

CCA Network Dialogue Series

Facilitated discussions on critical issues for
cervical cancer elimination

**Amplifying survivor voices to
accelerate the cervical cancer
elimination movement**

hosted on June 13, 2023

Q&A and resources

UPCOMING DIALOGUE

HPV Communication



Amplifying survivor voices in the elimination movement

In June 2023, CCAE's third network dialogue brought together partners from around the world to discuss with experts and each other the importance of amplifying survivor voices to accelerate the global movement to eliminate cervical cancer.

The following pages comprise a summary of the questions and answers given during the dialogue, and a list of relevant resources for reference.

Facilitator

Meenu Anand, Director, Global Cancer Prevention, American Cancer Society

Presenters

- Tamika Felder, Cervivor Inc.
- Benda Kithaka, KILELE Health Association

Discussion moderators

- Benda Kithaka, KILELE Health Association
- Mridu Gupta, CAPED
- Elle Pearson, Cancer Research UK
- Matt Lewis, American Cancer Society & Thelma Suson, Heroes for Hope

Session links

- [Link to session slides](#)
- [Link to Tamika's recording](#)
- [Link to Benda's recording](#)

Previous dialogue session reports

- [A Dialogue on Single-Dose HPV Vaccination: Efficacy, Implementation and Social Mobilization in partnership with PATH, Summary Report](#)
- [A Dialogue on Engaging Healthcare Providers to Increase HPV Vaccine Demand & Uptake in Communities, Summary Report](#)

Small group discussion highlights

How can survivors help us all progress towards elimination?

- We know from experience that having survivors at touchpoints throughout the prevention, diagnosis, and treatment pathway can prove beneficial to members of the public and patients alike.
- Survivors can mitigate the mistrust that some members of the public feel around state-led health interventions, as they are recognised as trusted sources of information. By sharing information and their personal stories about being survivors, rather than victims, they can make a difference to people's understanding and opinion of cervical cancer.
- Survivors can also connect to patients and provide crucial support networks from the point of diagnosis; helping patients navigate the health system, their emotions, and changes in their day-to-day life.
- We heard an example of events organised by a national Ministry of Health, at which survivors provided testimonies and encouraged women to go for screening. We also heard of a similar example of survivors discussing the importance of follow-up with women after they have undergone screening. Through this, it was possible to engage those who might have otherwise withdrawn from the pathway.

What difficulties have you faced when engaging survivors?

Unfortunately, identifying and engaging survivors can prove difficult for a number of reasons, outlined below.

- Many survivors have concerns around the judgment that they may receive if they speak openly about their cervical cancer experience, or if they are engaged in cervical cancer advocacy.
- In many cultures, a lot of this stigma stems from the narrative that negatively associates cervical cancer with sexual activity, and so this should be addressed at all levels.
- Logistically identifying survivors can also be complicated. There is no structured process to follow to identify or approach survivors with advocacy opportunities. Anything along these lines tends to happen on an ad-hoc basis currently.

Small group discussion highlights continued

How could we better support survivors to engage in advocacy?

- Engaging survivors requires sensitivity. It is essential to provide proper training and support for survivors prior to asking them to engage in 'live' advocacy settings in order to ensure that they aren't put into positions that they aren't comfortable with.
- This could be facilitated, in some part, by a peer learning network or digital platform for survivors, in which they could receive advocacy training and talk to each other and those living with cervical cancer.
- Younger survivors might feel more comfortable using social media to engage with the public or stakeholders, and could be approached to lend their voice to the conversation through social media.
- Alternatively, engaging survivors from cultures where there may be less stigma around cervical cancer could be an initial step in bringing survivor voices into the advocacy space, particularly if they are able to train survivors who may be less comfortable with public engagement around their diagnosis and treatment.
- In addition to survivors from other cultures, survivors who have experienced other conditions or illnesses, in addition to cervical cancer, may be able to reach and connect with wider audiences.
- Ideas could also be taken from other disease areas, which have successfully elevated the voices of survivors to bring about significant progress, such as breast cancer or HIV.
- Offering remuneration, in recognition of the emotional strain that survivors may experience when speaking about their diagnosis and treatment, could prove helpful in establishing respect and appreciation for survivors. It could also act as an initial incentive for encouraging survivors to engage with advocacy.
- Opportunities to learn from others on engaging survivors to support advocacy efforts would be welcome. For example, sharing examples of strong survivor networks that have successfully engaged in HPV vaccination, and the lessons they learnt along the way, would be helpful. It is felt that there is a lack of accessible case studies or evidence on this from which we can learn.

Resources

Cervivor, Inc

 <https://www.instagram.com/iamcervivor/>

 <https://www.facebook.com/cervivor/>

 <https://www.pinterest.com/iamcervivor/>

 <https://www.tiktok.com/@wearecervivor/>

 <https://www.twitter.com/iamcervivor/>

 <https://www.cervivor.org>

KILELE Health

 <https://www.facebook.com/KILELEHEALTHKE>

 <https://www.twitter.com/KILELEHealthKE>

 <https://www.linkedin.com/company/kilelehealthke/>

 <https://www.youtube.com/@kilelehealthke>

 <https://www.kilelehealth.org>

Learnings from polio campaigns

- <https://reliefweb.int/report/democratic-republic-congo/dr-congo-polio-survivors-advocate-behalf-immunization-efforts>
- <https://www.unicef.org/philippines/stories/polio-survivor-helps-families-overcome-vaccination-fears>

Learnings from women's cancer campaigns

- <https://uwocaso.org.ug/>
- <https://uwocaso.org.ug/report-on-the-orientation-of-outreach-workers-and-counsellors-on-hpv-vaccination-and-cervical-cancer-prevention/>

Learnings from meaningful engagement campaigns

- <https://www.who.int/publications/i/item/9789240073074>
- https://www.ourviewsourvoices.org/sites/ovov/files/2021-09/Global%20Charter_English_Final_2%20Sep_1.pdf