Operational Research on PMTCT - Lessons Learned and Gaps

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“Any research producing practically-useable knowledge (evidence, findings, information etc) which can improve program implementation (e.g. effectiveness, efficiency, quality, access, scale-up, sustainability) regardless of the type of research (design, methodology, approach) falls within the boundaries of operations research”

(GF, USAID, WHO, TDR, UNAIDS, WB)
Expert Consultation on Operations Research on PMTCT and Pediatric HIV/AIDS care

• Review operational bottlenecks to scaling up PMTCT and paediatric HIV CST in resource-limited settings

• Identify innovative approaches to address bottlenecks

• Map out key ongoing and planned implementation research projects

• Identify gaps in PMTCT and paediatric HIV CST-related implementation research in the broader framework of maternal, newborn and child health (MNCH);

• Define priorities for an implementation research agenda for PMTCT and paediatric HIV CST
Literature Review General Observations

• Published literature lags behind by 4-5 years
  ➢ Challenge in a fast moving, evolving field
  ➢ Abstracts more contemporary but lack detail
  ➢ Non peer reviewed or program literature better source; difficult to find systematically

• Few true OR/IR publications in peer review literature
  ➢ Majority program descriptions, pilot programs
  ➢ Challenges and barriers to effective program implementation described
  ➢ Rarely scientifically rigorous study of OR/IR interventions

• Wide variability in quality, data analysis, and conclusions
Lessons Learned- PMTCT effectiveness

- PMTCT programs are cost-effective in resource limited settings; rates <3-5% can be achieved
- Cost effectiveness of WHO prongs 1 and 2 will be > prong 3 in decreasing Ped. infection; ALL should be maximized, esp. in lower prevalence settings
- Ongoing data review/quality improvement, increased efficiency, and identification of and efforts to address “missed opportunities” critical to maximal effectiveness
- Site performance differences- mature programs better; short, intensive focused HCW training improves understanding/performance; ongoing training key; periodic audits of performance
- Newer/smaller/ART co-located sites- better uptake of combination ARV/HAART (starting easier than transition)
• Limited coverage - delay in moving services to periphery due to health system challenges; missed opportunities in private sector

• Progressive loss of women at every stage of PMTCT cascade - significant impact on effectiveness

• Cascade “non-adherence”-significant health structure issues add to losses (lack of staff/kits/drugs, failure to follow-up status, giving wrong information etc)

• Negative HCW attitudes, concern about confidentiality and stigma - barriers to uptake of PMTCT

• Counseling- most difficult to integrate in routine services due to manpower/training issues.

• Limited comprehensive evaluation of quality of counseling particularly infant feeding counseling.
• Use of peers in ANC feasible - requires adequate staffing, good training, ongoing supervision

• Differential understanding/confidence in counseling on different topics, infant feeding particularly

• Use of routinized opt out HIV testing increases uptake of testing in ANC, in maternity, among women and their partners

• Testing women of unknown status and retesting HIV negative women in maternity is feasible and acceptable; identifies seroconverters

• Inadequate quality HIV testing - discrepant results lead to mistrust in reliability of HIV testing as reason not to test

• Lack of access to HAART – barrier to HIV testing uptake
• Adherence to HAART higher in pregnancy than after delivery or in non pregnant women

• Non-adherence to PMTCT ARV- less educated, fewer ANC visits, smaller households, less disclosure, no facility delivery.

• Reasons for non-adherence – forgot, were afraid, labor progressed too fast, husband/someone else present

• Maternal support groups-
  ➢ increased uptake of ARV prophylaxis, exclusive breastfeeding
  ➢ service and support were much appreciated
  ➢ difficult to establish- need high levels of service utilization/HIV prevalence; HIV+ women willing to serve as mentor mothers; and access to ART.
• Partner involvement in ANC VCT/couple counseling (9-20%)- increased testing, use of NVP/formula/condoms

• Disclosure – rates ≤ 50%, some increased domestic violence in HIV infected women around disclosure of HIV status.

• Barriers to male participation - lack of knowledge on existence of services or need to go; too busy, cultural habit, women’s domain, fear of HIV testing

• Overall awareness/knowledge about HIV ; limited knowledge of PMTCT (unaware of transmission rates/timing, that ARV interventions decrease risk)

• Community mobilization/HCW feasible/acceptable - little data on impact on PMTCT

• Media- important source of HIV/PMTCT information
Lessons Learned- Health Systems /MNCH Integration

• Strengthening of health systems is needed for success

• Service “Compartmentalization”- major problem, poor referral networks

• Poor integration- missed opportunities for PMTCT and MNCH (+ Reproductive Health/Family Planning)

• Integration- may increase PMTCT uptake; PMTCT may improve MNCH services

• Poor integration/linkage with pediatric services- Poor follow-up of HIV-exposed/infected infants
• Family centered care models- effective and acceptable
• Inadequate number of HCW for PMTCT and Pediatric CST
• Task-shifting is feasible/effective in some settings
• Major inadequacies in data collection and reporting
• Data improvement intervention - series of trainings, data monitoring site visits, improved data collection tools, regular feedback
• Poor patient tracking for follow-up
• Improvement needed to target “hard-to-reach” populations
Knowledge Gaps - PMTCT Effectiveness

- Measurement of HIV free survival at 2 years - best method
- Impact of PMTCT services/access to ART on mortality rates
- Feasibility /effectiveness of home based PMTCT services in rural areas
- Feasibility/ cost effectiveness of both new breastfeeding prophylaxis regimens, including broader health benefit not just prevention of transmission
- Impact of improved health systems on PMTCT effectiveness
- Innovative methods of service delivery and/or tracking to maintain women in the cascade of services
- Optimal models for HAART delivery to pregnant women (in ANC, HIV clinics); linking PMTCT to HIV CST services
- Mobile urban populations – impact on cascade adherence
• Optimal retesting strategies for HIV negative women in PMTCT/PNC; interventions to keep negative women negative

• Strategies for monitoring and improving adherence to PMTCT regimens

• Stigma- impact on PMTCT outcomes; interventions to mitigate impact, improve HCW attitudes

• Quality of counseling – assessment /impact on PMTCT outcomes; interventions to improve quality

• Interventions to increase male involvement in PMTCT/MCH; address discordant couples

• Community engagement in PMTCT- effective strategies for improving PMTCT awareness/involvement; measuring the impact on PMTCT outcomes

• Role of private sector/TBAs/religion in PMTCT
Knowledge Gaps – Health Systems /MNCH Integration

• Integration/service delivery linkages- successful approaches to integration; quantification of benefits

• Training- needs; pre-service training/HCW pipeline analysis; comparisons (incl. CE) of different training approaches

• Health care workers- HCW policy analysis; successful approaches to HC workforce improvement; comparisons (incl. CE) of different cadres’ functioning; urban-rural disparities

• Health information systems- Extent of problems/loci of weaknesses; role of technology (feasibility, CE); successful approaches to improvement; effects of merging/linking data collection systems

• Successful approaches to supply chain improvement
• Effects of political will on program effectiveness

• Roles of NGO and FB providers

• Program management and governance- Successful approaches for improvement; comparative effectiveness of different program structures/management approaches

• Program Financing- descriptions, sustainability, outcomes, impact of various models

• Comparisons of health care financing options/service delivery models, including unit costs and CE of PMTCT & Ped. CST, rural/urban cost differences and other determinants
Top Five priority Research questions- PMTCT

1. Access to CD4 monitoring and ART treatment, if eligible—What are effective strategies for improvement?

2. Breastfeeding prophylaxis – What are effective strategies for implementation? Comparative effectiveness of infant versus maternal prophylaxis

3. Measuring PMTCT effectiveness- what are valid, feasible methods at program and population levels?

4. Community Strategies- How to increase PMTCT uptake?

5. Family and male partner involvement- Do these increase PMTCT uptake? How to increase both?
Top Five priority Research questions- Ped CST

1. Comprehensive CST for infants and children- What is optimal model for service delivery?

2. HIV-exposed infants- What are best models of service delivery?

3. Retention in care- What interventions (program, facility, community, household) have greatest impact, especially in the first 12 months of life?

4. What are the best interventions to support infant feeding recommendations?

5. How can the maximum number of HIV-infected infants and children be identified early?
Top Five priority Research questions-
MNCH integration

1. PITC and services for HIV-exposed infants- What is the feasibility/impact of integration in MCH services?

2. HAART for eligible pregnant women- What is feasibility/impact of providing in ANC?

3. Family planning services-What is appropriate timing, content and setting in MCH for HIV+ women?

4. How can community health workers and peers increase utilization of MNCH and HIV/AIDS services?

5. Integrating PITC into EPI services for children <5-What are benefits, challenges, cost-effectiveness, and effects on service utilization?
Top Five priority Research questions - Health Systems

1. Task shifting - What is effect/impact on scale up in different settings, facility levels, HCW cadres?

2. Data - What is effect of different approaches/models of collection on data quality/use?

3. Governance - What is effect of innovations to improve sub-national management of health services?

4. Financial accountability/management - What are cost-efficient models for delivering PMTCT/CST within MNCH services?

5. Logistics - What is impact of various approaches to supply chain management on services/scale up
Conclusions

Pediatric HIV is preventable!
Pediatric HIV is treatable!

• The challenge is in the implementation of what we know in settings with limited resources.

• Ministries, funders, and program staff are more likely to accept activities when the impact can be demonstrated.

• Implementation science is critical to provide strong evidence-based, scalable interventions to address current barriers to effective PMTCT/CST programs.
Tunaweza: Together, we can...

Eliminate Pediatric HIV