



MRS Awards 2021
Healthcare Research

Finalist:
Ipsos MORI

**Identifying HIV+ patients
at risk of dropping out of
care in South Africa**

SUMMARY

This study is the first of its kind to use primary market research data to predict which psychological, structural and social factors may lead to a HIV+ patient dropping out of care in South Africa. Whilst a lot of research focusses on how to find HIV+ patients, diagnose them and put them onto care, less is known about how to maintain them in care over many decades. This piece of research conducted by Ipsos was designed to bring insight into what the lives of patients are like when on treatment.

The outputs of this research include a predictive modelling tool which healthcare professionals can use to determine how 'at risk' their patients are from dropping out of care, and therefore tailor interventions and solutions to help patients navigate difficult scenarios. We plan to make the research widely available for the greater good of the HIV response in Southern Africa.

SYNOPSIS

Within the global HIV response, countries have signed up to the 95-95-95 goals in which 95% of People Living with HIV (PLHIV) know their status, of which 95% are initiated onto HIV treatment and 95% of those have reached viral suppression (a marker of medication effectiveness). Whilst much has been done to understand how to find patients and put them onto treatment, less is known about how to maintain viral suppression amongst patients, many who will be taking daily pills for the next 50-60 years (until there is a cure). The other benefit of viral suppression is that there is no chance for infected patients to infect others through sex.

Johnson and Johnson Global Public Health commissioned Ipsos to understand more about the reasons which can lead to patients becoming non-adherent after they are initiated. The research was conducted in South Africa, which has the largest HIV epidemic in the world, with an estimated 7.7 million people living with the disease.

Within South Africa and other countries, there is a considerable risk of PLHIV who are currently engaged in care becoming disengaged from this care down the line. These individuals who disengage can cycle back into the health system, but this time as sicker, costlier patients, with higher risk of drug resistance and the potential to infect others whilst not virally suppressed.

The research we designed comprised 3 stages. The first was a literature review to develop hypotheses of what could prompt someone living with HIV to disengage from care and stop taking their medication. The second was qualitative research, looking at the different internal and external factors which contribute to PLHIV disengaging from care. We spoke to PLHIV to understand periods of time in their lives when they became non-adherent and what were the factors and scenarios which meant that adhering became harder. The third stage was a quantitative survey to determine which of all the different factors we identified in the qual are the strongest drivers for stopping taking HIV pills. Each stage of research had to be designed in such a way as to capture all the relevant factors for non-adherence whilst tackling a very sensitive research topic among a vulnerable population. Due to the COVID pandemic, we were unable to interview respondents in person and had to mitigate for any research effects to moving interviews to telephone. However, through thorough piloting, we realised that there were some advantages to moving to telephone in that respondents were willing to share more. Through engaging with the South African health system, we were able to achieve permission for the health system to recruit patients on our behalf to ensure we were compliant with data protection laws and able to speak to patients by phone.

These three phases of research allowed us to identify and present to J&J profiles of PLHIV who are at risk of becoming non-adherent with their daily oral medication through identifying key factors that can lead to disengagement routed in the lived experienced of PLHIV in South Africa. We determined that patients under the age of 40 had the highest challenges with adherence and were disrupted by life events like birth of a child or fearing that their social lives such as ability to find a partner would be inhibited by pill taking. We were

able to produce a decision support tool which can be used by Healthcare Professionals to determine which of their patients are at risk of dropping off their oral medication based on life stage, attitudinal and behavioural statements so that healthcare professionals can tailor their support accordingly. For example, through recognising factors which lead to patients to disengage from care, Healthcare Professionals can choose to put patients on treatment regimens which fit better with their lifestyle or offer social care to those more at need.

Our research contributed significantly to the understanding of what causes PLHIV to stop taking their HIV pills, and of these factors, which could be mitigated through the option of patient support programs or changes of medication. It is one of the first studies of this kind focussing on the challenges PLHIV face in adhering to their oral medication from their own point of view.

“Throughout your presentation of the study, our internal team were texting me to say how useful this study is, and how many implications there are from the insights. We are grateful for your team’s leadership in managing this project and ensuring the delivery of a high-quality analysis in very difficult circumstances (the pandemic)” – Insight lead from J&J

We covered a breadth of factors from personal life-experience, to demographics, to clinic experiences and collected the information in an accurate and objective way, developing rich insight unlike any which has been seen in previous studies. We

were able to highlight the importance of ‘self acceptance’ as a pre-cursor to taking HIV medication, by bringing to life the stories of patients whose shock and fear after their diagnosis meant that they refused to accept this life changing event. We also highlighted that when people enter new romantic relationships, that moment when they tell their new partner that they have HIV represents a cliff edge, in which their new romantic endeavour can end which causes stress for patients which needs social support beyond medication alone. For some patient populations, the thought of needing to take tablets every day for the rest of their lives can be overwhelming, and we need to reframe HIV medication as something that “imprisons” them for “past mistakes” into something that can liberate them and help them to live life as normal. We also highlighted that certain patient groups have better coping mechanisms than others, and it is important for healthcare workers to recognise this upfront when tailoring care. We also highlighted the role of poverty in meaning that patients find it difficult to maintain routines around infrequent and casual work, and better solutions are needed to protect patients who often migrate across the country for income, to stop them being lost from the clinical system.

J&J plan to make the data available to a larger audience of public health organisations to support PLHIV as part of a commitment to the global good. This information will be key to the global HIV response, to better support PLHIV and provide support remain on treatment where they otherwise might drop off.