

## **Between HIV diagnosis and initiation of antiretroviral therapy: Assessing the effectiveness of care for people living with HIV in the public primary care service in Cape Town, South Africa**

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### **Abstract**

**Background:** While much is written about the scale up of HIV counselling and testing (HCT) and antiretroviral therapy (ART), little research has been done on the expansion of routine preART HIV care.

**Objective:** To assess the quality of preART care in Cape Town and its continuity with HCT and ART.

**Methods:** The scale up of the HCT, preART and ART service platform and programmatic support in Cape Town is described. Data from the August 2010 routine annual HIV/TB/STI evaluation, from interviews with 133 facility managers and a folder review of 634 HCT s who tested positive and 1115 clients receiving preART HIV care are analysed.

**Results:** Historically the implementation and management of preART care has been relatively neglected compared with the scale-up of HCT and ART. The CD4 count was done on 77.5% positive HCT clients and 46.6% were clinically staged - crucial steps that determine the care path. There were: gaps in quality of care - 32.2% of women had a PAP smear; missed opportunities for integrated care - 67% were symptomatically screened for tuberculosis; and positive prevention - 48.3% had contraceptive needs assessed. Breaks in the continuity of care of preART clients occurred with only 47.2% of eligible clients referred appropriately to the ARV service.

**Conclusion:** While a package of preART care has been clearly defined in Cape Town, it has not been fully implemented. There are weaknesses in the continuity and quality service delivered that undermine the programme objectives of provision of positive prevention and timeous access to ART.

### **Introduction**

Increasing access to effective HIV interventions is a priority in sub-Saharan Africa (WHO, 2009) where, in 2008, an estimated 22.4 million people were living with HIV and 1.9 million were newly infected (UNAIDS, 2009). Since early 2003 the scaling-up of provision of antiretroviral therapy has been a key programmatic goal, initially spear-headed by the WHO 3 by 5 initiative (WHO, 2003) and subsequently under the banner "Towards Universal Access" (WHO, 2009). The latter promotes country-driven processes within existing

national AIDS strategies and prioritises the expansion of positive prevention and care for people living with HIV in addition to antiretroviral treatment. Positive prevention targets HIV positive individuals to reduce behaviours associated with HIV transmission (King-Spooner, 1999). A meta-analysis of controlled trials found it to be efficacious in routine care settings when integrated with medical care and addressing health, behavior and well-being (Crepaz et al., 2006) and applicable in the African context (Bunnell et al., 2006). Positive prevention is supported by recent WHO guidelines (O'Reilly, 2008) on effective, evidence-based interventions for people living with HIV in resource-limited settings for whom antiretroviral therapy (ART) is not yet clinically indicated, i.e. "preART care".

Recent published research evaluates scaling up access to antiretroviral therapy (Makombe et al., 2007; Stringer et al., 2006; Severe et al., 2005; Bekker et al., 2006; Ferrandini et al., 2006; Cleary et al., 2008), but little is written on scaling up preART prevention and care. Integration of HIV services along the continuum of care from testing to ART has been programmatically poorly implemented with different funding streams, personnel, monitoring tools and indicators (Loveday, 2011). Evaluation of preART care is a gap in HIV care programmatic reporting.

This article describes the Cape Town experience of implementing preART care, assesses the effectiveness of this care and describes the extent of its integration with ART care in public primary care facilities in the district. Cape Town has a population of over 3 million and an antenatal HIV prevalence of 18.3% (PGWC, 2009). We document breaks in continuum between HCT, preART and ART services.

Access to HIV care by women using pMTCT services are not reviewed as not all ante-natal provision sites were reviewed.

## **Methods**

We describe the service delivery platforms for HCT, preART and ART in Cape Town, and key elements of programmatic support from the perspective of participant authors (KJ and VZ) who were district programme managers.

An evaluation tool was used to assess the effectiveness of care in each facility and information aggregated at a sub-district and district level. Evaluation tools to assess the programme effectiveness and quality were first developed in 2003 and refined annually (Scott et al, 2010). These are based on an evaluation framework proposed by UNICEF and the WHO (2001) for the evaluation of PMTCT programmes describing measurable components of programme effectiveness (Knippenberg, 1986). In our modified framework these conditions are: access to the target population, availability of key resources and capacity; quality of care; integrated care (HIV/TB/STI/Reproductive Health) and continuity of care.

### ***The 2010 Audit***

In August 2010 data was collected on the HCT and preART services as part of the routine annual HIV/TB/STI evaluation done in Cape Town. Sub-district TB HIV coordinators organised and led the audit teams and team members included facility and local programme managers. Audits were preceded by a routine half-day tool training, and planning the audit logistics. In some sub districts coordinators involved facility managers as self-audit is quality improvement process. In other subdistricts, facility managers did not audit their own facilities, as it was felt that involvement in the team might alter the accuracy and objectivity of the results.

Routine data, collected in facility-based registers and collated at district level were drawn from management data systems. Audit teams visited facilities over a period of one month. It took approximately three hours to interview the facility manager, assess the equipment in consulting and counselling rooms and do a set of HCT, preART, ART, STI and TB folder reviews. Non probability sampling was done, with ten folders sampled from each facility for each programme. Gathering data from 40 folders is achievable annually by local service managers, and enables all facilities to engage with their data in a participatory quality improvement process, the main objective of information collection. HCT folders were sampled from the HCT register starting a date 1 month before the audit and working backwards to select 5 HIV positive and 5 HIV negative patients seen over the preceding month. Ten preART folders were similarly sampled from the HCT Register with the additional criterion that the s had 5 to have attended at least 2 clinical visits after their HIV diagnosis. Denominators used in calculating indicators vary as clients are excluded if the question does not apply to them (e.g. contraception is not applicable to HIV positive children), and where there is missing data.

Facility data were entered in Excel spreadsheets and imported into STATA® version 9 for calculations of district proportions and confidence intervals for sampled data. Because proportional sampling had not been done it was necessary to introduce weighting factors. Data from the HCT folder reviews was weighted by the district proportion of HCT clients counselled in each facility. Data from the preART folder reviews was weighted against the district proportion of HCT clients diagnosed positive in each facility.

### **Findings**

#### ***HIV services in Cape Town***

Historically the implementation and management of routine preART HIV care has been relatively neglected, falling in the gap between the successful scale-up of initially HCT and then ART. The expectation of the HIV programme was that HCT is the entry point to the HIV services and positive clients held in care receiving a package of prevention and care with regular monitoring until eligible for ART. The implementation of this continuum in Cape Town is described in Panel 1.

Locally defined clinical guidelines exist, but service models for implementation of guidelines do not.

PreART services include a set of prevention, early detection and treatment activities (see Panel 2) and are provided at most public primary care facilities. Facility managers are responsible for implementing the delivery of preART services with little programmatic support. There is little routine health information on the quality and effectiveness of preART care. Possible models of care were not included in policy making and resources were not added. Existing staff were trained to deliver care. In some facilities there are dedicated HIV clinics with trained staff, while in others the general outpatient service offers HIV care in addition to other care. Approximately two-thirds of facilities are run by the local authority that are nurse-driven with doctor support, while in provincially managed facilities, both nurses and doctors provide first-line care.

HCT is provided within all public primary care facilities. However ART has been delivered at a sub-set of accredited sites. The scale up of HCT and ART was driven by provincial and district managers in response to analyses of local need and national directives. Additional funding for HCT was allocated for counsellors and rapid test kits and, staff, drugs and monitoring and evaluation systems were allocated for ART services.

### ***The 2010 assessment***

The full audit was conducted in 133 public primary level facilities in Cape Town , all of which offered HCT. Only 123 facilities offered preART care (midwife obstetrical services and youth centres did not) and 122 of these were audited (99%) for preART care. All 133 facility managers were interviewed and gave information on the training of 1307 clinical staff. Folder reviews were conducted using records of 634 clients found to be positive at HCT - "HCT clients" - and using records of 1115 known HIV clients attending for preART care - "preART clients". Five hundred and twenty-five (47%) of these preART clients were found to be eligible for ART.

Table 1 lists key audit indicators for 2010. Access to preART care depends on both access to an HIV diagnosis and continuity between HCT and preART services. The uptake of HCT was 456,145 (17.8%).

Whilst the location of HCT within the same facilities providing preART care should facilitate access, 77.5% of positive HCT clients had a CD4 count done and only 46.6% were clinically staged. CD4 testing takes place on the same day as HIV testing but staging takes place in preART care. Both assessments determine the care path of HIV-infected clients.

Two-thirds of clinical staff (professional nurses and doctors) were trained in preART care. 82% of facilities had functional stock control mechanisms for a basket of tracer HIV/TB/STI drugs and a minority of clinics - 4.5% - experienced drug stock outs in the last 6 months. Evaluation of quality of care was defined as adherence to the current local service guidelines. We found important gaps. Only 50.1% of clients were evaluated for social assistance and 32.2% of women had ever had a PAP smear done. There are missed opportunities for integrated care with 67.2% being symptomatically screened for

tuberculosis at their last clinic visit. There were missed opportunities for positive prevention in the care received: only 48.3% of clients had their contraceptive needs assessed, 61.2% were screened symptomatically for sexually transmitted infections and 42.5% were issued with condoms at their last clinic visit.

Breaks in the continuity of care occurred in preART service delivery with management plans only noted in 63.9% of HIV-infected patients accessing care. This compromises continuity of care in a context where patients are often seen by different clinicians. We found that patients are not monitored optimally for eligibility for ART (45.7% of preART patients were staged clinically and 88.5% had their CD4 count measured according to the current protocol). Furthermore only 47.2% of patients who were monitored and found to be eligible for antiretroviral therapy were referred appropriately to a ARV service point.

ART mostly function as a separate referral service within the primary care setting.

## **Discussion**

Timeous health information is an essential management tool to deliver an effective service, particularly during the early phases of programme implementation. The HIV programme, with its component services of HCT, prevention of mother-to-child-transmission (PMTCT), ART and care of co-infected TB patients has an extensive set of data elements and indicators collected through different registers.

While information assists in successfully managing the programme, registers create substantial administrative work (Jacucci et al, 2006; Nadol et al., 2008) within a health system that is already stretched (Coovadia et al., 2009; Steyn et al., 2008). Introducing yet another register to collect routine data on the care of patients diagnosed HIV positive, would be ill-advised as this data is best suited to cohort analysis and is an onerous form of data collection and analysis. The evaluation of preART care in the Cape Metropole shows that regular periodic audits are an attractive alternative. Audits provide a comprehensive snapshot and are especially useful for assessing inputs and processes – important components of a health information system at local level (AbouZahr and Boerma, 2005). Audits have the added advantage of creating the opportunity to engage sub district managers and facility staff in a quality improvement process that can be linked to operational plans within the facility and sub district.

This evaluation shows a break in the continuum of care between HCT and ART and supports the similar finding of Kranzer et al. (2010) who followed up a sample of HIV-infected clients attending primary care services in a periurban community in Cape Town. They found that only 62.6% attended for a CD4 count measurement within 6 months of testing HIV positive; one third of individuals with timely CD4 counts were eligible for ART and, two thirds of those were successfully linked to ART care. This break in continuity is likely to contribute to the problem of late presentation and initiation on ART described by Bekker et al. (2006), despite the high HCT uptake. Low CD4 counts on ART initiation are associated with high early mortality (Lawn et al., 2006; Lawn et al., 2008). This could be reduced by careful

management of preART services upstream with attention to continuity, quality and retention in care.

The break in the continuity of care between HCT and the ART service highlights the danger of parallel implementation of component HIV services and the need to facilitate patient referral between members of teams and across the continuum of care. Vertical and horizontal models of service delivery have been the focus of much debate in the literature (Travis et al., 2004; Coovadia & Hadingham, 2005). Whilst vertical models of implementation of ART offer initial programme advantages such as close management and quality assurance, disadvantages are now emerging. Our evaluation shows that, while there are close working relationships between programme components, fragmentation persists which impacts negatively on patient care with leakages from the system. The service delivery platform supports a smooth transfer of clients from HCT service to preART but vertical orientation persists, perhaps because different health cadres are involved. Until 2010 HCT was lay counsellors-driven while preART was nurse- and doctor-driven and guideline development and training focussed on specific components with little attention to how they fit together. Health workers need to see their role in relation to the team and within a continuum of care, which could be addressed through improved training, mentorship and supervision. New and existing models of service delivery must be adapted to support client care across the full continuum. The field of maternal, newborn and child health, while not addressing all the health needs of women, has begun to recognise the programmatic advantages of a continuum of care, conceptualising how it would work and assessing the effectiveness of a combination of interventions (WHO, 2005; PMNCH, 2006; Mangiattera et al., 2006; Bhutta et al., 2008; Kerber et al., 2007). The continuum of care is understood to work across time and place to avoid fragmentation or duplication of services, provide care for mothers and children, delivering comprehensive services rather than focusing on single health issues. These approaches have much to offer the design of HIV programmes, particularly with the current quest to integrate PMTCT programmes within the rest of HIV services, and HIV treatment services within maternity services. Research has shown that high loss to follow up occurs post delivery of women who are started on ART as part of the PMTCT programme (Kaplan et al., 2008). The prevention and therapeutic health needs of HIV positive men, women and children across the life cycle need to be addressed through services that retain clients in appropriate care.

We found that opportunities for HIV prevention interventions in preART services were being lost, particularly in relation to positive prevention. Proportions of patients who received support promoting safer sex practices, sexual health and reproductive health choices were low. This demonstrates the divide between prevention and care interventions: prevention is neglected within the clinical context and is seen as separate from therapeutic care activities. In much of the HIV literature “care” is synonymous with ART.

### *Limitations*

We have presented the Cape Town experience as an urban case study of some of the problems encountered in the scale up of preART HIV care. Cape Town is perhaps not typical

in that it has more financial, supervisory and management resources than many other districts in South Africa. But in identifying problems within a better-resourced programme we probably err on the side of underestimating the extent of the problems elsewhere. Pilot work done in a rural area in KwaZulu-Natal reveals similar programme challenges in delivering quality preART care (personal communication Loveday, Researcher, Medical Research Council, 2008). The lessons from this evaluation will have relevance to other developing country settings which have promoted the up-scaling of HCT and ART, without simultaneously developing, and actively managing the implementation of integrated models of preART care at district level. While we have demonstrated the role that preART care plays in the continuum of HIV services, we have not attempted to cost it. In our setting it has been assumed, perhaps erroneously, that preART can be absorbed by the existing public primary care services. The scale up of ART services has been accompanied by research on its affordability (Cleary and McIntyre, 2010) and additional resources have been made available. Similar costing studies need to be undertaken to inform the choice of model of delivering preART care in resource-limited settings and to motivate for additional resources.

The use of record reviews in this evaluation is a limitation as information recorded in a clinical folder does not necessarily reflect the completeness or quality of the service rendered. In busy settings notetaking is often poor and staff do not record all interventions. Customised HIV stationery was developed to prompt a quality consultation and aid notetaking. However the inclusion of checklists makes overrecording a possibility as staff may just tick all the necessary boxes. Even if the activity is done (for example, disclosure discussed) there is no guarantee that the topic is covered sufficiently to have impact.

This evaluation also has a number of statistical limitations. The quota method of sampling employed means that the sampling was not proportional to size of the service load or local HIV burdens: ten patient folders were sampled from each facility. There are precedents for this in other quality improvement processes (Moys, 2002) where the emphasis is on identifying major service gaps in an assessment-analysis-action-review process. At facility level, the number of folders reviewed is too small to give statistically precise results. At district level the aggregated number of folders reviewed becomes considerable (n=1115) but cannot be taken to be representative of all clients in HIV care in the district as non-probability sampling has limited external validity. We weighted the results of each facility using the case load of positive HCT patients in each facility as a means of reducing the bias as large facilities are relatively underrepresented and small facilities are relatively overrepresented. Large facilities if not adequately staffed may provide worse quality of care.

## **Conclusion**

This evaluation shows that while a package of preART care has been clearly defined in Cape Town, it has not been fully implemented. Additional resources have not been allocated, and there has been little guidance on service delivery models and on how to operationalise continuity between HCT, preART and ART. We have identified weaknesses in the continuity and quality of service delivered, and contend that the implementation of preART care is crucial to create a continuum of care for HIV positive clients from HCT through to ART. Only



then will then will the key programme objectives of provision of positive prevention and timeous access to ART be possible.

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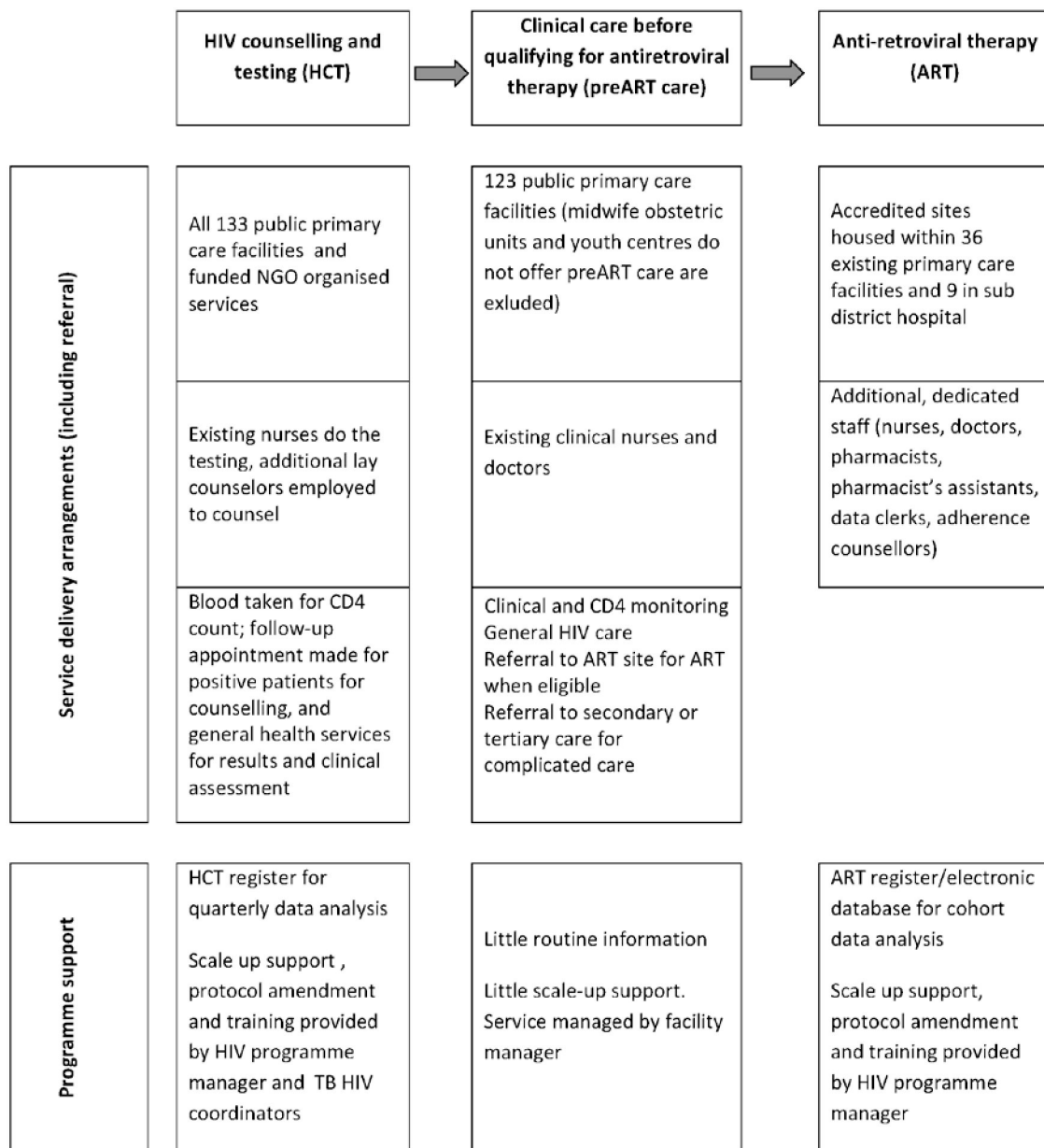
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Panel 1. The continuum of adult HIV services in Cape Town in 2010



**Panel 2. The package of nonART care for adults in Cape Town in 2009**

**Baseline clinical assessment** including:

- baseline WHO stage
- baseline syphilis test
- baseline PAP smear (if no normal PAP result in the last three years)
- baseline Body Mass Index

**Routine visits** including baseline visit :

- Diagnose and manage any opportunistic infections (and revise WHO staging if necessary)
- Assess reproductive health care (men and women)
- Assess condom use and offer condoms in the consultation room
- Symptomatic screen for STIs (and syndromic treatment if screen positive)
- Symptomatic screen for TB (and investigation if screen positive)
- Cotrimoxazole prophylaxis (unless stage 1 with CD4 > 200)
- Nutritional assessment (provision of nutritional supplements if the patient qualifies – BMI < 18.5 or > 10% weight loss or MUAC<23cm)
- Social assessment, including support around disclosure

**As indicated:**

- Ongoing counselling (including sexual and reproductive health): at least 3 sessions post diagnosis, then annually/6 monthly with CD4 result
- Repeat of CD4 count – annually if > 350; 6-monthly if <350
- Repeat PAP smear every 3 years unless abnormal result dictates earlier repeat
- Refer patient for ARVs if necessary – WHO 4 (excluding extrapulmonary tuberculosis) or CD4 < 200 (CD4 < 250 for pregnant women)

**Table 1. Assessment of quality of preART care and its continuity with HCT and ART**

Evaluation Domain	Data source	Indicator	Pro-portion (n)	95% CI
Access	Routine register and population data	% Annual HCT uptake (adults>15 years HIV tested)	17.8% (2729297)	N/A*
	HCT Folder Review	% Positive HCT clients with CD4 counts	77.5% (634)	73.3%-81.7%
		% Positive HCT clients clinically staged	46.6% (633)	41.3%-51.4%
	Facility Manager Interview	% Facilities offering daily preART HIV services	92.5% (133)	N/A*
Availability of key resources and staff capacity	Facility Manager Interview	% Clinical staff trained in preART care	65.5% (1307)	N/A*
		% Facilities with stock outs of cotrimoxazole	4.5% (133)	N/A*
		% Facilities with functional stock control mechanisms for a basket of HIV/TB/STI items	82.4% (114)	N/A*
Quality of care	PreART Care Folder Review	% Clients with notes on the customised HIV stationery	80.4% (1115)	76.6%-84.1%
		% Clients evaluated for social assistance	50.1% (1115)	45.4%-54.8%
		% Clients with Pap smear (women only)	32.2% (746)	27.2%-37.2%
		Clients with symptomatic TB screen and appropriate follow up at last visit	67.2% (1068)	63.7%-71.7%
positive prevention	PreART Care Folder Review	% Clients with contraceptive needs assessed (men and women) at last	48.3% (1072)	43.4%-53.1%

		visit		
		% Clients with symptomatic STI screen and appropriate follow up at last visit	61.2% (1104)	56.9%- 66.1%
		% Clients with condoms issued at their last visit	42.5% (1102)	37.8%- 47.1%
Continuity of care	PreART Care Folder Review	% Clients clinically staged at last visit	45.7% (1115)	47.1%- 50.3%
		% Clients with CD4 monitoring according to protocol	88.5% (1115)	85.6%- 91.4%
		% Clients with a management plan noted at last visit	63.9% (1115)	59.4%- 68.4%
		% Clients eligible for ARVs referred appropriately	47.2% (525)	38.4%- 65.1%

\*N/A as population was not sampled; entire adult population, staff complement or total public primary care facilities included.

The annual HCT uptake has as its numerator the number of clients tested, and the denominator is the adult population over 15 years