

# CONNECTED

young people and HIV self-test kits in Zimbabwe

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## INTRODUCTION

Zimbabwe's HIV prevalence rate is 15%,<sup>1</sup> including 4.1% of adolescents.<sup>2</sup> Only 49.5% of young people in Zimbabwe have comprehensive knowledge on HIV,<sup>3</sup> leaving 50.5% at possible risk of HIV infection. This report explores HIV self-testing as a mechanism for HIV prevention among young people. There are no clear policies or laws governing HIV self-testing.<sup>4</sup> Thus quality assurance, ethical use and minimal risks compromise the possibility of early treatment when used.<sup>5</sup> The report captures society's cultural and religious perspectives on HIV self-testing. Currently HIV self-testing is viewed as a limit to people's autonomy, affects confidentiality and raises issues of consent.<sup>6</sup> Zimbabwe is one of the countries piloting a roll out of HIV self-testing.<sup>7</sup>

## WIDER CONTEXT OF HIV

At least 75% of PLHIV globally reside in Africa.<sup>8</sup> An estimated 50% of people living with HIV (PLHIV) know their HIV status.<sup>9</sup> PLHIV reportedly transmit 50% of new HIV incidences.<sup>10</sup> This reflects why people knowing their HIV status is of global importance.<sup>11</sup> For example in China, the roll out of HIV self-testing is viewed as a means to ensuring the timely uptake of treatment.<sup>12</sup> This is because of slower diagnosing of new HIV incidences in health facilities.<sup>13</sup> The importance of HIV testing lies in early detection, as treatment can commence in view of managing one's viral load.<sup>14</sup> This is critical to mitigating the influences of new HIV incidences among a popu-

lation. For PLHIV, early detection enables better management of HIV through treatment and appropriately adjusting lifestyle to increasing lifespan. This has resulted in HIV no longer being viewed as a death sentence but a chronic disease.<sup>15</sup>

Other views argue that there is no evidence of 'cause and effect' in testing and prevention.<sup>16</sup> This is the challenge presented by sexual behaviour even when PLHIV know their status. However it is considered desirable for one's viral load to be undetectable, thus mitigating the possibility of new HIV transmissions. Factors such as service delivery, health infrastructure and research play a critical role in better managing the HIV epidemic. These are a challenge for African nations considering limitations caused by civil disruptions, poverty and resource-dependent government revenues.

A voluntary HIV testing drive at the University of Zimbabwe revealed that 47% of participants were HIV positive. This reflects a challenge in prevention at an education institute. The high prevalence rate that could translate into new HIV incidences in partner institutions during inter-university engagements, at social gatherings or in different regions when students are travelling. The dynamic of young people lifestyles and behaviour plays a critical role in HIV incidence and prevention.<sup>17</sup> The pilot roll out of free HIV self-testing in Zimbabwe is viewed as an approach to curbing the spread of HIV.<sup>18</sup> Especially considering that only 34% of men and 56% of women nationally know their HIV status.<sup>19</sup> One of the contributing factors to people not testing for HIV is the st-

igma associated with testing or getting treatment.<sup>20</sup>

Thus HIV self-testing presents an alternative that can address some of the issues mentioned above. This report supports research efforts considering better ways of addressing HIV transmission, treatment uptake and prevention. Although HIV self-testing is a newly accepted approach globally;<sup>21</sup> Kenya is the only African country to have adopted it since 2005 HIV self-testing.<sup>22</sup> Other countries rolling out pilot projects for HIV self-testing include Zambia, South Africa and Malawi.<sup>23</sup>

## LEGAL FRAMEWORK

HIV testing acknowledged as the starting point to prevention, care, treatment and support.<sup>24</sup> The administering and distribution of HIV self-testing remains a grey area in Zimbabwe. However, there are laws on HIV testing, along with others related to HIV.<sup>25</sup> The legislative framework is important given that HIV impacts on several issues including reproduction, livelihood and society. Concerns against HIV self-testing include the lack of counseling and post-diagnosis interventions for people that test in the privacy of their homes.<sup>26</sup> Similarly, the possibility of having false outcomes. This could be the basis of the Ministry of Health's reluctance on allowing the distribution of HIV self-test kits in practice.<sup>27</sup> The ministry's does however acknowledge the need to expand HIV testing coverage through alternative means.<sup>28</sup>

Section 76 of Zimbabwe's Constitution relates to the right to basic health with specific mention of reproductive health under section 76 (1) and chronic diseases under section 76 (2).<sup>29</sup> This means that all persons in Zimbabwe can receive HIV testing, counselling, treatment and support. The means for HIV self-testing would more likely be governed by The Medicines and Allied Substances Act of 1990 due to the need for test kits to be distributed. The Medicines Control Authority controls the distribution of medical devices; however it only identifies condoms and gloves.<sup>30</sup> The law is not sufficient in instances where culture and religion might be prioritised. Children and adolescents are most adversely affected by HIV/AIDS in Zimbabwe.<sup>31</sup> Laws have been changed to allow HIV testing from age 16; also limiting parental influence where a child's health is a concern.<sup>32</sup> This allays fears for sexually active adolescents in requesting permission to test for HIV from deeply religious or cultural parents.

## HIV SELF-TEST KITS

Individuals use HIV self-test kits for a diagnosis on their HIV status.<sup>33</sup> These were introduced in the 1980s however, the lack of treatment and reliability of results delayed international acceptance.<sup>34</sup> Where resources and capacity are limited; HIV self-test kits are innovative and cost effective.<sup>35</sup> These further eliminate challenges such as stigma and discrimination, costs associated with travel to health facilities, culture and even language. Several things complicate HIV self-testing; a) the need to get follow up lab te-

testing to ensure accuracy of results,<sup>36</sup> b) the possibility of self-test results leading to intimate partner violence<sup>37</sup> and c) the difficulty for people to understand instructions and interpreting results.<sup>38</sup> In addition, the three month window period for HIV to be detectable makes HIV self-test kits futile.<sup>39</sup> Thus HIV self-test kits will not be effective in isolation.

## METHODOLOGY

A qualitative method is used to capture young people's perspectives.<sup>40</sup> Using social constructionism; the report acknowledges bodies of knowledge as opposed to just one body of knowledge in issues of HIV/AIDS.<sup>41</sup> It aims to capture perceptions, experiences and social practices on HIV self-testing from young people in Zimbabwe.<sup>42</sup> In ensuring triangulation, multiple data collection tools are used to enrich the report and better understand the dynamics of culture and society.<sup>43</sup>

Semi-structured interviews are used to compliment observations made, to enable reflection on the meaning and experience of what is said in response.<sup>44</sup> Participants are encouraged to speak freely and rapport was established in recruitment to ensure openness.<sup>45</sup> A similar approach is adopted with focus groups; used to validate one-on-one interviews and observations. However, focus groups are not sufficient in addressing all research questions considering that HIV is a sensitive topic. Participants

Participants might feel more comfortable engaging in on an individual basis.<sup>46</sup> Recordings from all engagements are available to ensure full engagement in data collection activities. An inductive approach is used for data analysis to better understand the dominant themes in data collected. This is achieved through analysis of interviews and focus group transcripts.<sup>47</sup> To ensure consistency and objectivity in analysis; coding is integrated.<sup>48</sup>

## FINDINGS AND DISCUSSION

Informal interviews were held with key informants from the National AIDS Coordinating Agency (NACA), the Musasa Women's project (Musasa), Say What organisation (SW) and the Gays and Lesbians of Zimbabwe (GALZ). There is no difference in structures between civil society and government; key staff at project officer level relayed similar bureaucratic structures, complimented by traditional structures in remote locations. Due to the inability to secure foreign funds, civil society organisations are supported through the state. The challenge of funding is common throughout, however for NACA; more 'controversial' populations have become one of the only ways they can source HIV related funding. In turn funding is channeled to civil society. This presents a challenge for organisations that might not be politically affiliated or those serving 'controversial' populations.

Observations were made of health facilities in the following areas; Milton Park travel clinics, West End clinic, St Anne's hospital, Mont pleasant, Kensington, Norton, Borrow-

dale, Strathaven and Avondale. Public health facilities are unevenly distributed in Zimbabwe, with private health facilities more geographically accessible. Medical costs are a problem, along with the resourcing of public health facilities. One participant hinted at corruption as a reason for this:

*'It happens with specialists, they say that they don't have this or that and refer you to their friends or their own clinics. Which means one has to pay. So for the ordinary person who can't afford, they have to find their own way for treatment'*

Focus Groups provided significant findings with feedback in both verbal and written form. Three groups were engaged on their experiences and perceptions from the following institutions; officers within the Ministry of Primary & Secondary Education, geologists from the Mining sector, students from University, recent graduates, international youth organisations, local youth organisations and the National Institute of Health. The first focus group alone had perspectives from eight organisations. Notably only one receives of foreign funding due to working with key populations. There was an equal gender balance as a collective of all three groups. To supplement the sourcing of variant perspectives, an online survey was initiated with the option for further follow ups through telephonic interviews. Table 1 to 3 below present an overview of the discussions;

## Overview of focus group discussions

### What are the advantages and disadvantages of HIV self testing?

Advantages	Disadvantages
<p>Self confidence will be boosted, especially when HIV negative; early detection; the results are quick, one does not have to travel long distances; confidentiality; Can be cheap; reduces stigma; easy access; helps appreciate reality and moving on with life; one can know partner's status before engaging in sex; convenient; can be done anytime; increase of number of people who get tested; reduces stigma to closed communities; increases community participation; promotes health seeking behaviour</p>	<p>There is no pre or post test counseling provided, one's behaviour might not change – others can be in danger; kits might be costly, people can abuse; may lead to domestic violence; misinterpretation of results; follow up is not mandatory; knowledge requirements on using the kit; if tested positive, what next?; requires confirmation test hence use of more resources; no follow up for treatment; user friendliness for illiterate people; results can mislead during window period; its questionable; high probability of forced testing; false negatives; redundant testing; influences social issues; no linkage to care.</p>

Table 1

## Overview of focus group discussions

### What impact, if any, do you think culture and religion would have on HIV self testing?

Culture	Religion
<p>Promotes secrets amongst couples and family; vulnerable groups are stigmatized (sex workers, MSM, orphans); tension for married people i.r.o. domestic violence; people may not accept the consequences that the system will create in their marriages; dependent on the regions as some have accepted HIV/AIDS as a reality compared to others; blood can be an issue considering that its associated with witchcraft; you can be judged; women's rights may be infringed upon; myths and misconceptions are rife; socialization; male dominate the initiation of testing</p>	<p>Improves access to those who are afraid of visiting clinics; some religious sectors can advocate for incidence that promote risks to HIV; churches administered HIV testing before marriage; some religious sects will reject self-testing (Bazezuru/Mapossitori) as they do not recognize the use of medicine and HIV tests; Jehova's witness ('watchtowers') would not be allowed to use blood self-test kits; some religious teachings would defeat the purpose of self-testing; religious enabled multiple partner relations could compromise self-testing; apostolic discourage medical treatment so they may not accept HIV self-testing; prophetic religious communities or deliverance ministries may encourage using self-test kits for confirmation of healing; premarital sex is discouraged so there is no need; purity is priority, sex is taboo; no need for it as life is spiritual; no information on these groups; leaders are influential;</p>

Table 2

<b>Overview of focus group discussions</b>	
<b>Please describe the feasibility and impact of HIV self-testing in the below settings:</b>	
<b>Urban/city/town/modern setting</b>	<b>Rural/remote/village/outskirts setting</b>
<p>More feasible and people would opt for the idea; accessible testing and treatment; people have more resources, exposure and mobility; with positive results people will know their status, with negative there will be domestic violence; people already don't know their status; window period is a concern; access to health facilities and information is easy; more people will be reached; better information dissemination for effective kit use;</p>	<p>Few people will take up the idea; inaccessible and costly, language barrier; not feasible as there is a lack of knowledge, resources, ability to cover associated costs and mobility; more accessible; some remote locations have a lot of HIV awareness which is good for self-testing; suicide rates can increase; accessibility is caused by a lack of infrastructure (roads, medical facilities) and economic challenges; poverty; no access to global village (no internet/television); no media = no information; there are large distances for health facilities, smaller villages when testing, people will know the outcome of your result by the facial expression; good for scattered settlements; short supply of service providers; lack of right to privacy, cultural practices may be barrier</p>

Table 3

Targeted participants included reside in Bulawayo, Matabeleland North, Gweru and greater Harare province regions in view of diversifying views. In addition triangulation interview and focus group data was possible as the online surveys produced similar results. Table 4 and table 5 below present the results of the online survey:

Table 4: Survey results part 1 of 2
<p><b>Summary</b></p> <p>3 out of 13 participants had no knowledge on HIV self-testing as a concept, pilot or option            Only 2 out of 13 participants were willing to buy HIV self-testing kits, notably they are male            All participants think their peers would use HIV self-testing kits, with ages ranging from 20 to 30 years old            Only 1 participant did not feel comfortable with being contacted again</p>
<p><b>All believed their culture would allow for HIV self-testing</b></p> <p>1) I think it is vital to know your status so that you can get early treatment and also to avoid infecting others unknowingly.            2) HIV is now a socially accepted issue and no one in the Ndebele culture that I know of has thus far ridiculed HIV testing.            3) It is better to know than to hold a whole society in the dark at risk of death            It would help my peers as they might think they feel confident            4) I just think they will allow me            5) because I am Zimbabwean            6) People are moving away from stigmatization            7) we have accepted that the disease is real and its impacts are clear            8) because members of my culture understand the benefit of getting tested            9) This could possibly multiply the number of those who would get tested for some may be generally shy or more uncomfortable to go for testing in VCT centres. However, measures should be put in place to ensure that pre-counselling services are made in one way or the other.            10) yes they allow because in our culture people now understand about this virus and would want people to know their positions health wise            11) The pressure of living in fear eventually pushes one to want to know his results            12) I don't necessarily have a culture I'm mixed. We follow the bible            People in my culture have been reluctant to go get tested by someone. People were not sure about the confidentiality in a situation whereby one is HIV negative. I think people will take the self-testing kit.</p>

**Table 5: Survey results part 2 of 2**

**Only 2 believed their religion would not allow for HIV self-testing**

- 1) We are an open community that has various branches to assist those who are infected or affected by the diseases.
- 2) Christianity has no problem with HIV testing
- 3) Its good to worship God whilst you are aware of your status too
- 4) They will allow me
- 5) because i am christian
- 6) Times are changing and Hiv self testing is really a personal choice
- 7) through the fear of losing their lives they will
- 8) because it affects them too so testing is the only way out
- 9) The focus and the goal is to make sure that everyone knows his/her status in time and whats important now is trying to explore any other way of achieving that. Some will opt to go to VCTc but others would embrace Self Testing!
- 10) we allowed healthy living
- 11) Not Religious
- 12) It will I'm Christian
- 13) My religion has been always part of fighting HIV so testing is one other way in the procedure of fighting HIV.

Culture presented a complexity of challenges in both urban and remote areas. Patriarchy is perceived as a challenge, with risk of abuse or intimate partner violence when using a test kit as a couple with no professional oversight. For example; if there is a HIV positive test result; a partner can resort to violence. Focus group participants noted a complexity of men having multiple-concurrent sexual relations. Instances could occur where one man discloses 'the same HIV self-testing results with all of them, how will they know that he's cheating'. Some cultures accept polygamy as a practice, raising issues of privacy and confidentiality; where female partners can be subjected to involuntary testing to check fidelity. This remains a challenge even with standard testing services as health practitioners do not have insight into sexual practices among

the general population. Further highlighting patriarchy among young people: participants had always referred to women being HIV positive when giving examples.

Malawi's HIV self-testing pilot proved that partner testing and disclosure in relationships could be a success.<sup>50</sup> This is in line with focus group discussions that revealed value is added to relationships when information is accessible and women deemed equal. Discussions singled out cities or towns as environments where young people could easily take up consensual relationship self-testing. However some participants cautioned on the danger of one being tested without knowing. This could result in criminal, vindictive behaviour and discrimination. More especially for most key populations; a demographic that experiences bribery and extortion that would only increase with the availability of HIV self-test kits.

The use of self-test kits essentially presents a need to better educate and provide support services for people in the outskirts or those with strong spiritual beliefs. Religion poses similar complexities as culture. People's respect for religion can limit disclosure and informed consent. Law requires consent to be verbal or written,<sup>51</sup> however; 'informed' can be subjective when considering that the self-test can be used to prove that a prophesy of a pastor removing HIV came true'. Both focus group and online survey participants identified religious leaders as key to HIV prevention interventions. This is because of the influence they have on people's belief systems. This reflects arguments for a shift in HIV testing from health facility delivery to community delivery.<sup>52</sup>

Participants highlighted suicide and misinformation in using the self-test kit. More especially when there is a possibility of false test results. In addition, the window period remains a challenge as one can test during this period and believe they are negative. 'As an individual can be ignorant of their actual status whilst using the HIV self-test kit in these instances.' Participants further explored the CD4 count as it can increase whilst on treatment – or possibly decrease,<sup>53</sup> it could be argued that the HIV self-test could assist in determining whether the virus is detectable or not, essentially providing an indicator of the level of the virus in one's system. However the link between HIV self-testing and the update of treatment remains a grey area.<sup>54</sup>

## CONCLUSION

A better understanding is needed on young people's sexual behaviour after using an HIV self-test kit.<sup>55</sup> It is clear that HIV self-testing results are not reliable in confirming one's HIV status within three months of contracting the virus.<sup>56</sup> Calls have increased encouraging HIV testing to be rolled out in places of religion, residence and traditional practice instead of them having to go to health facilities.<sup>57</sup> This reflects the need to move from service delivery to community driven solutions. HIV remains a complex challenge for young people and multiple approaches need to be adopted to better ensure prevention. HIV self-testing is only a start in this process. This report reflects the influences of cultural and religious frameworks in relation to HIV testing. HIV self-testing is feasible within both frameworks and in society at large despite its many challenges.

More work is needed in establishing mechanisms to support people who are HIV negative as a gap exists in the follow up post-HIV testing. More research is needed to address the gap between HIV self-testing and the follow up care and support for all persons, whether negative or positive. In this regard, recommendations are presented below.

## RECOMMENDATIONS

'HIV/AIDS doesn't discriminate, people do.'<sup>58</sup> There is a need to eliminate discrimination in cultural, religious and legislative platforms. Women and key populations are at risk of having privacy, confidentiality and safety compromised within the HIV testing process. If self-test kits are rolled out with safeguards for this, intimate partner violence and other forms of discrimination may increase. Private consensual sex can be complex, considering that criminalisation of HIV transmission also encourages discrimination.<sup>59</sup> HIV self-test kits would only increase vulnerabilities faced by women and key populations where multiple concurrent relationships exist. Legal reform is needed to eliminate these forms of discrimination through repealing the HIV transmission law. In addition, HIV self-test kits and dispensaries should relay the ideal circumstances for self-testing and subsequent actions to take post-testing.

Young people need to be involved in HIV interventions; especially in design and evi-

dence building stages as this ensures inclusion and relevance for better uptake.<sup>60</sup> HIV self-testing should be rolled out to eliminate these challenges in view of at least ensuring more people are aware of their HIV status. HIV self-test kits should be distributed in multiple local languages to address the challenge of use and interpretation. They should also include messaging on safe sex, possible toll free call centers and online platforms that can provide advice, counseling and further information for those using HIV self-test kits. A mechanism could be put in place for tracking distribution, confirmation lab tests and treatment uptake; although complex, community collaboration with civil society and the state could enable this.

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