National HIV Research Agenda in Nepal 2013

(July 2013-July 2016)



Ministry of Health and Population
National Centre for AIDS and STD Control
Kathmandu, Nepal

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Government of Nepal
Ministry of Health & Population
NATIONAL CENTRE FOR AIDS AND STD CONTROL

4261653
4262753
4258219
Fax: 4261406
E-mail: ncasc@mos.com.np
Website: www.ncasc.gov.np
TEKU, KATHMANDU, NEPAL

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FOREWORD

It gives me pleasure to present the first **National HIV Research Agenda, 2013** developed with the rigorous effort to help ensuring the proper scientific understanding and informed response to the HIV epidemic. This research agenda document has outlined a broader framework of national HIV and STIs research, primarily focused on operational, implementation and health systems research, key research questions, research subjects and setting, research design and methods of data collection, sampling, potential research partner, estimated costs and timing of research implementation. I want to give special applaud to the technical team for building this document.

Research is a continuous process of knowledge generation and thus has very vital role to reflect the complexity and dynamics of HIV epidemic. It is the core component that bridges the gap between surveillance and Monitoring & EValuation within strategic information system. This book has addressed the issues which need to be addressed by all the external development partners, national research organizations, researchers and other scientific communities before planning any research intervention. Different prioritized agendas related to operational research, implementation research and health systems and policy research are incorporated here to guide the research interest on HIV in Nepal.

National Centre for AIDS and STD Control has been regularly coordinating and monitoring the related research activities. The National HIV/AIDS Strategy 2011-2016 has also focused the importance of research and identified it as one of the core areas to strengthen strategic information. National AIDS Research Library is established in 2009 to streamline the research conclusions and create a knowledge management centre. And now, this research agenda document has become one of the key milestones towards the advancement of research work in Nepal. I request all the researchers and agencies to merge their research plan focusing these agendas primarily. Also, researching the new research agendas would also be highly appreciable and noted for future priority.

The pertinent issues of HIV in the areas of prevention, treatment, care and support services and their modalities, health and community system strengthening, resource mobilization, efficiency and effectiveness of systems, policy and strategic agendas and the new innovative possibilities and recommendations are concretely presented as research agenda. Sharing the findings of the questions inbuilt will be beneficial for the country, system and people.

I am gratified to the scientists and professionals who have contributed their invaluable time and knowledge to support the technical team in various process of developing this output. I hope this document will surely be helpful to drive our understanding of HIV to brightest side and amplify the programme efficiency to achieve the goal of "Getting to Zero".

Dr Naresh Pratap KC
Director

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This ***National HIV Research Agenda in Nepal, 2013*** was developed in a consultative approach among the government, its technical and implementation partners, national networks related to HIV and STIs in Nepal, key populations at higher risk to HIV/STIs, and people living with HIV.

Special appreciation is deserved for the technical support of following individuals and agencies:

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- Dr Krishna Kumar Rai and Dr Ramesh Kumar Kharel, former Directors, NCASC
- Mr Shambhu Kafle, Strategic Information Focal Point, NCASC
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- Dr Bhimsen Devkota, Consultant, supported by USAID-funded SSP

We sincerely thank Dr Bhimsen Devkota, consultant supported by USAID-funded SSP for developing the final draft of the National HIV Research Agenda with technical staff members of Strategic Information Unit of NCASC. Special appreciation is deserved to Mr Deepak Kumar Karki, Surveillance Officer for developing the overall architecture of the National HIV Research Agenda in Nepal and coordinating among experts to finalize this agenda document. NCASC acknowledges the first technical workshop in November 2010 in Pokhara was supported by World Health Organization/Nepal.

We thank all the people, national networks related to HIV and STIs in Nepal, experts, organizations and people living with HIV for their inputs in formulating the research agenda in various themes – prevention of HIV and STIs, treatment, care and support among infected and affected individuals, health and community systems strengthening efforts.

We further acknowledge the support from USAID-funded SSP for their support in designing and printing this research agenda document.

ABBREVIATIONS

ADR	Adverse Drug Reaction
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Therapy
ARV	Anti Retro Viral
BCC	Behavioral Change Communication
CBPMTCT	Community Based Prevention from Mother-to-Child Transmission
CHBC	Community Home Based Care
CCM	Country Coordination Mechanism
CSO	Civil Society Organization
CSS	Community System Strengthening
DACC	District AIDS Coordination Committee
DFID	Department for International Development
DOHS	Department of Health Service
D(P)HO	District (Public) Health Office
EDP	External Development Partners
eVT	Elimination of Vertical Transmission of HIV
FCHV	Female Community Health Volunteers
FSGMN	Federation of Sexual and Gender Minorities Nepal
FSW	Female Sex Workers
GIPA	Greater Involvement of People Living with HIV/AIDS
HAART	Highly Active ART
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counseling
IBBS	Integrated Biological and Behavioural Surveillance
IDU	Injecting Drug Users
I/NGO	International/Non-Governmental Organizations
IPT	Isoniazid Preventive Therapy
JMMS	Jagriti Mahila Maha Sangh
M&E	Monitoring and Evaluation
MARP	Most At Risk Populations
MCHW	Maternal and Child Health Workers
MoHP	Ministry of Health and Population

MSM	Men who have Sex with Men
MSW	Male Sex Workers
NAC	National AIDS Council
NANGAN	National Association of NGO working in AIDS in Nepal
NAP+N	National Association of People Living with HIV/AIDS in Nepal
NCASC	National Centre for AIDS and STD Control
NDHS	Nepal Demograhpic Health Survey
NFWLHA	National Federation of Women Living with HIV/AIDS in Nepal
NHRC	Nepal Health Research Council
NHSP	Nepal Health Sector Program
NPHL	National Public Health Laboratory
NSEP	Needle Syringe Exchange Programme
OI	Opportunistic Infection
OST	Opioid Substitution Therapy
PHCC	Primary Health Care Centre
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
PWID	People Who Inject Drugs
POC	Point of Care
PPV	Positive Predictive Value
RCT	Randomized Control Trial
RH	Reproductive Health
RN	Recovering Nepal
SOP	Standard Operating Procedures
SSP	Saath-Saath Project
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
TB	Tuberculosis
TAG	Technical Advisory Group
TWG	Technical Working Group
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNICEF	United Nations Children Fund
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing of HIV
WHO	World Health Organization

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EXECUTIVE SUMMARY

Proven and evidence-based interventions are of paramount importance for achieving the national target of halving new HIV infections. Understanding the dynamics of the HIV epidemic through systematic evidence is critical for addressing the knowledge gaps for an effective policy and planning decisions in response to HIV and Sexually Transmitted Infection (STI). National Centre for AIDS and STD Control (NCASC) and its partners, therefore, developed the National HIV Research Agenda to inform research gaps and to enhance quality, coverage and effectiveness of HIV prevention, treatment, care and support services in Nepal. The research agenda have developed through review of HIV and STIs-related literatures and a series of consultative meetings and workshops. It encompasses priority research areas that focus on three broader research themes: (i) prevention of HIV and STIs (from all modes of transmission), (ii) treatment, care and support of infected and affected individuals, and (iii) health and community system strengthening efforts.

The National HIV Research Agenda is aimed to be useful to policy makers and top level managers, programme managers, donors, researchers, students, activists and social workers and general public.

The National HIV Research Agenda (given in chapter 4) includes national HIV and STIs research framework with clearly defined research questions and suggested research methods; implementation and co-ordination framework for moving the agenda forward; mechanism of reviewing, updating and sharing research findings and its utilization; plan of National HIV Research Agenda and costs, and pre-requisites for building on national and local capacity for undertaking implementing the prioritized research agenda for the next three years (July 2013 - July 2016).

The research agenda on prevention research has recommended generating new knowledge on four main themes- prevention of HIV transmission, prevention of STI transmission, prevention from sharing unsterilized injecting equipment (harm reduction) and prevention from mother-to-child transmission (PMTCT). The research agendas on prevention research focus in understanding the dynamics of HIV transmission among the key populations at higher risk of HIV and STIs transmission, HIV testing and counseling (HTC) services. The research agenda on prevention of STIs focuses on determining prevalence of STIs, perception of risk of STIs among key population groups and their broader health care needs and access to services.

The research agenda on prevention of needle sharing will focus in identifying knowledge gaps regarding effectiveness of drug treatment in HIV prevention, practice and accessibility of needle and syringe exchange programme (NSEP) among adolescents (14-18 yrs), burden of Hepatitis B and C among people who inject drugs (PWIDs), situation assessment of female drug users, adequacy of drug control law and policies, effective coverage of harm reduction services, individual and structural barriers of effective services, reasons of relapse after rehabilitation treatment of drugs among drug users and PWIDs, practice of drug use in cross-

border areas and behavioural assessment of clients on Opioid Substitution Therapy (OST) in Nepal.

The research agenda on PMTCT focuses on use of family planning (FP) services among people living with HIV (PLHIV) and key populations at higher risk of HIV (PMTCT prong II), exploration of cost-effective and feasible strategies to implement recent decisions to expand PMTCT to community level across country, maximizing benefit of antenatal care screening (PMTCT prong III), partner involvement in PMTCT, Option B+ for Nepal (lifelong antiretroviral therapy (ART) for all positive pregnant women) and timing of PMTCT interventions.

The recommended research agenda on HIV treatment comprises to optimize the access to CD4, survival of Nepali PLHIV on ART, extent and reasons for treatment failure, integration of PMTCT/ART into existing health services, knowledge of CD4 trends among various population groups in interventions, implementation of early infant diagnosis, adherence to ART, cost-effectiveness of HIV and STI treatment, retention in care for ART taking PLHIV, side effects of ARVs, impact of highly affective antiretroviral treatment (HAART) on sexual behaviour/transmission of HIV and other infections, profile of opportunistic infections (OIs) and effective management modalities and feasibility of Treatment 2.0 agenda in Nepal and ways of optimization for improved benefit to the PLHIV and health systems.

The recommended research agenda on care and support revolves around assessment of effectiveness and quality of services, impact and sustainability of services from community care center (CCC) and efficacy of community and home-based care (CHBC) models in Nepal, nutritional status of PLHIV and supplementary options, life course perspective of impacts of HIV, and exploration of more effective, friendly and community system driven care and support services for HIV infected and affected people and their families.

The HIV and STIs research agenda on health system strengthening are outlined for improving universal precautions in the health care settings, task redistribution and task shifting among health care providers, strengthening of laboratory infrastructures, assessment of total laboratory quality of practices, cost-effectiveness and financial sustainability of HIV programme at local level with improved community ownership.

Similarly, the research agenda for community system strengthening include participation of communities in the national HIV response, barriers to access services to the communities, quality and effectiveness of services delivered by the communities and their contribution in making the difference, exploration of strengthened community ownership and response, psychosocial health status of men who have sex with men (MSM)/ transgender people and prison inmates, and devising effective programme model for their health needs, good governance of civil society organizations working in HIV prevention to care. Moreover, the research agenda emphasize generating knowledge on means and strategies for improving research monitoring and surveillance, collection of quality data, and optimizing reporting and enhance utilization of the research findings for public health actions.

The research agenda has also incorporated specific research questions on gender

equality and social protection of the vulnerable groups of the populations especially sensitive to HIV and STIs in Nepal.

The research agenda has presented a plan for conducting HIV and STIs research activities considering the need evidence in time. The roll out plan is spread for four years, 2013-2016 and is costed (proposed). Moreover, the plan has also indicated potential research partners along with their roles to support HIV and STIs research in Nepal. The research agenda document also outlines a broader mechanism for improving coordination and linkage among key stakeholders, expressed human resource need for moving the research agenda and other resources.

1 CHAPTER

Introduction and Background

1.1 SITUATION OF HIV EPIDEMIC IN NEPAL

HIV is characterized as a concentrated epidemic in Nepal with HIV prevalence of 0.28 percent among adult aged 15–49 years in 2013. There are approximately 48,600 people estimated to be living with HIV, where four out of every five infections are transmitted through sexual transmission (NCASC 2013). People who inject drugs (PWIDs), men who have sex with men (MSM) and female sex workers (FSWs) are the key populations (KP) who are at a higher risk of acquiring HIV. Male labour migrants (who particularly migrate to high HIV prevalence areas in India, where they often visit FSWs) and clients of sex workers in Nepal are playing the role of bridging populations that are transmitting infections to low-risk general populations including spouses of migrants. The rate of occurring new HIV infections throughout Nepal has reduced significantly during the last five years essentially owing to the targeted prevention interventions among key population groups. However, it is critical to improve the effective coverage of proven prevention interventions, especially among new entrants engaging in high-risk behaviours, and to sustain these interventions for achieving the national target of halving new HIV infections by 2015.

The quality of the data on understanding the epidemic is critical, and it is essential to be challenged by quality research for fulfilling the knowledge gaps in programme improvement. With this views, National HIV Research Agenda is developed.

1.2 POSITIONING OF RESEARCH AGENDA IN NATIONAL RESPONSE TO HIV EPIDEMIC

Research is one of the vital elements of strategic information for understanding the gaps in the interventions as well as strategic knowledge on the dynamics of the HIV epidemic. Strategic information refers to the "kind of information needed to inform policy and planning decisions", which comes from four main sources: (i) surveillance, (ii) routine monitoring

and evaluation, (iii) health information systems, and (iv) research (Figure 1). The HIV strategic information and research framework is an important tool to identify a set of key indicators on the HIV epidemic.

Nepal has been following the principle of "three ones principle" adopted by the Joint United Nations Programme on HIV and AIDS (UNAIDS) since 2004. This approach emphasizes to establish a single national HIV/AIDS authority, a single national strategic HIV/AIDS plan and a single national HIV/AIDS monitoring and evaluation system. The research components contribute for generating knowledge as one principle of national strategic information system.

Nepal's National HIV Strategy considers monitoring and evaluation as the "third" one. This has been operationalized by establishing a national strategic information system for informed response to the HIV epidemic. A national HIV Strategic Information Technical Working Group (SITWG) was formed under the leadership of National Centre for AIDS and STD Control (NCASC) with the participation of key stakeholders, external development partners and civil society organizations (CSOs) in 2006. However it is not active as expected due to transitions at NCASC.

Based on the principle of "getting research into policy and practice", NCASC and its partners reiterates the development of National HIV Research Agenda to inform research gaps and to enhance quality, coverage and effectiveness of HIV prevention, treatment, care and support services. Primarily, the positioning of the research areas is to providing evidence for scientific scaling up/down of effective interventions, timely exploring of emerging and re-emerging of HIV epidemic among key population groups, and getting sustainable and effective health systems. Thus, the focuses of research are on: (a) operational research, (b) implementation research, and (c) health system research (Fisher & Foreit, 2002; Sanders & Haine, 2006; WHO/The Global Fund, 2009; Rujumba & Byamugisha, 2012).

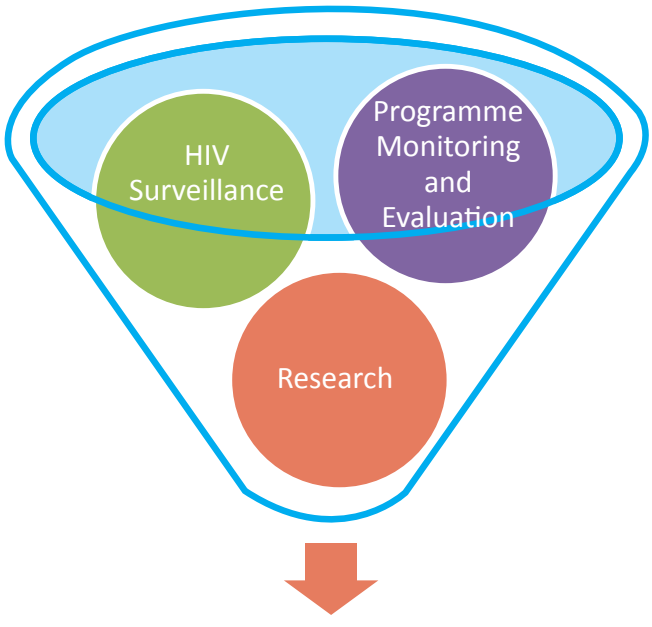

Figure 1: Strategic Information for Informed Response to HIV Epidemic in Nepal

1.3 NEED AND RELEVANCE OF NATIONAL HIV RESEARCH AGENDA

The National HIV/AIDS Strategy 2011-2016 asserts to strengthening strategic information for informed planning, programming and effective national response to HIV focusing on (i) HIV surveillance, (ii) routine program monitoring and evaluation and (iii) research. Though research is and should be an integral part of a systematic planning and programming on HIV and STIs, there is absence of National HIV Research Agenda in Nepal. It has resulted in lack of clear guidance for undertaking research on HIV and AIDS in the country. NCASC therefore organized a three-day technical workshop to develop a national HIV research agenda at Pokhara in November 14-16, 2010.

The workshop has proposed a tentative list of priority research areas that focus on three broader themes: (i) prevention research (including mode of transmission), (ii) treatment, care and support, and (iii) cross-cutting issues. The workshop had recommended moving ahead for a more participatory and consultative process in order to finalize the national HIV research agenda (NCASC, 2010).

NCASC, with support from USAID-funded Saath-Saath Project (SSP), therefore, undertook the following tasks:

- Prioritized research agenda (research questions focused to improve effectiveness, quality and coverage)
- Identified research methods
- Planned timing for implementation (and data need)
- Planned costs of each research agenda with an action plan
- Identified research partners and their roles
- Developed a research implementation and co-ordination framework
- Assessed research capacity and identify capacity development needs of NCASC and its key partners

1.4 OBJECTIVES OF THE RESEARCH AGENDA

The overall objective is to develop a National HIV Research Agenda to support the strategic information and knowledge for informed response to HIV in Nepal. It is expected that it will add new knowledge and enhance understanding around the key HIV and AIDS research agenda in Nepal.

This research agenda encompasses of:

- National HIV Research Agenda framework (research questions)
- Research concept notes for each research questions (in brief: methods, utility of research findings, potential research partners with roles, estimated cost)
- Research plan based on the National HIV Research Agenda with estimated costs (costed research plan)
- Research implementation and co-ordination framework for moving the research agenda (potential partners and their roles)
- Outline for methods/approaches for reviewing and updating the National HIV Research Agenda
- Research capacity development framework and plan based on the requirement of National HIV Research Agenda

The research agenda includes the national HIV/STI research framework with clearly defined research questions; research plan; implementation and co-ordination framework for moving the agenda; mechanism of sharing research results and its use; and methods/framework/ mechanism for reviewing and updating the research agenda.

Specific Objectives

1. To generate context specific evidence to fulfill the knowledge gaps on prevention of HIV and STIs among population groups in Nepal
2. To generate evidence for improved care, treatment and support for HIV infected and affected communities in Nepal
3. To generate evidence for efficient health systems and community systems for sustained response to HIV epidemic in Nepal and contribute to overall health system development

1.5 INTENDED USERS OF THIS DOCUMENT

Having a National Research Agenda is essential to set priorities to conduct HIV research for addressing the knowledge gap, assist develop plan for policy reform and programme improvement using the available knowledge and provide direction to conduct further research for adding new knowledge for informed response on HIV. Also the Research Agenda can be used, partly, for financing the HIV interventions and performance of assignments among the government, donors, and the civil society organizations. The National HIV Research Agenda is aimed to be useful to policy makers and top level managers, programme managers, donors, researchers, academicians, students, activists and social workers and general public.

2 CHAPTER

Mapping of Research on HIV and STIs in Nepal

2.1 SCOPING OF EVIDENCE-BASED KNOWLEDGE ON HIV

The search strategy in this review involved systematic electronic database searching, hand searching and grey literature searching. This study reviewed electronic research databases, and synthesized published and grey literature such as research articles, reviews and case reports published in peer and non-peer reviewed electronic and print journals and reports. As the search of databases may not locate all relevant sources, it was important to combine systematic database searching with hand searching of journals, searching of specialist websites and grey literature through personal and institutional contacts and tracking of references.

'Free text term' or 'key word search' was the first strategy used to map all relevant articles from multiple databases; Medline (1980-2012), Evidence-based Medicine (EBM) Reviews (1980-Feb 2012), ExcerptaMedica Database(EMBASE) (1980-2012), Cumulative Index to Nursing and Allied Health (CINAHL) (1990-2012) and Ovid Medline (1996-January 2012) and Google Scholar. For each search, the outputs were downloaded into MS Excel and screened later following the inclusion criteria. The main review criteria included; (i) original research or systematic review (ii) makes specific reference to STIs and HIV in Nepal, (iii) search terms had to be in the title, abstract or key words on the database, (iv) only English language publications, published from 1980 to December 2012. Books, book reviews, editorials, reports and news articles identified from other sources were also added to the review.

The following combinations of the key terms were used in database searching:

- 'HIV' AND (AIDS OR STI OR Nepal OR Prevention)
- 'HIV, AND ('Nepal OR Prevention' OR Treatment and care")
- 'HIV' AND ('Female sex workers' OR 'IDUs' AND 'MSM)'

The above-mentioned terms were also used for other manual searches. The

citations were initially screened on title and those retained were screened again on their abstracts. Only 115 articles obtained from manual and electronic searches were included for the review (Table 1).

Of the 115 papers and sources reviewed, nearly two third (73 or 63.4%) of the research papers were related to prevention research. Out of the papers appeared on prevention, they mainly covered

Table 1: Research done on HIV and STIs in Nepal as of December 2012

SN	Research themes	Number	Percent
1.	Prevention of HIV and STIs		
	Female sex workers	12	16.4
	People who inject drugs (including transmission from blood and blood products)	13	17.8
	Men who have sex with men /male sex workers/ transgender people	5	6.8
	Labour migrants	12	16.4
	Transport workers	6	8.2
	Young people	12	16.4
	People living with HIV (PLHIV)	2	2.7
	Other key populations at higher risk to HIV	3	4.1
	General population	8	10.9
	Sub-total (prevention)	***73***	**100.0 (63.4)**
2.	Treatment of HIV and management of co-morbidities		
	Co-infection diagnosis and management (TB)	14	53.8
	Other opportunistic infections	4	15.3
	Antiretroviral	3	11.5
	Laboratory diagnosis	5	19.2
	Sub- total (treatment)	**26**	**100.0 (22.6)**
3.	Care and support	4	3.4
4.	Health systems and policy research	1	0.8
5.	Cross-cutting issues (gender, social protection)	5	4.3
6.	Monitoring and evaluation	6	5.2
	Total	**115**	**100.0**

PWIDs (17.8%), FSWs (16.4%), labour migrants (16.4%) and young people (16.4%). The other areas of prevention research included transport workers (8.2%), MSM/MSW/TG (6.8%) and PLHIV (2.7%). The key populations at higher risk of HIV transmission covered 4.1% of the papers that appeared on prevention research. One in ten (10.9%) of the prevention research was based on general population.

Similarly, out of total 26 research papers (22.6%) on HIV and AIDS, more than half (53.8%) deal with co-infection, particularly, tuberculosis and HIV and STIs. Biological test-based research papers covered 19.2% of the HIV research papers, followed by OIs (15.3%) and ART (11.5%). The other thematic areas of HIV research included care and support (3.4% of total), cross-cutting issues (4.3%) such as gender-based violence, cultural and psychological issues on PLHIV, conflict and HIV and AIDS and training needs. Only one paper had appeared on health services research. Six out of 115 papers reviewed (5.2%) looked at research questions around monitoring and evaluation (Figure 2: Research Articles on HIV and STIs in Nepal as of December 2012).

2.2 GAPS IN HIV RESEARCH AGENDA IN NEPAL

The review of the research papers extracted during literature search was indicative that more research is necessary in the field of care and support, health services research, treatment and cross-cutting issues such as gender and inclusion of the key population at higher risk of HIV. In the field of prevention research, MSM/TG and transport workers tend to be less focused. The review also suggests lack of evaluation, intervention research, including economic evaluation.

In terms of methods most of the research papers suggest using descriptive cross sectional surveys. Case control studies, cohort studies and Randomized Controlled

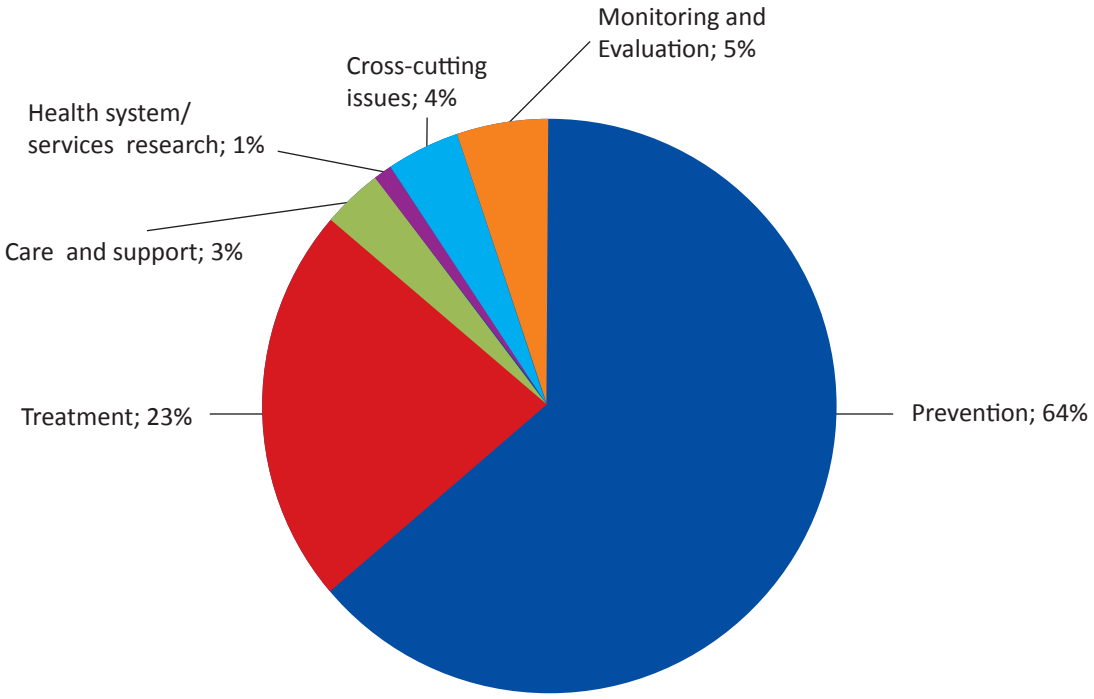

Figure 2: Research Articles on HIV and STIs in Nepal as of December 2012

Trials (RCT) seem less occurring. Another grey area of HIV research was the cost effectiveness and cost-benefit study. There seems enough room for more biological studies. The review also suggests that HIV research in Nepal seems lacking use of using systemic reviews and qualitative studies.

On the other hand, though Nepal Health Research Council (NHRC) updates national health research agenda occasionally. However, it has not extensively offered research agenda regarding HIV and AIDS.

2.3 CULTURE OF HIV RESEARCH IN NEPAL

In Nepal, despite the enormous disease burden, research is often viewed as expenditure rather than an investment (Sadana R, et al, 2004). Inadequate funding is recognized as the main barrier to health research. Moreover, there is no complete accounting of sources of funds and allocation to research agenda in health research. Research on HIV has received low priority as it is perceived that it is the external development partners that have to invest in HIV research. At present, most of the research works on HIV, though limited in number, have been undertaken with the financial support by the external development partners. NCASC, with support from United State Agency for International Development (USAID), the Global Fund and other agencies, has been conducting integrated biological and behavioral surveillance (IBBS) surveys among key population at regular intervals. Some International/Non-governmental organizations (I/NGOs) and networks of people infected and affected by HIV have carried out research works with support from the external partners. Until recently, "most health researchers in Nepal worked individually rather than based within institutions". Students from universities and medical colleges and hospitals have conducted some research on HIV including STIs. They have mostly focused on studying knowledge, attitudes and practices based on interview questionnaire, and advance studies involving large sample size, more human resources and costs are lacking. Moreover, HIV research is affected by issues mentioned in Section 2.2 above.

2.4 RESEARCH ISSUES PRIORITIZED FOR NEPAL

Research issues on HIV that need evidence-based knowledge are many in Nepal. The workshops on setting HIV research agenda held at Pokhara in November, 2010 and at Summit Hotel Kathmandu in August, 2012 has categorically recommended following key thematic areas for HIV research for the next five years (2011-2016) in Nepal.

The research issues prioritized are on prevention, treatment, care and support, health system strengthening and community system strengthening.

3 CHAPTER

Developing a National HIV Research Agenda in Nepal

3.1 METHODS USED AND PROCEDURES FOLLOWED IN DEVELOPING THE NATIONAL HIV RESEARCH AGENDA

Following methods and approaches were used while developing the National HIV research agenda:

Consultation with stakeholders and core group: A consultation meeting with stake holders was conducted in Kathmandu on August 2012. It was participated by NCASC Director, senior staff from Strategic Information (SI) Unit under NCASC, representatives from NHRC, Department of Health Services, National Public Health Laboratory under Department of Health Services (DoHS), FHI 360, UN agencies, USAID/Nepal, civil society organization and PLHIV networks. Around 30 participants took part in the meeting.

The meeting reviewed table of contents and approved them. It also discussed on potential research questions under each thematic area. Moreover, the consultant frequently consulted with the core group, consisting of three key staff from NCASC SI Unit and SSP Research Unit representative. The core group was extensively involved in developing the National HIV Research Agenda in close coordination with the consultant.

Desk review: The consultant reviewed available published research articles and grey literature on HIV, STI and related issues for understanding needs and situation as well as identifying the research gaps to be able to strategically plan for future research and avoid duplication. Moreover, Nepal Health Sector Plan II, current National HIV/AIDS Strategy 2011-2016 and proceedings of the "Technical Workshop on Data Sharing and National HIV Research Agenda" held at Pokhara in November 14-16, 2010 were reviewed. While undergoing the review, key thematic areas of HIV research - prevention, treatment, care and support, and health and community system strengthening efforts, including cross-cutting issues (gender, human rights, and social protection) were focused.

Core group residential meeting: One residential meeting of the core group was held in Pokhara on January 24-27, 2013. The meeting was planned following technical consultation with key stakeholders and primarily focused on reviewing the draft agenda document developed.

Expert group meeting: One a day expert group meeting was conducted in order to solicit comments and feedback of the draft Table of Contents with elaborated framework of the proposed research agenda. Preliminary draft agenda was shared in the second expert group meeting along with Technical Advisory Group (TAG) and incorporate the relevant comments in the draft document.

Thematic meetings: About 8-10 thematic areas were covered for discussion in order to generating research agenda including the cross cutting issues. All broader themes recommended by the Pokhara Workshop in November 2010 were considered as starting issues for specific thematic discussion. They include prevention of HIV/ STI, treatment of HIV and management of co-morbidities, care and support of infected and affected individuals, health and community system strengthening efforts, including cross-cutting issues such as gender equality, human rights and social protection. The details about the themes are as follows (but not limited to):

a) Prevention research

- Prevention of HIV through injecting drugs, sexual transmission (among male labour migrants and their wives/ partners, FSW , MSM/TG), PMTCT, blood and blood products
- HIV testing and counseling (HTC)
- Targeted prevention interventions (comprehensive) among key populations at higher risk of HIV, including harm reduction, behavioural change communication (BCC) and condom programming
- Prevention and control of STI
- Pre- and post- exposure prophylaxis, vaccines
- Quality assurance of laboratory investigations related to HIV

b) Research on treatment, care and support

- Antiretroviral therapy (ART) & Antiretroviral, prevention and control of opportunistic infections, including co-infection management (TB-HIV)
- Care and support activities (biomedical, nutritional, social, legal, economic, psychosocial) for infected and affected individuals and communities

c) Research on health and community system strengthening, including cross-cutting issues

- Strategic information-HIV surveillance, intervention, monitoring and evaluation, research
- Health system strengthening (leadership, governance, informatics, human capacity for national response to HIV, HIV and STI related laboratory and commodities management, and financing)
- Community system strengthening
- Gender equality, human rights, greater involvement of people living with AIDS (GIPA), social protection (economic, social, legal etc.), right-based approaches to respond HIV and gender based violence.

Research capacity building framework: Following consultation discussion with the SI team of NCASC and its strategic

information partners, a national level research capacity building framework has prepared considering the minimal requirements for effective implementation of the research agenda.

Workshop for prioritization of research agenda: The final draft of key research questions was presented during a one day workshop held at Lalitpur on 10 September 2013. It was participated by around 25 experts including network members. Please refer to Annex 3 for the prioritization tool.

With the key questions on each theme, eight established criteria – relevance, avoidance of duplication, feasibility, political acceptability, applicability, ethical acceptability, gender/human rights and social protection and need for new knowledge in particular were used and scored between 1-5 (1 = poor and 5 = very good/relevant), as mentioned in Annex 3 for details.

Final consultation meeting: Members representing national networks; JMMS, FSGMN, NAP+N and RN participated in a half day meeting at NCASC to review the research agenda and the agenda document was revised as per feedback provided.

Development of road map to move the HIV research agenda forward: The consultations carried out during the research agenda document development also provided the foundation for outlining a road map to move the agenda forward. This is mentioned in the succeeding sections.

Table 2: Key considerations made while prioritizing the research agenda on each theme

Broad areas	Key questions
Prevention	How to reduce the new infections by all modes of transmission? Are infections reduced significantly?
Treatment	How to save more lives? How to improve quality of life of PLHIV? How to improve adherence to therapy? How to optimize the treatment as prevention in Nepal's context?
Care and Support	Is the overall living condition of PLHIV improved? Is the impact of HIV mitigated among individuals infected and affected by HIV?
Health System Strengthening	How to adjust the system knobs for effective and efficient delivery of services in sensitive and sustainable manner? Through more capable and responsive health system?
Community System Strengthening	How to effectively engage the communities for demand creation and quality of service they received? (quality services are accessible)
Critical enablers	How to generate supportive environment for delivery and access of quality services to the communities at risk, infected and affected?

4 CHAPTER

National HIV Research Agenda in Nepal

The National HIV Research Agenda developed after series of consultations with different expert groups and stakeholders comprises with of the following thematic areas.

4.1 RESEARCH ON PREVENTION

The prevention research agenda are outlined to fulfill the knowledge gaps in reducing new infections based on the established mode of transmission.

Prevention from sexual transmission: HIV prevention

Reducing new HIV infection from sexual transmission is a central priority of all prevention intervention in Nepal as more than 85% of all HIV infections spread from sexual transmission. Safer sexual behavior is the recommended strategy to reduce transmission. For this, use of condom and microbicides, reduction of stigma and discrimination, and expansion of HTC and STI diagnosis and treatment services are prioritized.

Prevention from sexual transmission of HIV
1. What are the determinants for low coverage of HIV prevention services among labour migrants and their spouses?
2. What are the effective strategies for reaching out key populations at higher risk in changed context - such as high end sex workers, men who have sex with men (MSM) and transgender people (TG), male labor migrants and their spouses; and male/female who inject drugs?
3. What is the impact of behavioural change communication (BCC) interventions in reducing risk (promoting safer behaviour) among key populations?

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Prevention from sexual transmission of HIV
4. Does high risk behaviors exist among prison inmates in Nepal? If so what? What are the health service needs of prison inmates in Nepal? What could be the effective HIV prevention model for the prison inmates in Nepal?
5. What is the effectiveness of various options of community-testing of HIV among key populations in Nepal? (Cost-effectiveness and system analysis)
6. Is home-based testing for HIV for pregnant women, key populations at higher risk and spouses acceptable, feasible, and accurate in Nepal? (demand side)
7. How to improve coverage of HIV testing and counseling among key populations at higher risk to HIV in Nepal?
8. What are the most appropriate and effective communication strategies for improving access to the health services and enrich quality of living of PLHIV in rural and urban areas in Nepal?
9. What is the prevalence of STIs and HIV among overseas migrants and migrants to India (male and female labour migrants) staying for longer periods?
10. What are the level and impact of non disclosure of HIV to partners (concurrent and multiple)?
11. What are the risk behaviours among trekkers/tour guides in Nepal?
12. What is the mobility pattern of labour migration in Nepal? What are the HIV risk behaviours among them?
13. What determines access of condoms and lube among MSM and TG in Nepal? To what extent the TG in Nepal use hormones and what are its impacts?
14. What is pattern of concurrent and multiple sexual behaviours among general population (and young people) in Nepal?
15. What is the infection rate among sero-discordant couples? (also the couple of PWID)

To contribute to the knowledge on prevention of HIV through sexual transmission, following research agenda in the form of research questions are recommended.

Prevention of sexually transmitted infection (STIs)

The key areas of research on prevention of STIs include determining syphilis prevalence among ANC users and labour migrants, efficacy of syndromic management of STIs, perception of risk of STIs by the key populations, treatment seeking behaviours, effective use and access to injection Benjathin Penicillin, genotype based drug resistance assessment, drug resistance of Neisseria Gonorrhoea, baseline studies for reference CD4, use of point of care (POC) and use of CD4 machine in rural and urban settings.

The key research agenda recommended on prevention of STIs are:

Prevention from sexually transmitted infections (STI)
16. What is the treatment efficacy of syndromic management of STIs among key populations (FSW, PWID, MSM/MSW and TG) in Nepal?
17. What is the level of drug resistance of Neisseria Gonorrhoea among STI patients?
18. What is the level of perceived risk and treatment seeking behaviour of different STI among key populations, pregnant women and young people?
19. Why is STI prevention and control programme diluted in the bigger picture of HIV response in Nepal? (policy and system research)
20. What is the use and accessibility of injection Benjathin Penicillin?
21. What is the prevalence of active syphilis among ANC attendees? What is the prevalence of latent syphilis among labour migrants?
22. Does genetics play role in developing drug resistance?
23. What are the pathogens present in STI patients?
24. What is the reference/baseline CD4 value among STI patients?

Harm reduction/needle syringe exchange programme (prevention from injecting equipment)

Though HIV prevalence has declined significantly among PWIDs, still many new infections are being spread through use of non-sterile injecting equipment in Nepal. There are many issues, including the components and coverage of harm reduction services in Nepal, and beyond health needs of PWIDs. Often a high demand for services and non-uniform distribution of services are issues debated. Accurate size of PWIDs, legal issues of drug use and overlapping sexual and injecting risk behaviours, particularly among female drug users are more challenging.

Risk transmission from risk to general population, precise size estimation for resource management, introduction of human rights tools and parameters and broadening the services such as Hepatitis C Vaccine (HCB) and tuberculosis appear as the gaps in terms of HIV research. Thus, the research agenda has clear focus in identifying knowledge gaps regarding effectiveness of drug treatment in HIV prevention, practice and accessibility of Needle Syringe Exchange Programme (NSEP) among adolescents (14-18 years), burden of Hepatitis B and C among PWIDs, situation assessment of female drug users, adequacy of drug control law and policies, effective coverage and accessibility of harm reduction services, individual and structural barriers for accessing quality services, reasons of relapse after rehabilitation treatment of drugs, practice of drug use in cross-border areas and behavioural assessment of clients on OST.

Prevention of HIV from use of blood and blood products in health care settings

The research agenda on prevention of HIV from needle sharing focus on identifying knowledge gaps regarding effectiveness of drug treatment in HIV prevention, practice and accessibility of NSEP among adolescents, burden of Hepatitis B and C among PWID, situation of female drug users, adequacy of drug control law and

policies, individual and structural barriers of effective services, reasons of relapse after rehabilitation and treatment among drug users and PWID, practice of drug use in cross-border areas and access, barriers and adherence to Opioid Substitution Therapy (OST) in Nepal.

Elimination of vertical transmission of HIV (eVT)

Recent data shows about 28% PLHIV are females. HIV can be transmitted from mother-to-child during pregnancy, delivery and breast-feeding. Prevention of Mother-to-Child Transmission (PMTCT) can lower HIV transmission to newborns from 20-45% risk to <2% by using ARVs, safer delivery practices and modified infant feeding practices. As the HIV infection in Nepal is concentrated within key populations at higher risk of HIV, prevention efforts need to focus on women. This includes the biological, behavioural interventions as well as addressing the social and cultural factors.

Transmission through injecting drug use and blood products
25. What is the prevalence of Hepatitis B and C among PWID (male and female) in Nepal?
26. Are prevention and control services for Hep B and C available in formal/informal, public and private health care setting in Nepal (focused for PWID)?
27. What is the access, barrier and adherence to OST among PWID in Nepal (in reference to geography, socio-demographic, economic, culture and health systems)
28. What is the drug use pattern among PWID in Nepal? What is the efficacy of Methadone and Bupenrophine treatment programme (substitution) in Nepal? What is the impact of OST in reducing HIV and other STI, including cost-effectiveness analysis?
29. What are the policy gaps and discrepancies in various drug related policies in Nepal for ensuring decriminalization for PWID and supporting harm reduction?
30. How big is the size of female injecting drug users (FIDU) in Nepal? What are the socio-economic, cultural and service barriers faced by FIDU in Nepal?
31. To what extent condoms are used by the PWID and their sexual partners? What is the HIV prevalence among sex partners of PWID?
32. What is the magnitude of relapse after rehabilitation of drug treatment among PWID over time? Why do they relapse? What is impact of drug treatment programme in reducing HIV prevalence, including associated risk behavior?
33. What is the prevalence of genotype of Hepatitis C and Hepatitis B among key populations? What is the co-infection rate of HIV with Hep B, Hep C and TB among key populations? (Also prevalence of Hepatitis among FSW and MSM/TG)
34. How to improve the knowledge and practice on universal precautions of HIV transmission among health care workers in health care setting?

Nepal started PMTCT services in 2005. Facility and Community Based PMTCT (CB-PMTCT) are the key delivery approaches in Nepal. CB-PMTCT sites have been established at health post and primary health care centres (PHCCs) in districts. The government provides free ARV drugs and follow-up testing for the baby free of cost from 18 months.

Reaching out to all pregnant women living with HIV, particularly in the high prevalence areas and among key populations at higher risk, scaling up of CB-PMTCTs services, improved partner disclosure/ male involvement, reducing individual, social and system related barriers and promoting breastfeeding among women living with HIV are challenging in Nepal. The implementation of four prongs PMTCT services and new guidelines (ART early in pregnancy through postpartum, breast feeding for 12 months) appears to be more challenging. Moreover, improving quality of HIV testing by non-lab personal (CB-PMTCT and at labour and delivery in hospitals), effectiveness of mobile ANC or Sub-Health Post level HIV testing, exploring effective ways of breastfeeding by HIV infected mothers and identifying and promoting women's choices in service access are among the top challenges.

From research point of view, there is dearth of local evidence and salutation to address the challenges mentioned. As a priority for the next four years, research agenda on PMTCT need to focus on use of optimizing the FP services among PLHIV and key populations at higher risk (PMTCT prong II), exploration of effective strategy to implement recent decisions to expand PMTCT to community level across country, maximizing partner involvement in PMTCT, updating providers' knowledge on PMTCT, Option B+ for Nepal (lifelong ART for all positive pregnant women) and timing of PMTCT interventions.

On eVT, the recommended research agenda are:

Elimination of vertical transmission of HIV (eVT)
35. What is the utilization of PMTCT services by key affected populations and/or their spouses?
36. What is the rate of loss-to-follow up with PMTCT? Why there is higher loss-to-follow-up? How to reduce it?
37. What is use of FP services among PLHIV and key populations at higher risk in Nepal? (coverage by FP methods) What is the unmet need of FP among key population groups?
38. What is the average and marginal cost of scaling up of ART/PMTCT from various health facilities and/or by integrating into other programmes such as TB, MNCH?
39. Can we integrate syphilis testing (and Hb) into HIV testing during ANC at community level? What is the effectiveness of HIV and Syphilis testing (dual test) among ANC attendees?
40. What is the effectiveness of Option B+, its benefits and barriers in Nepal? (focus on ARV uptake, follow-up, side effects during pregnancy/breastfeeding)

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Elimination of vertical transmission of HIV (eVT)
41. What are the essentials for scaling up of provider-initiated testing and counseling (PITC) for PMTCT up to sub-health post level in terms of costs, quality and logistics support?
42. What should be strategies for optimizing integration of FP services into HIV prevention and care services (HTC, PMTCT and ART)? What are the cost and outcomes in scaled-up PMTCT services? (including cost-effectiveness analysis between models)
43. Does a PMTCT incentive work to increase access to ARVs in pregnancy/ breastfeeding?
44. Does earlier testing and ARV in pregnancy improve outcomes in Nepal?
45. What are the approaches/strategies being practiced to following-up infants tested by early infant diagnosis (EID)? What are the hindrances for following-up? What are the challenges for rolling out EID service in Nepal?
46. What are the underlining factors for participation and non-participation of partners in HIV testing with ANC attendees (and also in other services of complete PMTCT package)?
47. For the prevention of opportunity infections, what is the efficacy of (a) ART as prophylaxis for PMTCT, and (b) cotrim (Septrin) in Nepal?
48. How can we ensure HIV testing earlier in pregnancy, in Nepal's context of rural setting?

4.2 RESEARCH ON TREATMENT (eVT and ART)

About 26 percent of the total estimated people needing ARV drugs (27,000) are enrolled in ART in Nepal. Exploration of effective roll-out strategies for reaching the unreached from the expanded service sites across country is critical, so as not to miss the ones who need this life supporting health intervention. Loss to follow up, switching regimens with no evidence to do so, poor adherence to therapy and often variability of quality of services are the major issues.

The key challenges for treatment and care at the operation level include (i) ensuring total quality comprehensive HIV care, (ii) up-dating providers on advances in HIV medicine essential for providing care, (iii) minimizing loss to follow-up, (iv) early diagnosis and early start on care and treatment, and (v) pain management for end-of-life or severe pain limited (may need for accessible oral morphine).

Providing ART among special populations such as prisoners, labour migrants, current drug users, PLHIV with mental illness and older adults is challenging. Diagnosing viral failure and changing to appropriate 2nd line regimen, managing ARV side effects with limited options, ensuring and documenting adherence at ART clinic, ARV dispensing and follow-up for patients who live remotely or migrate internationally and improving

accessibility of post exposure prophylaxis (PEP) kits are the other challenges.

Understanding of profile of opportunity infections and co-infection management strategies are limited. Diagnosing TB among PLHIV, controversies of Isoniazid Preventive Therapy (IPT) for PLHIV, lack of information about the non-AIDS-related illnesses and lack of access to treatment of Hepatitis C appears to be more challenging within the complexities.

This document recognizes gaps of information on effective cross referral, drug resistance and side effects of ARV, difficulties of TB-HIV co-infection, common adverse drug reactions (ADR) in Nepali population on ARV, reasons for loss to follow up and catastrophic out of pocket expenses as the priority research gaps.

Therefore, following research agenda are recommended to fulfill the knowledge gaps in HIV treatment in Nepal:

Research questions: Treatment (eVT and ART)
49. What is the effectiveness (including cost-effectiveness) of POC (Point of Care) CD4 machine?
50. What is the positive predictive value (PPV) of POC CD4 machine in rural vs. urban area? To what extent the quality and effectiveness of POC testing differs with the sample referral in rural area?
51. What is the normal baseline CD4 and viral load in the Nepali populations? What is the mean CD4 at ART onset and rate of CD4 increase on ART in Nepal?
52. What is the impact of Highly Active ART (HAART) initiation on sexual behavioural change, so the transmission of HIV?
53. What is the spectrum and frequency of opportunity infections among PLHIV? And if any changes over the period on ART?
54. What are the differences (comparison of) in first line ARV regimens among PLHIV with treatment failure?
55. What the quality of life of PLHIV before and after ART treatment? How the socio-economic life of PLHIV changes after ART?
56. What is the cost and cost-effectiveness of ART in terms of public vs. private providers; peripheral vs. specialized/central hospitals?
57. What are the adoptions required in health care systems of Nepal in implementing new WHO recommendations for ART (treatment as prevention), including cost-effectiveness analysis?
58. Why do PLHIV in Nepal not adhere to ART? (identify barriers for adult and children, male and female, urban/rural and risk groups)
59. What is the survival rate of PLHIV taking ART? (age, sex and key populations)
60. What is the prevalence of non-communicable disease conditions among PLHIV (those who are on ART and those who are yet to initiate ART)?

4.3 RESEARCH ON CARE AND SUPPORT

Care and support are the critical enablers to ensure the quality of life of PLHIV and affected individuals and families. Thus, understanding the barriers for effective interventions and exploring the opportunities to enrich the scope of care and support services are important research priorities.

To address the knowledge gaps in providing good care and support service for HIV and STI infected and affected in the recommended research agenda on care and support revolves around assessment of effectiveness and quality of services, impact and sustainability of services from community care center (CCC) and efficacy of community and home-based care (CHBC) models in Nepal, nutritional status of PLHIV and supplementary options, life course perspective of impacts of HIV, and exploration of more effective, friendly and community system driven care and support services for HIV infected and affected people and their families.

Community Care Centre (CCC)
61. What are the gaps in policy and implementation of CCC? What are the approaches/ strategies to strengthen linkages between CCC and health care services through CHBC? What is the level of community involvement and ownership in CCC?
62. What is the impact of CCC in terms of prevention of HIV, ART adherence, nutritional status growth, OIs reduction, improved psychosocial health of PLHIV and health system strengthening?
63. Has CHBC helped increase ART adherence among PLHIV?
64. What is the nutritional status of PLHIV in Nepal, including availability of adequate nutritional intake in the community? What are the nutritional support schemes available for PLHIV in need? What could be likely sustainable options for providing nutritional support to PLHIV in communities in Nepal?
65. Does integration of CHBC programme with other services (HTC, PMTCT, ART, FP and ANC) increase service coverage? What is the potential of involving FCHV as CHBC workers and what is effectiveness of such involvement, if any? Is volunteer based approach of CHBC more meaningful and sustainable in resource-limited settings?
Impact mitigation
66. What is the health and beyond needs of children affected by AIDS (CABA) in Nepal? What is the level of access of CABA in term of educational, health and related services in Nepal?
67. What is the impact of the HIV-related interventions on CABA in Nepal?
68. What is the level of disclosure and its impact among affected families and children? When and how best to disclose HIV status of children?
69. What is the socio-cultural impact of HIV? What is the economic impact of HIV? What is the impact of HIV on education and accessing health services? What is the demographic impact of HIV? What could be the effective mitigation measures in reducing the impact of HIV in Nepal?
70. What is the impact of discrimination and exclusion of MSM and TG people on prevalence of HIV/STI? How to mitigate discrimination and exclusion of these groups?

4.4 RESEARCH ON HEALTH SYSTEM STRENGTHENING AND COMMUNITY SYSTEM STRENGTHENING

Health System Strengthening

A functional health system is a must for a successful scale-up and utilization of HIV prevention, treatment, care and support services and related products. The health system should strengthen capacity to respond not only to current demands but also to future emerging and reemerging STIs and HIV related problems. For the health system to be effective, it is necessary to have a mechanism to ensure that appropriate inputs and processes are in place and are based on an enabling environment with a strong leadership, strong programme management system, adequate human resource mix, and an efficient procurement and supply system (Ministry of Health and Social Welfare Tanzania, 2012). Moreover, the health system requires strategic information and a sound financial system for the sustainability of its programme.

According to World Health Organization (WHO), health system comprises of all the organizations, institutions and resources that are devoted to producing health actions. The components, structure and instruments used to establish the architecture of a health system is determined by political, institutional and economic considerations. Health systems have a responsibility to improve people's health and to protect them against financial cost of illness and treat them with dignity. The health system has six building blocks, viz. service delivery, health workforce, information, medical products, vaccines and logistics, financing and leadership.

Nepal's health system comprises of modern or allopathic medicine, traditional or Ayurveda medicine, homeopathy, Unani and others-Tibetan or Amchi medicine, acupuncture, Yoga etc. Nepal's national health system consists of regional health system, district health systems - based on primary health care and an integration of preventive health, community health and hospital care. The challenges of Nepal's health system are financial – external dependency for health programme, political instability and retention of health workforce at remote and rural areas, quality of care and infrastructure development. More importantly, lack of research evidences on health and community system that have direct implications on HIV prevention, treatment, care and support seems to be an even bigger challenge. A systematic review conducted during development of the HIV research agenda indicates that only one research publication (0.8%) was obtained out of 115 research papers on health and community system strengthening pertaining to HIV in Nepal.

The recommended research agenda on health and community system strengthening are:

Health system strengthening (HSS)
71. Does synergies and complementariness exist between HIV and other health services? (Linkage between key programs such as TB, Sexual Reproductive Health and Nutrition)?
72. What are the areas to be capacitated on building leadership in national and local response to HIV? What are the needs of capacity development in term of HIV programme management at national and local level?
73. What could be self-sustained financing options for HIV response at local level in Nepal?
74. What are the impacts (likely) of the integration of the HIV-related services to increase coverage and quality of services?
75. How effective is the supply chain of laboratory commodities? What is the quality of available laboratory technologies and strategies for diagnosis and monitoring of HIV, STI, and other opportunistic infections in different populations, including children?
76. What is the technical and economic efficiency of high cost biomedical equipment related to HIV related diagnostics? Value for money?
77. How effective is the current expense made towards the national response to HIV in Nepal? What are the resource needs for HIV response in Nepal? What are the most efficient investment cases for containing HIV epidemic in Nepal, and making population free of HIV in the longer term?
78. Is task redistribution necessary among health work force involved in HIV-related services in Nepal? What are the criteria to be incurred when preparing task shift among staff? What are the likely outcomes of task shifting while providing HIV related services in terms of quality of the serviced delivered, outcomes gained and costs incurred?
79. What is the potential for producing ARV in Nepal? Is it cost-effective?
80. What is the impact of sector wide approaches of delivery of targeted prevention interventions among key populations in health systems?
81. What is the impact of scaling up and/or down of HIV and STI prevention, treatment, care and support services in overall health system strengthening and vice-versa?
82. What is the contribution of various technical working groups (TWG) in strengthening of response to HIV, particular in terms of health systems? How does TWG supports to sustain the national response in the longer term?

Community System Strengthening

Community systems are defined as community-led structures and mechanisms used by community members and community-based organizations and groups to interact, coordinate and deliver their responses to the challenges and needs affecting their communities. This approach promotes the development and sustainability of communities and community organizations and actors, and enables them to contribute to the long-

term sustainability of health and other interventions at the community level. It aims to improve access to and utilization of formal health services and more crucially at increased community engagement.

> *Civil society organizations (CSOs) are vital for community system strengthening (CSS). According to UNAIDS, civil society comprises of AIDS service organizations, groups of people living with HIV and AIDS, youth organizations, women's organization, business, trade unions, professional and scientific organizations, sports organizations, international development NGOs, and a wide spectrum of religious and faith-based organizations both globally and nationally. The core components of CSS are: enabling environments and advocacy, community networks, linkages, partnerships and coordination, resources and capacity building, community activities and service delivery, organizational and leadership strengthening and monitoring, evaluation and planning (UNAIDS, 2011a).*

Nepal Health Sector Programme (NHSP) II has duly recognized the contribution of non-state sector by incorporating HIV as an important element funded through pool funding. It has made specific mention about the roles of NGOs, not-for-profit organizations and engagement of CSOs. At present, representation of key populations at higher risk and networks are involved in policy development (national policy and strategies and programme designing), programme implementation (targeted interventions by national network and NGOs), resource mobilization (proposal development to the Global Fund and other funding agencies) and development of accountability of national response (UNGASS, 2010; UNAIDS, 2011b).

However, strengthening capacity on technical and managerial issues of HIV response, developing and transforming the leadership within the communities, meaningful participation in all key areas/ events related to national response primarily to improve the service quality and coverage and community ownership for generating sustained impact are major areas where research is needed to generate evidence to frame and act on.

To strengthen the community systems and improve ownership and accountability, following research agenda are recommended:

Community System Strengthening (CSS)
83. What is the level of participation (by number and roles) of communities - key populations and PLHIV in HIV response in Nepal? (In terms of policy making, resource planning, programme implementation, monitoring & evaluation and advocacy)
84. What are the threats for social protection of PLHIV and affected communities (CABA, single women, and people with disability) and key populations at higher risk of HIV?
85. What could be the most effective models/strategies for providing care and support services among CABA, single women and people who are differently able in Nepal?
86. What is contribution of national networks (by roles and performance) in HIV response in Nepal? (In terms of policy making, resource planning, programme implementation, monitoring & evaluation and advocacy)
87. What is the status of governance practices by organizations working in HIV prevention to care?
88. How to decentralize the HIV response effectively for improved coverage and quality of services? (DACC, local resource generation, public private partnership, mobilization of female community health volunteers)
89. What are the barriers to accessing/delivering HIV-related services by the community? How to mitigate the barriers?

4.5 STRATEGIC INFORMATION (HIV SURVEILLANCE, PROGRAMME MONITORING, EVALUATION AND RESEARCH)

The strategic information covers HIV surveillance, programme monitoring and evaluation and research.

HIV surveillance

According to UNAIDS, it is imperative to understand the HIV epidemic in order to know the response to it. The HIV surveillance data can be obtained from routine cases reports, regular integrated biological and behavioural surveillance (IBBS) surveys among key populations, routine service data (people on ART, women on PMTCT, HIV tests), special studies such as Nepal Demographic and Health Surveys (NDHS), research (including operational research), and HIV data from modeling (EPP/Spectrum and Asian Epidemic Model). In Nepal, improving the quality of data from routine service delivery and using it for better understanding the epidemic and system capabilities and readiness for providing evidence for actions are the leading gaps.

Programme monitoring and evaluation

The scoping review indentified that data have been collected for monitoring the various interventions related to BCC, HIV testing and counseling, PMTCT, STI, ART, CHBC and CCCs. However, these data are often not adequately analyzed

and used to revise and redesign of the interventions. The current strengths of monitoring systems, tools and capacities are worth appreciating; however more needs to be done for strengthening and mainstreaming the efforts. Collecting quality data, its independent verification, analysis considering the needs for programme improvement and its effective use are the major challenges.

Evaluation is not done robustly; at times, implementers involved can be biased and also cause conflict of interest. Thus, evaluations needs to be urgently improved by ensuring independence and right balance in the evaluation team. Comprehensive evaluation of overall national response, using robust techniques (mix methods, surveys, epidemic modeling, health systems analysis and economic evaluation) and timely evaluation of specific interventions using appropriate methods are strongly recommended.

Research

Although numerous research have been conducted and are also currently underway, only few are planned after discussing with the system structures (NCASC in this case) and thus lack focus to address the real time need for improving response. Moreover, HIV research focusing on key population groups and geographical coverage is lacking.

To fulfill the knowledge gaps in strengthening of monitoring and evaluation, following research agenda are recommended:

Monitoring and evaluation
90. What is the extent of multiple reporting of HIV cases in the national system? What are the factors for multiple testing by clients? How can it be addressed effectively?
91. What is the current state of national M&E systems and framework elements, including capacities, in responding to HIV in Nepal? How can we strengthen national monitoring system for improved accountability?
92. Can we use routine HIV case reports data for understanding the level of HIV epidemic in Nepal (PMTCT data for general population)?
93. What is the extent of HIV cases and service statistics reporting from the private sector to the national M&E system? What are the reasons for poor reporting by the private sector in Nepal? What could be measures for optimizing reporting of HIV services from the private sector?
94. What proportion of HIV interventions have an evaluation/assessment plan? Are these plans implemented? How and how frequently? Who are involved in these evaluations?
95. What extent are research and evaluation findings being used to guide programme and policy decision making? Any updated account?
96. What are the factors affecting quality of data reported in national monitoring system? How to strengthen the data quality assessment exercises at various level? What extend are the data quality improvement recommendations implemented?

4.6 GENDER, HUMAN RIGHTS, GIPA AND SOCIAL PROTECTION

National HIV/AIDS Strategy, 2011-2016 has proposed broader directions to reduce HIV stigma and discrimination and mitigation of impact of HIV (NCASC 2012c). However, it has not spelled adequately the clear working strategies and directions to address the issues related to greater gender equality, protection of human rights, and social protection measures. The lack of issues among key populations at higher risk are inadequate, especially when the existing laws are ensuring equal access to rights services, participation, information and property among all Nepali people.

Few good examples of legal protection measures are rights of transgender people protected by the Nepal Supreme Court; and the right to education for CABA ruling by the court on October 2010.

The research opportunities here would be to find out the most effective strategies to advocate and implement social protection programme for infected and affected people within the national social protection framework, assess social groups at risk of social exclusion and/or discrimination due to HIV and assess impact of HIV on labour populations in their daily socio-economic life.

Following research agenda are recommended to fulfil the knowledge gaps in terms of social protection, human rights, gender equality and greater involvement of PLHIV and communities:

Cross-cutting (Gender equality, greater involvement of PLHIV, social protection)
97. What are the areas and strategies to mainstreaming HIV beyond health sector?
98. What are the effects of legal and policy provisions on HIV prevention, care and support? (For example, non-discrimination of PLHIV, rights of sexual identity, property inheritance rights of women)
99. What are the specific areas and effective strategies for public private partnership (PPP) for HIV prevention, care and support?
100. How are the gender-based discrimination, sexuality and HIV-related human rights violation cases documented and are they reported effectively? How is the legal support system for the victims of such human rights violations?
101. What are the effective approaches/strategies for providing care and support services for returnees and victims of trafficked and gender-based violence (GBV) and intimate partner violence (IPV) in Nepal?
102. How does gender-based violence and child sexual abuse affect the HIV epidemic? What is the linkage between GBV/IPV and HIV transmission across Nepal? Investigate in terms of (a) What did we do and how? (b) What are the benefits and no action/ effect? (c) What/how can we improve by when?

5 CHAPTER

Reporting of Research Finding and its Utiliztaion

5.1 MECHANISM AND METHODS OF REPORTING HIV RESEARCH FINDINGS

A good reporting of research results are always well planned and clearly stated in the research protocol. Approval of research protocol is often evaluated based on the plan for reporting the research findings. Using standard guidelines (Table 3) and procedures are strongly recommended as uniform requirements for reporting of the research results:

Table 3: Standard guidelines for reporting the research results

Guidelines	Description
CONSORT: Consolidated Standards of Reporting Trials	Evidence-based, minimum recommendations for reporting RCTs. Offers a standard way for authors to prepare reports of trial findings, facilitating their complete and transparent reporting, and aiding their critical appraisal and interpretation (25-item checklist).
MOOSE: Meta-analysis of Observational Studies in Epidemiology	Proposal for reporting meta-analyses of observational studies in epidemiology.
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses	Evidence-based minimum set of items for reporting in systematic reviews and meta-analyses. PRISMA has "focused on randomized trials, but ... can also be used as a basis for reporting systematic reviews of other types of research, particularly evaluations of interventions. PRISMA may also be useful for critical appraisal of published systematic reviews, although it is not a quality assessment instrument to gauge the quality of a systematic review."

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Table 3: Standard guidelines for reporting the research results

Guidelines	Description
QUOROM: QUality Of Reporting Of Meta-analyses	Checklist that describes the group's preferred way to present the abstract, introduction, methods, results, and discussion sections of a report of a meta-analysis.
REMARK: REporting recommendations for tumor MARKer prognostic studies	Guidelines for reporting of tumor marker studies.
STARD: STAndards for the Reporting of Diagnostic accuracy	Aims to improve the accuracy and completeness of reporting of studies of diagnostic accuracy, to allow readers to assess the potential for bias in the study (internal validity) and to evaluate its generalizability (25-item checklist).
STREGA: STrengthening the REporting of Genetic Associations	The purpose of the workshop was to develop evidence-based guidelines to promote clear reporting of genetic association studies, and reduce gaps in the evidence regarding potential methodological biases in such studies.
STROBE: STrengthening the Reporting of OBservational studies in Epidemiology	The STROBE Statement is referred to in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals by the International Committee of Medical Journal Editors. http://www.strobe-statement.org/

For more details, please visit: Research Reporting Guidelines and Initiative by Organization (http://www.nlm.nih.gov/services/research_report_guide.html)

Sharing the research results with the government and national technical and implementing partners and communities is strongly recommended to improve country ownership, especially through the followings:

a) Preparing *scientific research reports* (full and summary reports) for use by scientific communities and stakeholders at both national and global levels to contribute to the existing knowledge.
b) *Research fact sheets* to informpolicy makers, key development partners and concerned stakeholders of key findings and recommendations.
c) Prepare relevant *research briefs* in local languages for local organizations and communities

Reporting of research results (positive or negative) is often mandatory and is considered a moral responsibility of research agencies, funding agencies and researchers. The other recommended ways of publishing the research finding are:

- Writing scientific papers to publish in peer-reviewed journals (to inform wider scientific audience and contribute to science). To enrich better access to readers, publishing in open access journals is recommended.
- Writing conference abstracts and presenting paper and poster exhibitions.
- Updating research results on website, including slide share to other relevant social media.

- Other ways of communicating research findings such as use of technology, social media and putting research data/ results in trusted national, regional and global data hubs are encouraged.

5.2 UTILIZATION OF THE RESEARCH FINDINGS FOR POLICY REFORMS AND PROGRAMME IMPROVEMENT

Making data available precedes its utilization. Thus, disseminating the research results is essential. Data use is not automatic. Additional efforts are needed for planned activities to optimize the use of research results for informing policy choice and programme improvement (Parkhurst et. al., 2010).

Following efforts are recommended for improved utilization of research results in Nepal:

- Ensure the necessary quality of research data and its reporting.
- Advocacy for use of research findings through developing and sharing of national research plan and in calendars.
- Create demand for research based data.
- Ensure a system for data transferability to the local context and target groups. Thus, generating and reporting data and research results in compatible templates and systems is important.

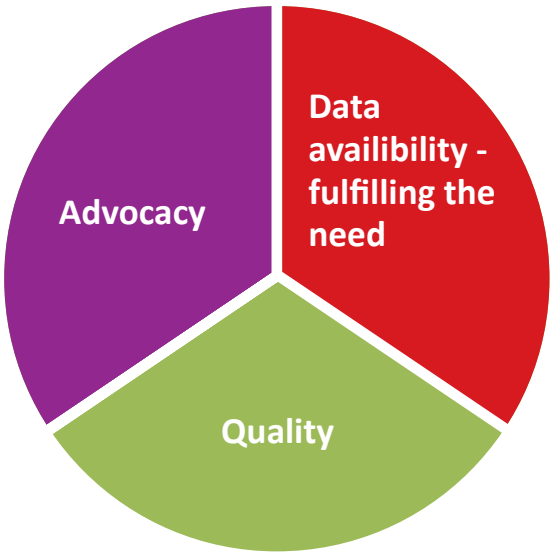

Figure 3: Research finding utilization process

- Build the capacity of individuals and institutions for setting up and strengthening research systems primarily of NHRC, NCASC and its partners.
- Ensure availability of required resources (both human and financial resources) for improved advocacy and utilization of the research results.
- Develop a habit and set a culture of looking for evidence during policy making and programme decisions. For this, setting up of a small technical working team can be critical to explore the research findings and its relevancy for policy reforms and programme improvements.
- Conduct round table discussions (in a small group and among relevant people) about the possible policy and programme implications from the specific and related research findings.

CHAPTER 6

Review of Research Knowledge and Updating National HIV Research Agenda

6.1 REVIEW OF RESEARCH KNOWLEDGE

Periodic review of new developments in HIV and in public health is essential to regularly update the National Research Agenda and ensure its usefulness.

It is thus recommended to conduct systematic review of published and gray literatures under the key themes: (a) HIV policy and systems, (b) epidemiology of HIV and STIs, (c) prevention of HIV and STIs, (d) treatment, care and support (e) health and community system strengthening in 2-3 years interval by trusted agencies and individuals.

6.2 WHY REVIEW AND UPDATE NATIONAL HIV RESEARCH AGENDA

To ensure the research agenda are fulfilling the knowledge gaps for right policy decisions and programme improvements, updating the Research Agenda is essential (Kamali, A, 2010). The review and update of the National HIV Research Agenda is recommended in three years interval.

6.3 HOW TO UPDATE THE NATIONAL HIV RESEARCH AGENDA

National HIV Research Agenda can be updated following the guidance below:

- Form a small technical team for updating National HIV Research Agenda under the leadership of the government (NCASC)
- Organize technical consultations on key thematic issue and discuss with experts, programme people and communities involved
- Seek expert opinions on key research agenda including study population, research settings, research design, methods of data collection, analysis and research utilization (Simpson KM et. al., 2013)
- Draft the updated research agenda
- Share the updated research agenda among small technical team of subject experts
- Revise the research agenda by incorporating the expert comment
- Share the updated research agenda with all stakeholders

CHAPTER 7

Plan of National HIV Research Agenda and Costs

7.1 OPERATIONAL PLAN OF NATIONAL HIV RESEARCH AGENDA FOR NEPAL: JULY 2013 – JULY 2016

This operational plan for National HIV Research Agenda is prepared to reflect upon the overall need for strengthening of the national HIV research, including systems strengthening and implementing specific research agenda to fulfill the knowledge gaps. This plan will also serve as evidence for resource generation.

Table 4: Operational plan of National HIV Research Agenda for Nepal: 2013-2016

SN	Key themes	Estimated Costs (US$)			
		July 2013 - July 2014	July 2014 - July 2015	July 2015 - July 2016	Total (US$)
1	Systems set up and strengthening (infrastructures, institutions, human resources, research library, ethical aspects)	80,842	65,147	71,515	217,504
2	HIV/STI research agenda [a]				
3	Capacity development efforts on HIV/STI research agenda	51,579	44,737	28,947	125,263
4	Linkages and collaborations	4,211	4,211	4,211	12,633
5	Research communication and utilization	14,211	53,158	5,789	73,158
6	Monitoring of research agenda roll outs	4,737	5,211	5,732	15,680
7	Review and updates of research agenda	-	2,632	-	2,632
Total (US$)		**155,580**	**175,096**	**116,194**	**446,870**

Notes:

a Since the research costs may vary for different research design, sampling technique and size, and the research team, the total cost of research is not included here. However, the importance of having total research costs in National HIV Research Agenda is fully acknowledged. Tentatively, a total of US$ 1,587,000 is estimated for core research costs for the entire research agenda (assuming that Nepali research scientists and/or research agencies will be doing the research works.

(1) 1 US dollar is equivalent to 95.00 Nepali Rupees.
(2) Consumables are budgeted as by 10% of annual increment.

Major sources of funding the resources needs are expected from the government, external development partners and private sector.

CHAPTER 8

Coordination and Implementation Framework for National HIV Research Agenda

For the successful implementation of National HIV Research Agenda, it is essential to set up and strengthen co-ordination and implementation arrangements at various levels.

8.1 RESEARCH COORDINATION MECHANISMS AND RESPONSIBILITIES

Establishing and strengthening national and sub-national health system structures is critical for ensuring the effective coordination and implementation of National HIV Research Agenda in Nepal. This will need to focus on understanding of the basics of research methods; recognizing the important research questions/agenda to fulfill the knowledge gaps for programme improvement in terms of effectiveness, coverage and quality; identifying the potential research partners; making enabling environment for research; monitoring the execution of research activities in the field; and using the research finding for informing policies and programme improvement.

Thus, engaging the existing structures and new partners in rolling out the National HIV Research Agenda will entrust mutual ownership and accountability, and simultaneously build research capacity of the related stakeholders at all levels.

8.1.1 National level HIV research coordination and implementation

NCASC under Ministry of Health and Population (MoHP) is leading the overall strategic information system planning, monitoring the execution of related activities being implemented by the government and its partners and reviewing and updating the systems and tools. Thus, similar roles have been defined for fostering the National HIV Research Agenda in Nepal. To ensure technical leadership and coordination, NCASC will set up a small specialized technical research team that consists of experts from the government, technical partners and civil society. This team will primarily be responsible for providing technical backstopping to design, monitor, advocate for use of research results, review and update of the research agenda.

NHRC will provide support to NCASC and its research partners on overall policy guidance primarily for the ethical aspect of all research conducted (NHRC, 2011).

NCASC will play the following research related co-ordination and implementation roles:

- Develop and update the Terms of Reference for research technical team under HIV-strategic information technical working group (HIV-SITWG);
- Strengthen the research collaboration among existing partner and explore potential partners, particularly from the private sector and global and regional research specific agencies and universities;
- Develop HIV and STIs related research technical guidance notes, policy papers, framework and share among the relevant stakeholders;
- Generate research related evidences and share;
- Build capacity of all related stakeholders in the country to conduct HIV and STI related research;
- Mobilize and allocate resources to strengthen national HIV/STI research system and capacities;
- Conduct research needs surveys and update research agenda

8.1.2 Local level research co-ordination and implementation

The existing health system structures at sub-national level such as Regional Health Directorates, District Health Offices, District Public Health Officers and District AIDS Co-ordination Committees will play vital role to monitor the ongoing research works, plan and execute local research agenda, share the relevant research results to fulfill the knowledge gaps in strengthening local response.

Various service delivery structures such as public and private hospitals, medical colleges, primary health care centres, health posts, sub-health post, NGO clinics and communities will play the roles of implementing the field research activities, primarily the operational research activities. They will also develop and execute own priority research activities following the National HIV Research Agenda document (Viergever et. al,. 2010).

8.2 TECHNICAL SUPPORT

This research agenda is envisioned to seek necessary technical support from various technical agencies such as NHRC, WHO, UNAIDS, UNICEF, UNFPA, UNODC, UNFPA, FHI 360, universities, individual experts etc. as and when required. A national HIV-research technical team formed under the leadership of NCASC director will provide hands on technical assistance on the specific agenda and/or questions related to the research. This team will be working independently with technical support from national HIV-SITWG.

8.3 RESEARCH PARTNERSHIP AND ROLES

Research is a multi-disciplinary function; therefore, a truly successful research environment and culture can be set up only with coordinated and shared responsibilities among various public and private agencies and individuals. This research agenda has envisioned implementing through coordinated efforts among key stakeholders.

Specific roles of key stakeholders are specified in Table 5 below.

Table 5: Roles and responsibilities of key stakeholders

Key stakeholders	Possible roles for coordination and implementation of research agenda
Ministry of Health and Population	• Overall policy guidance and high level leadership on HIV and STI research to fulfill the knowledge gaps for informed policy choice and programme improvements
NCASC	• Overall technical and managerial leadership on HIV/AIDS and STI research to fulfill the knowledge gaps for informed policy choice and programme improvements • Generate resources and build technical and managerial capacity of its research partners • Review of science of HIV medicine and public health to identify the critical knowledge gaps • Set research priorities, update the research agenda and share
NHRC	• Provide guidance for ethical standards and support NCASC and its research partners minimum ethical practices
Hospital and service sites	• Effectively execute the planned research activities following the established research protocols and national HIV/AIDS and STI research agenda • Plan and implement research activities of its own in line with the National HIV Research Agenda
RHDs, DHO, DPHOs, NHRC	• Monitoring the ongoing research activities, and develop capacity of local partners for HIV/AIDS and STI research activities
Technical agencies (WHO, UNICEF, UNFPA, UNODC, UNAIDS, FHI 360, Universities, experts)	• Provide needed technical support to rollout of National HIV Research Agenda in the country • Provide support to develop country led research capacities • Provide support to generate resources for robust research works • Advocate for better utilization of research results for public health actions
Other government line ministries	• Coordinate for setting research priorities in cross-cutting issues • Generate resources for implementing research • Monitor (and often participate in joint monitoring) of ongoing research activities
NGOs, CSOs (including networks, local NGOs, CBO)	• NGOs, CSOs are important players in HIV response especially at community level so their research roles are vital, especially in generating quality data as part of community system strengthening • Seek research technical capacity building support from NCASC to effectively execute research activities from these community settings

Contd...

Key stakeholders	Possible roles for coordination and implementation of research agenda
External Development Partners (EDPs) (USAID, World Bank, Global Fund, ADB)	• Provide support to develop country led research capacities • Provide support to generate resources for robust research works • Advocate for better utilization of research results for public health actions
Private Sector, including pharmaceuticals	• Generate technical and financial support for quality research works • Execute relevant basic, clinical/diagnostic and pharmaceutical research following the national priorities • Strengthen partnership with the government for research
Media	• Disseminate HIV and STI related research results released by the NCASC to the general public.

9 CHAPTER

Research Capacity Building Framework

Capacity building of NCASC and its current and potential research partners is essential to effectively implement the National HIV Research Agenda. Moreover, for establishing a sustainable research system and developing research culture among key stakeholders, capacity building efforts are required to robustly plan and implement it. This research agenda has envisioned the capacity development approach for fostering HIV research in Nepal as:

- **Comprehensive:** Incorporating all the major areas of research issues, methods, systems structures and partners.
- **Integrated:** Intergrating with the established structures of the government and fully aligning with them to generate synergy among the partners. Integration with NHRC, EDCD, FHD, CHD, NPHL, hospitals and national universities is a priority.

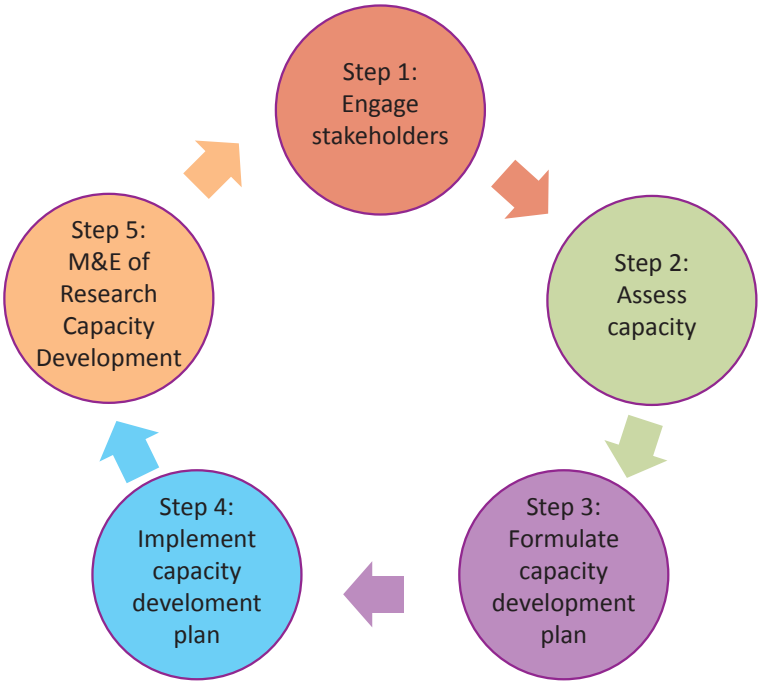

Figure 4: **Research capacity development process**

- **Building on:** Collaboration with NHRC and other partners' efforts is effective and recommended. This will increase wider ownership, develop trust, improve coverage, reduce cost and foster better research environment.
- **Country led and need based:** Government need to lead the entire efforts for building the research capacity; so research can be funded where there is a need.
- **Evidence driven:** Considering the state of existing knowledge on HIV and STI medicine and public health, research priorities are to be set and so the capacity development efforts are to be directed.
- **Sustainable:** Research capacity development activities are required to be planned and executed ensuring the sustainability both from the public and private sectors.

Followings are priority areas for capacity development on research on HIV and STIs:

- Basic trainings on research methodology
- Refresher training on research methods
- Special trainings on systematic review, clinical trials, qualitative studies, health systems and policy research, economic evaluations, research ethics, research communication, writing research papers
- Advanced training on research methods and analysis
- Management of research inventory/ library for example e-library
- Dedicated human resource for health (HRH) at NCASC for moving the research agenda

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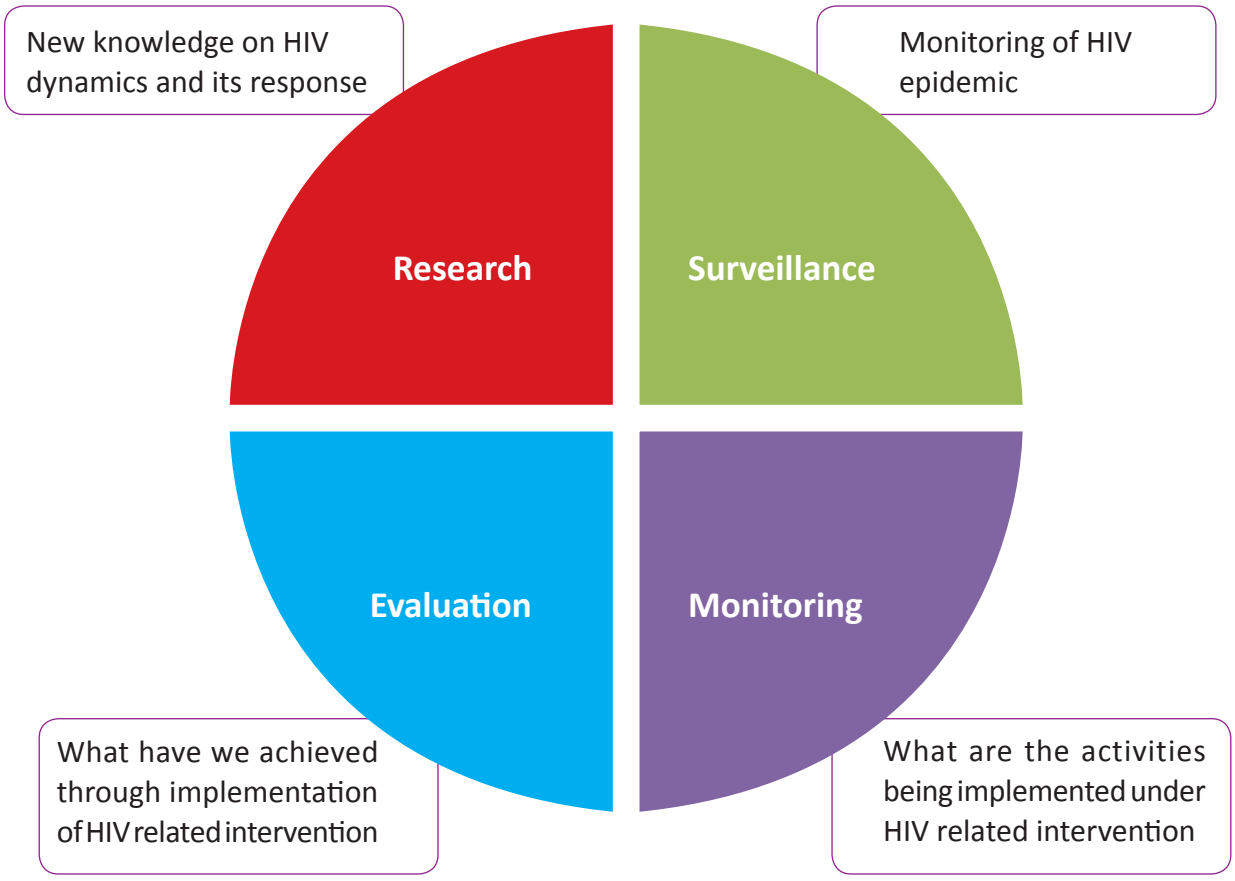
ANNEXURES

ANNEX 1: LINKAGES BETWEEN HIV RESEARCH, SURVEILLANCE, MONITORING AND EVALUATION



ANNEX 2: ETHICS ON HIV RESEARCH

The sensitivity of the research topic and vulnerability of the research participants/ patients calls for careful consideration of the research methods and tools employed, the levels of evidence sought and ethical requirements in order to collect evidence of the highest standard to inform advocacy and policy change.

Following ethical aspects should be taken into consideration while undertaking research on HIV:

- Are human participants required in this research? If yes, mention how many and offer justification
- What is the frequency of the participant's involvement in the research?
- What is the responsibility of the participants?
- Are vulnerable members of the population required for this research? If yes, offer justification?
- Are there any risks involved for the participants? If yes, identify clearly what are the expected risks for the human participants in the research and provide a justification for these risks.
- There is no any apparent risk for the participants in participating in this study.
- Are there any benefits involved for the participants? If yes, identify clearly what are the expected benefits for the participants.
- Is the technical and financial proposal approved/taken ethical clearance from NHRC and given consent by the Research Technical Team at NCASC?
- How do you take informed consent from the research participants? (written consent a must)
- Who is responsible for taking informed consent?
- Have you taken approval letter from NHRC for research data collection in the national, regional, district and local levels?
- Are local bodies, communities informed about the research?
- How do you share/disseminate the research findings to the participants and to the wider stakeholders?

Statements required in the Informed Consent Form should include:

- A statement that the human participants can withdraw from the study at any time without giving reason and without fear.
- State clearly how the participants can opt out the study.
- A statement guaranteeing the confidentiality of the research participants.
- If required, a statement on any compensation that might be given to the research participant and or their community.
- A statement indicating that the participant has understood all the information in the consent form and is willing to volunteer/participate in the research.
- Signature space for the research participants, a witness, and the date

(Informed Consent form should be developed and submitted in English and in the language appropriate to the research participants)

Note:
All the heath research protocols are required to get ethical approval from Nepal Health Research Council (NHRC). Please visit National Ethical Guidelines for Health Research in Nepal and standard operating procedures, Kathmandu, Nepal.

Available at: http://www.nhrc.org.np/guidelines/National_Ethical_Guidelines.pdf.

ANNEX 3: TOOL FOR HIV RESEARCH AGENDA PRIORITIZATION

Categories of 1, 2 and 3 carried out but information is not available

4 = Very few studies have been carried out in this area

5 = No studies have been carried out in this area

FEASIBILITY

1 = Extremely difficult

2 = Difficult

3 = Moderate feasibility

4 = Feasible

5 = Highly feasible

POLITICAL ACCEPTABILITY

1 = Politically unacceptable

2 = Low level of political acceptability

3 = Moderate level of political acceptability

4 = Reasonable level of political acceptability

5 = High level of political acceptability

RELEVANCE

1 = Not relevant

2 = Of little Relevance

3 = Relevant but not important

4 = Relevant

5 = Highly relevant

AVOIDANCE OF DUPLICATION

1 = Several studies exist and information is available

2 = Some studies exist

3 = Some studies have been carried out but information is not available

4 = Very few studies have been carried out in this area

5 = No studies have been carried out in this area

APPLICABILITY

1 = Not applicable

2 = Low applicability

3 = Moderate applicability

4 = Reasonable applicability

5 = Highly applicable

ETHICAL ACCEPTABILITY

1 = Ethically unacceptable

2 = Low ethical acceptability

3 = Moderate ethical acceptability

4 = Ethically acceptable

5 = High ethical acceptability

GENDER ISSUES

1 = No consideration to gender

2 = Little consideration to gender

3 = Moderate consideration to gender

4 = Reasonable consideration to gender

5 = High consideration to gender

NEED FOR NEW KNOWLEDGE IN THIS AREA

1 = No need for new knowledge in this area

2 = Little need for new knowledge in this area

3 = Moderate need for new knowledge in this area

4 = Reasonable need for new knowledge in this area

5 = High need for new knowledge in this area

For Further Information Please Contact:

National Centre for AIDS and STD Control
Teku, Kathmandu
Phone: +977-1-4261653, 4362753, 4258219
Email: info@ncasc.gov.np
Fax: +977-1-4261406
Website: www.ncasc.gov.np