No Data No More: A Tool to End the Exclusion of Trans & Gender-Diverse People in HIV Research
Brian Minalga (Fred Hutchinson Cancer Center) & Cindra Feuer (AVAC)

Presented at IAS 2023, the 12th IAS Conference on HIV Science

Background

Transgender and gender-diverse (TGD) people face multiple forms of structural exclusion and neglect in the global HIV response. We sought to quantify the inclusion of TGD people in milestone HIV clinical trials over the course of the epidemic. We also sought to devise a research and advocacy tool (Scorecard) to promote the meaningful inclusion of TGD people in future HIV research.

Methods

Conducted consultations with global TGD stakeholders to create No Data No More: Manifesto to Align HIV Prevention Research with TGD Realities. Synthesized the Manifesto into 13 scoreable indicators to assess studies for TGD inclusivity. Applied the Scorecard to 41 milestone HIV clinical trials conducted from 1991-2023 (protocols, clinicaltrials.gov, publications), including HIV treatment, ARV-based prevention, and vaccine/antibody studies.

An analysis of over 30 years of milestone HIV clinical trials confirms that transgender and gender-diverse (TGD) people are severely underrepresented in HIV research.

Results

Since 1991, TGD people have made up less than 1% of participants in 41 key HIV studies. The vast majority of the <1% were transgender women.

Next Steps

Promote the Scorecard as a research and advocacy tool to increase meaningful TGD inclusion in HIV clinical trials. Download the Scorecard below!