

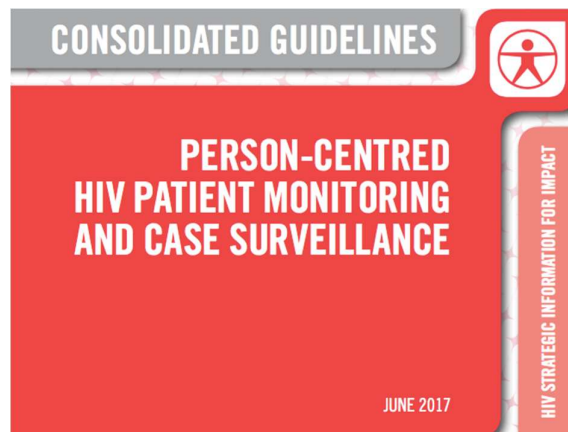
Report on the WHO AFRO regional workshop on unique identification and application to HIV patient monitoring and case surveillance: Pretoria, South Africa: 21-23 October 2019

"Implement person centred data for Mrs. Jones. So she feels comfortable that data is secured, that her life is made easier, will be able to get results, access to health, to medicines and prescription, not wake up at 4am to queue for a clinic that opens at 7am, will be able to have a cup of tea in the morning, think of Mrs. Jones in your own setting"

Meeting Presentation, Ms. M.P. Matsoso, Director General, National Department of Health, Republic of South Africa

1 Background

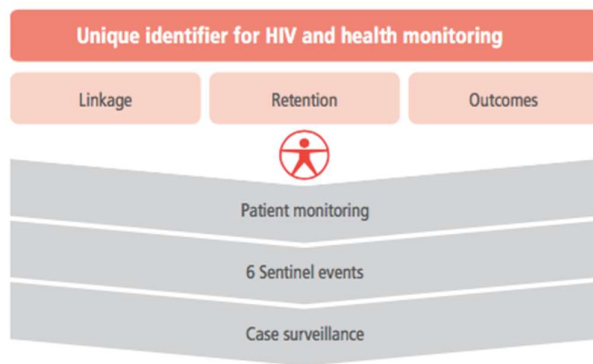
In 2017 WHO launched the consolidated guidelines on person centred HIV patient monitoring and case surveillance. The 15 recommendations, included 5 cross cutting recommendations on data systems, including the promotion and use of unique identifiers to develop person-centred health information systems. Two important use cases for implementing unique identifiers in the WHO person centred monitoring guidelines were patient monitoring and case surveillance.



WHO Consolidated guidelines on person-centred HIV patient monitoring and case surveillance, 2017¹

When applied to patient monitoring and case surveillance, unique identifiers contribute to retaining individuals in prevention, treatment and care services, deduplicating testing and treatment data, improving linkage between services, assessing outcomes and impact while ensuring confidentiality and security of individual health information. In addition, the adoption of unique identifiers is an important step in the transition from paper to electronic patient information systems which many countries in the region are undergoing.

¹ At : <https://www.who.int/hiv/pub/guidelines/person-centred-hiv-monitoring-guidelines/en/>



Unique identifiers for patient monitoring and case surveillance

Within this context WHO supported a workshop to bring together key countries in the region with the aim of building capacity in the adoption and implementation of unique identifiers and to support the development of country technical support plans. While the audience of the workshop was primarily HIV programme and data managers, the approaches to unique identification and possible solutions were cross-cutting across the health sector and the digital health plan.

2 Objectives of the workshop

The objectives of the workshop were to:

1. Introduce WHO global and AFRO guidance: to disseminate policy adoption and implementation guidance in the use and promotion of unique identifiers;
2. Introduce key components of implementing unique identifiers: to build capacity in the use and promotion of unique identifiers and support learning from country implementation experience;
3. Develop use cases for HIV person-centred patient monitoring and case surveillance: support countries in the development of use cases and develop practical implementation guidance for countries on unique identifiers for HIV patient monitoring and case surveillance with lessons learnt and best practices; and
4. Support countries in developing and refining short-term and medium-term technical and maturation plans for implementing unique identifiers for HIV person-centred patient monitoring and case surveillance.

3 Outputs of the workshop

The anticipated outputs of the workshop were to:

- Draft country technical support plans for adoption and implementation of unique identifiers for patient monitoring and case surveillance.
- Compile a meeting report with
 - implementation guidance for countries on unique identifiers with lessons learnt, best practices and updated country situational analysis for key countries; and

- individual country plans for moving forward in the implementation of unique identifiers for health in the short- and mid-term.

4 Workshop Report

4.1 Introduction

The WHO “Consolidated guidelines on person-centred HIV patient monitoring and case surveillance” were published to support countries in updating HIV patient monitoring and reporting tools, expanding existing HIV surveillance systems and investing in the adoption or expansion of unique patient identifiers. The guidelines contain fifteen major recommendations. Five of these recommendations applying to data systems, recommendations 11 to 15, were the primary focus of this workshop, and are described below in Box 1.

Box 1: Major recommendations on using unique identifiers for person-centred monitoring of HIV services

Recommendation 11. Promote and use unique identifiers in HIV patient records and data shared within the national HIV program shared within the national HIV programme. This **anonymous** code should be linked to their health records.

Recommendation 12: Transition progressively from paper-based to electronic patient information systems. Countries should use a tiered approach for transitioning from paper to electronic tools based on resource (electricity and networks) availability by site or setting, starting with high-volume sites, e.g. with more than 2000 patients.

Recommendation 13: Strengthen and establish different data security levels. Assess and establish different security levels for data elements and invest in robust databases and policies to protect security and confidentiality based on risks and benefits in individual settings.

Recommendation 14: Invest in data systems and ensure interoperability. Countries should invest in robust and secure data systems. As this is being done, strengthen the interoperability of electronic databases and opt for open-source standards for data systems.

Recommendation 15: Use individual data to improve programmes and long-term chronic health care. WHO recommends that data be linked to programme improvements and that evidence of these improvements be collected.

- **Strengthen retention and transfer** by supporting the routine sharing of information between clinics.
- **Ensure linkage** by supporting the routine sharing of information between testing, treatment, laboratory, pharmacy and other health services.
- **Strengthen integration with long-term chronic health care** by using unique identifiers to share information and link HIV to wider health services.
- **Invest in data analyst capacity**, including central and district data analysts and routine dashboards to feedback data in real time for programme improvement.
- **Invest in use of data for patient care at facility level for quality improvement**

Source: WHO Consolidated guidelines on person-centred HIV patient monitoring and case surveillance, 2017.

Countries were asked to review their implementation progress, both successes and challenges, on the implementation of the unique identifier. There was a strong emphasis on cross country learning and south-south sharing of experience.

4.2 Workshop outline

The workshop progressed logically through five consecutive sections, described here:

Section 1: Guidance and country lessons learned

- Guidance from WHO on
 - The workshop objectives and expected outcomes
 - WHO recommendations for person-centred HIV patient monitoring and case surveillance: the role of unique identifiers
 - WHO digital health global and AFRO strategy
 - Introduction to WHO accelerator kit for implementation and costing of digital interventions for HIV person-centred monitoring in development
- Learning from three countries: solutions and challenges in the use of HIV person-centred monitoring

Section 2: Key foundations of unique identifiers

- Principles and key elements for establishing unique identifiers and global best practices
- Interoperability and standards for interoperability
- Data security, confidentiality and ethical considerations

Section 3: Use cases for HIV patient monitoring and case surveillance

- Use of individual level data for patient care and programme improvement
- Country reporting on HIV patient monitoring as a use case for unique identifiers
- Country reporting on HIV case surveillance as a use case for unique identifiers
- Site visit to health facilities for demonstration of South African unique identifier system: patient registration use case

Section 4: Country determination of short- and medium-term action plans for policy adoption and scale up of the use of unique identifiers

- Identification of key gaps
- Description of existing country frameworks e.g. national digital health strategy
- Short- and medium-term priorities to address the key gaps
- Funding available (short- and medium-term)
- Sources of funding

Section 5: Country determination of technical support needs for adoption/implementation of unique identifiers

- Self-assessment of status on maturation pathway
- Plans for the adoption/implementation of unique identifiers and application to case surveillance and HIV patient monitoring
- Identification of short-term technical support needs for adoption/implementation

Annex 1 provides a summary of major outcomes of the workshop and next steps.

Annex 2 provides a curriculum on implementing unique health identifier with presentations from section 2

Annex 3 provides the presentation by each of the 11 participating countries on situation of unique identifier, implementation of the 5 recommendations, priorities and technical assistance needs.

4.3 Workshop: participating countries

- Benin
- Botswana
- Burkina Faso

- Cameroon
- DRC
- Ghana
- Malawi
- Rwanda
- South Africa
- Tanzania
- Zimbabwe
- Supporting institution: WHO collaborating centre for HIV Epidemiology and Research, University of Cape Town
- Technical partners: CDC, GFATM, UNAIDS, GIZ, UNICEF.

4.4 Section 1: Learning from three countries: solutions and challenges in the use of HIV person-centred monitoring

4.4.1 South Africa

Detailed feedback from South Africa is presented in Annex 3.

The Health Patient Registration System project in South Africa has to date registered 73% of the population. In this first phase, the Health Patient Registration Number (HPRN) is only linked with patient demographic data and going forward the country plans to link to clinical data. Following the presentation South Africa responded to several questions from other country participants.

- Financing of the project to develop and implement the Health Patient Registration System. Although the project is fully government owned, the work was enabled through substantial funding from Global Fund, CDC and the Bill and Melinda Gates Foundation.
- Time taken to get to the point where 73% of the population was registered on the system was six years from the point of conceptual design.
- It was estimated that the development of the system cost R32million. Additional costs for implementation include software maintenance and support, hardware, network infrastructure, connectivity and the logistics and human resources to operationalize the system at more than three thousand facilities. There was some discussion as to whether this should be considered an investment or expenditure.
- De-duplication is resource-intensive as it is not automatic but semi-manual.
- Although the HPRN is unique and distinct from the South African ID number, and contains no identifiers, patients are encouraged to present their national ID cards as this number is recorded as part of the demographic data and provides a further unique identifying link.

Conclusion: As the project matures an assessment will be made of benefits realized.

4.4.2 Botswana

Detailed feedback from Botswana is presented in Annex 3.

Botswana reported that the country continues to invest in the centralized proprietary Integrated Patient Management System (IPMS), and the decentralized Patient Information Management System (PIMS II). IPMS is linked to the laboratory and a good percentage of laboratory data is provided to the hospitals electronically. They are currently deciding whether to adopt a single centralized system or to link local systems through interoperability.

DHIS2 is used for data capture and aggregate-level reporting. IPMS and PIMS should talk to DHIS2 but paper-based data is consolidated at facilities and then captured in DHIS2 at district level. HIV data is transferred manually to the national data warehouse as there is no interoperability between systems. IPMS has modules for all diseases while PIMS can only be used for HIV.

The Botswana government's response to HIV is guided by their Third National Strategic Framework for HIV/AIDS which identifies priority districts and populations. Botswana has an extensive network of more than 700 healthcare facilities and all services require patients to present a birth certificate or national ID card. Birth certificates for newborns are issued at facilities so, although children only get their national ID cards when they reach 16-year-old, an estimated 98% children already have an ID number on their birth certificate. The policy of civil registration and using the national ID number for patient registration and identification purposes has worked well.

Regarding data use, there is limited culture of using data and there are also few people who are skilled in data use.

Conclusion: The use of the national ID card for patient identification purposes has worked well in Botswana. Gaps that need to be addressed are interoperability and data use.

4.4.3 Rwanda

Detailed feedback from Rwanda is presented in Annex 3.

By law every Rwandan aged sixteen years and older must have a national ID card. This national ID number is not used as an identifier for health service provision. The TRACnet system uses mobile phones for communication between remote HIV/AIDS clinics and administrative centers. TRACnet allows health providers to follow up on individual HIV/AIDS patients and to aggregate data at a national level. TRACnet has a facility-based identifier which is not unique across facilities.

When it came to case-based surveillance, Rwanda decided not to use the national ID as the identifier as this would pose the security risk of other personal data being accessed such as financial/banking or landownership. The identifier used is a temporary unique patient identifier, the UPID. The UPID is an alphanumeric code created through an algorithm using several fields including date of birth, gender, province and family names. Several questions about this identifier were raised by other country participants, especially with respect to the inclusion of identifiable personal data.

Conclusion: The country plans to extend the use of a unique health patient identification to patients without a national ID.

4.5 Section 2: Key foundations of unique identifiers

In this session chaired by Milani Wolmarans from the South African National Department of Health, three topics foundational to the implementation of a system for unique patient identification were presented in depth:

1. Principles and key elements for establishing unique identifiers and global best practices;
2. Interoperability and standards for interoperability; and
3. Data security, confidentiality and ethical considerations.

The first presentation examined the various design decisions and alternatives which should be considered when establishing a national identity scheme. The second explained the role of standards

for interoperability and how this related to a national identity scheme. The last presentation looked at the threats to security and privacy that could arise from a national identity scheme and highlighted the impact of design decisions on downstream risks and vulnerabilities.

Presentations in Annex 2.

In addition, technical presentations were delivered on Interoperability and Data Security which are in the annex 2.

4.6 Section 3: Use cases for HIV patient monitoring and case surveillance

4.6.1 Use of individual data for patient care and programme improvement

Professor Andrew Boule from the University of Cape Town addressed a plenary session on the use of individual level data for patient care and programme improvement, using the Western Cape Department of Health Provincial Health Data Centre as a case study. The concept of second generation health information systems that move away from aggregate data to person centred monitoring was highlighted as well as the need to move towards data collection embedded in clinical records. A consolidated data environment for person centred monitoring is now the primary data collection tool.

Presentation in Annex 2.

This session stimulated several questions from participating countries:

- Question: When data is collected in such a central “health data centre” is it then only available at a strategic level with no benefit for patient management at a local level? A: The reports generated by the health data centre can be accessible and actionable at any level of the health system
- Question: It would seem that several expert epidemiologists and doctors are needed for data management and analysis. What is the profile of personnel required for a health data centre? A: People with good data skills who are interested in the work are a good fit for a health data centre. They do not have to be experts.
- Question: Wouldn’t there be some risk when data is consolidated in one place, e.g. staff may not respect patient confidentiality or may make errors in handling the data? A: There is always the risk of data fidelity and there are ways to manage wrongdoing on the part of staff members.
- Comment: Although the system supports patient care, it looks very complicated and resource-intensive. If you invest in it, there is a risk that it may not be used for patient care.
- Question: How is loss to follow-up dealt with when patients go outside of the Western Cape Province? A: Once there is interoperability and visibility across the country, the full mobility of patients can be tracked.
- Question: The Single Patient Viewer allows you to see the time, the patient and the place involved in each health encounter. However what evidence is there that the health data centre has improved outcomes? A: Health outcomes will be improved when there are enough front-line staff at facility-level to react on the patient-level data and follow up.

4.7 Further reporting on Section 3, Section 4 and Section 5

The remainder of Section 3 dealt with country reporting on:

- HIV patient monitoring as a use case for unique identifiers
- HIV case surveillance as a use case for unique identifiers

Section 4 dealt with country description of existing frameworks and gaps as well as short- and medium-term plans.

Section 5 included further self-assessment, plans for adoption of UIDs and the identification of technical support needs.

The detailed country feedback can be seen in Appendix X

4.8 Country feedback on Key Recommendations 1 - 10

There was substantial feedback from countries that did not relate to the Key Recommendations 11-15 but to the other ten recommendations. This is summarized separately in this section.

Recommendation 2. Transitioning to “treat all”

- All the countries present in the workshop have transitioned to initiation irrespective of CD4 count.
- Some countries stated that this has led to an increase in the number of sites offering ART.
- As most countries already have mature cohorts there has been a paradigm shift from concentrating on ART initiation to ART retention.

Recommendation 5. Data quality review and use for quality care

- For person-centered monitoring to be effective, data quality exercises should be done as close to the source as possible as this is where the individual patient lists are required to manage care and services.
- When data is cleaned centrally, the clean data rarely flows back to the facilities meaning that the reporting will no longer reflect the reality on the ground.
- An additional reason for data quality audits to be done on site with staff producing and using the data is that correction of errors or misunderstandings will help to improve data quality through quality improvement processes.
- Concerns were raised that moving data quality audits closer to the ground would result in slowing processes down. This should not be a concern as “real time” data is only needed for interventions in health facilities such as recalling people who are late or have abnormal laboratory results.

Recommendation 8. Country situation analysis

- Country situation analyses key to implementing context appropriate solutions.
- Country situation analyses also important in generating “communities of practice” as countries will learn from each other when faced with similarities and challenges, e.g. where Burkina Faso was struggling with Tracker implementation and Ghana (southern neighbour) offered to help in resolving some of these issues as they had struggled for 2 years to implement DHIS2.
- The context should always come first and should guide decisions on software solutions. Often the donor driven nature of these programmes usually means that the software comes as part of the funding package.

Recommendation 10. Key population data

- The relative importance of key populations in a country is context specific and will depend on the type of epidemic (generalized or not).
- Several countries who still criminalize same-sex partnerships have developed unique identifiers specific to key populations; which raises grave questions on people security through data confidentiality and security.
- Key populations will vary from country to country, but always have in common that they are the most vulnerable and therefore require protection.

4.9 Country feedback on Key Recommendations 11-15

Country feedback has been summarized in **Table 1** according to the following topics, using the structure of the five key recommendations (11 to 15):

1. Existing use cases for unique identifiers (HIV patient monitoring and HIV case surveillance)
2. Existing frameworks, self-assessment and identified gaps
3. Plans to address gaps, plans for adoption of UIDs and technical support needs

4.10 Additional cross cutting points

The following points were discussed:

- The role of the different levels of the health system not sufficiently mentioned in data use. Roles of the district with respect to facilities; of provinces with respect to districts etc. At which levels of the health system are individual patient data required compared to aggregate data in PMS. Individual data required for recall of patients or identifying patients needing specific interventions; at higher levels individual data required for linkages subject to mechanisms for this and interoperability possible, but not for programme monitoring or reporting where aggregate data sufficient
- Importance of standardised clinical stationary for patient care and additionally for ease of digitizing by non-clinical health care cadres.
- As network challenges remain in many contexts and hybrid solutions recommended, the clinical folder (facility retained) and the patient held card/passport could remain paper based to support clinical care
- Data use for planning purposes needs to be emphasized
- Data tools do not solve problems on their own however easier simpler, more accurate and useful more likely to be used (also pleasant user experience)
- Global strategy for digital health needs to be promoted to support national adoption of digital health strategies.
- DHIS not interoperable with lab or pharmacy systems

5 Overall directions and next steps

- **Implementation of UID should be conceived as a journey** based on country situation, which is incremental and rolled out step by step. During the workshop countries have developed short term and medium-term priorities however it is critical to keep a 5-10-year view of building digital health capacity.
- Implementation should be based on a **country situation analysis** – not from the outside
 - Country situation analysis for unique identifiers (Situation analysis tool available in Annex 2)
 - Program benefits and no harm to patient care or to country data system
- There was great value in South to South Journey and sharing the country journeys with the support of partners
 - **Similar end point** – program improvement, unique identifier HIV and health, interoperability requirements and strengthen and secure data. Data is an intervention.
 - **South to South learning** – use social security and health wide UIs, experience with tracker and tier.net and EMRs, political priority of Digital Data, Key Populations, also risks.
 - **Finalize 12 country profiles** – status of implementation of recommendations, program issues, priorities for next steps short and medium term. Follow up with support and funders
 - **Partners** – South Africa, Path, CDC, PEPFAR, Global Fund, UNAIDS, UNICEF, 3 level WHO
- **Key learnings from the workshop include:**
 - The importance of introducing UID in HIV which links at minimum across health and potentially to other social services
 - Recognition that a community of data users, as well programmes, patients, and country capacity benefit from the use of UIDs.
- **Implement SDGs person centred data with benefits to individuals**

- A patient must feel comfortable that their data is secured, that their life is made easier, will be able to obtain their results, have access to health, to medicines and prescription, not wake up at 4am to queue for a clinic that opens at 7am and ultimately will have a better quality of life. This must be central and remain the basis for efforts to rollout unique identifiers.
- **The importance of unique identification is linked to** results-based M&E, programme benefits, reducing waiting times, improving patient care, loss to follow up, addressing drug and diagnostics wastage and strengthening use and uptake of health services
- **Concept of do no harm with regards to not only** patient care, but also country data situation (careful situation analysis) and data security is paramount.

<p>There were nine key issues that were raised in summary</p>
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| <ol style="list-style-type: none"> 1. Patient and Program benefits – build on country to do no harm 2. Journey – next steps to use health UID in all HIV monitoring, medium term country capacity. This is implementing the SDGS (disaggregated, person centre data and data use capacity) 3. Base approaches on country situation analysis – different stages in a common journey 4. Next Priorities and Medium term digital data plans – policy and country capacity 5. Involve partners and funding – major legacy of their support, many legacy data systems at the individual level 6. Key Population Data – important for NGOs and programs, links to national data based on policy and security 7. Unique Identifiers can be several – but need to work across health and over time across social services. Issues migration, child identity, use also in paper, confidentiality, chronic care, private sector 8. Strong policy requirements on interoperability and data security and sharing of data with a health information exchange. Differentiate security and reduce duplicate data systems 9. Step wise implementation showing the returns and benefits at each stage |
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The following next steps were identified:

1. Meeting summary and guidance

- Guidelines implementation in French and English
- Technical Presentations, South Africa
- Country Profiles from 11 countries
- Country Priorities and Support Requests

2. Follow up Support

- Country Situation Analysis tool for Unique Identifiers (country situation, options, strengths and weaknesses)
- Country Priorities: share with partners
 - Global Fund proposal planning call
 - PEPFAR COP planning call
 - WHO situation analysis and policy support (3 levels and HIV and Digital Health)
- Support country dissemination: WHO, UNAIDS, UCT, Global Fund

3. Person centred monitoring in LMIS: South Africa first half of 2020, patient data linked to drug and diagnostics stocks and numbers – improve care, reduce stockouts and wastage (5-10%)

TABLE 1 Country Feedback			
Recommendations in the WHO Guidelines	Existing use cases for unique identifiers (HIV patient monitoring and HIV case surveillance)	Existing frameworks, self-assessment and identified gaps	Plans to address gaps, plans for adoption of UIDs and technical support needs
Recommendation 11. Promote and use unique identifiers	<ul style="list-style-type: none"> The UID is key to integration and linkage in implementing person-centred monitoring services and with maturing cohorts relinkage into ART care has become increasingly important. UIDs are often created as alpha-numeric unique identifiers which contain the region or province where linkage to ART care first occurred followed by year or month and sequential linkage for that year or month. After several decades of ART care, there is a shift away from a specific UID for HIV only. In situations where there are several identifiers uniquely identifying one person, deduplication is required but is manageable. Before embarking in deduplication exercises, the fact that numbers will decrease must be acknowledged. Deduplication is best done on site i.e. the ideal time to confirm identity is when person is in front of you at the facility. When an identifier can be linked to multiple patients, this is problematic. There are benefits of the UID printed on labels for medication, 	<ul style="list-style-type: none"> There are several issues regarding the use of National IDs vs Health IDs and registration systems. There are confidentiality concerns with the use of National IDs. There are groups within countries requiring ART care who do not have National IDs, e.g. children and visitors. DHIS2 Tracker is not adapted as UIDs are created per episode (HIV, TB etc..) and not uniquely linked to a person. 	<ul style="list-style-type: none"> Ideally a UID should have a one to one relationship between the person being identified and the identifier. Best practice suggests that UIDs should be: <ul style="list-style-type: none"> Accessible: available when required Assignable: assign when needed by trusted authority after properly authenticated request Atomic: single data item - sub-elements have no meaning Concise: as short as possible Content-free: no external dependence Controllable: only trusted authorities have access Cost-effective: maximum functionality with minimum investment to create and maintain Deployable: implementable using a variety of technologies Must consider: <ul style="list-style-type: none"> Human readable vs machine readable UIDs The role of biometrics Intersectoral cooperation is important, e.g. instead of using

	<p>folders, laboratory samples and results.</p> <ul style="list-style-type: none"> • When creating UIDs it is important to make transcription as easy as possible by avoiding letters or numbers which could be confused ("0" vs "O"; 1 and 7 etc....). • For person-centred monitoring to be effective, data quality exercises should be done as close to the source as possible as this is where the individual patient lists are required to manage ART care and services. 		<p>mother's UID for baby, baby can be given own UID at birth.</p>
<p>Recommendation 12. Transition progressively from paper-based to electronic patient information systems</p>	<ul style="list-style-type: none"> • Most countries are using both paper and electronic systems simultaneously. • Facility-based temporary IDs are used for hybrid systems. • Incremental approach works well: "Perfect is the enemy of the good". • Focus on beneficitation before dependency. • "Do no harm" pragmatic incrementalistic approach. • "Step by step" approach but keep a 5 to 10-year view of building digital health capacity. • First pilot in a few sites and learn from mistakes. • Paper folder digitized into electronic system is not duplication. 	<ul style="list-style-type: none"> • Unique identifiers are not only linked to electronic systems and several countries have created health UIDs which were used in paper-based systems. • Infrastructure dependencies, electricity, connectivity and hardware and downtime procedures are challenges to transition to electronic systems. • Journey differs from one country to another, the sequence of events is not the same depending on epidemic context, etc. • Several countries have more than one electronic system in place, causing confusion and duplication. 	<ul style="list-style-type: none"> • The transition can be guided by: <ul style="list-style-type: none"> ○ Use of Accelerator Kits. ○ DIIG Digital Investment Implementation Guide. ○ Maturation pathways.
<p>Recommendation 13. Strengthen and establish security levels</p>	<ul style="list-style-type: none"> • Balance risks vs benefits. • Segmenting of data (internal encryption i.e. patient identifier encrypted within database). • Solutions are context-specific. 	<ul style="list-style-type: none"> • Issues of ownership of data. • Issues of data governance and stewardship. 	<ul style="list-style-type: none"> • Incrementally increase security based on risk-based assessment. • Cost of security is not necessarily infrastructure/hardware cost as a

		<ul style="list-style-type: none"> Physical location of DHIS data (one country has their data hosted in Oslo). Some data elements may be impossible to anonymize. “Yesterday’s security will not protect from today’s threats and today’s security will not protect from tomorrow’s threats.” The richest companies in the world have their wealth built on data which is quite different than the use of personal data for health. Personal data has become commodified; further reasons to have anonymous health UIDs. Several countries who still criminalize same-sex partnerships have developed unique identifiers specific to key populations; which raises grave questions on data security. 	<p>lot can be done within existing database.</p> <ul style="list-style-type: none"> Donors could push for more security. Confidentiality, integrity and availability, also known as the CIA triad, are the three most crucial components of security.
Recommendation 14. Invest in data systems and ensure interoperability	<ul style="list-style-type: none"> The health UID allows cross-cutting data and creates links between programmes. When creating Health UIDs good practice is to have the same UID linked across all health service points. There are some pragmatic context-appropriate technology choices (not donor driven). Software accounts for a small portion of the investment in a monitoring system (10%), people (70%), process (20%). 	<ul style="list-style-type: none"> The implementation of UIDs goes hand in hand with creation of stickers or labels to be used for lab requests medication etc. as this allows linkage. Partners operate in silos and use different information systems which can lead to fragmented ART care. Example of fragmentation is South African evaluation in 2012 which determined 42 different EMR systems being used. Dilemma faced by countries: is it better to focus on interoperability and keep two or several systems 	<ul style="list-style-type: none"> Can funders promote and require interoperability when systems are developed? Can WHO provide guidance on this? Remain guided by “it’s not about the software but about the health system”.

		<p>or is it better to invest in one system?</p> <ul style="list-style-type: none"> • Proprietary vs free “open source” or country-owned software results in tensions for development. • For different country contexts, interoperability will be different. • The less countries have plans and strategic directions in place, the more partners will disrupt. • Ongoing tension between interoperability and integration. (Interoperability is real-time data exchange between systems without middleware, integration requires middleware.) 	
<p>Recommendation 15. Use individual data to improve programmes and long-term chronic health care</p>	<ul style="list-style-type: none"> • Example of Western Cape Health Data Centre, and Single Patient Viewer and Reporting. • Individual level data is most useful at the facility level where staff require data broken down into “useful bits” i.e. TB nurse wants to have list of TB positive who have not started treatment or identifying people who had two consecutive high viral loads and require a medication change. • Individual level data needs to be “real time” to be useful whereas data for programme planning does not need to be “real time”. • If quality data is required, then a “lag time” for audits and cleaning is necessary. • Depending on use of data can be interpreted in binary or probabilistic manner (e.g. CD4 and HIV status). 		

	<ul style="list-style-type: none">• For programme improvements, data must be used at the point of care and then sent to the next level (district) where managers can decide which facilities require attention and mentoring.• As data moves up the health system in most cases individual level data is not needed as aggregate data between facilities can be compared for numbers in ART care or outcomes.		
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List of Annexes

Annex 1. WHO Presentation on Person Centered Services and data with major outcomes of the workshop and next steps

Annex 2. Curriculum on implementing unique health identifier

Annex 3. Country presentations on situation of unique identifier, implementation of the 5 recommendations, priorities and technical assistance needs.

