NATIONAL AIDS CONTROL ORGANIZATION Strategic Information Management Unit

## DRAFT REPORT OF TECHNICAL WORKING GROUP ON RESEARCH, EVALUATION, & KNOWLEDGE MANAGEMENT FOR NACP-IV PLANNING

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This report is a consolidation of the topics outlined in the TOR for the Sub Group on Research, Evaluation and Knowledge Management under the SIMU Working Groups for NACP-IV

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## **Progress in HIV / AIDS Research and Key**

Several research studies in the broad realm of HIV/AIDS have been conducted during the NACP-III. As always, many of these studies, in diverse disciplines, i.e. epidemiological, clinical, behavioral and social sciences have contributed to a much better understanding of the HIV epidemic in the country. The plans and policies laid down during NACP-III have provided a great impetus to NACO's role as the facilitator and promoter of HIV/AIDS research in the country.

What Worked in NACP III: The notable initiatives undertaken under NACO's leadership during NACP III are listed below.

- Constitution of the Technical Resource Group (TRG) on Research Evaluation and NACO Ethics Committee (EC) as the apex oversight bodies for research and evaluation priorities in HIV and granting ethical clearance respectively.
- Setting priority areas for Operational Research and Evaluation Studies in HIV.
- Development of Research Protocols.
- Reviewing, processing and approving research proposals.
- Establishing the Network of Indian Institutions for HIV/AIDS Research (NIHAR) consortium for facilitating and undertaking Operations Research and Evaluation studies in epidemiological, behavioural, social and bio-medical disciplines.
- Initiatives for building human resource capacities through:
  - National and regional workshops on subjects including ethics, operations research in PPTCT and pediatric HIV care and treatment, the current challenges and perspectives in HIV-AIDS research.
  - Awarding research fellowships under the NACO Research Fellowship Scheme (NRFS) for MD/ M.Phil/ Ph.D students.
- Dissemination of HIV research and evaluation studies at the National Conference on HIV/AIDS Research in 2011.

The NACP IV presents opportunity for overcoming existing challenges to research and evaluation. The challenges listed below are presented as two sub-components though the points are not mutually exclusive.

- Operations Research Studies
  - Scope for strengthening conceptual design and methodology for research studies. More accurate formulation of research questions—considering existing literature and studies undertaken—during the planning stage would enable firstly, clearer identification of the programme implementation problem; the underlying reasons for the identified problem; and, potential solutions for improving or overcoming the problem.
  - Operations research has a significant role in providing answers and testing possible solutions to the identified problem or study area. Most research, however, currently remains focused on processes or providing greater evidence to the problem area rather than identifying or

recommending tangible solutions. Thus further focus on identification of mechanisms for providing tangible solutions to the problem statement is required.

- More consideration is required on the follow-through phase wherein results and recommendations emerging from studies are disseminated to stakeholders and NACO.
- Stronger networking and collaboration between research institutes, universities, and Government ministries is required.
- Evaluation Studies
  - HIV prevention programmes are increasingly complex, multi-component and context-specific. Evaluating them as such requires sufficient formative research to be undertaken on the identified problem area, formulation of a robust design or methodology and explicit impact pathway for the study to yield conclusive and significant results.
  - The underlying behavioural theories leading to multiple behaviour changes and ultimately impact are difficult to assess. As such, ensuring sufficient data for evaluation is essential. Access to baseline data and other programme monitoring data collated during the intervention—that is subject of the evaluation study—would facilitate this.
  - Many services or interventions aim on affecting HIV risk factors and or vulnerabilities rather than averting HIV infections directly. Such a scenario may warrant need for an assessment of intermediate outcomes—that is, behavioural, social and structural changes—vis-à-vis changes in HIV incidence.

#### Gaps & Recommendations:

- 1. Quality of Research: Many studies received at NACO are rejected either because they are of no relevance to the programme or are simply written with the intent of publication in a research journal. There is a need to enhance the quality of HIV/AIDS research in the country. The need of the hour is research studies which ensure guidance to the programme and provide comprehensive insight into the key requirements and needs which the programme must prioritize to address. Research studies must guide the programme about the ways in which their outcomes can address the various interventions.
- 2. Need to conduct operations research on reducing vulnerabilities of HIV for different population groups. There is a need to conduct decisive studies focusing the vulnerable populations and newer populations who maybe at high risk for HIV within the given epidemic scenario. Studies focusing not only on the 'risks', but also on 'vulnerabilities' of the community should be conducted.
- **3.** How to innovate and integrate. Innovation and integration in research in HIV/AIDS must be enunciated and incorporated. There is a need to exploit the potentials of the cell phone era and utilization of newer knowledge and information technology for addressing programme needs. Studies suggesting ways to attempt integration and the research initiatives required for the same can be undertaken.
- 4. Need to develop comprehensive guidelines for submitting research proposals and guiding researchers about the procedures of proposal evaluation at NACO. Comprehensive guidelines

informing researchers about the proposal evaluation methodology & various research activities undertaken at NACO should be developed to streamline procedural lacunae in understanding NACO norms in this field.

- 5. Need to ensure greater and regular dissemination of Research outputs. The National Conference on HIV/AIDS Research (at the National Level) must be held once every two years. Moreover, regular dissemination workshops can also be held at the various SACs and other State agencies.
- 6. Need to conduct studies which evaluate the impact of prevention programmes and costeffective analyses. Such studies will help the programme in understanding existing loopholes and identifying newer strategies. These studies will also provide the programme specific directives.
- 7. Need to explore greater involvement of the private sector in the purview of HIV/AIDS Research. Utilization of private health care providers into the programme and the mainstreaming. Public-Private partnerships to evaluate quality of care. Research studies that can suggest ways in which Private corporate sector to deal with the drivers of the epidemic.
- **8. HIV incidence as an important Research area.** Incidence studies both at the national & state (SACs) levels will provide valuable inputs to the programme.
- **9.** Incorporation of KNOWLEDGE HUB as the central repository of all the research studies conducted across the country. The Knowledge Hub should serve as an important tool for all researchers and provide them up-to-date research data and information.
- 10. Need to analyze and update the existing <u>List of Priority Research Areas</u> to address the goals and motives of NACP-IV.

## Strategy, Approach & Mechanisms for promoting Research in HIV/AIDS

Focus for NACP-IV: Accelerating the reversal process and ensure integration of the next program response

**Over all guidance:** NACP-IV seeks to consolidate the gains of NACP-III and learn from the lessons of the previous program implementation. It aspires to further strengthen and decentralize the program management capacities to state and other district level in particular. The focus will remain as prevention oriented plan with adequate coverage of HIV care in the context of concentrated epidemic situation in India.

The cross cutting issues which require focus in all WG discussions are

- 1. innovation
- 2. integration and convergence
- 3. capacity building
- 4. GIPA
- 5. Gender

#### **Current status**

Access the current status of ICV/AISD research covering all the streams - clinical ands bio medical, behavioral, social and operational. Identify gaps in HIV/AIDS research to be addressed in the context of National AIDS prevention and control policy as well as key objectives of NACP-IV:

During NACP-III the research agenda for NACO was to position NACO as the leading national body, promoting and coordinating research on HIV/AIDS nationally through; developing guidelines, norms and standards for undertaking HIV/AIDS research; partnerships and networking with multiple stakeholders and established national academic and other research institutions; supporting capacity building in social, clinical & biomedical, basic and operational research related to HIV/AIDS and allied subjects; functioning as the central repository of all relevant resources, research documents and data base on HIV/AIDS in the country; and ensuring translation of research outputs into programmatic action and policy formulation.

#### Gaps:

The gap in the agenda is in context of the discussions held in the working group meeting which are:

- 1. Need for more involvement of states and NGOs in the operation research agenda development and implementation and the need for developing mechanisms to ensure it
- 2. There are multiple data bases and web based systems developed by multiple agencies which needs to be gathered to provide more comprehensive technical and scientific information
- 3. Information collected in the existing systems of, surveillance, estimations, CMIS, Field reports, reviews, evaluations and community voices to be collated in a single platform with

translation of the information to reach to suit to the understanding of relevant stakeholders.

- 4. Expanding the scope and responsibility of NIHAR institutions
- 5. Need to incorporate the existing institutional mechanisms available in other related system to explore the scope of integration and proportion of HIV related research for example: availability of IDSP system and epidemiologist at district level all over the country. (Director IDSP as agreed in principle to extend his support recently). DBT is involved in HIV research through INDO- US collaboration and the scope of sharing the information and incorporating the results in the national data base would help the over all knowledge systems. The scope of involving NHSRC, SHSRC, SIHFW, NSSO, SCTIMST, IPH, IIPHs etc needs to be looked into.

#### **Current Activity:**

To implement the agenda NACO under took the process of Setting Priority Areas for Evaluation & Operational Research (E&OR) in HIV/AIDS & Development of Research Protocols; Encouraging, Processing & approving Research Proposals; Coordinating activities of Technical Resource Group (TRG) on Research & Development and NACO Ethics Committee(EC); Dissemination of HIV/AIDS Research Outcomes, setting up the Network of Indian Institution for HIV/AIDS Research (NIIHAR) and under tool capacity Building Initiatives including NACO Research Fellowship Scheme (NRFS) for MD/ M.Phil/ Ph.D students.

#### Gaps:

- 1. Need for revisiting the scope of decentralizing the system already developed by NACO to state or regional platforms.
- 2. Integration of members from SACS, community and other relevant stakeholders like local NGO, research institutions in the NIHAR ethics committees, regional/ state level platforms
- 3. Revisiting the NRFS eligibility criteria by including people working in the field of HIV program implementation, encouraging gender equity

#### **Research Agenda for NACP-IV:**

During NACP-III, The research agenda for NACO was to position NACO as the leading national body, promoting, facilitating and financing research on HIV/AIDS nationally through decentralized manner by;

- 1. Encouraging development of State/ regional research platforms including state AIDS control Society and expanded NIHAR institutions
- Encouraging participation of other sectors/ departments and State bodies like IDSP, NHSRC, SHSRC, SIHFW, NSSO, SCTIMST, IPH, IIPHs, IIT, IIIT etc, in HIV research by including them in the NIHAR institutions
- 3. Expanding the number and scope of NIHAR institutes by including Non governmental institutes.
- Continue supporting capacity building in social, clinical & biomedical, basic and operational research related to HIV/AIDS and allied subjects directly and through the expanded network of NIHAR institutions

5. Functioning as the central repository of relevant research systems/documents (Surveillance, estimations, SIMS, field reports, annual reports, web based systems of NACO and other stakeholders in the field of HIV and Health) and data base on HIV/AIDS in the country, with mechanisms of periodic dissemination of information to, policy makers, general public and key stakeholders to ensure translation of research outputs into programmatic action and policy formulation

Suggest mechanisms to promote strong operations research on key areas that can support and guide the program implementation from time to time: as NACO has already developed a robust mechanism of priority setting through consultation at national level, other stakeholders and TRG members, similar mechanism , Technical Advisory group (TAG) can be developed at state/ regional level with inclusion of technically competent members of NGO, local research institutions, IDPS, SIHFW , SHSRC, Medical colleges and key departments of local university, SACS representatives and NIHAR members etc. These local TRG can review the proposals submitted to them thus take appropriate action before sending to the Ethics Committee. These Ethics committees may add community representatives and PLHIV community.

**Recommend a system for identifying priority research areas from time to time , inclusive of all stakeholders:** The TAG at state/regional level may identify a point person to coordinate the activities of the TAG and have access the database developed by NACO and other intuitions to provide more information to the TAG. All the priority research areas selected by TAG may be shared with national TRG and other TAGs to look for scope of multicenter studies, avoid duplicating studies and also can draw attention of resource members of national pool if resources are required. These state or regional level TAG and ethics committee can review the proposals bimonthly basis and forward to NACO depending on the status of the study (Fast Track or none fact track).

**Priority settings** can be done by keeping the local context, relevance, duration, nature and funding support for the study.

- i. Fast track: Studies of short duration with out major technical, no- ethical issues and wither which do not need much of financial support or no financial support may be fast tracked to National Ethics Committee for approval. This will include most of the student research and research scope available with in program mandate but will add technical rigor and ethical values
- ii. Multicentre studies and studies of complex methodological issues, with long duration, involving human subjects and were close observation needs to be done for both technical and ethical side can be revisited in detail as the routine process, as set- up by NACO in NACP-III in the state/ regional level.

# Explore how large number of research institutions in the country can be motivated to participate in the HIV/AIDS related research in collaboration with NACO and recommend approaches to strengthen institutional capacities in HIV/AIDS research:

Leveraging on existing systems: Many of the institutions have either Institutional review boards or ethics committees, attempt can be made to leverage on the existing systems of ethics committee. Any other resource available with the institutions like data analysis, and others should also be leveraged upon.

As institutions consist of not only faculty but also students the strategy may look in to involving both of them. Inviting the institutions participation in the regional and state level TAG and ethics committee will improve in motivating the faculty of the institutions.

Providing information/ access to the national data base of as per the knowledge management strategy of national program, boarding the scope of research fellowship- eligibility criteria, providing a scope to the emerging or potential researchers the scope of TAG and Ethics committee, publishing the research outcomes in the national knowledge and recognizing these researches at local and national level with certification, retaining them in the program by involving them as resources for program implementation/ training and those who have finished multiple studies giving them a scope to graduate from researchers to guide of young researches may be considered.

The national level capacity building efforts undertaken under NACO-III needs to be expanded to the new institutions which will be joining the expanded NIHAR and participate in state/ regional level mechanisms. As some development partners and international and national institutions have undertaken specific trainings for research components the same can be linked to the new and emerging institutions / research fellows / researches to improve their skills and quality.

#### Develop strategic approach on the subject for NACO-IV:

Building on the gains made so far in terms of systems like TAG and Ethics committee and NIHAR and the scope of decentralization along with expansion of research work. The inputs for research work may include population, health systems, and information systems, bio medical, behavioral and local factors that can influence the service delivery, management and policy making process. As health is a state subject and increasing number of states in recent past have formulated their state health policy and many are in making; research outputs from the HIV program can be feed in to the policy making process at state and central level.

Keeping in view the focus on accelerating reversal process and integration as key strategic areas, the approach can look in to new infections and deaths related to HIV in different sub populations and population as whole and look in to health and other systems integration with HIV program as key initial areas. An annual review of the process of research and development by NACO, on the basis of inputs from TAGs and TRG can set strategic areas of research for every year for over all country and state specific research needs. This list of areas can be updated or revisited on yearly basis.

#### Modified Research Fellowship criteria:

Eligibility Criteria: Students enrolled for MD, MPH, /M.Phil/PhD in relevant disciplines; Upper Age limit: 35 years or people working in health and allied systems (Public, Private, NGO) with post graduation in any discipline and experience of minimum of five years with age limit of 40 years.

Component of Grant: 40 fellowships awarded every year.

Grant Range: Rs. 30,000 – 1.5 lakhs.

Procedure for Approving Proposals: Programmatic or Academic Record, Quality of Protocol, programmatic/ Academic Achievements of candidate

## **Knowledge Management and Translation**

#### Introduction:

Under NACP-IV, it is envisaged to have an overarching Knowledge Management strategy that encompasses all the different programme areas. Apart from traditional Knowledge Management principles, the strategy will emphasize on Knowledge Translation as an important element of policy making and programme management at all levels. While Knowledge Management looks at systematic collection, synthesis, and dissemination of Knowledge in its various forms, the element of Knowledge Translation will help making the link between Knowledge and action.

While Knowledge Management looks at systematic collection, synthesis, and dissemination of Knowledge in its various forms, the element of Knowledge Translation remains of great importance as it will help to bridge the gap between Knowledge and Action.

The national HIV programme, at its fourth phase, would take tremendous advantage from capitalizing on the knowledge generated and accumulated so far from more than a decade of implementation and experience –among the population, the communities, the programme managers and the policy makers and from continuous information being generated and updated from the programme monitoring, surveillance, and research.

There are two main categories of knowledge, as they are generated in a different way and lay among different stakeholders: the knowledge generated by the programme and made available to NACO (Codified and explicit knowledge) and the knowledge generated by the communities and the practitioners from experience and practice (experiential and practitioner knowledge). Any system for knowledge management should look at ways to capitalize on both types of knowledge, and create ways for collection, cross fertilization and sharing of knowledge among between communities/ practitioners and programme managers and policy makers. This can be represented in the following diagram:



There are four main components of Knowledge Management. These are equally important and need all to be simultaneously in place to ensure effective knowledge management and translation that would be beneficial for the programme. These four components are as follows:

- a. Creation of Knowledge,
- b. Knowledge collection and storage,
- c. Sharing of knowledge (dissemination).
- d. Translation of Knowledge

#### Situation Analysis for each of the components, and recommended strategies:

#### a. Creation of knowledge:

India has very strong systems for generating various types of **data** from programme monitoring, surveillance, research and programme evaluation. This information is used regularly for programme management and decision making. The amount of data generated and made available to NACO is enormous in size and importance and variety. There is a large data base on programme monitoring regularly updated through CMIS / SIMS, a very strong surveillance system that provides regular update on epidemiological and vulnerability situation in different geographic areas of the country and among different populations, and an existing system that supports good quality research and programme evaluation.

However, All these sets of data are not regularly transformed into strategic knowledge that can be translated into actionable policies and programmatic decisions.

To understand more the process, the graphic below represents the process and steps to knowledge creation as it can be applied to the data sets available to NACO:



With NACO's Strategic Information Management Unit in place, and other M&E officers available in other programme divisions, and with the efforts of strengthening the existing information systems (SIMS), the initial three steps at the base of the pyramid are well taken in place (Collecting, Organizing and summarizing data). However, while several initiatives do exist, comprehensive and scientific data analysis and synthesis is rarely done in a way that would increase the knowledge capital. In addition the existence of separate M&E officers at programme divisions not allowing for cross-programme data analysis, the workload on officers in SIMU for managing the system rarely allows for the opportunity to do deep and comprehensive data analysis. Initiatives like district profiling using data triangulation method are excellent examples of ways to create strategic knowledge, but the amount of time taken for doing the analysis at national levels (not taking in consideration the effort made at sub-national levels for cleaning and summarizing the data) was too long and discontinuous.

#### **Recommended Strategies:**

- There is a strong need to reinforce the capacities for data analyzing and synthesis towards decision making, NACP IV provides the opportunity to overcome this challenge by creating a dedicated unit for data analysis and synthesis and compilation of other types of knowledge, this unit would also be in charge of translating the knowledge into actionable recommendations and policy briefs as required.
- Establish a scientific group, with envolvement of key partners (institutes) and stakeholders, to advise on the various methods used for data analysis (different types of modeling...etc.) and advise on the technical and scientific approach for data analysis to make sure the knowledge used for decision making is on strong scientific basis.
- Establish regular processes for identifying strategic knowledge gaps in form of questions that can be answered through further analysis of existing data, and establish systems for discussion and feedback on the results form data analysis and how it could be made useful for decision making.
- Encourage use of data triangulation methodologies using data from different sources to provide answers to strategic questions. Data triangulation endeavors can be done quickly and efficiently when appropriate process is followed for developing questions and finding answers.

#### b. Knowledge collection, documentation and storage

While the first section on creation of knowledge focuses mainly on creating knowledge from the data generated by and made available to the programme (NACO / SACS), this section is more about collecting and documenting the knowledge generated by different categories of population, or from other partners, Like other donor / implementing agencies, programme practitioners, clients and services users...etc. In addition to the need for building up the knowledge from the regular sources of data available to NACO, the knowledge capital needs to be reinforced through collection, synthesis, and dissemination of experimental knowledge, which results from implementation experience.

Apart from being consumers of knowledge, the different segments of users and programme beneficiaries are also able to contribute towards knowledge generation in some way or the other. Hence, the tremendous potential of people affected by HIV, the communities and grassroots field

workers will be a great strength in terms of the value of their inputs and feedback to the programme which is often classified as Tacit Knowledge or Experiential Knowledge.

Different systems are in place to provide opportunity to share experiences and discuss knowledge, some of them are based on electronic platforms like the Solution Exchange discussion forum, the NGO gateway...etc. Some others use different formal or informal channels for experience sharing. However, most of these systems are not set up in a way to allow for comprehensive documentation and collection of knowledge, and more importantly they operate outside of the national programme and rarely interact with it. This situation leads to missed opportunities for gathering and documenting good experiential and practical knowledge, and does not permit the programme to fully benefit from it.

#### <u>Strategies:</u>

- The NACP IV should provide the opportunity to systemize documentation and collection of knowledge, using different types of Information Technology, and should allow for more regular cross feed-back between the programme management, the programme implementation, the beneficiaries and the community levels. Various strategies for this will be developed further.
- There should be also established guidelines and processes for documenting best practices in a way that can be useful for learning / skills building, and for replication as appropriate.

#### c. Knowledge sharing and dissemination

Different users have different types of needs for knowledge. Depending on their role in the programme and other factors, the knowledge needs of different groups of people would be different. For example, the knowledge needs of a scientist, a person living with HIV, and a member of parliament would be different even if it is related to a single topic – for example, Antiretroviral Therapy (ART). While a scientist would be looking for research evidence, a person living with HIV might be looking for practical tips, and a member of parliament would need something which can inform public policy.

The dissemination and sharing of knowledge should consider the different needs of the various types of the users and tailored to be useful for them and should take different forms of passive and active dissemination.

Some of the central best practices undertaken during NACP III for information dissemination include the following:

- Access to programme data: The comprehensive data generated and available under CMIS on various programme indicators were available to stakeholders and implementers whenever it was sought by the latter. A due process was adhered to for ensuring data quality. Following submission of a formal application by the stakeholder / implementer, the request was forwarded by SIMU to programme division who validated the data pulled-up from CMIS. As final step, the required data was released by SIMU.
- CMIS bulletins: Under the leadership of SIMU unit; comprehensive quarterly / bi-annual / annual CMIS bulletins are made available includes analysis of programme indicators including for keys trends for TI; treatment, care and support; blood banks and blood safety; PMTCT; STI and ICTC etc.

These bulletins are to the advantage of planners, programmers and implementers for informed decision making as they aim to advance forward in achieving targeted results.

- Annual reports by the Department of AIDS Control (MoHFW): A pertinent programme monitoring document providing an update on key initiates undertaken by NACO and with partners during the previous annual year across all programme units along with short-term results achieved, if any. Based on most recent available routine and non-routine data; it provides a national-level overview on India's progression in achieving targets set under the NACP III policy and strategic plan to highlight any gap areas that require strengthening.
- Periodic updating of the NACO website and dissemination of newsletters, reports and data generated under NACO through this e-forum

Different publications and reports developed by NACO and partners are regularly disseminated among various stakeholders, and most of them are available in the NACO website. However, there is no systematic way for regular dissemination of programme data that can be for public use, and the few research articles that are published, are usually so in peer reviewed journals which are not accessible by everybody. This leads to different users referring most of the time to information that is either outdated or incomplete, and spend large amount of effort and time to get information that should normally be readily accessible, especially when it is generated using public funds.

Information and Communication Technologies (ICTs) can a play a catalytic role in improving the capacity of people in becoming efficient users of and contributors to knowledge. Apart from passive dissemination methods like website, knowledge hub, data-centre, e libraries, electronic newsletters and publications, dynamic initiatives like discussion forums, e-learning tools, and tele-health networks can be used to serve this purpose. All these tools can be placed together in the same platform for easy access to users.

There a plan to develop a Knowledge Hub (KH) for NACO in a form of a web site containing various applications and tools for passive and active dissemination, accumulation and sharing of knowledge. This platform can be central in the overall process of knowledge management as it will allow for sharing knowledge with al types of users beyond NACO's programme managers, and would help in knowledge translation to action. It is important to mention here that with the plethora of platforms (Data hubs – regional and sub-national data hubs, knowledge and training platforms ....) being developed by various stakeholders, it is important to ensure strong linkages (both virtual and technical) with the important ones for cross –feeding of information, and explore possibilities for harmonizing a one large platform for knowledge dissemination on HIV in India.

It is recommended that this KH be continuously developed and reinforced with additional tools for better knowledge management.

#### Recommended strategies:

• Establish various processes and channels for active and passive knowledge sharing and dissemination. Including seminars and technical discussions on various aspects of the programme or the situation of the epidemic with participation of different segments of the population

(communities, practitioners, NGOs, Programme managers, politicians...etc). These can be done also at state and even district levels.

- Develop a knowledge hub (KH) for NACO, linked to the NACO website, which can serve as a place holder for various tools for knowledge sharing. This KH should contain tools for presenting programmatic and epidemiological database with various forms of data presentation and synthesizing, electronic libraries, capacity building and e-learning tools, and discussion forums...etc.
- Ensure that the KH is regularly updated with the most recent data and reports, and is continuously strengthened with additional tools that would serve the needs of various users of knowledge.
- Strengthen the linkages with the Press and Media as they are an important vehicle for knowledge dissemination. The Media need to have their capacities built for proper understanding of technical aspects of the knowledge they are disseminating, and to ensure that the knowledge is disseminate in the right way to the right audience.

#### d. Translation of Knowledge

After knowledge is created and made available to the various types of users at described above, the whole process of knowledge management is only meaningful when this knowledge is translated into actionable decisions and policy orientation. Some knowledge is being very well used for programme management, and the India's programme is known for being strongly evidence based. However, not all the knowledge is being used optimally, and in most cases, the research studies aim for publishing and do not provide actionable directives for the programme, and limit themselves to "understanding the situation" and not to answering a question like " what needs to be done?". In other words, limiting to the exploratory and descriptive analysis, and not going to the inferential and prospective analysis.

The dichotomy is that whilst policy makers, funding agencies – and more importantly sub-national grass root level programmers and implementers – recognize the need for translating knowledge to practice, there is a knowledge to translation gap.

In order to overcome these gaps and dichotomies, the following strategies can be recommended.

#### <u>Recommended strategies:</u>

- Adapt the guidelines and directives to the context of use. This is very pertinent, for example, to the Targeted Interventions programme. Although guidelines provide evidence in a more usable form for practitioners and health settings than a plethora of primary studies, an important and additional necessary step is the adaptation of the guidelines to the context of use.
- Ensure that all research an evaluation studies, should not only consider the "understanding the situation", but should focus more to providing clear answers to "what needs to be done". This criteria can be added to the list of criteria for clearing and approving research projects.
- Ensure that all analytic reports developed by the data analysis team recommended above and by other key partners should include a thorough process of assessing various options for actions or directives that are well justified not only by existing data, but also, by prospective analysis of implications of different strategies or decisions made.

## Strategy, Approach & Mechanisms for Evaluation of Programme Interventions and Impact Assessment

#### Background

National AIDS Control Program of India has traveled a long distance and achieved several milestones during last one and half decades, particularly during the NACP-III. The key achievements of the NACP-III include a substantial coverage of FSWs, MSM and IDUs through TIs, scale up of counseling and testing services (74% of 22 million program target), proper management of STIs (15 million STI episodes managed in partnership with NRHM), massive distribution of condoms (5 billion condoms distributed/sold) and rapid scale up of ART services- nearly 400,000 PLHAs are on ART in 2011. On the monitoring and evaluation front, the national program made significant progress during last few years. A comprehensive strategic information management system was being rolled out recently, program data was effectively used for triangulation and planning purposes and operations research studies were conducted by the implementing partners. There was a major expansion of the HIV sentinel surveillance during the NACP-III. Presently the total number of sentinel sites is 1361, nearly 700% increase in just 12 years (176 in 1998). Two rounds of national behavioral surveillance (BSS) survey were carried out in 2001 and 2006. The third round of BSS was conducted in 2009 in six states including Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Uttar Pradesh and Manipur. An impact assessment of the TIs was undertaken by NACO.

The proposed key objectives of the NACP-IV are:

- To reduce total number of new cases (incidence) by 80% in high prevalent states and by 60% in low prevalent states
- To provide comprehensive care and treatment to all persons living with HIV/AIDS

#### **Evaluation of program interventions**

Evaluation is intended to build on the findings from monitoring and provide additional information on the relevance and appropriateness, reach and coverage, quality, efficiency, effectiveness, and efficacy of specific programs. It is important to use our resources wisely, so the extent and costs of evaluation activities should be commensurate to the size, reach and cost of the program.

A "program logic model" or "program impact pathway" should be constructed for the NACP-IV drawing on existing evidences. The program impact pathway must outline the key components of the NACP-IV and how all the components are intended to work together to reach measurable objectives. It should also identify the data that would be needed for conducting evaluations. Program should emphasize the importance of all three types of program evaluation: (1) process evaluation, (2) outcome evaluation and (3) impact evaluation. However, the most effective evaluation strategy would be to carry out the process evaluation for "most" of our interventions, outcome evaluation for "some" of the interventions and impact evaluation for only "few" interventions.

The program evaluation (process, outcome and impact) should ideally be planned at the initial phase of implementation of the program and factored in during the implementation to generate information required during the process. This would make the evaluation process easier and less costly. It is always very difficult to have a valid outcome and impact evaluation when there no baseline data from the time of start of the intervention/program. Also, it is very important to streamlining the program evaluation as part of the regular management of the program. It includes overall description of processes for agreeing on programs to be evaluated, factoring the resources for evaluation as part of the program implementation itself, who would do evaluation, role of partners, internal or external evaluation etc.

*i. Process evaluation*: A major focus needs to be given on process evaluations during the NACP-IV. Most interventions should conduct process evaluations including implementation assessments, quality assessments, operations research, case studies and cost analyses. Even, the interventions that are subjected to an outcome or impact evaluation should have implemented some level of process evaluation to identify any implementation problems which may negatively affect the intervention's effectiveness and document important information for the scale-up or replication elsewhere should this be warranted.

A "mixed methods" approach – combination of quantitative and qualitative methods with triangulation of different data sources- should be used for conducting process evaluations. This mixed methods approach will provide more complete information than applying one method as a definite gold standard.

*ii.* **Outcome evaluation:** Since NACP-IV is a large-scale national program, there must be a specific plan for conducting an outcome evaluation at the overall level. Even, it is important to conduct some outcome monitoring/evaluation at the individual project/intervention level, particularly for those interventions for which there is insufficient evidence that they work as they are new or simply have never been evaluated.

NACO should continue with the national BSS (once in two/three years) that would measure and track the outcome level indicators at the overall level. Ideally, the national BSS should be replaced with the national IBBS i.e. integrated behavioral and biological surveillance survey. IBBS will provide the key biological indicators such as HIV prevalence rate and STI prevalence rate that will be very important inputs for assessing impact of the program at the overall level.

*iii. Impact evaluation:* Impact evaluation of NACP-IV is warranted in which an attempt should be made to attribute long-tem effects (impact) to the program. This long term effects of the program will be the result of collective effectiveness of all activities of the NACP-IV. Impact monitoring can feasibly be done through national sentinel surveillance systems and repeated IBBS using triangulation of multiple, existing data sources. Also, application of simple epidemiological modeling (to assess the program impact), whenever necessary, was also suggested by some members.

It is important that long-term effects be interpreted in the context of results from process and outcome evolutions and program program output monitoring data to ensure that findings are plausibly linked.

A baseline for NACP-IV must be carried out so that outcome/impact evaluation could be carried out systematically. Also, cost effective analysis should be carried out by NACO.

Utilization-focused evaluation approach was should be adopted by NACP-IV. The core premise is that stakeholders' participation will enhance relevance and ownership and this utilization of evaluation. Stakeholders' participation in evaluation is now widely accepted within the evaluation community and there is growing evidence that it improves the quality of the evaluation results. The evaluation data should be collected with the strong intention of being used.

#### **Key recommendations**

- Focus on process evaluations most of the interventions should do process evaluations including quality assessment, operations research and cost analyses
- Conduct few outcome/impact evaluation at the intervention level (for new interventions)
- Carry out outcome and impact evaluation of the program at the overall level
- Conduct national IBBS in stead of national BSS in every second/third year
- Go beyond implementation of BSS/IBBS/HSS...design of the studies and the type of analysis should allow for attribution whenever possible
- Use evaluation data for program planning and improvement and making mid-course corrections
- Implement utilization-focused evaluation involving all the key stakeholders

### Newer and emerging areas of HIV/AIDS Research; Other Innovations

#### Research

During and prior to NACP-III, there has been significant evidence-based research planning and implementation of program was witnessed. Research conducted till date in India has focused on diverse population groups, geographies and disciplines. The research findings have been effectively used in informing the program implementation, improving the quality of implementation and its evaluation. With the research and improved number of data sources resulted from research, today the country has an estimated 2.3 million people infected with HIV. Estimates of the people living with HIV indicates the variation in magnitude of the problem by type of high risk population groups and the bridge populations. The proportion of women living with HIV among the total infected rose from 25 percent in 2001 to 39 percent in 2008. Additionally, the states that had a very low prevalence of HIV a decade ago shown to have high levels of HIV rates in selected districts of those states, largely attributed to the transmission of HIV fuelled by migration. In addition, research also indicated the importance of considering vulnerability factors (such as alcohol abuse, violence, trafficking, etc.) rather than focus on risk factors (consistent condom use, STI service utilisation) for better prevention, treatment and utilisation of support services. Special emphasis shall be given to research in NACP-IV to examine the newer and emerging areas of concern that goes beyond the level of the individual, with an aim of bringing all of the resources of a given community to address the structural barriers and mainstreaming of interventions. The potential of research in the newer themes of planned intervention activities in NACP-IV are greater and have not been studied fully in the past in the context of effectiveness of upscaled interventions.

#### Mechanisms for identification of newer and emerging research issues:

The initiatives that have undertaken during NACP-III such as: (1) engagement of national institutes in HIV/AIDS research; (2) regular consultative meetings to identify newer and emerging areas of research; (3) national (annual) HIV/AIDS conference to identify the knowledge gaps and identification of operations research priorities; (4) bi-annual review of the program and identification of research issues within the program; (5) capacity building of individuals and institutions on research; shall be continued as they are most effective means of helping the national AIDS control program.

#### Newer and emerging issues of research:

Following are the cross-cutting themes of research that can guide national AIDS control program. They include:

- 1. Translational research ('research/evidence to action') should be the focus in all studies.
- 2. Research around gender and related issues in prevention, treatment, care and support among HIV infected and affected populations.
- 3. Research on integration and mainstreaming of HIV prevention interventions within NRHM; their monitoring and impact measurement.

- 4. Operations research to approaches in positive prevention, reaching the intimate sexual partners, working with sero-discordant couples, and female migrants.
- 5. Research beyond individual determinants of HIV vulnerability and risk, for eg., towards the structural barriers, and approaches to address such barriers.
- 6. Mortality, survival analyses and quality of life post HIV diagnosis.
- 7. Role of migration/mobility in changing the epidemic situations between source and destination areas; high risk populations to low risk populations.
- 8. Management, coordination and infrastructure within HIV prevention, treatment and care programs & the community based program initiatives.
- 9. Transition from emergency to a stable epidemic: Newer themes and population groups emerging out of the change in epidemic; and to sustains the gains in reduction of HIV shall be researched.

#### Management and coordination of research activities:

- Engage institutions like ICMR, Pop Council, ICRW and other developmental organisations to form a core group of institutions under the leadership of NACO to guide the research and to leverage the increasing scope of work in the areas of epidemic, social-behavioral, and clinical research.
- Engage NGOs in research to bring new insights, make data immediate use for the program and also to make informed decisions in program planning and implementation.
- Build capacity of individuals and institutions for developing innovative methods of research to study various aspects of epidemic.
- Continue and strengthen the operations research training programs for individuals and institutions to work on HIV prevention, treatment and care approaches.
- Use of information, communication and technology (ICT) in research, monitoring and evaluation to be promoted.

## **HR & System Requirements for Research Activities**

#### DISCUSSIONS:

- A. There was an active discussion about whether we should have a standardized protocol and centralized analysis of data.
  - 1. Those in favour felt that this will ensure comparable statistics which are important for multicentric data collection.
  - NGOs differ in their capacity of Research analysis and those who are weak in this area would benefit from such system.
  - 2. Those against this felt that:
  - The strength of NGOs lies in their bringing in new insights and this will restrict the areas of research and will be donor driven agenda. Many NGOs are capable of doing quality research.

The consensus was that there should be a need assessment of the strength of individual NGOs and their area of interest.

Based on this, a capacity building should be done in specific areas e.g. documentation of experimental learning. A Review Committee can analyse this documentation results to decide which topics can be taken as full fledged research.

- B. The group also felt that
  - The NGOs should be respected for strengths they bring into the programme as they know the ground realities of the local area which can be looped back into the programme to strengthen it. They do not like helicopter Researches monitoring them.
  - Involvement of NGOs will maintain diversity.
  - Capacity building should be done in collaboration with the NGOs for involving them as a long term partner for the programme. NGOs should not be involved as short term interest till the funding lasts but a sustained partner.
- C. NGOs should also be involved for their input which can be valuable for
  - (a) Process evaluation
  - (b) Data use
  - (c) Data synethesis

- (d) Triangulation
- D. NGOs should be involved at all stages of linkages of NACO with SACS, Ministry of Health & FW and other ministries.

Key Recommendations (taken from presentation):

- Institution Based Research: List of Guidelines need to be formed from existing guidelines to promote more efficiency in process
- Involving the Private Sector in Operational Research: Actively engage NGOs and Groups or Associations who are working with – Children in Schools, Youth in schools, Out of School Children and Youths, Parents and Teachers.
- HR and System Requirements: NIHAR network can be tapped into more efficiently. Establish clear linkages between (NACO and SACS), NACP Research with Ministry of Health and FW and other ministries
- Well Defined Protocols and Research Methodology: These should be devised by NACO and recruit these agencies to conduct research in their sectors.
  - Data analysis should be centralized to maintain quality of Analysis
  - Multicentric Data on various issues
- Identify Key Issues for Research- 1: Disclosure to children on ART, what age is appropriate to disclose, when and how to disclose, how to involve school and community
- Identify Key Issues for Research 2: Attitudes of children and adolescent living with HIV, Attitudes of parents towards allowing children to mix with positives
- Identify Key Issues for Research 3: Children of Commercial Sex workers, How to engage them in the program.

# Coordination and compilation of research undertaken by different agencies

Information can be compiled using push and pull strategy. Push strategy would involve compilation of information to create database which could be obtained from all stakeholders, government (Central and State) and private (corporate, NGOs). The pull strategy would involve inviting an expert or group of experts on ad-hoc basis to provide information on a specific area, for instance, relevant issues related to subsets of HIV affected persons, and this would be personalised information. The compiled matter would be converted to explicit knowledge and grouped for dissemination for specific purposes e.g. to plan operational strategy, and provide information for translational research and program management.

For gathering this information motivation would be required. As soft ware usage is imperative for this task, it would be advisable to involve IT professionals from the start of planning the design for compilation. The compiled information should be dealt by an internal core group of professionals who should be trained in e-learning methods. Since the task of reviewing such information would be huge, it could be taken up by different related agencies on quarterly basis by rotation. This group will compartmentalise information which could include abstracts from conference proceedings and even non-formal information from UNAIDS solution exchange into confidential and non-confidential matter. An e-library for Indian data could be created which should provide free access to inform the public and program workforce. This would also serve as pre-print publication facility and ensure knowledge sharing at appropriate levels. The meta-analysis of publications and use of Cochrane library which is freely accessible in India could be made for periodic systematic review as thematic brief and to identify priorities for planning a program.

Since the National Knowledge Network is involved in providing net connectivity, an expert from that group should also be involved in the initial stage of planning to facilitate inter-agencies, interdepartmental, and system to system linkages to create HIV specific metadata. The possibility to link virtual libraries in the country could also be explored for specific information on HIV/ AIDS. Also large databases available with major programs like NRHM and other public health programs could be mapped to sift common factors involving HIV/ AIDS affected people to plan focussed programs for control of HIV/ AIDS. As in the case of National Program on Pharmacovigilance, software and connectivity with adequate security could be set up to instantly pick up signals received from mobiles, ipods etc. at the central point with regional ramifications. For all this a team will have to be built up for effective management.

## Dissemination and Use of research outcomes at all levels; Other Issues

#### Key Points discussed were:

- Dissemination is important and Information sharing should be promoted. Dissemination policy may be created. Dissemination should go hand in hand with use of research outcomes after expert review.
- Active versus Passive Dissemination was discussed and it was felt that active dissemination of key pieces of information was important
- Conferences and Meetings are a good way of information sharing and dissemination, Thematic national conferences should be held, however the group felt that there should not be too many on the same theme too frequently. An annual NACO conference should be a regular feature
- Changes in Communication environment as well as accessibility to various sources of information/knowledge was discussed and acknowledged. Creative use of newer innovations in communication was felt to be important.
- Knowledge hub is a solution to put together all the research studies conducted across the country.
- A Knowledge hub may be created:
  - $\circ~$  However it should not be a limited passive dissemination of information.
  - It should go beyond being a mere repository (strategic analyses, program evaluations to be included)
  - o IT professionals and national knowledge network groups should be involved
  - To develop the knowledge portal, NACO has been linked to Indiahealth portal.
  - The NACO Knowledge Hub (Portal) should permit cross talk with other portals and have linkages to the same rather than replicating existing sources.
  - Electronic Library of all Indian Research: An issue related to hosting of papers published in paid journals was discussed and availability of abstracts or pre-publication drafts was suggested.
  - The hub should try to provide access to various databases, the example of ICMR making the 'Cochrane' database freely available to the whole nation was cited.
  - $\circ\,$  A repository of knowledge gaps  $\,$  and researchable questions can be created and updated regularly  $\,$
  - A Panel of Specialists/experts in different fields networked all over India can be created and approached to review new publications/information as they appear on a fortnightly basis. The papers will sent out by the NACO SIMU team to the expert panels on a rotation basis so that 'reviews of Published Papers' may be uploaded to the NACO portal/hub in a timely manner.
- Dissemination of research findings specifically NACO funded studies was discussed. It was noted that 'Turn around Time' for dissemination of knowledge be it research or a consultation or an annual report is very important for timely use of 'knowledge/research findings' into program. Building 'Dissemination' as an outcome of studies funded by NACO into study timelines was suggested. Facilitation of timely conducted of studies by the funding agency or researchers who have applied for permission to do the study is important.
- Packaging and Active dissemination: Packaging of information for target audience, synthesizing and taking it to right people is important. 'Source', 'User ', 'Medium' and 'Content' should be

considered. Need to identify the mechanisms and people who would be important for active dissemination.

- Dissemination to community was felt to be very important:
- Community advisory board for research studies who likely utilize the results.
- Disseminate the results with communities in their own language.
- Disseminate HSS results to the communities regularly.
- Role of NGO's in creating and disseminating knowledge: Engaging NGO from the beginning, building capacity for documenting best practices and what doesn't work and creating a platform for them to share this is important. They can then actively engage in dissemination and utilization of the actionable research results
- Response by NACO to new information is important (needs further discussion). For example Press Releases on findings /results from studies conducted in India and abroad and NACO's response to the same. Thus new data and findings must be reviewed by key staff at NACO. Expert Committees can help in review of new data on a periodic basis
- Strengthen the manpower at NACO to host the dissemination is important.

#### What worked in NACP III in terms of Knowledge Dissemination?

NACO conducted the conference for dissemination meeting for sharing of information on the recent research studies was presented.

- National Conference on HIV/AIDS Research (19-21 January 2011 )
- Pre-Conference Continuing Education Workshop (18<sup>th</sup> January2011)
- IEC Programmes

#### What did not Work in NACP III?

- Conference dates need to be fixed well in advance to ensure maximum attendance
- NACO website as a portal of information was inadequate
- New developments and information from the field of HIV research could not be compiled, processed and disseminated adequately. This could delay the translation of knowledge into action

#### Key Recommendations:

- A dissemination policy may be created and dissemination should go hand in hand with use of research outcomes after expert review.
- An annual NACO conference should be a regular feature at a fixed time of the year to ensure good attendance
- Creative use of newer innovations in communication should be considered.
- A Knowledge hub may be created, which beyond being a mere repository /
- A Panel of Specialists/experts in different fields networked all over India can be created and approached to review new publications/information as they appear on a fortnightly basis.
- 'Dissemination' as an outcome of studies funded by NACO and building this into the timelines into study timelines was suggested.

- Active dissemination of information by aptly packaging and positioning information for different audiences like Researchers, Policy makers, MARPS and communities, lay persons, religious leaders etc
- Dissemination to community is felt to be very important:
- Engaging NGO's from the beginning, building capacity for
- Timely response by NACO to new information is important
- New data and findings must be reviewed by key staff at NACO. Expert Committees can help in review of new data on a periodic basis.
- Strengthen the manpower at NACO SIMU.