Assessment of strategic information on men who have sex with men and trans people in Estonia

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List of abbreviations

AIDS	Acquired immune deficiency syndrome
ARV	Antiretroviral medication for HIV
CEECA	Central and Eastern Europe and Central Asia
CS0	Civil society organization
ECOM	Eurasian Coalition on Male Health
EHPV	Estonian Network of People Living with HIV
GFATM	Global Fund to fight AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
IBBS	Integrated Bio-Behavioral Surveillance
KP	Key Population
LGBT	Lesbian, Gay, Bisexual, and Transgender People
MSM	Men who have sex with men
NGO	Nongovernmental organization
NIHD	National Institute for Health Development
NSP	National Strategic Plan
PLHIV	Person or people living with HIV
RAGSI	Regional Advisory Group on Strategic Information
SE	Size estimation
SI	Strategic Information
SRHR	Sexual and Reproductive Health and Rights
STI	Sexually transmitted Infection
TG	Transgender

Introduction

The first HIV case in Estonia was diagnosed in 1988, and since then a total of 9,711 (as of December 31, 2017). The rate of newly diagnosed cases of HIV has decreased over the last decade (from 46.0 cases per 100,000 in 2005 to 16.6 cases in 2017), but it has been quite stable in the last few years (20,6 cases per 100,000 in 2015 and 17.4 cases in 2016). Hetero- and homosexual transmission has increased as well as the proportion of cases among people older than 34 years (1, 2).

Men who have sex with men (MSM) have been identified as the group most at risk of HIV infection in the European Union (EU) / European Economic Association (EEA). 2016 HIV surveillance data from EU/EEA countries indicates that sex between men accounted for the largest proportion of cases diagnosed in 2016 – 40%. MSM accounted for 44% of new HIV cases in Finland, 36% in Sweden, 74% in Poland (3). Increasing of HIV prevalence among MSM is commonly observed trend in Baltic states (Latvia – 7.8%; Lithuania – 5.9%)(4).

The HIV prevalence among MSM is also reported in Eastern Europe and Central Asia: Ukraine – 8.5%; Georgia – 20.7%; Moldova – 9%; Russian Federation – 7.1% (Moscow) and 22.8% (St. Petersburg) (4). In Estonia, it is estimated that HIV prevalence among MSM is 2–3% (5). High rates of regional migration (e. g. 10,470 people immigrated to Estonia and 5,440 emigrated from Estonia in 2017) (6) and regional trans-border tourism (every year, approximately three million foreign tourists with accommodation and over three 5 million one day visitors travel to Estonia) can increase numbers of HIV and STI cases in Estonia.

Although MSM are recognized as a key population (KP) in most national HIV programs in the region, including Estonia (7), national budgets allocate little to no resources to HIV interventions that target MSM (there are no recognition of trans people as a KP). In most Central and Eastern Europe and Central Asia countries (CEECA), there are only a few HIV prevention services targeting MSM. These services are primarily available in major urban areas and are mainly funded by international donors, particularly the Global Fund to fight AIDS, TB and Malaria (GFATM) (8).

The situation with respect to trans people and HIV in all CEECA countries is even more concerning. There is virtually no data on the HIV epidemic among this group in the region. Though globally recognized as a KP in the HIV response, trans people are not included, separately or as a part of other KP, in national HIV/AIDS programs in CEECA.

Strategic Information

Strategic information (SI) is interpreted and used for planning and decision-making to improve the direction and focus of a program. Relevant data may be derived from a wide variety of sources (for example, monitoring systems, evaluations, program reviews, surveys, and case studies) and should be analyzed holistically and strategically to improve the direction of the program (9), (10).

SI is collected to inform policy and program decisions. The axiom "Know your epidemic, know your response" characterizes the SI necessary for the response to HIV. It recognizes that

epidemics and their contexts differ from place to place. Thus, knowing who is affected, how they became infected and where they are, is crucial.

An effective response to HIV at the country level requires SI that has been systematically collected and consolidated, analyzed and applied. SI must go beyond basic epidemiological data to address service access, coverage, quality, and acceptability. It needs to support quality services along the health sector cascade.

SI should also lead to a deeper understanding of the context of the epidemic, such as the vulnerability of certain communities, the risks to which certain individuals and populations are exposed, and the options for actions to alleviate the burden of HIV and mitigate its impacts.

Public health efforts are only as sound as the evidence on which they are based. Proven prevention and treatment initiatives must be strategically focused on the populations and settings in greatest need, and these programs need to be tailored to address the specific needs and circumstances of each target population. For groups with heightened risk of HIV infection, countries need timely, robust and reliable data on the size of each population, the burden of HIV (including prevalence and incidence), the prevalence and nature of behaviors that increase HIV risk and vulnerability, coverage of key HIV prevention and treatment services, and on social and structural factors that affect HIV risk and utilization of key services. National surveys have long provided critical SI on HIV prevalence, sexual risk behaviors, and on HIV testing data among the general populations in the CEECA region, but these national surveys have not provided any meaningful information regarding MSM and trans populations.

As MSM populations have long been recognized as an important factor in national epidemics in the region, some form of SI on MSM is provided by some countries. However, other countries have failed to provide the necessary information on MSM or have not provided any information at all. Understanding the population size of and HIV prevalence among each KP is critical for service planning and estimating service coverage. A number of countries have used integrated bio-behavioral surveys (IBBS) to generate useful SI on HIV risk behaviors, HIV burden, service utilization, and on the existence of HIV-related stigma or discrimination faced by MSM. However, no relevant data has been gathered yet on trans people in the region.

Methodology

After determining the focus of the assessment and identifying the questions to be answered, the appropriate methodology was selected to correspond to the assessment questions. This was done using a modification of the Delphi technique (11), which is a widely used and accepted method for achieving a consensus on real-world knowledge solicited from a range experts within certain topic areas.

For the assessment a scoring tool was used. The tool consists of the following sections: population size estimation, condom use, prevalence, service provision, community involvement in response, and advocacy. The sections are scored separately for MSM and Trans populations. The respondents insert the score which can be either 0 or 1. The total score for every section can range from 0 to 6. If the answer is yes, score 1 was given. If the answer was no, score – 0. In columns Links/references the respondents indicated links or references which

could prove the scores. In column Comments, the respondents made necessary comments to justify or explaining the scores (especially if the references/links were not available). Template of the table is presented below (Table 1).

|--|

Features	Scores	Links/references provided (If available)	Comment s
Data exists (on national level)			
If there is no data and score is 0, please skip the entire table and go to the next scoring table			
Data is reliable			
Reliable means that the data comes from the survey with statistical credibility			
Data is updated			
Data updated regularly once in 2-3 years;			
Data used by government			
Related data are shown and /or used in national plans and/or state funded programs			
Data is used by NGOs and communities			
Related data are used for fundraising, project planning and/or advocacy purposes			
Data is available by cities/regions			
Segregated data exists on city level/region level within the country			
Total score			

According to the template above 8 sections can be scored separately for MSM and Trans. Total maximum of available score for all sections is 92 (46 for MSM part and 46 for Trans).

Ethical Issues

Information collected through the assessment will be stored in compliance with confidentiality requirements. All participants (both individuals and organizations) will give their informed consent prior to participating in the assessment. All results will be processed and published in a generalized form, without revealing information that may lead to the identification of a respondent or organization.

Results

Size estimation

Summary

It is estimated that there are up to 9,000 homo- and bisexual men in Estonia (12). No studies have been conducted among Trans people.

Features	Scores	Links/references	Comments
Data exists (on national level)	1	Marcus U, Hickson F, Weatherburn P, Schmidt AJ. Estimating the size of the MSM populations for 38 European countries by calculating the survey-surveillance discrepancies (SSD) between self-reported new HIV diagnoses from the European MSM internet survey (EMIS) and surveillance-reported HIV diagnoses among MSM in 2009. BMC Public Health 2013;13:919.	EMIS study 2010 (12, 13)
Data is reliable	0		Data is old (from 2010)
Data is updated	0		No update study has been conducted (unless EMIS 2017 team repeats it)
Data used by government	1	Riiklik HIV tegevuskava aastateks 2017–2025 (National HIV action plan for 2017–2025). (https://www.sm.ee/sites/default/files/content-editors/Tervishoid/rahvatervis/hiv_riiklik_tegevuskava_2017_2025.pdf).	National HIV action plan 2017–2025 (7)
Data is used by NGOs and communities	0		
Data is available by cities/regions	0		EMIS study 2010 had national coverage.
Total score	2		

Table 3. Scoring the data on MSM size estimation

Condom use

Summary

There has been no significant decrease in HIV related sexual risk behaviour among MSM during the last 10 years (14). No studies have been conducted among Trans people. The last behavioural study was conducted in 2016 (14) and the main outcomes were:

- A third (30%) of all MSM had had unprotected anal sex during the past four weeks, and more than half (56%) of them had had unprotected anal intercourse within the past 12 months. More than half of respondents (55%) had had sex with casual partners (median number of casual partners was 3) during the past 12 months.
- Half of the MSM do not use condom consistently in casual relationships, and this has not changed in the last 10 years.
- Half of the MSM (54%) who have ever had anal sex with a man used a condom during the last anal sex.

Features	Scores	Links/references provided	Comments
Data exists (on national level)	1	References 13–20	Data has been collected in the biobehavioural studies in 2007, 2008 (15, 16) and internet studies in 2004, 2006, 2007, 2010, 2013, 2016 (14, 17-21).
Data is reliable	1	Internet studies have limitations due to internet based convenienc sample among mostly Estonian MSM living in capital city. People w better Internet access and comfort with technology may have been more overly represented. Biobehavioral studies have had limitation due to small sample sizes and recruitment only in capital city Tallin	
Data is updated	1		Yes. EMIS2017 included Estonia. Next national study is planned for 2020.
Data is used by government	1		National HIV action plan 2017–2025 (7)
Data is used by NGOs and communities	0		
Data is available by cities/regions	0		Data are available on county level, but as the sample size is relatively small, then for most counties the data is not representative
Total score	4		

Table 4. Scoring the data on condom use among MSM

Prevalence

Summary

The prevalence of HIV among MSM is estimated to be around 2-4% and this not changed much (5, 14). The latest behavioural study (14) revealed that:

- 3% of those who had been tested for HIV during their lifetime (2% of all the participants) were infected with HIV. All of them believed to have been infected with HIV during a sexual intercourse with an HIV-infected man.
- During their lifetime, MSM have been diagnosed with the following sexually transmitted infections: syphilis 3%, gonorrhoea 10%, trichomoniasis 7%, chlamydia 13%, anal or genital herpes 3%, hepatitis B 3%, hepatitis C 4%. However, the above presented data may be an underestimation of true infection rates, because the level of testing for both HIV and STIs was low (14).

No studies have been conducted among Trans people.

Features	Scores	Links/references	Comments
Data exists (on national level)	1	References 13–17	 HIV-prevalence studies: In 2007, for HIV-prevalence estimations, 59 MSM were recruited by using respondent-driven sampling (15); In 2008, 79 MSM were recruited by convenience sampling in gay venues and community-based organisations (16). In 2013, 43 MSM were recruited for internet-based testing (17). Self-reported data on HIV prevalence have been collected in 2010, 2013 and 2016 (14, 17, 18).
Data is reliable	0		Internet studies have limitations due to internet based convenience sample among mostly Estonian MSM living in capital city, and due to self-reports. People with better Internet access and comfort with technology may have been more overly represented. Biobehavioral studies have had limitations due to small sample sizes and recruitment only in capital city Tallinn.
Data is updated	1		Yes. EMIS2017 included Estonia. Next national study is planned for 2020.
Data is used by government	1		National HIV action plan 2017–2025. HIV prevalence among MSM is a separate indicator in national action plan.
Data is used by NGOs and communities	0		

Table 5. Scoring the data on HIV prevalence among MSM

Data available by cities/regions	0	Data are available on county level, but as the sample sizes have been small, then for most counties data are not representative.
Total score	3	

Service Provision

Summary

HIV-testing among MSM has slowly but steadily increased among MSM (Figure 1). According to the last national internet study in 2016, more than two quarters of the total sample (73%) had ever tested for HIV; 43% in the last 12 months (14).



Figure 1. HIV-testing among MSM, various studies (14, 16-21)

The distribution of information materials and condoms in gay-oriented bars and clubs has also been supported from the National Health Plan. Estonian Network of People Living with HIV (EHPV) and NIHD organize HIV rapid testing events in gay-oriented bars and clubs. Approximately 10% of MSM report that the last place they got tested for HIV was a gay-oriented bar and club, so this approach has turned out to be quite successful in recent years (22).

In 2012–2015, STI and blood-borne infections testing for MSM (free of charge and anonymous) was available in six larger cities across the country. Men who wanted to test only for STIs which can be detected from urine, rectal and pharyngeal samples (gonorrhoea, trichomoniasis, mycoplasmosis, Chlamydia and LGV), could do so by ordering and receiving the sample collection kit

by regular mail and receiving the results through the Internet (special web-site called "Test at home" — www.testikodus.ee). In 2014–2015, 330 men were tested. For example, C.trachomatis was positive in the urine sample among 2.8%, in anal sample in 4.5% and throat sample in 0.7% of tested men. No Lymphogranuloma venerum or syphilis cases were detected. Only one new HIV cases was detected and the prevalence of HBsAg ja HCV-positivity was low. This project was supported by NIHD through Estonian Research Council grant, but unfortunately the funding stopped (5).

No studies have been conducted among Trans people.

Features	Scores	Links/references provided	Comments
Data exists (on national level)	1	References 13–20	Data has been collected in the biobehavioural studies in 2007, 2008 (15, 16) and internet studies in 2004, 2006, 2007, 2010, 2013, 2016 (14, 17-21).
Data is reliable	1		Data have limitations due to internet based convenience sample among mostly Estonian MSM living in capital city. People with better Internet access and comfort with technology may have been more overly represented. Biobehavioral studies have had limitations due to small sample sizes and recruitment only in capital city Tallinn.
Data is updated	1		Yes. EMIS2017 included Estonia. Next national study is planned for 2020.
Data is used by government	1		National HIV action plan 2017–2025.
Data is used by NGOs and communities	1		Estonian Network of People Living with HIV (EHPV) uses the data to plan HIV rapid testing events.
Data is available by cities/regions	0		Data are available on county level, but as the sample size was small, then for most counties data are not representative
Total score	5		

Table 6. Scoring the data on coverage of MSM by HIV prevention services (basic package)

Features	Scores	Links/references provided	Comments	
Data exists (on national level)	1	References 13–20	Data has been collected in the biobehavioural studies in 2007, 2008 (4, 5) and internet studies in 2004, 2006, 2007, 2010, 2013, 2016 (14, 17-21).	
Data is reliable	1		Data have limitations due to internet based convenience sample among mostly Estonian MSM living in capital city. People with better Internet access and comfort with technology may have been more overly represented. Biobehavioral studies have had limitations due to small sample sizes and recruitment only in capital city Tallinn.	
Data is updated	1		Yes. EMIS2017 included Estonia. Next national study is planned for 2020.	
Data is used by government	1		National HIV action plan 2017–2025.	
Data is used by NGOs and communities	1		Estonian Network of People Living with HIV (EHPV) uses the data to plan HIV rapid testing events.	
Data is available by cities/regions	0		Data are available on county level, but as the sample size was small, then for most counties data are not representative	
Total score	5			

Table 6. Scoring the data on MSM coverage by HIV testing

Community-Driven Response/Community Involvement in Response

Summary

HIV and associated infections testing and care are provided for MSM on the same basis as for the general population (22). In 2003–2008, initially from the Global Fund grant and later form national funding, Gay and Lesbian Information Centre operated in capital city Tallinn. The center provided HIV-related information and free of charge condoms and lubricants. The publication of information materials and distribution of condoms in gay-oriented bars and clubs has also been supported from the National Health Plan since 2009. EHPV and NIHD organize HIV rapid testing events in gay oriented bars and clubs. Approximately 10% of MSM report that the last place they got tested for HIV was a gay-oriented bar and club, so this approach has turned out to be quite successful in recent years (23). But due to lack of donor's funds the initiatives are small scaled, not consistent and only in capital city (about one third of Estonian population lives in Tallinn). On community premises testing procedure is not conducted independently due to medical regulations (arrangement of medical facilities and existence of certified medical personnel). Community organizations can refer and accompany the beneficiaries to the sites of HIV testing. LGBT communities of Estonia are not also involved in the process of HIV prevention programs management on national level and in related survey analysis and/or management. However, during IBBS representatives of communities are involved on questionnaire piloting and survey promotion. In addition, most of community organizations lack the interest and/or capacity to be actively involved in service provision or HIV related surveys. No studies have been conducted among Trans people.

Advocacy Coverage

Summary

Since 1 January 2016, Estonia has recognized same-sex unions by allowing same-sex couples to sign a cohabitation agreement. In addition, following a December 2016 court ruling, same-sex marriages performed abroad are recognized in Estonia. Recent public opinion in the country from September 2012 among 1000 people found that approximately one-third of the population supports same sex marriage with almost half supporting partnerships. The results varied widely along ethnic lines with 51% of ethnic Estonians supporting recognition and 35% of Russian Estonians agreeing (24). While support of same sex marriage is not entirely explanatory for homonegativity, it provides an estimate of cultural support for persons with same sex attraction.

Advocacy in terms of provision of HIV related services for MSM is limited to rare meetings with NIHD representatives and journalists. Communities do not have any advocacy plan and there are no evidences derived from surveys what exact needs MSM have in terms of receiving HIV related services.

Research and Strategic Information

Summary

Gathering accurate data on HIV prevalence and risk behavior in MSM has posed a challenge for researchers in Estonia. There have been three studies where HIV-prevalence was estimated (5, 15, 16), with sample size ranging from 43–79 people. Thus, these sampling methods did not yield the desired sample size for HIV-prevalence estimations. At the same time, MSM participation in the consecutive Internet studies (2004, 2006, 2007, 2010, 2013, 2016) has been relatively high, especially in the European MSM Internet Study (14, 17-21). Unfortunately, the Internet does not offer the opportunity to gather biological material for testing to estimate HIV/STI prevalence rates. Also, no studies have been conducted among Trans people.

Features	Scores	Links/references provided	Comments
Research on unmet SRHR needs conducted among MSM in last 3 years	0		No qualitative researches have been conducted on unmet SRHR needs among MSM in last 3 years
Research findings used by government institutions Findings are shown and /or used in national plans and/or state funded programs	1		Research findings from EMIS 2009, IBBS studies and internet studies are used by NIHD
Research findings used by civil society organizations (CSO) Findings are used for fundraising, project planning and/or advocacy purposes	0		There are no documented cases how CSO or communities have used research findings
Strategic information derived from programs/projects is used by government SI is shown and /or used in national plans and/or state funded programs	1		National HIV action plan 2017–2025. HIV prevalence among MSM is a separate indicator in national action plan.
Strategic information derived from programs/projects is used by CSOs SI is used for fundraising, project planning and/or advocacy purposes	0		There is no documented cases how CSO or communities have used SI
Total score	2	•	

Table 7. Scoring the data on usage of research results and strategic information (targeting MSM)

Summary of results

Below in Figure 2 are shown the actual scores of Estonia and the maximum possible scores. In table 12 the scores a presented by sections.



Figure 2. Estonian scores and the maximum possible scores

The scoring shows that the quality and the need for SI (total MSM and Trans) are satisfied only by around 1/5 (21,7%). Two thirds of the gap comes to absence of Trans related data (0 in each section from available 46). Scores received actually is associated to MSM related SI. Therefore, if we look to quality of SI separately only for MSM (max. of scores for MSM SI – 46) we can see that quality and the need for MSM related SI is satisfied by 43%.

Table 12	. Scores	per sections	(MSM and Trans)
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Sections	MSM	Trans
Size estimation	2	0
Condom use	3	0
HIV prevalence	3	0
Coverage by HIV prevention services	5	0
Coverage by HIV testing	5	0
Involvement in provision of HIV services	0	0
Advocacy coverage	0	0
Usage of survey results and SI	2	0
Subtotal	20	0
Total score	20	

Conclusions

General considerations based on country scores

The quality and need for SI is satisfied in Estonia only by one fifth (21.7%) Absence/low quality of SI in the country is mainly determined by the following factors:

- Around half of the gap regarding SI is due to lack of information and research on Trans population
- Absence of MSM size estimations in Estonia (only EMIS study was conducted in 2009)
- Limitations in IBBS (mostly internet based convenience samples)
- Absence of advocacy activities in countries
- Absence of community involvement (MSM and Trans) in the implementation and management of research projects
- Weak development or absence of interest of community organization in HIV related issues

Conclusions based on size estimation

Data of size estimation of Estonian MSM has been derived from EMIS 2009 study only. The following issues have been identified regarding MSM size estimation data:

- Data is almost a decade old and has not been updated since 2009.
- Data from 2009 study is used by government and NGO sector. No new data is available.
- Data on city/regional level are not available
- The size of Trans population has not been estimated and it is not planned in nearest future.

IBBS and Internet studies

IBBS and/or internet based studies have been conducted and have been regularly updated. However, the following issues have been identified with IBBS data:

- Internet studies have limitations due to internet based convenience sample among mostly Estonian MSM living in capital city. People with better Internet access and comfort with technology may have been more overly represented.
- IBBS have had limitations due to small sample size for prevalence estimation (biological samples) and recruitment done only in capital city Tallinn
- As recent surveys are Internet-based studies, no testing was conducted. The data obtained is based on self-reported data.
- Data on prevalence and condom use among MSM is not used at all by the NGOs and is less used by government, however separate indicators for HIV testing and HIV prevalence among MSM are stated in National HIV action plan 2017–2025.
- Communities are not involved in the process of survey analysis and/or management. LGBT community organizations lack the capacity (survey skills, analytical skills, health related program management skills) to be actively involved in service provision or HIV related surveys.
- Data on city/regional level are not available
- Incidence among MSM has not been measured at all.
- No IBBS studies have been conducted among Trans people.

Service coverage and community involvement in HIV response

Community organizations involvement in HIV testing and prevention service provision is limited and mostly related to organization of HIV testing events in gay bars and clubs. In Estonia, HIV-testing can be provided only by health care organizations and personnel.

Advocacy coverage

There is no clear vision/understanding what exact HIV needs of MSM can be advocated on state level. CSOs do not have HIV advocacy plan. Therefore, there is no active involvement of community organizations and activists in HIV related advocacy actions. The advocacy process is limited to rare meetings with NIHD representatives and journalists. However, there is no documented cases of HIV related advocacy processes.

Research and Strategic Information

Gathering accurate data on HIV prevalence and risk behavior in MSM has posed a challenge for researchers in Estonia. Most of studies are internet based and collection of biological specimen are complicated. Prevalence data lacks reliability due to small sample size.

The involvement of communities in planning, implementation and interpretation of studies has been somewhat limited. There are no additional qualitative surveys on unmet SRHR needs among MSM and Trans in Estonia. Surveys on Trans population SRHR needs have not been conducted.

Recommendations

The main recommendations based on the outcomes are:

- It is recommended to conduct country based size estimation study of MSM (along with EMIS) using the best practices in the region and with involvement of international experts, Estonian public health specialists, MSM Community and NGO sector.
- Along with the internet based studies, "classical" IBBS with testing should be conducted to obtain more reliable data on HIV prevalence, condom use etc.
- Strengthen collaboration and coordination between public health sector and NGO sector including communities to reach the larger group of MSM and to achieve the reliable sample size in surveys.
- MSM community representatives should be more actively involved on planning phases of IBBS or SE studies in order to spread the information on ongoing or future studies among MSM community and to recruit the participants for studies.
- It is recommended to conduct MSM/Trans community organizations needs analysis and their capacity assessment in order to estimate how far communities can be involved in various HIV related surveys/programs.
- Qualitative surveys on unmet SRHR needs among MSM and Trans are strongly recommended to figure out whether additional services are needed for MSM/Trans.
- If additional needs or services emerge from abovementioned recommended surveys, Estonian public health specialists, MSM/Trans community representatives, NGOs and experts should elaborate the ways of integration of those services in Estonia's existing health care model.
- Based on revealed SRHR and health service needs, CSOs and communities should elaborate an advocacy plan for integration of additional services in existing healthcare model and/or how to involve communities in HIV service provision.
- Based on community assessment, it is recommended to build advocacy skills among MSM community organizations, activists and service provider organizations.
- To ensure the exchange of knowledge and best practices on data collection and usage, round tables, seminars, trainings, discussions should be arranged with involvement of community organizations, activists, NGOs, experts and state sector representatives.
- Special emphasis should be given to Trans issues (secure funds, planning and conduction of qualitative and quantitative surveys among Trans population in Estonia) as most likely this community is growing but very vulnerable and hidden.

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