NATIONAL AIDS CONTROL ORGANISATION DEPARTMENT OF AIDS CONTROL MINISTRY OF HEALTH AND FAMILY WEKFARE GOVERNMENT OF INDIA

TECHNICAL WORKING GROUP ON SIMU FOR NACP-IV PLANNING <u>STRATEGY AND KEY RECOMMENDATIONS FOR NACP-IV ON RESEARCH AND EVALUATION</u> (Report, 11-12 Aug 2011)

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.

Numerous notable initiatives were undertaken by NACO during NACP III. The Technical Resource Group (TRG) on Research & Development and the NACO Ethics Committee (EC) were constituted as the apex oversight bodies for research and evaluation priorities in HIV and granting ethical clearance respectively. Identification of priority areas for Research and Evaluation in HIV was undertaken involving various stake holders. The Network of Indian Institutions for HIV/AIDS Research (NIIHAR) consortium was established for facilitating and undertaking Operations Research and Evaluation studies in epidemiological, behavioural, social and bio-medical disciplines. Initiatives for building human resource capacities were undertaken by the organization of 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. The NACO Research Fellowship Scheme was initiated to build the capacities of young researchers in the field of HIV/AIDS in the country. Dissemination of HIV research and evaluation studies at the National Conference on HIV/AIDS Research in 2011.

Under NACP-IV, the research agenda of NACO must look forward to supplementing and streamlining existing structures as well as identifying and weeding out accessible lacunae in the system. Greater and direct participation of State Level and District level agencies in the research activities should be one of the major maneuvers in NACP-IV. Special emphasis should 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. Building Public-Private collaborations in Research & Development activities should be one of the major goals of NACP-IV. Efforts must also be made towards establishing augmented integration and convergence of NACO's research program with other important government and non-government agencies. In this regard, revisiting the existing and desirable Human Resource

component of R&D activities at NACO & aligned agencies shall also go a long way in intensification of the main aims and objectives of the Research Division at NACO.

I. <u>Progress in HIV /AIDS Research and Key Gaps</u>

- 1. Quality of Research: 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 who may be 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 of 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. Regular dissemination workshops, conferences, technical discussions 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 cost-effective 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. Research studies that can suggest ways by which Private corporate sector to deal with the drivers of the epidemic need to be undertaken.
- **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 List of Priority Research Areas to address the goals and motives of NACP-IV, to look for scope of multi-centric studies and for avoiding duplication of studies and for drawing attention to the national resource pool.
- 11. There should be a prominent feedback mechanism between Program managers, Program implementers and beneficiaries.

II. <u>Strategy, Approach & Mechanisms for promoting Research in</u> <u>HIV/AIDS</u>

- 1. Continue the existing system but strengthening and streamlining for timeliness, regular review system, feedback mechanism and the guidelines for submission of research proposal and review is essential.
- 2. It was felt that there is a need for more involvement of states in the operation research.
- 3. 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
- 4. Central repository The information collected through surveillance, CMIS, estimations etc need to be collated into single information. It will be the part of Knowledge Management.
- 5. **Expanding number, scope and responsibility of NIHAR** In the Sub –group discussion; it was felt that NIHAR institutes are concentrated in few states and cities which are not representative of entire country. So while expanding number of NIHAR institutes, there should be equitable distribution of institutes throughout the country. If any of the states do not have NIHAR institute, then responsibility to conduct research studies in those states, can be given to the member of NIHAR institutes from the nearby state.
- 6. For streamlining the existing system, stronger networking and collaboration between research institutes, universities, and Government ministries is required.
- 7. There is scope of integration with other National Health Programmes and different organizations such as, IDSP, DBT, NHSRC, SHSRC, SIHFW, NSSO, SCTIMST, IPH, IIPH.
- 8. It aspires to further strengthen and decentralize the program management capacities to state and other district level in particular In the Sub –group discussion; it was felt that there is need to establish Technical Advisory Groups (TAGs) at state level, which could be encompassed of SACS members, members from NIHAR from the concerned state, local NGOs, medical colleges, local research institutes, SHSRC,SIHFW,IDSP etc. These TAGs could first review research proposals from concerned states, and then could submit to state level Ethics Committee, before submitting them to NACO. The research proposals which are of shorter duration, which do not comprise of major technical or ethical issues and which entail smaller amount of budget can be forwarded directly to Ethics Committee at NACO. These will be identified as Fast Tracked studies. Remaining studies could be progressed through routine process.
- 9. TAGs will also identify priority areas in the HIV/AIDS Research and share with TRG NACO as well as with TAGs from other states. On the basis of inputs from TAGs & TRG, strategic areas would be set annually.
- 10. Ensuring translation of research outputs into programmatic action and policy as a part of Knowledge Management activities is crucial.
- 11. Capacity building practice for newly participating institutes could be undertaken either by NACO itself or through the competent NIHAR institutes from a particular state. Identification of NIHAR institutes capable of providing support to other institutes is necessary.
- 12. In Core Group Meeting; it was considered that capacity buildings of seven Regional Centres of STI need to be commenced to strengthen the Operational Research activities at these centres.

- 13. Research Fellowship Criteria regarding National Research Fellowship Scheme (NRFS) should be customized for those who are working in health & allied system with 5 years experience. Age limit could be relaxed for such by 5 years.
- 14. In the sub group meeting; it was felt that there should be a consortium of national level institutes and research development agencies to advise NACO on research. But this was strongly disagreed on the basis that there is already TRG and EC at NACO as well as NIHAR in the field. So there is no need of establishing any other structure.

III. <u>Newer and emerging areas of HIV/AIDS Research; Other</u> <u>Innovations</u>

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. 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 up-scaled interventions.

Newer and emerging issues of research:

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

- 1. Research around gender and related issues in prevention, treatment, care and support among HIV infected and affected populations.
- 2. Research on integration and mainstreaming of HIV prevention interventions within NRHM; their monitoring and impact measurement.
- 3. Identification and evaluation of Newer Preventive Technologies (NPT). For eg. Vaccine Research.
- 4. Operations research to approaches in positive prevention, reaching the intimate sexual partners, working with sera-discordant couples, and female migrants.
- 5. Research beyond individual determinants of HIV vulnerability and risk, for e.g., 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.

Mechanisms for identification of newer and emerging research issues:

(1) Engagement of national institutes in HIV/AIDS research

(2) Regular consultative meetings to identify newer and emerging areas of research

(3)National 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.

Management and coordination of research activities:

- 1. 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.
- 2. 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.
- 3. Build capacity of individuals and institutions for developing innovative methods of research to study various aspects of epidemic.
- 4. Continue and strengthen the operations research training programs for individuals and institutions to work on HIV prevention, treatment and care approaches.
- 5. Use of information, communication and technology (ICT) in research, monitoring and evaluation to be promoted.

IV. <u>HR & System Requirements for Research Activities</u>

- **1.** The Research Division at NACO should be supplemented with additional Technical Officer (01 Post) & Technical Assistant (01 Post).
- 2. Need to establish Technical Advisory Groups (TAGs) at state level, which could be encompassed of SACS members, members from NIHAR from the concerned state, local NGOs, medical colleges, local research institutes, SHSRC,SIHFW,IDSP etc.

<u>Coordination and compilation of research undertaken by different</u> <u>agencies</u>

- 1. 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).
- 2. **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 personalized information.
- 3. As software usage is imperative for this task, it would be advisable to involve IT professionals from the start of planning the design for compilation.
- 4. 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
- 5. The compiled information should be dealt by an internal core group of professionals who should be trained in e-learning methods.
- 6. Since the task of reviewing such information would be huge, it could be taken up by different related agencies on quarterly basis by rotation.
- 7. 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.
- 8. 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.
- 9. The possibility to link virtual libraries in the country could also be explored for specific information on HIV/ AIDS.
- **10.** 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.

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

- 1. Dissemination policy may be created. Dissemination should go hand in hand with use of research outcomes after expert review.
- 2. 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.
- 3. Knowledge hub is a solution to put together all the research studies conducted across the country, which could be the part of Knowledge Management.
- 4. 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.
- 5. Packaging and Active dissemination: Packaging of information for target audience, synthesizing and taking it to right people is important.
- 6. Dissemination to community was felt to be very important. Disseminate the results with communities in their own language.
- 7. Disseminate HSS results to the communities regularly.
- 8. Use of NGOs in dissemination and utilization of the actionable research results
- 9. 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.
- 10. Thus new data and findings must be reviewed by key staff at NACO.
- 11. Strengthen the manpower at NACO to host the dissemination is important.

V. <u>Strategy, Approach & Mechanisms for Evaluation of Programme</u> <u>Interventions and Impact Assessment</u>

Programme evaluation provide additional information on the relevance and appropriateness, reach and coverage, quality, efficiency, effectiveness, and efficacy of specific programs.

- In sub group meeting it was strongly felt that; NACP III didn't have a clear plan and design for evaluation at the beginning of the program cycle. Therefore it is necessary to develop a detailed impact evaluation design/plan specific to each of its major program elements / focus areas (prevention, care and support, basic services) at the beginning of NACP-IV, ideally within the first 6 months through a national consultative process and determine the evaluation questions, data elements and resources that are needed for this evaluation.
- 2. 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.
- 3. **Program should emphasize the importance of all three types of program 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. More importance would be given to the Impact evaluation.
- 4. Process evaluation: A major focus needs to be given on process evaluations. Most interventions should conduct process evaluations including implementation assessments, quality assessments, operations research, case studies and cost analyses. 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.
- 5. Outcome evaluation: at the overall level. 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 (in 2 or 3 years). 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
- 6. Impact evaluation: To attribute long term effects. It 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.
- 7. It was discussed that Concurrent evaluation can be processed through the available routine reporting system.
- 8. Use evaluation data for program planning and improvement and making mid-course corrections is essential.