

16 June 2020 DUC Meeting Summary

2020 June 16 Data Use Community (DUC) Kick-off Meeting

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. The DUC does this by providing a forum for those on the frontlines to share their experiences and perspectives, to learn from one another, and to direct investment in information systems based on the needs identified through the DUC. As a first use case, the DUC is exploring factors that contribute to retention issues and lost-to-follow-up (LTFU) of individuals living with HIV. LTFU may be influenced by multiple factors and is also site-specific requiring that interventions be contextualized for facilities, the populations they serve, and the availability of resources.¹

On June 16, 2020, the DUC held its inaugural meeting, bringing together various stakeholders to support better quality care through data use by collaborating across facilities, countries, care levels, and organizations. During the meeting, practitioners presented their experiences and research from Mozambique, Uganda, and Zambia on viral load suppression, root causes of missed appointments, understanding LTFU, and clinical mentoring to health care providers. This led to a rich discussion on the role of patient experience and satisfaction in retention in care as well as information systems investments made to improve retention, given limited resources. Several practitioners on the call noted that rudeness and poor treatment of patients are common in many facilities. These negative experiences occur from reception through provider interactions. There are little data available to practitioners about patient experience and its impact on LTFU. Further, practitioners noted that interventions to improve health workers' attitudes towards patient and patient satisfaction have not been widely disseminated.

Understanding the patient experience and what interventions are effective at improving patient experience will be an important contribution of the DUC. Understanding challenges around LTFU and patient experience require a holistic viewpoint and engagement of practitioners and decision-makers at all levels of the health system. In particular, it was noted in the meeting that community health workers (CHWs) have the greatest understanding of population context and leveraging technology to better engage with CHWs will be critical in mitigating factors influencing LTFU.

The presenters also discussed how the DUC could help practitioners access data that they can use to support clinical observations. For example, a practitioner might observe that HIV-infected children who were sick or malnourished at the time of their last visit are more likely to be later LTFU. Having access to data to confirm this observation will allow practitioners to advocate for specific interventions to address factors related to factors influencing LTFU that they have observed. The DUC can help to support practitioners by improving access to data as well as the skills needed to analyze and interpret data.

As many country programs have started to prioritize patient-level monitoring, it is important to understand from practitioners what their data needs are and how we as a community can work together to address last-mile obstacles in achieving HIV epidemic control. The DUC provides a forum to hear from those on the frontline of addressing the HIV epidemic and to better contextualize interventions and solutions to serve them.

1. De La Mata, N. L., Ly, P. S., Nguyen, K. V., Merati, T. P., Pham, T. T., Lee, M. P., Choi, J. Y., Ross, J., Law, M. G., & Ng, O. T. (2017). Loss to Follow-up Trends in HIV-Positive Patients Receiving Antiretroviral Treatment in Asia From 2003 to 2013. *Journal of acquired immune deficiency syndromes (1999)*, 74(5), 555–562. <https://doi.org/10.1097/QAI.0000000000001293>blocked URL