NATIONAL AIDS TRUST

Toolkit –
communicating about
HIV

FRAME WORKS UK

Introduction

This practical guide for communicating about HIV in the UK was created by FrameWorks UK in partnership with National AIDS Trust. It draws on insights from FrameWorks' research into related issues, and was also informed by a workshop with a range of HIV activists and sector organisations.

About FrameWorks UK

FrameWorks UK is a not-for-profit, mission-driven organisation, specialising in evidenced-based communication strategies that shift hearts and minds. They help charities and other organisations communicate about social issues in ways that create change, through practical guidance underpinned by their framing research.

Read more about FrameWorks UK here.

Communicating about HIV: the challenges

At FrameWorks we've identified three mindsets – deeply held patterns of thinking – that repeat across social issues. When these mindsets are first and foremost in our understanding, they can be the biggest barriers to change.

■ **Individualism:** The idea that our outcomes are a narrow result of our own choices and effort. Thinking in this way can make it harder to see the role and impact of our systems and surroundings.

■ **Fatalism:** The sense that the problems we're facing are too big and too complex to solve. This makes it much harder for us to recognise that solutions exist, or that they could make a difference.

■ **Othering:** The idea that we are in competition for finite, and often scarce, resource – 'us' versus 'them'. This makes it much harder to make the case for collective action at scale, or any kind of targeted support for specific groups.

By working together in the workshop, we also identified a number of specific challenges when communicating about HIV:

- ■ **Low levels of salience (perceived importance and prominence) around HIV.**

- ■ **Some people think HIV is 'solved' or part of our past.**

- ■ **Stigma is acknowledged – but often misunderstood.**

- ■ **Potential tension between narratives on living well with HIV and HIV prevention.**

- ■ **Low narrative alignment across the sector.**

This guide offers framing strategies to address these challenges in communications about HIV. Framing doesn't mean having to use the same messages – it's about using the same ideas, which can be tailored to suit an organisation or individual's voice. When many of us work together to use shared framing strategies, it creates a much clearer, stronger story.

The recommendations in this guide are designed to answer the following questions:

Q1: Why does this matter – and what's it really about?

Q2: How does this work – and if it's not working, why not?

Q3: What can we do about it?

Framing HIV communications: what to do

Q1: Why does this matter – and what's it really about?

Recommendation: Appeal to the shared value of interdependence

When we tap into a shared reason to care, it primes people to think in more collective ways and helps to show why this matters. Interdependence is the idea that what affects one of us affects all of us, that when some people are struggling it affects everyone, and that support for one of us strengthens all of us.

- Invoke the idea of interdependence early on in your communications.
- Talk about the individual and the collective benefits of change.
- Talk about how things are, could, or should be (where change is still needed, or society is falling short).
- Use collective terms, such as we, us, and our.
- Consider referencing other campaigns and issues to reinforce the idea that we are all connected.

Examples

Together, we can make sure everyone living with HIV gets the support they need.	When **everyone** has the care they need, **our communities thrive**.	**We stand with** people living with HIV. We are all part of the same society, and we are **stronger together**.
We work **together** with partners to improve care for **those of us** living with HIV.	We can decide – **as a society** – to not let HIV stand in the way of anyone living their life to the full.	When people living with HIV are discriminated against, it **hurts each and every one of us**.
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Recommendation: Highlight our shared needs

Talking about shared needs gives us an accessible way to talk about health inequality and rights – it can be used as a means of explaining or defining these concepts in less loaded terms.

- Make the connection early on to orientate the conversation.
- Give examples of our shared needs, whether or not we are living with HIV, such as access to healthcare and being able to live with dignity.
- Start with the collective before the specific. First establish shared needs, then drill down to targeted support.
- Consider linking with other campaigns and activists, to amplify each other's calls for the same shared needs.

Examples

Instead of...	Try...	Why?
"We fought hard for PrEP – an effective drug that prevents the transmission of HIV. And we'll keep fighting for everyone living with HIV to get the treatment they need to live a long and healthy life."	"**We all need access to medical care to support our health**. That's why we fought hard for PrEP – an effective drug that prevents the transmission of HIV. And we'll keep fighting for everyone living with HIV to get the treatment they need to live a long and healthy life."	By starting with a universal, shared need we show what this is really about, and define this as an issue for us all. In this case, we've also highlighted a shared need across prevention and care for people living with HIV – it's all about access to medical care.
"It isn't right that so many people living with HIV still face discrimination at work. We need to right this wrong."	"All of us **should be able to thrive at work**. But too many of us living with HIV still face discrimination in the workplace. Not only is this holding us back as individuals – it also means that workplaces are missing out on the skills and perspectives we can bring. Righting this wrong will mean that work works better for all of us."	Highlighting the shared need that is being threatened by discrimination collectivises the issue. This example also weaves in the value of interdependence to show why this matters.

Recommendation: Use explanation to build understanding

Effective explanation ensures that we're filling in the gaps for people, rather than leaving holes in our communications, which might be filled in with assumptions or stereotypes.

- Try showing rather than telling – add context and give examples.
- Use step-by-step explanation. This means simply and explicitly making the connection between causes and outcomes. Use language like 'Because', 'So', and 'As a result' to make the connections.
- Avoid technical terms or jargon – spell these out and bring them to life by explaining them well.

Examples

Showing rather than telling:

Instead of telling...	Try showing...	Why?
"There are profound inequities in the fight against HIV. While new data shows an increase in HIV testing amongst white gay and bisexual men, this improvement is not experienced by other groups, particularly women."	"Women are being left behind in the fight against HIV. Far too few women are offered HIV testing, leading to a higher number of women being diagnosed with HIV late, when it has started to affect their health. We know it's possible to reverse this trend, as we've seen an increase in HIV testing amongst white gay and bisexual men. HIV testing could be made more widely available in other services that women are more likely to access, to address this inequity."	The first example tells us that this inequity exists, but it doesn't show us how it comes about. The risk of not explaining inequity is that, without more context, people are likely to default to individualised ways of thinking about the issue, rather than seeing systemic issues that could be solved through collective action. We also miss opportunities to build understanding and support.

Step-by-step explanation:
Note the linking words and phrases in bold

"Undetectable = Untransmittable

"Effective treatment and access to testing for those of us living with HIV is essential, as it allows us to live healthy lives to the full and also protects our sexual partners. **Because** when we are on effective treatment, **this leads to** a lower level of HIV in our blood. When levels of the virus are extremely low this is called an undetectable viral load. **This means** that HIV cannot be passed on through sex."

To mitigate against the potential tension between narratives on living well with HIV and HIV prevention, explain each of these ideas well when they are the focus of your communications, using the recommendations above to do so. Here is an example of how to do this using the Shared Needs framing:

Instead of...	Try...	Why?
"Although, when properly treated, HIV today is a manageable condition, we are still working towards the goal of zero new transmissions by 2030."	"We all need the right support and healthcare to thrive. That's why we think it is equally as important to campaign for better treatment of people in the UK who are living with HIV as it is to work towards the goal of zero new transmissions by 2030."	Tie the two narratives together by reinforcing the shared needs of everyone, which encompass the needs of people living with HIV and the wider needs we all share to live well.

Recommendation: Add context to individual stories

We need to be mindful of how individualism can dominate stories told from firsthand experience. This makes it harder to see the role of systems in people's lives – and our collective responsibility for solutions.

- Ask questions that draw out context – such as what support is or isn't available.
- Consider topping or tailing stories with a few sentences to add context or further detail that supports the story.
- Tell diverse stories of shared experiences to show scale and avoid stories being written off as exceptional.

Questions that can draw out context

- What options/opportunities did you have then/do you have now?
- What support did you have/should you have had?
- What would have helped you?
- What barriers made it harder for you to get the care/support you needed?
- Are there other people in the same situation as you?
- Does this affect a lot of people? Why, or why not?

Recommendation: Explain stigma and put it in context

When we state that stigma exists and causes harm, but we don't explain how this happens, this can lead to a number of responses. People may reject the idea that the stigma exists, they may become defensive, or they may reason, fatalistically, that stigma is just something we have to live with. We also risk people minimising the effects of stigma to interpersonal conflict or hurt feelings – instead of building understanding of the very real barriers to support and services that stigma can cause.

- Explain unconscious bias early – and before descriptions of harm.
- Talk about systemic, as well as individual, consequences – short and long term, such as barriers to services and opportunities.
- Talk about the role of media before the actions of people.

Examples

Instead of...	Try...	Why?
"Too many people living with HIV still experience stigma. This stigma takes its toll. Stigma-induced shame prevents people from coming forward for HIV testing and can even lead to people avoiding seeking treatment. We need to reduce stigma today."	"The legacy of media coverage of HIV in the past can still affect our attitudes and behaviours in ways we don't realise. All of us need to feel safe and welcomed when accessing healthcare, or sharing things about our health, but many of us living with HIV still face discrimination which makes this much harder. We need to change the narrative and reduce the stigma which creates barriers to essential support."	Talking about the impact of media and the role this has played in shaping unconscious bias helps to explain how stigma happens, and how there is still work to be done, as a society. In this example, we talk about a systemic aspect of the issue – access to healthcare. This helps to broaden people's understanding of the impact of stigma and how we can all play a part in tackling it.

Note

Beware of mythbusting

Multiple studies have shown that mythbusting – repeating unproductive beliefs in order to counter them – tends to inadvertently remind people of them, reinforcing false ideas.

Instead, focus on the facts and explanations which you do want people to take away.

Instead of...	Try...
"Myth: If you have sex with someone living with HIV, you will get HIV too. Fact: People taking effective HIV treatment cannot pass on HIV through sex. Effective treatment reduces the amount of the virus (your viral load) to very low, undetectable levels. Being undetectable means the level of HIV in your blood is so low, you cannot pass on the virus."	"Fact: People taking effective HIV treatment cannot pass on HIV through sex. Effective treatment reduces the amount of the virus (your viral load) to very low, undetectable levels. Being undetectable means the level of HIV in your blood is so low, you cannot pass on the virus."

Recommendation: Show that change is necessary AND possible

Going out with a pure 'crisis' message isn't the best way to raise awareness and gain support. For people to get behind us, we need to balance urgency and efficacy – the need for change and the sense that change is possible – instead of triggering fatalism and the disengagement that comes with it.

- Talk about concrete solutions that will improve the lives of those of us living with HIV and continue to bring the rates of transmission down. Talking about progress and successes – and the tangible solutions which got us here, also helps to create a sense of efficacy.
- Give everyone a role to play. When we explicitly talk about what people can do to help improve things, it makes them part of the solution, and also increases salience.
- Consider using sequencing to balance urgency and efficacy. For example, you could start with efficacy (we can act) before urgency (we need to act) or start with what we have to gain, before what we stand to lose. Sequencing like this might not feel right for all campaigns and communications, but will be for some.

Examples:

Sequencing – efficacy before urgency

See how the second example starts by building a sense that change is possible. This helps to prime people to think in more 'can do' ways, rather than triggering fatalism

Instead of...	Try...
"There are still many barriers to people living with HIV having good health. Many of these barriers are created by inequities in our health system leading to disparities in treatment outcomes. This is despite the UK having some of the best HIV treatment outcomes in the world. We have the advances in treatment that could benefit many more people and now we must work together to close these gaps and make the UK a place where everyone living with HIV gets the care and support they need."	"The UK has some of the best HIV treatment outcomes in the world. We have the advances in treatment that could benefit many more people and now we must work together to make the UK a place where everyone living with HIV gets the care and support they need. Because we know there are still many barriers – created by inequities in our health system – which are holding people living with HIV back from having good health."

Sequencing – efficacy / urgency positioning

Whichever sequencing you choose, make sure that there is a balance of urgency and efficacy, not just a pure crisis message. Both of the below examples strike the balance, but the emphasis is altered by changing the sequencing.

Efficacy before urgency

"As a society, we've come a long way. Incredible advances in treatment and prevention mean the goal of ending new HIV cases by 2030 is in reach.

But there is so much more to be done. Rates of sexually transmitted infections are higher than ever, demand for services is ever increasing, and access is limited for many of us.

If our leaders are serious about progress, they must act fast and put in place the changes that are needed to end new HIV cases by 2030."

Urgency before efficacy

"There is so much more to be done if we are to end new HIV cases by 2030. Rates of sexually transmitted infections are higher than ever, demand for services is ever increasing, and access is limited for many of us.

As a society, we've come a long way. Incredible advances in treatment and prevention mean the goal of ending new HIV cases by 2030 is in reach.

But if our leaders are serious about progress, they must act fast and put in place the changes that are needed to reach this goal."

Sequencing – losses / gains positioning

Leading with what we stand to lose

"Right now, too many people living with HIV are not getting the support they need. It's standing in the way of them living their lives to the full and holding our communities back.

For example, they may not have access to appropriate mental health care and have no one to help them advocate for this.

We need to change this. Together we can strengthen our communities by making sure everyone gets the support they need."

Leading with what we have to gain

"When everyone has the care they need, our communities thrive. We can decide – as a society – that everyone with HIV should be able to live their life to the full.

Right now, too many people living with HIV are not getting the support they need. For example, they may not have access to appropriate mental health care and have no one to help them advocate for this.

We need to change this. Together we can make sure no one is left behind."

Note

Use numbers to support your story, not to tell it

Without context and explanation, numbers can reinforce unhelpful mindsets and, in the case of prevalence stats, fuel fatalism, the sense that the problem is 'too big to solve'. Ask yourself these questions before including numbers:

- Are they helping to build understanding?
- Could they be fuelling fatalism or reinforcing stigma?
- Is there another number which could better support your story, such as one which shows the impact of a solution?
- If you took the numbers out, would your point still land?

NATIONAL AIDS TRUST

We're the UK's HIV rights charity.
We work to stop HIV from standing in
the way of health, dignity and equality,
and to end new HIV transmissions.

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