National AIDS Control Organisation
India's response to HIV & Sexually Transmitted Infections
Ministry of Health & Family Welfare, Government of India
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RE-IMAGINING FUTURES
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ASSESSING THE ROLE OF CARE SUPPORT CENTRE IN PROVIDING

COMPREHENSIVE CARE TO THE PLHIV IN INDIA

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EXECUTIVE SUMMARY

The goal of Care Support Centre (CSC) is to improve the survival and quality of life of PLHIVs through early linkages to ART and enhanced adherence to care, support, and treatment services. The CSC intervention has evolved over the past decade, and it becomes important to evaluate the achievements, outcomes, current programmatic challenges and to understand the strategic options for providing the care and support to PLHIV in the near future.

A qualitative study was conducted with a sample of 12 CSCs in six States in order to assess the care support centres in India and document how the various models implemented by multiple stakeholders and related strategies implemented so far.

The findings highlight importance of CSCs in the treatment support, retention, adherence, referral and linkages, and psychosocial support for PLHIV. FGDs with the PLHIV highlighted the satisfaction with the services. The implementation approach is indicator-driven and has been inferred to be a top-down approach for the provisioning of differentiated care through nine priority areas, however, there is scope for further broadening of this approach.

This technical brief discusses pros and cons of the implementation models. During the study period, there has been transitioning of some interventions from one model to another. Further, there is a need to examine sustainability, ownership, capacity building, supportive supervision and monitoring and effectiveness while choosing a model for care and support services for PLHIV.

THE ISSUE

Care and support play crucial role in a PLHIV continuum of care. HIV patients need social, psychological support which influences their treatment retention.

More than 12 lakh PLHIVs have been actively associated with the Care Support Centres in past year…

During NACP IV, the Community Care Centres (CCCs) was remodelled as CSCs, incorporating a community centred integrative approach. The CSC had a single countrywide model initially and was implemented by Alliance India as a principal recipient (PR) of The Global Fund (TGF) grant with key responsibility of designing, developing and rolling out the model. The intervention, named 'Vihaan Care and Support' operated through several state-level PLHIV networks and NGOs, which in turn supported district-level PLHIV networks and other organisations to deliver care and support services to PLHIVs. The Vihaan program has evolved over the years and is presently in its fourth phase. The program introduced a patient-centric approach of prioritising certain services in order to ensure treatment adherence. This study looks into the differentiated care approach of service provisioning and its effectiveness.

Recent changes due to transition of some CSC projects have led to concurrent existence of three governance models. It is important to understand these models and document the characteristics, gaps, challenges of each of the models.

THE STUDY

The CSC Vihaan program has been working for more than a decade and has adopted a differentiated care approach since last couple of years, it is important to document the role of CSCs in the life of PLHIV and the services provided by these centres.

OBJECTIVE

- **To assess the differentiated care approach in the CSC program for improving treatment adherence and treatment retention among PLHIV**
- **To document the facilitators and barriers, associated with implementing key services at CSCs**
- **To document the best practices under the CSC program**

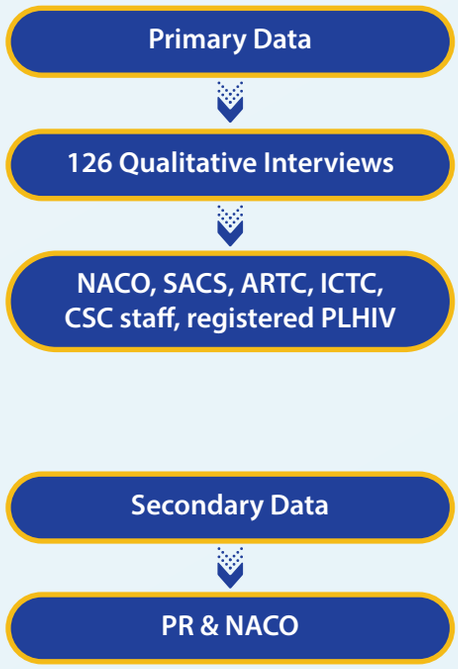
THE METHODOLOGY

The study was carried out in twelve districts in six states across India. A qualitative approach was adopted to collect the primary data from the field. Aggregate Secondary data was provided by implementation agencies and NACO which helped to provide an overview of the performance of the individual CSC NGOs and the states.

Table 1: Study States and Districts

States	Districts	CSC Models
Maharashtra	Thane	PR managed TG based
	Washim	PR managed
Karnataka	Bengaluru	PR managed
	Bagalkot	PR managed
West Bengal	North 24 Parganas	SACS managed
	Cooch Behar	SACS managed
Manipur	Churachandpur	PR managed
	Imphal West	PR managed
Uttar Pradesh	Allahabad	PR managed
	Bareilly	PR managed
Gujarat	Bharuch	NMH managed
	Rajkot	PR managed

Figure 1: Data Collection



FINDINGS

STAKEHOLDER DRIVEN MODELS

Figure 2: Three governance models of CSCs

TGF funded PR managed (n = 258)

- Provisioning of adequate resource and infrastructure
- Robust monitoring and evaluation system
- Tailor-made service delivery for clients
- Established reporting system

NACP funded SACS managed (n = 52)

- Ownership or willingness to implement CSC
- Wide reach and coverage of population
- Lack of clear guidelines or training modules
- Shortfall of point person for program implementation
- Funding issues - delayed funding

State funded PR managed (n = 9)

- Sustainable and self-sufficient financing, uncertainty about scale-up
- Dependence on the PR for implementation
- Funding issues- lower salary scale and travel allowance

> *"At the CSC level when Vihaan implemented the biggest challenge was staff management. The salaries in the Global supported CSC are higher than the state funded CSC. Here the salaries are stagnant since the operations started so it does make a difference.."*
>
> **(IDI, SR partner – state funded PR managed)**

Priority Indicators Performance (2022-23)

- Around 88% of the clients were followed for initial 6 months and continued treatment
- About 2 lakh (88%) of the LFUs and 72% of the MIS clients were tracked back with definite outcome. Definite outcomes include death, opted out of ART, private ART and retrieval to ART centre.
- LFU cases brought back on ART were reported to be in 55000-60000 range for the previous two years. Overall, more than a third LFUs have been brought back to ART
- More than 90% of the clients were followed for CD4 and Viral load testing
- More than 90% of the clients were followed for 2nd and 3rd line treatments

Differentiated Care Approach (DCM Model)

Focuses on

- Treatment initiation, linkage, retention
- Follow-up, testing
- Indicator driven, hence top-down

Lacks focus on

- Psychosocial needs - not a key indicator
- State specific needs - model same throughout nation

Facilitators

- The presence of peer led networks
- Psychosocial support to PLHIVs
- Robust monitoring system by partners
- Funding through state for certain CSCs
- Patient prioritisation
- Social linkages

Barriers

- Ownership of data at SACS level
- Infrastucture and HR constraints at SACS for transitioned states
- Data duplications and errors
- Poor data quality might result in delay in recieving data from ARTC
- Lack of co-operation at ARTC, ICTC level
- Lack of capacity building at CSC level

> *"When I have heard about this disease, I became frightened and I get connected with didi I talked with her and after talking with her I get mentally free and able to handle my stress and I am thinking positively and it is easier for us to handle the crisis of this disease"*
>
> **(FGD, PLHIV)**

> *if we are not given man power then we cannot plan anything, who will implement, who will supervise, we can plan anything we can think lots of thing, but who will do this, I will do this and they will monitor, or I will send the report and someone will be attending the ART CSC coordination meeting, but who will do this*
>
> **(IDI, SACS official)**

Best Practices

Use of mobile-based technology for follow up of patients, regular updates, during COVID

COVID specific services e.g. Multi month dispensation and community drug dispensation

Appointing district-specific ORWs to ensure coverage

Integrative approach using state infrastructure to run CSC in government premises

LEARNINGS

- The study establishes significant role of the CSCs in terms of ensuring treatment continuity and providing psychosocial support to HIV patients.
- The research has documented how the various CSC models operationalise. Implementation challenges from each of the CSC models are helpful in planning the future program direction.
- Various aspects of strong monitoring mechanism by PR partners have been put forth which can be adapted by the states which also mean more resources at SACS level
- Preparedness of SACS for transition is a concern and capacity building on technical and monitoring grounds and is needed.

Possible Approaches of Program Service Delivery for Future Implementation

	CSC implementation-PR model	CSC implementation - governed by SACS			
	PR supervised	**TSU supervised**	**DISHA supervised**	**ARTC based**	**SACS supervised**
Operation	CSC activities are implemented through SSRs (predominantly CBOs)	CSC implemented by CBOs in field, governed by SACS with technical support (preferably Vihaan SR)	CSC implemented by CBOs in field, governed by SACS with supervision by DISHA at district who reports to SACS	CSC implemented by ORWs appointed at ARTC, governed by SACS with technical support	CSC implemented by CBOs in field, governed by SACS with technical support (preferably Vihaan SR)
Challenges	Limited ownership at SACS, Lack of data and governance by SACS, sustainability as it is donor funded.	TSU model has had operational challenges resulting in dependence on external partner and sustainability of model	Capacity building of DISHA, DISHA has multiple competing responsibilities that would compromise their supervisory role. One district-one CSC may not work due to wide variation in PLHIV numbers	ORWs stationed at ARTC may have role conflict with care coordinator. This model does not leave space for CBOs and community's voice. NACP may not be able to hire given the HR capping	SACS lacks HR to supervise and monitor. This will be especially a challenge for bigger states with large number of PLHIV unless positions are created specifically for this under NACP

KEY RECOMMENDATIONS

The capacity of SACS should be strengthened in the areas of robust monitoring mechanism, provision of technical assistance including filling vacant positions, and infrastructure. Current HR positions at SACS may need to be reviewed considering the need for adequate support to implement CSCs.

Operational guidelines and training modules should be developed to bring clarity in terms of transition and better implementation of the CSC program in case of the SACS models. Follow-up with patients could be through multitude of methods – home visits, messages, calls, etc.

A robust monitoring mechanism at the national and state level should be developed in order to ensure the smooth functioning of the program especially with transition & explore possibility of leveraging the experience of PR for the same.

Program ownership at the SACS level may need to improve ensuring data ownership, better program awareness, and better engagement at the state level including improved co-ordination between SACS and the CSCs.

Focus could be on maintaining of quality and timeliness of data sharing between the partners and making granular data shared among ARTC, CSC and SACS.

There is a need to bring more clarity to the overlapping roles and responsibilities of the HR at the CSC between ORWs Peer counsellors and ARTC level.

Alternative ways of connecting with the HRG population need to be strategized in the context of the practicality of the TG-based CSC such as support from local TI projects to local TGs.

The role of DAPCUs in terms of CSC program implementation need to be re-looked including specifics to be included in the operational guidelines.

The SR partners have potential to provide monitoring and technical support to CSCs.

Decentralisation of the CSCs on the basis of PLHIV load and geographical context would ensure better coverage.

Cost analysis across the three models presented in the study can be proposed in the form of a desk research. This will be helpful in order to better understand the program cost of each of the models.

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ACKNOWLEDGEMENTS

We would like to thank AS&DG, NACO and Joint Secretary, NACO for their guidance and support to undertake this study. The study was undertaken as part of Strategic Information (Research & Evaluation) under NACO. The team also expresses heartfelt thanks to the study participants, all State AIDS Control Societies, mentors and experts for their valuable support throughout the study. We would also like to acknowledge PEPFAR and USAID for design and printing.

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