

TB COMMUNITY,
RIGHT AND GENDER
ASSESSMENT IN
DEMOCRATIC
REPUBLIC OF THE
CONGO

2018

REPORT

TB COMMUNITY, RIGHT AND GENDER ASSESSMENT IN DEMOCRATIC REPUBLIC OF THE CONGO 2018

REPORT

“This report is made possible by support from the Stop TB Partnership, funded by The Global Fund and USAID”

TABLE OF CONTENTS

ACRONYMS AND ABBREVIATIONS	5
Message from Stop Tb Partnership	6
ACKNOWLEDGEMENTS	7
SUMMARY	8
I. INTRODUCTION	11
1.1. OBJECTIVES	12
II. METHODOLOGY OF PROCESS	13
2.1. MULTI-STAKEHOLDERS WORKING GROUP	13
2.1.1 Composition	13
2.1.2. Planning of CRG assessment	13
III. TB EPIDEMIOLOGICAL PROFILE	15
IV. DESK REVIEW	18
4.1 DATA FOR ACTION FRAMEWORK FOR TB KEY POPULATIONS	18
4.2 LEGAL ENVIRONMENT	20
4.3 GENDER	23
4.4 LEGAL FRAMEWORK	24
4.5. TB KEY POPULATIONS PRIORITIZATION	24
4.6. DATA COLLECTION	27
4.6.1. Focus groups of priority key populations	27
4.6.2. Key informant interviews	28
4.6.3. Cartography of key populations	28
4.6.4. Observations of behaviors and gathering places of key populations.....	28
4.7. FINDINGS ENDORSED AT VALIDATION WORKSHOP	30
4.7.1. DATA FOR ACTION FRAMEWORK FOR TB KEY POPULATIONS	30
4.7.1.1. PLHIVs	30
4.7.1.2. TB Contacts	32
4.7.1.3. IDUs and hemp / tobacco smokers	34
4.7.1.4. Key people working for and / or with key populations	36
4.7.2. LEGAL ENVIRONMENT	38
4.7.2.1. General situation	38
4.7.2.2. Information gathered from desk review	39
4.7.2.3. Knowledge at level of Justice and human right officers	39
4.7.2.4. Role of civil society organizations	39
4.7.2.5. Barriers of TB screening and treatment services	39
4.7.2.6. Prison situation	41
4.7.2.7. Stigma and discrimination of people with TB	42
4.7.2.8. Tuberculosis and Justice	42
4.7.2.9. Legal accompaniment (prison peculiarities)	43
4.7.2.10. Specificity: Confidentiality and secret	44
4.7.2.11. Right to work	44
4.7.2.12. The displaced of wars	44
4.7.3. GENDER	45
4.7.4. TB RESPONSE FINANCING	45
4.8. RECOMMENDATIONS ENDORSED AT VALIDATION WORKSHOP	46
4.8.1. DATA FOR ACTION FRAMEWORK FOR TB KEY POPULATIONS	46
4.8.1.1. PLHIVs	46
4.8.1.2. TB Contacts	47
4.8.1.3. IDUs and hemp / tobacco smokers	48
4.8.1.4. People working with key populations	49
4.8.2. LEGAL ENVIRONMENT	50
4.8.3. GENDER	51

V. CONCLUSION53
VI. ANNEXES54

ACRONYMS AND ABBREVIATIONS

Aids : Acquired Immune Deficiency Syndrome
ART : Anti retro-viral treatment
BCG : Bacille de Calmette et Guérin
CAD : Club des Amis Damien
CBO : Community Base Organizations
CCM : Coordinating Country Mechanism
CEDA : Centre d'Excellence Damien
CEDHUC : Centre d'Etude et d'Expertise en Droits humains et criminologie
CORDAID : Catholic Organization for Relief and Development Aid
CRG : Community, Right and Gender
CSO : Civil Society Organization
DOT : Directly observed treatment (Traitement directement observé)
DRC : Democratic Republic of the du Congo
EGPAF : Elizabeth Glaser Pediatric Aids Fondation
FOSI : Forum SIDA
HIV : Human Immunodeficient Virus
HP : Health for Prisoners
IDU : Injectable drug User
LGBT : Lesbians, gays, bisexuals and transgenders
LNAC : Ligue nationale antituberculeuse et antilépreuse du Congo
MDR-TB : Multi-Drug-Resistance to Tuberculosis
MSM : Man have Sex with Man
NAP : National Aids Program
NGO : Non-Government Organization
NSP : National Strategic Plan
NSDP : National Sanitarian Development Plan
NTP : National Tuberculosis Program
PATI : Programme antituberculeux intégré aux soins de santé de base/primaires
PHD : Provincial Health Division
PLTC : Provincia Leprosy and TB Cordination
PLVIH : People Living with HIV
PSSP : Projet santé sans prix
RACEF : Réseau des Acteurs Communautaires pour l'Enfant et la Famille
RACIJ : Réseau des associations congolaises des jeunes
RB : Ruban Blanc
RENADEF : Réseau National pour le Développement de la Femme
SDGs : Sustainable Development Goals
STHC : Screening and Treatment Health Centers
TB : Tuberculosis
UNAIDS : United Nations for Aids
UNION : Union Internationale contre la tuberculose et les maladies respiratoires
USAID : United States Agency for International Development
WHO : World Health Organization

Message from Stop Tb Partnership

The tuberculosis (TB) response needs a paradigm shift – becoming people and community centered, gender sensitive and human rights based. There is a need for country specific data and strategic information key, vulnerable and marginalized populations. There is a need to facilitate an enabling environment to effective prevention, diagnosis, treatment and care – which requires legal and gender related barriers to be analyzed, articulated and alleviated. The Stop TB Partnership CRG Assessments are the tool for National TB Programmes to better understand and reach their epidemics. With TB being the leading cause of infectious disease deaths globally, and with over 10 million people developing TB each year, this disease continues to be a public health threat and a real major problem in the world.

The Stop TB Partnership's Global Plan to End TB and the World Health Organization (WHO) End TB Strategy link targets to the Sustainable Development Goals (SDGs) and serve as blueprints for countries to reduce the number of TB deaths by 95% by 2030 and cut new cases by 90% between 2015 and 2035 with a focus on reaching key and vulnerable populations. The Strategy and the Plan outline areas for meeting the targets in which addressing gender and human rights barriers and ensuring community and people centered approaches are central.

Ending the TB epidemic requires advocacy to achieve highly-committed leadership and well-coordinated and innovative collaborations between the government sector (inclusive of Community Health Worker programs), people affected by TB and civil society. Elevated commitment to ending TB begins with understanding human rights and gender-related barriers to accessing TB services, including TB-related stigma and discrimination. It has been widely proven that TB disproportionately affects the most economically disadvantaged communities. Equally, rights issues that affect TB prevention, treatment and care TB are deeply rooted in poverty. Poverty and low socioeconomic status as well as legal, structural and social barriers prevent universal access to quality TB prevention, diagnosis, treatment and care.

In order to advance a rights-based approach to TB prevention, care and support, the Stop TB Partnership developed tools to assess legal environments, gender and key population data, which have been rolled-out in thirteen countries. The findings and implications from these assessments will help governments make more effective TB responses and policy decisions as they gain new insights into their TB epidemic and draw out policy and program implications. This provides a strong basis for tailoring national TB responses carefully to the country's epidemic – the starting point for ending discriminatory practices and improving respect for fundamental human rights for all to access quality TB prevention, treatment, care and support services. The development of these tools could not be more timely, and the implementation of these tools must be a priority of all TB programmes.

Dr Lucica Ditiu,

Executive Director, Stop TB Partnership



ACKNOWLEDGEMENTS

The national tuberculosis Program (NTP) of DR of the Congo table, in its national strategic Plan for tuberculosis 2018 – 2020, on improving the health status of the population by reducing the socio-economic burden due to TB so that It is an effective participant in the integral and sustainable development of DRC. To do so, it provides: strategies based on evidence, promoting human rights and gender in the fight against TB, and intensification of TB screening in special populations.

The Club des Amis Damien (CAD) has an experience to work in the awareness of the population and the accompaniment of TB patients as part of the fight. In this respect, we thank Stop TB Partnership for allowing us to conduct this Data for Action Framework for TB Key, Vulnerable and Underserved Populations, Legal Environment and Gender assessment in TB on basis of Community, Rights and Gender (CRG) tools in DRC. This work has provided information and proposals that could guide country interventions in favor of improving the national response to TB. Hoping that results of this work will certainly serve as evidence for several planning of the different stakeholders in the fight against TB.

On behalf of CAD and national consultants, the National Secretary and coordinator of DRC CRG tools Assessment expresses his thanks to all participants who took part in the priority-setting workshops for key populations and validation of field collected data, as well as to investigators and managers of health and justice sector and organizations who received us during our various field missions. Thanks also to the key populations, in this case TB contacts, PVVIH and injecting drug users and hemp met for sharing with us their experiences, constraints and advice in TB care.

We would also like to thank the National Tuberculosis Program (NTP), the Provincial Leprosy and TB Coordination (PLTC) and Provincial Aids Coordination offices of Kinshasa, Kongo Central and North Kivu, as well as the actresses and actors of the Prime Ministry, Health provincial ministries, Justice, Social Affairs, provincial governments, representatives of people living with HIV, with Tuberculosis, NGOs, technical partners and UN agencies. Thank you to all those who have supported this process, and have resulted in this participatory qualitative assessment report.

SUMMARY

The Democratic Republic of Congo (DR Congo) is among the 30 High TB Burden Countries, the high TB/HIV burden countries and the high MDR-TB burden countries. Furthermore, DR Congo is among the 20 countries with the highest estimated numbers of incident TB cases (that share 84% of the global TB burden) and among the 20 countries with the highest estimated numbers of incident MDRTB cases. It is also one of ten countries ranked in order of the size of the gap between notified cases and the best estimates of TB incidence in 2017,¹.

Among other challenges and limitations, the National Tuberculosis Programme is implementing a passive screening strategy to reach those suspected of having TB. The strategy does not however consider or take into account the specific barriers to access that that TB key and vulnerable populations face.

To find and treat all people with TB and to achieve the World Health Organization (WHO) End TB Strategy targets countries must abandon the passive, top down disease programmes of the past and adopt a radical new approach. According to the Stop TB Partnership and as articulated in the Global Plan to End TB, this approach should strive for equity and address the structural, social, socioeconomic, human rights, (R) and gender (G) drivers of the disease and ensure the meaningful engagement of empowered people and affected communities (C) in the TB response who know their rights. This Community, Rights and Gender (CRG) approach aligns with the World Health Organization (WHO) End TB Strategy that states that policies and strategies for the design of the overall national TB response, and the delivery of TB care and prevention must explicitly address human rights, ethics and equity. To support country efforts to implement a CRG approach to TB, STP developed assessment tools to generate and strengthen data and strategic information on gender and human rights-related barriers and key populations which can subsequently be used to inform programmatic planning and for action. In 2017 UNAIDS conducted the TB/HIV Gender Assessment and between June and December 2018 Club des Amis Damien with support from Stop TB Partnership and under the leadership of the National TB Control Programme conducted the Legal Environment Assessment for TB² and used the Data for Action Framework³ to identify and prioritize TB key populations in DR Congo.

Three prioritized key populations in the provinces of Kinshasa, Kongo Central and Nord Kivu (Person living with HIV, TB contacts, people who inject drugs) were identified. The assessment results indicated the need to address the barriers to access to find the missing people with TB among these populations.

In general, the following findings have been noted:

Access to TB care services is difficult in some TB health facilities due to fees for consultation, TB testing including radiology, and sputum examinations. The lack of information on TB care and its free access does not allow people to get tested and benefit from TB treatment on time in case of positive results due to lack of financial means.

¹ World Health Organization Global TB Report 2017

² Legal Environment Assessment for TB

http://stoptb.org/assets/documents/communities/StopTB_TB%20LEA%20DRAFT_FINAL_Sept%202017.pdf

³ Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations

<http://www.stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf>

Problems with the supply of TB drugs and laboratory inputs, drug stock outs, and lack of TB / HIV testing and care in some health centers do not allow patients to receive appropriate TB / HIV co-infection care.

Generally, discrimination and stigmatization of TB patients is highly accentuated, and sometimes they are indexed in their living environments, their right is not respected by health care providers and community. Old practices of discrimination and family stigma remain to date because the population is not adequately informed about TB. The indispensable involvement of the community with the appropriate expertise does not always benefit from adequate funding to address the problems of these populations.

The lack of awareness of the rights to health and access to TB care, the restrictive application of the DOT strategy, especially in rural areas, lack of nutritional coverage, non-respect of the confidentiality of the TB results for some and serological status for others by the care providers.

From the above, in order to significantly reduce barriers to TB care and improve its legal environment, the recommendations made are as follows:

To fill the gaps in services:

- Revise national TB policies and guidelines to integrate gender, human rights and key populations aspects into TB care, ensure its dissemination and make it available at all levels (health care workers, community members and other stakeholders in the fight against TB), to ensure its effective implementation.
- Develop active case finding strategies and invest in interventions to find the missing people with TB, especially among key populations.
- Remove consultation, diagnostic examinations (radiography, microscope and others) and treatment of tuberculosis costs to enable patients to easily access screening and treatment;
- Provide new TB diagnostic tools to all health facilities; To ensure the use of new technologies for quality screening for all
- Provide nutritional support to TB/HIV co-infected patients as part of patient support to enable them to successfully follow TB drugs and ARV treatment.
- Reduce significantly the time to test and report results to improve adherence to treatment of PLHIV.
- Ensure the regularity of TB drugs in the health care facilities and introduce a monitoring system to report and respond to stock outs.
- Develop the advanced strategies to facilitate the accessibility of key populations to TB screening and treatment including human rights and gender-sensitive aspects.
- Introduction of the new short-term TB treatment.

To fill the data gaps:

- Conduct a TB stigma assessment to understand the burden of TB in different settings and along the cascade of care.
- Set up a community-based real time monitoring system to strengthen; the TB M&E data on barriers to access, responsiveness, equity and quality of TB services and hold TB service providers to account. **(Community-based monitoring)**
 - o Violation of confidentiality
 - o Stock outs
 - o Drug side effects
 - o Out of pocket expenses
 - o Treatment interruptions
 - o Barriers to access
 - o Quality of services
 - o Stigma

- CBM data collected should be disaggregated by age, gender, key population
- Develop age and gender disaggregated data collection tools at all stages of TB prevention and care.
- Conduct studies on the prevalence of tuberculosis in relation to the population in general and the key populations in particular, on the behaviors, attitudes and practices (CAP) of populations in relation to TB, and on the specific needs Key populations for proven evidence.
- Collect and analyze gender-specific data on health providers, including community-based providers, at all levels, as well as program staff.
- Conduct studies on socio-cultural determinants increasing vulnerability to TB, HIV / TB co-infection, and HIV for adults.
- Collect and analyze gender-specific data for all categories of key and affected populations for HIV, TB and co-infection, including children, the elderly and people with disabilities.

To improve TB legal environment:

- Initiate a law project amending and supplementing Law 08/011 of 14/07/2008 on the protection of the rights of PLHIV/AIDS and affected people by including the aspects related to the care of TB patients and children less than 5 years in contact with people with tuberculosis.
- Ensure effective legal coverage for discrimination, stigmatization or other cases of deprivation of rights of people with TB and those affected.
- Define a framework for consultation between the NTP, civil society organizations and legal actors for discussions, solutions and implementation of actions to counter the stigma and discrimination of people with TB in general and key populations especially in health facilities and the community.
- Establish a gender TB and HIV coordination group, and enable the participation of women and key populations in the coordination of HIV and TB struggles and actions
- Invest substantial funding in community-based medical and legal support actions in the fight against TB (advocacy, awareness, recovery of lost to follow-up, nutritional support, access to screening and treatment, building capacities, etc.).
Raise population awareness on TB and all cross-cutting aspects of rights, gender and person-centered care.
- Ensure the vulgarization and dissemination of the Patient Charter for Tuberculosis Care at all levels.

I. INTRODUCTION

Tuberculosis (TB) is a disease that carries a heavy economic and social burden. DRC with more than 100,000 cases of TB notified each year is among the 30 countries that support 80% of the global burden of TB resistant (MDR-TB)⁴. According to WHO and in accordance with three lists drawn up to evaluate TB strategy, DRC is among 14 countries with a high burden of morbidity for both TB and co-infection TB/HIV⁵.

In past, role of communities and community organizations working on TB were limited mainly to a few tasks in provision of services. Lessons learned from these other public health interventions, in particular the HIV response, underscore the importance of community engagement and participation in all aspects of advocacy, planning, implementation and program monitoring.

Stop TB Partnership concentrates its efforts to ensure that communities are empowered and ready to play an important role in: Advocacy for adequate funding and appropriate policies as well as better access to care; Participate in planning and implementation of care services; Monitor TB services by acting as a watchdog. It has therefore developed three tools, including TB/HIV gender, legal environment and data for action framework on key, vulnerable and disadvantaged population assessment, which are essential for progress in the area of communities, rights and stigma.

Democratic Republic of Congo is struggling to ensure TB screening in more cases based on estimates of incidence of the disease in the country. The National Tuberculosis Program is implementing passive screening in order to reach more suspected TB cases across the country, but the problems related to geographic, financial and cultural accessibility do not close gap in cases to be predominantly detected from key, vulnerable and disadvantaged populations⁶.

Gender, Rights and Community assessment tools provide a framework to help programs identify and estimate size of key populations, allowing them to further estimate TB levels to which they are facing as well as identify multiple contextual issues that affect access to diagnosis, treatment and care. This framework allows programs to plan services, overcome barriers and assess progress.

We would like to point out that first evaluation of HIV and TB sexo-specificities or gender assessment in the DRC was conducted by UNAIDS in 2017, and initial assessment of human rights and gender barriers to HIV services and TB in the DRC was conducted by HEARD Cabinet in 2018.

These actually assessments are entirely complementary to those which were conducted before.

These assessments are based on information gathered from key informants and targeted key populations. It certainly presents incompleteness to extent that not all stakeholders have been able to join process and all desired documents could not be collected.

⁴ Guide de prise en charge de la tuberculose PATI 5, Edition 2015 révisée en décembre 2017

⁵ Rapport épidémiologique 2017, PNLT

⁶ Directives nationales sur les populations spéciales TB 2018

1.1. OBJECTIVES

The general objectives are to assess different TB legal aspects, identify different key populations and their specificities in the fight against TB.

Objectives of TB care data for action framework for TB Key

1. Prioritization of key populations for rapid assessment
2. Rapid assessment of priority key populations to refine operational definition (eligibility)
3. Identify gaps in service and data to be addressed in TB care.
4. Formulate the recommendations aiming at filling gaps in TB services and data.

Objectives of the Legal environment assessment

1. Rapid assessment of legal environment to create a favourable legal environment for people affected by TB.
2. Identify gaps in services and law in TB care.
3. Formulate recommendations to address gaps in services and legislation of TB care.

II. METHODOLOGY OF PROCESS

2.1. MULTI-STAKEHOLDERS WORKING GROUP

2.1.1 Composition

The process began with establishment of Core Group with role of coordinating the assessment and direction of entire process as well as report validation, which composed of:

- Representatives of General Secretariat for Health, National TB and HIV/AIDS Programs,
- WHO Representative
- USAID Representative
- Stop TB DRC Delegates
- DRC Red Cross Delegate
- Representatives of NGOs working in justice sector
- Representatives of Key Populations Associations.

The multi-stakeholder working group was composed of representatives from Ministry of Health, key populations and those working with key populations in TB, and with knowledge on qualitative research:

- Delegates from General Secretariat for Health, National TB Program and National Aids Program, Ministry of Justice, the CCM/DRC and Provincial Leprosy and TB Coordination of Kinshasa.
- Delegate of Global Fund Principal Recipient (CORDAID).
- DRC Red Cross Delegate
- Delegates from civil society organizations working on TB and HIV issues: Stop TB DRC, Damien Foundation, Elizabeth Glaser Foundation (EGPAF), UCOP+ (Congolese Union of PLHIV Organizations), RACOF (Réseau des Associations Congolaise des Jeunes), LNAC (Ligue National Anti-tuberculeuse et Anti-lépreuse League du Congo), Fondation Femme Plus, CAD (Club des Amis Damien), RACEF, ADEEFHA, FACID/ABEI, Ruban Blanc (RB) and PSSP (Projet Santé Sans Prix).
- Key populations: pygmies, PLHIV (People Living with HIV), former TB patients, IDU and MSM.
- Human rights activists: CEDHUC, HP (Health for Prisoners).
- UNAIDS Delegate

DRC CRG assessments in TB were conducted by a team of three national consultants: Mr Patrick NSIMBA, Dr. Michael SELEMANI and Mr Jules TOLOKO, a PNLT delegate: Dr. Colette KINKELA and a coordinator: Maxime LUNGA NSUMBU. It was supported by the Club des Amis Damien's Staff.

2.1.2. Planning of CRG assessment

TB care data for action framework for TB Key, vulnerable and underserved populations, legal environment and gender assessment in DRC took place from June 2018 to December 2018 with the main steps:

- Orientation Meeting,
- Documentary review,

- Prioritization workshop,
- Field data collection,
- Data analysis and reporting,
- Validation workshop,
- Restitution meeting,
- Final report, translation into English and submission.

On July 12, 2018, the orientation meeting hosted in Kinshasa focused on presenting project and launching assessments of different legal aspects inherent in TB, data aspects of different key populations and TB and HIV sexo-specificities issues. The meeting was attended by stakeholders, policy makers and other civil society organizations in the country to gain an overview of CAD-led process in selected DRC provinces.

The specific objectives assigned to this meeting are to:

- Establish a core group of stakeholders in fight against TB for better involvement and monitoring of assessment process,
- Validate list of multi-stakeholders for composition of technical working group,
- Approve principles, methods and process for prioritizing key populations and rapid assessment.

Table 1: Calendar of main steps:

N.	Key steps	Period
1	Orientation meeting	July 2018
2	Prioritization workshop	July 2018
3	Field data collection,	July – September 2018
4	Data analysis and reporting	October 2018
5	Validation workshop	November 2018
6	Restitution meeting	November 2018
7	Final report, translation into English and submission	December 2018

V. TB EPIDEMIOLOGICAL PROFILE

Tuberculosis is a public health issue in DRC. WHO has compiled three lists to categorize and classify countries with a high disease burden: list of sensitive TB, list of HIV TB co-infection and list of MDR/RR TB. DRC is among the 14 countries that are included in three lists⁷.



According to 2017 epidemiological report of National Tuberculosis Program (NTP), country profile is summarized as follows: Since 2015, NTP has functioned with 27 Provincial Leprosy-Tuberculosis Coordinations (PLTC) and program covers all 519 Health Zones (HA) with 1873 Screening and Treatment Health Centers (STHC). TB/HIV co-infection Activities took place in 354 HA (Health Areas).

In 2017, NTP notified 151832 TB cases in all forms, compared with 132515 in 2016, an annual rate of increase of 15% compared to target expected at the end of 2017 of 173,359 cases. This makes a gap of 21.527 cases. With a 2017 population estimated at 87491755 according to National Strategic Plan (NSP), TB observed incidence per 100,000 populations is 172 cases in the Democratic Republic of Congo (DRC). There is a disconnect between reported national incidence of 172 per 100,000 H and the WHO estimate of 323 per 100,000 H with an interval of 209-461 according to 2017 Global TB Report.

Detection rate is therefore 53%. Men account for 56% of notified cases and women 44%. The sex ratio Male / Female is 1.3. Children represent 11% while the target is 20%. From the 2017 notification, note that there is 64% of patients who know their HIV status while this proportion was 54% in 2016. Progress is clear but target set in 2017 was that 100% of TB patients should know their HIV status. Among TB patients tested for HIV, TB HIV co-infected cases accounted for 10% in 2017 and this proportion was 12% in 2016. This means that HIV prevalence among TB patients decreases as number of cases tested increases. Of these co-infected HIV TB patients, 91% were put on cotrimaxazole and 82% were on ARV.

The 2016 cohort assessment shows that success rate is 89% and the death rate is 4%. Of all the notified cases, 125,157 cases developed pulmonary form, or 82%, of which 99,426 (NP + relapses) were bacteriologically confirmed, representing 66% of all notified forms. Clinically diagnosed cases represent 17% (25731). This proportion was 16% in 2016.

⁷ Rapport épidémiologique 2017, PNLT

Only data from 3 key populations are collected and reported by NTP, PLHIV, prisoners detected TB in prisons and miners detected TB at some mine sites in the country. The remaining key populations are not taken into account or documented.

The national summary of 2017 results is shown in table below⁸:

Table 3 : 2017 TB Epidemiological Results

⁸ Rapport épidémiologique 2017, PNLT

NOTIFICATION TB SENSIBLE						
2 017			2016		Accroissement	%
NPTB+	93 555		82 387		11 168	14%
RECH TB+	4 961		4 560		401	9%
ECHECS TB+	523		394		129	33%
RETOUR DE TRAITEMENT TB+	387		496		-109	-22%
TOT TB+	99 426	65%	87 837	66%	11 589	13%
NP TB/C	23 069		18 448		4 621	25%
RECH TB/C	2 331		1 900		431	23%
HORS RECHUTE TB/C	331		359		-28	-8%
TOT TB/C	25 731	17%	20 707	16%	5 024	24%
NP TEP	24 959		22 354		2 605	12%
RECH TEP	1 210		947		263	28%
HR TEP	352		440		-88	-20%
TOT FORME PULMONAIRE	125 157	82%	108 544	82%	16 613	15%
TOT TEP	26 521	17%	23 741	18%	2 780	12%
AUTRES	154		230	0%	-76	-33%
TOTAL CAS INCIDENTS	150 085		130 596		19 489	15%
TOTAL	151 832		132 515		19 317	15%
POPULATION PSN	87 491 755		85 026 000			
INCIDENCE POUR 100000H	172		154			
INCIDENCE ATTENDU OMS	323		324			
TAUX DE DETECTION	53%		47%			
DONNEES DESAGREGUEES						
2 017			2 016		Accroissement	%
Total de cas incidents repartis	149 763		126 998			
Hommes	83 778	56%	71 487	56%		
Femmes	65 985	44%	55 511	44%		
Enfants 0-14 ans	16 933	11%	14 213	11%		
Adultes	132 831	89%	112 785	89%		
Sex Ratio H/F		1,3		1,3		
Prisonniers TB	1 541	1%	636			
Mineurs TB	2 577	2%	1 269			
CO INFECTION TB VIH						
2 017			2016		Accroissement	%
Patients TB connaissant leur statut	96 897	64%	71 065	54%		
Patient TB VIH +	9 688	10%	8 344	12%		
Patients TB VIH+ sous Ctx	8 796	91%	7 413	89%		
Patients TB VIH+ sous TARV	7 982	82%	6 241	75%		
PVV chez qui la TB a été recherchée	146 480		90 368			
PVV TB-	127 283	87%	78 688	87%		
PVV TB- sous INH	49 206	39%	14 408	18%		
TB PEDIATRIQUE						
2 017			2016		Accroissement	%
Enfants 0-4 ans TB TTF	5 607	4%	4 880	4%		
Enfants 5-14 ans TB TTF	11 326	8%	9 333	7%		
Enfants 0-14 ans TB TTF	16 933	11%	14 213	11%		
Enfants 0-14 ans M	8 655	51%	7 386	52%		
Enfants 0-14 ans F	8 278	49%	6 827	48%		
Enfants 0-5 ans sous INH	13 045		4 725			
Enfants 0-4 ans TB+ (NP+RECH)	387		280			
Enfants 5-14 ans TB+ (NP+RECH)	3 821		3 224			
Enfants 0-14 ans TB+ (NP+RECH)	4 208		3 504			
Enfants 0-4 ans TB/C	2 420		2 020			
Enfants 5-14 ans TB/C	2 533		1 757			
Enfants 0-14 ans TB/C	4 953		3 777			
Enfants 0-4 ans TEP	2 810		2 580			
Enfants 5-14 ans TEP	4 992		4 352			
Enfants 0-14 ans TEP	7 802		6 932			
ISSUES DU TRAITEMENT						
2017, COHORTE 2016			2016, COHORTE 2015		Accroissement	%
Enregistres	128 292		117 074			
Succes	113 693	89%	104 160	89%		
DCD	5 230	4%	4 784	4%		
ECHEC	675	1%	669	1%		
PDV	4 057	3%	3 611	3%		
Non evalue	4 637	4%	3 682	3%		
TB PR						
2 017			2 016		Accroissement	%
Présumés soumis au Xpert	10 981		5 116			
TB MDR/RR confirmés	893	8%	709	14%		
TB MDR/RR parmi les nouveaux cas	326	37%	126	18%	200	159%
TB MDR/RR parmi les cas de retraitement	559	63%	583	82%	-24	-4%
TB MDR/RR mis sous Schéma long	9		72			
TB MDR/RR mis sous Schéma court	830		562			
Taux de succes schéma court (cohorte 2015)	95%		79%			
Taux de succes schéma long (cohorte cohort)	86%		71%			
Délai de mise en traitement	19 jours					

VI. DESK REVIEW

This step was to collect existing information based on country and international documents, which is planned in terms of human rights, stigma and key populations and highlight what is happening, level of achievement, what is not done and obstacles, what is not planned and could be done.

In terms of law, international agreements and treaties take precedence over country laws, it is in this context that various international treaties, agreements and other protocols relating to health in general and specifically with TB as well as aspects of co-infection TB/HIV and key populations were consulted first. National laws related to health and human rights, as well as protocols, strategies and other policies related to health, were consulted to collect elements relating to TB specific aspects, in particular provisions related to care access or discrimination and stigma.

In terms of measures, strategies, interventions that can make TB environment more favourable, following elements were collected:

- Extension of coverage according to epidemiology of tuberculosis in the country.
- Ensure increase of domestic resources to ensure regular and sufficient supply of anti-tuberculosis drugs and risk-bearing (e.g. withdrawal of partners).
- Application of innovative resource mobilization policies (internal and external).
- Collaboration between different ministries (health, Justice and interior).
- Strengthening collaboration between NTP, community and civil society organizations.
- Strengthening Mixed public-private partnership

Below are types of documents reviewed and clear quotes

4.1 DATA FOR ACTION FRAMEWORK FOR TB KEY POPULATIONS

NTP PATI-5 TB Care Guide: Defining Key Populations under NTP “4.2.4. Target population groups for screening: People spontaneously who have been consulting care structures; people living in close contact with an index TB case namely: a case of pulmonary TB and/or a case of tuberculosis appeared in a child under 5 years; especially if they have suggestive symptoms described above. People with high suspicion of HIV infection or positive HIV serology; vulnerable or high risk specific groups of TB: prisoners, children under age of 15 years (especially those under the age of 5 years), displaced persons, refugees, military personnel, mine workers, health care workers, diabetics, etc.”4.2.6. Investigation of TB contacts: This is a strategy to increase screening through active TB research with an index case”⁹.

2018-2020 National Strategic Plan of fight against TB¹⁰: “Throughout the world, a particular accent is attributed to paediatric shape considering vulnerability of this age group. As in all developing countries, infantile TB raises many problems in DRC. It is probably sub-diagnosed, sub-declared and its care is not optimal “Page 45;” several risk groups require a particular attention.

The NTP will work to meet these challenges by targeting its efforts and by adapting methods according to aimed targets: people in contact of TB patients (their houses, work,

⁹ Guide de prise en charge de la tuberculose PATI 5, Edition 2015 révisée en décembre 2017

¹⁰ Plan Stratégique National de lutte contre la tuberculose 2018 -20-20

educational institutions, etc.); Prisoners and employees in prison; minors, population which lives around mines, families of minors; taken refuge and moved; health workers. In 2016, NTP initiated a mapping of functional prisons by province; it indicates that 9 prisons with a prison population of between 1,000 and more house 65% of the country's prisoners (16.507 / 25.479), while 13 prisons with a population of more than 300 would house 5,871 prisoners out of a total of 25,479, or 23%. "Page 47; there are several craft (home-made) mining sites in which the TB seems to be active: diamond mines in Kasai Oriental and Kasai, copper and cobalt mines in Lualaba around Kolwezi, gold mines in South Kivu, Maniema and Ituri. To date, exact extent of problem is not well known by NTP, and few structured actions are taking place there.

To make TB environment favourable, NTP "intend to further increase number of TB health centers (CSDT), while resorting to the implementation of small TB treatment center (CST) in constellation and networks around the CSDT to further reduce distances" Page 37. "NTP has developed a transport guide sputum samples to improve access to quality diagnosis of all suspected of TB, including in resistant shape in TB drugs, through implementation of a transport system sputum samples of patient towards

laboratories at every levels "Page 52." Revision of diagnostic algorithm to include new targets and diagnostic tools, Strengthening of mixed Public Private Partnership in struggle, Implementation of specific strategies for certain vulnerable population, Strengthening capacity of community-based organizations (CBO) and other resource persons for their better involvement, update guide of coverage and extension of TB / HIV activities, implementation of One Stop Shop model, application of innovative resource mobilization policies (internal and external), strengthening of program collaboration with Community and civil society organizations, Advocacy for implementation of a social protection policy for TB patients "(Table N ° 11: Methods for prioritizing problems, pages 85-87).

To improve access to TB care, "NTP plans to increase national coverage of TB screening activity, strengthening sputum samples transportation mechanisms, intensifying TB screening activities for special groups, improving active screening of TB case finding in children, realize contact tracing around TB index cases, strengthening collaboration with all community and civil society organizations in TB care, strengthening the involvement of other care providers, regular supply of laboratory inputs, information support for screening and normative documents, promote TB infection control, collaboration with programs and related sectors (intra and inter sectoral collaboration) and promote gender and human rights in TB control. (4.3 Intervention strategies selected by objective, page 107)

2014 CAP survey (behavior, attitude and practice): In general, 8.9% of households have a good level and 26.2% have an average level of knowledge about TB. (Page 92 / Table 22)¹¹.

TB Care of Special Populations¹²: Some population groups require specific management in fight against TB given special conditions in which they live. For example, these human groups are known as "special populations", including: TB contacts, People living with HIV (PLHIV), Prisoners, Miners (mine workers), Refugees/ Wars displaced, Healthcare personnel, Military and police, Diabetics, Cross-border and local residents, Indigenous peoples (pygmies), Injecting drug users and tobacco smokers, Sex workers (PS), Street Children / Orphans, Academia and Internships. Injecting drug users (IDUs) are a high-risk population for HIV.

Combined factors related to lifestyle and social marginalization are responsible for high rate of HIV infection in this category; because of fragility of their health and HIV infection they easily

¹¹ Enquête CAP 2014 sur la tuberculose en RDC

¹² Guide de prise en charge de la tuberculose des populations spéciales

contract, search for TB or co-infection TB / HIV is a priority. Smokers experience not only dependence but also destruction of bronchopulmonary apparatus with lung cancer complications. This condition facilitates TB development in human body. There is a strong association between drug and tobacco users in several countries. Today this is a priority for WHO and UNION.

2017 epidemiological report: In 2017, 1,541 TB cases were detected in prisons. Kinshasa reported 782 or 51% of all cases (Page 39). The 2017 data reported from various provincial co-ordinations shows a total of 2,577 TB miner patients detected in some mine sites across the country. Fifteen TB provincial coordinations reported the cases. These are: South Ubangui, Kasai, Lomami, Sankuru, Haut Katanga, Lualaba, Tanganyika, Maniema, North Kivu, South Kivu, North Ubangi, Bas Uele, Haut Uele, Tshopo and Ituri. This distribution is predominantly in the eastern regions and Ituri province reported more cases (Pages 39 - 40)¹³.

HIV and TB Gender Assessment in DRC 2017: HIV Prevalence among injecting drug users passed from 13.3% to 5.9% in 2016. The existence of this community estimated at more than 4,000 (National Aids Program 2016 preliminary report) requires particular attention, given prevalence observed at this group level in other countries 23. There are no disaggregated data by sex or data on female partners of injecting drug users (Page 17)¹⁴.

Patients Charter for TB Care: Dignity, to be treated with respect and dignity; have social support from family; community and national programs. Information, have information on available care services, be informed of treatment condition, known drug names, dosage and side effects; have access to your medical records in the local language; have peer support and the volunteer advice¹⁵.

2018-2021 National Strategic Plan for HIV: The general situation of key populations has not been investigated by a recent national survey. However, recent programmatic data report much higher proportions of PLHIV than in the rest of the population¹⁶.

Various measures, strategies, interventions that can make TB environment more favourable are defined in 2018-2020 TB NSP and 2018-2021 HIV NSP, various NTP guides including, TB care guide (PATI 5), special populations management guide, MDR-TB guidelines, pediatric tuberculosis management guide, and community actors training manual.

4.2 LEGAL ENVIRONMENT

Universal Declaration of Human Rights¹⁷: Article 25 speaks of health as a fundamental right, Article 7 states that everyone has right to equal protection against any discrimination that would violate this Declaration and against any incitement to such discrimination. Article 25 stipulates that everyone has right for a standard live of health adequate and well-being of himself and his family, including food, clothing, housing, medical care as well as services social needs; she has right to security in unemployment, sickness, disability, widowhood and old age situation, or in other cases of loss of her means of subsistence as a result of circumstances beyond her control.

¹³ Rapport épidémiologique 2017, PNLT

¹⁴ Evaluation sexospécifique VIH et TB en RDC 2017

¹⁵ Patients Charter for TB care 2006.

http://www.stoptb.org/assets/documents/global/plan/IP_OMS_Charte_FR_Epreuve.pdf

¹⁶ Plan Stratégique National de lutte contre le VIH 208 - 2020

¹⁷ Déclaration Universelle des Droits de l'Homme. <http://www.un.org/fr/universal-declaration-human-right/index.html>

Declaration of Alma-Ata on Primary Health Care of September 12, 1978: Strongly reaffirms that health, which is a state of complete physical, mental and social well-being, and is not merely the absence of disease or disability, is a fundamental human right, and that achieving the highest attainable standard of health is an extremely important social goal of worldwide concern and involves the participation of many socio-economic sectors other than the health.

The flagrant inequalities in health situation of peoples, both between developed and developing countries and within countries themselves are politically, socially and economically unacceptable and are therefore a matter of common concern to all country.

Economic and social development, based on a new international economic order, is of fundamental importance in order to ensure highest attainable standard of health for all and to bridge health gap between developing countries and developed countries. The promotion and protection of health of peoples is prerequisite for sustained economic and social progress as well as contributing to a better quality of life and world peace.

Every human has right and obligation to participate individually and collectively in planning and implementation of health care destined to him.

Governments have a responsibility for health of populations that can only be fulfilled by providing adequate health and social services. Primary health care is essential health care based on practical's methods and techniques, scientifically sound and socially acceptable, made universally accessible to all individuals and families in the community with full participation and at a cost that the community can support¹⁸.

International Covenant on Economic, Social and Cultural Rights of 1966: Article 12 (1) says that the States Parties to the present Covenant recognize right of everyone to enjoyment of highest attainable standard of physical and mental health she is able to reach¹⁹.

The Maputo Protocol: Condemns female genital mutilation and states "right to health and control of reproductive functions". It states a number of human rights, such as food, health, education, dignity, peace. It also focuses on gender inequalities, condemns discrimination against women, and decides on the inheritance, succession and rights of widows²⁰.

Sustainable Development Goals²¹: In its objective 3 talks about good health and wellbeing, by 2030, eliminate preventable deaths of new-borns and children under 5 years, all countries having to seek reduce neonatal mortality to 12 per 1,000 live births at most and mortality of children under 5 years to 25 per 1,000 live births at most. End the HIV/AIDS, tuberculosis, malaria epidemics as well as neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases. Strengthen prevention and treatment of the abuse of psychoactive substance, including narcotics and alcohol.

¹⁸ Déclaration d'Alma-Ata sur les soins de santé primaires du 12 Septembre 1978.

https://www.who.int/topics/primary_health_care/alma_ata_declaration/fr/

¹⁹ Pacte International relatif aux droits économiques, sociaux et culturels de 1966.

<https://www.ohchr.org/FR/ProfessionalInterest/Pages/CESCR.aspx>

²⁰ Le Protocole de Maputo. http://leprotocoledemaputo.org/french_protocole.pdf

²¹ Objectifs de Développement Durable (ODD).

http://www.undp.org/content/undp/fr/home/sustainable_development_goals.html

Ensure that everyone benefits from universal health coverage, including protection against financial risks and providing access to quality essential health services and essential safe, effective medicines and vaccines at an affordable cost²².

Support research and development of vaccines and medicines for communicable and non-communicable diseases, which primarily affect people in developing countries, provide with affordable cost access to essential medicines and vaccines, in line with the Doha Declaration on the Agreement of Trade-Related Aspects of Intellectual Property Rights (TRIPS) and Public Health, which reaffirms the right of developing countries to take full advantage of the provisions of this Agreement which provide flexibility when it is about protecting public health and, in particular, ensuring universal access to medicines.

Mandela Rules: A set of United Nations standard minimum rules for the treatment of prisoners and access to care for priority diseases talks about health in the prison environment and access to care for people living and working in prisons²³.

Constitution of 2006 as amended in 2011: Talk about first of all in general of the right of all Congolese to receive quality care, to fully benefits from its dignity and to be treated without discrimination whatever its status. Article 47 relative on protection of persons living with HIV, as amended in 2016, does not only address aspects of the rights of PLHIVs but also their obligations, including non-living clandestinely, protection of the partner, and deals with aspects such as TB / HIV co-infection but also aspects of stigma and discrimination²⁴.

2018-2021 National Strategic Plan for HIV: The vulnerability of key populations, youth, adolescents and OVCs (orphans and vulnerable children) exposes them to risks of infection and of sexually transmitted infections (STIs). To eradicate human rights violations (stigma, discrimination, right to health, right of gender equality, right of physical security) associated with HIV, the focus is on the strategy of "Positive Health, Dignity and Prevention" that underscore the importance of simultaneous and holistic care of prevention and treatment as well as leadership roles for people living with HIV in removing political and legal barriers²⁵.

The 1940 Criminal Code of the DRC: as amended and supplemented by the presidential decree of 2004 clearly defines the penalties related to different offenses, the penal code allows generally, to punish wrongdoing such as discrimination and stigma, no assistance to person at risk and other forms of lèse-majesté cases²⁶.

Protection of PLHIV and Affected Persons law²⁷ : Speaks in its article 1, paragraphs 2,3 and 5, to fight against any form of stigmatization to discrimination of PLHIV and affected people, to guarantee and protect the rights of PLHIV and those affected, and reaffirm the fundamental rights and freedoms of these categories of people.

²² Objectifs de Développement Durable (ODD).

http://www.undp.org/content/undp/fr/home/sustainable_development_goals.html

²³ Mandela Rules. http://www.un.org/en/events/mandeladay/mandela_rules.shtml

²⁴ Constitution de la République Démocratique du Congo du 18 Février 2006.

<https://www.wipo.int/edocs/lexdocs/laws/fr/cd/cd001fr.pdf>

²⁵ Plan Stratégique National de la riposte au VIH/SIDA 2018 - 2021

²⁶ Code Pénal congolais de 1940 tel que modifié et complété en 2004.

<https://www.wipo.int/edocs/lexdocs/laws/fr/cd/cd004fr.pdf>

²⁷ Loi 08/011 portant protection des personnes vivant avec le VIH et personnes affectées

It refers to a confidential test as a test procedure consisting to use of an identification number or a symbol in place of the name of the individual tested and allowing the laboratory conducting the test to attribute the results to the number used or the identification symbol in Article 2 (15).

Patients 'Charter for Tuberculosis Care'²⁸: The Patients' Charter explains the rights and obligations of people with TB. It gives them, as well as their entourage, means to get personally involved with this knowledge. Initiated and developed by patients around the world, the Charter allows a relationship with health professionals mutually beneficial. The Charter establishes how patients, community, public and private health authorities, as well as governments, can work as partners in an open and positive relationship, with the aim of improving care and increasing the effectiveness of health processes. This allows everyone to be more accountable to others while stimulating mutual interaction or "positive partnership". Developed in tandem with the International Standards for TB Care to promote a patient-centered approach, the Charter takes into account the principles on the right to health and human rights of the United Nations, UNESCO, WHO, the Council of Europe, and other national or local charters or conventions. The Charter puts into practice the principle, of greater TB patient's implication, which affirms that the participation and empowerment of patients is the catalyst for effective collaboration with health professionals and authorities, and that they are essential for the victory of fight against TB.

4.3 GENDER

HIV and TB Gender assessment in DRC²⁹: No TB epidemic prevalence statistics, no sex disaggregated data for TB mortality in the DRC. In TB case notification: men account for 56% and women 44%, Tuberculosis epidemic affects more men than women. But the lack of gender-specific data as well as prevalence does not explain this result. This lack of data also misses therapeutic outcome at central level.

Women participate less than men in decision-making about health care and different aspects of household life. It is with regard to one's own health care that woman is the least associated with decision-making since in 53% of cases the spouse decides mainly; in 36% of cases, the decision is taken jointly and it is in only 11% of cases that it decides mainly. 56% of men aged 15-49 years decided mainly about their own health care. Working does not seem to have an influence on women's participation in decision-making, but having worked and being paid for in money favors women's involvement in decision-making. In almost three out of ten cases (29%), women decide themselves from the use of the money they earn, but in 30% of cases, it is the husband / partner who decides mainly. Only 7% of women decide mainly the use of money earned by their husband / partner. In 46% of cases, the decision is in 46% of cases it is the man himself who decides. Stigma is also a major barrier to access to health care, especially for men. HIV is perceived - especially in rural areas where misinformation is omnipresent - as a disease that affects homosexuals and people with light morals. Many would not want to be considered type of someone who does not take care of himself or who has multiple partners simultaneously.

Transgender people and TB issues are not included in the legal texts on the gender issue, and this national gender policy has not been updated for almost 10 years.

²⁸ Patients Charter for TB care 2006.

http://www.stoptb.org/assets/documents/global/plan/IP_OMS_Charte_FR_Epreuve.pdf

²⁹ Evaluation sexospécifique VIH et TB en RDC 2017

4.4 LEGAL FRAMEWORK

DRC is a country with a civil law tradition and therefore the main provisions of private law date back to the 1804 Code Napoléon. However, Congolese law is mainly based on Belgian law which it shares the general characteristics. Congolese law has at least seven sources: The Constitution, international treaties and agreements, legislation, regulations, customary law, jurisprudence and doctrine.

Article 215 of the Constitution provides that international law is a basis of Congolese law³⁰. In terms of Congolese national laws and policies, in terms of health, DRC laws are much more generic, hence the need sometimes to adapt them, to refine them, to specify them, as the law for protection of people living with HIV. To alleviate this situation, but also to align itself as much as possible with international policies and norms, the country has ratified several international agreements, treaties and declarations which take precedence over national laws.

Democratic Republic of Congo does not have a specific law on TB beyond the law establishing and organizing the National TB Program (NTP). However, as stated above, it has a However, as stated above, it has a wide range of usable and stacking laws that allow the TB legal environment not to be a great legal desert.

In terms of legislation, the Constitution makes distinction between organic laws and ordinary laws. Unlike ordinary laws, organic laws organize important areas of public life of the state.

In terms of customary and tribal law, custom is recognized in article 207 of the Constitution. Customary and tribal law is another basis of the DRC's legal system, as 60% of the population lives in rural areas. Customary law regulates both personal status and property rights in different communities¹. The term customary law does not refer to simple practices and practices that have acquired this character over time, but to a normative system implemented by legitimate law-making bodies (such as patriarchs, family councils, clan, and tribal chiefs). Finally, customary law is not of general application, but only applies to the traditional community from which it originated.

Since laws at the national level are more widely consulted by lawyers, it is preferable that these laws be more complete and detailed.

4.5. TB KEY POPULATIONS PRIORITIZATION

In view of multiplicity of key populations identified throughout the world and in DR of the Congo in particular, it is necessary to be able to prioritize these populations. The prioritization is done in order to specifically define the key populations on which the evaluation will be conducted.

As part of this assessment, the prioritization of key populations is being done to accelerate the country's efforts towards achieving the goal of WHO's End TB Strategy by improving case research among population subgroups faced at higher risks / exposures, such as 5 to 10 times more vulnerable and less likely to be recruited by the population (more marginalized due to legal, human rights, gender and economic barriers to access government services).

A two-day key population prioritization workshop from 19 July to 20 July 2018 at the Bethany Center in Kinshasa was organized. It was attended by 29 people including 13 women and 16 men from the stakeholders from technical working group. This prioritization was based on the

³⁰ Constitution de la République Démocratique du Congo du 18 Février 2006.
<https://www.wipo.int/edocs/lexdocs/laws/fr/cd/cd001fr.pdf>

Key Populations Prioritization Tool developed by Stop TB Partnership as well as the sampling of key populations prioritized for this assessment.

During the workshop, groups worked on:

- Identify potential key populations for TB care,
- Prioritization of key populations according to the consequent prioritization,
- Select 2 or 3 key populations as targets of the assessment,
- Definition of sampling of the key populations selected,
- Enrichment of field tools.

Stakeholders involved in the prioritization process of key populations were representative of people living with HIV, former TB patients, indigenous peoples (Pygmies), organizations working in the fight against TB, HIV / AIDS, drug addiction (UDI), human rights, lesbians, gays, bisexual and transgender (LGBT) and gender as well as representatives of Health and Justice Ministries.

During the workshop, each stakeholder worked particularly on the basis of their experience with key populations targeted by TB, either because they represent them or because they work for them.

Due to the lack of official data on key populations, direct experiences and knowledge from key populations have made it possible to truly reflect the exact reflection of key populations, taking into account some inclusive criteria among others, key populations with significant number of people with TB for whom TB interventions are not or poorly planned and delivered by the NTP.

Results

The plenary discussions led to the final prioritization of key populations by completing the Stop TB Partnership prioritization tool based on data presented by the 6 working groups each working on up to 5 different key populations.

There were 12 prioritized key populations for prioritization out of a total of 29 key populations listed and analyzed by the working groups. It should be noted that these key populations come from the lists of the DRC and Stop TB Partnership. Prioritization scores from the highest to the lowest of 12 selected key populations are as follows:

Board 2: List of the selected key populations and score at the prioritization workshop:

N	Key populations	Final score
1	Prisoners	9,5%
2	PLHIV (people living with HIV)	9,5%
3	TB Contacts	7%
4	Injecting Drug Users (IDU) and smokers	4,5%
5	Lesbians, gays, bisexuals and transgenders	4,5%
6	Homeless	4,5%
7	Mine workers	4%

8	Refugees	4%
9	Internal displaced (country)	4%
10	Militaries and police officers (Men and woman)	3%
11	Poor urbans	3%
12	Borders and waterfronts	1,5%

From this work, 3 key populations are paramount according to allocated scores to each of them. Considering that many have control on prisoners and which are sold out on planned activities in 2018 – 2020 TB NSP, these ones are not deducted as primordial key populations for this evaluation although can be found on top of list.

Board 3: List of prioritized key populations:

N	Prioritized key populations	Final score
1	PLHIV (people living with HIV)	9,5%
2	TB Contacts	7%
3	IDU and smokers	4,5%

These three key populations have been selected to serve as CRG assessment targets in DRC.

Measurable definitions of key populations

Measurable definitions which resulted to sampling of key populations have been formulated during prioritization workshop based on eligible criteria well defined for this qualitative research.

Board 4: Sampling of the priority key populations:

Key population	Criteria
PVVIH	Men and women, aged of ≥ 25 years and under ART since 8 months and regularly attending or not a self-support group.
TB Contact	Men and women, age of ≥ 25 years and which the index cases have a bacillus charge +++ or which the result of the Xpert is Rif + and staying 2 months or more in the same household then the index case.
UDI and Smokers	Men and women, aged of ≥ 19 years, been taking tobacco, hemp or been injected drug during the 6 last months in the counter or smokehouse.

4.6. DATA COLLECTION

Data collection of Gender, Rights and Community assessment on TB based on CRG tools of Stop TB Partnership has been realized in health provincial divisions of Kongo-central, North-Kivu and Kinshasa in DR of Congo during period from 21st July to 7th September 2018.

Methodology used during data collection was articulated around below points:

- Organize focus groups with key populations, and community and civil society organizations.
- Organize deepened interviews with key informers, and health care workers working on TB.
- Collect information that may be a burden to access TB care for key TB populations;
- Gather data collected according to the research tools.

The focus was on:

- Know TB reality and how it is perceived at grassroots level.
- Have an idea about TB legal environment.
- Check data collected during documentary review.

Descents on field have allowed knowing reality of tuberculosis and the way in which it is perceived, to have an idea on exposition risks to sickness of key populations, barriers and obstacles in access TB services.

Impartial time for data collection being well limited, 2 concerned health zones (HZ) by health provincial division (HPD) have been selected, to know: Matadi and Nanza health zones for Kongo-Central, Goma and Karisimbi HZ for North-Kivu and, Bumbu and Selembao HZ for Kinshasa. The consultants team has been strengthened by 30 investigators, with gender composition (12 women and 18 men), because of 10 per HPD. The investigators have been recruited under the defined criteria considering the gender, experiences in fight against TB and or HIV, and in human rights and also experience in TB contact tracing and other field surveys. The groups of the investigators were constituted of former TB patient representatives, PLHIV, community relay (RECO), IDU, lawyers and representative of ONG: UCOP+, PSSP, RACQJ, CAD, FOSI.

The choice of these health sectors and the investigators have been operated during the briefing meetings and the preparations of field visits, with TB and HIV provincial coordination's teams. All 30 investigators and the 3 TB provincial supervisors have been briefed on assessment objectives, targets, tools and data collection mission.

The qualitative data have been collected on the strategic base of the theoretical saturation in which the collected data become redundant, indicating that no new information can be collected.

4.6.1. Focus groups of priority key populations

The focus groups were made up of priority key populations, TB care providers, associations' representatives working in fight against TB and HIV, and TB patients occurring cases.

Focus group participants were located through contacts or services working with these key populations.

Upon of total of 15 expected focus groups, 14 were organized in which 5 at Matadi in Kongo-Central, 5 at Goma in North-Kivu and 4 others at Kinshasa. Each group was constituted of 8 participants and 4 observers average which have been selected according to their status as key populations concerned by this assessment, people working with populations or as person at risk of exposure to TB. In total, 5 focus groups of people working for or with key populations, 9 focus groups of key populations were organized.

112 persons have participated in these discussions in which 75 men and 37 women (49,33%), the dispatching by key population is presented like: 15 men and 9 women PLHIV, 14 men and 10 women TB contacts and 20 men and 4 women IDU. The age groups were 25 to 63 years old. Focus groups were held in Matadi, Kongo-Central on July 26, 2018 for PLHIV, on July 27, 2018 for TB contacts and IDU and smokers, in Goma, North Kivu. August 14, 2018 for PLWHIV and TB contacts, August 14, 2018 for IDU and smokers, in Kinshasa on September 3 for PLHIV, on September 4, 2018 and on September 6, 2018 for IDU and smokers.

4.6.2. Key informant interviews

Key informant interviews were conducted with 41 individuals, including 9 women and 32 men between the ages of 35 and 65, working for and / or with key populations in 3 sites visited as part of this assessment. The choices were made on purpose for some and according to their sensitivity for others. The participation of women in this process of gathering information through group discussion has not been satisfactory considering the small number of women that can be justified by the fact that most positions of responsibility are animated by men both in state institutions, private than civil society.

Different stakeholders in the fight against TB have been involved in this process, starting with the administrative and health authorities at national and provincial levels. In this category, we count adviser of Minister of Social Affairs, office director of governor of Kinshasa, mayor of Goma city, health provincial Minister, provincial executive secretary multi sectoral of Aids, chiefs of health provincial divisions, TB provincial supervisors and district medical officers, and nursing supervisors of health zones concerned. TB nurses and laboratory technicians. also, civil society platforms and organizations leaders, community organizations of PLHIV leaders and those working for and with injecting drug users. In another category, a traditional practitioner and a pastor were interviewed. The interviews were conducted from July 25 to July 28, 2018 at Matadi, from August 11 to August 15, 2018 at Goma and from August 30 to September 5, 2018 at Kinhsasa.

4.6.3. Cartography of key populations

The cartography of key populations for TB control is not available at any of the visited sites, only the number of prisons and some mine careers are listed at public administration and the provincial health division levels. There are still some health facilities in some prisons and mine careers that provide TB treatment.

At the level of NTP, the same observation was made concerning this cartography. It should be noted that there are only prison lists and estimates of number of prisoners for some prisons, list of some mine quarries and number of their TB care facilities by TB provincial coordination.

4.6.4. Observations of behaviors and gathering places of key populations

The general knowledge of key populations about TB in the 3 sites retracts much more into local beliefs and customs with the stereotype of witchcraft and or other cultural phenomena related to beliefs. Some people, many of whom are IDUs, equate TB with an inherited disease

or a bad spell, the effects of drug taking, hard liquor and tobacco, which forces them to consult traditional practitioners rather than going to the health centers for TB detection and treatment.

At North Kivu, IDUs are more concentrated in Birere, Virunga and Goma areas (hemp smokers) among them are those commonly known as Mai-bobo who are street children, devoted to drugs. In Kongo Central, there is a high concentration of this key population in Nzanza commune and often gather at night in smokehouses. This key population prefers to live in hiding for fear of being arrested by the services of the order and incarcerated.

People living with HIV live reluctantly for fear of discrimination. They prefer to be in support groups (peer educators) where they feel better and more open and can share their problems and find solutions

Some observed TB contacts prefer not to share the same roof, utensils and other effects with their relatives suffering from TB for fear of being contaminated.

4.7. FINDINGS ENDORSED AT VALIDATION WORKSHOP

4.7.1. DATA FOR ACTION FRAMEWORK FOR TB KEY POPULATIONS

4.7.1.1. PLHIVs

Information gathered from the desk review:

The care of PLHIV has always been part of the main strategic thrusts of the NTP. TB / HIV co-infection activities are currently organized in all provinces of the country. Data are collected and made available to both programs (NTP and NAP) by the TB provincial coordinating and Aids provincial coordinating structures³¹.

The two programs ensure the design, planning, implementation, supply of tests, inputs and specific drugs for co-infected TB / HIV patients, monitoring and evaluation activities and results, and this is in Global Fund grant framework "Unique concept note TB-HIV 2015-2017, then 2018-2020 with a new approach One Stop Shop / Single counter". Care providers are trained on TB-HIV co-infection in most health areas. The data is showing the reduction in HIV burden among TB patients is growing as the number of patients experiencing status increases³².

Comprehensive coverage of HIV activities in HZs remains low, supplies sometimes erratic with stock out and sometimes delays due to overstocks in drugs, tests, reagents and inputs to fight TB / HIV co-infection

Activities to reduce the burden of TB among PLHIV are still very low compared to TB gateway: low access of PLHIV to TB prevention, TB screening (48%), TB treatment (404 ZS without preventive treatment with INH for TB-HIV patients)³³. The involvement of community organizations in activities to fight TB / HIV co-infection is very low.

Information gathered from focus groups:

In general, people living with HIV are recognized by their weakened state of health, the appearance of tasks on the skin and an unkind behavior at the first contact caused by the discrimination they suffer from.

PLHIV who develop TB often know it through the screening test carried out, either by microscopy or radiography in TB care structures. The most commonly observed symptoms are prolonged cough, weight loss, lack of appetite, sputum with blood, body fatigue, repeated fever...

TB treatment are insured, but some people have difficulty to cope antiretroviral drugs (ARVs) because of with the number of tablets given and their severe side effects, and the fact that their serological status is not respected by some care providers disclosing it, push them to give up the TB treatment. The proportion of PLHIV who develop TB is low, and many of them do not receive TB testing.

TB is a concern for PLVIH because it causes a lot of deaths; especially immunocompromised

³¹ Plan Stratégique National de lutte contre la tuberculose 2018 - 2020

³² Rapport épidémiologique 2017, PNLT

³³ Plan Stratégique National de lutte contre la tuberculose 2018 – 2020

cases are the most exposed. The fact is that when a person suffers from HIV and tuberculosis, feels depressed in society.

Health services available for TB and HIV care are not adequate enough because the two services are not often found together and HIV care is not fully covered in some countries. Nevertheless, most facilities providing TB services in cities are tested for HIV, some facilities are remote from populations, especially those in rural areas, and others experience drug breaks from time to time. Biological monitoring is not systematic for all PLHIV, some control exams are paying and nutritional support is not covered.

With regard to other populations who are victims of barriers to access TB care services, men who have sex with men and women who have sex with women, truck drivers, teachers, conveyors, drug users and hemp smokers, sex workers, the militaries.

Information gathered from interviews:

Because of their experiences and knowledge related to TB, some PLHIVs claim to recognize prolonged cough, lack of appetite, intense fatigue, weight loss, abdominal bloating, weakness, high fever, shortness of breath, heartache, repeated vomiting of blood, spitting with blood, stretched shoulders and stuttering, weight loss, red lip, change in skin color, difficulty breathing, pain in of the chest, fast breathing as TB symptoms. TB test is made by sputum microscopy and the GenXpert machine as well as radiography. TB patients are treated on an outpatient basis in health facilities that have these services with appropriate medications that improve health during treatment and eventually cure TB. Most PLHIV are waiting to observe TB symptoms mentioned above for examination because they have no information that any PLHIV should be screened for TB.

TB is perceived as a dangerous, contagious and serious disease caused by food insufficiency, excessive intake of tobacco and alcohol, and directly attacks the lung. It kills and spreads from one person to another, but it's curable after a regular and correct treatment. TB / HIV co-infected patients do not often receive support from the community, their families, and live separated from others, while isolation is no longer part of the care guidelines. It should also be noted that preventive treatment with INH is not sufficiently insured for PLHIV in whom TB is excluded. According to PLHIV, treatment for 6 to 8 months is free of charge at health facilities level. But, for some, traditional practitioners also detect and treat TB.

TB worries PLHIV more and more because today it is the first one cause of their death; its spread is done by ambient air and constitutes a cause of discrimination, stigmatization and rejection of TB patients by community and their families. And side effects of TB drugs combined with side effects of ARVs increase patient's suffering, but, insurances to cure from a free and correct care offered by many health facilities across the cities mitigate the concern.

Because of TB screening among PLHIV, it should be noted that the willingness of PLHIV to be screened of TB is low. They are screened for TB only when their health status deteriorates further or when advised by nurse or community health workers. Some of them encourage their loved ones to get tested if they see TB symptoms. In addition, PLHIV claim that 2-3 people who are family members and / or acquaintances of a PLHIV have suffered or are suffering from TB.

TB services available in cities are moderately adequate in most health facilities; with some behaviors displayed by health facilities including TB screening cost and referral of patients elsewhere for further examination (e.g. GeneXpert) push them to stop treatment.

Findings summary:

The PLVIH are more exposed to TB because of their immune deficiency and poor living conditions including the precariousness in which most of them live.

Access to TB care services is difficult in some TB health facilities due to fees for consultation, TB testing including radiology, and sputum examinations. Lack of information on TB care, do not allow people to carry out the test and benefit from TB treatment in time in case of positive results because of lack of financial means. Some PLHIV prefer to live off others because of the fear and shame of stigma and discrimination in the community.

Problems of unequal supply of TB drugs and inputs, stock-outs and the lack of diagnostic and treatment tools in some TB and HIV health facilities do not allow patients to receive appropriate and adequate TB / HIV co-infection care. In most cases, TB services are separated from those of HIV or not offer in HIV health facilities. It is difficult for TB / HIV co-infected patients in this situation to benefit from quality care as they have to move from one service to another or from one health facility to another involving the means of transport and this affects the time required to perform the tests, obtain results, and put them into treatment. The conditions of reception of patients are lacking, for fear of contamination or by disrepute, patients are received outside exposed to all bad weather, and nursing staff takes a lot of time to receive patients. The availability of TB drugs in treatment facilities is not well guaranteed. Health coverage in terms of TB care for PLHIV is good in big cities although both services are not often offered by the same care providers.

The lack of respect of human dignity, stock-outs of TB medicine, patient negligence, poor reception, food insufficiency, distances to be covered to reach some TB health facilities, poverty, the duration of waiting for medication at the health center, stock out of TB inputs, stigma and discrimination of TB patients in the community and health facilities, lack of information about TB, lack of transportation costs to reach remote health facilities, bad beliefs, and ignorance are barriers to TB screening and treatment

Some TB nurses are untrained and have difficulty delivering as they should. The regularity of supply of TB inputs and drugs structures is not well ensured, the lack of management of drug stocks at the level of health facilities which leads to distribution of TB drugs in expiry phase to patients, lack of provision of INH preventive treatment in health facilities, lack of vulgarization of TB policies or guidelines does not allow patients to claim their rights in case they are not respected, lack of quality diagnostics tools in some health facilities, duration of diagnosis, long duration of treatment, poor motivation of care providers, failure to maintain confidentiality of patient status, and poor collaboration between care providers and community workers to ensure the support and patients endorsement.

4.7.1.2. TB Contacts

Information gathered from the desk review:

The different approaches developed in NTP TB care Guide for Special Populations do not take into account this key population. No guidelines are defined to improve the care of this category of population although the TB contacts patients are included in the list of NTP special populations included in the guide of TB care and the guide of care of special populations mentioned above.

It should be noted that active research approach for TB cases is included in NTP 2018-2020 TB NSP for this population with activity of TB contact tracing around TB index cases³⁴,

³⁴ Plan Stratégique National de lutte contre la tuberculose 2018 - 2020

bacteriologically confirmed, MDR and Paediatric TB, transporting sputum specimens from TB people affected by TB among TB contacts, data of which can be found in community organizations CAD, LNAC, Fondation Femme Plus and AALTB that have been doing these activities for more than 3 years, but not in NTP 2017 epidemiological report and previous years.

Information gathered from the focus groups:

The information gathered from TB contacts shows that it is difficult to identify people who are in constant contact with patients in the community. Those who develop TB find it by symptoms developed by a family member who has already suffered or suffers from TB. TB screening is done by microscopy and HIV testing is recommended and offered to those who are screened positive by health care providers. TB treatment is available, but the long duration of treatment, the poor reception by some health care providers, the distances separating the patients from health centers, especially in rural areas, push them to stop treatment. The patients are still rejected, discriminated and stigmatized by community, although TB care is integrated and offered in different health centers without any distinction since the sanatorium was abolished. The most common symptoms of TB in this key population include coughing, weight loss, fatigue, lack of appetite, sweating, spitting with blood, chest pain, smoking and alcohol.

TB worries a lot because it kills, impoverishes and it's contagious. It is considered as a shame disease, so people who presume suffering from TB prefer to consult traditional practitioners and look for healing in churches than going to TB screening and treatment facilities. Ignorance, lack of interest, lack of information about TB and lack of a suitable service for tracing relatives of TB patients does not promote routine TB screening in this key population.

Concerning other populations who are victims of barriers to access to TB care services, PLHIV, drug addicts, street children, alcoholics, hemp smokers, soldiers, prisoners, diabetics, TB patients, police officers, truckers and conveyors and Dockers (people working in the seaport) are named.

Information gathered from interviews:

Experiences and knowledge about TB differ from person to person. TB is a disease like any other caused by a bacterium, it is serious but curable. It caused by bad luck, witchcraft and excessive consumption of alcohol, mutual sharing of tobacco and hemp, common use of utensils, and common use of public transport. The symptoms of TB are: prolonged cough, weight loss, high fever, sputum with blood and difficulty breathing. Screening tests are done in facilities providing care for TB; the treatment is free and lasts 6 months. TB worries because it is contagious and can kill if you are not treated; treatment is long and painful with a lot of side effects.

TB care services are available in specialized health facilities, treatment is free, and health education is provided by nurses and community members where they are operational. Access to TB care in the cities is easy, but some cases of limit to this access to care are made by some providers or health facilities by fees for consultation, diagnostic tests and the beginning of treatment. Voluntary TB testing is not systematic, therefore it difficult to go quickly to the health center for TB testing by ignorance, by waiting for symptom onset or by fear and shame to be stigmatized

The vulnerability to TB of this key population is increasing because of poor living conditions of people living in poorly ventilated and overcrowded homes, in unhealthy environments, food insecurity, promiscuity, poverty, disease chronic and recurrent, also lack of information to prevent this disease, so that many people who live with those with TB develop the disease.

Summary of findings:

Access to TB care service is a problem because of fees, including consultation costs and other diagnostic tests that do not allow low-income people to benefit from it, failure to respect patients' rights by providers and the community that borders on stigma and discrimination. Poor living conditions, unsanitary environment, concentration of populations in very narrow spaces, poverty practices, lack of information on TB increase the risk of exposure to TB.

TB services are inadequate, patients are put on treatment for a fee, regularity of drug supplies is difficult from time to time, drugs stock-outs in repetition do not allow regular monitoring of TB treatment and promote the trafficking of these products by health care providers and the patients in search of recovery pay them, treatment duration seems long and laborious requiring a food support which is not planned either, setting aside of TB patients in care facilities discourages patients from going to health center publicly and some of them negotiate with providers to be received on time and in another local. The delay between the consultation and the diagnosis with late rendering of results until beginning of treatment, number and volume of TB medication to take in fasting make it difficult to adhere to treatment.

Not all laboratories are equipped with the GeneXpert machine. Those who have this machine form a network with the few surrounding laboratories to benefit all the patients of this area this quality diagnosis, but there is a problem of sputum samples transportation in a context of geographical inaccessibility and mean of transport for patients who have to travel to diagnostic site.

4.7.1.3. IDUs and hemp / tobacco smokers

Information gathered from the document review:

This key population is one of many in TB care guide for NTP special populations. Some strategic guidelines are also defined to improve the care of this category of population.

TB data in relation to this population do not exist, neither at NTP level, nor at level of community organizations engaged in the fight against TB in DRC. No intervention is planned to reach this population. NTP 2018-2020 TB NSP does not include any activities for IDUs and smokers.

Information gathered from the focus groups:

Injection drugs users and smokers of hemp are people who, by neglect of a balance diet, often seem appear weak, some of whom display behavior that may be less considered in community. This key population is one of the most vulnerable categories to TB. Many of them develop tuberculosis and resort to traditional practitioners to whom they are easily admitted although they spend money on unsuitable care and waste a lot of time before arriving in TB health facilities. The most known signs of TB in this key population are coughing, weight loss, fatigue, lack of appetite, sweating, spitting with blood, chest pain, tobacco and alcohol.

Access to TB care services is not easy because of a number of reasons, including the fact that these key populations are considered as a threat to society because injecting and narcotic drugs are banned by Congolese law. No strategy promoting their access to TB care is developed to bring TB services closer to them therefore they are often object of contempt by health care providers and community, pushing them to live almost in hiding for fear of being arrested. Health services do not offer TB care taking into account of specificities of different populations, poor patients who do not benefit from food kits.

IDUs fear that TB is a serious disease that can kill, they are aware of their level of risk of exposure, and believe that their physical condition, the conditions in which they live, and their attitude vis-a-vis of health facilities do not spare them from this disease.

IDUs recognize that they are not alone in this situation of marginalization in health care system, PLHIV, street children, alcoholics, prisoners, diabetics, TB patients, truckers and conveyors suffer the same injustices.

Information gathered from interviews:

Because of their experiences and knowledge, TB is a contagious disease that kills, but it's curable if the patient is treated appropriately. People suffering from TB are separated from their families and do not share the same utensils so that others are not contaminated. By the 1990s, TB was known as a disease caused by the same virus as AIDS and leprosy, so the patients are directly quarantined.

TB directly affects the lungs, causing TB patient to cough all the times, spit blood, feel physical weakness, lack of appetite, high fever, and become skinny. TB screening is done by microscopy and radiography in the appropriate health facilities. Its treatment is free and effective, but the duration requires enormous sacrifices. Many injecting drug users and hemp smokers suffer from TB, and others die without being treated.

IDUs and smokers worry about being rejected by their neighboring, losing their jobs, contaminating their surroundings, dying while having TB. The majority of interviewees are aware of health centers where TB can be tested. People affected by TB among them are referred or escorted to health centers by family members or community members who support them. It is difficult for IDUs to be voluntarily screened for TB if they are not sensitized and if they are not guaranteed a good reception at health care facilities.

Care services available for TB detection and treatment in the cities are adequate in most cases, but some cases deplore the behavior displayed by care providers in some facilities where screening is paid, however, other health facilities refer patients elsewhere for other examinations (eg. GeneXpert), and drugs stock out make difficult the treatment follow-up, no nutritional support policy is put in place to support very weak patients.

Summary of findings:

Access to TB care is difficult in some cases due to lack of financial means, lack of information on the cost of treatment, drugs stock out, stigma, discrimination, self-stigma, fear to be arrested by narcotic police, clandestinely live; also non-hospitalization or late hospitalization of patients suffering from severe form of TB and are supported by their own families, as well as non-respect of rights of IDU patients and hemp smokers by care providers.

Being a IDU or hemp / tobacco smoker increases the risk of exposure to TB through excessive alcohol intake, hemp, drugs, undernutrition, poverty, unsanitary environment, sharing solidarity mutual drug abuse, ignorance of TB, fear of not being admitted to health center and immune deficiency.

Barriers to IDU and hemp / tobacco smokers accessing TB screening and treatment can be summarized in terms of stigma, discrimination, rejection of the patient by community and care providers, ignorance and neglect, lack of means to provide health care, no desire to quit smoking, lack of transportation, lack of will and distance to travel.

4.7.1.4. Key people working for and / or with key populations

Information gathered from interviews:

The different people working for or with these three key populations from whom the information is collected include: health care workers (nurses, laboratory technicians and doctors), health authorities, civil society organizations and community organizations members, traditional practitioners and pastor.

From Interviews, it is showing that access to TB screening, testing, and care is almost free except for a few specific examinations and hospitalization of patients. TB treatment is effective; taking medication is done every day under the supervision of the nurse; the control examinations are done 2 months after the start of treatment, 5 months and 6 months at the end of treatment. PLHIV get benefit of TB screening. Difficulties of access are caused inter alia by non-confidentiality of statutes of patients; non-consensual follow-up of patients with unwanted, unplanned home visits by any person; discrimination and stigmatization; lack of information on TB; clandestine use of drug users and smokers for fear of being apprehended by narcotic police; stock out of tests and medications; bad beliefs (witchcraft, bad luck), self-medication, lack of financial means, shame and fear of having TB.

There are no specific guidelines for hospitalization or confinement of persons for TB treatment. Nevertheless, for people affected by TB drug resistance in a state of severe complication requiring hospital follow-up (respiratory failure, bed-ridden, serious adverse effects), the provisions are taken on a case-by-case basis to relieve them and this in a definite time.

These people interact with key populations through consultations, health education before taking medication by nurse or a community member, home visits, community outreach, counselling. According to them, key populations do not care too much about TB not because they are not interested, but because of ignorance or fear of disease. The main reasons are: self-stigmatization, lack of information, populations not taken into account in different health and community care programs, little or no awareness of TB and bad beliefs at all; except PLHIV who have a higher level of concern than TB contacts as well as IDUs and smokers of hemp / tobacco.

Although there are TB screening and treatment facilities in each health zone, the willingness to be tested for TB is low among contacts of TB patients and injecting drug users and hemp smokers, and it is average for PLHIV. The level of TB infection in these key populations can be high by being exposed to disease in relation to immune deficiency, undernutrition, mutual sharing of narcotics, precarious living conditions, but no statistical data are available to inform about this.

In relation to quality of TB services, opinions are divided. Some people believe that the offered services for TB screening and treatment are adequate because of availability of drugs, materials and laboratory inputs, different TB and HIV tests, free treatment, presence of care providers in health centers, effective management of TB, participation of health community workers in the follow-up of patients. For others, services are not adequate because there are no attractive measures of retention of patients under treatment to reduce number of interruption of treatment, laboratories are badly or under equipped, results of examinations take a lot of time before being given to patients, discrimination against key populations, untimely stock out of medicines and cartridges, demotivation of care providers who are underpaid or not, lack of qualified medical staff, lack of free medicines for side effects, lack of nutritional support for MDR and poor patients, low awareness of community, irregular supply of TB drugs and inputs, payment of treatment in several care facilities, permutation of trained staff and presence of untrained care providers in health centers. The new medicines and diagnostics recommended

by WHO are not available to everyone. Availability is relative to donor funding depending on whether cases are detected and GeneXpert machines do not cover the entire country.

Summary of findings:

Barriers/obstacles to TB screening and treatment are financial (lack of means of transportation, consultation fees, not free of testing), geographic (distance to reach remote health facilities, pockets of insecurity in the eastern part of the country) and educational characterized by a low level of knowledge for population about TB. Lack of information on TB, discrimination, workload of care providers, narcotics police who track down hemp smokers, lack of mechanisms to facilitate screening of isolated or specific populations, self-medication, stigmatization, bad beliefs, lack or stock out of laboratory inputs and drugs, ignorance, shame, habits and customs, criminalization and clandestinely live of drug users and hemp smokers, lack of willingness of key populations to be screened for TB, fact of being rejected by community, duration of treatment, side effects of drugs, duration of results, demotivation of health care providers, food insufficiency, lack of nutritional support, breach of confidentiality results and status of patients and negligence of patients with treatment are challenges faced by care providers, health community workers and patients in fight against TB.

In addition to PLHIV, TB contacts, and injecting drug users and hemp smokers, key populations facing barriers to accessing TB care services are street children, people in vulnerable situations, prisoners, police and military, refugees, minors and indigenous peoples. All these key populations have an increased risk of TB because of poor living conditions, poverty, immune deficiency, malnutrition for the most part, unsanitary environment and promiscuity, poor lifestyle, behaviors and unfavorable health practices (e.g. mutual sharing of drugs, cigarettes and utensils), ignorance of TB and non-vaccination of children with BCG.

The provision of TB services to these key populations suffer from some difficulties such as: Good working conditions are still not gathered, some rooms are narrow and poorly ventilated, there are some laboratories of fortunes especially in rural areas, lack of space adapted to accommodate patients who are standing upright under sun even during rain, stock out of drugs and laboratory inputs, insufficient equipment and work materials, lack of mapping of community organizations and NGOs fighting TB, lack of awareness materials, lack of motivation of care providers, low financial coverage for supervision from provincial level to local level, low funding for community activities, lack of specific national health policies and guidelines TB in favor of these key populations, unfavorable health behaviors related to their attitudes, practices and beliefs and lack of mapping of these key populations.

4.7.2. LEGAL ENVIRONMENT

4.7.2.1. General situation

Knowledge of TB at general population level is low, only TB care providers and community support providers to TB patients have an acceptable level. It also appears that this knowledge is related to level of literacy and level of education. Those who have some education have information as vulgarized in panels (cough of 2 weeks should be consulted) or through media (not often), least educated have for most part a false knowledge of TB ranging from "very serious illness with fatal outcome" in urban areas up to "curse or bad luck" in rural areas. However, even for those who have some knowledge, it is clear that knowledge is more accurate among those with medical training or who frequent hospitals than for rest of educated population.

Special population is a term in NTP language that refers to populations most at risk and able to easily develop TB by their condition or lifestyle. As part of alignment to a universal language, STOP TB Partnership calls them "Key Populations"³⁵. Our field visit revealed a paradox: being most fragile population against TB, this one that had to be most informed on TB to be able to better protect itself and especially to have attitudes that save. However, apart from PLHIV (those attending self-help groups or those close to civil society organizations) knowledge of TB is very low. In Goma, many drug users and other smokers do not even know that TB is curable. In Matadi it is a blow of fate for most. For some, drugs, especially sniffing or injectable, make it possible to guard against all diseases. In Matadi, some TB patients thought well before becoming sick that TB was a disease reserved for people living with HIV. If we report to prisoners, street children, smoking tobacco and hemp as well as cross-border, TB is defined according to context of each category; cold disease, dust sickness or sickness due to confinement; but danger lies in fact that for all special population met, "TB is a very serious disease with fatal outcome with or without treatment".

On side of authorities and opinion leaders among others some parliamentary, pastors, mayor of the city, chief of district, executives of premature, as well as town hall of Kinshasa and some provincial ministries, knowledge of TB is very basic, that is to say, its character is serious and requires urgent care. Much work remains to be done on knowledge of point of view followed and lived of patient. Pastors have also evolved through their knowledge that is no longer exclusively related to witchcraft or evil spirits. The problem lies only in involvement of decision-makers in fight against TB because for authorities, this fight is only in health sector and all other sectors of life are not affected by this disease. That is problematic vision in multi-sectorial context.

The general situation in African prisons is alarming, and DRC is no exception to rule. Reality at prison level often associates overcrowding (Matadi 715 prisoners with a capacity of 200, Goma 613 prisoners with a capacity of 150), precariousness and dilapidated facilities. Given this unflattering picture, a good knowledge of disease management is necessary for a good management of TB with its highly contagious character specially in low-income and promiscuous environments. Hence, importance of necessary TB control both by health workers and by all staff of prison and even prisoners. However, it has been noted on 3 prisons visited only one has trained health care providers for patients in situ (where service is available). Administrators, guards and prisoners are very little informed and this has serious consequences.

³⁵ Données pour l'Action pour les populations clés vulnérables, mal desservies et a risqué, touchées par la tuberculose, Document de travail Septembre 2017 de Stop TB Partnership.

On other hand, civil society networks and organizations report that management of our prisons is so tightly closed that often those who have information have difficulty approaching prisons, especially when it comes to interact with prisoners. Some prisoners with TB information turned out to be former health care providers at stops. Follow-up of prisoners with TB who have completed their sentence has a problem (address, care site, etc.) because of information from their destinations is not clear.

4.7.2.2. Information gathered from desk review

The NTP 2018-2020 TB NSP and NAP 2018-2021 HIV NSP are strategic documents that become law once they are ratified by Head of State, especially since they deal with aspects of policies and control protocols to be implemented, but also cross-cutting interventions to implement for facilitating access to care, awareness, but also highlight aspects of fight against stigma and discrimination.

The National Health Development Plan 2017-2021 reflects will of Government and its partners to provide effective and realistic solutions to health problems of people of DRC.

The Congolese legislation includes several old laws, but legislator's effort is in sense of adapting to new realities, responding to urgency or harming a community or a group of people by creating new laws. (e.g. law protecting PLHIV and affected persons).

4.7.2.3. Knowledge at level of Justice and human right officers

Legislation and health are two areas that are supposed to evolve in synergy. There is evidence that in context of diseases such as TB or HIV / AIDS, laws aspects must be permanent in view of all that there are realities in terms of stigmatization, discrimination, deprivation of fundamental rights.

Here too, fact is that justice officials have very little knowledge of TB. In three provincial health units visited, no TB training was organized for court workers in recent years. This is all the more paradoxical because they are many training on HIV/AIDS and/or sexual violence. Knowledge that these justice agents have on TB are either of their experience (history of tuberculosis in the entourage) or, rarely of media. This is all more flagrant because law is also silent on TB, and this sentence, which combines hope and fear heard by a prosecutor, is proof of this "legislator has surely not found it necessary to look into TB as it is a curable disease.

4.7.2.4. Role of civil society organizations

At level of civil society, TB organizations working in field have enough information about disease, but these are not numerous. However, those working in field of HIV/AIDS do not have enough. Majority of organizations are involved in development of national health guidelines and policies, NTP and National Aids Program strategic plans at national level, and implementation of national TB and HIV policy programs in collaboration with support structures at local level.

4.7.2.5. Barriers of TB screening and treatment services

Different barriers to TB screening and treatment services identified in land-based information related to access rights can be summed up in terms of:

- Ignorance of population on rights to health and access to TB care.
- Some supposedly free fees are paid.

- Binding application of DOT strategy, especially in rural areas.
- Lack of nutritional coverage.
- Stigmatization and discrimination of TB patients.
- Non-respect of confidentiality of results for some and serological status for others by care providers.
- Selective access of key populations to health care facilities.
- Insufficient TB care services and trained care providers in prisons and other health facilities.
- Very long time for waiting diagnostic results and beginning treatment.
- Some key populations living on margins of law are hardly supported in TB.
- Use of Traditional Practitioners for TB Care.
- Non-respect of patients' rights by health care providers.

From point of view of health actors:

Access to TB care is free, and services offered to everyone, but financial implications come in details of care that goes from screening (consultations, laboratory balance, and radio) to treatment (therapeutic education, treatment, nutrition). Only sputum examination (zhiel nielsen) and TB treatment are free even though some people charge for it. Consultation of patients has a cost for establishment of file; the radiography is made with fixed costs and as well as biological monitoring.

Hospitalization of patients suffering from severe form of TB (MDR-TB) is not effectively ensured, except for a portion of MDR-TB patients from Kinshasa who are cared for free at "Centre d'Excellence Damien (CEDA)" level which unfortunately does not have sufficient infrastructural capacity to cover all cases of city while other cities seek its services

Demotivation of care providers is due to fact that they no longer collect premiums, except some that are copied in projects benefiting from performance contract awards although these are not sustainable. This situation does not favor effective implementation of DOT strategy and push some care providers to give patients their TB drugs for several days without direct observation.

From point of view of people with TB and their relatives:

From point of view of people with TB and their families, access to TB care is a real obstacle course. Everything is complicated from diagnosis to treatment.

Points that represent real challenges and that tend to be discouraging are:

- ✓ Arrival at hospital: of course that TB is a serious disease, very contagious and of urgent care, TB patient is taken care of like patients of other pathologies, he must pass by sorting, queue, purchase of card, normal circuit of patient. When we know asthenic side, precariousness of TB patients is a difficult journey.
- ✓ Hospital fees: Patients often come to hospital with information that TB treatment is free; this is understood as TB care services are free. But, great is their surprise in noting that apart from treatment and zhiel exams for controls, everything is paying off. "Person who asked me to get tested for my cough at health center asked me to go with at least ten thousand Congolese francs, the time to find them I went to the hospital 2 months later, "reported one patient in Matadi.
- ✓ DOTs: treatment directly observed by care provider is a very effective strategy that has been proven particularly in terms of percentage cure or adherence rate. However, this strategy shows its limits in context of a health policy that does not bring health services closer to populations. In fact, some DOTs sites are often far from the patients' homes,

very far away even in Goma and Matadi, patients in the state they know are traveling long distances to care. Remember, moreover, that treatment is given on an empty stomach. Effectiveness of treatment directly observed in rural areas leaves something to be desired because sites of care are often difficult to access.

- ✓ Nutrition: Although different plans define nutrition strategies for TB patients, it is clear that on ground nutritional support hardly exists. What is done is in ad hoc ways by some stakeholders but not really as a national policy strategy.

From point of view of key populations:

For key populations interviewed, access to TB care has access to health care first, which requires improvement in order to be able to treat TB well because it is an integral part of primary health care. Most of those with TB are subject to hospital stigma and discrimination. Tobacco smokers and hemp in Matadi report having been repeatedly denied access to hospital or poorly treated because of their status, gays in Goma are experiencing same situation. Given this context of difficult access in general, it is clear that in case of TB, access becomes more complicated.

Peculiarity of PLHIV their TB care is free, but form of TB of PLHIV is often clinically diagnosed, they must use radiography and Tub-Lam that cannot be accessed without money, TB screening of PLHIV is not systematic, Aids patients are placed in the same pavilion as TB patients, even if this is only temporary, this behavior is suicidal.

From point of view of civil society organizations:

First of all, it is very important to note a fact; there are very few organizations that deal with TB specifically. Most operational are those located in the urban environment, specifically in Kinshasa, having only antennas within the country. Most interviewees do not know which structures of civil society to orient themselves in case of need of information, accompaniment of access to care or support related to TB. For many, only option is the hospital. This situation has a consequence that these TB patients cannot be rescued in case of need, can stop treatment at any time if they think that they are not satisfied, or if they do not support anything.

For rest, some structures engage in bad practices that go against national TB guidelines and policies:

- ✓ Payment of care that even sometimes obscures patients referred by community.
- ✓ Lack of confidentiality on part of care givers.
- ✓ Difficulty of applying treatment directly observed for reasons of physical access to remote care sites and to ensure nutritional coverage.

4.7.2.6. Prison situation

The prison situation is in red. One of three prisons visited does not have health facilities properly speaking, another has a precarious structure with agents untrained, poorly equipped and little motivated. Access to TB care for prisoners is very complicated; diagnosis is done outside prisons for structures visited except in Kinshasa, which leads to problem of transporting sputum samples to TB screening structures and preservation of these samples. 14 TB patients in Kinshasa and Goma are waiting for their medication. Nutritional support to patients is not planned, everyone eats common dough. There are no special pavilions for TB patients; patients stay in same rooms with other prisoners. TB tests are done outside of health zone where prison is located, which leads to a delay in diagnosis and care.

In case were the prisoner is aggrieved in these rights, he can appeal to the courts and tribunals.

Caregivers are not very motivated; they often use former prisoners who are themselves untrained on TB care. This burden appears to them more as a punishment than as an opportunity for real jobs, hence many cases of resistance. There is also problem of non-continuation or discontinuation of treatment for patients who have served their sentences, but there is no systematically organized follow-up mechanism either by service providers or prison administrators and less by civil society organizations, which leads to lost sight of TB patients.

There are some principles of the Mandela rules that are repeated in Congolese law, such as the principles of separation, care and feeding of prisoners. But detainees make fewer or no remedies when their rights are not realized, among other things because many are not well informed of their rights.

4.7.2.7. Stigma and discrimination of people with TB

We cannot talk about legal environment of people affected by TB, without mention stigma and discrimination. It is clear that in face of all that TB patients know as a problem in terms of access to care or other nutritional problems, biggest problems reported are discrimination, stigmatization and more self-stigmatization. "I sent my wife and my children to live with her family", said one patient in Matadi; "I was given a studio in our plot with my own utensils, bedding and clothes for five months" says one MDR-TB patient in Kinshasa; "nurse always receives us in a shed about ten meters from hospital, it is there that he brings us drugs, it is as if we will contaminate everyone in health center if we enter ". And from judicial point of view, this attitude opens door to several abuses: dismissal, breach of lease, family rejection, poorly given care, etc.

The lack of TB information is all more fragrant as it also affects care providers especially in rural areas, this is mainly due to fact that for some care providers are not trained and have a medical perception of fight against TB, and even then there is a real need for capacity building. Law is very clear, any discrimination or stigmatization should be banned³⁶, but law should be specific for TB as it is for HIV.

What coverage for people who undergo it? Much is said but little is done, from point of view of patients, affected people and stakeholders, law is silent, legal authorities are often not informed of acts of stigmatization, health authorities have not put in place reporting mechanisms of stigma and discrimination perpetrated in health facilities, civil society organizations are not very effective in terms of advocacy, and community less informed about its rights often does not know what it should do to recover them. TB patients are victims; no law protects them in a specific way. Clear penalties should be set to deter those who practice such practices, including punishing with clear sentences of imprisonment and/or damages, dismissing or suspending offending care providers.

4.7.2.8. Tuberculosis and Justice

In terms of TB, our law in the DRC is silent. However, PLHIVs, people with disabilities and others have found coverage in our constitution, TB is lagging behind.

None of them think that existing laws cover fact that treating the question of health in general, also covers field of TB. Actors in fight against TB do not exercise effective advocacy or lobbying on legislator because and as disease is curable, need to promulgate a TB-specific law is slow in coming.

³⁶ Loi 08/011 portant protection des personnes vivant avec le VIH et personnes affectées.

No TB case has been defended in courts by a prosecutor and lawyer interviewed, but they have already had TB patients to defend for other cases. Legal empty and ignorance of TB are so blatant that it is clients or legal actors do not bring disease to situation that pushes them to seize intense judicial. Workers who are dismissed from work without compensation due to asthenia inherent at TB symptoms or side effects of TB drugs, but link is still not made specifically with TB in case of this injustice, and similar cases are legions.

Legal agents believe that we should not wait until TB laws are created to be active, we can already use existing laws and treaties ratified in case. For example, Work Code does not mention TB, but it does guarantee some support and legal cover for any incapacitated patient linked to his "chronic" illness. Discrimination against law protecting PLHIV and affected people can be adapted for TB patients. For example, at Kinshasa and Goma a few cases of people affected by TB incarcerated by police were released after the police became aware of the information about the illness they were suffering from

Above all, it is necessary to create a law guaranteeing protection of people with TB, because empty and unspoken in terms of law and TB does not facilitate task for easy and specifically precise interpretations on several aspects such as isolation of patients, marginalization, stigmatization, nutrition, overall care, rights and responsibilities of patients and effective free of care.

At end of justice, people with TB have very little or no support at level of existing legal clinics that are much more focused in legal support of PLHIV and sexual violence. This lack of structures that can accompany patients with TB in case of needs or when they are violated in their rights cannot strengthen health system, but again it requires a reinforcement of capacities of actors who manage these clinics in TB and sex-specific aspects.

4.7.2.9. Legal accompaniment (prison particularities)

Prisoners also have rights; these rights are guaranteed by constitution of Democratic Republic of Congo and various international charters and treaties signed by the country.

The observation on ground is that prisoners are left behind, unable to rely on themselves or, strictly speaking, on their families. Prisons are plethoric, which is not surprising because many who are referred are awaiting trial, but prison should be reserved for those who have already been tried and convicted. This has repercussions on hygienic and sanitary situation of prisoners, among others promiscuity, undernourishment, limited health care because it cannot satisfy everyone.

Coughers in prisons are entitled to a quick consultation and diagnosis, which is not case either, because diagnosis must be made outside prison or because of lack of available personnel in these prisons. Patients diagnosed of TB have right to begin their treatment immediately, that is not case because it requires a requisition outside to be provided with drugs, waiting can take days and distribution of drugs often starts late. Other non-sick prisoners have right to be protected from contamination by being away from contaminating coughs but except in Kinshasa, this is not case because there are no specific flags to take care of this kind of ill.

Every prisoner has right to health care, but in many prisons in country, penitentiary health centers exist only in name. Faced with this unfavorable legal situation, we must resort to either the inter-ministerial charter on prisons. TB provincial coordinations find precarious situation of prisons at posteriori, civil society organizations that are close to prisons are very few and many work are on judicial problems and not on health problems.

4.7.2.10. Specificity: Confidentiality and live clandestinely

Confidentiality and secret are both linked in good and bad sense for HIV as well as for TB. PLHIVs think that morbid habit that is becoming more and more entrenched, especially in hospital environment is non-respect of confidentiality. Many of victims who suffer from these acts prefer to live clandestinely, and this situation influences willingness of PLHIV to be screened for TB. Law guaranteed PLHIV and the persons affected confidentiality³⁷, so any person who breaks it must suffer wrath of law, unfortunately it is not what happens on ground. Patients change care sites to avoid be recognizing or stigmatizing, others prefer not to come; others having learned beforehand do not even come for first consultation.

On other side, many TB patients, in term of confidentiality, do not reveal their HIV status to their partners and do not want to be tested for HIV again but without being noticed, and others do not reveal their TB state. Resulting abuses are numerous, dangerous and suicidal. Problem is acute in persuading people with TB who do not want to be tested or given treatment.

When communicating data, only the encrypted data is shared. The identity of those affected by TB is found in the laboratory and treatment registers at the health center level.

The CBOs working in the follow-up of TB patients have developed several strategies to look for cases, to persuade some of them and to bring them to TB screening facilities, but task is not easy because lack of legal tools of community to strengthen their actions.

4.7.2.11. Right to work

The Work (labour) Code does not specifically mention TB, but we know that TB has specific peculiarities that affect work of some one. TB is a contagious disease whose long and tedious treatment affects performance of a person doing some work. Work code arbitrates employer-employee relationship, as long as it guarantees employee good working conditions, a decent wage and adequate social security, as well as guaranteeing employer profitability, profit and satisfaction of a good job³⁸.

There is duality in arbitration of work code on cases of people with TB having to temporarily stop working because of illness. According to work code, any employer can be released from his employee for reasons of profitability, within limits of contract that binds them. Same code guaranteed to sick person health coverage of his employer, and long course of his social insurance. Only cases of work-related accidents are covered over long term by employer. This is difficulty of a TB employee in front of his employer in terms of right, and when we know that social security fund that should cover resignation of employer does not work properly, we understand ordeal of TB patient who then becomes a social case, it is even worse if he is economic guarantor of family, fallout is catastrophic. In reality, in absolute terms, work code protects employer more than employee.

4.7.2.12. The displaced of wars

The conflicts of the armed groups and the ethnic tensions create the security incidents which cause the displacements of the populations especially in the East of the country (Province of North Kivu and Ituri). A large part of the population no longer goes to health centers, including people affected by TB and HIV. Since the management of tuberculosis should not be interrupted for fear of promoting the emergence of bacterial strains pharmacoresistantes TB Provincial Coordinations have developed the Contingency Plan to curb this situation.

³⁷ Loi 08/011/ portant protection des personnes vivant avec le VIH et les personnes affectées.

³⁸ Loi 015/2002 portant code de travail.

4.7.3. GENDER

services for screening, diagnosis and management of tuberculosis in children are poorly organized, elderly are not considered as vulnerable people and are therefore not specifically supported. There are no programs targeting men where they gather or work and focus on behavior change to access services.

Tribal / customary law has a strong influence on daily life in rural areas and gives much more benefit to the man than woman. In terms of customary practices, there are those that involve the married woman. In the Equator province, for example, a man may give his wife or one of his wives to a visitor for proof of great friendship. At the Banyamulenge, in South Kivu, a bride first mates with her stepfather before her husband can know her. During her husband's absence, the husband's brothers mate with the woman on the pretext of preventing him from going elsewhere³⁹. The Pygmies' population lives in vassal relationships with the Bantu population and is even integrated into Bantu families where their wives and daughters are subjected to forced sex by their masters⁴⁰.

4.7.4. TB RESPONSE FINANCING

There is no accessible information system that documents both national and external spending on TB in the country, and legislation that allows government to fund civil society. International donors financing civil society are also not legislated.

On the other hand, in the fight against tuberculosis, the Government signs a contract with Global Fund to release the counterpart funds at level of 15% on 100% of financing of the grant. The 5% of this counterpart funds are intended to strengthen HIV, TB and malaria civil society organizations.

The laws are of national obedience and guarantees for any Congolese citizen regardless of the environment in which he lives. The health-care budget at the sub-national level is not allocated because the retrocession of 40% of the financial revenues provided for by constitution from the national to the provincial level suffers from non-implementation.

³⁹ Evaluation sexospécifique VIH et TB en RDC 2017

⁴⁰ Evaluation sexospécifique VIH et TB en RDC 2017

4.8. RECOMMENDATIONS ENDORSED AT VALIDATION WORKSHOP

4.8.1. DATA FOR ACTION FRAMEWORK FOR TB KEY POPULATIONS

4.8.1.1. PLHIVs

Operational definition:

People living with HIV are people with positive serological status and a state of health often weakened by low immunity, who are exposed to TB because of precarious situation in which they live and experience limitations access to TB care.

Action to fill the gaps in services:

- Increasing the number of trained health personnel trained in TB and HIV;
- Effective implementation of TB health directives and policies at the local level (health facilities and health zones) for all PLHIV;
- Removal of consultation, diagnostic examinations (radiography, microscope and others) and treatment of tuberculosis costs to enable patients to easily access screening and treatment;
- Ensure the regularity of supplies of anti-tuberculosis drugs and those against side effects, laboratory materials and inputs, at the level of all TB/HIV co-infection health facilities;
- Improve the reception of patients in health centers to facilitate adherence to TB treatment;
- Establishment of a service or system of adequate follow-up of TB/HIV co-infected patients put under treatment.
- Make GeneXpert machines available in all TB/HIV co-infection health facilities;
- Ensure the strict respect of the rights of PLHIV patients under TB treatment according to the professional ethics, the confidentiality of the results and serological status of the patients, and the respect of the hours of distribution of the TB drugs which must be taken under observation of the care providers.
- Provide nutritional support to TB/HIV co-infected patients as part of patient support to enable them to successfully follow TB drugs and ARV treatment.
- Reduce significantly the time to test and report results to improve adherence to treatment of PLHIV.
- Expand coverage of TB care by integrating TB/VIH co-infection care services into private and conventional health facilities.
- Reduce significantly the time to test and report results to improve adherence to treatment of PLHIV.
- Ensure the hospitalization of co-infected MDR-RB/HIV patients.
- Rehabilitate the health infrastructure and equip all health facilities with new diagnostic tools to improve TB screening and treatment services.
- Ensure a consistent motivation for health care providers in charge of TB/HIV co-infection.
- Ensure the TB screening in any PLHIV before start ARVs treatment.
- Establish community strategies to recover lost to follow-up among TB/HIV co-infected patients.
- Ensure the provision of TB and HIV/AIDS care in the same health facilities and by the same care providers to improve the quality of the care services of co-infected patients.

Actions to fill the data gaps:

- Develop new guidelines of TB/HIV co-infected patients care, taking into account the gender aspects.
- Develop new tools of co-infected TB/HIV patients care disaggregated into gender, age and sex.
- Document the social, biological and economic determinants that limit access to TB/HIV co-infection care.
- Inform about the PLHIVs who have been stigmatized and discriminated in their immediate environment (care facilities, family and community) because of suffering from TB.
- Inform about PLHIVs who have received nutritional and/or social support for TB care.
- Inform about PLHIVs whose confidentiality has not been respected by health care providers.
- Measure the rate of interruption of TB treatment by PLHIVs due to ruptures of anti-TB drugs and failure to respect patients' rights.

4.8.1.2. TB Contacts

Operational definition:

These populations include any person (family members, work colleagues, friends, school and universities colleagues, neighbors of the plots, medical staff, room neighbors in prisons and dungeons, church members) who live daily in community around a TB bacteriologically confirmed, multidrug-resistant, ultra-resistant, clinically confirmed and paediatric patients for a specified period of time, who do not have TB-related information or have limited access to TB screening.

Actions to fill gaps in services:

- Bring TB care services closer to patients to reduce distance travelled by patients, and eliminate financial burden on means of transport.
- Increase community awareness of TB to increase knowledge of population.
- Provide nutritional support to very low TB patients.
- Organize home visits to follow-up TB patients under treatment, recovery of lost to follow-up and search for people who can be screened for TB.
- Develop approaches to reduce discrimination of TB patients at level of care facilities, families and community.
- Ensure regularity of TB drugs in all TB care facilities.
- Ensure good health education to inform TB patients about importance of treatment
- Integrate TB care services into all existing health facilities (hospitals, polyclinics, hospitals, health centers, health posts).
- Implement free TB treatment in care facilities.
- Equip TB care facilities with quality materials and to establish a system facilitating access to TB screening and treatment for contacts of TB patients.

Actions to fill data gaps

- Integrate aspects related to people to be screened for TB into diagnostic and treatment tools.
- Define indicators related to TB diagnosis and treatment concerning this key population.

- Inform about contacts of TB patients who have benefited from TB sensitization, and TB screening and treatment.
- Inform about contacts of TB patients who have been victims of discrimination and stigmatization.
- Break down data into gender, age and sex

4.8.1.3. IDUs and hemp / tobacco smokers

Operational definition:

These populations include injectable drugs users, hemp and tobacco users, drug addicts, alcoholics, strong liquor takers, drug users who live to retrench from community in hiding, Malnutrition, unsanitary conditions, are not readily accepted by some care providers as well as community and have a lot of access limits to TB care.

Actions to fill gaps in services:

- Develop practical and effective approaches of patients TB care among IDUs and hemp/tobacco smokers.
- Create groups of peer educators of IDUs and hemp/tobacco smokers among cured TB patients to facilitate involvement of this key population in fight against TB.
- Provide nutritional support to any TB patient to strengthen their immune system while taking TB drugs.
- Develop active search strategies for people to be screened for TB among IDUs and hemp/tobacco smokers.
- Facilitate TB detection and treatment of IDUs and hemp/tobacco smokers at level of care facilities.
- Conduct sensitization sessions for groups of IDUs and smokers to improve their knowledge of tuberculosis and to obtain their willingness to be screened for TB.
- Increase awareness of community and families close to IDUs and hemp/tobacco smokers on TB.
- Reduce waiting time to access diagnostic service, have exams and results returned.
- Rehabilitate care infrastructures to improve conditions of reception of patients.
- Equip health facilities with new equipment and adequate work materials.
- Make mapping of TB health facilities available to population.
- Reduce duration of TB treatment for reducing interruption of treatment for IDUs and hemp/tobacco smokers.
- Ensure effective free TB diagnosis and treatment for facilitating access to care for IDUs and hemp/tobacco smokers.
- Strengthen number of health care staff with trained health care providers to properly care for this key population.
- Increase number of TB health facilities by integrating TB care in community centers and other health facilities across the country.
- Ensure respect of patients' rights by health care providers.

Actions to fill data gaps:

- Develop mapping of IDUs and hemp/tobacco smokers by health zone to determine home of this key population.
- Inform about IDUs and hemp/tobacco smokers who are victims of stigma and discrimination by care providers and the community in TB care.
- Break down data into gender, age and sex.

4.8.1.4. People working with key populations

Actions to fill the gaps in services:

- Revise national TB policies and guidelines to integrate gender, human rights and key populations aspects into TB care, ensure its dissemination and make it available at all levels (health care workers, community members and other stakeholders in the fight against TB), to ensure its effective implementation.
- Ensure the regularity of TB drugs in the health care facilities and introduce a monitoring system to report and respond to stock outs.
- Develop active case finding strategies and invest in interventions to find the missing people with TB, especially among key populations.
- Definition and implementation of advanced strategies to facilitate accessibility of key populations to TB screening and treatment including human rights and gender-sensitive aspects.
- Introduction of a new short-term TB treatment.
- Bring TB screening services closer to key populations (mobile TB screening).
- Ensure regular supply of TB drugs and laboratory inputs in care facilities.
- Strengthen capacity of care providers in TB and TB/HIV and in other aspects of patient rights.
- Improve working conditions of TB care providers by paying their premiums and rehabilitating the infrastructure.
- Invest in financial and technical support of community organizations and civil society.
- Promote use of new technologies for quality screening.
- Strengthen involvement of community including key populations in TB care.
- Improve conditions for reception of TB patients in care facilities.
- Produce new TB messages appropriate for key populations.
- Provide TB care facilities with medication for side effects.
- Provide nutritional support to TB/HIV co-infected patients as part of patient support to enable them to successfully follow TB drugs and ARV treatment.
- Provide new TB diagnostic tools to all health facilities;
- Ensure the use of new technologies for quality screening for all.
- Develop a new TB vaccine that will benefit to everyone without distinction of age.
- Integrate TB care in the care specialized facilities of IDUs and hemp/tobacco smokers.

Actions to alleviate difficulties in providing services to key populations:

- Ensure vulgarization and make available national TB guidelines and policies for key populations at all levels (health care workers, community members and other stakeholders in the fight against TB).
- Set up community surveillance system for TB care that responds to needs of patients and helps to improve TB services.
- Strengthen community member's capacities engaged in fight against TB.
- Provide community members with tools to raise awareness and actively search for suspected TB among key populations.
- Invest in active search of people affected by TB to be screened in the community and among key populations.
- Motivate community members for more active involvement in fight against TB.
- Ensure permanently premiums of TB health care workers.
- Involve key populations in fight against TB by training them as peer educators.

Actions to fill the data gaps:

- Conduct a TB stigma assessment to understand the burden of TB in different settings and along the cascade of care.
- Produce mapping and size estimates of key populations at all levels.
- Set up a community-based real time monitoring system to strengthen; the TB M&E data on barriers to access, responsiveness, equity and quality of TB services and hold TB service providers to account. (Community-based monitoring).
 - o Violation of confidentiality
 - o Stock outs
 - o Drug side effects
 - o Out of pocket expenses
 - o Treatment interruptions
 - o Barriers to access
 - o Quality of services
 - o Stigma
- CBM data collected should be disaggregated by age, gender, key population
- Develop age and gender disaggregated data collection tools at all stages of TB prevention and care.
- Break down TB screening and treatment data into key populations, specifying children, adolescents, youth and adults, taking into account gender, age and sex.
- Conduct studies on the prevalence of tuberculosis in relation to the population in general and the key populations in particular, on the behaviors, attitudes and practices (CAP) of populations in relation to TB, and on the specific needs Key populations for proven evidence.
- Conduct studies on socio-cultural determinants increasing vulnerability to TB, HIV / TB co-infection, and HIV for adults.
- Develop new TB diagnostic and treatment tools including specific information of key populations and disaggregated data on gender and age and.

4.8.2. LEGAL ENVIRONMENT

Creating favorable TB environment:

- Define a framework for consultation between NTP, civil society organizations and legal actors for discussions, solutions and implementation of actions to counter stigma and discrimination of people with TB in general and key populations especially in health facilities and the community.
- Set up community surveillance or observatory mechanisms for acts of limited access to care (discrimination and stigmatization) for people with TB in health facilities and in the community.
- Conduct advocate activities to decision-makers, legal authorities for their commitment in fight against TB.
- Ensure effective medical and legal coverage for TB to anyone with this disease.
- Raise population awareness on TB and all cross-cutting aspects of rights, gender and person-centered care
- Ensure the vulgarization of national and international laws on TB care in community to enable key populations to know their rights and duties.
- Ensure the vulgarization and dissemination of the Patient Charter for Tuberculosis Care at all levels.
- Clearly define guidelines for support or role of social and civil society leaders in fight against TB.

- Invest substantial funding in community-based medical and legal support actions in fight against TB (advocacy, awareness, recovery of lost to follow-up, nutritional support, access to screening and treatment, building capacities, etc.).
- Disseminate national guidelines on key populations TB care.
- Establish a gender TB and HIV coordination group, and enable the participation of women and key populations in the coordination of HIV and TB struggles and actions

Actions to fill the gaps in services:

- Effective implementation of national guidelines and policies for TB care.
- Ensure free TB services (screening, treatment, biological monitoring, nutritional support) everywhere and for all.
- Ensure regular premiums payment of TB care providers.
- Rehabilitate TB treatment infrastructures and equip them with quality materials.
- Ensure regular supply of TB drugs and inputs and drugs against side effects to TB health centers.
- Strengthen number of TB care workers and their capacities.
- Strengthen capacity of legal actors and civil society members in fight against TB, including cross-cutting issues (rights, gender and person-centered care)
- Increase coverage of TB care by bringing health care services closer to populations, including key populations, based on advanced strategies, public-private-mixed approaches and community care sites.
- Provide medical and legal support to TB patients.
- Produce community tools for legal follow-up of people with TB.

Actions to fill the gaps in existing legislation:

- Advocate to decision makers, legal and health authorities to create TB laws.
- Initiate a law project to protect people with TB, TB/HIV co-infection and those affected to submit for parliament vote.
- Initiate a law project amending and supplementing Law 08/011 of 14/07/2008 on protection of rights of PLHIV/AIDS and affected people by including aspects related care of TB patients and children less than 5 years in contact with people affected by TB.
- Initiate a law project to clearly listing key populations in TB field to submit for parliament vote.
- Ensure effective legal coverage for discrimination, stigmatization or other cases of deprivation of rights of people with TB and those affected.
- Develop national health guidelines and policies for TB control for key populations, taking into account specificities of each of them.
- Initiate a law project ensuring a consistent and regular nutritional support to all TB patients during treatment to be submitted for a vote in parliament.

4.8.3. GENDER

- Ensure policies, guidelines and programs respond to masculinity and cultural norms that discourage treatment, and include traditional healers and cultural leaders in the TB response.
- Develop the advanced strategies to facilitate the accessibility of key populations to TB screening and treatment including human rights and gender-sensitive aspects.
- Create male-friendly TB diagnosis and treatment facilities, times and locations.

- Collect and analyze gender-specific data on health providers, including community-based providers, at all levels, as well as program staff.
- Collect and analyze gender-specific data for all categories of key and affected populations for HIV, TB and co-infection, including children, the elderly and people with disabilities.
- Revise national gender policy Integrating F / H equality issues into equitable access to health services, including sexual and reproductive health, and gender equality in decision-making at home household level.
- Provide additional psychosocial support for women in care roles.

V. CONCLUSION

CRG tools assessment realized in DR Congo by the Club des Amis Damien in 3 provincial health divisions prove relevance and need to implement interventions in favor of key populations often ignored and/or marginalized as a result of their status. Personalities met as well as the resource persons constituting target of assessment welcomed this work and would like to have this exercise extended to other topics in particular on proportion of people stigmatized and discriminated in fight against tuberculosis and constitute an important barrier.

Key populations are still to this day marginalized and among which some still live in secret preferring to be screened in churches, in practitioners or die out of ignorance rather than to consult services of care appropriate.

Generally, discrimination and stigmatization of TB patients is highly accentuated, and sometimes they are indexed in their living environments, their right is not respected by health care providers and community. Old practices of discrimination and family stigma remain to date because population is not adequately informed about TB. Indispensable involvement of community with appropriate expertise does not always benefit from adequate funding to address problems of these populations.

In order to overcome various challenges facing path of key populations of tuberculosis patients, there is a need to multiply actions aimed at involving multi-stakeholders, and multiply advocacy activities to increase engagement of government.



VI. ANNEXES

The multi-stakeholders and their organizations

Names	Organizations
NGIKA Richard	General Secretariat of Health
Dr UKILA TAGA Jackson	CCM – DRC
MUJINGA BIMANSHA	Ministry of Justice
KANYINDA TSHIONGO Junior	Ministry of Justice
NSENGA Christine	National Tuberculosis Program (NTP)
Dr KINKELA Colette	National Tuberculosis Program (NTP)
Dr BONDONGA Caroline	National Aids Program (NAP)
Dr BATULI Thomas Serge	UNAIDS
LOMBO POLO Gloria	DRC Red Cross
LEBEKE Rossin	Kinshasa Provincial Leprosis/Tuberculosis Coordination
TOLOKO Jules	Kinshasa Provincial Leprosis/Tuberculosis Coordination
KAMUISI Jeannette	CORDAID
Dr NDJIBU Papy	Elizabeth Glaser Pediatric Aid Foundation
BUSHIRI Constant	Action Damien Belgique
MULUMBA Ben Joseph	RACEF / STOP TB RDC
OMARI Thérèse	Fondation Femme Plus
MAVULA Ange	UCOP+
TAKONGO Philippe	LNAC
NTUMBA KAPINGA Léonie	ADHEEFA
MBUYI Laure	RACOF
LONZOLO Felly	Projet Santé Sans Prix
YAMBA Louis	CEDHUC
KATUNU MUKANGI	FACID/ABEI (Organisation des peuples autochtones)
ALISHO ADI	Health for Prisoners (HP)
Dr SELEMANI Michael	RENADEF
K. MULUMBA Alain	RACEF
Dr CHIRIMWA Lydia	RENADEF
TORGONGA GOY Papy	Ruban Blanc (RB)
BADILA Dany	Health for Prisoners (HP)
NSIMBA MATA Patrick	Club des Amis Damien (CAD)
BALANGA YALUFI Moscky	Club des Amis Damien (CAD)
LUNGA NSUMBU Maxime	Club des Amis Damien (CAD)

List of documents examined

Desk Review of Data of Key Population Assessment

- Plan Stratégique National de la Tuberculose 2018 – 2020
- Rapport épidémiologique du PNLT 2017
- Directives nationales de prise en charge de la tuberculose PATI 5
- Directives nationales de prise en charge des populations spéciales TB
- Rapport d'étude CAP 2014
- Données pour l'Action pour les populations clés vulnérables, mal desservies et à risque, touchées par la tuberculose de Stop TB Partnership
- Charte de patients pour les soins de la tuberculose
- Plan Stratégique National de la riposte au VIH/SIDA 2018 – 2021
- Evaluation des sexospécificités liés au VIH et à la tuberculose en RDC

Desk Review of Legal Environment Assessment

- Déclaration universelle des droits de l'homme
- Déclaration d'Alma-Ata sur les soins de santé primaires du 12 septembre 1978
- Charte de patients pour les soins de la tuberculose
- Pacte International relatif aux droits sociaux et économiques de peuples
- Déclaration de Harare 1987 du 3 au 7 août 1987
- Le protocole de Maputo
- Objectifs de Développement Durable
- Mandela Rules
- Constitution de la RDC 2006 telle que modifiée en 2011
- Plan Stratégique national pour la lutte contre la TB 2018- 2020
- Plan Stratégique National de la riposte au VIH/SIDA 2018 – 2021
- Le code pénal de 1940
- Loi 08/011 du 14 Juillet 2008 portant protection de PVVIH et des personnes affectées
- Données pour l'Action pour les populations clés vulnérables, mal desservies et à risque, touchées par la tuberculose de Stop TB Partnership.

Agenda of meetings of Multi-Stakeholder Working Group

1. Orientation Meeting

Date	Starts	Ends	Session	Presenters	Session Type
12/07	08h30	09h00	Registration		
	09h00	09h10	Welcome remarks	General Secretariat of Health NTP CAD	Panel
	09h10	09h20	Introductions & Meeting Objectives	CAD	
	09h20	10h30	Presentation of the CRG Tools assessment 2018 Project	CAD	Presentation (Questions & Answers)
	10h30	11h00	Coffee break		
	11h00	11h30	Presentation on HIV/TB gender assessment 2017 results.	Fondation Femme Plus	Presentation (Questions & Answers)
	11h30	12h00	Presentation on TB Key Pop	CRG national consultants	Presentation (Questions & Answers)
	12h00	12h30	Presentation on TB legal environment	CRG national consultants	Presentation (Questions & Answers)
	12h30	13h30	Approval of the list of multi-stakeholder working group members, sites and agenda of CRG tools assessment in DRC	NTP CAD	Panel
	13h30	14h30	Lunch		
	14h30	15h00	Next steps for project	NTP CAD	Panel
	15h00		Meeting close		

2. Prioritization workshop

Date	Starts	Ends	Session	Presenters	Session Type
19/07	08h30	09h00	Registration		
	09h00	09h15	Welcome remarks	General Secretariat of Health NTP CAD	Panel
	09h15	09h30	Introductions & Workshop Objectives	CAD	
	09h30	10h00	Presentation of TB Epidemiological profile of DRC	NTP	Presentation (Questions & Answers)
	10h00	10h30	Coffee break		
	10h30	10h50	Contextual Situation country on Key Pop and access to TB care : <ul style="list-style-type: none"> • What does the law say? • What do international agreements say? • What the different plans (NSPs, AOP, etc.) provide • What is reported 	CRG national consultants	Presentation (Questions & Answers)
	10h50	13h30	To complete TB Legal Environment desk review.	Structured Group Work Group presentations	
	13h30	14h30	Lunch		
	14h30	15h00	Presentation of Key Pop and Legal Environment data collection tools	CRG national consultants	Presentation (Questions & Answers)
	15h00	16h00	Group work on enrichment of TB Legal Environment tools	Structured Group Work Group presentations	
	16h00	16h50	CRG projet team meeting	CAD	
Date	Starts	Ends	Session	Presenters	Session Type
20/07	09h00	09h15	Recap of day 1	Participant	
	09h15	10h15	Presentation of Key Pop (DRC and Stop TB documents)	CRG national consultants	Presentation (Questions & Answers)
	10h15	10h45	Coffee break		
	10h45	11h15	Presentation of Key Pop prioritization tools	CRG national consultants	Presentation (Questions & Answers)
	11h15	13h30	Group work on Key Pop scoring	Structured Group Work	
	13h30	14h30	Lunch		
	14h30	15h20	Presentation of group work and final Key Pop prioritized	CRG national consultants	Panel (Group presentations and Plenary)
	15h20	16h30	Presentation of sampling principles and Sampling of key populations prioritized	CRG national consultants	
	16h30	17h00	Closing Ceremony of the workshop	General Secretariat of Health NTP CAD	Panel

3. Validation Workshop

Date	Starts	Ends	Session	Presenters	Session Type
08/11	08h30	09h00	Registration		
	09h00	09h15	Welcome remarks	General Secretariat of Health NTP CAD	Panel
	09h15	09h30	Introductions & Workshop Objectives	CAD	
	09h30	10h00	Presentation of Field missions	CRG national consultants	Presentation (Questions & Answers)
	10h00	10h30	Coffee break		
	10h30	11h30	Presentation of information gathered of LEA and Key Pop desk review	CRG national consultants	Presentation (Questions & Answers)
	11h30	12h30	Presentation of Key Pop field data collection findings	CRG national consultants	Presentation (Questions & Answers)
	12h30	13h30	Presentation of LEA field data collection findings	CRG national consultants	Presentation (Questions & Answers)
	13h30	14h30	Lunch		
	14h30	16h30	Group work on Key Pop et LEA information gathered of the desk review		Structured Group Work
Date	Starts	Ends	Session	Presenters	Session Type
09/11	09h00	09h30	Recap of day 1	Participant	
	09h30	10h30	Presentation of group work		Group presentations
	10h30	11h00	Coffee break		
	11h00	13h30	Group work on Key Pop et LEA field data collection findings		Structured Group Work
	13h30	14h30	Lunch		
	14h30	16h00	Presentation of group work on Key Pop findings	CRG national consultants	Panel (Group presentations and Plenary)
Date	Starts	Ends	Session	Presenters	Session Type
10/11	09h00	09h30	Recap of day 2	Participant	
	09h30	10h30	Presentation of group work on LEA findings	CRG national consultants	Panel (Group presentations and Plenary)
	10h30	11h00	Coffee break		
	11h00	12h30	Group work on Key Pop et LEA recommendations		Structured Group Work
	12h30	13h30	Presentation of group work on Key Pop and LEA recommendations	CRG national consultants	Panel (Group presentations and Plenary)
	13h30	14h30	Lunch		
	14h30	15h30	Presentation of Key Pop and LEA findings and recommendations approved	CAD	Presentation (Questions & Answers)
	15h30	16h00	Closing Ceremony of the workshop	G.S. of Health NTP CAD	Panel

Prioritization of key populations tool used

Populations clés à considérer	Score 1	Score 2	Score 3	Score 4	Score 5	exposition et barrières sociétales	Score 6	Score combiné pour faciliter la discussion sur la priorisation	Discussion sur la priorisation et justification des populations clés prioritaires
	À risque ou exposé aux risques environnementaux	À risque ou exposé aux risques biologiques	À risque de / exposés aux risques de comportement	Obstacles juridiques et économiques à l'accès aux services	Les droits de la personne et les obstacles liés à l'égalité des sexes dans l'accès aux services	Max 5	Estimé (et / ou des données officielles, si disponibles) Contribution au fardeau de la tuberculose dans le pays (Cis ou tuberculose active de toutes formes)	Score total (Somme des scores 1-6)	
	(Espace surpeuplé, mal ventilé, résident dans les zones de tuberculose zoonotique)		(Drogs / usagers de / dans la bouche de / autre, partageant l'équipement de tabagisme)	(Criminalisation, pauvreté)	(Stigmatisation, discrimination)			Max 10	
	0 - None 0.5 - A little 1 - Substantial	Réduction de l'immunité, mauvaise	0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial	1 - Very Low (<1%) 2 - Low (1-3%) 3 - Medium (3-5%) 4 - High (5-10%) 5 - Very High (>10%)		
		0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial	0 - None 0.5 - A little 1 - Substantial			
Les réfugiés	1	0.5	0.5	0.5	0	2.5	2.5	2.5	Espace surpeuplé, mal ventilé, résident dans les zones de tuberculose ,mauvaise nutrition et les obstacles économiques les empêchent à accéder aux services
Déplacés internes (pays)	1	0.5	0.5	0.5	0	2.5	2.5	2.5	Espace surpeuplé, mal ventilé, résident dans les zones de tuberculose ,mauvaise nutrition, la pauvreté
Populations nomades	0.5	0.5	0.5	1	0	2.5	2.5	2.5	accès aux services limités suite aux multiples déplacements avec risque de se retrouver dans les indémiques
Travailleurs des prisons	1	0.5	0	0	0	1.5	1.5	1.5	Ils sont exposés par le fait qu'ils s'occupent des prisonniers dont les taux de tuberculose en prison seraient jusqu'à 10 fois supérieurs à ceux que l'on observe dans la population civile.
Travailleurs aux camps de réfugiés	1	0	0	0	0	1	1	1	Ils sont exposés par le fait qu'ils s'occupent des réfugiés dont le risque d'attraper la TB est élevé
Les prisonniers	1	1	1	1	0.5	4.5	5	9.5	La vulnérabilité
Les utilisateurs des drogues et les fumeurs de tabac	0.5	1	1	0.5	0	3	4	7	Le comportement à haut risque, partageant régulièrement le tabac de toute forme. * Ils sont pauvres et exposés à la criminalité sont souvent stigmatisés et discriminés par la population suite à leur statut social
Les militaires et les policiers	1	0.5	1	1	0	3.5	5	8.5	Sont sous payés et vivent dans la pauvreté, la promiscuité et le manque d'hygiène dans les camps
Travailleurs du sexe/ Les professionnelles du sexe (PS)	0	0.5	0	0	0.5	1	1	2	Ont des relations sexuelles avec multiple partenaires, et quelques fois non protégé. Vivent la discrimination et la stigmatisation
Clients du sexe	0	0.5	0	0	0.5	1	1	2	Vivent la discrimination et la stigmatisation
Lesbiennes, gays, bisexuels et transgenres	0	0.5	0	0	0.5	1	1	2	Vivent la discrimination et la stigmatisation
Populations autochtones	0.5	0	0.5	0.5	1	2.5	2.5	2.5	*Vivent dans des hâtes mal ventilées *Ils se partagent le tabac traditionnel *Ils sont pauvres *Absence des données épidémiologiques sur la TB
Sans-abri	0.5	1	1	1	1	4.5	4.5	4.5	*Ils vivent a la belle étoile et sont donc exposés aux intempéries de toute nature *Ils mangent difficilement ce qui a une incidence sur leur immunité * Ils sont stigmatisés et discriminés par la population ils ont un comportement violent
Personnes ayant une déficience mentale ou physique	0	0.5	0	0.5	1	2	2	2	les conditions d'incarcération et le manque d'hygiène ne sont pas adaptés et exposent les prisonniers au risque accru des maladies *Ils vivent dans des espaces surpeuplés et souvent mal ventilés
Pauvres urbains	1	1	1	1	1	5	5	5	*Ils se mangent difficilement ce qui a une incidence sur leur immunité *Ils se *Absence des données épidémiologiques sur la TB
Pauvres ruraux	1	1	1	0.5	0	3.5	3.5	3.5	*Ils vivent dans des espaces souvent mal ventilés. *Ils sont sous alimentaires, manque d'hygiène
Personnes vivant avec le VIH	0	1	0.5	0.5	1	3	5	8	Vulnérables à cause de défiance immunitaire. Vivent la discrimination et la stigmatisation
Les personnes atteintes de silicose	1	1	1	0.5	0.5	4	1	6	
Les enfants de la rue /orphelins	0	1	1	1	1	4	1	6	Ils sont abandonnés a leur triste sort, vivent dans la pauvreté, ne sont pas pris en charge médicale et socialement.
Personnes à risque de tuberculose zoonotique	0	0	0	0	0	0	1	1	
Travailleurs en santé communautaire /sensibilisation	1	1	0.5	0	0.5	3	1	4	Ils sont en contact permanent avec les malades. Ils sont presque pas motivés, parcourant des longues distances pour atteindre les communautés et les malades. Ils sont pauvres
Le personnel soignant	1	1	1	0	0.5	3.5	1	4.5	Ils sont en contact permanent avec les malades. Ils sont sous payés et pauvres
Travailleurs des hôpitaux	1	0	0.5	0	0.5	2	1	3	Ils sont en contact permanent avec les malades. Ils sont sous payés et pauvres
Les transfrontaliers et migrants	1	1	1	1	0.5	4.5	4	8.5	Ils sont nomades et ont des rapports sexuels non protégés qui les exposent au risque des maladies.
Les mineurs (travailleurs de mines)	1	0.5	1	0.5	0	3	3	3	Ils vivent dans les conditions précaires et sont éloignés des structures de santé. Ils ont des rapports sexuels non protégés qui les exposent au risque des maladies.
Les contacts des tuberculeux	1	0.5	1	0.5	0.5	3.5	3.5	3.5	Ils sont exposés par le fait de vivre ensemble avec les malades de la tuberculose
Les milieux universitaires et internats	1	0	0.5	0.5	0	2	2	2	Ils utilisent des odors et homes mal aère et sont exposés au risque de contamination
Diabétiques	0	1	0	0.5	1	2.5	2.5	2.5	Ils sont faible a cause de leur immunité et le regime alimentaire exige par le traitement du diabete

Key populations focus groups

HPD	Key Pop	Date	Place	Participants	Age groups	Sex	
						H	F
Kongo-Central	PLIHVs	26/07/2018	Bureau UCOP+	8	25-45	5	3
	TB Contacts	27/07/2018	CSDT Baobad	8	25-48	6	2
	IDUs	27/07/2018	Bureau de la DPS	8	19-40	8	0
Nord-Kivu	PLIHVs	14/08/2018	Bureau FOSI	8	25-60	6	2
	TB Contacts	14/08/2018	CSDT Virunga	8	25-48	5	3
	IDUs	15/08/2018	Bureau PSSP	8	25-60	6	2
Kinshasa	PLIHVs	03/09/2018	Bureau de ICW	8	25-63	4	4
	TB Contacts	04/09/2018	Centre Mère/enfant Bumbu	8	25-48	3	5
	IDUs	06/09/2018	Selembao	8	30-49	6	2

Appendix D. Interview Guide–Focus Groups

Participants should be those who fulfill eligibility as a member of the key population.

Consent: (Review consent, answer questions, interviewer signature)

Domain 1: “General information about the population”

I would like to discuss, what are the main health issues for members of the key population (specify population in a non-discriminatory manner-may want to ask how they preferred to be called-and use this term throughout)

- How do you know other members of the key population (use term agreed upon) that you know? How would you assess their health? Their well-being?
- What do you think increases the risk or exposure to TB among this key population? And why? (May have to describe TB a little bit here)
- How did you find out you had TB ? Describe the test(s) you had and provided you the tests and where? What was your experience with the testing process? Any suggestions.
- Did you undertake TB treatment ? How was the treatment experience? What was the most difficult? Did you think about stopping the treatment? Why?
- How many of your friends have had TB ? How did they find out they had TB? If they undergo treatment? If no, why?

Domain 2: “TB and access to TB related health care” Ask for stories to describe any question below.

According to your experience, what are the main issues and challenges concerning TB and your peers?

- Do you know of a place where the population/your peers might be screened for TB in this town? Do you think the population/your peers are worried about TB? Why or why not?
- Do you think most of the population/your peers have been screened for TB?
- What do you think are some of the barriers to why the population/your peers do not get screened for TB?
- Do you think many of the population/your peers have TB active disease that poses a threat to other people (May have to describe TB a little bit here)? If so, what do you think should be done about that? Why do you think that TB disease among the population/your peers poses a threat? Why do you think they have TB disease? How are they getting TB?
- Do you think the health services available to the population/your peers for TB screening are adequate? If not, why not? If yes, why? How can we improve the services available for the population/your peers to be tested for TB?
- Do you think there are adequate health services available for TB treatment for the population/your peers? If not, why not? If yes, why? How can we improve the services available for the population/your peers to be treated for TB?
- What are the symptoms and signs that are most characteristic for TB?
- Have you heard about the population (an individual case or group) having obstacles to TB healthcare service uptake or a positive story of them benefitting from TB healthcare service provision?

Information sheet and consent

INFORMATION SHEET

Hello, my name is _____ and I work with _____. The goal of this interview is to assess Tuberculosis (TB) related health care access and experiences among different populations. The questions we ask you will help us assess barriers to TB health care, specific exposures and risk to TB and key gaps in information. Your responses will help us to improve services for different populations in this country. This interview should take no more than one hour. You are free to leave the interview any time without any consequences. You are free to not answer any questions that are not comfortable for you to answer.

Participation in this survey is anonymous, no record of a name or any other personal information relating to you will be kept. Once the interview is completed the transcripts of the discussion will be analyzed by researchers. Results of the survey will not disclose any information specific to you individually.

We thank you for your time to help us with this important work. Before we start I must ask you to state that you understand everything I just explained to you and to answer any questions you have.

CONSENT FORM

I, _____, hereby give my consent to participate in the interview.

Data Subject's declaration of informed consent:

1. I have been informed about the specified and additional purpose(s) for which my opinions will be collected, used and disclosed, as described above.
2. I understand that my opinions may be used and disclosed for secondary purposes that are necessary to achieve the above described specified purpose.
3. I voluntarily make this declaration and freely consent to the participation in the interview.

Signed at (place).....on (date).....

.....

Interviewer's Signature

Key informants interviews

N.	Place	Key Informant	Sector	Date	Age	Sex	
						H	F
1	DPS Kongo-Central	Chef de division provinciale	Santé	26 juillet	55	H	
		Médecin chef de zone de Matadi	Santé	25 juillet	65	H	
		Médecin chef de zone de Nzanza	Santé	25 juillet	55	H	
		Infirmiers Superviseur de zone de santé de Matadi	Santé	26 juillet	53	H	
		Infirmiers Superviseur de zone de santé de Nzanza	Santé	26 juillet	49	H	
		Coordonnateur SC santé	Société civile santé	26 juillet	45	H	
		Infirmiers Titulaires hôpital provincial de Matadi	Santé	27 juillet	46		F
		Infirmiers Titulaires CSDT Baoba	Santé	27 juillet	52	H	
2	DPS Nord-Kivu	Maire de la ville de Goma	Politique	15 août	64	H	
		Pasteur de l'Eglise...	Confession religieuse	15 août	48	H	
		Chef de division santé	Santé	15 août	58	H	
		Médecin Coordinateur Provincial TB	Santé	11 août	57	H	
		Secrétaire exécutif provincial SIDA	Santé	11 août	62	H	
		Technicien de Labo	santé	14 août	48	H	
		Tradi-praticien	Santé	15 août	56	H	
		Directeur de nursing hôpital général	Santé	15 août	52	H	
		Journaliste	Presse	15 août	47	H	
		Infirmier Superviseur de zone de santé de Goma	Santé	13 août	48	H	
		Infirmier Superviseur de zone de santé de Karisimbi	Santé	13 août	42	H	
		Infirmiers Titulaire de CSDT Virunga	Santé	13 août	49		F
		Infirmiers Titulaire de CSDT Karisimbi	Santé	13 août	53	H	
		Coordonnateur Forum Sida	Société civile santé	14 août	52	H	
		Coordonnateur PASCO	Société civile santé	11 août	53	H	
		Coordonnateur SIOD	Société civile santé	11 août	35	H	
Coordonnateur RACOL	Société civile	15 août	36	H			
3	DPS Kinshasa	Directeur de cabinet	Ministère des affaires social	4 septembre	56	H	
		Directeur de cabinet Adjoint du Gouverneur	Hôtel de ville	4 septembre	62	H	
		Ministre provincial de la santé	Santé	4 septembre	52	H	
		Médecin coordinateur provincial TB	Santé	30 aout	54		F

		Chef de division santé	Santé	5 septembre	61	H	
		Médecin chef de zone de bumbu	Santé	30 aout	59	H	
		Médecin chef de zone de selembao	Santé	30 aout	H		
		Infirmiers superviseur de zone de santé de selembao	Santé	30 aout	58		F
		Infirmiers superviseur Sida zone de santé de Bumbu	Santé	30 aout	51		F
		Infirmiers superviseur TB zone de santé de bumbu	Santé	30 aout	54		F
		Infirmier titulaire CSDT Siloe	santé	1 septembre	45	H	
		Infirmier titulaire CSDT M&E Bumbu	santé	1 septembre	52		F
		Coordonnateur de l'ONG Jeunesse espoir	santé	6 septembre	27	H	
		Coordonnatrice d'ICW	santé	6 septembre	52		F
		chargé de S&E de UCOP+	santé	6 septembre	35	H	
		Chargé de programmes de Forum Sida	santé	6 septembre	44	H	

Appendix B. Interview Guide—key informants who work with the key population

Note: not all questions may be relevant to all interviewees. This is for those who are working with the key population and know about TB. Consent: (Review consent, answer questions, interviewer signature)

Domain 1: “General information about the population”

- What is your experience with the population’s (specify key population) experiences and preferences about access to TB screening, testing and care? How are you interacting with them (If providing services or interacting with them through research, ask about types of services and research or other activities)?
- What do you think puts the population (specify key population) at increased TB risk/exposure?

Domain 2: “TB and access to TB related healthcare”

- How do you rate the concern about TB among this population? (If they are not concerned: What are the reasons for it?)

2.2. Testing

- Do you know of a place where this population might be screened for TB in this town? Where?
- How do you rate the willingness in this group to get screened for TB?
- What are some of the barriers why this population does not get screened for TB?

2.3. TB infection

- How do you rate the level of TB infection in this population compared to the general population? (If the level is high: What is the reason for that? What should be done about that?)

2.4. TB health services

- Do you think the health services available to this population for TB screening are adequate? If not, why not? If yes, why? How can we improve the services available for this population to be tested for TB?
- Do you think there are adequate health services available for TB treatment for this population? If not, why not? If yes, why? How can we improve the services available for this population to be treated for TB?
- What are some of the barriers for this population to be treated for TB?
- Any challenges you are faced with when providing services to this key population? Any suggestions how to mitigate that?

2.5 Case studies

- Have you heard about the population (an individual case or group) encountering obstacles to TB healthcare service uptake or a positive story of them benefitting from TB healthcare service provision?