

DESK REVIEW & ANALYSIS OF IEC MATERIALS IN SUB-SAHARAN AFRICA FOR COMMUNITY-LED APPROACHES TO CERVICAL CANCER PREVENTION THROUGH HIGH-PERFORMANCE HPV SCREENING TOOLS, INCLUDING SELF-

COLLECTION

DIGITAL SEARCH, AND ENGAGEMENT OF CIVIL SOCIETY ORGANIZATIONS



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ACKNOWLEDGEMENTS

This report documents two components of a FIND Project, namely the conduct of a desk review and an inventory of identified information, education and communication (IEC) materials for cervical cancer prevention and control.

The FIND-supported 'Civil Society Organizations Training on Focus Group Discussions Planning, Conduct and Analysis' will be described and an analysis of the collective output of the focus group discussions conducted will be submitted as a separate report.

This project was conducted in partnership with FIND and is part of the larger project to support community-led approaches for cervical cancer prevention through high-performance human papillomavirus (hpHPV) screening tools, including self-collection.

The review of IEC materials was conducted from November-December 2022. Additional analysis of selected IEC materials took advantage of the FIND Training for Civil Society Organizations (CSOs) from 19 countries in Africa — a virtual didactic training carried out on 8, 9, and 15 December 2022 via Zoom. Participants were invited to compare and contrast selected awareness materials and to comment on strengths, weaknesses and opportunities for improvement of said materials, and this feedback is also reported here.

"They [self-sampling IEC materials] are acceptable materials] are acceptable, because the fear of being handled by occasionally young practitioners or practitioners of a different gender prevents many women from practicing or participating in cervical screening."

focus group discussion training participant

ACKNOWLEDGEMENTS	2
BACKGROUND	4
Preamble	4
EXECUTIVE SUMMARY	6
Desk review of IEC materials	6
Engaging CSOs/CBOs working on cervical cancer across Africa	7
DESK REVIEW REPORT	8
DESK REVIEW FINDINGS	9
Participating countries	11
Formats and platforms/channels	11
Target population/audiences	12
Ownership/sources	12
Language and key messaging	13
Materials with standalone messaging on HPV testing	13
Use of imagery	13
INSTRUCTIONAL LEAFLETS FOR SELF-COLLECTION – INSIGHTS FROM FOCUS	
GROUP DISCUSSION TRAINEES	14
Leaflet A (Vaginal swab HPV test)	14
Leaflet B (Visual aid used at screening venue)	15
Leaflet C (Evalyn [®] Brush by Lancet)	16
DISCUSSION AND CONCLUSIONS	17
RECOMMENDATIONS	19

BACKGROUND

PREAMBLE

In October 2022, KILELE Health entered into a partnership with FIND to establish a network of motivated African CSOs, to build knowledge and co-develop communitycentred approaches to boost participation in and demand for cervical screening using hpHPV testing, including selfcollection of cervical samples. **The scope of work included two streams:**

Collating any currently available IEC materials

or tools in all formats used to inform women about cervical cancer screening, notably across the 19 high burden countries in Africa, and creating a searchable inventory of these materials.

2

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Identifying, engaging and championing the selection, collation into a database and training of CSOs and communitybased organizations (CBOs) working on cervical cancer from across Africa (either from a cancer and/or HIV perspective) on community-centric approaches for community engagement. Specific reference was made to three focus countries – Kenya, Malawi, and Lesotho.





DESK REVIEW OF IEC MATERIALS

A total of 123 IEC materials¹ were inventoried from across 19 African countries with a high burden of cervical cancer.² These were sourced from both the internet and through proactive requests to civil society groups, international non-profits, and national cervical cancer programmes. There were no publications identified related to IEC-specific research conducted in any of the 19 countries to help inform our desk review.

Reviewed materials were in a range of formats, notably 91 posters, 11 videos and five infographics. Other formats included flipbooks, flyers, Ministry of Health manuals, banners and leaflets (two of each) and a brochure, a slide player, a consent form, a flipchart, a fact sheet and a booklet.

Only 16 out of the sampled 123 IEC materials referenced HPV testing, eight of which also described self-collection of samples for cervical cancer screening. The remaining 107 reviewed items were high-level information materials on cervical cancer, bearing little or no reference to the global ambition towards elimination of cervical cancer and, when screening was referred to, with little reference to the new modalities recommended by World Health Organization (WHO) guidance and guidelines.

From the analysis it was evident that many Ministries of Health and community organizations are yet to fully embrace the global elimination strategy and customize locally relevant IEC materials to incorporate messaging in this regard as well as information on new options for cervical screening.

Most of the IEC materials reviewed are owned by local nongovernmental organizations (NGOs), with only a few coming from government agencies including Ministries of Health. This underscores the importance that local organizations play in reaching communities with crucial information about disease prevention and control and building demand for these services.

There is clear potential for a quality core IEC tool with standardized messaging from a trusted source that can be adapted by African organizations (potentially in partnership with Ministries of Health) in accordance with local needs to accelerate uptake of preventive interventions for cervical cancer elimination.

Further, we recommend co-designed implementation research to inform best practice on how such a tool is utilized in key communities, and also include performance indicators that would help shape periodic review and to keep information updated and relevant.

LINK to the full searchable inventory of IEC materials identified by country and other key words <u>https://www.finddx.org/wp-content/uploads/2023/03/20230308_desk_review_iec_africa_FV_EN.xlsx.</u>

List of high burden countries: Burundi; Cameroon; Comoros; Eswatini; Ethiopia; Gambia; Guinea; Kenya; Lesotho; Liberia; Malawi; Mozambique; Namibia; Nigeria; Rwanda; Tanzania; Uganda; Zambia; Zimbabwe.

ENGAGING CSOs/CBOs WORKING ON CERVICAL CANCER ACROSS AFRICA

Through personal referrals and the snowballing of contacts from various networks in which KILELE Health is represented, and with assistance from FIND, we engaged with 19 organizations from across Africa working in cancer and/or HIV.

Particular attention was paid to ensure representation from both the cancer and HIV focus areas for the three focal countries: Kenya, Malawi, and Lesotho.

Other countries represented include Burundi, Cameroon, Comoros, Eswatini, Ethiopia, the Gambia, Guinea, Liberia, Mozambique, Namibia, Nigeria, Rwanda, Tanzania, Uganda, Zambia, and Zimbabwe.

Almost all contributing organizations represented were community-based or local NGOs, except one that had a Ministry of Health staff representative whose role included community engagement. The range of activities by the organizations included community engagement, policy-based advocacy, and provision of services. With diverse geographical reach within their respective countries, the organizations served both people living with cancer and populations living with HIV.

Each organization identified 1-2 representatives who contributed to this phase of the project.

To augment the lack of depth of information on IEC materials identified through desk review and outreach, participants in the training were asked to contribute their reflections on three examples of leaflets supporting self-collection.

Despite the current lack of national materials and direct experience, participants in the focus group discussion training expressed great enthusiasm for the opportunity of self-collection in their respective settings. This new tool was perceived to be more acceptable to women, and participants felt it would increase uptake of HPV screening and likely become the preferred method for secondary prevention of cervical cancer.

DESK REVIEW REPORT

METHODOLOGY

The literature review for IEC materials was carried out systematically using an empirical approach to identify the IEC materials already in existence relating to cervical cancer prevention, with emphasis on screening and HPV. The literature review was guided by the question, "What are the available IEC materials that educate communities about cervical cancer secondary prevention, with emphasis on the 19 high burden countries in Africa?".

DATA SEARCH STRATEGY

To answer this question, the following electronic databases were searched for primary studies: PubMed, Medline, Scopus, Cochrane library, Science Direct, Embase, and Google scholar. IEC Materials associated with cervical cancer high burden countries in Africa were included. Boolean operators were used to combine the terms 'cervical cancer OR HPV' AND 'HPV OR prevention OR awareness' AND 'screening'. For grey literature, a search was carried out through Google and by visiting specific websites such as in-country Ministries of Health and specific organizations (WHO, Unicef, PATH, etc.). Due to the limited number of IEC materials secured through this search, additional materials were obtained from submissions by FIND community focus group discussion training participants, as well as information accessible on digital platforms, social media, and organizational websites. For comparability, the team made efforts to secure a minimum of 15 materials from the three FIND focal countries, and at least five materials from the non-core countries. Even then, it proved difficult to get targeted IEC materials on the subject matter.

INCLUSION AND EXCLUSION CRITERIA

The inclusion criteria for this research were IEC materials that concentrated on the primary, secondary, and tertiary prevention of cervical cancer, as well as those that targeted the 19 high burden countries in Africa. The study did not include IEC materials focused on prevention messaging for cancers other than cervical cancer, and also excluded messages on cervical cancer from countries other than the ones that were targeted. Further, emphasis was placed on three focal countries: Kenya, Malawi, and Lesotho.

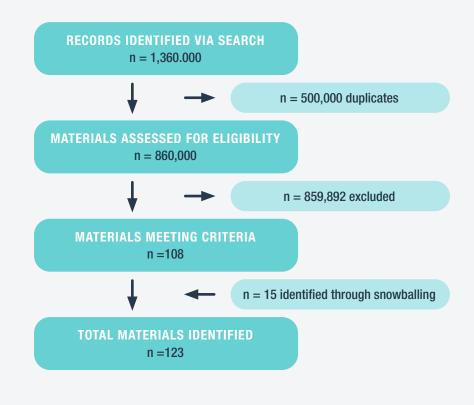
DATA REVIEW PROCESS

The IEC materials were collected and collated through online web searches, using Medical Subject Headings (MeSH) terms and keywords like "Cervical Cancer Awareness," "HPV Testing," "Cervical Cancer Treatment," and "Informational Educational and Communication Materials on "Cervical Cancer," "HPV Self-Collection," and "Cervical Cancer Screening." To quantify the materials for thematic analysis and presentation of the results, the collected IEC materials were examined using descriptive statistics.

DESK REVIEW FINDINGS

9

The online database search generated 1,360,000 IEC materials of which 860,000 remained after validation of the materials and removal of duplicates. These IEC Materials were assessed for eligibility. A further 859,877 IEC materials were excluded because they addressed solely cervical cancer treatment and not prevention, or their focus was on countries other than the 19 designated nations in Africa. **At the end of this process, 123 IEC materials were identified for final review.**³



Approximately half of the identified materials (47.97%) specifically addressed screening for cervical cancer, with most detailing HPV screening (20.33%), followed by Pap smear (4.88%) and visual inspection of the cervix with acetic acid (3.15%). A further 26.02% of materials addressed HPV vaccination for girls, but were included for interest in the HPV messaging. In terms of volume, materials building awareness of cervical cancer in the general population (10.57%) followed and then a smaller set of materials targeting women living with HIV (3.25%).

Each IEC material was reviewed independently and categorized according to: country, owner of the materials: international NGO, local NGO, or Ministry of Health (with or without a partner organization). The focus of each material was documented as primary, secondary and in some instances combined with tertiary prevention and target audience was noted. A brief synopsis of the content was also added to a data extraction template to support synthesis and interpretation. A detailed narrative of the findings across the 19 high burden countries in Africa, follows in the next section.

^{3.} Full searchable inventory of IEC materials identified by country and other key words https://www.finddx.org/wp-content/uploads/2023/03/20230308 desk review iec africa FV EN.xlsx.

PARTICIPATING COUNTRIES

The IEC materials in this analysis were from 19 different African countries with the highest burden of cervical cancer, namely: Burundi, Cameroon, Comoros, Eswatini, Ethiopia, The Gambia, Guinea, Kenya, Lesotho, Liberia, Malawi, Mozambique, Namibia, Nigeria, Rwanda, Tanzania, Uganda, Zambia, and Zimbabwe. In some Countries such as Kenya and Malawi, it was easier to find IEC materials from both the online search and the participants, than it was for others such as Comoros where online searches did not readily identify any IEC materials.

FORMATS AND PLATFORMS/CHANNELS

Due to the digital nature of the desk review, the majority of the materials identified (87.9%) are available electronically, with the remainder (12.1%) supplied by participants in the focus group discussions as scanned examples, as these were either not intended to be made available online or had yet to be posted by the respective Ministries of Health.

The majority of the materials reviewed (74.2%) were posters with a few examples in the form of videos (8.7%), infographics (4.0%), flyers (1.6%), banners (1.6%), leaflets (1.6%), flipbooks (1.6%), and manuals for healthcare workers (1.6%). Other formats included flipcharts (0.8%), Ministry of Health guidelines (0.8%), fact sheets on cancer (0.8%), booklets (0.8%), brochures (0.8%), automated slide presentations (0.8%), and consent forms (0.8%).

The most common platform used for dissemination of materials was Facebook (52.85%). Other platforms included Twitter (13.82%), organizational websites (18.7%), Instagram (0.81%), via participatory CSOs/CBOs (12.20%) and YouTube for the videos (1.63%) as shown in figure 1 below.

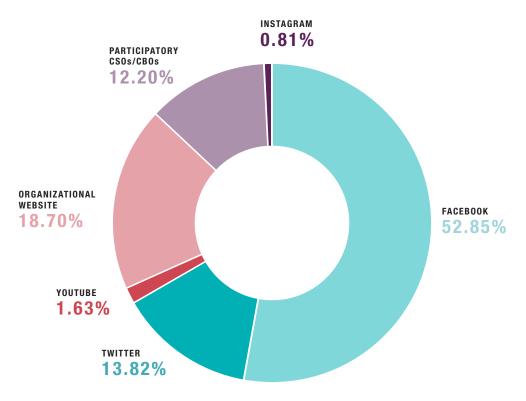


FIGURE 1. Source of IEC materials



TARGET POPULATION/AUDIENCES

Materials identified were predominantly national materials intended for a broad public audience with calls to action to get screened. Nearly all the materials reviewed (75%) were intended primarily for women and girls, with the broader public as a secondary focus.

One fifth (20.2%) of the reviewed IEC materials had a more specific educational messaging targeted at women and/or healthcare professionals. Four percent (4%) targeted health care providers with the main goal of providing instructional guidance on cervical cancer prevention as mandated by the relevant Ministry of Health. The remainder of IEC materials (0.8%) targeted men with a generic call to action.

OWNERSHIP/SOURCES

The majority of the materials examined (79%) were owned by non-state-actors, such as universities, faith-based groups, NGOs, medical associations, and CSOs. Interestingly, materials owned by Ministries of Health (13.7%) and those issued by the global and African regional offices of WHO at (7.3%) were represented but did not dominate. The dominant distributors of materials were local NGOs (n=76, 61.8%), and international NGOs (n=47, 38.2%).

Only Lancet Laboratories emerged as a prominently mentioned private sector entity in the materials reviewed.

LANGUAGE AND KEY MESSAGING

English was the language used in the majority of materials (83.7%). A smaller percentage (14.6%) were in local African languages, some of which included a side-by-side translation into English. English captions were available for the videos, even when local language was being used. Swahili was the most common African language, used in 1.6% of the materials. Other languages included Chichewa for Malawi and Zambia, French for Burundi and Rwanda, and Dholuo in Kenya, catering to their respective local communities.

The majority of the materials reviewed covered general awareness such as general information on cervical cancer causes, incidence levels, risk factors, signs and symptoms, prevention modalities, and treatment options. While some materials introduced prevention interventions, including HPV vaccination and screening methods available, these were generally high level with a call to action for women, girls, and the public to take action for prevention.

Only a small number of materials (18.7%) described the specific interventions of HPV testing and self-collection. Of these materials,12.2% were in combined promotion of information about HPV vaccination and screening, as well as risk factors. A few (7.32%) of the materials were a call to action directly related to commemorative days such as the International Women's Day, National Cervical Cancer Awareness Months, and World Cancer Day. Also included in messaging were some campaign promotional materials such as calls to action to attend free screening linked to special golf days or awareness walks.

The video format was the vehicle of choice for sharing the lived experiences of women in the local community. This included both women's stories related to precancers as well as actual cervical cancer. The other popular use for the medium of video was health provider instructional video encouraging the community to take prevention steps through HPV vaccination and screening.

Of note was the fact that very few (4.07%) of the materials referenced the global strategy towards the elimination of cervical cancer as a public health problem, reflecting the time lag between the launch of the initiative in November 2020 and the percolation of the message into public-facing materials.

MATERIALS WITH STANDALONE MESSAGING ON HPV TESTING

Almost all materials referencing HPV testing as a screening modality did so alongside other options. Only materials produced by Lancet Laboratories were standalone information on HPV testing, with the specific intention of instructing women on the use of their self-collection device, with further explanation of the process of HPV screening to improve outcomes for prevention.

USE OF IMAGERY

All materials used a mix of imagery, text and graphics. Where people were depicted, photographic images (24.40%) and illustrations (23.58%) were favoured equally; only a small sample of IEC materials (1.63%) combined both styles. The cervix was described in the subset of materials (18.70%), with the images frequently using a combination of illustrations and a more detailed picture of women's reproductive systems.

INSTRUCTIONAL LEAFLETS FOR SELF-COLLECTION — INSIGHTS FROM FOCUS GROUP DISCUSSION TRAINEES

During the focus group discussion virtual training session, representatives from 14 countries across Africa (20 organizations) were invited to share their views on three different types of instructional leaflets for self-collection. Immediate feedback was captured during the discussions and in addition, trainees were invited to read through the IEC Materials in their own time and respond to questions on the merits and drawbacks of each of the three leaflets. Below is a summary of the responses.

LEAFLET A (VAGINAL SWAB HPV TEST)



PowerPoint: Women's business – A pilot of Human Papillomavirus (HPV) self-sampling of Aboriginal women from rural Western NSW communities: Evaluating a Nurse-Led Community Page 8

http://www.ruralhealth.org.au/14nrhc/sites/default/files/Campbell%2C%20Laurinne%20PPTs%20B5.pdf



Strengths

- It is straightforward, easy to understand, and has only a few stages to follow.
- It clearly outlines the steps to handle samples (well-defined, straightforward, and direct).
- Even those without formal education may follow the instructions and carry out the test.
- The inclusion of illustrations to explain how to carry out the self-test and the posture for women to fill in the screening makes it simple to understand.
- For those who might have trouble reading, the leaflet's use of graphics makes it easy to understand.
- The steps are covered in detail (in both images and words).
- Sample results are available within an hour, saving time compared to going to the doctor, where one must wait for a while before being seen.
- Leaflet is multi-coloured, which adds to its appeal.
- Knowledge shared is helpful for HPV screening and cervical cancer prevention.

Weaknesses

- Language barrier an illiterate woman will not understand the leaflet.
- For the benefit of women worldwide, translation into the local language would be ideal.
- The details mentioned are too few. To improve the leaflet, some additional details must be included.
- Difficult to read because it is crowded.
- The lettering is very small.
- Extensive list of instructions can be intimidating.
- Gives the impression that the process is challenging.

LEAFLET B (VISUAL AID USED AT SCREENING VENUE)



A public health approach to cervical cancer screening in Africa through community-based self-administered HPV testing and mobile treatment provision pp 18: <u>https://www.medrxiv.org/content/10.1101/2019.12.19.19015446v1.full.pdf</u>

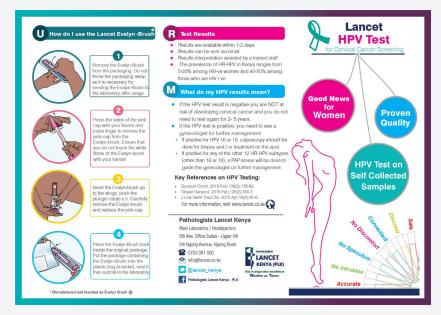
Strengths

- The test can identify high-risk HPV genotypes.
- It is a confirmatory test used to determine whether the infection is brought on by HPV type 16, 18, or 45.
- The screening method shown in the pamphlet is highly accurate and up to 99% sensitive.
- Diagrams are effective to convey the information.
- Increased colour appeals to the intended audience.
- Representation of African women in the images creates a sense of familiarity and acceptability.

Weaknesses

- The leaflet is unclear and overstuffed with details, some of which are superfluous.
- The depiction of a woman presented in the leaflet does not adequately convey the position one should adopt when performing self-screening.
- Illiterate women might find it difficult to apply the content because they may find it difficult to follow and understand.
- Laypeople may have difficulty managing and storing kits with liquid medium.
- The leaflet does not specify how soon the sample must be submitted to the healthcare facility that provided the kit.
- The device used for cervical cancer screening is large, rusted, and unsettling. It resembles a drill. After viewing this image, women will be hesitant to seek screening services in health facilities.
- Content is cluttered.
- The lettering is very small.

LEAFLET C (EVALYN[®] BRUSH BY LANCET)



Pathologists Lancet Kenya Facebook Ad

https://web.facebook.com/lancetkenya/photos/a.561222684006645/3611968985598651/?type=3&_rdc=1&_rdr



Strengths

- The information is useful for promoting health and enlisting social support for service use. It is appropriate for usage in public areas with a large population, such as rallies and campaigns. It is respectful and culturally sensitive.
- The HPV test described can be carried out by a medical professional or by women on their own as a self-sample collection.
- It gives information about the results, such as how to interpret the results and when the results will be released.
- The material says HPV test is the most reliable method to conduct a self-examination.
- All women can safely utilize the screening test described in the IEC materials.
- Condoms and water-based lubricants can still be used by women.
- Colourful, clear, and not overly cluttered.
- Instructions provided for performing an HPV test are simple to follow.
- Explanation of the test results is given in straightforward terms.

Weaknesses

- The pictures don't depict the actual situation.
- The procedure is lengthy and not user-friendly for lay people, making it difficult to follow.
- The samples might be invalid if the instructions are poorly executed.
- The leaflet is silent regarding the deadline for submitting the sample to the healthcare facility that provided the kit.
- Lack of background information on cervical cancer, which could be added to make the IEC material better.

DISCUSSION AND CONCLUSIONS

Despite the large amount of data that appeared during initial online searches, the large majority were out-of-scope. The team spent a lot of time engaging with others to be sure that materials in use were captured despite not being available online. However, even with snowballing through personal referrals from the various organizations that KILELE Health is affiliated with and assistance from FIND, it was difficult to secure IEC materials.

From the vast body of hits, only a paltry 123 IEC materials met the inclusion criteria. Uppermost in our own minds was that if it is difficult for us to locate IEC materials, that this must also be the case for the public and women that wish to improve their own cancer health literacy. It is clear that Africa lags behind in the production and dissemination of IEC materials that communicate cervical cancer elimination strategies.

The materials were readily categorized with respect to format and other criteria in the inventory which can be accessed here: <u>https://www.finddx.org/wp-content/uploads/2023/03/20230308 desk review iec africa FV EN.xlsx</u>.

From the desk review, it is evident that social media platforms play a key role in the dissemination of IEC materials. CSOs have confirmed that this is as much a financial consideration as anything else. This, however, may hamper the reach of the same information to women who cannot access digital platforms, who do not have a mastery of English language, or are not literate, or simply prefer IEC materials in a different format.

Our analysis clearly points to the critical role of non-state-actors in carrying content to communities, especially local organizations that take on a key role as originators and disseminators of IEC materials. Despite English currently being the predominant language in our cohort materials, organizations have made some attempts to customize materials to their local languages, which suggests there is demand for information from communities. Again, financial constraints may be the reason for the lower level of local language materials to date.

There is a dearth of information on the WHO global strategy towards the elimination of cervical cancer as a public health problem and the recommended interventions thereof, with most of the materials reviewed covering general information on cervical cancer causes, incidence levels, risk factors, signs and symptoms, prevention modalities, and treatment options. This suggests that owners of materials are drawing on globally available information such as Globocan/Cancer Today, but have yet to translate the most recent globally agreed 2030 targets and guidance into national materials, with perhaps complex reasoning behind the time lag between the launch of such initiatives and the percolation of the message into public-facing materials.

There is a noticeable tendency to combine calls to action on cervical cancer screening with awareness events, such as dedicated cervical cancer awareness days and World Cancer Day. While the offers often include access to free screening, this is an indication that countries have yet to transition from a campaigns-based screening and early detection approach to a routine, population-based care approach that true cervical screening entails, pointing to both a weakness and an opportunity.

Two audiences are largely targeted by the materials currently in the public domain: girls and women; and healthcare workers at the community and primary care levels. This outcome points to an unmet need for tailored materials that address these two distinct but related needs. Further, there was little or no tailoring of materials to specific sub-groups of high risk of vulnerable populations, other than a small number of materials targeting women living with HIV. This points to further work required to identify these sub-groups in the context of sub-Saharan Africa and develop more targeted messaging.

The use of videos to share women's stories of their personal lived experiences is encouraging and something on which can be built with strong advocacy in favour of women-centric services and the choice of self-care options related to hpHPV testing and self-collection, as these move beyond simple instructions for use.

The lack of implementation research identified in our desk review suggests that current materials in use are not informed by robust examination of African attitudes and beliefs or particular needs of national and sub-national communities.

The varied and valuable feedback from women on the self-collection materials indicates that women are ready and interested in contributing to the co-development of such materials and that there is room for improvement of current early materials in use.

Learnings from both the IEC desk review and the focus group discussions provide a useful foundation for the generation of a "target product profile" of a suite of IEC materials that can undergo further co-development with the emerging coalition of CSOs-CBOs we have recruited. Working in partnership with the CSOs-CBOs, FIND has an opportunity to leverage existing organizational communication platforms and the strengths of each organization in community mobilization to build synergies and avoid wasteful duplication of efforts, while ensuring sustained depth of reach into the communities with knowledge and interventions for cervical cancer elimination.

The coalition can also provide a soundboard for FIND R&D ambitions in this project as well as co-design and play a role in the implementation research that will consolidate the core IEC materials that can boost community demand for hpHPV services and self-collection. The coalition is also a ready network of advocates with strong connections to other advocacy organizations that can drive national and regional advocacy towards accelerated scale-up of these services to achieve the 90:70:90 targets by 2030.

RECOMMENDATIONS

Explore the role of a central "template" resource that is adaptable to individual country needs, with the ability to be branded by partner organizations. The objective is a set of resources and a collaborative platform that is considered an expert and trusted source of quality materials as well as a peer-to-peer best practice exchange.

Initiate this work with a "target product profile" describing a suite of IEC materials and the following properties:

- Co-development and -design of public-facing materials across the continuum of awareness (screening and treatment of precancerous lesions, early detection of cervical cancer, its management and care), including messaging related to the global ambition to eliminate cervical cancer.
- Evidence-based, tailored messaging to address cultural and religious attitudes and misconceptions.
- Evidence-based, focused messaging to motivate women to initiate their firstever screen, and speak to known populations at higher risk, such as women living with HIV and women in remote communities.
- Options to be able to provide easy translation into African languages.
- Options for multiple use of the core digital resources, including printing or conversion to different educational formats.
- Best practice use of video and social media platforms to magnify the voices of women with lived experiences in the screening and management of precancer and cancer.
- Potential for aligned development of volunteer/community health worker and education and training materials with/or on behalf of Ministries of Health with monitoring and evaluation of their impact.
- Shaped by a programme of implementation research to support optimal promotion and dissemination of the materials and measure impact of their use in African communities.

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