



Empowering Youth: A Citizen Science Digital Intervention to Reduce HIV Stigma and Promote HIV Self-Testing in Kazakhstan

Gaukhar Mergenova



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Disclosures

- Funding provided from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the Fogarty International Center (FIC)
 - o R21TW012017 (PIs: Davis & Mergenova)
- All study protocols received approval from the IRBs at Columbia University and Al-Farabi Kazakh National University.
- No conflicts of interest to declare.





- KZ-Based Investigative Team
 - <u>Gaukhar Mergenova</u> (Multiple PI; GHRCCA)
 - Assel Terlikbayeva
 - Sholpan Primbetova
 - Denis Gryazev
 - Olga Balabekova
 - Valera Gulyaev
 - Pavel Gulyaev
 - Akbota Tolgenova
 - Youth and Community Steering
 Committee Members (~25)
 - Youth Volunteers (~25)

- <u>US-Based Investigative Team</u>
 - Alissa Davis (Multiple PI; Columbia)
 - Laura Nyblade (RTI)
 - Joseph Tucker (UNC-Chapel Hill)
 - Weiming Tang (UNC-Chapel Hill)
 - Karsten Lunze (Boston)
 - Nabila El-Bassel (Columbia)
 - Susan Rosenthal (Columbia)
 - Yihang Sun (Columbia)
 - Sara Landers (Columbia)
 - Azamat Kuskulov (Columbia)

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HIV in the Region

CHANGE IN NEW HIV INFECTIONS AND AIDS-RELATED DEATHS, BY REGION AND GLOBAL, 2010–2020



Kazakhstan had

large increase

in EECA HIV infections:

increase of 73% since 2010

Source: UNAIDS epidemiological estimates, 2021 (https://aidsinfo.unaids.org/).

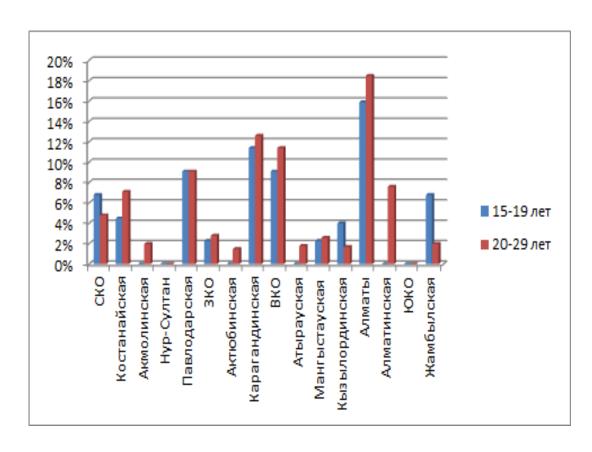




HIV among Adolescents & Young Adults in KZ

- One in four new HIV infections occur among adolescents and young adults (AYA).
- Rates of HIV among AYA are rapidly rising (projected to increase 28% by 2030).
- AYA have low HIV testing rates in the country compared to other groups.
- HIV-related stigma is a major obstacle to HIV-related protective behaviors, including HIV testing

Distribution of reported cases of HIV infection by region, 2019







Manifestations of Stigma

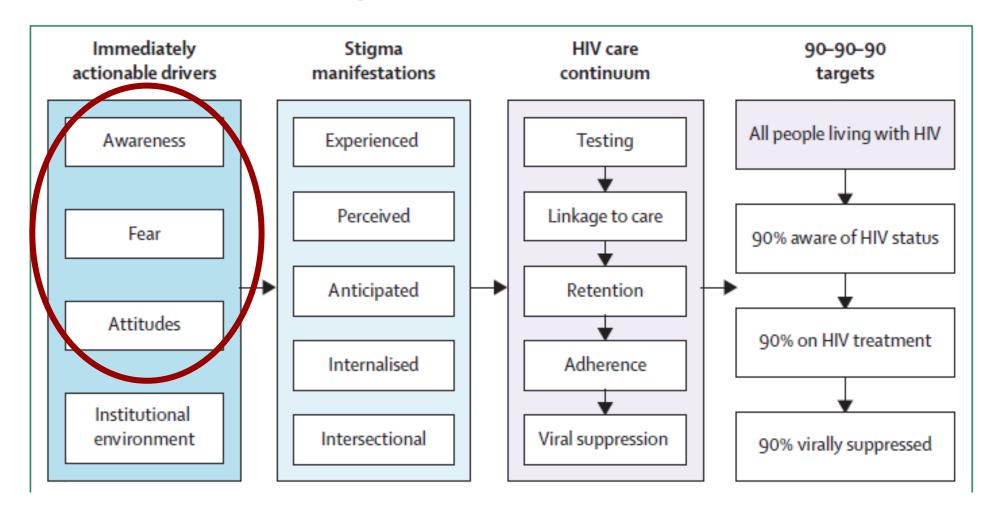
- <u>Experienced stigma</u>: actual experienced or enacted interpersonal acts of discrimination
- Perceived stigma: perceptions of the prevalence of stigmatizing attitudes in the community and among health-care providers
- Witnessed stigma: hearing stories or witnessing events of how stigmatized individuals have been mistreated

- Anticipated stigma: the fear or expectation that one will experience stigma
- Internalized stigma: taking on (internalizing) experienced or perceived stigma and accepting it as just and true
- Intersectional stigma: convergence of multiple stigmatized identities within a person or group, or intersecting of stigmas experienced by individuals who are part of multiple marginalized groups





HIV Stigma Framework







Study Aims

Aim 1:

To develop a crowdsourced digital HIV stigma reduction and self-testing intervention for youth in Kazakhstan.

Aim 2:

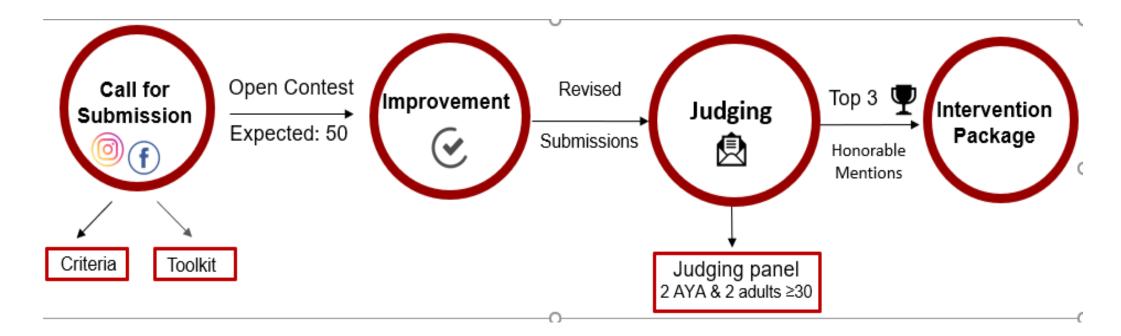
To test the crowdsourced HIV intervention to determine its efficacy in reducing HIV stigma.





Phase 1: Develop a Crowdsourced Intervention Package

Theme: Reduce HIV Stigma to Promote HIV Testing

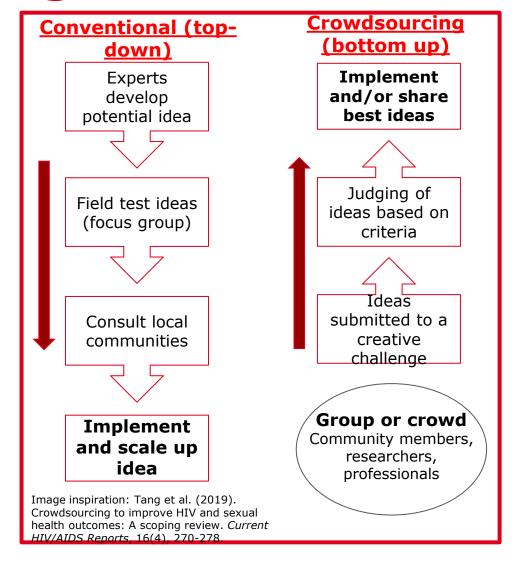


RIAS What is Crowdsourcing?



Crowdsourcing is a powerful tool that can engage the local community to reduce HIV stigma and promote HIV testing and other protective behaviors.









Eligibility & Contest Details

- Between ages 13-29 years
- Languages: Russian or Kazakh
- Individual or group submission
- Can submit more than one submission

Submissions with an identifiable photo, video, or audio of anyone were required to sign & submit a media release form

- Submission categories: Audio, video, image, text
- Submissions should be focused on reducing HIV stigma to promote HIV testing

Top 3 prizes were given in each age category (13-18 and 19-29)

1st place – iPad (~\$500 USD)

2nd place – Smartwatch (~\$300 USD)

3rd place – Smart speaker (~\$150 USD)





Phase 1: Contest promotion and advertisement



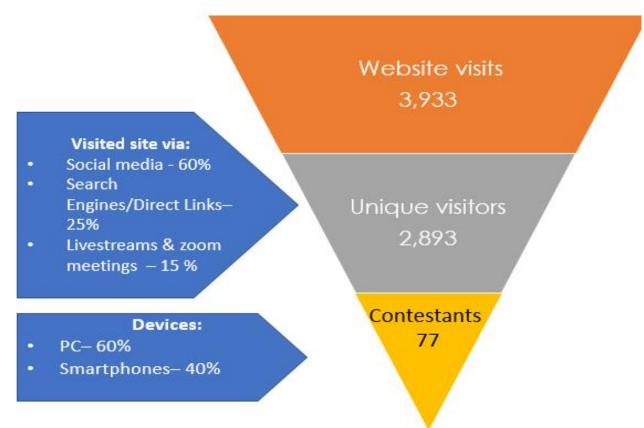








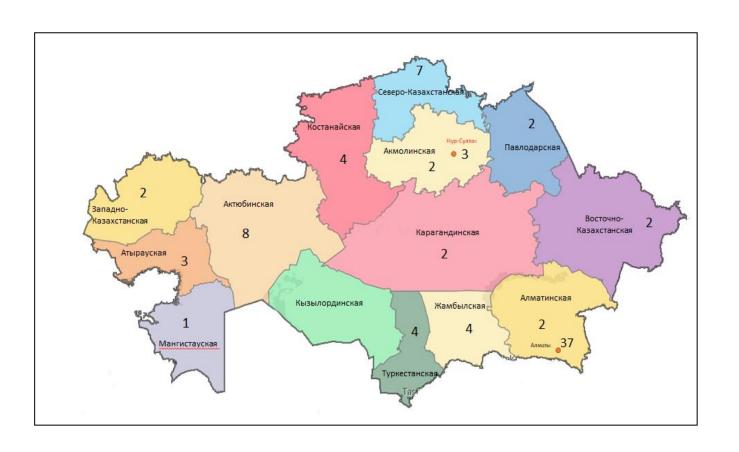








Phase 1: Crowdsourcing contest





77 contestants

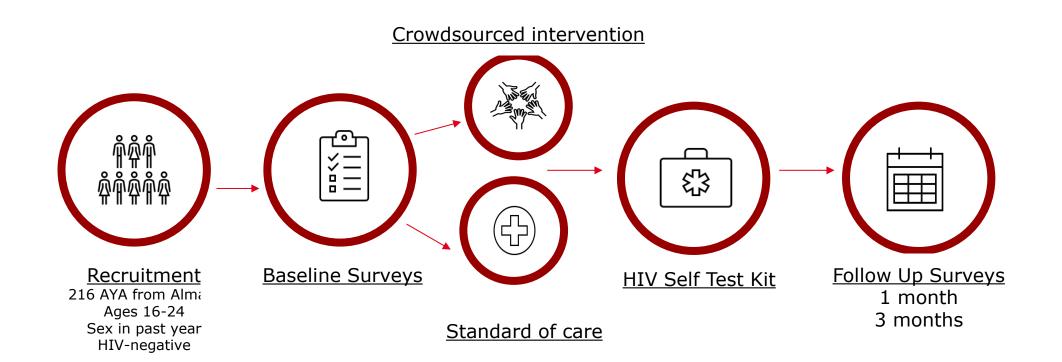


96 submissions





Phase 2 Randomized Controlled Trial







Methods

- o Informed consent and screening completed online.
- Received surveys and assigned digital content (intervention or control) electronically via Qualtrics.
- **Primary outcome:** HIV stigma (Stangl. et al.)
- Secondary outcome: Ordered HIV self-test kit

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Methods



- Conducted multilevel linear mixed models to assess within group and between group changes in mean stigma.
 - Random effects for intercept and fixed effects for time (categorical), study arm, and their interaction.
 - Models adjusted for baseline stigma levels, age, sex, sexual orientation, prior HIV testing, and if the participant had submitted content to the crowdsourcing contest.
- Also conducted moderation analyses by sex.
 - Controlled for false discovery rate (FDR) using Benjamini-Hochberg methods.
- For secondary outcome of HIV self-testing uptake, conducted logistic regression to examine whether the intervention was associated with increased HIV self-testing uptake in the follow-up period.



Table 1: Sociodemographics (N=216)



Characteristic	Overall N (%)	Intervention Arm N (%)	Control Arm N (%)	p-value
Sex at birth				0.14
Male	100 (46.3%)	46 (41.4%)	54 (51.4%)	
Female	116 (53.7%)	65 (58.6%)	51 (48.6%)	
Sexual Orientation				0.23
Heterosexual	166 (76.9%)	89 (80.2%)	77 (73.3%)	
Sexual Minority	50 (23.1%)	22 (19.8%)	28 (26.7%)	
Ethnicity				0.49
Kazakh	121 (56.0%)	58 (52.3%)	63 (60.0%)	
Russian	65 (30.1%)	37 (33.3%)	28 (26.7%)	
Other	30 (14.0%)	16 (14.4%)	14 (13.3%)	
Tested for HIV prior				0.03
to the study?				
Yes	63 (29.6%)	40 (36.0%)	23 (22.5%)	
No	150 (70.4%)	71 (64.0%)	79 (7.5%)	
HIV Test Ordered at Baseline				0.03
Yes	46 (21.3%)	17 (15.3%)	29 (27.6%)	
No	170 (78.7%)	94 (84.7%)	76 (72.4%)	
140	Overall	Intervention Arm	Control Arm	
	Mean±SD	Mean±SD	Mean±SD	
Age	19.7±2.4	20.1±2.4	19.4±2.4	0.02
HIV Stigma Scale	47.6±10.2	47.1±10.1	48.0±10.3	0.53



Table 2: Adjusted Mean Changes of Perceived Community Stigma from Time 1 to Time 3



Study Arm Intervention (Arm 1)			Control (Arm 2)			Between Group	P- value	
Time Point Outcome	Time 1 Adjuste d Mean (SE)	Time 3 Adjusted Mean (SE)	Within Group Change (95% CI)	Time 1 Adjusted Mean (SE)	Time 3 Adjusted Mean (SE)	Within Group Change (95% CI)	Difference in Mean Change (95% CI)	
HIV Stigma Total	47.48 (0.71)	44.60 (0.75)	-2.87 (-4.67, -1.08)**	47.89 (0.74)	47.32 (0.79)	-0.58 (-2.46, 1.31)	-2.30 (-4.90, 0.30)	0.08
Perceived community HIV stigma	24.65 (0.45)	23.28 (0.47)	-1.36 (-2.44, -0.29)*	25.05 (0.47)	24.74 (0.50)	-0.31 (-1.44, 0.81)	-1.05 (-2.60, 0.51)	0.37
Fear & judgement stigma	11.12 (0.35)	10.56 (0.36)	-0.56 (-1.31, 0.20)	11.24 (0.36)	11.08 (0.38)	-0.16 (-0.95, 0.63)	-0.39 (-1.49, 0.70)	0.48
Perceived HIV healthcare stigma	5.80 (0.14)	5.57 (0.15)	-0.23 (-0.58, 0.11)	5.90 (0.15)	5.89 (0.16)	-0.02 (-0.38, 0.35)	-0.21 (-0.72, 0.29)	0.48
Perceived HIV test stigma	5.92 (0.13)	5.56 (0.14)	-0.73 -1.07, -0.39)**	5.70 (0.14)	5.64 (0.14)	-0.07 (-0.42, 0.30)	(-1.16, -0.18)*	0.032



Table 3: Subgroup Analyses of Mean Change in HIV Stigma from Time 1 to Time 3



Outcome	Potential Moderato r	Level	Intervention (Arm 1)		Control (Arm 2)			Adjusted	P-	Test for	
			Time 1 Adjusted Mean (SE)	Time 3 Adjuste d Mean (SE)	Adjusted Mean Change (95% CI)	Time 1 Adjusted Mean (SE)	Time 3 Adjusted Mean (SE)	Adjusted Mean Change (95% CI)	Difference in Mean Change (95% CI)	value	Moderation
Stangl Total HIV Stigma	Sex	Male	47.44 (1.09)	47.80 (1.16)	0.36 (-2.43, 3.14)	47.63 (1.02)	46.41 (1.12)	-1.22 (-3.87, 1.43)	1.58 (-2.26, 5.42)	0.56	0.0015
		Female	47.55 (0.91)	42.39 (0.96)	-5.16 (7.48, -2.84)*	48.24 (1.06)	48.17 (1.09)	-0.07 (-2.70, 2.56)	-5.09 (-8.59, -1.58)	0.012	
Perceived Community HIV Stigma	Sex	Male	24.40 (0.68)	24.66 (0.72)	0.27 (-1.40, 1.93)	24.35 (0.64)	24.03 (0.70)	-0.32 (-1.91, 1.26)	0.59 (-1.71, 2.89)	0.61	0.0024
-		Female	24.88 (0.57)	22.37 (0.60)	-2.51 -3.89, -1.12)**	25.74 (0.66)	25.37 (0.68)	-0.37 (-1.94, 1.20)	-2.14 (-4.23, -0.04)	0.091	
HIV Fear & Judgement Stigma	Sex	Male	11.47 (0.54)	11.46 (0.57)	-0.004 (-1.18, 1.18)	11.90 (0.51)	11.47 (0.55)	-0.43 (-1.56, 0.70)	0.42		0.80
_		Female	10.85 (0.45)	9.89 (0.47)	-0.96 (-1.94, 0.02)	10.67 (0.53)	10.75 (0.54)	0.08 (-1.03, 1.19)	-1.04		
HIV Healthcare Stigma	Sex	Male	5.49 (0.22)	5.90 (0.23)	0.41 (-0.13, 0.94)	5.64 (0.21)	5.45 (0.23)	-0.19 (-0.70, 0.32)	0.60 (-0.14, 1.33)	0.15	0.0058
		Female	6.05 (0.18)	5.36 (0.19)	-0.68 -1.13, -0.24)**	6.15 (0.21)	6.27 (0.22)	0.13 (-0.38, 0.63)	-0.81 (-1.48, -0.13)	0.052	
HIV Testing Stigma	Sex	Male	6.10 (0.20)	5.77 (0.21)	-0.32 (-0.85, 0.20)	5.75 (0.19)	5.48 (0.21)	-0.26 (-0.77, 0.24)	-0.06 (-0.79, 0.67)	0.87	0.0375
		Female	5.78 (0.17)	4.77 (0.18)	-1.00 -1.44, -0.56)**	5.69 (0.19)	5.81 (0.20)	0.13 (-0.37, 0.63)	-1.13 (-1.80, -0.46)	0.004	

 $^{*=} p \le 0.05, **= p \le 0.01$



Table 4: Adjusted Relative Risk of Intervention Status Associated with Ordering an HIV Self-Test Kit during the 3-Month Follow-Up Period



48 out of 216 AYA ordered an HIV test in the follow-up period

Variable	ARR [95% CI]	P- value
Study Arm Intervention	1.13 [0.98, 1.32]	0.099
Control	Ref.	

^{*}Model adjusted for history of HIV testing (prior to study or at baseline), submission of content to study crowdsourcing contest, and if participant had a main intimate partner (e.g., girlfriend/boyfriend, spouse).

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Limitations

- Study was conducted among AYA in one city in KZ. Further work is needed to replicate findings.
- Study was conducted entirely online, so there may have been some sample bias toward AYA who are more engaged online than those who are not.
- Study was under-powered for secondary outcomes (i.e., HIV testing uptake). Larger studies are needed to determine if HIV stigma reduction interventions can lead to greater HIV testing uptake among AYA.

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Conclusions



- Findings suggest the crowdsourcing intervention was effective at reducing HIV stigma among AYA females in Kazakhstan compared to KZ Ministry of Health materials.
- Crowdsourcing may be a promising, low-cost method of engaging community members to develop HIV stigma reduction and testing interventions in other settings.







Questions?

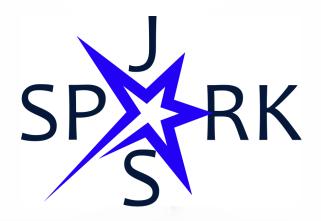




Extra Slides



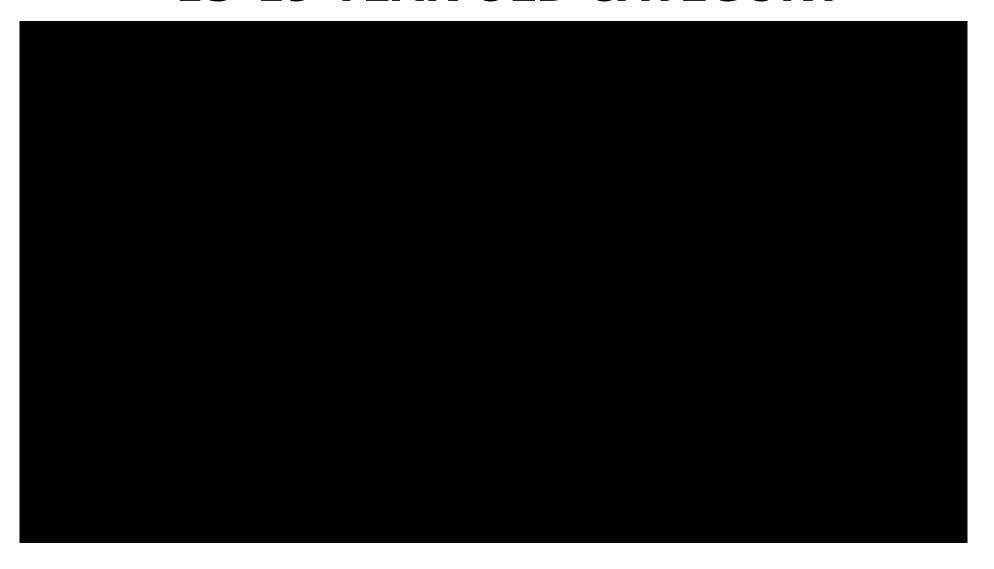
WINNING ENTRIES







13-19 YEAR OLD CATEGORY





20-29 YEAR OLD CATEGORY





Crowdsourcing Feedback







Crowdsourcing Results

Average score: 3.4 on a 5-point scale

75 out of 96 submissions met eligibility criteria
 Excluded if unrelated to HIV testing or stigma, were low quality, plagiarized, or had stigmatizing content

39 of the 75 submissions scored 70% or higher on the 5-point scale

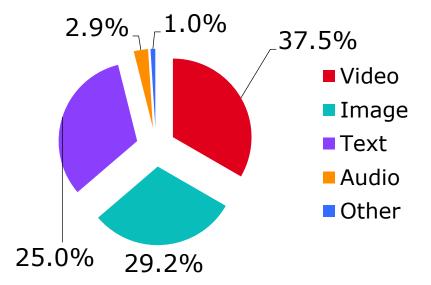
Challenges

30 of the 96 submissions had stigmatizing content or misinformation 10 revised and resubmitted after feedback

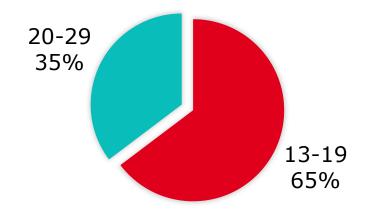




Submission Characteristics



Average score: 3.4 on a 5-point scale

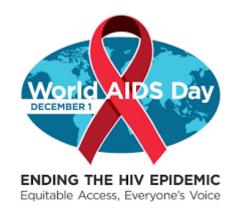




Dec. 2021 Jan. 2022

- Contest was announced on World AIDS Day -- Dec. 1st, 2021
- Series of mass protests began in Kazakhstan on Jan.
 2, 2022, after a sudden surge in gas prices
- Feb. 2022

 Russian troops invaded Ukraine on Feb. 22, 2022



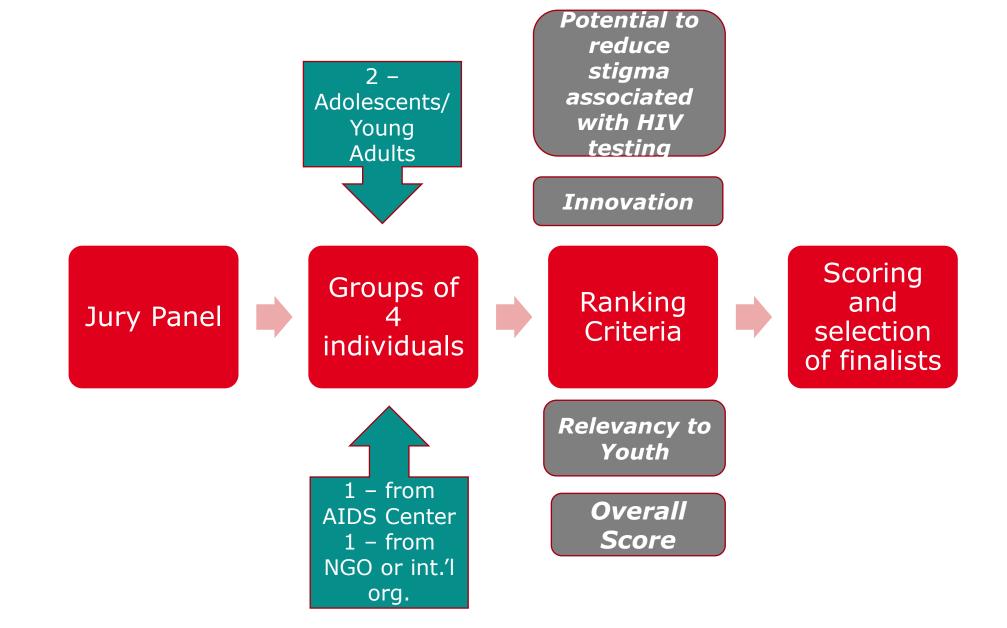




Deadline for the competition extended to March 31st, 2022

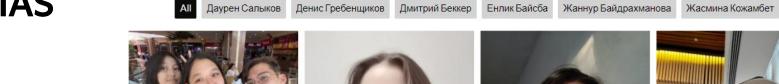


Overview of Judging Process

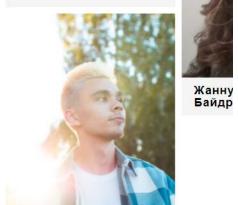


призеры!

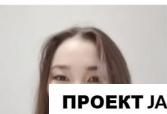




Жасмина Кожамбет



RAUMO PRAKAUIIIMVAD



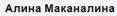


IPOEKT JASSPARK

Арина Гаппарова

Асан Зере







Камила Юсупова



Раимбек Рахметов



Анвар Сафиулин



Нуржан Кенесбай

РУССКИЙ КАЗАКТІЛІ НОВОСТИ КОНКУРС

TPOEKT JASSPARK

РУССКИЙ

ҚАЗАҚТІЛІ НОВОСТИ КОНКУРС



MAXIM PANCHENKO

MIRAS MURZAKHAN SANDIZAIRA MERGEN

ZHAMILYA KANIEYVA

ZHANDOS ALI BROWN



DANIYAL MAITEKOV

Публикация материалов в соцсетях, участие в разработ и оформлении сайта, привлечение и работа с лидерами мнений и пабликог лля рекламных постов, поись



проведения презентаций о конкурсе, написание постов, переводы материалов на английский язык.



ANUAR RAKHIMBEKOV

Помощь в привлечении участников конкурса, переводы на казахский язык, помощь в подготовке сценария промо роликов, участие в съемках роликов, рекомендации и экспертное мнение.





кампаниях и прямых эфирах,

участников конкурса, создание баннеров для соцсетей.

помощь в привлечении



РУССКИЙ ҚАЗАҚТІЛІ НОВОСТИ КОНКУРС

IPOEKT JASSPARK



AKBOTA TOLEGENOVA

Организация и участие в промо кампаниях и прямых эфирах, помощь в привлечении участников конкурса, переводы на казахский язык.

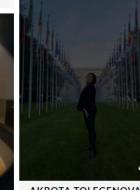


MALIKA BEKEN

Озвучка роликов, помощь в подготовке сценария промо роликов, участие в съемках роликов, рекомендации и экспертное мнение.

съемках роликов, рекомендации и экспертное мнение.

РУССКИЙ



AKBOTA TOLEGENOVA

Организация и участие в промо кампаниях и прямых эфирах, помощь в привлечении участников конкурса, переводы на казахский язык.



AMIRALI KUANYSH

КАЗАК ТІЛІ НОВОСТИ КОНКУРС

Рекомендации и экспертное мнение.



ZHAMILYA KANIEYVA

Помощь в подготовке сценария промо роликов, участие в съемках роликов, рекомендации и экспертное мнение.