Learning from London’s HIV elimination efforts to improve community leadership and partnership across health systems

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HIV: 39,000 people living with HIV in London

- Extraordinary progress since first reports of AIDS in the 1980s
- HIV important ongoing public health and inequalities concern:
  - 1,600 undiagnosed
  - 8,000 may have transmissible levels of HIV
  - High levels of stigma and discrimination which reduces quality of life, testing, treatment and care
  - Underserved and marginalised communities disproportionately affected

- People on effective treatment cannot pass it on U=U
London’s HIV partnership working

- Needed a radically different approach, fully embracing expertise of people living with HIV and the voluntary sector.
- HIV improvement community launched in March 2020, £3m over 3 years – 13 projects led by 22 voluntary sector organisations working closely with 9 NHS trusts in London.
How did we do it?

• Quality Improvement approach with a relentless focus on the needs of the whole person rather than just their health condition.

• Projects brought together regularly to promote continual learning, sharing of skills and information as an adaptive network, collaborating across the system in London.

• Partnership was given: freedom, funding, support and the stability of a three-year duration, all provided in a unique environment for the projects to flourish.
FAST TRACK CITIES LONDON IMPROVEMENT COMMUNITY

Our projects launched across 3 themes

2020

Testing
Improving quality of life and psychosocial support
Working with underserved communities

4,750+ people tested
850+ test kits distributed

Test in a range of settings including

Faith settings
Homeless shelters
Health clinics
Community organisations
Mobile clinics in communities

Working directly with

22
Voluntary and community organisations + their local partners
9
Hospital trusts

People in our social groups for mothers of young children say...
I feel more connected with people like me, it helps me break through the feelings of isolation

We are supporting...

70 people struggling with alcohol and drugs
92% are undetectable
HIV status recorded increased from only 50% up to 95%

Many people tell us...
I've never been tested in the UK for HIV...
I've never heard of PEP or PrEP...

Educational videos
150,000 views

We've seen
100%

benefits secured

£1.1m+

People diagnosed with HIV and getting treatment
740+
people receiving psychosocial support

People receiving psychosocial support report...
I feel less isolated and more confident

Ending HIV stigma and discrimination in London
Ending new cases of HIV
Preventing unnecessary deaths
Why it worked

• People living with HIV instrumental in co-designing the improvement community from the outset, now involved in many of the projects.

• Targeted and personalised services, adapted to people’s needs, designed by people living with HIV.

• Many examples of improvement collaboratives across the NHS, but rarely focused on voluntary sector leadership and on tackling inequalities to this extent.

• Wider partners have been involved, e.g. faith leaders trained to talk to their congregation about HIV, training for support workers in homeless hostels, brief intervention training for drug and alcohol workers to support people with misuse issues.
What next?

• Each new diagnosis saves the NHS around £140k by avoiding future transmission of HIV, improving health outcomes and avoiding admissions or intensive care by diagnosing before its needed.

• This is a blueprint for managing long-term conditions in the NHS with the support of patients, communities and the voluntary sector.

• Embedding peer support into NHS clinics is improving health outcomes, retention in care and lost to follow ups, as well as quality of life, stigma and discrimination. Clinicians reporting a transformed way of working.

• London’s partnership led to routine HIV testing in ED programme (launched 1 April 2022) which is causing referrals back into these projects.