The Cascade of Care:
How HIV data models shape understanding of "monitoring and evaluation", and "surveillance and survey"

UCoE - AIDS Research Center Atma Jaya Virtual International Seminar, 29 June, 2021, online

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Please cite as:
* Handayani, A., Hegarty, B., Pillai, P., Spreadborough, K. (2021) The Cascade of Care: How data models shape understanding of "monitoring and evaluation", and "surveillance and survey". DOI: https://doi.org/10.26188/14784783
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Abstract:
This paper sets up the context in which the Cascade of Care is applied to HIV prevention in the Indonesian context. The Cascade of Care, hence forth referred to as the cascade, is a component of the broader Continuum of Care which is focused on the process from being at risk of HIV through to HIV prevention.
This paper first outlines the cascade as a data model, which is a core component of providing policy makers and funders a high-level picture of progress towards HIV prevention. The paper considers the implications of the 90/90/90 approach to HIV prevention - "90% of all persons living with HIV (PLHIV) are aware of their HIV status, 90% of all people who know their status are receiving antiretroviral therapy (ART), and 90% of those on ART are virally suppressed".
The paper then considers two main components required to supply data to the cascade. First, monitoring and evaluation which emphasises that data should be used to drive decisions is examined. Second, surveillance and survey is considered which are the tools by which this data is collected. Throughout the paper, consideration is given to the purpose of the cascade and how the cascade shapes conceptualisation of these key

CATEGORIES
- Public Health and Health Services not elsewhere classified
- Health Care
- Data Structures

KEYWORDS
data · HIV · Indonesia · Cascade · Cascade of Care · Care

Pre-print is open access on Figshare here:

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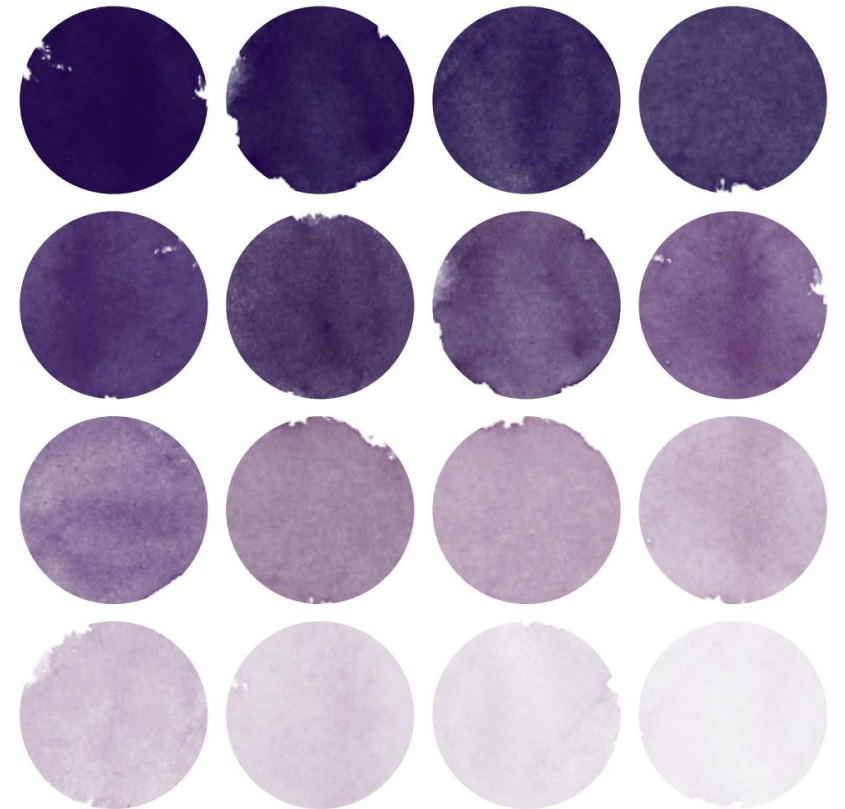
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"Quality data are required to measure service access, service uptake, populations covered, quality and acceptability along the entire continuum of HIV services"

- World Health Organization, 2016, p. 28.

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1. Context and introduction

2. Discussion of the models

3. Monitoring and Evaluation, and Surveillance and Survey

4. Bringing it all together

5. Open discussion

Figure 1.1 Using the cascade to highlight gaps and linkages in HIV services - Philippines
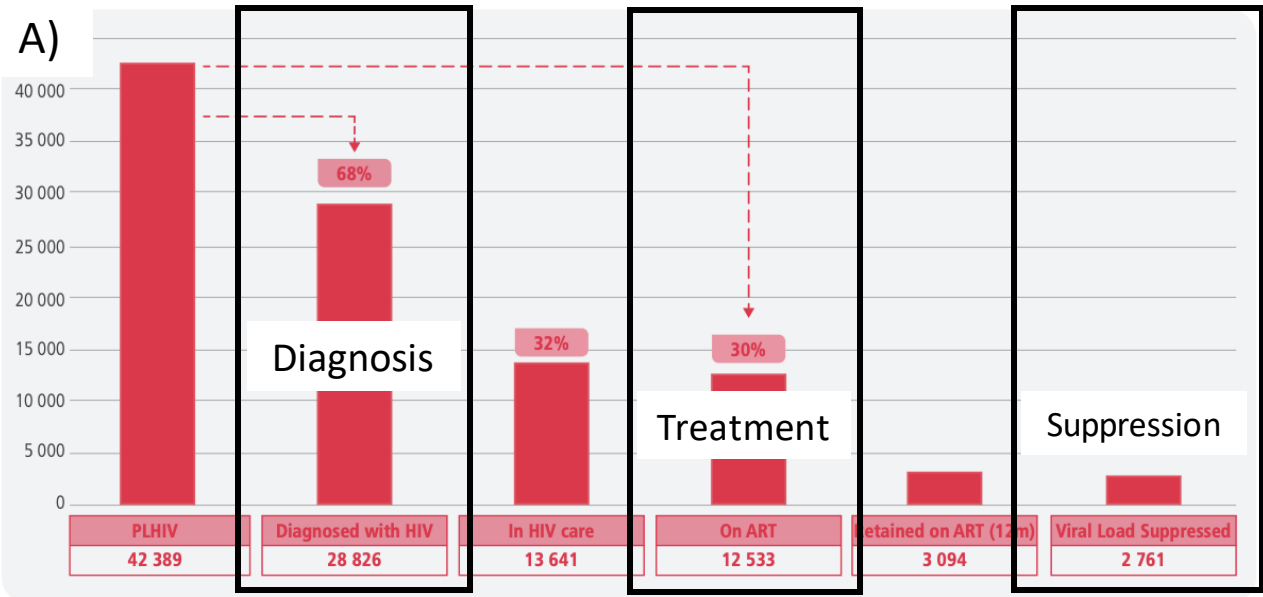
Figure 1.5 Cascade analysis to quantify progress and gaps towards the 90-90-90 targets

A)

PLHIV	Diagnosed with HIV	In HIV care	On ART	Retained on ART (12m)	Viral Load Suppressed
42 389	28 826	13 641	12 533	3 094	2 761

Diagnosis — 68%
Treatment — 32%, 30%
Suppression

B)

Diagnosis — 90%, 205 724, 55%, 126 604
Treatment — 90%, 185 151, 27%, 60 753
Suppression — 90%, 166 636, 21%, 47 205
43%

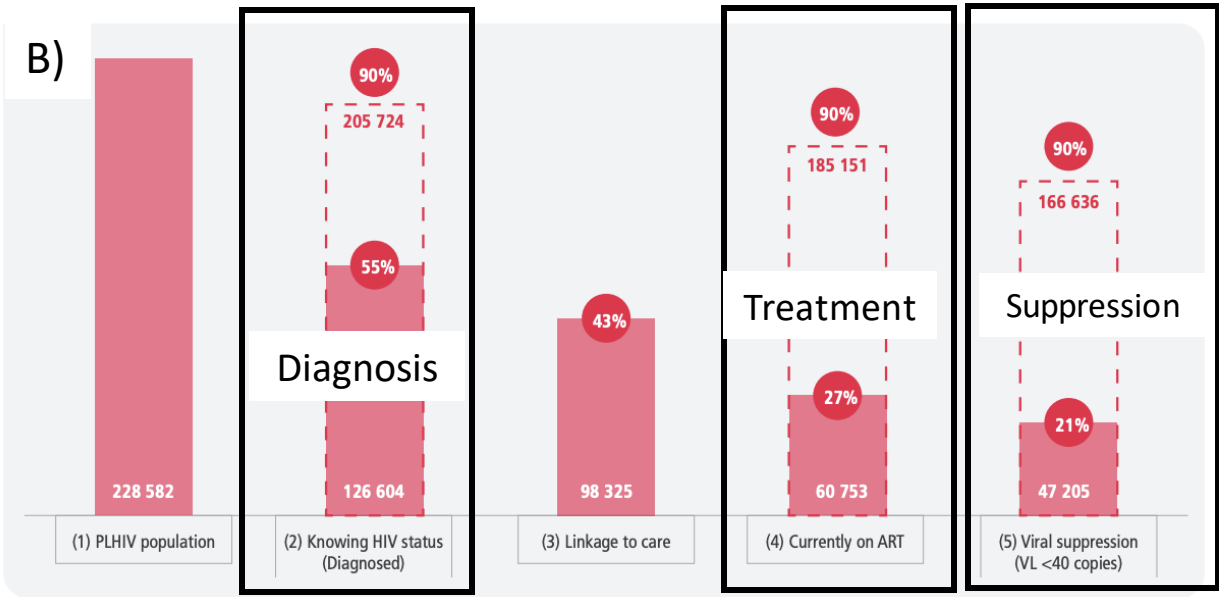| (1) PLHIV population	(2) Knowing HIV status (Diagnosed)	(3) Linkage to care	(4) Currently on ART	(5) Viral suppression (VL <40 copies)
228 582		98 325		

Figure 1.17 Longitudinal care cascade, La Romana, Dominican Republic, 2011

C)

Diagnosis — 100%
In care within 3 months — 65%
Treatment — 36%
Suppression — 4%

Diagnosed	In care within 3 months	On ART	Virologically suppressed at 12 months

Adapted from: Ref. (6).
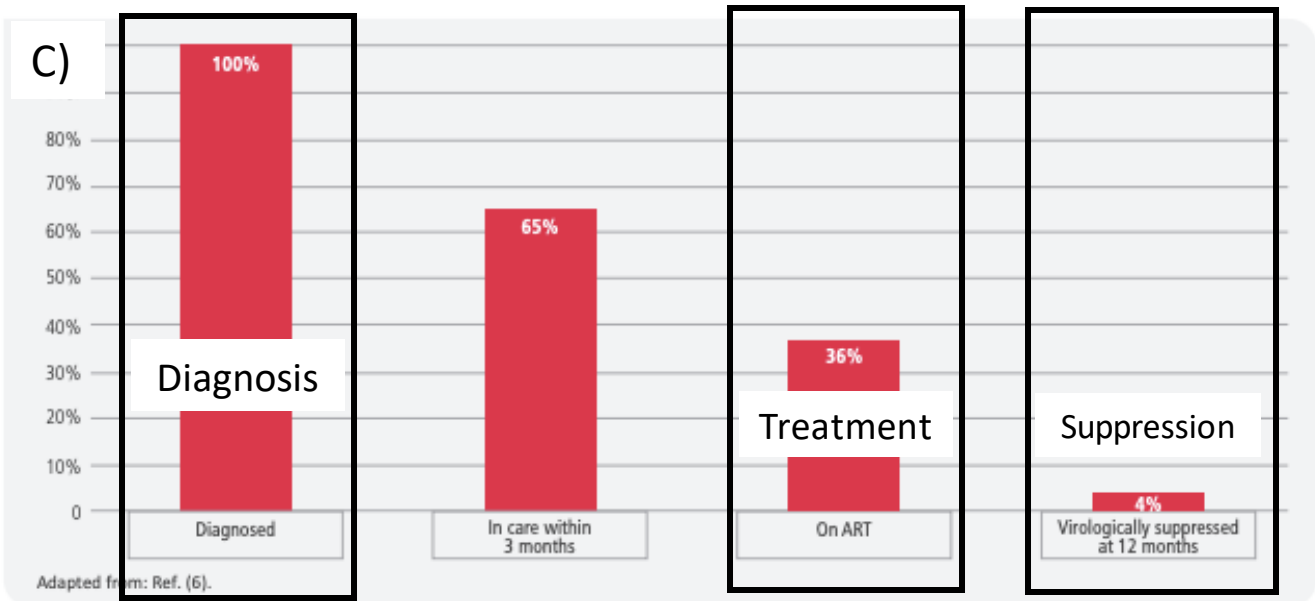
LINKAGES Cascade Framework

ENABLING ENVIRONMENT

⊟ **Human rights**   ⚖️ **Gender equality**   ✋ **Zero tolerance for stigma, discrimination, and violence**

Advocacy

Identify key populations

Reach key populations

Prevention

Diagnosis

HIV-

HIV+

Newly Diagnosed

Known Positive

± **Key populations know status**

Treatment

90%

Enroll in care

90%

Initiate ART

Sustain on ART

Care and treatment as prevention

Suppression

90%

VL **Suppress viral loads**

Ongoing engagement with all KPs on prevention, including access to condoms, lubricants, needles/syringes, and psychosocial support. Regular STI screening and treatment, HTC, and PrEP for HIV-negative KPs.

Earliest access and adherence to ART for HIV-positive KPs upon HIV diagnosis, in support of treatment as prevention, and regular STI screening and treatment

Community engagement and capacity development

1. Identify key populations

Prevention services

Continuous prevention and testing for HIV-negative KPs, timely HIV results

3. Test key populations

4. Diagnose PLHIV

5. Enroll in care

Diagnosis

2. Reach key populations

Outreach, HTC promotion/linkages, and HIV literacy

Retained in care; determination of ART eligibility

ART adherence

Timely ART initiation

6. Initiate ART

Suppression

7. Sustain on ART

Treatment

8. Suppress viral loads

Suppression

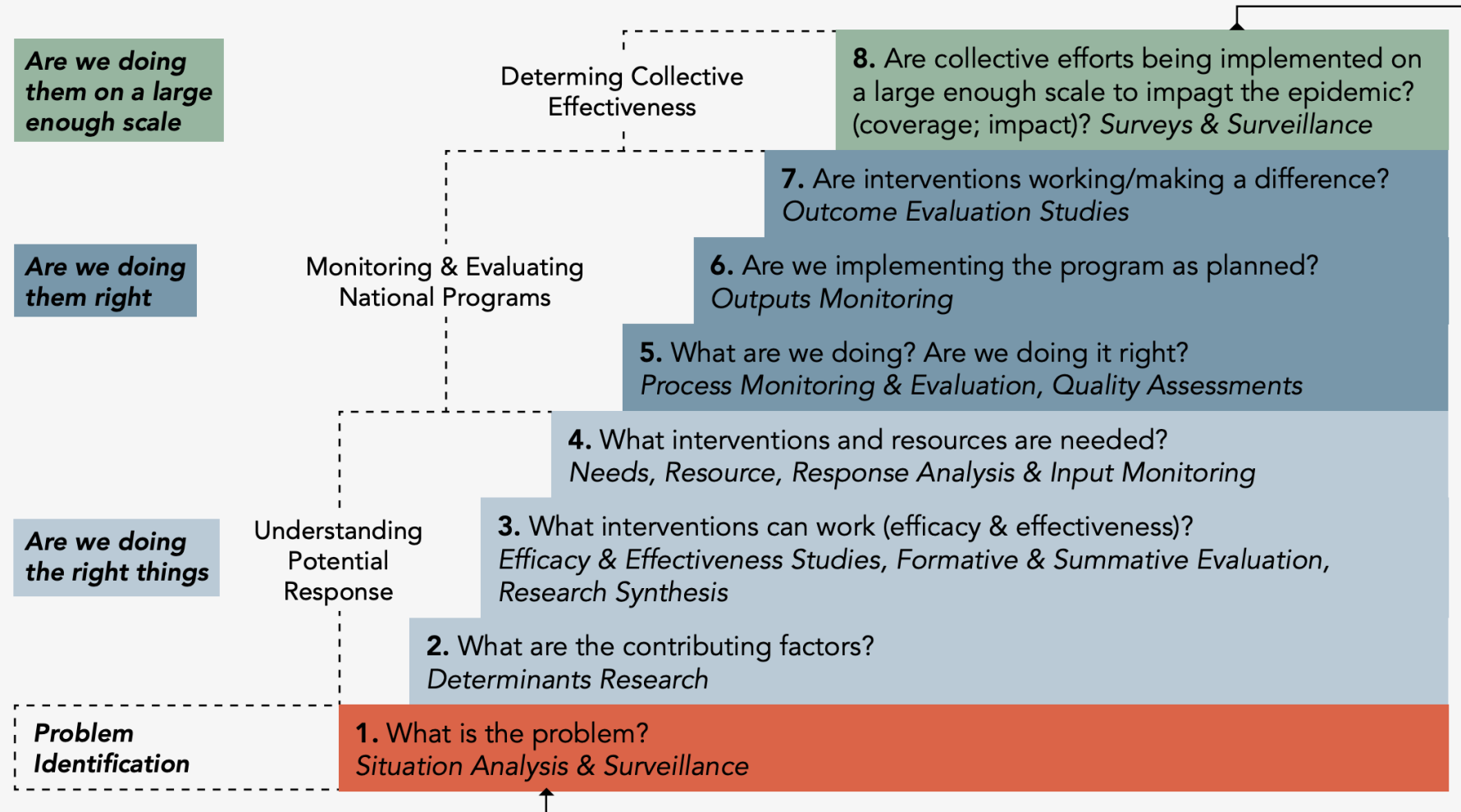# Monitoring and Evalutation (M&E)

Evaluation	Monitoring
"The systematic collection of information about the activities, characteristics and outcomes of a specific programme to determine its merit or worth" (UNAIDS, n.d., p. 14).	Refers to the collection of data for evaluating program performance: e.g. "serosurveillance, behavioural surveys, routine programme monitoring" (UNAIDS, n.d., 47).

FIGURE 1. A PUBLIC HEALTH QUESTIONS APPROACH TO HIV MONITORING AND EVALUATION

Are we doing them on a large enough scale

Determing Collective Effectiveness

8. Are collective efforts being implemented on a large enough scale to impagt the epidemic? (coverage; impact)? *Surveys & Surveillance*

Are we doing them right

Monitoring & Evaluating National Programs

7. Are interventions working/making a difference? *Outcome Evaluation Studies*

6. Are we implementing the program as planned? *Outputs Monitoring*

5. What are we doing? Are we doing it right? *Process Monitoring & Evaluation, Quality Assessments*

Are we doing the right things

Understanding Potential Response

4. What interventions and resources are needed? *Needs, Resource, Response Analysis & Input Monitoring*

3. What interventions can work (efficacy & effectiveness)? *Efficacy & Effectiveness Studies, Formative & Summative Evaluation, Research Synthesis*

2. What are the contributing factors? *Determinants Research*

Problem Identification

1. What is the problem? *Situation Analysis & Surveillance*

Source: Rugg D, Carael M, Boerma T, Novak J. Global advances in monitoring and evaluation of HIV/AIDS: from AIDS case reporting to program improvement. In: Global Advances in Monitoring and Evaluation of HIV/AIDS, Rugg D, Peersman G, Carael M (Eds). New Directions for Evaluation, 2004; 103:33–48.

Figure from UNAIDS, n.d., p. 16.

M&E in the context of the cascade

- M&E implimentation has increasingly been shped by the cascade

- This results in increasing biomedicalisation of how HIV is understood and addressed

- This biomedicalisation of M&E further reinforces its use in the cascade

M&E = treated HIV as the end point of a series of steps through which a patient moves.

↓

Each of these steps is focused on achieving viral suppression

↓

Emphasis on "treatment as prevention".

↓

Critique = "HIV care" defined narrowly in terms of **biomedicalisation, and** a goal of viral suppression.

Surveillance and Survey (S & S)

United States Centres for Disease Control

"[the] ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control,"

UNAIDS/WHO Working Group

"early-warning systems for the detection of changes in diseases or patterns, which allow for the necessary interventions to be put into practice to prevent new infections" (2003, p. 71)

Surveillance

- Surveillance relies on the collection of various kinds of data about the population

- Two types of surveillance
  - Syndromic surveillance - Data from routine reporting including case reporting (total number of tests undertaken, the number who test positive, the number who enrol in care)
  - Sentinel surveillance - Focused on periodic testing and behavioural surveys among at risk populations.

- Surveillance for HIV at the broadest level relies on the collection of various kinds of data and an important feature is focussing on data from key populations.
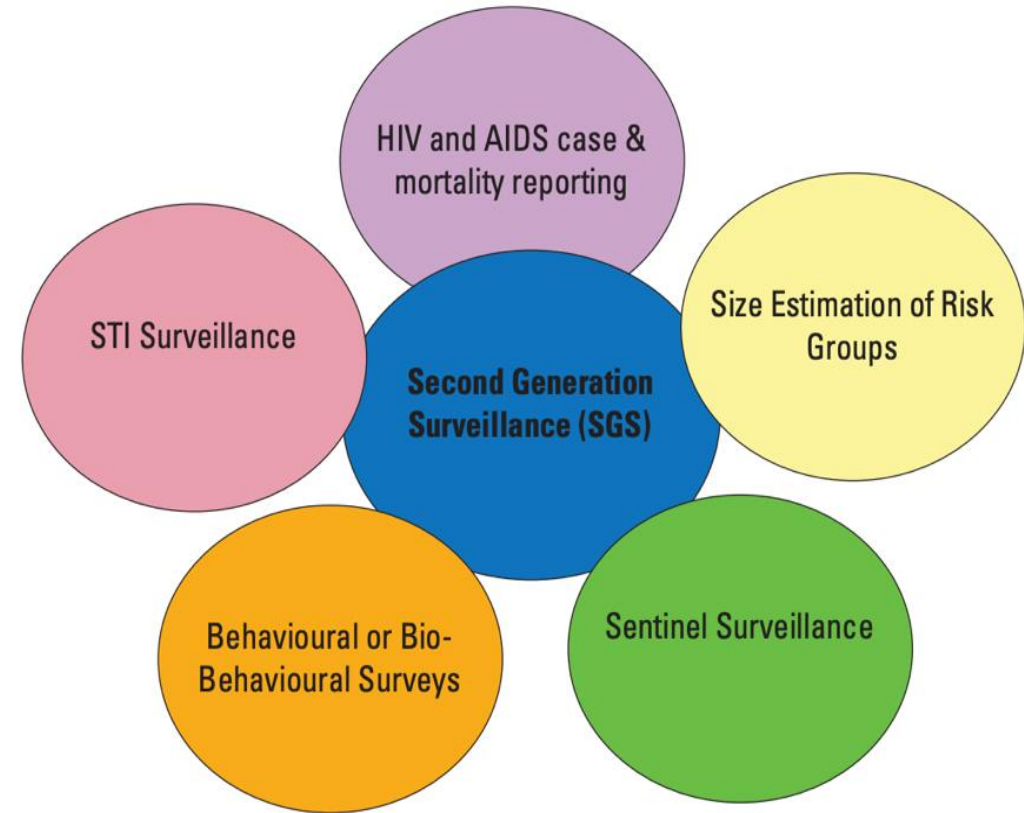
Components of HIV second generation surveillance

HIV Surveillance in Indonesia

- It appears that most of the data collections that comprise of "second generation surveillance" are used in Indonesia.

- This information appears to be collected and stored in "SIHA" (the Indonesian HIV/AIDS Online Data System) in a systematic manner

- Instances of data collection that can be classed as more traditional forms of "public health surveillance" are included in SIHA.

- A method of data collection that informs the M&E used to report to the cascade is the periodic biological and behavioural surveys of key populations through the Behavioural and Biological Survey (IBBS) in Indonesia undertaken once every three years

S and S in the context of the cascade

- Surveillance is an important part of the data collection mechanisms that makes the M&E possible
- WHO describes the close relationship between surveillance and M&E in HIV programs with the following key objectives
  - Surveillance tracks how the epidemic in a region is changing
  - M&E activities track how programmes are responding to the epidemic
  - The activities should be designed to be complementary so the outcomes and outputs correspond to the activities planned
- There is limited research about how surveillance is defined relative to the cascade model in Indonesia.
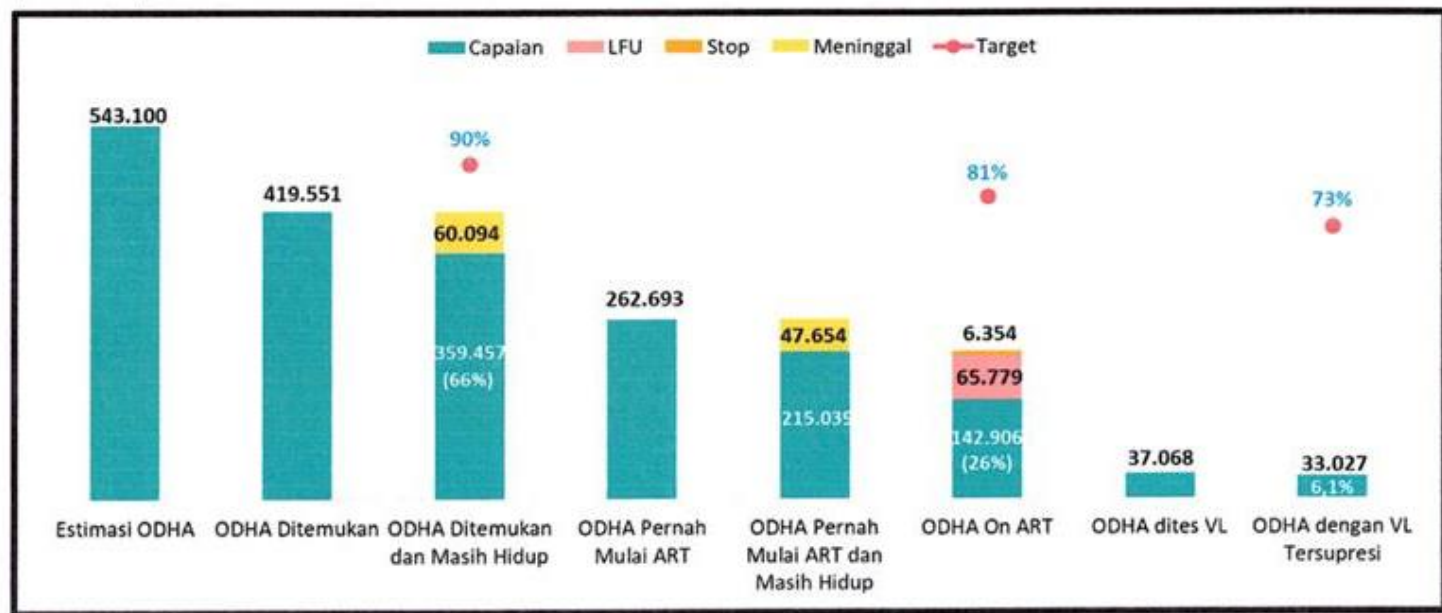
2020 - Laporan Triwulan 4 (October-Decembe 2019) (Quarterly HIV report produced with data collected in SIHA – HIV/AIDS Information System), Indonesian Ministry of Health

Gambar 9. Bagan Alur Pelaporan M&E terpadu LKB HIV
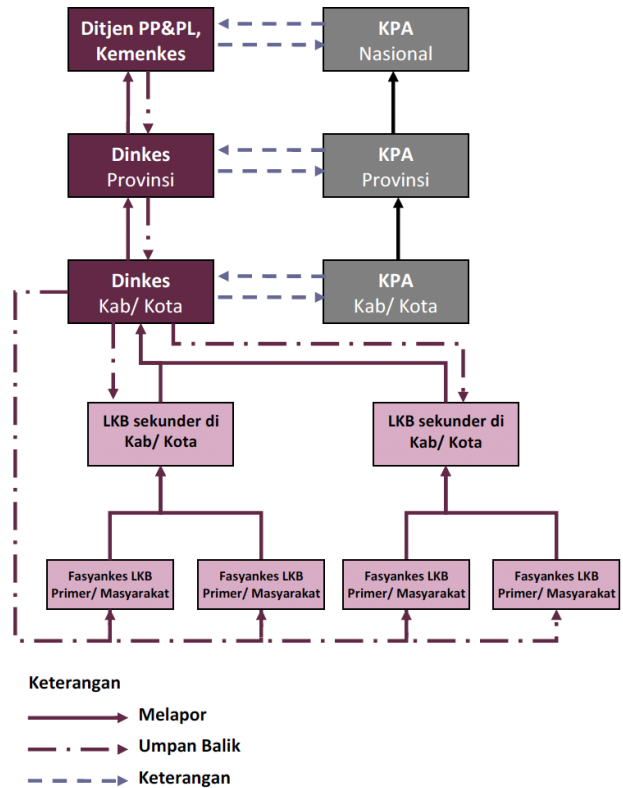
2012 - Pedoman Penerapan Layanan Komprehensif HIV-IMS Berkesinambungan

Tata Cara Pengisian Data Pasien di tingkat layanan/fasyankes Sampai Dihasilkannya formulir peLaporan
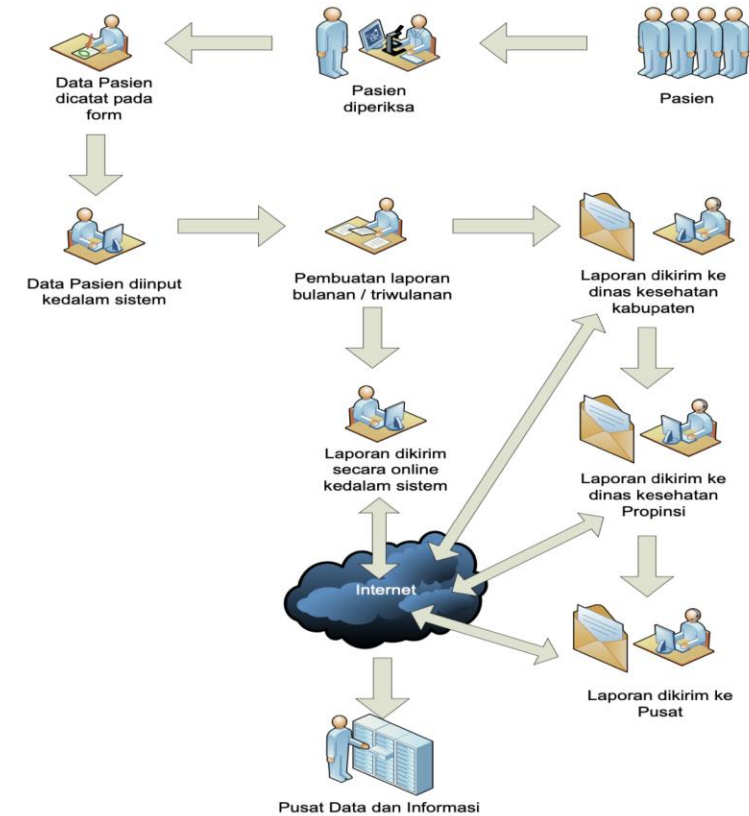
2015 - Petunjuk Teknis Pengisian Formulir Pencatatan dan Pelaporan Program Pengendalian HIV AIDS dan IMS (SIHA)

How do you use the cascade model?
Where do you get your data from for the cascade?
How do you collect your data for the cascade?
What are some problems with data collection?
How do you collect data across different organizations? What other/partner organizations do you work with to collect data at other steps in the cascade?
What other data should we be collecting that we are not?

References

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