

## **Increasing Access to HIV/AIDS Information in Rwanda and Uganda through Social Media: a Call to Action for Health Librarians**

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### **Abstract:**

*An ethnographic study on HIV/AIDS information behaviour conducted by the lead author in Sheffield, England among persons affected personally or indirectly by HIV/AIDS included British nationals, Africans, Europeans, and Americans revealed that people used the Internet for information such as the disease itself, transmission routes, and socio-economic aspects of living with HIV. However, this research also revealed that people felt Internet information-seeking had attached stigma and was often a source of contradicting, misleading, outdated, inaccurate, or excessively-technical information.*

*Using this research as a backdrop for analysing online HIV information sources in Rwanda and Uganda, HIV resources were searched as a member of the public might search with Google and Facebook, for local-language materials as well as English. Disappointing examples for Rwanda include: a Google site offering a free DVD in Kinyarwanda by post on caring for an HIV/AIDS person rather than immediate access; a site with Kinyarwanda information described by one user as inadequate; and free educational materials requiring registration. For Uganda one group offered digital literacy help to find English-language materials because that is the official language. Searching Twitter with “HIV Rwanda” and “HIV Uganda” led to several sites with mostly English but some local language responses*

*and stigma was addressed. Facebook had less than expected information focused on the two countries. Most encouraging was Yahoo link to video in Kinyarwanda from a recognized source. This overview suggests that African health information librarians should participate in the creation as well as discovery of relevant information in languages and formats easily accessible to the public for distribution on Social Media in addition to the Internet and the social media. The health librarian is uniquely positioned to serve as a link between reliable, language-appropriate medical information and the lay public who often have mobile phones even if they have no computer access.*

**Keywords:** HIV/AIDS, Information Needs, Social Media, Internet, Rwanda, Uganda

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## **Problem Statement and Literature Review**

Despite the enormous gains already made and what can be achieved reversing HIV/AIDS globally huge challenges lie ahead because in 2015 there were 2.1 million [1.8 million–2.4 million] new HIV infections worldwide, adding up to a total of 36.7 million [34.0 million–39.8 million] people living with HIV [1].

HIV still remains a daunting challenge to Uganda where the adult prevalence rate is 7.07%. In countries such as Rwanda sharp decline has been registered, the prevalence in urban areas (6%) is three times higher than in rural area where the prevalence is 2 percent [2]. In order to respond to the world commitment to end HIV epidemic by 2030, a multi-sectoral approach that promotes participation of people of concern, cooperation, and collaboration and coordination across key sectors, including but not limited to health, psychosocial, and information must be adopted. This is in line with an ethnographic study conducted on HIV and information behaviour which emphasised that attempts to fight HIV/AIDS should not only focus on the cure of HIV but also the social cultural interactions that can hinder or promote the fight against HIV/AIDS [3].

## **HIV/AIDS-Related Information**

Information is an important resource for persons affected by or infected with HIV/AIDS as well and the entire community for the prevention and management of HIV/AIDS [4]. Persons infected with or affected with HIV/AIDS need information on medication, social welfare, HIV transmission, and more often than not turn to the Internet to satisfy their information needs consequently information is the only known HIV vaccine [5]. However, information on the Internet could sometimes be inadequate, excessive, outdated, alarming, stigmatising, and misleading which can lead to avoidance behaviours [6], thus undermining the benefit that can be obtained from information for the prevention and management of HIV/AIDS.

## **Access to Mobile Phones and Computers**

World Bank figures show Rwanda's population at close to 12 million and Uganda's at over 39 million. [7] The Rwanda Utilities Regulatory Authority (RURA) reported nearly 9 million mobile phone subscribers in 2017[8] and Uganda had 23 million subscribers in 2016 with nearly 38% of the total population subscribing to internet services. [9] Therefore, it is reasonable to believe that a significant number of residents with access to mobile phones and sometimes computers may search the internet for information.

## Social Media and HIV/AIDS information

Social media are computer-mediated technologies that facilitate the creation and sharing of information, ideas, and other forms of expression via virtual communities and networks [10]. The social media is characterised with the creation content that is so compelling enough that users are left with no option but to share it with their social networks. The Internet has become an embedded part of everyday social life because of the mobile media which allows users to perpetually surf across social media applications. The Internet is increasingly being used as a source of health information. Consequently, the Internet possess great potential as a method of HIV prevention, management and outreach since interventions can be delivered with high-level of anonymity. Embracing the social media can be an answer to Uganda's health system that is grappling with challenges, such as poor physical infra-structure, inadequate professionals [11]. The most common benefits to using social media to communicate about HIV have been reported such as access to information, enhanced ability to communicate, having an anonymous identity, a sense of social and emotional support, establishing a virtual community, and geographical reach [12].

Despite Social Media's capacity to expand an individual's network to access information, scant studies have investigated health librarians' involvement in social media for purposes of increasing access to HIV/AIDS-related information. Therefore, this paper seeks to explore ways in which health librarians in Rwanda and Uganda can harness the opportunities provided by the Social Media to increase access to HIV/AIDS-related information.

### Research Design, Methodology, and Analysis Techniques

English, Kinyarwanda, and Luganda were selected as the languages to use in this study. Our first step was to search the 5 terms which represent HIV/AIDS-related information needs [3] in the 3 languages in the Google search engine. Then the same terms were searched in social media (Facebook) in the 3 languages. English has been the official language of Uganda since 1962 and Luganda is the most commonly-spoken local language there. [13] In Rwanda in 1994, English was added to Kinyarwanda and French as an official language, although French was subsequently dropped as official in 2008. [14] Kinyarwanda is spoken by 99% of Rwandans. [15] A search of French terms provided too few hits to document. See Table 1 below for the terms in English, Kinyarwanda, and Luganda that were used to search for HIV/AIDS information.

**TABLE 1: SEARCH TERMS**

English	Kinyarwanda	Luganda
HIV/AIDS Transmission	Uko agakoko ka SIDA kandura	Okusasanya Siliimu
HIV/AIDS Management	Uko wabana n'uburwayi bwa SIDA	Okwerinda okusasanya n'okwejanjamba
HIV/AIDS and Social Welfare	Imibanire y'umurwayi wa SIDA n'abandi	Siliimu Emikwano, emipya, Okufuna omubeezi, Emirimu
HIV/AIDS Medication	Imiti igabanya ubukana bwa SIDA	Eddagala lya siliimu, Obujanjabi
HIV/AIDS Prevention	Kwirinda ubwandu bwa SIDA	Okuziyiza siliimu

Health librarians in Centre Hospitalier Universitaire de Kigali/Kigali University Teaching Hospital (CHUK) in Rwanda were also contacted in order to try and identify examples of how social media has been used to increase access to HIV/AIDS-related information.

The analytical process entailed counting the number of hits per key word in Google and on Facebook to identify the coverage of HIV/AIDS-related information in the Kinyarwanda, Luganda, and English languages respectively.

## Findings

This section presents the findings from the searches that were conducted. Tables 2 and 3 present the findings from Google and Facebook respectively. The languages are represented by the first letter as follows: E-- represents English, K-- represents Kinyarwanda and L-- represents Luganda.

**Table 2: EVALUATION OF RESEARCH ON THE GOOGLE SEARCH ENGINE**

<b>Keywords English Kinyarwanda and Luganda</b>	<b>Hits in English--E</b>	<b>Hits in Kinyarwanda--K</b>	<b>Hits in Luganda--L</b>
<b>E--HIV/AIDS K--SIDA L--Siliimu</b>	61,600,000	512,000	1,670
<b>E---HIV/AIDS transmission K--Uko agakoko ka SIDA kandura L--Okusasanya Siliimu</b>	719,000	37	9
<b>E--HIV/AIDS management K--Uko wabana n'uburwayi bwa SIDA L—Okwelinda okusasanya n'okwejanjamba</b>	41,000,000	15	0
<b>E--HIV/AIDS Social welfare K--Imibanire y'umurwayi wa SIDA n'abandi L--Siliimu Emikwano, emipya, Okufuna omubeezi, Emirimu</b>	1,390,000	24	0
<b>E--HIV/AIDS Medication K--Imiti igabanya ubukana bwa SIDA L--Eddagala lya siliimu, Obujanjabi</b>	1,140,000	32,000	3
<b>E--HIV/AIDS Prevention K--Kwirinda ubwandu bwa SIDA L--Okuziyiza siliimu</b>	37,300,000	73,000	32

As noted in Table 2 above, there are millions of hits in English on Google but hits in Kinyarwanda and Luganda are very limited. For instance, a general search on HIV/AIDS in English returned 61,600,000, hits 512,000 in Kinyarwanda and only 1670 in Luganda. Further

search was carried out on Facebook and the results are presented in Table 3 and further explained in the narrative below.

**Table 3: Health Information in Rwanda and Uganda through Facebook**

<b>Keywords English, Kinyarwanda, and Luganda</b>	<b>Hits in English</b>	<b>Hits in Kinyarwanda</b>	<b>Hits in Luganda</b>
E---HIV/AIDS transmission K--Uko agakoko ka SIDA kandura L--Okusasanya Siliimu	4038	5	11
E--HIV/AIDS management K--Uko wabana n'uburwayi bwa SIDA L--Okwelinda okusasanya n'okwejanjamba	729	60	0
E--HIV/AIDS and Social welfare K--Imibanire y'umurwayi wa SIDA n'abandi L--Siliimu Emikwano emipya, Okufuna omubeezi, Emirimu	2248	110	22
E--HIV/AIDS Medication K--Imiti igabanya ubukana bwa SIDA L--Eddagala lya siliimu, Obujanjabi	1218	250	0
E--HIV/AIDS Prevention K--Kwirinda ubwandu bwa SIDA L--Okuziyiza siliimu	2806	285	12

As indicated in Table 3, on Facebook the search terms HIV/AIDS Transmission/Uko agakoko ka SIDA kandura/Okusasanya Siliimu, resulted in 4038 hits found in English, 5 results in Kinyarwanda, and 11 Luganda. Our results showed that there were 457 relevant hits in English (218 search results are relevant information about Rwanda in English and 239 information about Uganda also in English are relevant.)<sup>2</sup> in Kinyarwanda and 5 in Luganda were relevant information for these particular terms through Facebook social media. The findings also showed that the search terms HIV/AIDS Management/Uko wabana n'uburwayi bwa SIDA/Okwerinda okusasanya n'okwejanjamba provided hits of 729 in English, 5 in Kinyarwanda and 11 in Luganda. The search demonstrated that 147 results in English were relevant to the search term, while all result in Kinyarwanda and Luganda were irrelevant to the search term as indicated in the Table 3. Based on search terms HIV/AIDS Social Welfare/Imibanire y'umurwayi wa SIDA n'abandi/Siliimu Enikwano, emipya, Okufuna omubeezi, Emirimu, the hits included 2248 in English, 250 in Kinyarwanda and 0 in Luganda. The research revealed that 127 out of 2248 hits were relevant in relation to the search term in English, while there was no relevant information in Kinyarwanda and Luganda.

Furthermore, the search terms HIV/AIDS Medication/Imiti igabanya ubukana bwa SIDA/Eddagala lya siliimu, Obujanjabi, showed that there were 1218 hits in English, 250 in Kinyarwanda and 0 in Luganda found. The study specified that among those hits only 95 results in English and 45 in Kinyarwanda contained information relevant to these particular search terms.

The study determined that the terms HIV/AIDS Prevention/Kwirinda ubwandu bwa SIDA/Okuziyiza siliimu provided 2806 results in English, 285 in Kinyarwanda and 12 in Luganda. The research stated that among the results, 170 for the English, 18 for the Kinyarwanda and 12 for English were relevant information, including videos and images for these terms.

## **Discussion of Findings**

English-language terms returned many more hits than equivalent translations in Kinyarwanda and Luganda; most of the results returned across the three languages were not only irrelevant but in inappropriate formats. It is interesting to note that, although English is the official language both in Uganda and Rwanda, a section of the population cannot speak, read, or comprehend material written in English, especially in Rwanda. Thus, the need to develop information products that in local languages to be responsive to the needs of the local communities.

The use of social media for HIV/AIDS related information is proposed by these authors because it is much quicker to develop and to disseminate resources in the local language via Facebook and other social media platforms.

After this study was conducted, a visit was paid to the Centre Hospitalier Universitaire de Kigali /Kigali University Teaching Hospital (CHUK) on 26 May 2017. This library was chosen because it is the largest health-information library in the University of Rwanda system. The purpose of the visit was to know whether the medical librarian at CHUK employed social media to disseminate health information. The health librarians reported that they neither know the social media nor use it. The visit thus provides insight into the apparent lack of knowledge in the medical library community about how social media can be employed to disseminate health information to the general public.

This paper suggests that Health Librarians need to be trained and equipped with essential skills in using appropriate social media to repackage and disseminate HIV/AIDS-related information, particularly in local languages in order to satisfy the information needs of persons infected with or affected by HIV/AIDS. This can go a long way in addressing scarcity and/ or lack of HIV/AIDS-related information. Social media platforms are proposed because they have the capability provide varying designs and features, such as options for anonymity, vary formats audiovisual presentations which can be tailored to meet the needs of target populations. This finding is corroborated by a systematic review that was done in North Carolina, USA in which the social media was cited to be an invaluable tool in disseminating HIV/AIDS information [10] . This re-emphasises the need to employ the social media to disseminate information in life threatening and stigmatising contexts.

Two limitations are noted. The searches were done on Search Engines in Rwanda which might affect the number of hits in Luganda. The authors are not professional translators and it is possible that a professional translator might come up with different search terms.

## Conclusion

Although possession of --or access to-- computers might be limited in Rwanda and Uganda, especially in rural areas, the use of mobile phones is pervasive in both countries as shown above. Health-information librarians are uniquely positioned to be leaders who participate in as well as encourage the development of appropriate, understandable, and reliable resources about HIV/AIDS in local languages and English (the official language in both countries) in order to fill the gap that has been documented in this study and to encourage dissemination of the information on social media outlets such as Facebook, Twitter, and other electronic media in addition to reliable web sites. Particular attention should be focused on the number of persons in each country who function in local languages in order to prioritize materials in the languages that will reach the greatest number of citizens. With 99% of Rwandans functioning in Kinyarwanda, that is not difficult, but in a country such as Uganda with Luganda and Swahili widely spoken in addition to English, thought might be given to finding or developing materials in both Luganda and Swahili. This study suggests that medical librarians need formal training about the various modes of social media as well as how to make use of social media for educating the public about relevant health issues. This training should be extended to the entire team of health professionals including nurses, physicians, and others as information-seeking by the public continues to expand through increasing access.

In addition, the paper suggests that health librarians have duty to lobby search engines to provide information that can satisfy health information needs of the local people who may not search well-established medical sources such as Medline. Search engines should put in place control mechanisms as the Wikipedia did to ensure information credibility, particularly life-saving health information. The information can then be disseminated using appropriate social media, in an appropriate Language.

## References

1. UNAIDS. Global AIDS UPDATE. Un aids [Internet]. 2016;17 Suppl 4:S3-11. Available from: <http://pesquisa.bvsalud.org/portal/resource/pt/mdl-15080170>
2. National Institute of Rwanda (NISR)[ Rwanda], Ministry of Health (MOH) [Rwanda] and ICF International Rwanda Demographic and Health. Survey 2014-15 Rockville Maryland USA:NISR,MOH and ICF International;2015.
3. Namuleme R. Information and HIV/AIDS: an ethnographic study of information behaviour [Internet]. University of Sheffield; 2013. Available from: <http://etheses.whiterose.ac.uk/3772/1/NamulemeRobinah18.03.13.pdf>
4. Veinot T. A multilevel model of HIV/AIDS information/help network development. J Doc [Internet]. 2010;66(6):875–905. Available from: <http://www.emeraldinsight.com/doi/10.1108/00220411011087850>
5. Albright KS, Gavigan K. Information Vaccine: Using Graphic Novels as an HIV/AIDS Prevention Resource for Young Adults. J Educ Libr Inf Sci. 2014;55(2):178–85.

6. Case D. Looking for Information. A Survey of Research on Information Seeking, Needs and Behavior. Elsevier; 2007.
7. World Bank. Population, total [cited 29 May 2017]. Available at (<http://data.worldbank.org/indicator/SP.POP.TOTL>)
8. Times Reporter. Mobile Phone Subscribers Hit Close To 9 Million, Rura December Report Shows. New Times [Cited 29 May 2017]. Available At <Http://Www.Newtimes.Co.Rw/Section/Article/2017-01-26/207427/>
9. Wainaina E. Uganda's internet penetration at 37.4% of population. Techweez. Cited 29 May 2017. Available at <http://www.techweez.com/2016/03/04/internet-penetration-uganda/>
10. Taggart T, Grewe ME, Conserve DF, Gliwa C, Isler MR. Social media and HIV: A systematic review of uses of social media in HIV communication. Vol. 17, Journal of Medical Internet Research. 2015.
11. Akena FA. Traditional knowledge in HIV/AIDS treatment and prevention program in northern Uganda. Fam Med Community Heal [Internet]. 2016;4(1):46–52. Available from: <http://www.ingentaconnect.com/content/10.15212/FMCH.2016.0106>
12. Taggart T, Grewe ME, Conserve DF, Gliwa C, Isler MR. Social media and HIV: A systematic review of uses of social media in HIV communication. Vol. 17, Journal of Medical Internet Research. 2015.
13. English rules in Uganda, but local languages shouldn't be sidelined. November 5, 2015. [cited 30 May 2017]. Available at <http://theconversation.com/english-rules-in-uganda-but-local-languages-shouldnt-be-sidelined-493810>
14. Rwanda to switch from French to English in schools. The Guardian. 14 October 2008. [cited 30 May 2017]. Available at <https://www.theguardian.com/world/2008/oct/14/rwanda-france>).
15. Sibomana E. The acquisition of English as a second language in Rwanda: Challenges and promises. Rwandan J Educa. 2014; 2(2): 19-30.