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RESULTS BULLETIN



Celebrating 8 Years of CASPR Advocacy Success

This final edition of the CASPR Results Bulletin brings together stories of some of the Coalition's achievements over the past 8 years. The stories in this issue were shaped by conversations that began during the 2024 annual meeting, where partners were asked to think beyond activities and organizational results, and reflect on the broader, cross-cutting outcomes collaboratively achieved.

Read on to find examples of CASPR's impact across its three priority areas: policy & advocacy, research preparedness, and research translation. These stories reflect how CASPR partners have shifted systems and expanded access to HIV services for communities by influencing national policies, building trust in research through GPP, amplifying community voices in clinical trials, and ensuring science is communicated accurately in media. The stories also highlight how CASPR has established a robust, intergenerational advocacy network, connecting both seasoned and new advocates to sustain momentum in the fight against HIV.

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Intergenerational African Advocates Collaborate to Shape National HIV Prevention Policies and Frameworks in Eastern and Southern Africa

Advocates from the Coalition to Accelerate and Support Prevention Research (CASPR) have leveraged a nuanced understanding of science and strong partnerships to influence national policies in Eastern and Southern Africa that promote equitable access to HIV prevention services, and advance choice - expanding the range of available HIV prevention options and addressing the unique needs of key populations. CASPR's success in advocating for access, equity, and choice through strengthened community leadership and engagement with government Ministries of Health (MOH) resulted in the availability of diverse HIV prevention options in Zambia and Uganda and the inclusion of recommendations in national guidelines in Kenya, Lesotho, Malawi, and South Africa. These achievements highlight how collaboration and strategic advocacy are driving progress to secure greater choice and equity in HIV prevention. The accomplishments of CASPR partners prove that community-driven advocacy can reduce barriers and expand access to HIV prevention.

CASPR's success in driving policy change is due in large part to the Coalition's in-depth knowledge of HIV prevention science and research. Over a span of eight years, the Coalition tracked HIV prevention research, following products closely as they moved through the research pipeline and into regulatory and rollout phases. Maintaining science literacy as an ongoing priority allowed CASPR partners to craft evidence-based advocacy messages, gain recognition from influential decision-makers – including policymakers, researchers, and product developers – as well as build critical credibility with civil society and community members.



The Mast, Tuesday November 19, 2024 5

DVR widens HIV prevention products for women

Kasanda Obermeyer

By Benedict Tembo

ZAMBIA is among 11 African countries that have granted regulatory approval for the Dapivirine Vaginal Ring (DVR), an innovation which promises the choice for HIV prevention products for women.

The DVR, a topical drug that is inserted into the vagina and must be replaced after one month, has been made available by the Global Fund to Combat HIV/AIDS and TB and the Children and injectable PrEP, and behavioural interventions, by providing an additional layer of protection that is self-administered, private and promotes bodily autonomy for women.

Treatment Advocacy and Literacy Campaign (TALC) programme officer Chilufya Kasanda said combining the ring with targeted education on comprehensive HIV prevention and expanding access to other prevention options can offer women a robust package.

"Additionally, pairing the ring with community-based accurate information, and advocating for equitable access to the Dapivirine Vaginal Ring.

"Through community outreach and education initiatives, TALC helps demystify the ring, addresses myths, and encourages open dialogue, which reduces stigma. TALC also engages with policy-makers to ensure that the ring is adopted in the Zambia Consolidated Treatment and Prevention Guidelines as an additional HIV Prevention option to offer choice," she explained.

Kasanda said advocating for the development of the Dapivirine Vaginal Ring Implementation Plan under the Ministry of Health will not only pave way for rolling out, but also for the country to benefit from the recently announced initiative by CIPF in partnership with the Global Fund, which will provide rings in countries implementing Global Fund HIV grants and Zambia is among the beneficiary countries. She said public discreet and self-managed HIV prevention tool.

"For example, in certain rural areas of South Africa, women have reported that the ring allows them to protect themselves without needing to negotiate condom use with their partners, who may not be supportive. The ring's impact on these women's lives shows the power of accessible, user-controlled prevention options that respect individual autonomy and privacy," she said.

Benefits

Kasanda is of the view that investing in the Dapivirine ring could yield significant economic benefits by preventing new HIV infections, which reduces healthcare costs related to long-term HIV treatment and care.

"By reducing HIV incidence, the ring can also contribute to a healthier workforce, thereby increasing productivity and reducing economic burdens on families and communities, target regions could reduce costs like KUKRA Health to ensure consistent supply.

And Global Fund's Advisor for HIV Prevention and Product Introduction Chris Obermeyer said although the GF wasn't engaged in the development of the product it funds the procurement, distribution, and service delivery of the product across several countries. The GF, the co-convenor of the long-acting PrEP Coalition alongside RHAD, PEPFAR, Unitaid, and UNAIDS, is the largest procurer of rings for programmatic use globally. Through its partnership with CIPR access and scale-up will be expanded.

On challenges, Obermeyer cited getting the correct information out there about product effectiveness when used as directed while the cost is high.

"We are working to address both of those through stronger communications as well as our partnership with

Zambian periodical, The Mast, recognizing the work of CASPR partner, Chilufya Kasanda of TALC, in advocating for DVR in Zambia.

In Zambia, CASPR partner TALC, with support from other civil society organizations and local journalists, facilitated the expansion of available HIV prevention options. Through data-informed advocacy that included media initiatives, round table dialogues, and lobbying, TALC convinced policy makers and the MOH to include the Dapivirine Vaginal Ring (DVR) and injectable Cabotegravir (CAB) for PrEP in the national Consolidated Guidelines for Treatment and Prevention of HIV. TALC convened strategic meetings with the MOH and the International Partnership for Microbicides (IPM) to advocate for the allocation of funds towards procuring the DVR for female sex workers, resulting in the MOH's commitment to purchase up to 4,000 rings for this population. In the case of CAB for PrEP, TALC's advocacy with policy makers and manufacturers around pricing and rollout procedures, as well as education with community members, was instrumental to its successful launch in Zambia. The Choice Manifesto, a call to action developed by CASPR partners outlining the importance of choice in HIV prevention, was a critical tool in TALC's advocacy efforts.

Advocates supported by CASPR mentorship programs have also played a pivotal role in shaping national policies, agendas, and frameworks across multiple countries. AVAC Advocacy Fellows have successfully influenced healthcare guidelines and policy reforms, such as integrating standardized HPV screening and anal health care into

national guidelines in Kenya, securing the inclusion of PrEP family planning services in Malawi's Elimination of Mother-to-Child Transmission (EMTCT) roadmap, and shaping Lesotho's correctional services healthcare policy.



Flyer announcing Uganda's Community Drug Refill initiative, conceptualized and led by AVAC Fellow alumna, Ruth Akulu.

Fellows have also driven national action, including the launch of Uganda's Antimicrobial National Action Plan and participation in high-level policy committees. Additionally, Fellows have contributed to legislative efforts, such as redrafting a decriminalization bill in South Africa, and expanding HIV prevention access, demonstrated by the implementation of the PrEP pharmacy model in Uganda. These achievements demonstrate how CASPR-supported mentorship strengthens advocacy to influence national health systems and advances policy changes that promote access and equity in national HIV prevention agendas.

CASPR's collaborative advocacy efforts have significantly advanced HIV prevention policies across Eastern and Southern Africa, ensuring greater access, equity, and choice in HIV prevention options. Through strategic partnerships, data-driven advocacy, and community leadership, CASPR and its partners have influenced national guidelines, secured funding commitments, and expanded choice. The successes in Zambia, Uganda, Kenya, Malawi, Lesotho and South Africa underscore the power of community-driven advocacy in shaping national health frameworks that better serve diverse populations.

From Principles to Practice: CASPR's leadership in Advancing GPP

CASPR's advocacy to clinical trial funders and researchers for the adoption and integration of Good Participatory Practice (GPP) guidelines has significantly influenced the inclusion of stakeholder engagement in research globally. As a result of CASPR advocacy, researchers are increasingly integrating GPP principles into clinical trial design and conduct, transforming the role of stakeholders and creating more inclusive, ethical, and community-centered research.

Led by an international working group, the GPP guidelines were developed in collaboration with UNAIDS in response to ethical controversies identified during the pre-exposure prophylaxis (PrEP) trials for oral TDF/FTC in Cambodia and Cameroon in 2005. The guidelines are meant to provide trial funders, sponsors, and implementers, with systematic guidance on how to effectively engage with stakeholders in the design and conduct of biomedical HIV prevention trials, emphasizing a participatory approach to research grounded in transparency and accountability. In 2007, the guidelines were published, and AVAC facilitated a series of consultations with diverse stakeholder groups in Africa, the Americas, Asia, and Europe to validate the

importance of clinical trial funders and cities adopting the GPP guidelines for HIV prevention research. AVAC and other groups have published several adaptations over the years, including GPP for Tuberculosis (TB) drug trials (2012), emerging and re-emerging pathogens (2016), and TB vaccine research (2017).

The GPP guidelines form the basis for CASPR's advocacy for inclusive, community-centered HIV prevention research. By consistently engaging in global community accountability boards and groups (GCABs and GCAGs) for clinical trials, CASPR has influenced trial design and implementation to incorporate GPP principles, strengthening engagement mechanisms for HIV prevention research. From 2016-2018, AVAC and the Microbicide Trials Network (MTN) held a series of regional and country consultations to inform the design and conduct of trials testing the Dapivirine Vaginal Ring (DVR), namely MTN-034 and MTN-042. Community perspectives drawn from the consultations ensured trial protocols resonated with the lived realities of adolescent girls and young women (AGYW) and set a precedent for ongoing community engagement. The robust nature of these consultations ultimately contributed to broad support for the DVR among AGYW in trial communities and countries.

When the results of the Evidence for Contraceptive Options and HIV Outcomes (ECHO) trial were unexpectedly released in 2019, CASPR mobilized quickly to ensure GPP guided the response. CASPR partners played a critical role on the ECHO GCAG to prioritize meaningful engagement of African women and collaborated with family planning networks to facilitate an integrated response. Because of CASPR's leadership, the ECHO Management Committee demonstrated a commitment to GPP that allowed for open discussions around ethics and placed women at the center, ensuring information about the results were accessible and that women understood what the findings meant.

In Gilead's PURPOSE 1 trial, CASPR partners held researchers accountable to community demands through membership on its GCAG. In PURPOSE 1, CASPR's influence as leaders on the GCAG led to protocol changes that allowed pregnant and breastfeeding participants to continue using the study product after a reconsenting process. They ensured GPP principles were included in and adhered to throughout the design, implementation, and dissemination of results by providing support and training on GPP to research implementers. Nandisile Sikwana, Regional Stakeholder Engagement Manager for AVAC and member of the PURPOSE 1 GCAG noted when PURPOSE 1 results were released, "We applaud Gilead's commitment to GPP in this and other PURPOSE studies. While we wait for data from the study...it is imperative that planning for the study's next phases be accelerated." This highlights the importance of maintaining GPP principles throughout the research to rollout process, beyond clinical trials and towards ethical access of prevention products to communities. It also demonstrates how GCAG members keep researchers and funders accountable to bringing the community along every step of the way. Through strong stakeholder engagement mechanisms, CASPR has helped integrate community voices into decision-making processes in ways that fit community contexts and needs, ensuring HIV prevention research aligns with the needs, values, and rights of communities.



Advocates meet to understand ECHO results in Nairobi, Kenya

CASPR has also driven systemic changes in research ethics and stakeholder engagement practices by elevating GPP within normative guidelines at the global and national levels. For example, the World Health Organization (WHO) released new guidelines for clinical trials in 2024, emphasizing the importance of patient, participant, and community engagement for more efficient and equitable trials. AVAC provided inputs to ensure guidelines prioritize community involvement in creating fairer and more actionable clinical research. In South Africa, HAVEG's strategic submissions to the Department of Health (DOH) resulted in the inclusion of recommendations for strengthening stakeholder engagement practices through the Research Ethics Committee (REC) review process in the national ethics guidelines (DOH 2024). The updated guidelines now emphasize the need for adaptive engagement strategies and contextual responsiveness. They include recommendations on tailoring the intensity of stakeholder engagement to participant vulnerability, study risks, and the complexity of study design.

While there is still much work to be done, CASPR has laid the foundation for GPP to become an international standard in clinical trials. AVAC has promoted GPP adoption across research networks and developed the GPP Body of Evidence, a suite of resources offering tools and best practices for implementing GPP throughout the clinical trial lifecycle. FHI360 developed a theory of change to measure GPP across HIV clinical research and many GPP trainings led by AVAC, Wits RHI, HAVEG, and IAVI have produced cadres of GPP Champions dedicated to ensuring that GPP principles are not only recognized but actively adhered to in research, moving beyond tokenistic engagement to meaningful and sustained stakeholder engagement in HIV prevention research. GPP ensures that research is conducted with communities, integrating their voices and priorities at every stage.

As Dr. Michelle Temeris, of the University of Capetown stated, "we really must see our community members as having a role beyond that of just a potential trial participant but to engage them right from the beginning, from the protocol design, from all our planning pre-study, the conduct of the study, and most important to the dissemination of the results—whether they be positive or negative." This sentiment reflects the growing recognition that GPP is necessary for conducting successful community-centered research. Through sustained advocacy and strategic partnerships, CASPR has influenced the growing acknowledgement and operationalization of GPP across HIV prevention clinical research trials.

Bridging the Gap Between Science and Communities by Translating the Science of HIV Prevention Research

The Coalition to Accelerate and Support Prevention Research (CASPR) has strengthened community engagement in HIV prevention research through sustained advocacy toward translating complex clinical trial findings into accessible information. CASPR has built a network of informed advocates who actively participate in research, consult on clinical trials, and break down scientific knowledge on behalf of their communities. These efforts have also contributed to more accurate and credible journalism on HIV prevention science, strengthened relationships between advocates, governments, and researchers, and improved the dissemination of research findings to communities. By equipping advocates with the tools to engage meaningfully in scientific spaces and share knowledge, CASPR has ensured that HIV prevention research is both accessible and actionable for the communities its advocates serve.

CASPR's approach to research translation is reflected in targeted programs that seek to strengthen the research literacy skills of civil society partners and advocates. The Clinical Trial Design Academy (CTDA) is one such example, training a cohort of 20 African-based advocates to partner with researchers, industry, and regulators as they determine how to make critical decisions on the design and conduct of next-generation HIV prevention trials. CTDA members have gained a deep understanding of clinical trial processes, leading to their selection for participation on global community advisory boards and groups, as well as in ethics review processes. Several CTDA members participated in a Merck consultation on the MK-8527 efficacy program, studying a monthly HIV prevention pill, where they provided feedback on the study's protocol design and ethical considerations for trial implementation and results dissemination. Their contributions helped shape the study in a way that aligned with community needs and secured commitments that findings from the trial would be shared transparently and accessibly. CASPR advocates therefore play an influential role in making HIV prevention science more inclusive. Participants of the CTDA reported feeling more confident in their ability to influence research, as reflected by Ulanda Mtamba, Executive Director of the GEM organization in Malawi and CTDA participant, who noted, "Serving on a Research Ethics Committee (REC) in Malawi, the Academy has enhanced my knowledge and skills necessary to proficiently review protocols."

Beyond individual capacity strengthening, CASPR ensures that its partners are equipped to translate and disseminate critical updates on the HIV prevention pipeline in ways that are accessible and actionable for both communities and stakeholders. When the HIV Vaccine Trials Network's (HVTN) major vaccine trials (HVTN 702, 705, and 706) were discontinued due to lack of efficacy, CASPR advocates played a critical role in navigating community responses and facilitating accurate, informed discussions.

CASPR quickly mobilized its network to communicate the findings clearly, counter misinformation, and maintain community trust in HIV prevention research. Similarly, CASPR advocates have been at the forefront of translating the results of the PURPOSE 1 and PURPOSE 2 trials, which evaluated the effectiveness of Lenacapavir, a long-acting injectable PrEP. By proactively responding to and translating trial outcomes, CASPR strengthens community engagement, understanding, and trust in research. This reinforces CASPR's role as a bridge between complex scientific developments and the communities that stand to benefit from them.



CASPR partner, Ntando Yola (APHA), translating the science in realtime to advocates in CASPR's Research Literacy Zone at IAS 2023.

Recognizing the influential role of journalists in shaping community understanding of HIV prevention research, CASPR also invested in strengthening journalists' skills to report accurately on science. The Media Science Café (MSC) program has equipped journalists with the knowledge and tools to accurately report on HIV prevention research and the rollout of new products. Cafés were convened by journalist organizations in Kenya, Malawi, Uganda, Zambia, and Zimbabwe, bringing together journalists, scientists, and advocates in informal discussions, where they engaged directly with scientists to improve their understanding of complex biomedical research.

Journalists in the MSC network played a key role in providing robust media coverage of key trial results, such as the HVTN vaccine trials and PURPOSE 1, helping to build understanding and trust in HIV prevention efforts within communities. By strengthening relationships between journalists, researchers, advocates, and governments, the MSC program broadened avenues through which communities receive accurate information about HIV prevention. As one media café journalist shared, “being a health reporter, I find these science cafés very informative, and they help me in writing stories from an informed perspective and return trust and credibility from my audience.”



Media Science Cafe conveners represent CASPR at the Africa Health Agenda International Conference (AHAIC) in 2023.

Through initiatives like the Media Science Café, CASPR ensures that HIV prevention research is accurately translated not only for advocates but also for the public, increasing trust in HIV prevention efforts.

CASPR’s work in research translation empowered advocates to bridge the gap between science and communities. With stronger research literacy, advocates have been able to disseminate clear, accurate information on HIV prevention, building trust and shaping clinical trial research design and implementation. CASPR’s support for journalists also enhances credible science reporting, strengthening trust among communities, governments, and scientists while combating misinformation. These efforts ensure that HIV prevention research is both understood and applied, ensuring meaningful community engagement in HIV prevention research.

About the CASPR Results Bulletin

The Results Bulletin is a newsletter developed by the CASPR Monitoring, Evaluation, Results, and Learning (MERL) Team, providing updates, news, and insights on results from CASPR partner advocacy on a quarterly basis.

The newsletter aims to inform and engage CASPR partners and other stakeholders about the progress, challenges, achievements, and lessons learned from CASPR initiatives. The newsletter also serves as a platform for sharing best practices, success stories, case studies, and resources related to MERL.

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Thank You!

It is only through the ongoing support of CASPR partners that we are able to continue and fulfill the MERL purpose.

Thank You!