Dettaglio abstract

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Title: Implementing an Electronic Patient-Reported Outcomes (ePROs) system in PLWH management: experience of Icona cohort

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Abstract
Background: Care for people living with HIV (PLWH) passes towards the ability to collect individual's health and well-being reported directly by the patients (patient reported outcomes, PROs). Here we describe implementation of a mobile app (e-QoL) to collect PROs in ICONA cohort, in order to integrate the longitudinal data collection of the cohort and patients self-reported measurement.
Materials and Methods: e-QoL is a mobile app developed with Flutter framework for Android and iOS to provide a tool for collecting ePROs and integrating the data collection with the pre-existing Icona web application. Pts specific login credentials, are centrally set in the Icona dataset. No questionnaire data is saved on the mobile device of PLWH. Each patient that agrees to participate, receives the login credentials and a brochure with instructions. The app is structured in 3 areas: 1) informative section on the importance of PROs, 2) main section collecting 9 validated questionnaires: EQ-5D-5L, PHQ-9, GAD-7, ADH, AUDIT-C, HIVDQoL, HIVTSQ, HIVSRQ, W-BQ16, 3) a "Daily" section for reporting weight, blood pressure, waist circumference and smoking status. All questionnaires should be complete once year, the EQ-5D-3L every 6 months. In this analysis, the results from the first year of implementation were reported.
Results: From 2.2022 to 2.2023 10 ICONA centers started the recruitment of PLWH in the Icona eQoL app. 106 out of 4012 PLWH followed in the 10 centers filled at least 1 questionnaire, for a total of 718 questionnaires. 11.9% of participants were female, median age 45 y (IQR 36-56), 76% MSM, 13% previous AIDS diagnosis, 93% suppressed HIV-RNA, median CD4 cell count 674 cell/ccm (526-979). To be ART experienced (p=0.02), MSM (p<0.001), and university education level (p=0.001) were associated with higher probability of downloading eQoL App. 53% of PLWH reported a very good/optimal general QoL and 47% very good/optimal health status (HIVDQoL questionnaire). The treatment satisfaction score was 95.3% (IQR 88.9-98.6) (HIVTSQs). A moderate/severe depression was reported in 21% of PLWH (PHQ-9) and a moderate/severe anxiety in 17% (GAD7). An analytical description of the results for the questionnaire collected is shown in table 1.
Conclusions: ePROs can be an important tool for management of PLWH, and their implementation in observational research setting could identify specific profile of PLWH, providing causal pathways to clinical outcomes, but it needs more specific efforts for adequate implementation. People with technological or language barriers may be ones with higher burden of unmet needs and may need assistance to complete them. The first year of the electronic collection of PROs in ICONA cohort documented mental health disorders despite high level of general QoL and health status. These data can help to inform interventions that ensure long-term retention in care and maintenance of good physical and emotional health.

Table 1. Descriptive statistic for overall score or principal items of PROs collected

EQ-5D-3L, VAS, median (IQR)	85.1%	74.7-91.2
ADH, Adherence, median (IQR)	100%	31.9-100.0
HIVDQOL, general QoL, median (IQR)	2	1-2
Very good/optimal	43	53.7%
HIVDQOL, Health Status, median (IQR)	1	1-2
Very good/optimal	45	47.9%
HIVTSQs, Treatment Satisfaction, median (IQR)	95.8%	88.9-98.6
PHQ-9 score, median (IQR)	6	4-9
PHQ-9 score, Depression, n(%)		
None	16	29.63
Mild	27	50
Moderate	9	16.67
Moderatly/Severe	1	1.85
Severe	1	1.85
GAD7 score, median (IQR)	5	3-7
GAD7 score, Anxiety, n(%)		
Minimal	19	38
Mild	23	46
Moderate	4	8
Severe	4	8
AUDIT-C score, median (IQR)	3	1-4
Hazardous Drinking, n(%)	38	45.2
WB-Q16, General Well-Being, median (IQR)	17	14-19