

## Fast-Track Cities London

### Draft proposals to tackle HIV-related stigma in London – have your say



MAYOR OF LONDON



## **Executive summary**

We know that in order to get London to zero new infections, zero preventable deaths and 100 percent of people living well, we must combat HIV stigma.

The London Fast-Track Cities initiative has secured a pot of funding for the next three years to address stigma as part of its work, with an ambition to make London an HIV-friendly city by 2030.

The Fast-Track Cities London Leadership Group set up a stigma subgroup to look at the current evidence on stigma, review existing work aimed at tackling stigma and draft an initial action plan. The stigma group has a wide membership including the voluntary sector, statutory organisations, clinicians, and people living with HIV.

The stigma subgroup has identified three key areas of focus to further London's response to HIV stigma: self-stigma, stigma in places/environments and stigma in wider society and has developed a change model to tackle these three areas.

Now the stigma group is looking for feedback on the draft plans from people living with HIV, the HIV sector and other stakeholders. The stigma subgroup wants to make maximum use of the collective expert knowledge and experience of the sector and the lived experience of the London HIV community in order to add value to work already happening in London.

## **The vision**

The vision for this work is to bring about social change to make London an HIV friendly city. Londoners will feel comfortable being open about their HIV status, will not experience inequality based on their status and will be able to live well. The Fast-Track Cities London roadmap (Appendix A), shows the steps we must take as a city to get to zero by 2030, the vision of what 2030 will look and feel like for London, and shows the relationship between the stigma work and the other workstreams.

## **The draft proposal**

Using the learning from similar initiatives such as Thrive LDN, Time to Change and Dementia Friendly Hospitals, this work would be founded on generative social action, face to face encounters, social media communities, peer support and advocacy and new commitments from organisations and institutions to do more.

The stigma group feels strongly that addressing intersectionality is key to tackling HIV stigma, by considering HIV stigma in the context of other societal discrimination. In addition, this work would look to tackle HIV stigma not only for people living with HIV but also those affected by HIV i.e. the family members and partners of people living with HIV and HIV negative people from 'high risk groups' who can also experience stigma in relation to their potential to contract HIV.

Fast-Track Cities London is proposing to create three workstreams to do the following:

**1. Tackle self-stigma by empowering people living with, affected by and at higher risk of contracting HIV.**

The proposal for this work is to create and grow a group of visible HIV ambassador role models and to set up and run an empowerment programme for cohorts of people living with, affected by and at risk of HIV to develop resilience, confidence and other skills needed to be truly empowered to stand up to stigma.

The vision is for the ambassadors to be visible and share their stories with both the HIV community itself and face to face and on social media aimed at the wider public. The vision for those who complete the empowerment programme is to create a self-sustaining model where those who complete the programme go on to share their own story as a new member of the ambassador's group and assist with the next cohort completing the programme.

**2. Create an 'HIV friendly' NHS and other government services**

Phase 1 of this work would focus on the NHS, including hospitals, GP practices and dentists. The proposal is to create an HIV friendly charter, laying out specific commitments to be met in order to be accredited as HIV friendly. Organisations would be asked to commit at board level, and then evidence what has been put in place against each commitment in order to receive the HIV friendly kitemark.

The proposed key commitments for organisations are to implement staff training, to run an internal campaign using a dedicated communications toolkit and to put in place a zero-tolerance policy to discrimination, with a clear reporting process.

The kitemark award process would include an annual review of continued commitment and adherence. Phase 2 would expand the HIV friendly charter to other government services such as care homes, the police force and housing offices.

**3. Shift the general public's perception of what HIV is in the 2020s for people living with HIV and those around them.**

The vision for this work is to create a strong 'come join us' call to action to create a social movement for change. The proposal is to create a separate brand as the umbrella to this call to action, similar to what was done for Thrive LDN.

The stigma group sees this work being largely driven by storytelling through social media, promoting the voices of the ambassador group formed by the peer empowerment work. The aim of this work would be to normalise HIV with a strong and positive narrative.

## Evaluation

Evaluation for this piece of work will be complex due to the complexity of both the subject being tackled and the system itself, where multiple interventions are already taking place to address stigma.

Members of the stigma group will be taking advantage of a masterclass run by Public Health England and the Greater London Authority on evaluation in complex public health interventions, which will support the members with designing a robust plan for evaluation.

## What will look and feel different?

In 2030 Londoners will be able to say:

- I do not stigmatise people living with HIV, at higher risk of HIV or those affected by HIV
- I am not afraid of contracting HIV from people living with HIV
- I do not experience stigma or discrimination based on my HIV status or any characteristics associated with a higher risk of HIV
- I feel free and able to be open about my HIV status without fear of stigma
- I have full trust that organisations that provide public services to me are HIV friendly
- I feel empowered to challenge stigma or discrimination when I witness it

## Next steps

The Fast-Track Cities London Leadership Group and the stigma group invite you to feedback on these draft proposals by emailing [hlp.londonftci@nhs.net](mailto:hlp.londonftci@nhs.net) by Monday 20 January 2020.

Your comments will be used to inform a face to face engagement event on Friday 31 January 2020, which will be a workshop style event to further shape these plans.

The stigma subgroup would like feedback on the following questions particularly, though comments on other aspects of the proposal are also welcome:

1. Do you support the three priority areas proposed? If your answer is no, please tell us what two to three key priorities you think are the most important for London to tackle?
2. Do you have any suggestions that would add to the current proposal of how best to approach one or more of the three key activities proposed?
3. Is there anything within the proposal you disagree with? Please provide detail to explain your position.
4. Are you already doing work that addresses or overlaps with one or more of the three proposed pieces of work? If yes, please use the survey link to give us further detail on your work:  
<https://www.surveymonkey.co.uk/r/MP3KBGR>
5. If you answered yes to question four, how would you suggest the work proposed by this group could best add additional value to what is already being done?

## Introduction

The Fast-Track Cities London business case to the NHS England London Regional Executive Team laid out a three-year programme of work to accelerate London getting to zero. One of the key workstreams set out in the business case was the stigma workstream. The business case detailed three key activities to tackle stigma:

- *Reshaping the public perception of HIV*  
Changing the perception of HIV from a death sentence to a long-term condition that people can live well with, and one in which when virally suppressed there is no onward risk of transmission.
- *Making the NHS a completely stigma – free organisation and rolling this out to other government services.*  
Behaviour change amongst staff and employers in the NHS to ensure zero stigma within healthcare settings.
- *Reaching the groups not currently engaged with services*  
Finding ways of reaching specific segments of London's population who do not come forward for testing and treatment because of stigma.

In order to tackle stigma effectively in London, the stigma subgroup wishes to engage widely with individuals and organisations working with London's HIV community. The stigma subgroup has used its knowledge and experience as a small representative group to create a draft proposal for wider engagement.

### 1. Taking stock of existing work

As the starting point to designing work around stigma, the stigma subgroup has considered existing work in London which specifically focuses on HIV prevention and/or stigma.

#### *The London HIV Prevention Programme*

Local authorities fund a London HIV Prevention Programme as part of their public health responsibilities, which centrally focuses on health promotion methods and access to testing and treatment. The work described in this document, funded by the NHS, is focused on tackling societal stigma and self-stigma to secure self-empowerment and a supportive environment for people living with HIV in order that they may achieve their fullest health and life potential.

The programme's Do It London campaign uses multiple marketing methods mixing a traditional marketing and advertising approach with targeted in-reach into community spaces and via social media channels.

The proposed work on stigma is a social movement, amplifying the stories of Londoners, normalising HIV via experiences of people living with HIV. It is founded on generative social action, face to face encounters, social media communities, peer support and advocacy underpinned by new commitments from organisations and institutions to do more.

Collectively both are seeking to reinforce the message that U=U and HIV does not mean a death sentence today. An element of both will be mutually supporting in that lower stigma reduces barriers to testing and treatment and greater awareness of modern treatment options reduces fear and stigma.

The other existing projects the stigma subgroup felt were particularly relevant to consider in our planning based on the types of interventions we are proposing are summarised as follows:

Aimed at individual level knowledge building, and behavior change:

- i) Public Health England's Changing Perceptions campaign
- ii) Terrance Higgins Trust's 'Can't Pass It On' campaign

Aimed at specific environments/places:

- iii) CHIVA's 'Educate Yourself: Working Towards HIV Friendly Schools'
- iv) The Homerton as a stigma - free zone
- v) Testing faith – faith leaders in several faith venues across eight London Boroughs
- vi) SHIP training – GP practices

Aimed at self-stigma:

- vii) Interventions such as peer mentoring support via organisations and clinics, workshops such as newly diagnosed course and social groups and meet ups. These are carried out by several HIV organisations and individuals to tackle isolation and self-stigma.

In addition, the stigma subgroup has looked at the current London baseline metrics on stigma already available:

- i) Positive Voices survey  
This was last completed in 2017 and provides London with some data of self-reported experiences of stigma.
- ii) The Stigma Index  
This survey has just been repeated in 2019 with a comprehensive set of questions relating to all aspects of stigma with the new data expected to be available in early 2020.
- iii) National AIDS Trust (NAT) public attitudes survey

The most recent public attitudes survey was completed by NAT in 2011, however, NAT are already in the process of recommissioning this survey to run in 2020. NAT have kindly agreed to allow Fast-Track Cities London an option to add additional questions or enhance the London sample size in order to collect an up to date baseline of the London public's attitudes to HIV ahead of any interventions.

## 2. Defining the change model

### 2.1 Learning from similar initiatives

The stigma subgroup has worked on design principles and a change model of how to effectively tackle stigma based on the available data and evidence of what works. This was done by reviewing NAT's comprehensive literature review: 'Tackling HIV stigma: What works?' and by looking at the change models of similar initiatives including Thrive LDN, Time to Change and Dementia Friendly Hospitals.

Both Thrive LDN and Time to Change are social movements which have used extensive engagement with both experts by profession and by experience as well as campaigns, to start an open conversation with Londoners about mental health and wellbeing.

Thrive LDN generated over 420,000 interactions and work with partners on several citywide and local projects across London. They also held community workshops, in partnership with the Mental Health Foundation, in 16 of the 32 London boroughs to start conversations on a community level.

Time to Change is a growing social movement working to change the way we all think and act about mental health problems. Time to change has focussed work on addressing stigma in the workplace, working with children and young people and using champions to address stigma at community level.

Dementia Friendly Hospitals is a fantastic model for the work proposed on creating HIV Friendly organisations. In October 2012 the Dementia Action Alliance, in partnership with the NHS Institute for Innovation and Improvement, launched a Call to Action for the improvement of care for people with dementia in hospitals.

The goal of this work was that by March 2013 every hospital in England would have committed to becoming a dementia friendly hospital, working in partnership with their local Dementia Action Alliance. 164 acute and non-acute trusts made that commitment, with 88 submitting action plans and joining the Dementia Action Alliance. The Dementia Friendly Hospital Charter is the second phase of the Right Care initiative, now called Dementia Friendly Hospitals. Hospitals are being encouraged to sign up to the charter.

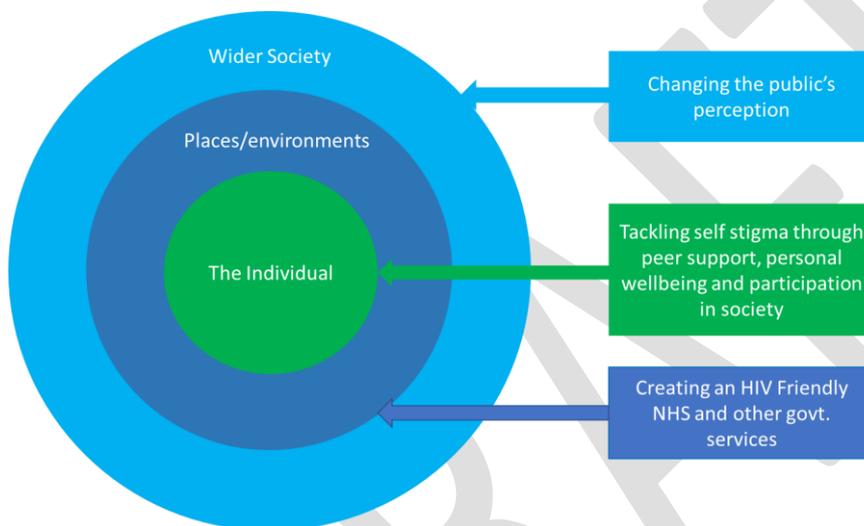
In order to tackle HIV stigma, London needs social change like this. The ideal situation for change occurs when mounting grassroots pressure merges with national or regional leadership committed to the same change. Fast-Track Cities London, with its strong buy in

and support from regional and national leadership, is well placed to act as the mechanism to link leadership with enhanced grassroots action.

## 2.2 Proposed model of change

The stigma subgroup discussed a broad model of tackling stigma at each level to achieve the stated aims i.e. in the HIV community itself, in the places and environments where we know stigma exists and the perceptions of wider society of HIV today.

Figure 1: Broad model of change



Enabling local communities and grassroot groups to address self-stigma and external stigma would mean:

- ‘In-reach’ into unheard communities by using existing relationships and knowledge in local communities.
- Using arts and culture to engage new and diverse audiences by sharing the impacts of stigma and to shift the perception of HIV in these communities.

We have borrowed from the Thrive LDN model for change to think about our approach as follows:

Figure 2. Approach to change<sup>1</sup>



<sup>1</sup>Adapted from 'Ensuring all Londoners have an equal opportunity to good mental health' Purpose x Thrive LDN

Borrowing from the 'Time to Change' model the stigma subgroup also wants to create space for open dialogue, where positive examples of tackling stigma can be shared as well as an acknowledgement of instances where stigma still occurs. The Dementia Friendly Hospitals model also provides us with a fantastic way of using the top leadership level of organisations to buy into adopting a charter, which puts in place all the necessary policies, environment and staff knowledge to create a friendly environment for service users.

### 2.3 Principles

Within the proposed change model, the stigma subgroup felt it was important to agree the principles on which all the stigma work will be based. These principles are drawn from the expertise and experience of our stigma subgroup members, work already completed, such as the NAT report 'Tackling HIV stigma: What works?', alignment with the ethos, aims and ambitions of the Fast-Track Cities initiative itself and the roles of the Fast-Track Cities London Leadership Group as articulated on the Fast-Track Cities London roadmap.

The stigma subgroup's proposed principles for tackling this complex problem are as follows:

#### a. *Being community led*

Keeping people living with HIV at the centre, and for the work to be led and where applicable delivered by people living with HIV. To create mobilised, empowered community members in order to transcend the power structures where stigma still exists.

*b. Using the right language*

Ensuring the language used does not reinforce stigma and considers intersectionality. Ensure the language used means something to the people we are trying to reach.

*c. Putting the 'human' back into HIV*

Ensuring a focus on the whole person living with HIV rather than the virus as a 'separate entity' and focusing on normalising rather than sympathising. Framing the problem as not HIV – but rather the way people sometimes react and respond to HIV. Including conversations about sex to break down taboos about discussing sex as the first step to also discussing HIV. Being aware of intersecting issues and how these contribute to inequity of access to care and support.

*d. Naming stigma and making people aware*

Making it clear what stigma looks like in practice and how it impacts people's lives.

*e. Strengthening the collective response to stigma across the UK*

Ensuring we remain connected to other UK cities to work together where possible to strengthen the response to stigma nationally.

*f. Continually improving and learning about the most impactful ways to tackle stigma*

Ensuring interventions to stigma are robustly evaluated to add to the evidence base of what works.

*g. Focusing on intersectionality and health inequalities*

Acknowledge and support efforts to tackle broader health and social inequalities that are impacted by and reinforce stigma. People living with HIV are diverse and therefore diverse approaches are important to ensure inclusivity. A focus on the depth of reach into the communities not currently engaged with HIV.

*h. Stimulates wider social action*

Ensuring that fighting stigma is a collective responsibility of society and involves social action. The process for this is not a command and control model but one in which multiple activities are contributing and celebrated, both those that are centrally directed and those that emerge more organically.

*i. Has additive value to existing work tackling stigma*

Recognition of existing work tackling stigma and ensuring any work commissioned provides additional value to existing work.

### 3. Proposed workstreams

#### 3.1 Tackling self-stigma (the individual)

Self-stigma affects the way individuals feel about themselves as well as how they perceive and manage external stigma and discrimination, and for some it can have a significant impact.

The existence of self-stigma demonstrates the complex relationship between social norms, stereotypes and concepts of good or bad behaviour, and the way these translate into how we feel about ourselves. Support for people living with HIV has long been recognised as an important aspect of treatment and care, in part because it reduces self-stigma which is linked to better adherence to ART and health seeking behaviours.

The evidence tells us that providing opportunities to discuss stigma and the factors contributing to it with peers is an important component of tackling stigma. Peer support workers who have lived experience can play a pivotal role in the support of people living with HIV's wider care needs, both at diagnosis and throughout a person's care pathway. Self-stigma may be a part of a greater range of emotional issues and may exacerbate existing emotional or mental health needs. Peer support may be one of a range of interventions that are of use in dealing with self-stigma. We recognise that peer support can also be effective when used in conjunction with other emotional wellbeing interventions such as counselling or brief interventions. Psychological support improves both mental and physical health and reduces the risk of HIV transmission. The availability and quality of psychological support for people living with HIV is currently variable. The NAT review on what works also recommends creating programmes for people living with HIV which combine skills building activities, peer support and opportunities to discuss stigma and its effects and to promote opportunities for people living with HIV to speak as a community in challenging stigma and discrimination.

The stigma subgroup proposes two key activities to tackle Londoner's self-stigma:

- i) A group of visible HIV community ambassadors

This group of ambassadors would represent the full range of diversity within the HIV community and will serve as role models in tackling HIV stigma. The Fast-Track Cities London Leadership Group would be able to draw on this group's expertise and experience to support and promote all parts of the programme including addressing Trust boards/CCGs to advocate for them to adopt the HIV friendly charter, speaking at events, and promoting the public facing work. This initial group of ambassadors would also be used to reach into communities to connect the programme with communities in the places they go and to create the first couple of vignettes in the form of visual stories described in more detail in section 3.3, to begin to share stories to engage the wider public in what it means to be HIV positive today.

ii) Empowering the HIV community through development and support

To add additional value to existing peer support and peer mentoring services, the stigma subgroup proposes using an outward facing team to engage with communities on their terms using the visual stories created by the ambassador’s group. The aim would be to create a sustainable infrastructure to support ongoing cohorts of people living with HIV. The cohorts would work through a series of learning and skills building sessions to develop their resilience, knowledge, and speaking skills to truly empower them to stand up to any stigma witnessed or experienced. The model for these cohorts could be that people would, having gone through the development journey themselves, go on to support others through the same journey. They may also become ambassadors themselves and so in this way the ambassador’s group and a movement of open discussion about HIV would grow. For those willing to take part, we would invite those who have gone through this journey to add their story to the those being shared in the public facing work.

Sustainability would have to be an important consideration in this piece of work, as well as considering the numbers of people who would need to be trained to reach a large enough threshold.

Based on the proposed change model this part of the work would look to **ENGAGE** those currently not interacting with HIV services **TO** reach underserved communities in the places they already go so **WE CAN INFLUENCE** the narrative on HIV including misconceptions and myths about what it means live with HIV today, **TO ACHIEVE** empowerment of people living with HIV who currently don’t feel confident to be heard and **REALISE** a change in challenging stigma and stigmatising behaviour.

3.2 Tackling stigma in the NHS and beyond (places/environments)

The places and environments we know people living with HIV experience stigma are a key focus area in getting to zero stigma. As described in the business case, the NHS has a significant role to play in this, given that the 2017 Public Health England Positive Voices survey results showed that HIV stigma still exists within healthcare settings.

2,148 London survey participants answered the survey with results on healthcare stigma as follows:

Because of your HIV status, have you experienced any of the following in a healthcare setting in the last year in London?	
Been worried that you would be treated differently to other patients?	13.7%
Avoided seeking healthcare when you needed it?	8.2%
Been treated differently to other patients?	6.4%
Felt that you were refused healthcare or delayed a treatment or medical procedure?	4.1%

In order to address stigma in healthcare settings and other government services, the stigma subgroup proposes the following:

**In phase 1:**

The stigma subgroup will focus on developing an 'HIV friendly' charter for NHS organisations to sign up to. The aim will be to make this charter simple for NHS organisations to implement while covering the key commitments needed to ensure a real impact.

The charter will be made up of three main components: commitment to a 'zero tolerance' policy on HIV discrimination, commitment to training a minimum percentage of patient facing staff, and support for staff living with or affected by HIV. It will ask for board commitment to ensure full buy in from organisational leadership, and for evidence of meeting the criteria in order to be awarded the HIV friendly kitemark.

a) A zero tolerance policy

NHS organisations would have to evidence the existence and visibility of a reporting mechanism for any incidences of stigma, and that a review of all policies has been undertaken to ensure none perpetuate or allow for stigmatising behaviour.

b) Staff training

Organisations would need to evidence they have trained a majority percentage of patient facing staff and managers using the free training package provided. The content of the training will be based on the principles described above to ensure the training is meaningful, engaging, and impactful, and will likely include personal stories and experiences of people living with HIV to involve people living with HIV in developing and delivering the training, and to virtually connect people living with HIV with those not living with HIV.

Based on advice from Health Education England and Trust learning and development departments the online training would likely be 20 – 30 minutes long and would be hosted on the national e-learning for health (e-lfh) staff training system already used by NHS organisations. We would bring on board a learning and development professional/s as part of the design group to ensure the training is high quality and that learning and development leads would be confident promoting this training to their staff. Alongside the training, face to face talks to staff by people living with HIV and a communications toolkit for promoting the training would be developed and provided to Trusts and CCGs as part of the charter package. Evaluation would be carried out through pre- and post-training surveys sent to Trusts via a link to disseminate to all staff.

For primary care, the stigma subgroup proposes linking in with existing HIV training for GPs to include the e-learning module as part of the training course, with evaluation alongside their current evaluation process. An invitation will go out for existing training programmes that

already deliver pan-London GP training to bid for additional funding in order to deliver and evaluate this alongside their existing training.

c) Be visibly HIV friendly

This will be a way for Trust and GP surgeries to make visible the commitment to being stigma-free. The vision for this is to have something that celebrates the achievements of the London HIV sector in tackling HIV to date and highlights the 'last yard' in getting to zero together.

Organisations who meet all the above criteria will be awarded the HIV friendly kitemark on an annual renewal basis, with the need to submit up to date training data.

In year two and three, this charter will be extended to other government services for example housing offices, job centres, the police and care homes following a similar process to the NHS. The specification for the training will stipulate that the content is suitable for this wider audience.

Based on the proposed change model this part of the work would look to **ENGAGE** healthcare workers and NHS staff **TO** promote the positive message of where London has got to in its HIV response while highlighting the impact of stigma that still exists in healthcare settings so **WE CAN INFLUENCE** the understanding of healthcare workers of people living with HIV, **TO ACHIEVE** reduction in stigmatising clinical behaviours and **REALISE** a stigma free NHS.

### 3.3 Reshaping the public perception (wider society)

The stigma subgroup believes that in order to create the social movement needed to really change the attitudes and behaviours of the London public, a strong 'come join us' call to action is needed. As Fast-Track Cities London is not a professional focused brand, the stigma subgroup proposes creating a public-friendly brand as an umbrella for this call to action.

The stigma subgroup sees this work being largely storytelling driven using social media and other online channels rather than a picture/poster-based campaign, promoting the voices of Londoners living with and affected by HIV. The aim of this work would be to normalise not sympathise and sow a strong and positive opportunity to live well and stigma free.

The stigma subgroup sees the narrative of this piece combining a celebration of the amazing achievement of how far treatment and quality of life has come for Londoners living with HIV with how close London is to getting to zero. The stigma subgroup wants it to be educational to help the general public understand how stigma is standing in the way of the 'last yard' in getting to zero.

Evidence of what works in tackling HIV stigma tells us that the most effective way to tackle stigma is through exposure to personal experiences and having direct personal contact with people living with HIV. By their nature, these types of interactions put a limit on the number of people who can be reached. The stigma subgroup proposes using virtual exposure to people’s real stories in order to connect people living with HIV and people not living with HIV. The stigma subgroup proposes putting out a tender for this creative visual campaign to allow bids for the most creative, visually engaging idea that will ignite the public’s interest and have a legacy as a cultural piece documenting London’s last hurdle in eliminating HIV.

Based on the proposed change model this part of the work would look to **ENGAGE** the general London public **TO** join a call to action so **WE CAN INFLUENCE** understanding, empathy and knowledge, **TO ACHIEVE** a coming together of Londoners with a new perception of HIV to **REALISE** a stigma free London.

#### 4 Project phasing:

Funding of £800,000 per year for year 1 and 2 and £750,000 for year 3 has been secured through the business case to NHS England (London Region) to support this work, including programme delivery and other associated costs. Commissioning of the individual pieces of work described in this first draft proposal is yet to be determined, based on the final shape of the plans.

Should the workstreams proposed be broadly supported, the stigma subgroup proposes standing up the HIV friendly charter and the social change piece straight away, as the first pieces of work which can be easily designed and commissioned, while building the ambassador’s network and designing the infrastructure for the peer support work, which would then receive more resource in years two and three.

High level project phasing for the proposed workstreams			
Area	Phase 1	Phase 2	Phase 3
Individuals	Create ambassadors group. Establish infrastructure and fund for 3 years’ worth of community peer support.	Create and build community peer support. Evaluation review point.	Phase 2 based on evaluation.
Environments /places	Launch NHS friendly charter (Trusts, GPs, dentists, pharmacies)	Evaluation: care homes.	Evaluation: job centres, housing office, the police

Public perceptions	Launch of 'call to action': procurement of brand and social media work.	Launch on World AIDS Day. Post evaluation review of next phase of work required.	Phase 2 based on evaluation.
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