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Valerya Sokolchik *

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Research Article

The Social Model for Research Ethics Committees Regarding to Engaging Communities in Health Research in Eastern Europe and Central Asian Countries *(Based on Tb-Related Research)*

Valerya Sokolchik [1]*, Sarymsakova Bakhyt [2], Kudaibergenova Tamara [2], Sahakyan Hayarpi Gagik [3] and Muradyan Mariam[3]

[1] 1 Belarusian Medical Academy of Postgraduate Education, Belarus

2 Astana Medical University, Kazakhstan

3 Yerevan State University, Republic of Armenia

4 I.K. Akhunbaev Kyrgyz State Medical Aacdemy, The Kyrgyz Republic

***Correspondence Author:** Valerya Sokolchik, Belarusian Medical Academy of Postgraduate Education, Belarus.

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Abstract

Tuberculosis remains a significant public health challenge worldwide, affecting millions of people every year. Addressing this problem requires not only effective treatments and interventions but also active community engagement in research. Research ethics committees (RECs) play a vital role in ensuring that research aligns with the community needs and actions, making research more applicable and the results more disposable for interested communities. However, there is a clear gap in the consideration of community engagement practices by RECs in TB research.

Keywords: community engagement; non-governmental organizations; tuberculosis

Abbreviation

CE – community engagement
REC – research Ethics Committees
IEC - Independent Ethics Committee
IRB - Institutional Review Board
TB – Tuberculosis
RCB – Republican Centre on Bioethics (Belarus)
SOP - standard operating procedure
LMIC – Low and middle income countries
CAB - community advisory board
NGO - Non-governmental organizations
GHRCCA- Global Health Research Center of Central Asia

Introduction:

Tuberculosis remains a significant public health challenge worldwide, affecting millions of people every year. Addressing this problem requires not only effective treatments and interventions but also active community engagement in research. Research ethics committees (RECs) play a vital role in ensuring that research aligns with the community needs and actions, making research more applicable and the results more disposable for interested communities. However, there is a clear gap in the consideration of community engagement practices by RECs in TB research.

This article aims to address this gap by studying the current community engagement practices of RECs in TB research and proposing a social model for RECs that increases research applicability and results utility for interested communities. By analyzing the current practices of RECs in TB research, we aim to identify the most significant challenges and best practices of community engagement. Based on these findings, we propose a social model in which RECs act as a bridge between stakeholders involved in TB research, particularly researchers and communities. This model ensures that TB research aligns with the community's needs and actions, making research more applicable and results more usable for interested communities.

Overall, this article highlights the importance of community engagement in TB research and the critical role that RECs can play in facilitating this process. By adopting a social model of community engagement, RECs can ensure that TB research aligns with the practical needs and expectations of communities, leading to more effective interventions and improved public health outcomes.

Methods:

Achieving objectives, research team selected the methods of desk review and qualitative interviews. Investigators drew on their working experience in the field of biomedicine, examined the existing literature on open science, and current practices of scientific research by Research Ethics Committees. The study focused on TB-related medical research, as it provides an excellent example of socially oriented medical practices.

The project, titled "Mapping Ethics Committee (IEC/IRB) Practices for Engaging Communities in Health Research in Eastern Europe and Central Asian Countries: Social Innovative Models for Implementation and Transferring the Results of TB-Related Research," was approved by WHO/TDR and involved a research team consisting of representatives from Armenia, Belarus, Kazakhstan, and Kyrgyzstan. The team studied the TB-related research practices in respective countries and summarized the experience of society engagement in medical research. The team aimed at unraveling RECs current community engagement practices in TB research in the four countries of Eastern Europe and Central Asia regions (Armenia, Belarus, Kazakhstan and Kyrgyzstan), and researchers conducted over 40 interviews with stakeholders, including REC members, healthcare managers, medical doctors specializing in TB-related disease, researchers, representatives of patient organizations and TB patients, and representatives of non-governmental organizations (NGOs).

The interviews were conducted between June 2021 and June 2022, and the research study and questionnaire were in advance approved by the National Committees of Bioethics of the participating countries. The experts had an option of partial disclosure of personal data and complete anonymity was guaranteed for patients. The questionnaire had 11 questions and was divided into three parts. The first part focused on understanding the problem of community engagement in research processes and the availability of guides and recommendations regarding community engagement in medical research. The second part inquired about the existence of current scientific projects related to TB research in the country and identified the primary barriers to community engagement in medical research. The final part asked about REC practices for engaging communities in TB-related research. By integrating findings from interview data and comprehensive literature reviews on the utilization of community engagement (CE) in research, we conducted an in-depth analysis to generate evidence-based recommendations aimed at enhancing the efficacy of CE practices in the realm of scientific research.

Results:

Community engagement encompasses a comprehensive involvement of community members throughout the entire research process, encompassing various stages such as the identification of study topics, planning and design of the research, enhancement of recruitment strategies, data collection and analysis, as well as the interpretation and dissemination of research findings

(Han, HR., Xu, A., Mendez, K.J.W. et al., 2021). From the author's point of view community engagement can help ensuring that research is conducted in a way which is culturally sensitive, respectful of community norms, and that it addresses relevant community needs.

The authors of the article identified the most complex problems and barriers for community engagement in Health research in Eastern Europe and Central Asian countries. However, the perception of what "community" means varies depending on the expert. To resolve this, the authors adopted the definition developed by van Mastrigt et al. (2015) that defines community as "the residents of settlements where health research is conducted, potential study participants, all other residents in the immediate locality, and stakeholders from outside the area".

However, there are many different interpretations of what community engagement means. For instance, representatives of international organizations see community engagement as a preliminary assessment or screening of the needs of key groups. In contrast, researchers perceive community engagement as the process of identifying the needs of the involved groups and determining how those needs can be fulfilled (Table A). They also prefer to conduct community engagement as a process of including representatives of society in reviewing processes. The authors define community engagement as the meaningful participation of communities, especially if communities are affected by research finding in the research process. The CE can help ensure that research is conducted in a way that is culturally sensitive, respectful of community norms, and that it addresses relevant community needs.

Table A (Problems of community engagements)

- *"Our patient often does not understand where the treatment ends and where the research study begins. Even participating in the scientific project, they (patients) do not expect new knowledge of the research; their expectations are limited to personal bonuses and there are no altruistic goals. In this context, patient organizations are useful because think wider than individual patients and think about the public good" (researcher);*
- *"There is a misunderstanding among administrations/policy leaders of various levels, as well as leaders and community members, about the importance of community engagement for the improving the effectiveness of TB control" (medical doctor);*
- *"There are no specific guidelines for community engagement, or…we are not aware of them. There are small blocks in general documents, but there is no separate way to work with communities regarding TB" (researcher)*
- *"I don't know of any such guidelines [guidelines* for community engagement*]. Existing practice is obtaining approval of research projects through the Ministry of Health." (medical doctor)*
- *"In general, we are not aware of healthcare projects/research on TB. I only know those carried out by international organizations, with the support of the Global Fund, for example, I know the research about short treatment regimens (MSF)" (NGO representative);*
- *«In our country, the concept of community engagement is relatively new and is therefore understood differently. In general, community engagement is limited to invitations to become participants of certain studies. There are no relevant requirements, or research culture to make research process transparent as much as possible for the public" (Healthcare manager).*

Analyzing the answers of experts about the difficulties and problems of CE in research, the authors noted that there are barriers in modern society (here the reference is made to post-soviet countries, but not only) that prevent the CE in research process. These barriers include very little research on TB aimed at key populations, a lack of guidelines at the state level on tuberculosis community engagement, poor informational support at state agencies, difficulties in accessing key populations due to gender issues, stigmatization, as well as cultural issues of hiding tuberculosis. These are also the lack of financial resources for projects, non-willingness of healthcare top managers to cooperate projects and resources with non-governate organizations, the lack of communication according to TB-related research between republican institutions and universities, attending physicians and researchers.

The experts also noted the shortcomings of medical care for patients with TB: poor detection of contact people because of shortage of personnel at the primary care level and their non-willingness to work with “dangerous” TB patients, the lack of skills to work with available express diagnostics equipment, poor work of sanitary and epidemiologic services, absence of health promotion work at the primary level of healthcare, lack of communication skills of medical staff, the absence of psychologic care for TB patients and week financial support of TB patients. We cannot miss the deficiency of patient’s literacy about the TB, poor consciousness and responsibility of parents and relatives toward TB patients, language barriers between medical workers and patients and their relatives (at some countries). At the same time, most experts noted that these problems are not raised by REC, which isolate themselves from communities reviewing research related with socially dangerous diseases.

Financial, political, legal, gender-based, social and educational barriers were considered as the main ones.

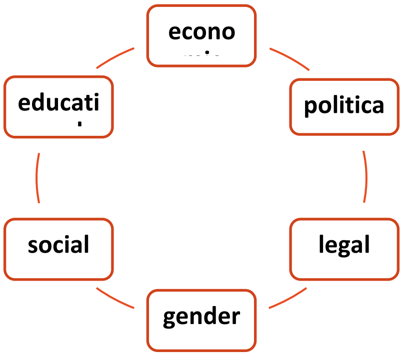

Figure 1: The most significant barriers for CE in the Health Research in Eastern Europe and Central Asian countries

Financial barriers are identified by experts through problems with lack of money, experts also stressed that public funding (Government funding) for TB programs was very low. Political barriers are connected with “authority priorities” (Table B).

Table B (Economic and political barriers)

- *“Almost all previous research is carried out with the money of international funds” (researcher);*
- *“TB-disease is well-paid by international organizations and money sometimes is more interesting than patient’s problems” (medical doctor);*
- *“For example, “***” (a patient organization) is a puppet structure created "from above" that is not so much interested in patients as in "cut from money"" (medical doctor);*
- *«Lack of funding is one of the main problems for organizing effective community engagement events…” (researcher).*

Legal barriers were determined by the researcher’s included imperfection of documents and practices of REC activities; imperfection of the penitentiary system in terms of work with prisoners suffering from TB disease. There are also some gender barriers which were explained that women are less involved in the proposed activity and projects for TB patients. Mostly such projects and programs are less targeted at women (Table C).

Table C (Gender barriers)

“In a religious family in the south of the country, if the research participant is a woman, then her husband or someone from malerelatives should be always sitting next to her and so that the woman will not be able to fully open up and always answer the questions of the researcher in a stereotyped way” (medicaldoctor);
“Mostly TB- projects and programs are less targeted at women” researcher);
“Gender disbalance is not recognized as an important issue in networking with community representatives” (Healthcare manager).

Researchers obtain that the social barriers are the most serious ones in TB research. At the level of public opinion there is stigmatization of patients with TB disease. Prejudices against TB-patients and TB-disease need to be changed in the minds and psychology of society (like the prejudices against HIV was mostly decreased), also medical and social workers have to be careful with the confident information of TB patients, including information of medical secrecy of prisoners. The specificity of TB- and HIV-patients is their fear of stigmatization and discrimination from their inner circle. (Table D).

Table D (Social barriers)

“Society doesn’t have much knowledge about TB, whereas social advertising about this problem practically doesn’t exist. Moreover, if people find out that someone in the house (or in the team) is has TB, serious dissatisfaction, fear and even panic flare up…. There are serious problems with medical secrecy: the dispensary must invite patients for treatment, but it is absolutely impossible to do this in secret (for example, all residents know what the TB dispensary does and who are treated there)” (medical doctor);
“TB is strongly associated with poverty, which means lack of access not only to normal living conditions, food, etc., but also low access to electronic devices, the stable Internet, and other modern communication channels. This leads to the exclusion of such people from effective interaction in digital format” (patient).

Some country’s experts also noted educational and language barriers (Table E).

Table E. (Educational and language barriers)

–"As a rule, patients do not even know the names of the drugs they are given, the plan of treatment, etc. (and healthcare workers do not seek to explain them some "medical information"" (member of REC);

–"Local nurses and local doctors had to be engaged to help with problems with local dialects; although we translated the instruments into the native language, there were problems with terminology for patients (medical doctor)";

–"People may be embarrassed to speak out in the presence of professionals, they are afraid of appearing "stupid", poorly educated and insignificant. This barrier must be overcome through education and massive information" (member of REC).

Consequently, the work on CE in health research in the countries of Eastern Europe and Central Asia does not meet the requirements of the modern open science approach. In fact, community engagement is complicated by many obstacles for all participants in the research process. According to the authors of the article and interviewed experts in the countries under study, little attention is paid to the role of REC for CE in research, however, RECs have to be a tool that can manage the processes of community engagement in research (and direct these processes).

In general, REC and community engagement are both critical components of responsible scientific research. By working together, REC and researchers can ensure that research is conducted in a way that is ethical, responsible, and is addressing the needs and concerns of the community.

The study concludes that research RECs should play a leadership role in coordinating and creating conditions for engagement in health research for all communities. The authors suggest that RECs create a special SOP for the ethical review of participatory research to increase community engagement. The proposed social model emphasizes the role of RECs in providing ethical support for community engagement and increasing the protection of community interests. The recommendations for RECs on community engagement in participatory research include identifying the purpose and goals of community engagement, determining who should be engaged as a community, and being aware of the community's culture, economic conditions, political, social, and power structures, norms and values, demographic trends, history, and perceptions of engagement initiatives. Ethics committees need to have a working definition of what a community is to determine whether a study is community-based (MacQueen et al., 2001). Furthermore, they must determine whether a study is participatory, that is, with the communities' engagement. Therefore, the study suggests that RECs create a SOP for the ethical review of participatory research to increase community engagement. The recommendations for ethics committees on community engagement in participatory research include few steps (Pic.2)

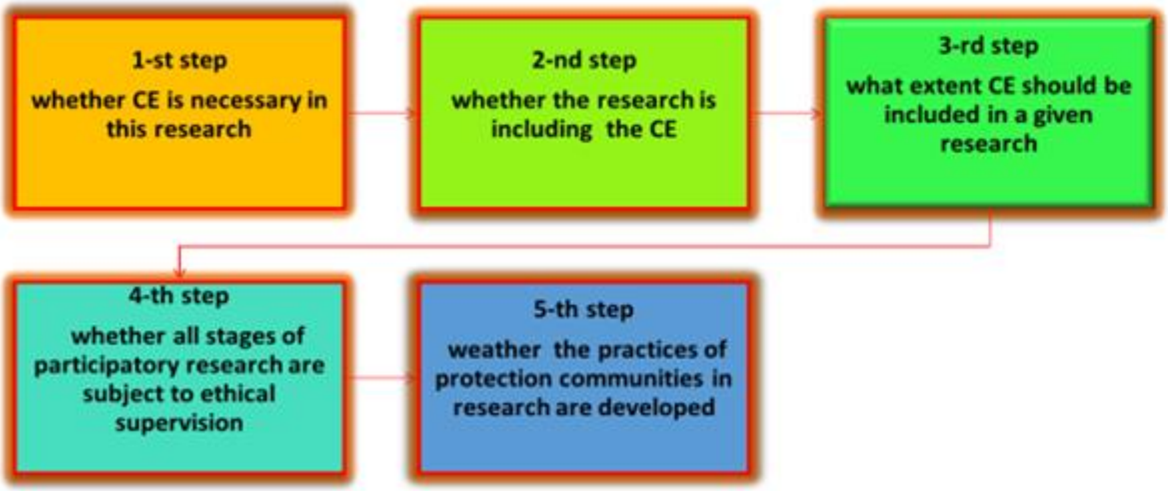

Figure 2: The social model for EC reviewing Health Research with CE

To ensure that research practice is truly participatory, it is important for RECs to ask specific guiding questions. One effective approach is to determine whether stakeholders are involved as active partners in various stages of the research process, including the formulation of research questions, selection of research methods, analysis, interpretation, and application of results. If the answer to this question is "yes", then the research can be considered participatory. This approach distinguishes participatory research from basic research, which typically involves only researchers. As a working definition of what participatory research is, we propose to use the following: participatory research is a systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and acting or effecting social change (Green et al. 1995).

When deciding to what extent collaborative research should be applied in each research project, one rule of thumb is to consider the complexity of research and analysis methods. If these methods are highly technical and time-consuming, it may not be necessary or justified to involve volunteer participants (Green L.W. et al,2001). However, if the methods are not overly complex, involving volunteer participants in the research process can be beneficial, especially if they are given the opportunity to help formulate research questions and interpret results. Ethical committees need to carefully consider the extent of community participation in each specific study.

To define the upper and lower bounds of community participation in participatory research, ethical committees can refer to guidelines developed by Lourence et al (2001). Maximum participation occurs when stakeholders remain active partners throughout the study, while minimal involvement is when stakeholders are involved only at the initial and final stages of the study. Ethical support at all stages of the study is necessary for maximum participation, while an ethical review at the study planning stage is sufficient for minimal community engagement.

The goal of this approach is to promote community engagement in the development of scientific knowledge and the protection of human rights. It allows society to directly participate in the formulation of topical problems and receive the results of scientific research. In the context of biomedical research, stakeholders include not only researchers and scientists but also sponsors, customers, medical doctors, authorities, patients, and representatives of patient communities. Ethics (Bioethics)

Committees play a significant role in promoting community engagement in biomedical research. Overall, by following these steps, RECs can ensure that participatory research practices are ethical, inclusive, and beneficial for all stakeholders involved.

RECs have to pledge a broad discussion of the proposed studies (in agreement with the research team) with representatives of the relevant patient communities, human rights organizations, representatives of NGOs, etc., especially if we are dealing with research devoted to socially dangerous diseases (TB, AIDS, drug addiction, etc.). “Research is of no use unless it gets to the people who need to use it" — Chris Whitty, head of NIHR and the government’s Chief Medical Adviser.

In summary, the open science approach in biomedicine involves various actions that need to be taken by researchers and RECs to promote transparency, community engagement, and responsible data sharing. These actions include developing open science policies, creating open research databases (King, K.F., Kolopack, P., Merritt, M.W. et al., 2014.), involving patient communities in the research process through open discussions and webinars, carefully reviewing and storing patient data (Ritchie H., et al.,2022), and disseminating research findings through open sources and public speaking. Additionally, REC should publish analytical reports on their activities, develop a website for publicizing their work, and build partnerships with communities for health improvement (Sokolchik, 2021). The overall goal of these actions is to promote ethical and responsible research practices and engage all stakeholders in the research process.

Discussion

We found that the RECs in Armenia, Belarus, Kazakhstan, and Kyrgyzstan are lacking in community engagement practices in TB research. The “community engagement” is a relatively new phenomenon in the post-soviet countries and uncovered in the national legislations in all countries involved.

Our study revealed several barriers that limit community engagement in TB research.

Considering the definition of “community” as “the residents of settlements where health research is conducted, potential study participants, all other residents in the immediate locality, and stakeholders from outside the area” (van Mastrigt et al., 2015) we identified from our study findings the following possible categories of stakeholders involved in TB research: state organizations, healthcare institutions, patients and RECs.

We consider the problem of neglection of TB as more of an ethical issue than a political or financial one. Tuberculosis is an epidemic of injustice (JH Darbyshire 1998) Grange, J., & Zumla, A. (1997). Over time, tuberculosis epidemic, despite efforts to eliminate it, turned into a pandemic. One of the reasons of it might be another kind of injustice at TB: if the disease doesn't threaten people in rich countries, we even considered as a pandemic. TB kills people in almost every country in the world (1.6 million in 2021). Looking at these numbers and geographic coverage, TB meets all the requirements to be considered a pandemic (20 March 2023 by Peter Sands, Executive Director, The Global Fund). Injustice is ethical problems that requires ethical solutions. Therefore, the role of RECs is increasing in this regard.

The revealed in our study barriers to community engagement at the identified key stakeholders involved in TB research in studied countries can be considered by RECs as the targets for their community engagement practices. RECs need practices to ensure that communities are ethically engaged in research in a culturally sensitive way, with respect of community norms, and address the relevant community needs at all stages of research including identifying study topics, planning, and designing the study, strengthening recruitment strategies, collecting, and analyzing data, and interpreting and disseminating findings (Han, HR., Xu, A., Mendez, K.J.W. et al., 2021).

In fact, RECs limit their activities to procedural ethical aspects of risk assessment of individual participants and do not pay attention to the interests of entire communities. Current ethics review procedures and ethics committee guidelines operate overwhelmingly within a biomedical framework that rarely considers the general experience of research involving local communities. They primarily focus on the principle of risk assessment for individuals, but not for communities. Therefore, ethics committees may inadvertently put communities at risk by continuing to use procedures that are inappropriate for community-based research. For example, the qualitative community-based research (often stigmatized, marginalized populations) based on ongoing community engagement in research from design to dissemination, consider the community as a unit of identity with right to pursue its own interests and values. The community has autonomy to set priorities for partnership and research with the researcher, which must be recognized and respected, as a lack of awareness and critical reflection on ethical considerations can perpetuate the same problems that this methodology seeks to address, namely inequality, oppression, and marginalization (Flicker, S, 2007). This problem is urgent and serious in the LMIC countries, including countries we studied (Sarymsakova 2022).

Our study findings are new. There is a lack of studies on the RECs practices on community engagement in TB research in the Eastern Europe and Central Asian countries. That is a great issue for TB research especially in Central Asian countries as LMIC under-investigated, inherited the Soviet centralized healthcare systems, undergoing rapid transitions and facing a double burden of communicable and non-communicable diseases countries (Adambekov S. *et* 2016; Verma M and Kalra S. 2020).

The RECs in studied countries need to consider developing alternative processes for reviewing TB research and any other research in the public health and healthcare system - ethical review that addresses the unique challenges and concerns associated with engaging community to protect and respect its autonomy. New principles or rules are needed to include communities in a constructive partnership in the field of organizing and conducting community-based research in public health [Childress, 2002; Sarymsakova 2022].

Possible pathways to help RECs to develop new mechanisms to engage communities in a constructive partnership in the field of organizing and conducting community-based research in TB research and any other public health research might be the practices of community engagement advised by the participants of our study including an establishment of community advisory board (CAB); crowdsourcing; establishment of bioethics’ promotion center; cooperation with NGOs.

Our study findings support the conclusion that the RECs review process presents a unique opportunity to support stakeholder engagement practices in research studies. The value of community engagement and REC’s review processes was strongly endorsed (Wilkinson, A., Slack, C., Thabethe, S., & Salzwedel, J. (2022). Also, they support a conclusion that thoughtful analysis of meaningful stakeholder engagement in research is important, where researchers engage stakeholders, and RECs analyze studies for such engagement (Furniss, D. et al. 2015; Tindana et al., 2020); Ntabe, A. C. (2020)), as “it is vital for all stakeholders to work together in securing the conditions that will enable participant-led research to flourish” (Vayena et al., 2016).

Considering the results of our study and other lessons learned from studies on community engagement in health research *(*Ntabe 2020*)* such as “it is not sufficient for researchers to maintain high ethical and scientific standards in a study; in many cases, it is equally important and necessary for them to work very closely with the communities through various flexible mechanisms. In cases where community engagement is relevant, participation should commence from the very start of the protocol development. Participation should focus on the methodology, participant selection, the procedures for the study results disseminations at different points of the research and finally on enhancing informed participation. Any consultation with the community after the protocol is developed may be regarded as cosmetic rather than as genuine community engagement" (Ntabe, A. C. (2020) we suggest a further social model for RECs review of community engagement practices in health research.

The social model we propose to increase community engagement in research is based on the work of RECs to develop a special SOP for the ethical review of research studies that affect the community interests. Our suggested social model makes it possible for communities directly to participate in the development of scientific knowledge, including the formulation of topical problems and their consideration; it also permits to directly obtain the scientific research results; to influence the previously "closed" scientific knowledge and to defend human rights (Green LW, Mercer SL., 2001).

Along with research and scientists, sponsors and customers of research, medical doctors as well as authorities, patients, and representatives of patient's communities (included communities of patient's relatives) become the stakeholders of the open science approach in medicine. The significant role to promote community engagement into biomedical research is given to RECs, who can stimulate the policy development, thinking about definition of the open science policy in the country; stimulation of the commitment of scientists through education, encouragement of community engagement (using case studies, recommendations, guidelines, etc); creation/registration an open research database; promotion the events and popular science publications focused on public awareness with the results of scientific investigations.

The RECs are also suggested to apply the community engagement practices we found in our study to initiate consideration of the proposed research problem/tasks (design, methods) in patient communities through the organization of open discussions among interested community members/online debates and webinars by the research group (researcher). The results of these discussions / debates (suggestions, comments, amendments, etc.) must be considered by the next REC meeting, where stakeholders (doctors, heads of medical institutions, social workers, representatives of patient organizations, etc.) invited as experts to discuss research applications. It is recommended to have a broad discussion of the proposed studies (in agreement with the research team) with representatives of the relevant patient communities, human rights organizations, NGO representatives, etc., especially if the study focused on socially dangerous diseases (TB, AIDS, drug addiction, etc.).

Since the feature of the open science approach in biomedicine is the obligation to make informed decisions regarding the widespread use of databases in science the inadmissibility of using patient data in the public domain and careful storage of such data (Ritchie H., et al.,2022) the RECs must: review research on the confidentiality of participant's personal data, considering their informed consent; at the end of the study, consider the ongoing study again to determine how and what data/methods/statistics/soft- and hardware and other components of the study could be used in the public domain with fixing the decision in the appropriate protocol and transferring the protocol to the researcher and interested scientific organizations; recommend for the research team (researcher) the organization of public discussion of the obtained results, which need to take place with the involvement of stakeholders; consider at the meetings of the REC annually the dissemination of scientific research through publications in open sources, public speaking, meetings with representatives of patient's communities, other forms of education, followed by analytical publication of received data at popular mass-media.

Realizing The Open science approach REC need to encourage an open publication and education of researcher (open educational resources for researchers and for communities) the creation and registration of open databases for medical research (with respect of the ethical standards of scientific and medical activities, including an extremely careful attitude to confidential information and its protection); initiate the involvement of young scientists and IEC members in creation and development of such databases; stimulate the development and expansion of open databases, considering the constant ethical support for their using; inform scientists / the public about the availability and rules for using open databases in medical science (King, K.F., Kolopack, P., Merritt, M.W. et al., 2014.).

Open evaluation of research projects requires REC to cooperate with the Councils of Young Scientists, other organizations within the scientific community develop a website (page at the website), where to publish constantly open data on the composition of the IEC, planned meetings, studies under consideration, as well as information on the popularization / dissemination of data obtained by researchers, information on available open research databases, analytical materials on the activities of EC (common ethical and methodological mistakes of researchers, best practices for disseminating research results, ways to communicate with stakeholders, etc.); to publish annual analytical reports on the activities of the REC (Sokolchik, 2023) .

The strong point of our study is that we conducted it in a homogeneous environment of the former Soviet Union countries, with a common post-Soviet heritage in the field of healthcare with common issues and achievements with relatively similar economic and social conditions of the LMIC countries. The limitations of our study in that the "community engagement" is a relatively new phenomenon in the post-soviet countries. Having no clear understanding of the phenomenon, it was hard for participants to respond to the questions comprehensively, so our data might be limited in quality.

Our study results are robust because as experts into the research were involved the participants from real practice of TB research, acting members of research projects teams, NGO, healthcare facilities and RECs. Our study team members have great national and international ethical background, practical and research experience more than 20 years in the field of ethical review of health research.

Further exploration in countries studied is needed to assess the public good of the TB research, public engagement, and transparency in ethical review by RECs (Ballantyne and Schaefer, 2018); what would be the RECs instruments for review of operational research, that is critical to maximizing the efficiency and effectiveness of interventions to eliminate TB (Ajay MV. Kumar 2020). It would be helpful to explore in 3 major thematic complexities of community engagement in TB research: "tokenism" (processes risk being "tick-box"); "toxicity" (practices, inadvertently having negative consequences); "tailoring" (processes need careful variation in intensity) (Wilkinson et al., 2022); to explore potential harms to community members, including bystanders as community engagement can improve the identification of bystander risks, effective approaches to minimizing them, and transparency about bystander risks for host communities (Shah, et al., (2020). Bystander risks are especially important at TB.

Community engagement should be implemented with a leading role and responsibility of RECs to ensure the effective, adequate, and ethical community engagement practices. The authors hope their study findings provide all stakeholders with greater insight into the community-based research and practice of community engagement and the implementation of community-engaged initiatives to the health improvement in the LMIC post-soviet countries in the Eastern Europe and Central Asia region countries.

Best Practices in the Studied Countries

The establishment of CAB as an example for providing a practice on community engagement was suggested by experts from Kazakhstan. The Columbia University Global Health Research Center of Central Asia (GHRCCA) established CAB for the research projects. CABs build and foster partnerships between researchers and local study communities impacted by different infections, including HIV/AIDS. CABs provide feedback into all aspects of the research study including: 1) developing research questions; 2) developing recruitment plans; 3) reviewing study assessments or procedures; 4) discuss ethical considerations around your research; 5) provide different perspectives into the data interpretation; and/or 6) considering non-traditional dissemination methods. CAB members provide input to protocol teams, particularly in adapting sample consent forms for local use and in developing other study materials. CABs are responsible for evaluating the impact of studies on local communities. They serve as a voice for the community and study participants. CABs bring specific, unique expertise to the research process, by participating in the processes of defining the research agenda and informing researchers of local issues or concerns that can affect the conduct and successful implementation of the scientific agenda. CABs provide advice on scientific, ethical, and operational issues regarding study design, recruitment, and protection of study volunteers. Face-to-face meetings facilitated by research staff provide opportunities for CAB members to share their community expertise and gain new skills. To ensure CAB autonomy and to reduce the potential for conflict of interest, CAB members are volunteers from the research community and are not paid staff members at the GHRCCA.

The crowdsourcing experience as a practice for community engagement was suggested by experts from Armenia and Kazakhstan. The term “crowdsourcing” is more vastly used as a financial term. The similarity between financial crowdsourcing and crowdsourcing in health-related research is the recruitment of interested people. Crowdsourcing generates public benefit and solves publicly important issues, and the solutions are shared with the wider public. According to the WHO Crowdsourcing Guide, the engagement of communities into the health-related research involves three stages, such as organizing a steering committee, soliciting entries, promoting (WHO, 2018).

However, the overall objective of this method is to improve public health. Furthermore, the guide defines the two overarching categories, crowdsourcing to engage communities for its mobilization and those seeking for more outputs through community engagement. The study of Infectious Diseases of Poverty brought forward a conclusion according to which crowdsourcing is more effective at improving behavioral outcomes rather than on clinical outcomes. TB is more often the spread of the disease is conditioned with the behavior more often reasoned by the social status of the patients, e.g., seasonal labor migrants, socially vulnerable groups, and families etc. During the qualitative research, among the public agencies and organizations represented by the participants of the survey, positive experiences of the community engagement were monitored. Among the activities of the project Enforcing fight against TB and HIV/AIDS in Armenia, there are [1]. social psychological support to TB patients and their family members, [2]. social campaigns and networking among the community leaders, healthcare providers and TB patient, [3]. events for reintegration for TB patients who lived through TB with positive outcomes. However, neither the National Program 2016-2020 nor 2021-2025 on the Management of TB in Armenia have specific objectives of community engagement which may contain the elements of crowdsourcing are monitored. The National Program 2016-2020 objectives mention the necessity of cooperation between the CSOs (National Program 2016-2020) and government for monitoring and improving the TB management for the protection of human rights, equality, and ethic principle according to the targeted international standards. Crowdsourcing is a relevant methodology for the community engagement in relation to the TB. While assessing the appropriateness of the method it is of a key importance to understand that TB is a social/behavioral disease, and the approach of the method is creation and generating of the crowd wisdom.

The experience of cooperation with NGOs as a practice for community engagement in TB research was suggested by experts from the Kyrgyz Republic. The NGOs demonstrated large experience in community engaging into their research and activities in the TB area. Experts practice of community engagements in the field of TB included: engagement of TB patients into the study of digital technology "electronic pill box" or drug dispenser for the convenience of taking drugs with family members engagement; heath education of TB patients in regions of the country; engaging ex-TB-patients to help patients who doubts about the effectiveness of the treatment, to conduct conversations, using a peer-to-peer method and data collectors; engaging migrants themselves as field workers and supervisors in research projects; engaging international organizations and NGOs into working groups on legal documents development; involving ex-TB volunteers to facilitate access to key populations; involving local nurses and local doctors in regions to help researchers to solve problems with understanding local dialects; establishing NGOs and seeking for cooperation; MoU of NGO with religious administration; including NGO representatives into the Public health coordinating council; involving NGO representation into medical students practice and education; engaging international foundation into training of professionals for assistance to TB patients like street lawyers.

The resources of NGOs about community engagement would be great help for RECs to relay at the ethical review of TB and other community-based research. NGOs have their own guidelines for community engagement and advocacy they developed in cooperation with international organizations (guide for engaging vulnerable groups, guide on how to involve the sick; guide for working with the population; guide for working with religious leaders; clinical guideline for health care workers and issues on worker burnout and patient burnout). As example was the work of the TB patients NGO with the Muftiyat (an administrative territorial entity under the supervision of a mufti) for 10 years on imams’ education on TB in coping with stigma and helping the sick; mutual development health education leaflets on TB issues. The Ministry of Health approved their guidelines for ACSM (advocacy communication social mobilization). The KNCV-Kyrgyzstan has a great experience on the community engagement within their projects on introduction the second line and third-line TB drugs, BPAL treatment. The NGO "Socium" assessed the social needs of people with TB and HIV. NGOs in Kyrgyzstan collaborate with international organizations like the Red Crescent Kyrgyzstan, USAID, and their projects on TB elimination. The Global Research Institute (GLORI Foundation) in Kyrgyzstan has great experience on community engagement and the guidelines resources within a range of projects on TB among external labor migrants within unique project CARAVAN.

An establishment of bioethics’ promotion center as a practice for community engagement was suggested by experts from Belarus. The experience of the Republic of Belarus regarding dissemination of transparent and full ethical (bioethical) information through open public events, lectures, round-tables, open student’s competition, etc., and also through website and social media is valuable. The Republican Centre on Bioethics (RCB) was created at 2018 as a public center aimed to educate society in the field of biomedical ethics, to disseminate advanced ethical ideas and views in society, to attract people for solving modern ethical problems in medicine (in particular, the problem of CE). At the website of RCB everybody may get information about current events in bioethical sphere, last applications, actions, and projects like announcement of Committee on Bioethics of the Republic of Belarus regarding situation with Covid-19, volunteer’s activity during Covid-pandemic, opportunity to study bioethics, last actual articles, and events of research activity, etc. Looking through this website important information about the status and development of bioethics in Belarus can be received. One section of the website is devoted to research ethics, where the main legal documents, recommendations for investigators, sample forms of informed consent, interesting materials of research achievements are allocated. Special section with problematic and controversial articles is devoted to current ethical issuers of Public Health and medicine in general. Through the website information the most motivating ethical events like conference about alternatives of using animals during preclinical trials, open public discussions were shared for all interested. All these publications and ideas' dissemination activity are aimed to inform the RECs members and population in general about the problems and achievements in the field of bioethics, especially at the situation with Covid-19. In 2022 the RCB, with the support of UNESCO, organized a series of educational events "Bioethical University", which included online classes on the basics of biomedical ethics led by experienced tutors, online webinars on problematic issues of modern healthcare ethics, open lectures and master classes for young researchers, as well as the final Forum in Minsk, where the problems of biomedical ethics were discussed by medical researches, scientists, medical doctors, members of REC, healthcare authority, representatives of public organizations, invited guests from Russia, Kazakhstan, Kyrgyzstan **(Bioethics Belarus).**

These community engagement practices we found in our research might be of value to help RECs to develop their review mechanisms to engage communities in a constructive partnership in the field of organizing and conducting TB research and any other community-based studies. The results of our study can help researchers understand the intentions and concerns of RECs and appreciate the benefits of ethical review being seen in a more positive light, less burdensome for them to work with, making TB research more accessible to practitioners and researchers (Furniss, D. et al. (2015).

References

1. Ballantyne A, Schaefer GO, (2018). Consent and the ethical duty to participate in health data research. *Journal of Medical Ethics*; 44:392-396
2. Bergold, J, & Thomas, S. (2012). Participatory research methods: *A methodological approach in motion.*
3. Dickert, J.M, Neal, T.M.S, & Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health*, 95;1123-1127.
4. Flicker, S, Travers, R, Guta, A, McDonald, S, & Meagher, A. (2018). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Empirical Research on Human Research Ethics,* 13(5), 580-591.
5. Furniss, D. *et al.* (2015). Ethics, Governance, and Patient and Public Involvement in Healthcare. In: Fieldwork for Healthcare. Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies. *Springer, Cham.*
6. Green, L.W, & Mercer, S.L., (2001). Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *American Journal of Public Health*, 91(12), 1926-1929.
7. Halabarodzka, M, Sokolchik, V, et al. (2020). Recommendations for obtaining informed consent in biomedical research. *Retrieved from.*
8. Han, HR, Xu, A, Mendez, K.J.W. et al. (2021). Exploring community engaged research experiences and preferences: a multi-level qualitative investigation. *Res Involv Engagem*, 7-19.
9. Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19(1), 173-202.
10. King, K.F., Kolopack, P., Merritt, M.W., et al. (2014). Community engagement and the human infrastructure of global health research. *BMC Medical Ethics,* 15-84.
11. MacQueen, K.M., McLellan, E., Metzger, D.S., Kegeles, S., Strauss, R.P., et al. (2001). What is community? An evidence-based definition for participatory public health. *American Journal of Public Health*, 91(12), 1929-1938.
12. National Institutes of Health. (2018). *Protecting human research participants.*
13. National Program of the Republic of Armenia on TB Management 2016-2020.
14. Ntabe, A. C. (2020). Rethinking the practice of community engagement in health research: *the case of the tenofovir trials in Cambodia and Cameroon.*
15. Sarymsakova B, Kudaibergenova T, Sokolchik V. (2022). The Role of Ethics Committees in Involving Communities in Tuberculosis Research. *Research scientific conf, Minsk 17-18 of November 2022.* Vol. 2 / Institute of Philosophy of the National Academy of Sciences of Belarus; red. A. A. Lazarevich (prev.) [and others]. - Minsk: *Four quarters*, 262-266.
16. Shah, S. K., Miller, F., & Fernandez Lynch, H. (2020). The role of community engagement in addressing bystander risks in research: the case of a Zika virus controlled human infection study. *Bioethics*, *34*(9), 883-892
17. Sokolchik, V.N. (2021). The role of ethical committees in protection of human rights regarding to biomedical research and tests in the Republic of Belarus. *Proceedings of BSTU, ser. 6: History, Philosophy*,1 (245), 146-150.
18. Tennant, J., Beamer, J.E., Bosman, J., et al. (2020). Foundations for open scholarship strategy development. *MetaArXiv.*
19. Tindana, P. O., De Vries, J., & Kamuya, D. (2020). Ethical challenges in community engagement practices in research during the COVID-19 pandemic in Africa. *AAS Open Research*, 3-23
20. Wallerstein, N., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice*, 7(3), 312-323.

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