

Published: June 2016

## Future needs for characterising the care cascade

*Jack Olney - Research assistant for the HIV Modelling Consortium, Imperial College London.*

As we progress toward the end of the fourth decade of the HIV epidemic, substantial progress has been made in reducing the morbidity and mortality of those living with HIV (1,2), particularly due to the availability of antiretroviral therapy (ART) (3). However, we must pause, and assess the current state of the epidemic to understand where limited resources are best utilised. At present, countries are inadequately prepared to evaluate the prospect of achieving the UNAIDS 90-90-90 targets by 2020, but with further enhancements they could be (4).

With the release of the WHO Consolidated Strategic Information Guidelines (5), countries are provided with a template, in the form of a depiction of the “Care Cascade”, permitting them to quantify the state of care as it currently stands. The Care Cascade begins by characterising all infected individuals in a population, before illustrating the cascading loss of patients at each stage of care between diagnosis and viral suppression. These losses were first quantified in an African setting by Rosen & Fox in 2011, where they illustrated that on average only 18% of persons living with HIV were retained in care until ART initiation (6). Over the last several years however, the concept of the cascade has gained traction within the HIV community (7,8) and countries are now beginning to produce estimates of their national cascades in order to evaluate the efficiency of current care programmes. Furthermore, with the release of the UNAIDS 90-90-90 targets, countries must determine what changes must take place in order to achieve these goals (4).

### *Data issues*

In the interim, the WHO have developed the Strategic Information Guidance which explicitly defines each pillar of the cascade and provides information to countries on how to quantify each indicator (5). To

facilitate this process, the WHO convened a meeting in Marrakech, Morocco in late 2015, where representatives and WHO regional officers from over 30 countries, representing over 90% of the global burden of HIV, came together to quantify the cascade. During the week-long workshop, national strategic information teams worked to generate national cascade estimates. Several important questions arose during the Marrakech meeting: Primarily, how should the quality of data being assessed be represented? How should model-based estimates be compared to observational data? And, how should countries alter their data collection practices to improve cascade estimates?

Additionally, data presented in Marrakech suffered from various issues, mainly stemming from the lack of a common denominator across the cascade, as individuals contributing towards one bar (e.g. “the number of persons living with HIV (PLHIV) engaged in pre-ART care”) did not always contribute to the previous bar (e.g. “the number of PLHIV aware of their serostatus”) due to the use of different data sources. Furthermore, some countries were not able to estimate the number of PLHIV aware of their serostatus at all. This is unfortunately an inherently tricky value to estimate accurately as cohort or observational studies may not be entirely representative of the national sub-population of PLHIV. In addition, other countries reported nonsensical increases between cascade indicators, for instance higher numbers of “PLHIV aware of their serostatus” than “total PLHIV”. This is likely due to variation in the sources of data, as in many cases mathematical models were used to produce estimates of “PLHIV”, whereas observational studies were used to estimate the number of “PLHIV aware of their serostatus”. This again highlights the lack of a common denominator throughout the cascade. Lastly, very few countries

provided high quality data on all cascade indicators, making further analysis of gaps in care, and extrapolation to estimate the achievement of future targets, inconvenient.

### *Improving cascade reporting*

Nonetheless, in response to these issues, the WHO is promoting efforts to improve and consolidate measurements along the cascade (5). This will allow countries to better understand where gaps in care persist, and indicate the position to prioritise spending. Additionally, by linking care outcomes to service delivery, the impact of investments can be more easily assessed. Strengthening case-reporting, analysis and disaggregation of cascade data will also facilitate the identification of bottlenecks in care. Finally, with support coming from the WHO and collaborating consortia, countries can be guided through the rollout of improvements to data collection strategies and assisted in generating cascade estimates. Given the currently available data, one promising idea put forward was to develop a “traffic light” system, whereby a group of experts collectively rank the quality of data from best to worst, and assign a colour to each. For example, “green” would indicate reliable well-informed data, “amber” for representative data with caveats, and “red” for unreliable and likely biased data. This “traffic light” system is a powerful tool for illustrating the variable quality of available data, and additionally may further highlight the need for countries to strengthen data collection strategies.

However, considering the range of data issues to be addressed, countries should consider taking a graded approach to quantifying the cascade. The first priority should be to estimate the entire cascade using any available data, including that of questionable quality, to produce a snapshot of care. This would include data characterised as “red” in the above scheme. Secondly, individual estimates should then be improved, to strengthen the view of the cascade and iron out any discrepancies resulting from poor prior estimates; turning

any “red” data points into “amber” and “green”. Finally, the gold-standard for cascade analysis is to include linked common denominator data across the cascade. For example, using denominator-linked data between stages, where the same individuals counted in the denominator of one indicator are also counted in another. Or denominator-numerator linked data within stages, where the same individuals counted in the numerator of one indicator are also counted in the denominator; for example, given a subset of the population living with HIV (the denominator), enumerating the number of individuals of this subset that are currently engaged in care (the numerator) (8).

These advances will aid countries in understanding their cascades. Yet, the crucial element missing in cascade analyses thus far is a means of determining the trajectory of patients moving through care. For example, a cross-sectional analysis of a particular cascade may imply a large gap between patients enrolled in pre-ART care and those initiated onto ART; but, this does not indicate changes in the rate at which patients initiate treatment, or consider the adoption of the treatment guidelines. Therefore, additional detail is hidden that may naturally reduce this apparent gap in care. In order to better understand the trajectory of patients moving through each cascade, we must identify sources of data that allude to cascade indicators in the years prior to 2015. This will allow inference on the magnitude of change in each indicator. Alternatively, countries will need to collect and disseminate longitudinal data on the cascade. However, as the concept of the care cascade has yet to fully mature, reliable sources of data representing indicators in previous years are scarce and longitudinal data even more so.

To conclude, it is critical for countries to improve data collection practices, and aim to collect denominator-linked data to characterise the cascade. Additionally, countries should collect data annually, to facilitate cascade evaluation on an annual

basis, and enable progress to be monitored as we move toward the UNAIDS 2020 goals, only to refocus efforts on achieving the 95-95-95 targets in the subsequent decade (4). There is still time for countries to make significant progress and realise the 2020 goals, and if data collection methods are burnished in the next four years, analysis of the changes required to achieve the 2030 goals will become straightforward. It is therefore crucial for countries to focus on producing reliable data, pragmatically analysing their cascades, and working in collaboration with the WHO/UNAIDS to achieve these national targets in a timely manner, reducing mortality and improving outcomes for patients afflicted with HIV.

*Jack Olney - Research assistant for the HIV Modelling Consortium, Imperial College London. Research interests: Mathematical modelling of health systems providing ART in sub-Saharan Africa to gain insight into deficiencies in care, the downstream impacts on population health, and how interventions targeting these deficiencies can improve patient outcome. [jack.olney11@imperial.ac.uk](mailto:jack.olney11@imperial.ac.uk)*

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