How we monitor the “Programme”

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Hierarchy of intent

- Clinical care
  - Identify where or with whom to intervene
    - Missed appointments or disengaged from care
    - Suboptimal monitoring or treatment
    - Clinical risk mitigation
  - Quality of care and clinical governance
    - Audits, morbidity and mortality surveillance

- Manage programme performance at each level
  - Key outcome metrics
    - within facility, across facilities, across subdistricts, etc.
    - Cohort reports on enrolment, retention, virologic completion

- Resource allocation
  - Monthly reports on enrolments and retention

- Strategic information to inform programme design and evolution
  - True outcomes and impact, required occasionally not continuously
  - Cohort studies, surveys, occasional large data exercises
  - Morbidity and mortality surveillance
Linking what we do to the hierarchy

Other data sources

- Household surveys (4-yearly)
- Resistance surveillance
- Consolidated laboratory data; drug procurement
- Thembisa model
- Cohort studies
- Vital registration, morbidity surveillance

Three Tier System (Patient information system)

- outputs (monthly) and outcomes (quarterly) for facility management
- reports at facility level for patient management
The three-tier approach to ART monitoring

<table>
<thead>
<tr>
<th>Tier 1 - Paper registers</th>
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<tbody>
<tr>
<td>- Immediate solution while waiting for hardware to be procured</td>
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<td>- Ideal for small facilities with low enrolment</td>
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<table>
<thead>
<tr>
<th>Tier 2 – Offline electronic register</th>
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<td>- Quick back-capture directly from paper registers</td>
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<tr>
<td>- Offline, simple yet robust system</td>
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<td>- Can scale up quickly and relatively inexpensively</td>
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<th>Tier 3 – Networked electronic medical record</th>
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<td>- Can collect a larger dataset and offers more management functions</td>
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<td>- Can be used as a sentinel surveillance database for answering more complicated clinical questions and tracking patient movement</td>
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<td>- Correctly utilising sentinel sites takes the burden of collecting large data sets away from the rest of the HIV &amp; ART facilities</td>
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Source: Osler, JIAS 2014
Current challenges with routine monitoring
Dynamic patient population

- Enrolment
- True LTF
- Exaggerated LTF
- Retained in care more robust
- Silent transfers and interrupters
- Silent transfers and return to care
Number of people on ART in South Africa

- DHIS (public sector only)
- THEMBSIA Model (pub+pvt)
- UNGASS reports public sector
- CCMT 2009 report
- National HIV household survey
- NHLS viral loads* (adjusted 1/0.75)
- Johnson 2012 (Public sector)

*Carmona, Bronze, MacLeod: Monitoring and Evaluation of Effectiveness of CCMT Programme

3,094,896 patients on public sector ART, end March 2015
Viral load completion (VLD) and suppression (VLS)

Duration on ART in months

Reported 2012/13
Reported 2013/14
Reported 2014/15
Viral load testing loop

Blood taken

Got to lab and tested

Result returned to facility

Result in folder

Result seen by clinician

Result in clinical record keeping

Result transcribed into register

Management information
Where to integrate automated results retrieval

On-the-fly results retrieval

PMI

Registry / front desk

Observation room

Clinical areas

Pharmacy
Opportunities
If we can get connectivity right then

- **PMI and patient registration** essential first step
  - Ensures all data no matter how and when transferred, are linkable

- **Results retrieval on the fly on patient arrival**
  - Strengthen the PMI and patient flow past registry on arrival
  - Properly printed pathologist signed reports, printed and filed on the fly, placed on the top of the folder, available to clinician and backoffice
  - Data collected by backend systems (lab, TIER.Net, RxSolution), much more readily linkable no matter how it is transferred upwards

- **Opportunity to test, mature and assess infrastructure readiness for….**
With better linkage and patient identifiers we can pursue

- **Increased interoperability of TIER 2 systems**
  - HPRS / PMI integration
  - Connection to health exchanges for retrieval and sharing of clinical data, including laboratory and encounters with the intention of improving the quality and efficiency of reports for local patient and facility management

- As stability improves and infrastructure matures, readiness for a **TIER 3** (networked) system can be properly assessed, and migration can be incremental

Avoid multiple electronic patient information systems in the same facility

Ensure a single TIER 3 system within entire jurisdictions, linked to HIS strategy and enterprise primary care system

Identify the right tipping point
3. Person-level data, keep it simple and coherent

- Routinely collected person level information
  - Three potential sources, stick to two
    - Patient information systems
    - Laboratory systems
    - Event based data specially collected
      - Dedicated registers
      - Notification (sometimes referred to as case-based surveillance)
  - Add value, limit dependency, until mature
    - Reports; Query engines/ API’s for hybrid systems
    - Single-patient viewer
  - Follow a federated health exchange model
    - Responsible party is the deliverer of care
    - Pass through curated data from province to national
  - Clear understanding of difference between information for clinical care, facility management and strategic purposes
High level architecture and data load process

Sources* Extract, Transform, Load, Curate

Repositories

Access

- Clinicom
- PHCIS/EKAPA
- TIER/ETR/EDR
- JAC/CDU
- NHLS
- PACS/ECM
- Mortality
- PPIP/CHIP
- mHealth

Daily or periodic database pulls
or loading of exports

OpenHIM (real-time)

Staging

Holding

Source archive

Core tables
Lookup tables
Mapping tables

Person

Place

Episodes

Code

Date (time)

Household

Facility

Clinical

Patient

Anonymous view(s)

Analysis view (anonymous)

SP layer for connectors

Operational reports (eg. Sharepoint)

Applications (eg. SPV, PHCIS)

- OpenHIM

* No record is ever changed in any source system
4. Digitise HIV testing (and all point of care tests)

- Leverage the incredible LIS
- Avoid new case registers
- Audit trail in the facility, send a copy with other specimens
- Remunerate the laboratory for data capture
- Ensure dedicated test codes so as not to hold the NHLS responsible for test quality, and clearly identify as PoC tests in results retrieval

Benefits
- Tests for the whole cascade on one system
- Can replace testing registers
- Triangulate with patient information systems as they start capturing broader HIV care (e.g. TIER.Net HCT module)
- Huge benefit to health exchange / centralised data
5. New cohort data elements

- Interruptions (ITR)
- Return to care (RET)

- Benefits
  - Temporally stable metrics on time to first loss
  - Ability to follow “
Comparing trends to first versus current loss to care status

Loss to follow-up or death by calendar period

Based on 30,000 patients from Khayelithsa, South Africa
6. Mortality and morbidity surveillance

- Link mortality and cause of death into the nascent health exchanges
- Work backwards to find missed opportunities where we see
  - Deaths
  - HIV associated events
  - 40% of deaths in 2012 in the WC were in patients who were previously on ART
  - 60% of medical inpatients in a WC district hospital in 2012 were HIV-infected, 2/3 ART exposed (Meintjes 2015)
- M&M approach common to many conditions, but with a population focus
  - what went wrong anywhere in the system prior to the event
Impact of ART on adult survival – total deaths by age and year

Source: Rapid mortality surveillance report 2013: SA MRC: Dorrington, Bradshaw, Laubscher, Nannan
Summary
Linking what we do to the hierarchy

Other data sources
- Household surveys (4 yearly)
- Resistance surveillance
- Consolidated laboratory data; drug procurement
- Thembisa model
- Cohort studies
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Three Tier System (Patient information system)
- reports at facility level for patient management
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Proposals

- Expansion of the PMI / patient registration systems
- Incremental transition to TIER 3 until tipping point reached
- Clear approach to integration and use of person-level data linked to nascent health information exchange aspirations
- Digitise point of care tests
- New cohort data elements
- Person level mortality and morbidity surveillance linkable to other service data