Fast-Track CITIES

Appendix B: All feedback received on the original proposal

Key points of the feedback received via email as of 19.02.2020

The feedback received said:

1. **Intersectionality** must be addressed, and ambassadors should represent **all people** living with HIV. Although choosing not to mention key populations in the proposal, there is **concern** this may mean some communities are **excluded**.

2. Empowerment programmes **should go beyond training one cohort of ambassadors**; plans for **continuity and sustainability** need to be considered so impact extends beyond the Fast Track Cities Initiative funding.

3. True empowerment should make sure ambassadors learn **transferrable skills** that will help in **gaining employment**.

4. There is **overlap/possible duplication** with the proposed work and other **already existing initiatives** (Emerging Communities Programme, METRO Charity; Positively UK projects i.e. Project 100; Positive Voices, Terrence Higgins trust).

5. Engaging and empowering communities should be enhanced through community organisations where people living with HIV are **already accessing services**. The proposal should **build on existing initiatives** (mentioned in point 4); such organisations are **well-placed** for ensuring engagement and empowerment of communities across the FTCI proposal.

6. Empowering the HIV community through continuous development which needs to be **led by people living with HIV**, and needs to be **participatory, creative, trauma sensitive** and **draw on skills already in the community**.

7. Empowerment programmes must consider **structural issues** and **intersectionality** so those **most marginalised** are **motivated** and able to **participate**.

8. Ambassador proposal work should be **adjustable** and **adaptable**; a **one size fits all** model should **not** be used. Making sure those who have completed the programme **pass on their experiences is important**.

9. **Other training** such as **mental health awareness**, **trauma management** and **computer skills** should be considered.

10. **Mental health support** was mentioned in the proposal but not addressed; peer support is vital but full support needs to go beyond this.

11. How will **ambassadors appeal** to anyone **beyond the HIV sector**?

Key points of feedback received from the stigma engagement event workshop and individual reflections session:

The feedback received at the engagement event said:

1. We must ensure ambassadors receive **adequate preparation** and **ongoing** support and supervision throughout the ambassador and peer support training process.

2. We should ensure the peer support work plans are holistic; they encompass the **complexities** of a person and co-morbidities too.

3. We should workshop and **research lived experience** around self-stigma to **inform design** (and engaging **outside of usual suspects**).

4. We must ensure robust **training**, and **capacity building** is included in the work design.

5. We need to link with the **improvement collaborative** to ensure work design is not being duplicated and to work with those who are **already engaged**.

6. We need to consider having a **real paid incentive** for people to be an ambassador.

7. We must have clear **terms of engagement and protocols for ambassadors,** so they have clarity in expectations of them.

8. We need to ensure ambassador training embraces a **trauma informed approach** and considers **mental health support** and training.

9. We need to consider the **tension** between supporting an **individual vs. the population** in the ambassador/empowerment programme and think about **how** we will best support the ambassadors we are training.

10. This work needs to be **co-produced** from a range of voices. We should endeavour to have **workshops** around **beliefs** or a '**London wide sense check'** so we are not '**lazy'** around **grouping** people.

11. We need to consider **multi-agency work/support** as people living with HIV may have **pre-existing vulnerabilities and co-morbidities**. We also need to consider the **multiple layers of stigma** that may impact people living with HIV.

12. We need to be clear on communicating **what we mean by 'peer'**. People belong to different peer groups and we must ensure people understand what peer support is so they do not feel excluded from accessing support.

Stigma in places/environments:

Key points of the feedback received via email as of 24.01.2020

The feedback received said:

1. The charter is recognised as **important** and **required** across health and social care.

2. There is some **overlap** with existing work - a kite mark called **Positive Allies** from The University of Sunderland.

3. The charter should recognise **intersectionality** to be **inclusive** of all people living with HIV, including **undocumented migrants**.

4. The **timescale** to **expand** the charter beyond the NHS should be reviewed; waiting up to **two years** before expanding to government bodies/other organisations is **too long**.

5. Collecting **stories** from healthcare workers about HIV stigma is a good idea.

6. Working with **existing initiatives**, such as the **Healthy Workplace Charter** should be considered.

7. The charter is important, because **to tackle wider stigma** we need to **start in our own backyard first**. Specifically, feedback has been received regarding the experience of an individual living with HIV and **clinicians denying a link between antivirals and diabetes**.

8. Sometimes NHS staff have **little knowledge of initiatives** operating within **their hospitals**. The charter was supported as an **important first step** but warned that **changing culture** requires adequate **resource, training, monitoring and revision.**

9. Care needs to be taken in the **use of the positive voices survey** as **evidence** of HIV stigma within healthcare settings as it **measures perceived stigma**, which may represent **internalised** as **opposed** to **experienced/externalised stigma**.

Key points of feedback received from the stigma engagement event workshop and individual reflections session:

The feedback received at the engagement event said:

1. More thought is required on how we plan to **incentivise trusts** and create **meaningful kitemarks** that NHS staff would be willing to support – how will we sell it?

2. We need to **define** exactly what we mean by **'stigma friendly'**.

3. We should undertake **baseline testing** by implementing a number of **pilot programmes** in those hospitals we know are keen to implement - quick wins which might encourage other trusts to follow suit.

4. Lets begin by **targeting** the places we know people are **experiencing stigma** E.g. Dentists, A&E.

5. We should **acknowledge** clinical confidence and knowledge are often a **barrier** for primary care.

6. **No shaming** – we should think carefully about the **language** we use and move away from the term 'zero tolerance'.

7. Why don't we **survey NHS staff** and understand what methods they think would support the creation of a 'HIV friendly' environment.

8. We should facilitate a **feedback/reporting process** or portal where patients are encouraged to **share their experiences** creating links with peer support and **empowering people** to challenge negative experiences.

9. **CCGs and local authorities** should be involved.

10. More consideration could be placed on **addressing ALL forms of stigma**, not just HIV E.g. Hep C, Hate crimes.

11. Strong links and shared learning should be maintained across each of the **3 key areas as they all overlap**.

12. We need to encourage people to **start using their GPs** – start with primary care and dentists.

13. We need the NHS to implement a **primary care model of HIV as a long-term condition** – through trained lead GPs.

Stigma in wider society: Shift the general public's perception of what HIV is in the 2020s for people living with HIV and those around them:

Key points of the feedback received via email as of 24.01.2020

The feedback received said:

1. Public engagement or promotional **material** needs to **highlight U=U.**

2. The proposal should recognise and capitalise on the **impact of PrEP**, especially with **marginalised communities**.

3. **Concerns were raised about** creating a separate HIV brand for London, given there are already other stigma campaigns running in London, for example, Do It London, Can't Pass It On, It Starts With Me and National HIV Testing Week and other social media campaigns.

4. A suggestion was made that rather than creating a new campaign, the focus should be on amplification of **an already successful campaign** by providing **additional funds**. The FTCI proposal and Healthy London webpages are **conflicting**; the proposal suggests creating a new brand but a Healthy London web page suggests FTCI is looking to drive forward and amplify work.

5. Where is the **evidence** is suggesting **social media works better than poster-based campaigns**?

6. Having a campaign with a **mechanism to represent images** and **content** from people living with HIV is a **necessity**.

7. Using **Thrive** and **Time to Change models** is a good idea**,** as the use of such models have worked for certain organisations. There is an **opportunity** to **share methods** to contribute to success.

8. Although the Do It London campaign is very high profile and does a great job with combination prevention, it doesn't explicitly deal with stigma and the involvement of the HIV community is not there, particularly the African community.

Key points of feedback received from the stigma engagement event workshop and individual reflections session:

The feedback received at the engagement event said:

1. We need to find the **current gaps** in reach and topic of existing campaigns (i.e. THT and LHPP) and **segment** the campaign to **address** these gaps.

2. We should target **schools** to ensure the next generation do not hold stigmatising views of HIV.

3. We should ensure any campaign is both **positive and celebratory**.

4. We should create **HIV allies** as part of the campaign to raise awareness and shift stigma **outside of the HIV sector**, for example by engaging with supermarkets and car dealers.

5. We need to **strengthen** what we **have already** and work with already existing campaigns to link up and boost communications.

6. We need to be aware of where communities **consume their information** (i.e. newspapers/TV, not always on mainstream social media). In particular, we must consider that **those not living well with HIV** may be the **hardest to reach**. The campaign to shift societal stigma should have a wide reach and this means reaching all people living with and without HIV.

7. Tackling societal stigma should not rest alone on people living with HIV. We must include the **HIV-** population as well as people living with HIV in any campaign plans.

8. Education about HIV **cannot** rest solely on the U=U message. There will **always** be people **not living well with HIV** and it is important to ensure they **do not** feel **marginalised** or **othered** by this kind of campaign. We must ensure a campaign has a wide focus, whilst simultaneously raising awareness about key topics, such as PrEP and U=U.

9. If we want to change the public's perception, we need to **engage with people outside the HIV world directly** by having separate engagement events and to work that would **appeal to the wider public**.

10. We need to do something big and bold and different to what has been done by existing campaigns. We should consider doing a **large march** across London/a big **south bank festival**/and or **story lines in soaps** or other **TV programmes** people already watch for enjoyment (**not documentary style**).

11. We should **use influencers/icons** to tackle stigma as a way of reaching the **wider public**.

General Feedback:

The feedback received said:

1. The **language** in the document is **not accessible** for all. It is quite **hard to read** and requires you to have **at least a graduate degree** (as measured by the Gunning Fog Index), to fully understand the content. This is **contradictory** to the **proposal**, which states ensuring proposed **work is accessible** for all.

2. All people living with HIV should be **included** in any work, however it is a necessity to recognise **different communities** face **different intersectional stigmas** and **different initiatives** will need to be considered to tackle such stigmas. Differences should be spelt out at **early stages** so at implementation there is not a realisation that communities have been excluded and any work should be made wholly accessible.

3. There is **concern** about the **sustainability** of the work once funding has come to an end.

4. Asking for **feedback**, working in **collaboration**, **learning** from what exists, **created by people living with HIV** will add the **best value**.