













Definition of linkage to care and challenges in monitoring

Dr Valerie Delpech

















Acknowledgements People living with HIV



Sara Croxford, Meaghan Kall and the team at PHE Megan Auzenberg, Watipa Rosalie Hayes, Yusef Azad and Deborah Gold, NAT Anastasia Pharris, Teymur Noori, Andrew Amato ECDC Dorthe Raben, the CHIP team and Integrate Partners Sylvia Petretti, Ewan Summersby and the Positively UK team













Integrate

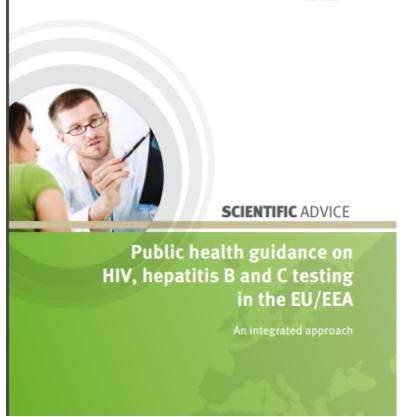
Talk Overview

Agreed definition
Sources of data
monitoring challenges
who cares?



Early Warning signs, Impact of the MCP, Cambodia, Watipa 2018





Dec 2018

Principle 3.

- Linkage to care is a critical part of an effective testing programme Ensuring that people diagnosed with HBV, HCV or HIV are transferred to treatment and care services is an essential element of any testing programme.
- Testing services need to include a well-defined referral pathway to link people diagnosed to both clinical care and support services.
- This pathway should be communicated and made easily accessible to all staff within the service. Linkage to care need to occur in a timely manner and processes introduced to enable follow-up on any non-attendees.



'Patient entry into specialist HIV care after diagnosis, measured as the time between the HIV diagnosis date and either the first clinic attendance date, first CD4 count or viral load date, or HIV treatment start date, depending on data availability'

Linkage is considered prompt if within 3 months of diagnosis.'



WP 4

Review existing literature on linkage to HIV care in Europe

'The variety of settings, time periods, populations and definitions utilised, made it difficult to compare measurements between countries and studies. "

EACS 2015

Linkage to care following HIV diagnosis in Europe: a review of the literature



Sara Croxford¹, Dorthe Raben², Flona Burns³, Valerie Delpech¹ for OptTEST by HIV in Europ

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BACKGROUND

- · Linking people who test HIV-positive to accessible and culturally appropriate care and support services is a crucial step in the HIV continuum
- · Delayed Inkage to HIV care is associated with delayed receipt of antiretroviral medications, faster disease progression and increased
- Though there have been efforts to describe existing definitions of retention in HIV care,? there is little work to date describing linkage into care in Europe
- · We reviewed the existing literature on linkage to care following HIV diagnosis and discuss the variation in definitions applied in Europe.

METHODS

- · A literature review was conducted using Publied and Google Scholar to search for relevant academic publications.
- A PICO framework was utilized to design the search strategy
- Population: people newly diagnosed with HIV; Intervention: HIV diagnosis; Comparison: none; Outcome: linkage into care
- Database search: "HIV" and search terms including: "linkage to care", "integration into care", "entry into care", "enrolment in care", "newly diagnosed in care", "engagement in care", "treatment cascade" and "continuum of care".
- To be included, studies had to be in English, set in the World Health Organisation (WHO) European Region and published before June 2015.
- · A grey iterature search was performed to find relevant conference proceedings and

RESULTS

- Overall, >1,000 titles/abstracts were reviewed and 22 studies included, from Belgium, Denmark, France, Georgia, Greece, Italy, the Netherlands, Poland, Russia, Spain, Ukraine and the United Kingdom.
- Seven studies defined linkage to care as the time between HIV diagnosis and first CD4 count and/or viral load, with prompt linkage defined as a measurement taken. 1-6 months after disprovis (Table 1).
- Delayed Intage was defined by Ndlaye et al as presentation to care with advanced HIV disease and HIV diagnosis +6 months before initiation of care (cohort data from Beiglum (Brussels) and Northern France (Nord Pas-de-Calais) 1997-2007: 16.7% (ne-95)).²⁴
- . The studies used registration or enrolment at an HIV clinic as a marker of being linked to care; three studies, attendance to an HIV specialist appointment; two, first HIV consultation; and one, an HIV unit referral. Two studies presented the proportion receiving HIV care (Table 1).
- Van Beckhoven et al provided an estimate without defining linkage to care (Belgium 90.3% (n=3646); surveillance data 2007-2010).*
- The majority of measurements relied on HIV surveillance data (n=11), with five studies presenting aub-national data from a variety of settings, such as hospitals in a particular area or city; in four studies, data were collected from a single clinic

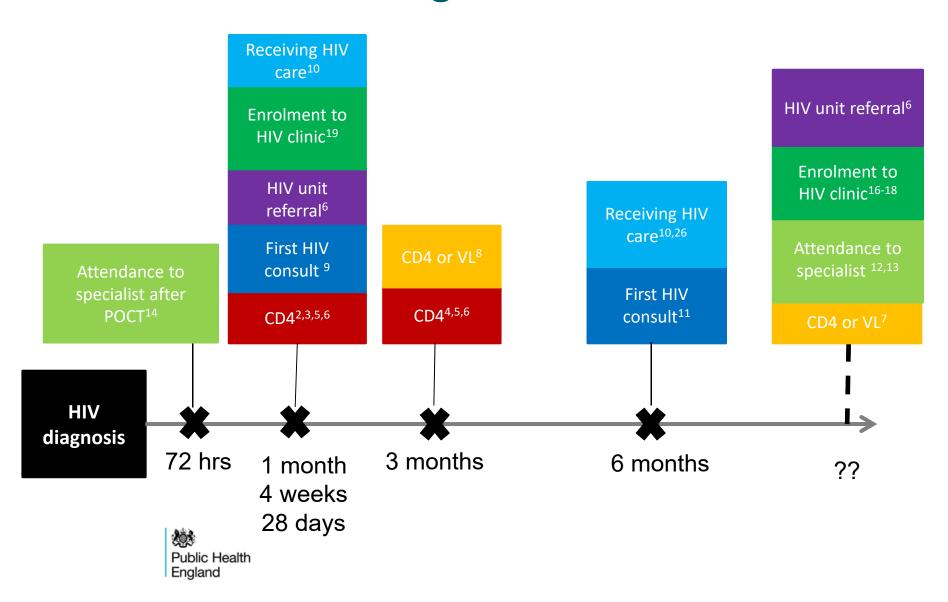
Table 1: Definitions of Injuge to care presented in the literature: WHO European region, June 2015

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	Heliatory 2018 ¹¹	Decembri	Patricipal report many	1005-3010	BM (504)
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Office Countries (September 1997)	Addresists Retrest 2016	Projecti	Community siring	2019-2011	789.4(7)
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rittin Emorte of deposis	Sevin 2002	United Kingdom (Constant)	Christmanny	1000.300	MP4 (300)
	Supports 2010	France	Sentens	2040	1984

CONCLUSIONS

- There are many definitions of linkage to care following HIV diagnosis that have been applied in the Iterature from
- The majority of studies rely on aboratory data which, deepte being relatively reliable, may not always accurately reflect the date when a satient is integrated into HIV specialist
- The variety of settings, time periods, populations and definitions utilised, takes it difficult to compare
- A standard working definition of linkage to care is necessary to ensure consistent monitoring of the quality of HIV care and patient dinical outcomes.

Croxford et al, 2015 Definitions of linkage to care in the literature



Systematic review and meta-analysis Croxford et al 2016-7

- Total number of records: 4,716
- Number of studies included: 24 linkage to care estimates: 22 factors for poor linkage: 7
- Data from 19 countries; 89,006 people
- Ability to compare estimates of linkage to care between studies was limited by the varied populations, settings and methodologies
- Meta-analysis of 12 studies measuring linkage at three months: 85% (95% CI: 75%-93%); heterogeneity high
- Factors for poor linkage: HIV acquisition heterosexual contact/ injecting drug use, younger age, lower education, feeling well and diagnosis outside an STI clinic













Integrate

How do we monitor linkage to care?

- community and clinic level
- national surveillance systems
- european level (Tessy, surveys, DD)













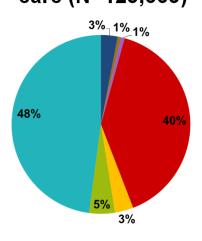


Recommended Indicators to Measure Testing Services in European and International Guidelines

	COBATEST	OptTEST/HIV	Testing
What data do they collect?	Network	in Europe	Week
Disease(s)	HIV/ HCV/ Syphilis	HIV	HIV / viral hepatitis
Setting	CBVCTs	Healthcare	All
Persons attending service (N)	✓	✓	✓
HIV tests performed (N)	\checkmark		
Reasons for HIV testing (e.g. risk behavior/factors)	✓		
Clients/patients offered test (N)	N/A	✓	\checkmark
Clients/patients accepting a test (N)	N/A	✓	✓
Clients/patients reporting previous HIV test (N)	✓		
Clients/patients with reactive/positive screening result (N)	✓	✓	✓
Clients/patients with reactive/positive screening result who had a confirmatory test (N)	✓		
Clients/patients with a positive confirmatory test result (N)	✓		
Clients/patients linked to care (N)	✓	✓	✓

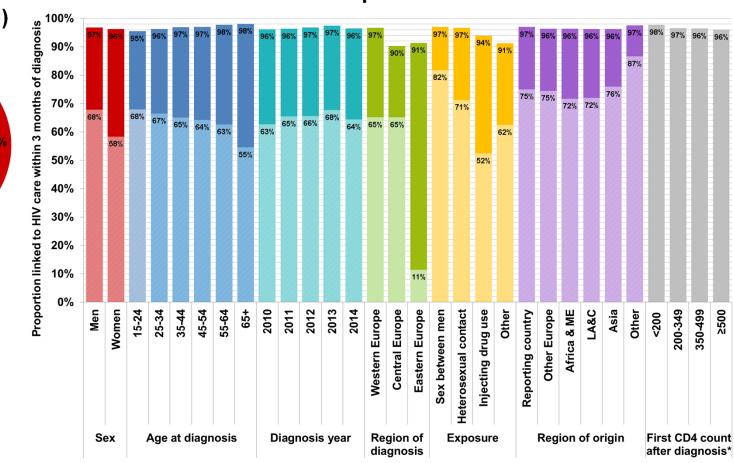
Linkage to care in Europe, ECDC Tessy data

Criteria applied to calculate linkage to care (N=125,665)



- Diagnosed previously
- Previously in HIV care
- Died within 3 months of diagnosis
- Missing CD4 data
- Incomplete diagnosis/CD4 dates
- Included in analysis

Prompt linkage to HIV care following diagnosis in Europe: 2010-2014

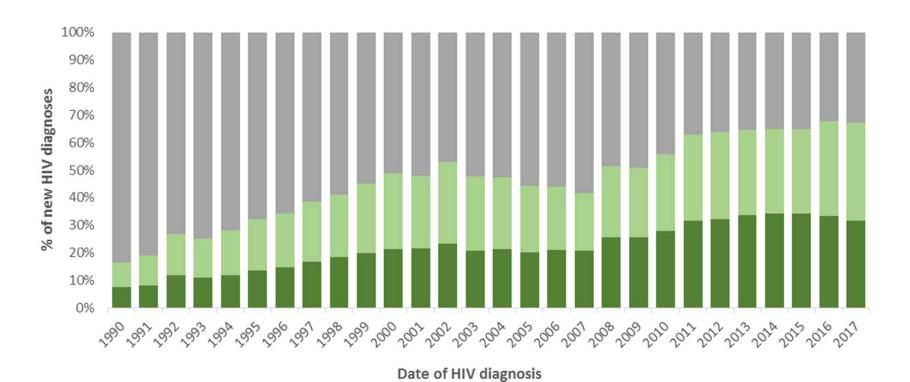


^{*}Sensitivity analysis not possible as CD4 required for breakdown

CD4 at diagnosis as reported to TESSy, **WHO European Region**







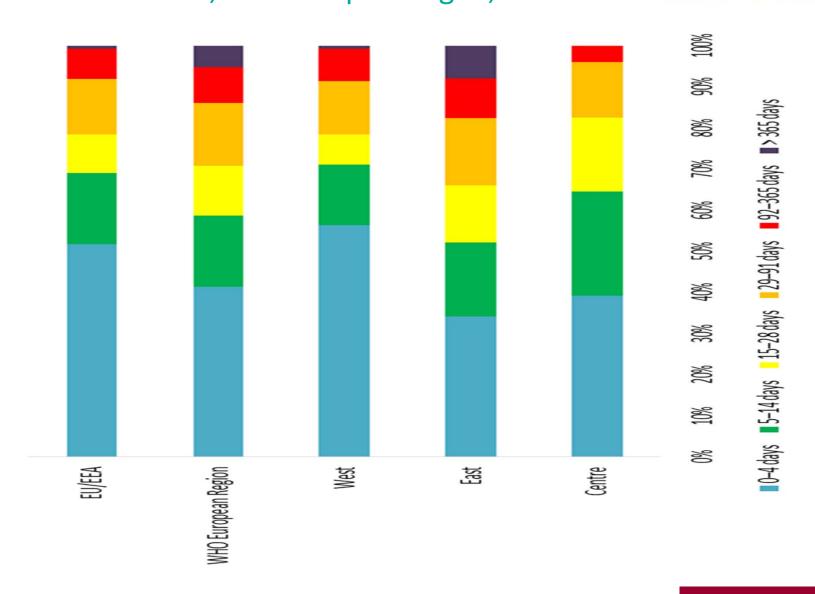
■ 350+ ■ <350 ■ no CD4 reported

Source: TESSy, 2019

Time to linkage to care after HIV diagnosis, by route of transmission, WHO European Region, 2017

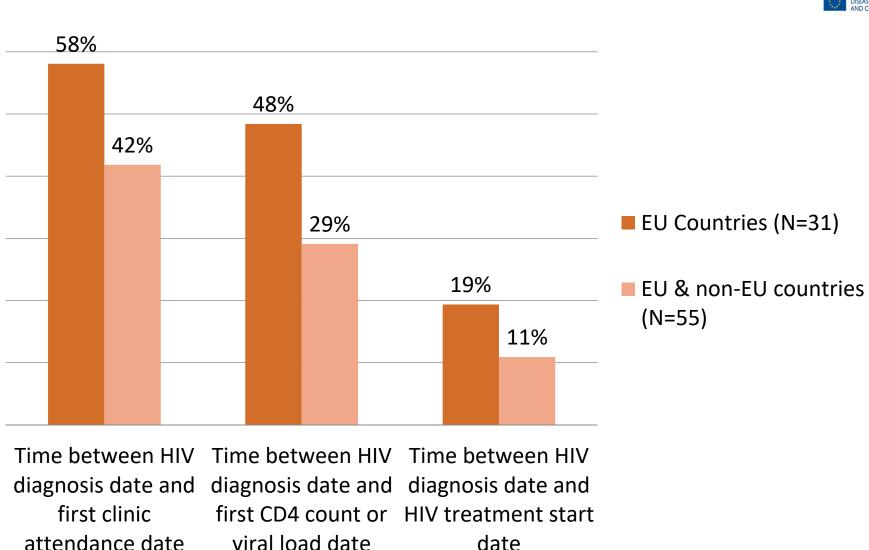




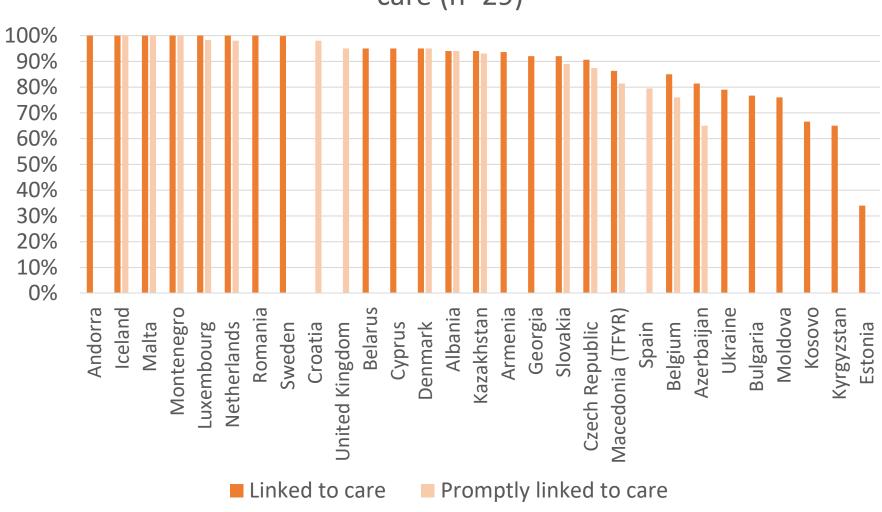


Dublin Declaration Monitoring 2018 Proportion of Countries Using Each Data to Calculate Linkage to Care for HIV Diagnoses





Dublin Declaration Monitoring 2018 % of people diagnosed in the last 12 months linked to care (n=29)

















Challenges

How do we monitor holistic care?

What is care?

Who cares?

PO4/07

1 million rapid HIV tests: results of innovative AHF testing and linkage to care programs across Europe

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Background

HIV testing and early detection remain a challenge in Europe. According to UNAIDS 75% of people living with HIV know their status and in Eastern Europe number of new infections is rising. Innovative approaches are needed to increase awareness of HIV status and effectively link to care.





Deputy Mayor of the

Testing at the railway

Results

1,052,265 tests were performed and 41,676 people learnt about the HIV status (4% seropositivity). 72% of the tests were performed in non-EU countries and 88% of reactive results were found there. Seropositivity in non-EU countries was 4.8%, while in EU 1.7%. In years 2013-2017 linkage to care was on average at 66%. In 2015-2017 across all the countries the highest seropositivity was in the age group 25-49 years- 5%, 3% among people older that 50 and 2% among 15-24 year old. Analysis for Ukraine in 2017 shows high efficacy of testing in medical facilities where indicator disease testing was used. Total 117,278 tests were performed of which OSITIVITY).

5,694 people learn abo seropositivity).

	total tests
Ukraine	432,921
Russia	325,041
	22.524

	2010-2017				
	total tests	HIV+	Seropositivity (%)	Linkage* (%)	
Ukraine	432,921	21,172	4.89%	13,722	64.81%
Russia	325,041	15,488	4.76%	10,939	70.63%
Estonia	68,560	1,386	2.02%	468	33.77%
Netherlands	15,454	164	1.06%	87	53.05%
Lithuania	85,093	1,161	1.36%	827	71.23%
Greece	56,405	818	1.45%	716	87.53%
Portugal	47,753	875	1.83%	513	58.63%
ETW		612	2.91%	84	13.73%
Totals		41,676		27,356	65.64%
* The Linkage to care is	shown for the	years 2013	-2017	Victory -	100

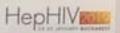
Fig. 1 Results of AHF Rapid testing program in Europe 2010-2017



Two years on the road to Meet, Test and Treat Sex Workers in Rome: the need for targeted interventions.

E. Tetil.¹, D. Masci¹, G. Rodoguino¹, L. Rosi¹, B. Coladarce¹, M. Patti¹, E. Rossi¹, M. Barra¹

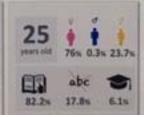
"Will Marsin Foundation, Rome, Rally Reference Diseases Clinic, for Vergata University, Name, Italy



Background. Innovative strategies are needed to identify and link to care key populations such as sex workers for which Villa Maraini Foundation's "Meet, Test and Treat" campaign.

Methods. Evaluation on a voluntary basis and prior informed consent of Sex workers in Rome reached by the street unit was performed from October 2016 to October 2018. For HIV/HCV assessment OraQuick HCV Ab and Alere HIV ½ Ag/Ab Combo rapid tests were used in finger stick. Sex workers made a questionnaire to assess risk behaviours. In case of positive tests, they were promptly taken in charge by Infectious Diseases Clinic of Policlinico Tor Vergata.

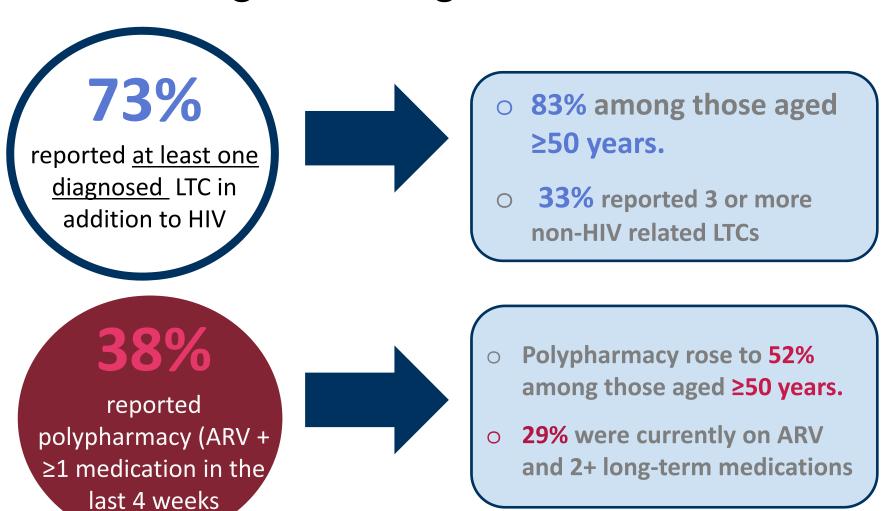






Results. 1651 sex workers were contacted in two years of street activities (52 night trips with the camper), 951/1651 performed the HIV/HCV rapid test. HIV seroprevalence in this population was 4.3% (41/951 – median age 25 years old, 87.8% transgender). 17/41 were already aware of their

Positive Voices Living with Long-term Conditions



















Positive Voices is a unique survey of the lives and experiences of people living with HIV in England and Wales. Between January and September 2017, people were randomly sampled from 73 HIV clinics and invited to take part in a survey issued by Public Health England. Over 4,400 people completed the survey. which was more than half of those asked



About 1 in 20 of all people who are living with HIV in England and Wales completed the survey

The survey asked about: health and wellbeing, non-HIV health conditions and medications, experiences with healthcare, met and unmet needs, sex and relationships, lifestyle issues, and financial security. The questionnaire was designed in collaboration with people living with HIV, academics, clinicians and NHS commissioners. PHE has provided data for the report, but does not necessarily endorse the content expressed within.

CHANGING PERCEPTIONS

Changing Perceptions is a community-led project, shaped and guided by people who responded to the Positive Voices survey.

Through workshops, a large and diverse group of people with HIV shared personal experiences and directed the Positive Voices data analysis. The result is a series of reports and a web resource that aim to change perceptions about living with HIV. The project is supported by Positively UK, National AIDS Trust (NAT), Watipa and researchers from Public Health England.



























Integrate

72% of people with HIV

42% of people with HIV

needed advice to manage

long-term conditions

have at least one other

long-term condition

POSITIVE OICES INSIGHTS

- Due to effective HIV treatment, we are living longer and with this our health and support needs are changing. Three out of every 4 (72%) people living with HIV had at least one other diagnosed long-term health condition. This equates to over 60,000 people managing HIV plus another longterm condition every day.
- Services must adapt to respond to the complex health issues facing people with HIV into the future – 42% of people with HIV said they needed advice on how to manage their long-term health conditions, and a third (33%) reported that this need was unmet.
- Nearly all (98%) respondents were on HIV treatment, and a third (38%) are also taking another prescribed non-HIV medication.
 Two-thirds (62%) said they needed HIV treatment advice.



People with HIV on HIV treatment



People with HIV also taking a prescribed non-HIV medication



People with HIV with a need for HIV treatment advice

 Many of the needs around HIV appear to be met, but managing multiple conditions and medications can lead to anxiety if the right support and information is not available. Work remains to educate GPs and other healthcare providers about side effects and drug interactions.

OVERCOMING ISOLATION WITH A LITTLE HELP FROM MY PEERS

Ben, aged 65, North Yorkshire

When I was first diagnosed with HIV in 2000, I was pretty ill and quickly ended up in intensive care for a few days, then in an isolation ward. I was divorced, with no partner, and my parents were both dead. I had young teenage children but I decided not to tell them about my diagnosis and burden them with fears of HIV.

In those first days and weeks I felt very alone. I was so ashamed and angry with myself...how could I have let this happen? Contracting HIV made me feel stupid, and dirty and ashamed. It was not something I wanted to tell other people about. But on the other hand, I really wanted to get a sense of what this all meant and what the future might hold. Although the doctors and nurses were great, they were busy and more concerned with my physical wellbeing, not my emotional state.



POSITIVE OICES INSIGHTS

- HIV support services, often provided by charities or voluntary organisations, are a lifeline to many people with HIV. They provide specialist support and advice and connect people living with HIV to share experiences and build resilience.
- Two out of every 5 (44%) women with HIV had used such services at some point after their diagnosis, and the vast majority (88%) said this support had been important for their health and well-being.



Proportion of women with HIV who had used HIV support services



Proportion of women with HIV who found these services important

- However, of the estimated 10,000 women who needed peer support in 2017, nearly half (45%) did not get it.
- Furthermore, 3 out of every 10 women who currently use HIV support services said they found them more difficult to access in the past 2 years.



3 out of 10 women using HIV support services found them harder to access over the past two years



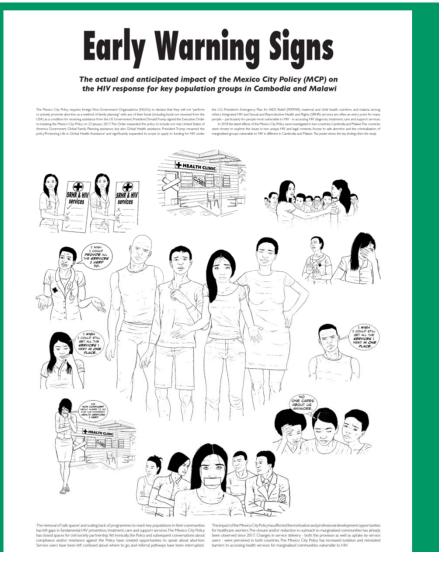
45% of women with HIV who needed peer support did not receive it Depression and isolation is difficult to cope with and the facilities and social spaces available to HIV+people are becoming more and more difficult to access. Funding is constantly being reduced for mental health and well-being. HIV-related stress is inevitable.* CLAIRE, 61



Impact of the Mexico City Policy

The Mexico City Policy requires foreign NGOs to declare that they will not "perform or actively promote abortion as a method of family planning" with any of their funds (including funds not received from the USA) as a condition for receiving assistance from the US Government.

The Policy prohibits NGOs from providing counselling or referrals for safe abortion services, and advocacy to decriminalize abortion or expand abortion services.





PO4/06

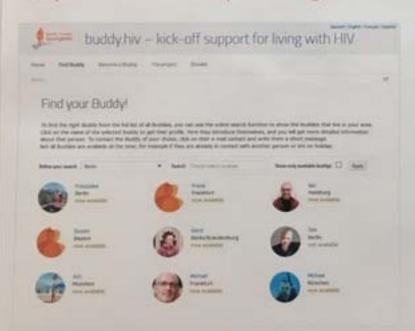
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"Be my buddy"

How peer educators can support linkage to care and fight stigma

What offers do people who are confronted with a newly diagnosed HIV infection want? How do we guide them in healthcare system?

In 2015 "Deutsche AIDS-Hilfe" started a peer based Buddy-Project. With this project, People who have recently been tested HIV-positive had the chance to choose a HIV-positive "buddy" as a companion for the first steps after diagnosis.



A lesson we learned: the project was better accepted when the buddies used their own local networks then if the project management did this work.

And an interesting side-effect came up: people who participated in the project became committed multipliers and lobbyists against HIV-stigmatization.

	31.12.18	31.12.17	31.12.16	31.12.15
Annual users	80	75	54	64
First Contacts	63	63	54	64
Follow Up Users	17	12	25	28
Training- sessions	1	1	0	4
Trained Buddies	77	63	51	51

Conclusions

Peer-Projects develop their best effect if the peers have good resources in the background















- Local solutions led by community
- Integrated approaches focussed on what people need and care about
- Information collected to understand whether needs are met, and used to improve the wellbeing of people
- Systems and services that are accountable to their users and open to scrutiny
- Share and adapt what works (rather than simply scaling up)
- Design a process of reviewing and sharing best public health practice















Thank you

Acknowledgements

People living with HIV

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