



OptTEST Kick-off Meeting. 2nd Sept 2014
*Jean Monet Building,
EU Commission,
Luxembourg*

**WP 7: Stigma and legal barriers to the
provision of HIV testing treatment and
care services
from Desire to Reality**

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**PEOPLE
LIVING
WITH
HIV
ARE...**



PEOPLE LIVING WITH HIV ARE...

...experts in knowing (from their lived reality) the effects that stigma and discrimination have had, and continue to have, on testing, treatment, and care ...

“ Guess it comes down to a simple choice really. Get busy living, or get busy dying. ”

**- From the movie
*The Shawshank
Redemption***

2 . Point of Departure -Overview

- **Objective**

To increase knowledge on the effect stigma and discrimination (as well as structural legal barriers to HIV testing) has on uptake of HIV testing and treatment particularly in most affected groups and regions by 2016

- **Methods**

Enabling networks of PLHIV to use their own data to inform advocacy and build partnerships with health care providers

Identifying legal and regulatory barriers to take up and availability of testing , treatment and care services

- **Activities**

Methodology developed to document strategies, advocacy tools created , illustrative and innovative case studies researched and produced; all that address HIV related stigma and discrimination

- **Outputs**

Best Practice Manual on evidence based interventions to reduce HIV related Stigma

Best Practice Toolkit to facilitate a more supportive legal and regulatory environment

2 . Point of Departure – Countries

- **Stigma Index Countries that are part of the EU project**
Estonia, Germany, Greece (TBA) , Poland, Portugal

Stigma Index Countries that are not part of this (funding) but that will be used for analysis and comparison purposes

- **Belarus, Ukraine**

Countries that will be looked at in relation to the legal and regulatory barriers

- **All of the EU countries**

Milestones

OptTEST for HiE	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	M13	M14	M15	M16	M17	M18	M19	M20	M21	M22	M23	M24	M25	M26	M27	M28	M29	M30	M31	M32	M33	M34	M35	M36	
WP 7 Stigma and criminalisation as a barrier to the provision and	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	
To increase knowledge on the effect stigma and discrimination (as well as structural legal barriers to HIV testing) has on uptake of HIV testing and treatment particularly in most affected groups and regions by 2016																																					
Milestone 1: Compilation of data from PLHIV stigma index countries in the region																																					
Milestone 2: Methodology to document strategies to address HIV related stigma developed and approved; New advocacy resources section on OptTEST Website																																					
Milestone 3: Case studies (25) and completed interviews with key stakeholders on innovative strategies (25)																																					
Milestone 4: Final report on lessons learned on strengthening advocacy, law enforcement sensitisation and improved legal literacy																																					
Milestone 5: Stigma and legal barriers best-practice manual available on OptTEST website																																					
Deliverable 7: Best-practice manual on evidence based interventions to reduce HIV related stigma																																					
Deliverable 8: Best-practice toolkit to facilitate a more supportive legal and political policy environment																																					

3 . Workplan for WP7

Participating partners: PHE, CHIP, GNP+ (plus involvement of Stigma Index partners, and LP re Legal barriers) first 6 months activities – Milestone 1

Compilation of data from PLHIV stigma index countries in the region – Estonia, Germany, Greece (TBA) Poland, Portugal	Responsible:	Status:	Comments:		
	GNP	on track	a database has been devised – data is being cleaned and entered. We are also using this to enter and interrogate data from non EU countries in the wider European region		

4. Monitoring and Evaluation

Specific objective 5: To increase knowledge of how stigma and legal barriers to HIV testing affects the uptake of HIV testing and treatment, particularly in most affected groups and regions by 2016			
Baseline data	Process Indicators	Output Indicators	Outcome Indicators
A full review of exiting information on stigma & legal barriers in the region	Measure/identify Country/Regional barriers to testing and linkage to care by M10	25 case studies (identified in collaboration through WP 4 and 5) and completed for review by M24' This is a consolidation of Legal barriers and Stigma barriers 25 interviews with key stakeholders informing these case studies also completed where appropriate	Compilation of existing stigma index data and methodology by M12 Production and dissemination of approved toolkit and manual to mitigate context-specific stigma & legal barriers by M36.
	5 different country strategies to counter stigma to testing/treatment developed and agreed upon by M12	>50 stakeholders comments regarding stigma and legal barriers incorporated in draft manual by M12.	Focus-group interviews (with the 5 PLHIV networks) and other stakeholders to gauge effectiveness of toolkit and manual in development in aiding advocacy efforts to reduce barriers to testing and treatment; periodically from M24-34
	Documented and agreed upon identification and classification of barriers to linkage i.e. stigma/ criminalisation / lack of appropriate infrastructure/ resources/ policy, etc.) By M18-20	The development and validation of a context-transferable stigma index to measure the impact of stigma on access to testing and linkage to care by M20	Integration/utilisation of new stigma index within the 'treatment cascade' notion (SO2:WP4)
		Development of transferable guidelines as to mitigate (stigma) barriers to testing and care	75 stakeholders demonstrating appropriate knowledge of how to mitigate known barriers (stigma) to testing and care

5 . Regulatory Documents

- **PLHIV Stigma Index**

The implementation of the tool itself on which this work-package is based has already occurred in the countries that we are working with

The ‘secondary’ analysis requires no further permissions

6. Stakeholder analysis, dissemination strategy, target groups

	WP 7
Content	<p>The WP will enable networks of PLHIV to use the data they collect to inform advocacy and build partnerships with health care providers to ensure better and more equitable access to services - especially amongst key populations. Good practices to scale up testing will be produced and disseminated.</p> <p>To increase understanding of the effect of legal and structural barriers to HIV testing and uptake and treatment and care services</p> <p>Both to be looked at particularly in most affected groups (Key populations)</p>
Primary stake-holders	<p>PLHIV Networks Health Care Providers Community Based Organisation (for both elements of WP7)</p>
Secondary stake-holders	<p>Key populations – and for the purposes of the work these ‘Key Populations’ have been defined later Legal and regulatory authorities</p>
Key messages	<p>Stigma and Legal /Regulatory barriers negatively impact upon the treatment cascade</p>
Goals	<p>Provision of resources that enable stakeholders to address these issues in country</p>

7 . Synergies

- For discussion

WP2:

Dissemination by and for PLHIV groups – which is absent at the moment

WP4:

We are agreeing with WP4 on the best division of labour re desk research for both the legal and regulatory work as well as stigma research

WP5

We are agreeing with WP5 re baseline questions that are going to assist

WP7

We would welcome a clear agreement as to what the treatment cascade (continuum) is within this project

External Synergies to be considered:

Other work currently that is in planning coordinated by AIDS Action Europe for the European HIV Legal Forum (non-EU funded)

Treatment Continuum -Overview

- **Some thoughts**

We had a good a lively discussion yesterday re both the wording of things (continuum v cascade)

The involvement of community based and PLHIV organisations in the treatment continuum – the value of a community based service delivery model and how this fits in the picture.

Legal and Regulatory Barriers

Our current definition

- **Criminal Law and Public Health regulations as they relate to people with HIV and Key populations**
- **Regulations that govern HIV Testing and access to the treatment continuum**

Key Populations – what do we mean

- Whose definition are we using ? UNAIDS, GFATM, IAS, all have slightly differing definitions of Key Populations .

We would suggest as appropriate for the region and the work that we are doing we need to have a specific definition.

Guiding Principle for determining the defined Key populations is that they are:

Groups (or individuals) that face an increased burden and/or vulnerability to HIV due to a combination of biological, socio-economic, and structural factors combined with lower access to services due to human rights violations, systematic disenfranchisement and criminalization within the specific country context in which they live .

As such Key Populations within this project will always include

- PLHIV whatever their known (or assumed) route of Transmission
- Gay, bisexual and other men who have sex with men
- People who inject drugs
- Sex Workers
- Migrants
- Transgender people
- Prisoners and incarcerated People

References

- Initial Workplan (for partners only) available at <https://www.dropbox.com/sh/i1ttoikqyp384yu/AABLoIbWyxrvUTXcywcri9gVa/WP7/WP7%20work%20plan.docx?dl=0>
- A community based treatment cascade model: <http://www.ifrc.org/Global/Documents/Secretariat/AIDS%20conference/1281400-HIV-leaflet-LR.pdf>
- PLHIV Stigma Index Results in selected European Countries Late testing, Late treatment: http://newsite.hiveurope.eu/Portals/0/HIVStigma_Report.pdf
- GNP+ Criminalisation Scan: <http://criminalisation.gnpplus.net/>