change upon hearing about your HIV status?



Additional Responses

Some of the additional responses to this question give us a glimpse of the ways in which the crew's attitude changed.

- '...when I disclosed my status, I saw the crew exchange an uncomfortable look and I could sense a feeling of unease.'
- 'Once disclosed they both put on gloves and was the first thing said when taken into hospital.'
- 'I felt judged.'
- 'One of the crew said he needed to 'double glove' when I told them about my status.'

These comments suggest some crews appear to have had a level of discomfort, or even fear, whilst their patients sensed they were being judged.

Attitudes [3]



Staff Feelings

How accurate were the patients in their assessment of the discomfort of staff?

When asked, over a fifth of staff admitted to having felt uncomfortable treating an HIV positive patient.

Have you ever felt uncomfortable treating an HIV positive patient?

Yes
22 %

No
78 %

A further question aimed to explore what was at the root of the feelings of these staff:

What were your initial thoughts when the patient disclosed their HIV status?

Some responses clearly demonstrate the fear factor that the patients detected:

- 'Apprehension, concern for myself and crew mate about contamination.'
- 'Risk to myself or other HCPs. I would ask more info regarding their status.'
- 'I don't want to cannulate or take a BM from this patient.'

Others appeared to have moved on from fear to condescension:

- 'How difficult it might be... to risk being made to feel embarrassed or ashamed for simply having an ongoing health problem.'
- 'What a shame.'

Quotes to Consider



‘One of the crew said he needed to ‘double glove’ when I told them about my status.’

‘I felt judged.’

‘Early in my career I treated [HIV positive patients] with more caution. Of late, through better education, [I’ve treated them] no different or raised concern’



Knowledge and Training [1]



Appropriate Questioning

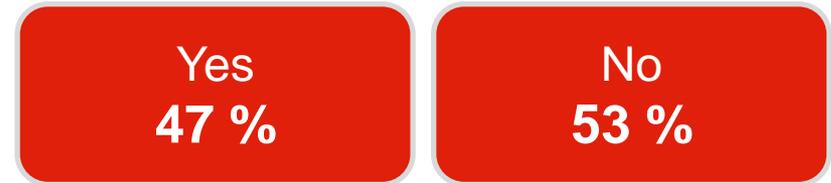
Most encounters were unrelated to a patient's HIV status:

Was your encounter with NHS Ambulance Services related to your HIV status?



And yet many patients were asked unrelated questions, demonstrating a lack of understanding of HIV alongside a lack of insight into how unnecessary questioning may be inappropriately intrusive.

If your medical complaint was not related to your HIV status, would you say that the crew questioning was appropriate for your specific medical complaint?



Additional Responses

- 'What's your viral load.'
- 'How long have you had it?'
- '[they asked] how I became infected.'
- 'I explained the treatment I was on, and that I am undetectable, but it was clear they didn't understand what this meant.'

Knowledge and Training [2]



Priorities and Discretion

Seldom, if ever, is informing hospital staff of a patient's HIV status going to be a top priority. However, nearly a fifth of staff weighed this with such importance that they made it their highest priority at handover.

On arrival at hospital, was informing the hospital staff about the patient's HIV status your highest priority?

Yes
19 %

No
81 %

In addition to this, about the same proportion of staff were not felt by their patients to have done so discretely.

Did your ambulance crew disclose your HIV status to the receiving hospital staff in a discrete manner?

Yes
56 %

No
21 %

Not sure
23 %

This illustrates how a lack of knowledge can lead to inappropriate behaviour, questioning on factors not relevant to the presenting complaint and causing upset in the process.

Continued...

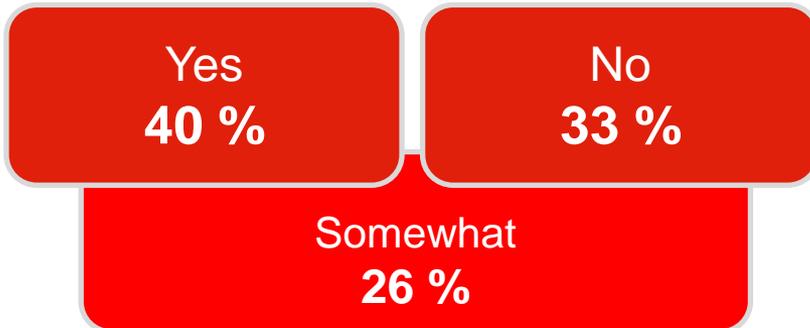
Knowledge and Training [3]



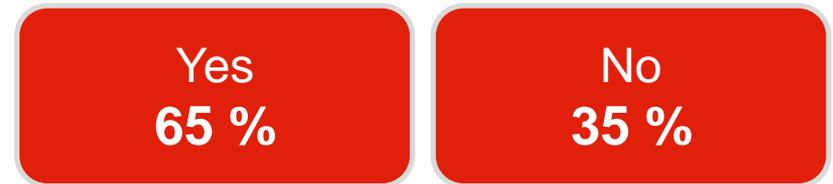
Adequacy of Knowledge

Patients in the survey made a less favourable assessment of the ambulance staff's knowledge than the staff did themselves.

If your medical complaint was related to your HIV condition, do you feel that the ambulance crew treating you had sufficient knowledge of HIV to treat and assist you appropriately?



Would you say your knowledge of HIV and its treatment is adequate for the role you perform and the patients you encounter?



In this survey we are not asking patients and staff about the exact same encounters. Nevertheless, there is a large discrepancy between staff self-evaluation and patient evaluation of staff. This suggests that there is a considerable element of staff 'not knowing what they do not know'.

Continued...

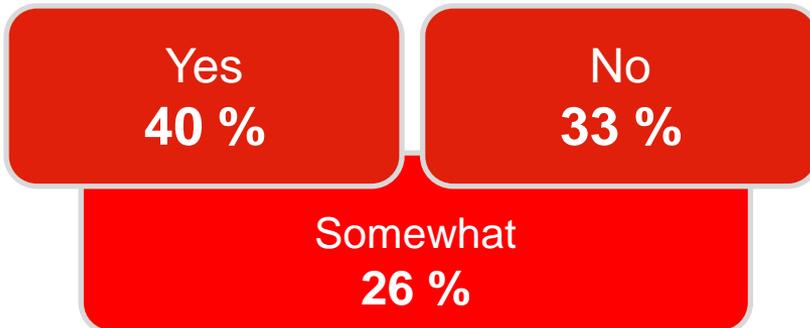
Knowledge and Training [4]



Adequacy of Training

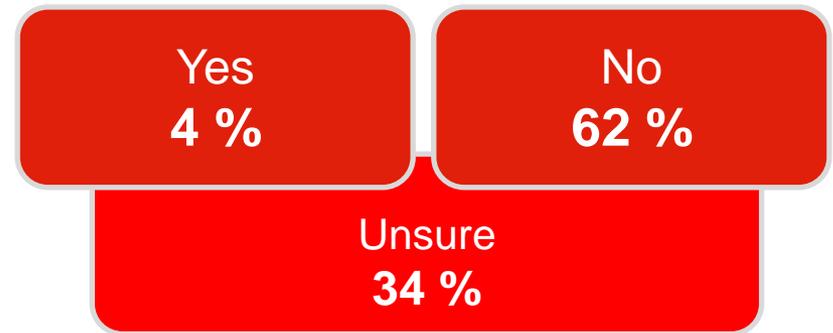
An individual clinician's responsibility to keep their knowledge up-to-date is a duty shared with their employer. Patients were asked how they felt ambulance services are meeting this obligation. This demonstrated a similar level (or lack!) of patient confidence in ambulance services, similar to that shown towards individual clinicians.

Do you feel NHS ambulance services are adequately trained or equipped to assist people living with HIV?



Here is an indication of currently how much the onus is placed on individuals rather than organisations:

Does your NHS trust provide you with training specifically about HIV?



When the same question was asked of the group of attendees of the HIV workshop at the National Ambulance LGBT Network Conference 2019, a similarly small proportion indicated that they had ever had any specific HIV training.



Double-Gloving

Whilst wearing two pairs of gloves may be common practice in operating theatres, it is not part of the universal precautions used in ambulance services, where it is generally reserved for special precautions with hazard Group 4 Infections (e.g. Ebola). Double-gloving for HIV patients therefore suggests a distorted view of infection control risk.

Historically, a higher level of precautions was applied prior to improved understanding, as outlined, for example, in this Sussex Ambulance Service document from 1985, shown on the right.

To be clear, the application of universal precautions to prevent infection is totally adequate when handling patients living with HIV and other blood-bourne infections.

2. ACTION BY OFFICER IN CHARGE OF STATION

2.1 The Officer in Charge must ensure that the crew detailed for transporting known A.I.D.S. patients will dress themselves in the appropriate protective clothing carried in the ambulances i.e. masks, gowns and gloves.

Extract from Sussex Ambulance Service
document from 1985

Knowledge and Training [6]



The continuation of this practice, much of which was recent, suggests how out-of-date some ambulance crews' knowledge is.

Have you ever practised 'double gloving' when treating an HIV positive patient?

Yes
16 %

No
84 %

How recently?

0 to 3 years
65 %

4 to 6 years
15 %

7 to 10 years
15 %

10+ years
5 %

Specific Knowledge

PARTNER1 study results published in 2014, (reinforced by PARTNER2 in 2018) proved that HIV was untransmissible by an HIV positive person where their viral load is undetectable due to effective treatment. A majority of staff in the survey were aware of the term.

Do you know what the term 'undetectable' means?

Yes
83 %

No
17 %

Another question regarding specific knowledge was asked of staff as an indicator of how up-to-date they might be

Knowledge and Training [7]



about HIV. The use of Pre-Exposure Prophylaxis has been proven to be very effective in preventing new HIV infections. The PrEP IMPACT trial has been running since 2017 – knowing about it demonstrates more recent knowledge.

Do you know anything about PrEP?

Yes
58 %

No
42 %

Patient Evaluation

The following question mirrors the friends and family test used to evaluate NHS services.

Would you recommend the ambulance service to any friends or relatives who are HIV positive following your experience?

Yes
81 %

No
19 %

Comparing this with the friends and family test results for ambulance services at the time of this survey, reveals a stark contrast:

Yes
91 %

No
3 %

Continued...



Following your experience with an NHS ambulance service, would you be confident about accessing services again?



Patients having confidence in using the ambulance is more than just 'customer service'. If, through a lack of knowledge and exclusionary attitudes we cause a cohort of patients to be less inclined to call us, we are being discriminatory and risking some patients' health and ultimately their lives.

A Bit More Detail

Patient Survey – June 2019

There were 59 respondents who replied to a request for HIV positive people to report on their experience of using the ambulance service. The request for respondents was primarily done using social media links to a Survey Monkey capture.

The survey was completely anonymous and no information was collected about the location of the respondent, or which ambulance service the person had used. There were 16 questions in total and the survey enjoyed a 100% completion rate.

Staff Survey – August 2019

There were 100 respondents to this survey and an 86% completion rate. 91% of those responding had interacted with patients living with HIV in the last 12 months.

The survey comprised 18 questions and was aimed at current/previous ambulance staff. The survey was promoted using internal ambulance bulletins and social media.

Conclusions and Actions



The findings of the patient survey, like other surveys we have conducted, indicate the ambulance service enjoys high acclaim for its clinical care and response in emergency situations. Qualitative feedback suggests there is however some 'clumsiness' when it comes to appropriateness of questioning.

Ill-informed ambulance clinicians are undoubtedly having an impact on patient experience by asking questions and making assumptions that may have nothing to do with the presenting condition.

The staff survey also shows that many people feel their knowledge is not up-to-date. For this reason we need to ensure information is accessible and help staff

keep themselves informed.

The second part of this resource demonstrates how easy it is to present information that is accessible and current.

The National Ambulance LGBT Network commits to updating information regularly and makes a recommendation to every Trust to make this available to everyone whilst promoting self-empowerment.

Keeping people informed about treatments and good care helps people to feel valued. If we can make people feel valued and treat confidently we will also reduce stigma.

#InformedCare is great care.



Updating Your Knowledge on Treatments and Best Practice

This information pack was put together in November 2018 to update ambulance staff on the current position about HIV and the treatments available, and also the latest good practice guidance.

The pack was a collaboration between Alistair Gunn from the National Ambulance LGBT Network and Kat Smithson from the National AIDS Trust.

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World AIDS Day

takes place every year on

1 December

and it is the perfect time to remind ourselves how we can provide the best support to people living with HIV across the country.

www.worldaidsday.org

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Stay Informed



In this pack you will find out more about....

Up-to-date facts and figures about HIV in the UK

Information about HIV prevention and treatment

Providing the best service to people living with HIV

Where you can find more information

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Introduction



HIV has not gone away, but the context has changed

If a person is diagnosed in good time in the UK, they have a normal life expectancy. This is because HIV treatment, Antiretroviral Therapy, is now so good. Treatment also means that most people living with HIV in the UK can not pass it on.

HIV testing is therefore vital as getting diagnosed in good time is good for the health of the individual and good for public health.

HIV stigma still exists

HIV stigma is often related to stereotypes, prejudice, preconceptions and, often misguided, fears about HIV transmission risk.

Stigma is often unintentional, but it significantly affects people experiencing it and is barrier to ending HIV once and for all. **This is why it's so important to know the facts.**



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The Statistics



- More than **100,000** people are living with HIV in the UK.
- Treatment prevents vertical transmission of HIV (during pregnancy, childbirth or breastfeeding). In the United Kingdom the risk is less than **0.5%**.
- **16%** of the population believe you can get HIV from kissing. **This is not true.**
- Sadly, **18%** of HIV positive people report feeling suicidal in the last twelve months.

Most people living with HIV in the UK can not pass HIV on:

- **88%** of people living with HIV in the UK are diagnosed.
- **96%** of those diagnosed are on treatment.
- **97%** of those on treatment are virally suppressed and **can not pass HIV on.**

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The Statistics



- Lambeth has the highest prevalence of HIV in England. **1 in 60** people (aged 16 to 59) in Lambeth are living with HIV.
- Gay and bisexual men are disproportionately affected by HIV. It is estimated that **1 in 13** gay or bisexual men in England have HIV.
- In London it is estimated that **1 in 8** gay and bisexual men have HIV.
- Other marginalised groups are disproportionately affected by HIV including migrants and Black and Minority Ethnic (BME) groups.
- **1 in 29** black African heterosexual women and **1 in 43** black African heterosexual men are living with HIV in England.
- It is estimated that less than **1 in 100** people who inject drugs are living with HIV. This is because of effective harm reduction over the years.



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The Statistics



- For the first time since the start of the epidemic HIV diagnoses are decreasing in the UK. **They decreased 28% between 2015 and 2017.** Importantly this is linked to decreasing acquisitions.
- This was first seen amongst gay and bisexual men and is now being seen in other groups. It is due to combination HIV prevention that includes:
 - Increasing testing amongst gay and bisexual men, meaning more people are aware of their status and on treatment.
 - People being put on treatment quickly after diagnosis.
 - Outreach, information and condom provision and use.
 - People taking Pre-Exposure Prophylaxis – a drug that prevents people from acquiring HIV.

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PrEP: Pre-Exposure Prophylaxis



Pre-Exposure Prophylaxis (PrEP) is a drug that can be taken by a HIV negative person to prevent them from acquiring HIV.

As of 2018, in England PrEP is only available on the NHS through the PrEP IMPACT Trial. However, spaces are limited and many people at risk of HIV buy the medication themselves online or through private providers.

The treatment takes the form of a daily tablet. The most commonly prescribed tablet is Truvada and is actually also used as HIV medication and is taken by many people living with HIV in the United Kingdom.

PrEP is almost 100% effective when taken properly and is a really important prevention option for many people at higher risk of HIV.

Taking PrEP through the NHS also offers the opportunity to engage people in sexual health services as they visit their clinic frequently for testing and support.

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PEP: Post-Exposure Prophylaxis



People who have been exposed to HIV, or suspect they could have been, can be given **Post-Exposure Prophylaxis (PEP)**. This treatment, which lasts one month, uses antiretroviral therapy to stop HIV from taking hold.

To be effective, people who think they have been exposed to HIV must start the treatment within 72 hours of the risk event.

All sexual health clinics can help people access these medications and will provide support to people who need it. Most clinics offer a 'drop-in' style service to people requiring PEP.

If sexual health services are not available all A&E departments can provide an initial course of treatment. A&E should refer people to sexual health clinics for a follow-up service and full risk assessment.

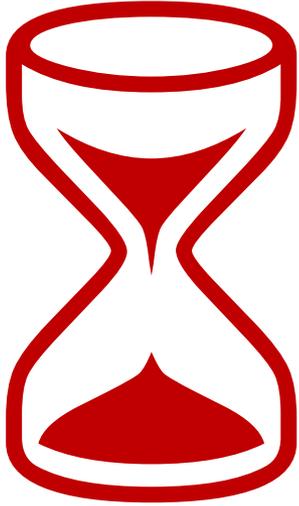


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PEP: Act Fast!



PEP needs to commence within 72 hours of the exposure

It is very unlikely that ambulance staff will be called to attend someone because they have been exposed to HIV. Many people will self-refer themselves to an appropriate service.

You may however become aware of a risk while taking a medical history. There are a few situations when a person may have been at risk of HIV. These are:

- When a sexual assault has occurred (and it includes exposure risk).
- When a person has been injecting drugs and could have shared injecting equipment.

In these situations it is important you gain the trust of the patient and advise them they need to talk about this to a clinician. You may offer to be their advocate and sensitively pass information on if the person agrees.



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Treatment of People with HIV



The main treatment for people with HIV is **Antiretroviral Therapy (ART)**.

This works to lower the amount of infection in the body and can be highly effective. Modern treatments are able to suppress the infection to the extent that people can be classified 'undetectable'.

HIV treatment usually means that people can live full and healthy lives. Several studies have also concluded that someone that is undetectable **cannot pass HIV** on to another person.

Some people do experience side effects from ART, although newer medications are much better. Some people who have been living with HIV for a long time may have taken older medications which had much worse, and some long-lasting side effects.

Most people living with HIV will be very aware of their status and treatment plans. Many will be very reluctant to talk about this to people they do not have an established relationship with.



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Stigma of HIV



Despite the massive advances in knowledge about HIV and its treatment, there is still a lot of stigma attached to it.

Being diagnosed as HIV can be distressing for some people.

As well as understanding what this means for their health, people often have concerns about what other people will think.

Progression in public perceptions and knowledge have not kept pace with that of treatment and this often leads to false perceptions and stigma.

Mental health is often affected with many people living HIV experiencing self-stigma. **1 in 5** people living with HIV report having suicidal feelings.



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Providing Good Care



- You should follow the universal precautions for infection prevention and control for all patients. Universal precautions are completely sufficient to prevention transmission of HIV and **there is no need to take additional precautions.**
 - You do not need to ‘double glove’.
 - Do not tell people about the person’s HIV status who don’t need to know for medical reasons (for example if they are prescribing medication).
- **Treat everyone with dignity and respect.** Your treatment of people will have a huge impact on how people view health services in general and our role is to be supportive to everyone. Do not judge people and allow people to speak openly about their lives.
- Being aware of the stigma linked to HIV is a positive step towards offering informed support.



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Let's Talk!



What can we do to spread the word and improve the care provided by the ambulance service?

- The first thing is talking about it. This pack has been designed so you can pass it to colleagues or hold an event and share the information. The more people that understand, the better our services will be.
- Challenge the myths. Your colleagues may not be as informed as you are and you can play a part in keeping our workforces informed.
- Take part in the World AIDS Day red ribbon campaign. This improves awareness and also helps raise money to support research and education.

Visit www.worldaidsday.org/the-red-ribbon/order for more information.

- Stay informed. Have a look at the next slide for useful links.



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Useful Information and Links



E-learning Resource

- NAT has an e-learning resource for health and care staff that also has a quiz at the end:

www.nat.org.uk/we-inform/training-and-learning/e-learning

Useful Organisations

- National AIDS Trust – based in the UK and lots of useful information

www.nat.org.uk

- Terrence Higgins Trust – UK organisation supporting people with HIV

www.tht.org.uk



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A Bit More Detail [1]



HIV and AIDS

HIV (human immunodeficiency virus) is a virus that damages the cells in your immune system and weakens your ability to fight everyday infections and disease.

AIDS (acquired immune deficiency syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by the HIV virus.

While AIDS can't be transmitted from one person to another, the HIV virus can.

www.nhs.uk/conditions/hiv

Pre-Exposure Prophylaxis (PrEP)

Pre-exposure prophylaxis (or PrEP) is when people at very high risk of HIV infection take HIV medicines daily to lower their chances of getting infected. PrEP can stop HIV from taking hold and spreading throughout the body. It is highly effective for preventing HIV if used as prescribed, but it is much less effective when not taken consistently.

Because PrEP is still reasonably new, there are differing claims about how effective it is. All agree there are major benefits to people in high risk groups.

One American website claims daily PrEP reduces the risk of getting HIV from sex by more than 90%. Among people who inject drugs, it reduces the risk by more than 70%. Your risk of getting HIV from sex can be even lower if you combine PrEP with condoms and other prevention methods.

Wide scale trials involving the NHS began in 2017 and some early findings from the PARTNER2 study are showing promising results.

One website linked to the main manufacturer of the medications is keen to suggest that PrEP is most effective when used alongside the use of condoms and use of safer injecting practices for intravenous drug users. It is clear that PrEP offers more choice for people and allows people greater choice in the risk taking behaviours they may practice.

www.cdc.gov/hiv/basics/prep

Truvada

Truvada is a prescription medication most widely used for PrEP, and also widely as part of the treatment of PEP and people who have contracted HIV.

The clinical ingredients of this drug are emtricitabine (200mg) and enofovir disoproxil fumarate (300mg). The drug is produced by a number of pharmaceutical companies, with Truvada being the registered trade name for the first company who developed it.

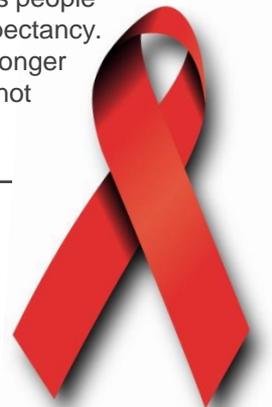
Whilst there are proven benefits to using this medication, there are a number of potential side-effects which include kidney and liver problems and bone weakness. People taking the medication require regular blood tests for kidney and liver function.

The suggestion is effective treatment can prevent infection and also reduce the amount of virus in people already infected. It is highly likely this means people can enjoy a normal life expectancy. It is important to state the longer term impact of the drug is not yet fully understood.

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A Bit More Detail [2]



Post-Exposure Prophylaxis (PEP)

PEP treatment (sometimes called PEPSE) is a combination of HIV drugs that can stop the virus taking hold. It can be used after the event if you've put yourself a risk of HIV transmission.

To work, PEP must be taken within 72 hours, and is known to work most effectively when taken within 24 hours.

PEP is not a 'morning after pill' for HIV, and it's not guaranteed to work. It's meant as an emergency measure to be used as a last resort, such as if a condom fails during sex.

www.tht.org.uk

What Does 'Undetectable' Mean?

'Viral load' refers to the amount of virus in the blood. It is measured by a simple blood test which also shows how well antiretroviral treatment is working at protecting the immune system from other potential illnesses.

An 'undetectable' diagnosis means that the level of HIV in the body is so low (under 40 copies/ml) that it is non-infectious to other

people. Some healthcare workers talk about 'viral suppression' (where HIV levels are under 200 copies/ml). Either of these diagnoses means there is zero risk of you passing on the virus to other people.

It usually takes people a while to adjust to new medicines, and the same goes for HIV treatment. Simply being on treatment doesn't automatically mean that a person is undetectable and it's very common for viral loads to fluctuate, particularly early on after starting a new treatment regime.

People might look and feel perfectly healthy, but simply feeling fine isn't a good indicator of what your viral load looks like. The only way to know that a person is undetectable is through regular viral load monitoring.

www.avert.org

Undetectable and Transmission

As well as very obvious health benefits to reducing the amount of virus in the body, it is also now thought people who are 'undetectable' will not transmit the virus to other people.

A number of extensive studies have consistently shown that no new infections have occurred in HIV discordant couples (where one is HIV positive and the other not).

HIV in the United Kingdom

New HIV diagnoses continue to be high in the UK. In 2015, there were 6,095 new cases (4,551 men and 1,537 women) and 43% of the infections occurred in London.

Gay and bisexual men continue to be the highest risk group of contracting the virus with 55% of new infections being amongst this group.

In 2015 it was estimated that 101,200 people in the UK are living with HIV. Public Health England estimates that between 10% and 17% of these are unaware they have the virus.

73% of people that are HIV positive have successfully been treated with antiretroviral medications and have the virus suppressed.

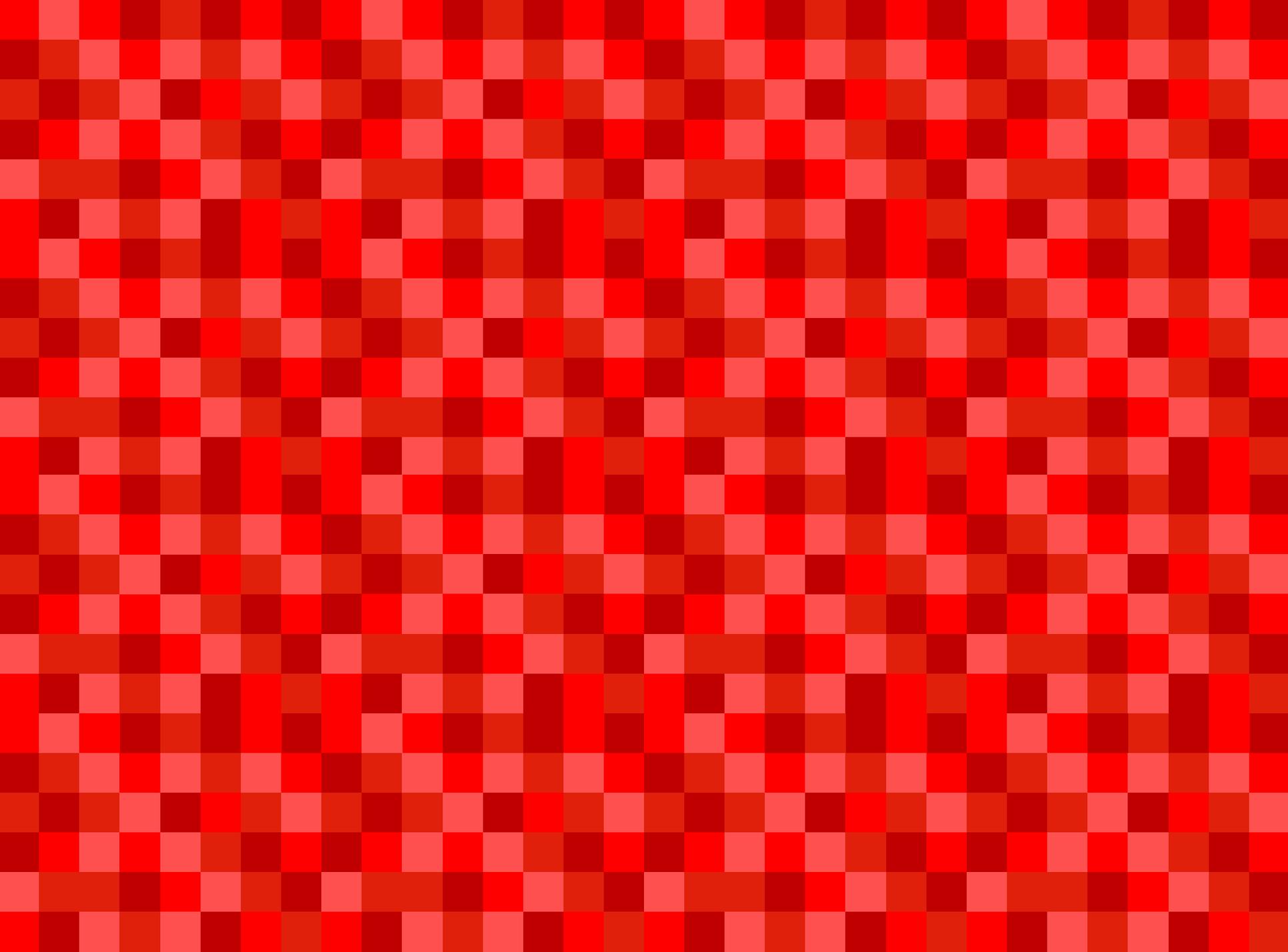
www.gov.uk/phe



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For more information about the National Ambulance LGBT Network visit:

www.ambulanceLGBT.org



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CPDme
Development for Life