KEMRI | Wellcome Trust

Consultative Workshop on Research Data Access and Use for Public Health Decision-Making

Meeting Brief - June 2023

Key messages

As part of a consultative workshop held on 23rd May 2023 in Nairobi, stakeholders from the Ministry of Health, County Departments of Health, County and Sub-County referral hospitals and research centers discussed approaches to optimize access to and use of surveillance data to inform public health planning/ decisionmaking. The key recommendations and ongoing actions proposed by the workshop attendees included:

- Development of standardized protocols and associated standard operating procedures (SOPs) for routine surveillance data access and sharing
- 2. Digitization and integration of routine surveillance data
- Employment of a standard set of approaches for reviewing research studies and accessing research data/ output at the County level
- 4. Strengthening the capacity of County Department of Health officials to interpret and evaluate research findings
- Development of audiencespecific visualization approaches for displaying research data/ outputs
- 6. Development of pathways for communicating findings and recommendation to end users
- 7. Engagement of stakeholders at the research study development phase

Background

There is a lack of clarity on the extent to which surveillance data generated by researchers/ academia are accessible to policy/ decision makers. This is particularly true at the sub-national level. Even when accessible, it is not clear to what extent research surveillance data are used to inform public health planning and decision-making. Researchers at the KEMRI-Wellcome Trust Research Programme (KWTRP) convened a half-day 'Consultative Workshop on Research Data Access and Use for Public Health Decision-Making' on 23rd May 2023 in Nairobi. The workshop brought together representatives from the Ministry of Health (MoH), County Departments of Health, County and Sub-County referral hospitals, and research centers. Sessions included an expert panel discussion, presentation of a KWTRP data dashboard and group discussions on how to improve access to and use of research data. The overall aim and objectives of the consultative workshop were as follows:

Overall aim

To initiate dialog between a wide range of stakeholders on how research surveillance data can contribute towards public health planning and decision-making

Specific objectives

- 1. To understand key MoH priorities for communicable disease prevention and control and evidence gaps
- 2. To identify approaches to optimize access to and use of research surveillance data for public health planning and decision-making
 - a. Understand the extent of the use of research surveillance data for decision-making within the current context
 - b. Identify barriers & facilitators to access and use of research surveillance data for decisionmaking

Key discussion points

Priorities that can be informed by surveillance

Workshop attendees proposed several priorities that can be informed by surveillance. Of note, these priorities were not only restricted to infectious diseases, but also extended to non-communicable diseases as well as health system, administrative and managerial aspects (Figure).

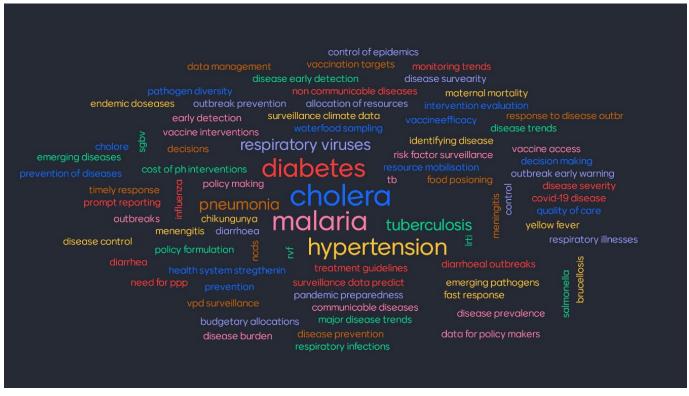


Figure. Word cloud representing priorities that can be informed by surveillance

The priorities proposed by workshop attendees align well with the Ministry of Health's overall mandate to reduce morbidity and mortality, recognizing the contribution of not only infectious causes but also non-infectious causes. Surveillance is a vital component of early detection and response towards the '7-1-7' goal (early detection within 7 days of an outbreak, rapid reporting within 1 day and response within 7 days).

Priorities at the county level revolved around delivery of targeted interventions. This could be achieved through comprehensive case profiling, hotspot mapping and demographic surveillance for risk factor identification. Integration of multiple surveillance data streams, e.g., health and environmental data, was considered essential for effective delivery of targeted of interventions.

Recommendations on approaches to optimize access and use of data/evidence for decision-making

Workshop attendees shared several tangible examples of instances where data were used to inform public health planning and decision-making. These examples were predominantly at the national level and data were more likely to be applied towards decision-making when MoH was involved in data generation and when there was involvement of influential partners/ funders. Attendees expressed a need to optimize access to and use of not only research surveillance data, but also data collected as part of government-led health surveillance (i.e., routine surveillance). Furthermore, it was noted that routine data can complement research data/ outputs, for example, linking COVID-19 case data to SARS-CoV-2 genomic sequence data to inform genomic surveillance policy recommendations. Therefore, the recommendations expressed applied to both research and routine surveillance data/ evidence.

Recommendation and context



1. Develop standardized protocols and associated standard operating procedures (SOPs) for routine surveillance data access and sharing

Access to routine surveillance data is limited by several factors including:

- Privacy protection concerns particularly in view of the Data Protection Act
- Lack of clarity on data ownership and the processes for requesting restricted data

Creation of standardized data sharing protocols, and associated SOPs, which are aligned with Data Protection and Public Health Acts as well as other efforts such as NACOSTI's National Research Policy, can improve access to research and routine surveillance data.

2. Digitize and integrate routine surveillance data



The mixed electronic and paper-based data capture inhibits integration of multiple routine surveillance data streams. In turn, the absence of integrated routine surveillance datasets limits the analysis of routine surveillance data to inform public health planning/ decision-making. It was noted that rollout of electronic medical records (EMR) remains a MOH priority.



3. Employ a standard set of approaches for reviewing research studies and accessing research data/ output at the County level

There is marked heterogeneity in access to research data and use at the county level. Some counties have established processes for accessing research data/ outputs. These include:

- Requiring review of research protocols by county research committees
- Requiring dissemination of research findings to the county research committees
- Including members of county research committees as co-investigators or collaborators in research protocols to enhance access to research data/ outputs
- Digitizing access to research protocols and research data/ outputs

Yet, some counties do not have established processes for accessing research data/ outputs. Furthermore, even for counties where some process has been established for accessing research surveillance data/ outputs the methods of access are not always optimal, e.g., access is not digitized. In addition, such processes are not always followed.



4. Strengthen the capacity of County Department of Health officials to interpret and evaluate research findings

County Department of Health officials may not always have the necessary technical expertise to interpret the research findings shared with them, to assess the quality of the research findings, or to assess the appropriateness of the recommendations proposed



5. Develop audience-specific visualization approaches for displaying research data/ outputs

Data visualization is an important tool for displaying research data/ outputs in a readily interpretable format to various audiences. Data visualization tools such as dashboards can improve access to research data/ outputs and their use for public health planning/ decision-making. However, data visualization approaches need to be tailored to specific audiences



6. Develop pathways for communicating findings and recommendations to end users

Although researchers have developed processes for sharing findings with stakeholders at the Ministry of Health and County Departments of Health, research findings/ outputs and recommendations do not always reach all levels of the target end-users, e.g., health facility staff and community members. Attendees shared instances where deployment of data-driven interventions has failed due to lack of community engagement.



7. Engage stakeholders at the research study development phase

In some cases, stakeholders are only engaged at the implementation phase of research studies. Failing to engage stakeholders during the research study design phase can result in incorrect assumptions – for example regarding disease burden where researchers may not have access to routine/ clinical surveillance data – which in turn can negatively impact the quality of the research study and the subsequent findings.

Outstanding challenges

When research findings and recommendations are shared with key stakeholders, the recommendations may not always be implemented due to barriers such as cost and competing priorities. These are more complex challenges for which no concrete recommendations were proposed.

Summary and next steps

Several important recommendations for optimizing access to and use of data for public health planning/ decisionmaking emerged from the consultative workshop. A subsequent consultative workshop is planned for September 2023. The follow up workshop is expected to focus on identifying pathways to implementation of the aforementioned recommendations, including the role of researchers in implementing the recommendations.

Acknowledgments

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