



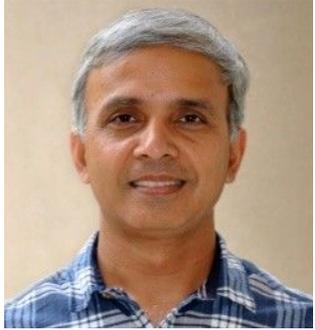
Digital Square Webinar: Data Use Community Maturity Framework

December 2, 2020

Agenda

- Welcome and Introductions - Amanda BenDor (5 min)
- Presentation on Data Use Community Maturity Framework - Manish Kumar and Annah Ngaruro (40 min)
- Questions and Closing (15 min)

Introductions



Manish Kumar has over 20 years of experience in health systems strengthening and global digital health. Currently, he is the principal investigator and Senior Technical Specialist- Health Systems Strengthening for the PATH-Digital Square supported DATIM Support and Maturity Model project at the Carolina Population Centre of the University of North Carolina at Chapel Hill. He is the technical lead for the maturity framework activity of the Data Use Community. Kumar also supports a CDC funded health informatics project as a partner in the PATH-led consortium. He is currently involved in global maturity model efforts and led the maturity model research activities under the USAID-MEASURE Evaluation project.



Annah Ngaruro is a Project Management Institute-certified Project Management Professional and a Certified Information Systems Security Professional with 20 years of experience developing and supporting health information systems for variety of US government agencies. She is currently the DATIM Data exchange and Interoperability portfolio lead responsible for providing the Office of the U.S. Global AIDS Coordinator and Health Diplomacy Program Results for Impact Monitoring and Epidemic Control with portfolio leadership and product ownership for the data exchange and interoperability portfolio within the DATIM systems teams.

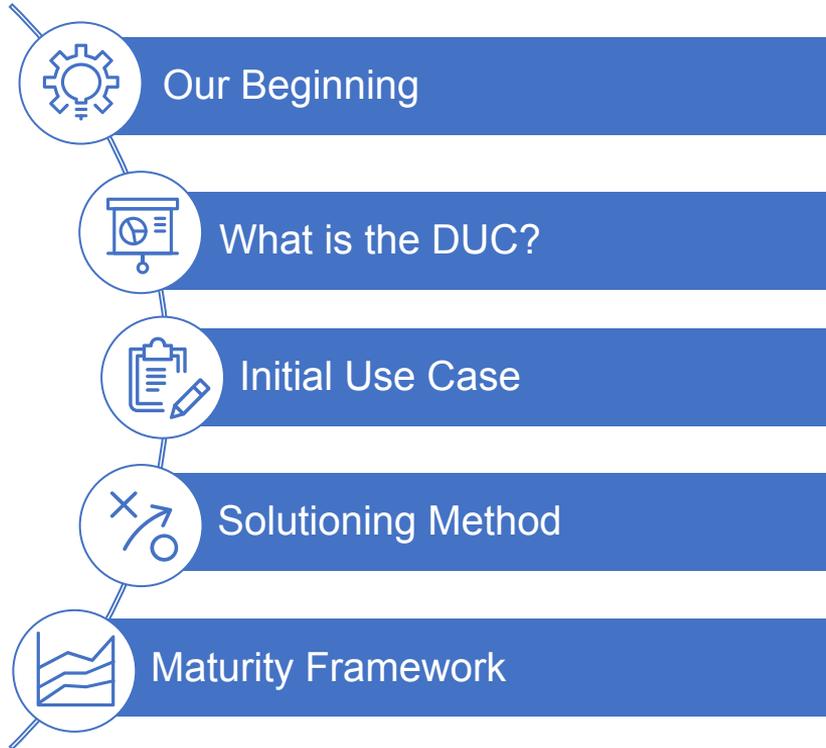


Data Use Community

Improving health and healthcare data sharing

Data use and system maturity framework

Agenda





Our Beginning

The Data Use Community

started as a team addressing an integrated HIV case identification and surveillance system. The goal for the initial team was to provide considerations for an integrated approach that supports HIV case-based surveillance, recent infection surveillance, unique means of identifying persons within HIV surveillance, and programmatic monitoring. The work done in this group culminated in producing part of the PEPFAR Country Operational Plan 2020 titled, "Impact-Driven Information Systems and Data Management Investment." The DUC-related portion starts on page 360. The creation of the DUC was formed to address three key needs:

Practitioners can share on which interventions, tools, and processes are working

Donors will have the opportunity to align investments and strategies

Everyone understands the real needs and challenges from the field



What is the DUC?

What We Do

The DUC is a community of practice working to support better quality care through data use by collaborating across facilities, countries, care levels, and organizations. The community can address these complex problems by collaborating with subject matter experts, country teams, and other stakeholders to shape best practices and share technical frameworks and artifacts from already implemented solutions. This will drive the ability of each country to formulate customized solutions to address its specific data issues.

Initiated by PEPFAR, the DUC offers the community a way to involve and engage with a multitude of agencies, organizations, and stakeholders.



Drawing from
on-the-ground
country experiences



Shaping and
consolidating best
practices



Sharing technical
frameworks and
artifacts from already
implemented
solutions



Being responsive to
individual country
needs and helping
them form
customized solutions
to address their
specific needs

Values

1

People providing care and services in countries are the experts: The community recognizes that people in the positions of data collection, aggregation, and use are best suited to understand their challenges and generate ideas and evaluate opportunities for meeting data collection and sharing goals.

2

This community encourages multiple perspectives: To work through the complex data use needs and opportunities, the community can intentionally seek out voices from in-country providers, facilities, multiple aid organizations, implementers, and others involved in the complex challenges that are identified by the group.

3

This community is a safe space for collective learning and sharing: To meet the complex challenges that the community seeks to address, the DUC will include all perspectives without judgment or penalty. The goal will be to share real experiences on the ground and learn from them.

Guiding Pillars



Clinical Care

Ensure that any recommendations for addressing retention issues are aligned with other efforts to improve the quality of care along the clinical cascade.



System

Ensure that data collected and managed in existing systems, paper or digital, are described and implemented using standardized tools and data models and are appropriately staged based on a country's current capability.



Policy

Develop and identify the necessary policy, guidelines, and legal frameworks for critical issues involving patient confidentiality, data security, data sharing agreements, and related legal and legislative concerns.

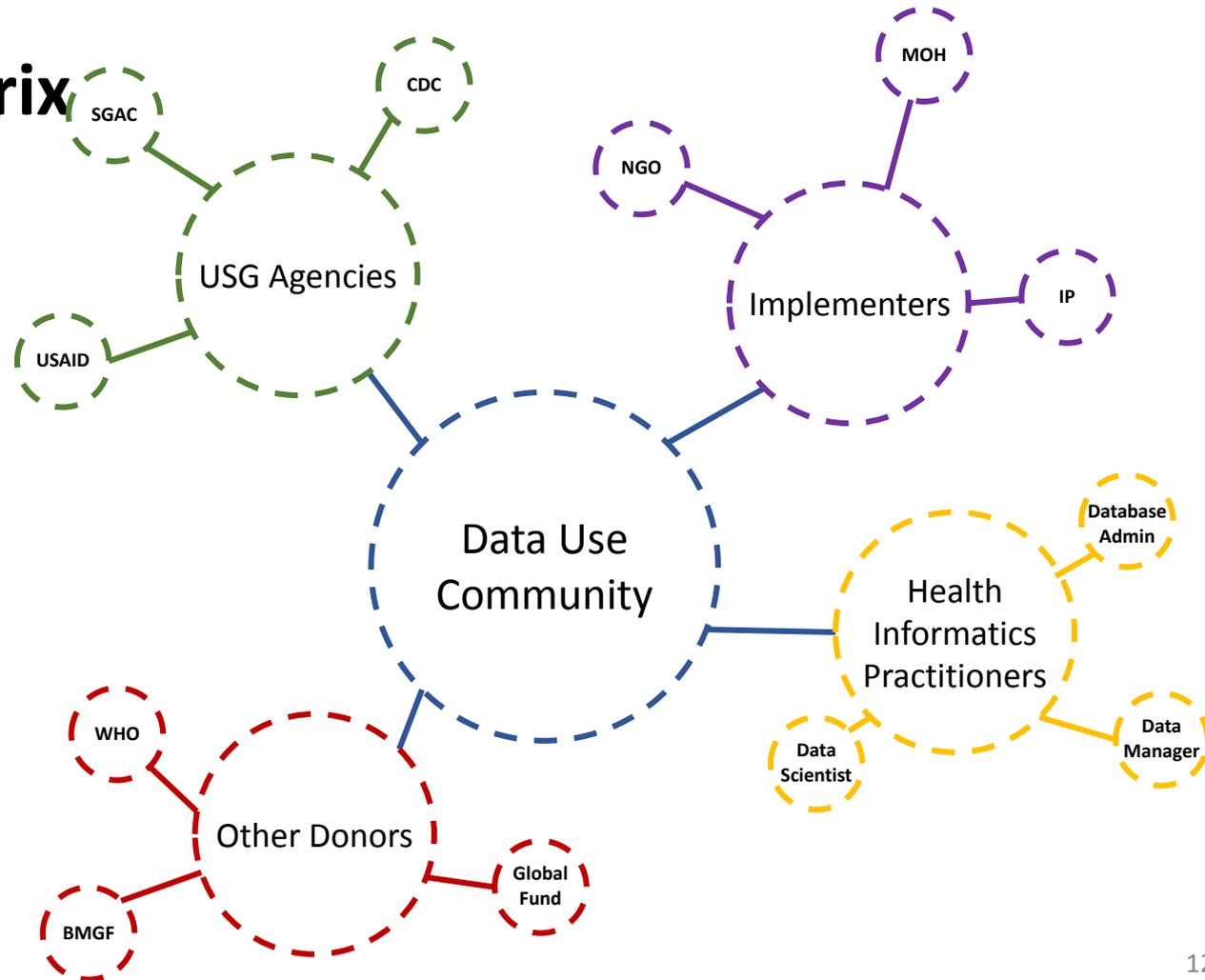


Data Reuse and Analysis

Ensure that the data systems support the ready reuse of data for a variety of purposes, such as monitoring and evaluation, improving the public health response, case surveillance, syndromic surveillance, and quality improvement initiatives.

Relationship Matrix

As an independent initiative, DUC is an open community that collaborates with and participates in a variety of different groups and partnerships. Many of these groups engage in synergistic projects that align closely with the DUC. These groups not only help inform and shape the DUC, but also provide key insights into the current challenges and opportunities.





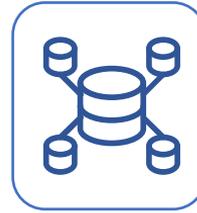
Initial Use Case

Retention and Lost-To-Follow-Up

The DUC proposes to initially focus on guidance regarding approaches for enhancing retention and reducing lost-to-follow-up (LTFU). As many countries supported by PEPFAR approach epidemic control, it is becoming clear that some of the remaining “last-mile” obstacles can only be addressed through the use of longitudinal patient-level data. Alongside retention and lost-to-follow-up, the community will encourage the use of this framework for other areas of the HIV continuum and for other disease domains as well.



The reporting timeframes (e.g., quarterly) for the data used in monitoring the programmatic interventions designed to address these obstacles are too protracted to be effective at impacting patient care.



As the lack of real-time, patient-level longitudinal data has become a more visible sticking point to the attainment of epidemic control, PEPFAR country teams have begun to ask for assistance in addressing these last-mile obstacles.



Many PEPFAR country programs are already prioritizing investments in patient-level information management approaches in their health systems, with an increasing focus on point-of-care delivery.

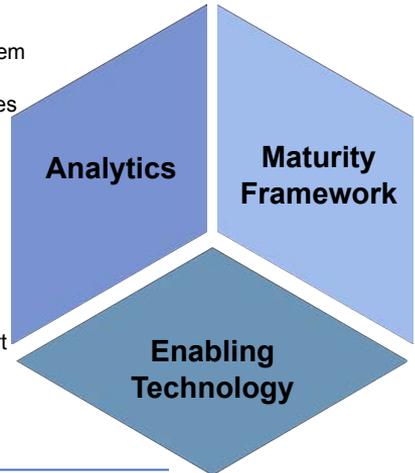


Solutioning Methods

Solutioning Methods

Leveraging Pre-Existing Data Sets

Engage community to develop user stories/problem statements from research and community experiences & analysis and develop analytic models to answer key health questions

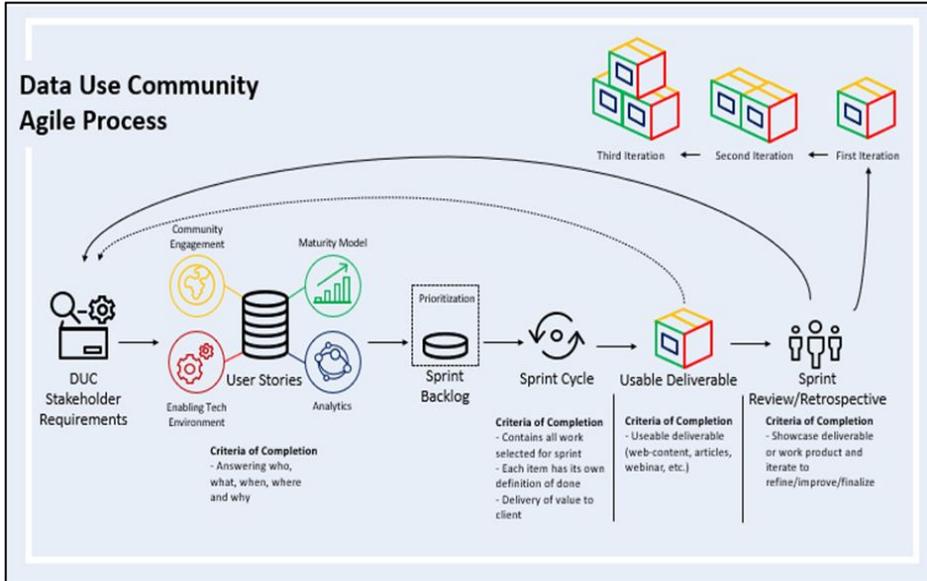


Iteratively refine dimensions & attributes to develop a tool for community data use and system maturity assessment, planning, and improvement monitoring

Develop, catalog, and support use of digital health tools to enable clinical and programmatic decision-making



Data Use Community





Maturity Framework

Data Use and Systems Maturity Framework

Context: The initial focus use case of the Data Use Community (DUC) is to work with community members to:

1. identify data challenges around the management and use of systems to capture individualized data in efforts to improve retention.
2. Use program priorities for the development of technical approaches to address these challenges.
3. Share technical approaches within a data use and systems maturity framework
4. Support OU teams to use maturity framework to readily understand the applicability of an approach in their setting

Purpose: The purpose of the maturity framework is to guide the assessment of data use and systems capability to routinely monitor and improve data use and system attributes associated with loss to follow up (LTFU) at facility, above-site, and other levels.

The goal is not to produce specifically defined or universal data or tracking tools, but rather to make sure that any tools used are optimized in HMIS environment to provide the necessary and essential information.

Overview: Maturity Framework Development Process

Step 1: Identify user story (ies)

Step 2: Identify maturity dimension (s) relevant to the chosen user story

Step 3: Describe attribute (s) for each of the dimension

Step 4: Describe key capability statements associated with selected attribute (s)

Step 5: Describe assessment question (s) for each capability statement (s)

Step 6: Explain how response to assessment question (s) connect with maturity of dimensions, identification of next steps/interventions.

Step 7: Administer maturity assessment, identify next steps/interventions

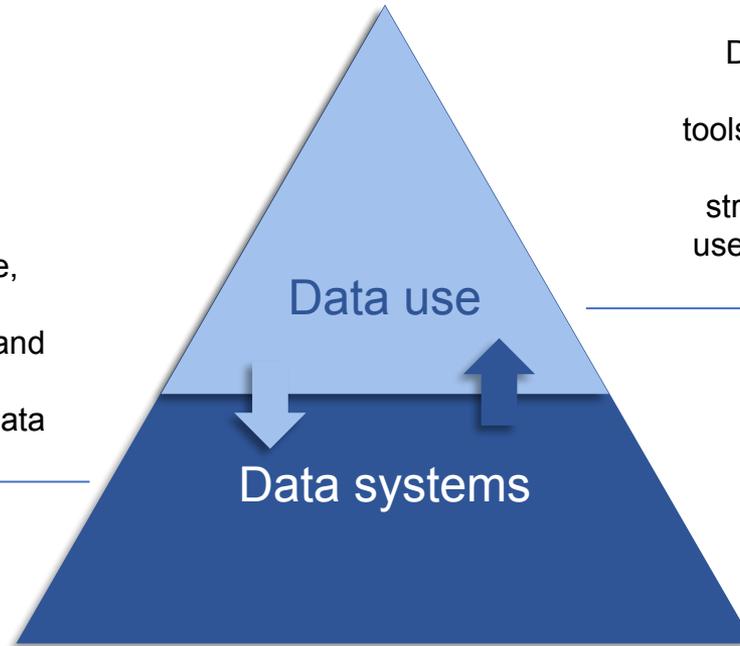
Step 8: Update maturity framework (comprised of framework, assessment tool, and 'how-to-guide')

5-Level Maturity Framework

Two interlinked dimensions...

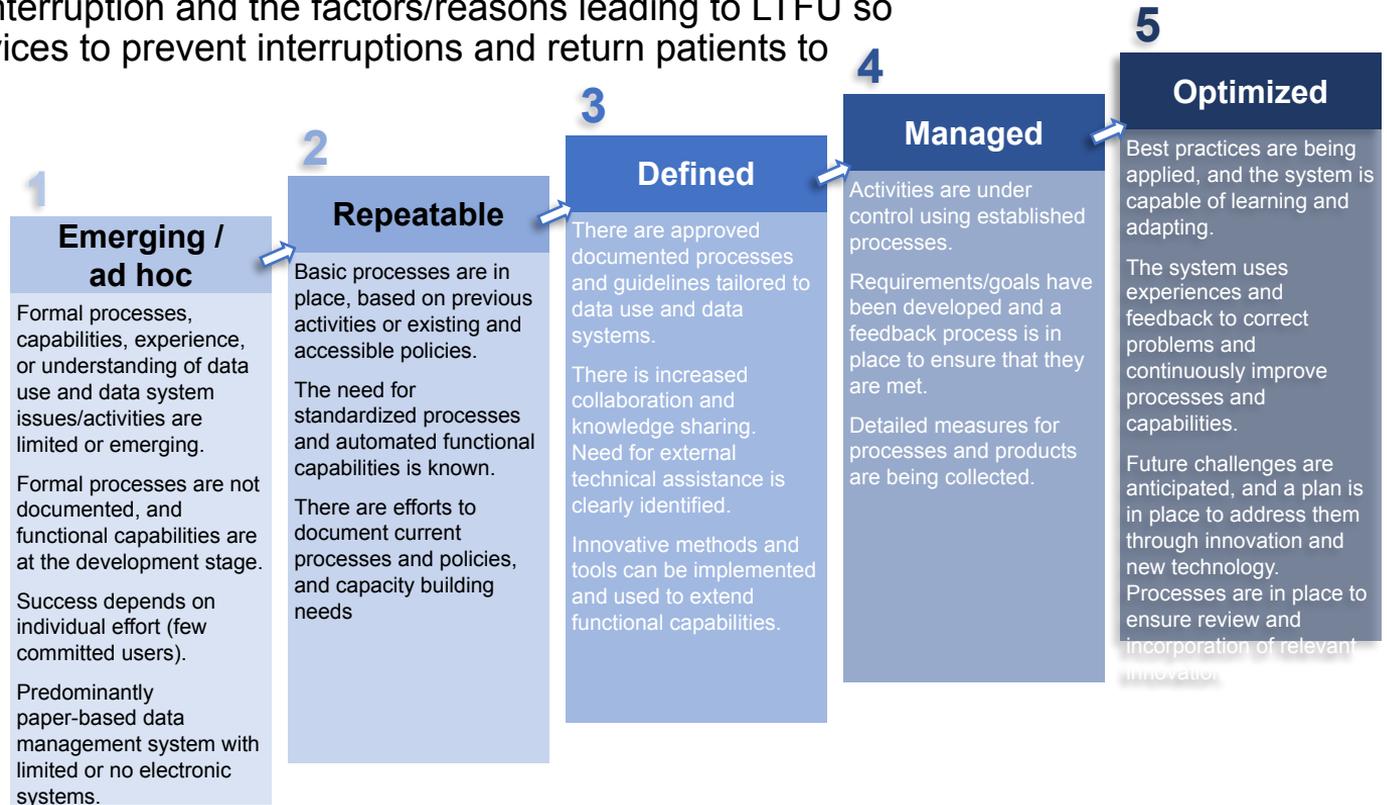
Data systems refers to guidance, people, tool, and processes associated with data collection and reporting, client record, data governance, data sharing and data change, and staff training.

Data use encompasses reporting, development and use of specific tools, identifying and addressing root causes, process monitoring, strengthening and supervising data use capacity, improving data quality, and data review and action.

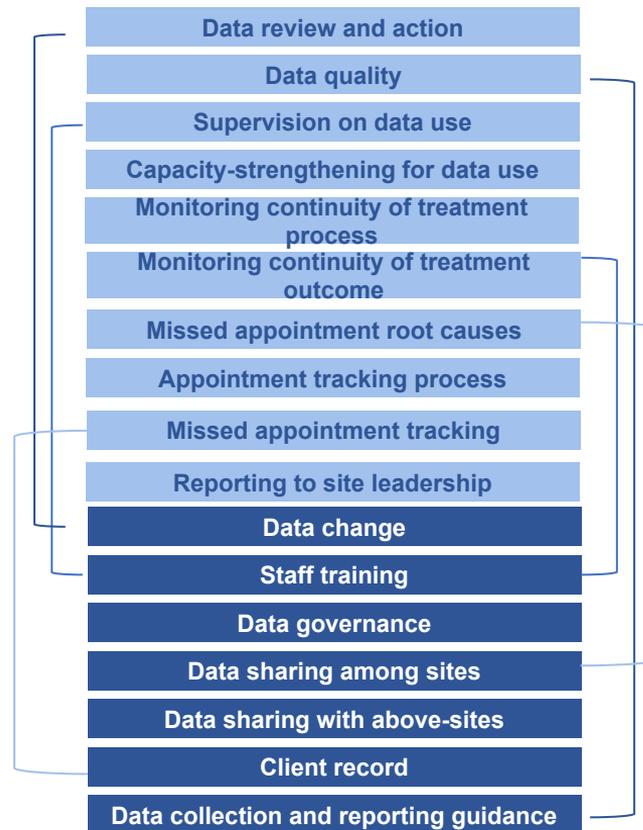
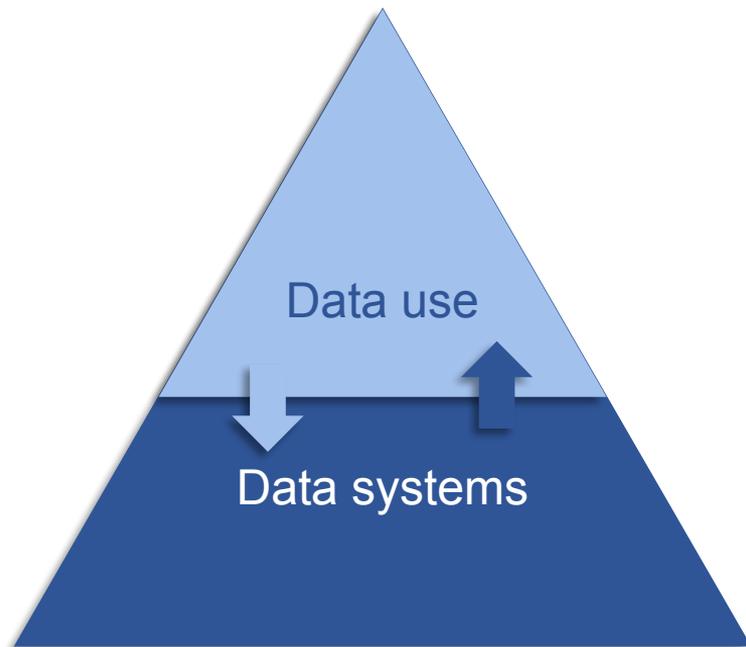


5-Level Maturity Framework

User Story 1: As a site level manager, I want to understand who is experiencing treatment interruption and the factors/reasons leading to LTFU so that we can improve services to prevent interruptions and return patients to care.



Two interlinked **dimensions**... ...with shared / interconnected **attributes**



Each attribute has **characteristics** corresponding to each level in the framework

EXAMPLE

Dimension: **Data use**

Attribute	1 Emerging / ad hoc	2 Repeatable	3 Defined	4 Managed	5 Optimized
Appointment tracking	Health facility does not generate appointment lists or the process to generate appointment lists is unstructured and ad-hoc.	Health facility has a documented process to generate an appointment list but experiences challenges in generating such a list.	Health facility follows a standardized process to successfully generate and review quality of an appointment list in terms of completeness, accuracy, and timeliness.	Appointment scheduling tools are integrated with the electronic patient record system.	Health facility routinely reviews and updates appointment management processes to inform missed appointment tracking and process monitoring.
Data review and action	Health facility may review data, but reviews happen on an ad-hoc/ irregular basis and follow a non-standard process (i.e., does not use any standard tools).	Health facility has some processes in place for generating reports and tables for data review.	Health facility has standard procedures in place for generating reports and tables for data review on a regular basis.	Health facility uses reports and data visualizations for data review. (The reports/visualizations are updated on a regular basis [monthly, quarterly, etc.] Health facility takes action based on review of the data in the system, based on changes or other information.)	Health facility uses near-real-time reports and data visualizations for data review and analysis, including to forecast potential challenges and inform early interventions to avoid or mitigate the challenge.

Maturity Assessment Question (Illustrative)

Instructions:

- You are required to select one of the following choices for each of the option statements.
 1. Not applicable
 2. Do not know
 3. Planned for future
 4. In progress
 5. Accomplished
- You can add comments to contextualize your response.
- Add data source to support your response.

Maturity Assessment Question (Illustrative)

Q.D1A2. Does your facility have an appointment tracking process?

Code	Option Statement	Option Choice	Data Source
L1.1	No appointment list is generated	1	
L1.2	Appointment list generation process is unstructured/ad-hoc	4	
L2.0	A documented process to generate an appointment list exist but experiences challenges in generating such a list	5	
L3.0	Follows a standardized process to successfully generate and review quality of an appointment list in terms of completeness, accuracy, timeliness	4	
L4.0	Appointment scheduling tools are integrated with the electronic patient record system	3	
L5.0	Routinely review and updates appointment management processes to inform missed appointment tracking and process monitoring	4	
Comment:			

Thank you!

Join Us.

Data Use Community

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Questions?



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