

**37th Union World Conference on Lung Health:
The Role of Community Advocacy in Improving
TB-HIV Programmes and Policies
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JAVID SYED: Good morning, everyone. My name is Javid Syed. I work at the Treatment Action Group in New York and me and Eleonora will moderate or just facilitate the process today. The reason why I am up here is because I am the director of the TB/HIV project at the Treatment Action Group and part of our work is to build a community movement to increase PWA Networks to get more involved in TB work, especially in high-burden countries.

So, part of that work has entailed engaging activists who are already doing a lot of AIDS advocacy and treatment activism to increase the awareness of how TB/HIV works together. Because still people live the experience of two diseases, one patient, because the silers [misspelled?] of TB/HIV are so vertical. Even after we have experienced those diseases in our own body, we do not sometimes understand what the interaction is. So, that is me.

ELEONORA JIMENEZ: Good morning, everyone. My name is Eleonora Jimenez and I coordinate the TB/HIV Monitoring and Advocacy Project for Public Health Watch, which is a program of the Open Society Institute in New York. For the last three years, Public Health Watch has been supporting and funding TB/HIV activism and advocacy both at the national and global level.

And we welcome you today to hear five speakers, five phenomenal activists, who have engaged in TB/HIV advocacy at the local, regional and global level. And they are here to share with you their strategies, their approaches and, most importantly, their recommendations for the future for TB/HIV advocates.

I also want to mention that we are going to have an interactive session this morning. We welcome your participation and your questions and we would also like to ask everyone that when they do have a question, to please come up to the microphone so that we can be able to hear your questions and your comments. So, with that, I will introduce our speakers.

JAVID SYED: [Interposing] So one of the things that we learned from our experience last year, because last year was the first year that we organized a panel of activists who were doing TB/HIV and Justevee [misspelled?] advocacy, was that we wanted to give people a lot more, and how does it link to the theme of this year, which is health care resource strengthening? Was that we wanted to really highlight the ways in which community activists on different levels of engagement can really contribute to policy formulation as well as implementation on a global level as well as on a national level. And as the TB movement for community engagement is still somewhat in its inception phase, how can these different

actors play a role along with, of course, the NTP [misspelled?] managers, the other policy makers and funders, to ensure that community voices are in it and that the policies and programs that are formulated actually reflect the community's priorities?

So as you will hear from the different activists, their experiences are quite different. Some of them have engaged in the Stop TB Partnership and have utilized that as a way of engaging further on a national level and then some of them have been straightforward PWA activists who have, because of the strength in advocacy networks that the HIV-AIDS world has created, used that as an early-warning signal, a system, for TB programs, to monitor TB programs. So, I hope that you will be able to get a sense of the ways in which activists on all different levels can participate in this dialogue.

The other thing that we learned from last year was that we spent a lot of time describing why OSI and TAG was doing this work and we did not have enough time to have people talk to each other. So the way we structured this session today is that we are just going to have the speakers give a really brief, five minute description of what they are doing and then we are just going to open it up for question and answers, both from each other as well as from the audience. So we are hoping for this to be really interactive. So if you do not want to use the microphone and just have it be a much more interactive

process, you might have to move front a little bit so that we can hear your questions clearly.

So with that, we will just turn it over, and go ahead and introduce the first speaker.

ELEONORA JIMENEZ: Our first speaker is Samvel Grigoryan from the Armenian National AIDS Foundation. Our next speaker is Tamara Gvaramadze from Georgian Plus Group. We have Carlos Garcia de Leon from AVE de Mexico. We have Lillian Mworeko from TASO and we have Pervaiz Tufail from the National Program of TB People.

SAMVEL GRIGORYAN: Good morning, ladies and gentlemen, TB/HIV activists, community activists. Let me introduce myself, I am Dr. Samvel Grigoryan and I am representing the Armenian National AIDS Foundation, one of the major and famous NGOs in Armenia, which has implemented TB/HIV advocacy project in 2005-2006. The project was launched in 2005 and we began to develop multi-stakeholder response to TB/HIV co-infection in Armenia, targeting institutions like country coordination mechanism on HIV, AIDS and TB issues as one agreed national coordinating opportunity.

In the country, medical institutions, non-governmental organizations, communities affected by TB/HIV were advocated for better communication and information exchange between TB and HIV national programs. Project activities included organizing awareness-raising workshops, disseminating advocacy

materials among policy makers, physicians, affected communities, organizing round-tables to initiate [inaudible] from HIV and TB programs. CCM medical institutions, NGOs affected communities.

The results of the projects, briefly, were adoption by the CCM members of the resolution, to form a CCM working groups responsible for coordination of HIV, AIDS and TB national programs. Diversial [misspelled?] for NGOs representatives resulted in increased communication and preparation among representatives and organizations that represent TB/HIV activists. Diversial [misspelled?] for physicians succeeded in providing recommendations to enhance comprehensive health care services to people co-infected with TB and HIV. Diversial [misspelled?] the recommendation of the round table discussions was made for better intern program cooperation between HIV and TB national programs. I would like to mention, also, some concrete and visible alt [misspelled?] counts of our projects.

So, after TB/HIV advocacy activities and communication by world organizations, reference system and surveillance for HIV among TB patients and TB among HIV patients was improved in the country. Special approval forms were developed in the country and more HIV patients were tested for TB, better comprehensive health care services provision if needed, and more TB patients were tested for HIV in the country with further comprehensive services provision.

So, for all patients in Armenia currently, for all HIV patients, TB treatment DOTS implementation is available widely, free of charge and for all TB/HIV co-infected patients, ARV treatment is available free charge country-wide. Of course, we should mention that these activities are widely supported by different international organizations and donor organizations, especially Global Fund to Fight TB, HIV and Malaria. [Inaudible] some other organizations. W2 [misspelled?] is a technical partner organization.

And at the conclusion, I would like to mention that 91 appropriate support and information key stakeholders demonstrate a commitment to TB/HIV collaboratively. These also require the continued engagement of TB/HIV advocates, including communities most affected by TB and HIV. Thank you.

TAMARA GVARAMADZE: Hello, everybody. I am going to present Georgian Plus Group and its work in the frames of two TB/HIV projects funded by OSI. I will give you a brief overview of the TB/HIV situation in the country and then short information about the Georgian Plus group itself and then I will talk about our projects.

As regards to HIV AIDS, Georgia is low prevalence. But it is considered to be having a high potential risk for development of epidemic. Since September of 2004, under the Global Fund, everyone who needs ARVs gets them for free in

Georgia, and this is a great achievement to which Georgian Plus Group has significant contribution.

In regards to TB, Georgia is considered one of the high-burden TB countries in Europe. Due to the decline in the social and economic conditions of the entire population and the deterioration of prophylactic and treatment components of public health service the TB is spreading at a frightening rate. Also, the MDR-TB and TB/HIV co-infection are declared the major challenges in finding TB in Georgia, as well as in the world. Currently, TB/HIV component of GFATM project in Georgia is small and undeveloped. But we are hoping that it will get more attention in the future.

In regards to the Georgian Plus Group, it is the first self-help group of PWAs in Georgia. As its main goal, it has improving the quality of life of people living with HIV/AIDS. When Georgian Plus Group started its activities, there were not only no community activity in the field of HIV/AIDS, no community representation in any of the decision-making bodies. And today, after almost four years of existence, ARVs are available for everyone for free, Methadone program is available for every eligible person. There are two self-help groups of PWAs in Georgia. The community representative is on the CCM, and TB/HIV joined body has been organized and met two times and has a community representative on AIDS. And [inaudible] has earned also [inaudible] so that we have a voice and our lenders

very often give interviews and we have close connections to the media and we have some sources and activities aimed to raising awareness of the general public in Georgia. Which is a very important component of all of our projects.

As regards to our TB/HIV projects, the first one, they were conducted over 2005 and 2006. The first one was preventing the spread of TB among HIV-positive community of Georgia. And the second one was decreasing the risk of TB spread amongst of [inaudible] HIV-plus community.

In the frames of this project, we identified targets to be of two types, the providers and the receivers of the services. And we developed activities aimed to both of those targets. And we also used a network of other NGOs, HIV/AIDS service-providing NGOs, and TB service-providing organizations and other civil society organizations to implement the activities that were outlined in our project.

And also, we reached out of the borders of Georgia to the South Kokosis [misspelled?] region because [inaudible] a very specific small region and the countries Georgia, Armenia and [inaudible] are situated there, have longtime historical and cultural relationships that make it easy to develop joint strategies and joint activities. It is very short, I did not fit in five minutes but I hope I will have some more time to go into details. Thank you.

CARLOS GARCIA DE LEON: Okay, it is my turn. I am Carlos Garcia de Leon and I am from Mexico from an NGO named AVE de Mexico. We have 16 years working on the HIV/AIDS fields but when we began this project, we were blind about the TB related with the HIV AIDS situation. That was something that was just in front of us, or sometimes inside of our bodies, but we cannot look at that.

So this project was a very good opportunity to begin to increase the personal awareness of the people of my organization and of course with others. The project is not only working in the national level in Mexico, it is trying to work in the regional level in all Latin America. So we began at making a meeting in the context of Treatment Action Forum that was held in Mexico last November in Guajaca, Mexico, and we have some international and regional participants from five of the most leading networks in the Latin America region. One that is working human rights, close related with HIV/AIDS, one that is from the People Living with HIV/AIDS, other from the Sex Workers and one about treatment and, of course, the women living with HIV/AIDS in our region. And we have three of the most important networks of the national levels, and of course activists and policy makers and medical workers.

It was so impressive how we began to work because in that meeting, it was similar than when the AIDS epidemic began. There were a lot of basic questions about TB and HIV/AIDS co-

infection about symptoms because, as I told you, we were blind about this situation and it begins to increase awareness. So we have more than 143 participants in this meeting and that [inaudible] our work.

The interesting thing about our project is how we began in the national level, to make some kind of partnerships that allows us to influence the policy development and of course the policy implementation. With national TB and the national AIDS program, we began to have some kind of different partnership. Of course we have a long relationship with the national AIDS program, we were close, we know each other, sometimes we have a lot of fights, but it is common in the AIDS work and in the AIDS world. But we have never been close with the national TB program and we find a lot of political will, a lot of sensitivity. So, now we have more than one year working together and interchanging experiences and sharing many of our commitments.

So what happened after that meeting? We began to work together, increasing the number of people living with HIV AIDS and are working in this project, in this program, in this movement, because it was so interesting. There were a lot of gaps of knowledge in us about the TB issues, and there were a lot of gaps in them about the HIV/AIDS situation, particularly in the social situations like [inaudible] of a nation and many others.

So now we are co-participating in the signing for example Courses for Nurses [misspelled?] that we are having nationwide. And this I tell you because we find a lot of sensitivity in the national TB program. We can now work together really closely so we are happy about that. But we find a lot of resistance in the states AIDS programs about the TB issues. So we are [inaudible] that closeness, trying to move on the agenda with them.

And we finally create some kind of working group that came from the Stop TB Partnership from Mexico City that is working on dealing with those issues. There are a lot of political issues about, I am not speaking about NGOs working on these issues, about leadership and about commitment and we have to solve these situations to reinforce the work that we are trying to do.

In the regional level, we have a lot of awareness about the TB and AIDS situation and how they are co-related. They promise to include the co-infection in the advocacy agendas, but it is so difficult because we find that there is a lot of resistance to put something extra in the agenda even though there is no specific resource, there is not some kind of motivation. So we have to go on and to try to improve the way that we are working with the regional networks because of course they say, we have enough with our work with the Sex Workers, we have enough work with the human rights situation.

So we were thinking at the beginning that making an advocacy strategy will be so easy and helpful just to add the confection issue in their agendas. But it is not the same thing that is happening in a national level. And we noticed that we need more face to face [inaudible] to work on that.

Finally, what I want to say is that now we have a better [inaudible] than when we began to work with the national TB program and the national AIDS program to implement how policies are created and developed. And I think that we are just in the first steps to work much better at it and to have the influence of the activists and the people living with the HIV/AIDS in those [inaudible]. Thank you.

LILLIAN MWOREKO: Good morning, everybody. My name is Lillian Mworeko. I am standing in for Dr. Idium Garrera [misspelled?] and I will be sharing the TASO experience from Uganda. The TASO experience regarding TB/HIV and our involvement is a partnership of non-governmental organizations, community based organizations, and networks of people living with HIV and AIDS in Uganda. And this came out as a result of the [inaudible] that we had from the international community regarding the dangers of TB and more especially, to the community of people living with HIV and AIDS.

And again, as activist who have been involved in HIV and AIDS work, will realize that we could not sit back and wait when we knew that this was an issue of death and life, and more

especially to people who are living with HIV and AIDS. And therefore recognizing that we are talking about two diseases in one patient, it was inevitable that we have this partnership. And again, one of the issues that we considered so important was that for us to do work in TB, we needed to begin with policy.

We realize that it is that policy therefore where decisions are made regarding cooperation, regarding integration of services, and also the activities that need to be carried out in [inaudible] TB and HIV. And therefore, we said that we needed to begin with policy and decision makers. And therefore, our experience is that we have been more engaged with the national TB programs to ensure that they are [inaudible] policies in place to ensure that there is a very good working relationship between the communities and program managers to make sure that we [inaudible] their response against TB.

Now, in this partnership, what have we done? This is something that started in 2004, and so far what has happened is that as the communities living with the diseases, we have been involved in developing policies. And [inaudible] right now, we have a TB/HIV policy in Uganda, and this was developed in partnership and in consultation with the communities.

As the communities, we have carried out advocacy trainings, we have so far had six trainings in advocacy, because we believe that for us to get to engage with the

program managers, to engage with people who make policies, we have to have skills in negotiation, we have to have skills in advocacy, we will also have to have skills in public relations [misspelled?]. So that is why we have come up with these trainings.

We have participated in the [inaudible] conference that happened in our country in 2004. And as we speak now, we have representation on the National Country Coordinating Mechanism. We have two people who are representing the communities and we have also had communication strategies for TB/HIV developed because we believe that people need to know what we mean by TB/HIV and this was developed [misspelled?] with [inaudible] special.

And in this partnership, we realize that people do not have information about TB and HIV, especially information that is targeted to the specific people and in a simple language. So we have so far developed 1,250 brochures giving the situation of TB and HIV in our country, but also encouraging [inaudible], especially women who are incurring the burden of TB and HIV to get involved in this kind of work.

And last here again as TB/HIV activists, we have to know that those drugs [inaudible] out for TB and we are lacking the international community [inaudible] because we realize that if we are [inaudible] the international community, they would get to us and support us in dealing with the countries

situation. And in this way, the international [inaudible] to go to know what was happening, they joined us and later on, we had the situation at [inaudible]. But if we had not traced this issue [inaudible], it was not going to be at risk. So there is a lot that we are doing as we shall [inaudible] but one of the key messages that we would like to leave with you is that, we have learned that existing structures are very, very important in dealing with TB. And this is what we have done in our country.

And as [inaudible] forward, we recommend that the [inaudible] approach that we use to deal with HIV and AIDS, which has given us success, should be reprocated [misspelled?] for TB. And we have also learned and we recommend that we need to reprocate the best practices that we have learned from HIV and AIDS so that as we tackle TB, we are not starting from scratch, but we are learning from what has happened. Thank you very much.

PERVAIZ TUFAIL: Thank you so much. I am Pervaiz Tufail. I am from Pakistan working with an organization called National Group of TB People. And my experience is a little different from these people because I am more involved in the upper level because I am working as a community representative, and patient representative of the Stop TB Partnership. And I am also working with the DOTS [misspelled?] Benton Working Group as a core group member.

I have a little bit different perspective from my colleagues. And why I got involved in this process, this is very important for me and thanks to OSI and TAG because when I worked with them, as an ex-TB patient, I was not knowing what the TB was even, and what is happening on ground in my country [inaudible].

But when I joined OSI and TAG as an advisory committee member, I got to know what the TB is and what is happening around [inaudible] are. And which provokes me to get more into it and then I started thinking about how I can be more proactive and active, regarding the issues of the community. And with reference to the patients and community perspective, when I was working and I am still working with the DOTS Expansion Working Group and Stop TB, my major concern and my major focus is to raising patients' concerns and issues with the Stop TB, with the policymakers, and with the community perspective as well. And this was a great opportunity for me and for my community, and especially the patient who is suffering from the disease.

And being at Stop TB and as a Core Group Member, I always raise and try to focus on the patients' perspective and always try to give the patients' perspective and always focusing on the agenda of the patients and I always try to give the high perspective and always focusing on how we can be more

visible at all levels, particularly at upper levels first and at the grassroots level second.

And this was a great opportunity for me and which provided me to share what the ground [inaudible] are and how it is happening and how as the patient for community we can work together at all levels and I always advocate for patients' rights and patients' perspective whether I was participating in in-person meetings at the WHO and working groups, or whether I am participating through conference calls or through discussing by e-mails and the concern was always remain same [inaudible] we can work together and highlight patients' perspective and their issues.

My work was always focusing on [inaudible] versus patients' involvement, empowerment and advocating for their rights. It was a great opportunity for me in that I was able to participate in the global [inaudible] too and I, along with my other community people, we all focus in letting the patients' perspective, particularly the patients' involvement and empowerment, should be reflected in the global plan. And it is the pleasure of ours, this is not reflected in the global plan too, particularly the component [inaudible], which is very important for us.

And in the same time, I am new to this advocacy activity. I was able to participate in the national standard of care, and I was also able to participate in the patient charter

development, which is a very important document for us and this is one of the key documents now, which is in the global plan and in the group [inaudible] as well too, so it is another important treatment of ours.

What makes a good visibility of mine due to this upper level of involvement that I was having access to, the National TB Control Program. And I am very happy to share with you people one of the great achievements. Two years back, I had a meeting with Nester [misspelled?] TB Control Program and he said we want you to be in the Nester TB and HIV working committee. And this was a great achievement, and he also said that, we want to have you at the CCM so you can bring the patients' perspective, particularly the TB patients' perspective, in our policy level documentation.

So this is one of the great achievements. And at the grassroots level, I am very happy to share with you that I am the product of this whole process and this [inaudible] group of TB people which is the only one patient representative organization in Pakistan, this is also the product of this whole process. And this is also a great breakthrough from the people at the grassroots level that they can come together, we can sit together, we can come up with our own agenda and action plan which we can advocate at all, like grassroots level, regional level, national level and have a bigger global plan and with the WHO.

So in short, I know that I do not have too much time, the lesson that I am really happy to share, with the lesson through this whole process because this process is challenging and frustrating. Challenging like I have a pack of not many people from the grassroots level, particularly the TB patients, who are looking at me, what I am working for them, what I am advocating for them, and this always provokes me, whether I am doing justice with this title, the Community Representative or the Patient Representative, which I sometimes got very frustrated, sometimes I got very much motivated, sometimes I wondered what I was doing, always questioning myself whether I was doing right or wrong.

So within all this process, the lesson which I was learned that the consistency - if we are consistent with our cause and commitment, we will definitely get the result. Because many times, I got frustrated when I was giving calls to my National TB Control Program, I want to fix my meetings, I want to have the time, I wanted to go over there, but there was no response.

I got frustrated but I started continuing [inaudible] into, into, into, and into. And at the end, I got success. The patients are always very much that we have to be very patient as an advocate or as an activist. And the follow-up is also very important. If we do the follow-ups, we will definitely get the desired result. And most important is

management of frustration and anger. This is very much important. If we manage our frustration and our anger, like having at all level, this will be the great success to us. And thank you very much again for giving me the opportunity to speak here. Thank you so much.

JAVID SYED: So as you heard from a lot of the speakers that they have been working on various different levels and also to various different strategies. I know that, I want to invite you folks to ask questions if you have any right now. Please. And I would also invite you to unpack some of these words like engagement and strategy because I think the devil is in the detail in how we do this work.

JOSTEN AMIR [misspelled?]: [Interposing]. I am Josten Amir. I am working for AIDS Foundation East West. We are an organization working on HIV in Eastern Europe and Central Asia. We are founded in Holland. First I would like to say to organize this session because I think it is really exciting to have all of these fantastic representatives here of several parts of the world to share experience with us. But my questions are, specifically or the representatives of Georgia and Armenia.

We are trying to engage in [inaudible] in central Asia at the moment and one of the big problems, and that is, I think maybe all over the former Soviet Union, is that you have the TB system and you have AIDS centers and they do not talk to each

other but they sometimes do not even want to talk to each other. They are enemies. So how did you manage to reconcile this or to get these very different parts of the health care system, with very different histories because the TB system is old, AIDS system is new? How did you manage to get them talking to each other? I am very curious about that.

TAMARA GVARAMADZE: I will tell you about this here, how it works in Georgia. We were able to start talking about it at a CCM meeting. Because the director of Georgian Plus Group is a member of CCM and they had TB hospital and TB programs and also [inaudible] some members of CCM. And it is a good place to start talking about it. But we did not have this negative attitude from both of them, especially onto TB people part, they were weaning themselves to initiate something like a joint effort to create some coordinating body.

Although initially they were unwilling to get a community representative on this body, but eventually, we were able to convince them that it is a good idea to have someone from the community. Right now, they have just had only two meetings and I attended one of those meetings and it was really very interesting because I was observing how people on both sides were trying to figure out what they can do together and how they are going to do this.

They were using the WHO guidelines about collaborative activities on TB/HIV collaborative activities. But they were

talking about problems, practical problems that again, on the paper, everything is very logical and very good and implemental but to do it practically, there are obstacles that are very hard to solve. As an example, there is a problem of having one hospital or one institution where a TB/HIV patient can go and can have comprehensive treatment and care, both TB and HIV, for both diseases. And they were talking about how and where this department of hospital may be constructed.

And again, everything comes down to resources, to lack of material resources to implement everything. But, the good thing is that there are people who are thinking about it and are willing to solve the problem.

MALE SPEAKER: Maybe I will disappoint you because in our country, national HIV, AIDS and TB programs do not fight and the centers may not fight. They collaborate and since last year, in our country, TB and HIV AIDS issues addressed by CCM. So CCM made the decision to include TB issues and malaria also, in their framework.

So, this is a high-level tribune where TB and AIDS program managers sit together and think together and address TB/HIV collaboratively. And our project which was implemented by OSI Support, also helped to [inaudible] this joint address of HIV and TB. So, we succeed to bring together on different levels of starting from communities along governmental organizations and physicians will deal with HIV and TB and

managers level also. Even more we succeed to organize the workshop for CCM members, and finally the resolution was adopted to address TB/HIV collaboratively.

This is in the process, of course I agreed that AIDS services are more advanced in our region, I mean CIS, former Soviet Union, Constance [misspelled?] region. But TB services after global [inaudible] opportunity they became also advanced. Technicals, different supports on different levels from W2 and [inaudible] other supported organization came and they have to be advanced. So step by step, TB specialists, they improve their level, I mean in terms of collaboration, in terms of advocacy and joint activities.

MALE SPEAKER: I thank you very much, I am very impressed by those experiences and I think that countries in Central Asia and other countries in CIS can learn a lot from your experiences, so maybe we can after this session exchange...

TAMARA GVARAMADZE: I have on thing to add to the said. In Georgia, a very strong force that is driving TB forward is that the First Lady of Georgia, Sandra Roelofs is TB Ambassador, and she has sent down through the [inaudible] a great and amazing work and raising money for TB. And now we are going to have a new TB hospital and they are planning to have a TB/HIV department. So these personalities, individual people, can make a difference, if they are authorities and if they have enough political power and worldwide authority.

So you should maybe try to find someone at that level to support TB and HIV collaborative efforts. You can suggest it in this region, there will be some all ready who may be engaged in this.

JAVID SYED: I think the theme of political will is certainly something that we can touch upon again, because I think the way we get to political will, could be very contact specific. But I think it is really important in how it actually allows for certain people in power who might be resistant to actually rethink their ideas.

In relation to that, before [inaudible] take your question, I wanted to point out two documents that – document that, one of them is this one that is outside on Civil Society Perspectives on TB/HIV which documents some of the successful strategies of previous OSI grantees and then this one which looks at the monitoring of TB projects and of TB policy in five countries and also documents how civil society has engaged in improving and strengthening TB policy. And then these are the two, we will come back to later. Martin [misspelled?].

MARTIN CASTAILLANOS [misspelled?]: Thank you. My name is Martin Castaillanos [misspelled?]. I am the [inaudible] under director of the National TB Program in Mexico. My director is [inaudible] and she is here too.

Because my English is not too good, I have to write a little bit but I want to say to all of you, thanks because we

learned about the whole [inaudible] today. The fact is in HIV and TB co-infection is a big problem and this one can not be solved from the [inaudible]. So the fact is that we need to work with the NGOs, very important issue for us, the only way to see the advance in this issue is working together with NGOs talking about HIV and AIDS together.

Now, we know that NGOs working with us cannot talk about AIDS without talking about TB and we cannot talk about TB without taking about AIDS. So we are increasing the work, the task force and the human resources thanks to the AVE de Mexico, they are working very hard with us in the training courses, the Stop TB network before we [inaudible] network but now is Stop TB noticing network. And we are so glad to work together with Carlos Garcia de Leon and his team about this important issue for us and we do not have a lot of problem with the co-infection yet but we do not want a big problem about it. And that is why we are working very hard with them. Thank you.

JAVID SYED: Thanks, Martin. So, do other people have questions already? Please come to the front, come to the microphone here.

MALE SPEAKER: [Inaudible] Isaac [misspelled?] working assisted TB program on one of these [inaudible] the south eastern part of Nigeria. [Inaudible] commitments [inaudible] encompass. My question is to the last presenter, especially in the area of stigma for the TB patient cessation.

Back home, the problem that we are experiencing is that you have this high level of stigma against TB patients, even the ex-TB patients. What has been the experience, maybe in Pakistan or in the course of your working with the Stop TB Partnership, in the management of these social stigmas in the light of community advocacy, especially when you talk to the management of UNGA [inaudible]. Thank you very much.

PERVAIZ TUFAIL: Thank you so much and I think this is a very important question and with reference to the stigma [inaudible] I would like to give my own personal example. When I opened up my [inaudible] and shared that I am an ex-TB patient, my family members – we live in an extended family members in Pakistan and the marriage is very important in my country.

When I opened up the stigma and one of my family members said oh, you are telling other people that you are an ex-TB patient, you will never ever get married. So this is one of the stigma issues if somebody shares that he or she is suffering with the disease. The first reaction by the society is that he or she should be excluded from everything. The advocacy issue for and other advocated is de-stigmatization of the disease. And what we are doing, particularly at the [inaudible] level, we are trying to establish a group of people who are suffering from the disease and working with them, first

try to understand what the disease is. And the second is how we can de-stigmatize by opening up ourselves.

This is one of the issues that we did not have any prominent figure in my country who is suffering with the disease and who can [inaudible] that I am suffering with the disease. With reference to address the stigma discrimination at the policy level, at the upper level, especially with the Stop TB level, we are trying to establish the [inaudible] like we are trying to have a different kind of approach and we are focusing on the bottom of approach which is very important.

If the patient did not understand themselves, by their own, there will be no process to address this issue, and it is very important [inaudible] said that working together is very important. If we work separately, if I am working differently, you are working differently, Goman [misspelled?] working differently, and the [inaudible] working differently, there will be no [inaudible]. We are all a family and still there is a question, who is the head of the family? [Inaudible] is the head of the family, and [inaudible] is the head of the family and the patients are the head of the family.

But there is a joint effort needed and de-stigmatizing activities only can be addressed if it is awareness. And more awareness, more visibility of the patients, more understanding of the disease, more inclusive working jointly together will be addressing that [inaudible]. Thank you.

AMAZA [MISSPELLED?]: Good morning, it is Amaza [misspelled?] from Brazil. Both Tamara and Carlos mentioned something that really strikes me as concerning, the possibility of doing regional work. This is something that I would like to ask you, specifically regarding Mexico, in terms of population and complexity, the country is so big that I ask, how is that possible to do practical work, not only networking with the networks but also doing practical [misspelled?] to influence the national policies?

Actually, this is a question for all the members because this is something that I would like to ask each one of you. If you think that it is possible to do work in the regional level, the sub-regional levels, the neighbor countries. That is the main impact actually, the national policies because in terms of Mexico, I believe that the complexity of the country as in Brazil, I think that it is possible to network with neighbor countries or other countries but it is very hard to actually influence and change the policies in the country as they have to regard budget and other specifics of the health system and so on and so forth.

And then I ask Tamara also and Samvuel and Javid and Pervaiz, I know that Pervaiz has a lot of work in the regional, and how this can impact. In terms at least of neighbor countries [inaudible] of Mexico, if that is possible at least to do impact work in Central America, for example.

JAVID SYED: Thanks, Amaza [misspelled?].

CARLOS GARCIA DE LEON: Thank you, Amaza [misspelled?].

Of course, Mexico is a really complex country because it is so big and our geographical position, our [inaudible] is so uncomfortable.

A long time ago, at the turn of the century, the Mexican president says so far from God to near to the states. So, in many ways, we are in an uncomfortable way, but Mexico is the pass for many immigrants from Central and South America that are crossing to the United States. And of course, many Mexican immigrants, that is a lot of movement.

So we were thinking at the beginning of the project that we can have some kind of influence, Mexico has some kind of leadership with Central America and there are a lot of partnerships and cooperation possibilities, particularly AIDS issues. The national entities of public health based in Mexico that it is a [inaudible] institute with UN-AIDS provides us with a lot of diplomas and courses for the Central America and the English Caribbean countries.

So, there is a possibility of this kind of influence. But I have to say that in terms of this project, we try to work with the networks because we work so often with them because we are Latins more than North Americans in our culture. And there are a lot of things that we share and learn from our experiences and projects.

But I have to say that we were just in the first steps to do that. Particularly, for example, I am part of LACASO [misspelled?]. I represent the Latin American and the Caribbean region in the National Consulate AIDS Services Organizations and there is no movement in my own network. Because it is more than an awareness now we know about a problem, now we began these kinds of discussions. But we have [inaudible] of discussing it by mail with another [inaudible] that it is mentoring abolition to love the project.

So I think that we can impact a region, in the other side, we have beautiful experiences, and I say the word beautiful because they are really well. For example, the National [inaudible] and you can receive care and treatment for TB outside Mexico and the United States, and in this side in Mexico. So we are trying to think in [inaudible] society discussions, something similar to mix and work with the co-infection, probably with Central America but it is so difficult because of the [inaudible] project. Of course, every country is independent so we have the possibilities but we do not have anything as a product.

JAVID SYED: Thanks. Pervaiz, you had something to add?

PERVAIZ TUFAIL: Yeah, I think this is very important and I will appreciate that the need is to document the things. If something is happening in Pakistan, it is not documented.

And so many beautiful things are happening, I know so many movements, especially the involvement of [inaudible] people in India is going on. But there is no such document which can be shared.

And we, somebody from India, we were sitting together and there is a great idea that came up that they are planning on having a national conference involving patients from all over India and they also invited me to be there. And I am sharing my experience, what I have learned from this experience and they are also sharing their experience. And when they [inaudible] they will be doing the same exercise within their particular countries, particular regions. And I am trying to do the same in Pakistan.

So the ideas we can come of [inaudible] collective efforts, what we are doing, and this perspective sharing is a good idea. And one of the good ideas that we can have influence at the regional level that my ex-TB control program and the Dr. Corom Shahee [misspelled?], he is recently shifted to Afghanistan.

Afghanistan is a country which needs a lot and we were discussing how we can share our experiences and how I can give my input by designing, the patients' perspective and community involvement, so there should be some kind of regional things going on. But there is a need to share experience in the [inaudible] shared like this conference, a local level

conference, a regional level conference. In south [inaudible], we have in India and Pakistan, we have the same tradition, we have the same values, we have the same [inaudible]. And the thing that is also the same, [inaudible] we can share and have some kind of [inaudible] exchange programs, or experience sharing and training and exercises. This would definitely make an impact.

JAVID SYED: Did you have a question?

TAMARA GVARAMADZE: May I also comment on the regional?

JAVID SYED: Yeah, go ahead, Tamara, comment -

TAMARA GVARAMADZE: Just to answer [inaudible] question about regional things specifically. The regional sub-[inaudible] is very specific because these three countries are geographically separated from the rest of the world, so they have to stick together.

Despite the - culturally, they are not so similar, but the fact that we all were part of the Soviet Union and we have the - there is no language barrier between these countries because we can communicate in Russian. Because it is geographically very close, and there is a lot of immigration and traveling between these countries, this makes our relationships - if we even did not want to have them, we have to and as the proof of this, I can say that not only is it in the fields of HIV, AIDS or TB, people are trying to communicate

but I know that there are other regional coalitions in other fields, STDs and other medical and non-medical.

This region is always kind of considered as a unity because it has many, many common problems created by its geographical situation, by its common history and we have very similar mentalities in our countries. For instance doing our two day seminars that we hold for where [inaudible] NGOs working in our HIV AIDS field and there are no TB organizations, unfortunately, not only in Georgia but also in Armenia and [inaudible].

But those who wanted to somehow engage in TB/HIV activities during this seminar we learned that there are so many similarities a little bit with national specificities so that we can come up with some – we can reach each other because when you have many solutions or many ideas of how to solve the problem, you are closer to actually solving this problem. And that was very helpful and we are now working on raising funds to be able to organize these seminars regularly. And we hope that we will have them.

JAVID SYED: Samvel, perhaps you and Lillian, because I know that you are part of a network that works not only across Africa but also internationally. So, Samvel.

SAMVEL GRIGORYAN: In our case, we can talk about two types of two levels of regions and regional activities. First is the major regional level which is CIS region, former Soviet

Union countries region and second is a smaller region, which is [inaudible] region, three countries Armenia, Georgia and [inaudible]. So at the two types of levels, we have a different regional, joint activities and cooperation.

At the CIS levels, we have our established corporation for more than 15 years. At [inaudible] smaller regional levels, so during the last two years, we had the different regional meetings and workshops. Our CCMs would meet to discuss different issues at the CCM levels, addressing TB/HIV also, collaboratively.

We had, on HIV, AIDS issues, the W2 organized lead workshops on universal targets for 2010 setting up at the country levels and then moving toward the [inaudible]. And finally by the end of this month, W2 will organize a regional meeting at the ministers' level and the national TB and HIV AIDS program managers also are invited where TB/HIV issues will be addressed also at this high level meeting. So these steps and series of activities are implemented at regular paces.

LILLIAN MWOREKO: Okay, thank you very much. I think in addition to what is already said, it is important that now we begin engaging regional bodies that already exist. And in my case, for example, we realize that we already have bodies that are existing, we have regional networks, we have regional bodies that bring together [inaudible] and international [inaudible] but also important that we have regional offices

for [inaudible]. So these bodies at different levels need to get engaged and it is our role as activists, as advocates to make sure that they get – we hook them up so they can be part of the process.

Also, looking at this and directing it to the first question that was asked, how we can get these different groups to buy the [inaudible], begin speaking together and especially, the policy and decision makers is that, first of all, we need to get the policies that are already in place by the bridge [misspelled?] and guidelines and make sure that this policies, when they get to the different levels are interpreted to fit within the systems and structures of what is already existing.

So that we do not take these guidelines and policies as Bible truth but they can be interpreted to fit the current [inaudible] interpretation of this different groups. So that for example, when you talk about integration, people should be able on their own to decide what they understand by integration.

When you talk about corroboration, they can themselves define on what activities, what programs they want to corroborate. IN that way, they begin talking and I can assure you that what is happening at the international level, at country level, can be replicated at different levels so that we are not forcing them to work together but they can decide at what levels they want to work together. Thank you.

JAVID SYED: And one good reflection of that particular point that Lillian just made is this example that even the panelists are exemplified, is that Armenia, the work happens to the CCM so though the WHO recommends a coordinating body, but when TB/HIV was created, Armenia has decided to not actually make a separate body but just work through the CCM because it already has many of the same stakeholders there. But many other countries, they have decided to create a separate CCM so I think that is another example of how a WHO policy gets interpreted to meet the countries specific contexts. Pervaiz, and then your question, please.

PERVAIZ TUFAIL: I think into this, if we want to have a regional impact, we should have come all together with a single or might be two point agenda. And we should have one document which we can proceed and go over that. And I think this patient's chart is one of the good documents and this is [inaudible] by the WHO and this addresses all the patients and other issues. If we can make focus of this – we can advocate for this, this would be a good start and we can have a regional impact on that because this is a good document. And along with that, WHO's policy are existing, WHO has an interim TB and HIV policy. And this is also reflecting that we can work together and this is a good document to follow at the regional level, particularly at the country level, to make some sort of regional impact on that. Thank you.

JAVID SYED: Your question, please?

EFKO HOSKRE [MISSPELLED?]: My name is Efko Hoskre. I am working for Project Hope in Uzbekistan. I have a question, or more or less for all of the members of the panel. I realize that the subject of this discussion is TB/HIV in particular, but I am wondering in Uzbekistan, in Pakistan, in most countries, the vast majority of TB patients are not people living with HIV. They are TB patients.

Being a TB patient, ideally, is something you are for six months and then you are cured and that is it. A person living with HIV/AIDS will always live with HIV/AIDS. So, I am wondering, in your experience, in your associations, is there any such difference? Are just TB patients, are they participating in your associations, and is there any reluctance from their part because they think, well, in six months, I am no longer a patient, or is there equal participation?

PERVAIZ TUFAIL: I think this is a very important question and, as far as my country experience is concerned. We are not having patients' representatives, especially the people who are suffering with the TB and they are not visible anywhere. And we did not have any patients' representative organization, even. And these two approaches are going differently like National TB Control Program is doing their own, National AIDS Control Program is doing their own. And there is no connection in between.

And most of the things being done is, unfortunately by the National AIDS Control Program. And this lack of visibility is very much there. And [inaudible] stigma is [inaudible] to this TB, especially TB in my country. As I shared earlier, when I shared about myself, there not many things happening around.

But this is very important that we need to make this TB issue more highlighted at every [inaudible] particularly at the grassroots level and we should be focusing on the patients' perspective, what they are thinking about the disease and how they are feeling. And this is very important as I earlier said, last year I had my meeting with my National TB Control Program manager and he said, just come with some kind of patients' perspective and how we can make them visible, how we can involve them in our planning and ongoing actions.

But what I am doing, I am trying to make them visible in my country and we have come up with the Patients Representative Organization, this is only the TB patients organization and we have come of it our own agenda. Though we are collaborating, we are working together, but we are focusing with our own agenda and one of the coalitions, we are focusing disease awareness, about the disease and we are trying to understand, but first ourselves what the disease is and then disseminating this information broadly to everywhere. So people should understand this is a disease, this exists, and

this is a killer disease and this is a silent killer. And there should be awareness regarding this disease and definitely working together is a good lesson.

But the need is the TB people should come together, they should come in front, like the HIV people. HIV people are very much like visible around in my country. But there are no TB people there. I do agree with this, there is a need of shift, particularly from HIV to TB and TB to HIV and TB people should come with their own agenda and come together and focus on their rights and they should demand, because there is no demand from their side and they are not coming together. They are not asking for policies.

My focus is we should come together, especially the TB patients and go to the National TB Control Program, from there to upper lever, the WHO and making TB high on the agenda. Thank you so much.

JAVID SYED: I think linked with your question is also another observation around a strategy, which is that there is certain other health issues that people can get cured of but because it has been politicized around gender issues or around issues of poverty that they then become a focal point of organizing. So even if you are cured of the health issue that you are politicized through that experience and then, of course, not all patients that go through a treatment regimen will turn out to become activists, but that if you have a

politicization of the health issue, then you can actually address – get a community of activists out of that experience to see what of that experience did not meet the needs.

In India, for example, there are people who are organizing not around TB, but are organizing around poverty or are organizing around the need for access to care in their communities and making that the focal point of their organizing and then in that context, also taking on the issue of TB. So we should also be a little creative in seeing what are the priorities that communities are coming to the table with and seeing how we can integrate TB into that work. Yeah, please go ahead.

MALE SPEAKER: Thank you for your nice presentation, sir. I certainly learned from the experiences, but in [inaudible] so many advocacy activities going on, collaborative activities but I am not sure how much impact it has increasing, what we call [inaudible] counseling and testing. Especially with regards to TB patients, getting TB patients tested for HIV, [inaudible] in some settings, it is not an issue.

As one of you mentioned, TB programs is [inaudible] HIV programs [inaudible]. So in some settings it is difficult to bring these centers, or sites close to each other. [Inaudible] to testing. Because our ultimate, because until we test this patient, we know they are [inaudible] we cannot offer them much help. I do not know in your activities, if this has made a

significant impact as to increasing the acceptance of these tests. At the same time the [inaudible].

Again, I think I need to learn more from the Mexican experience especially in relation to the [inaudible] issue. We have a similar situation we are also bordered by a country and it sometimes can [inaudible] those patients, you said they put them on treatment, along the line they cross to the other end of the border where they actually leave. If I can give you [inaudible] to your collaboration with the counterparts, [inaudible] to seek continued treatment from [inaudible]. Do you have any difficulty in getting back the treatment outcome? Please if I can learn because getting them [inaudible] in the order is one thing but after completing treatment, getting back the treatment outcome.

JAVID SYED: Okay, so there are two questions there. One is whether there is an increased outtake [misspelled?] of VCT amongst TB patients. And the second one is, how do you actually manage communities that are migrant and ensure that they not only have access to services but also have a coherent surveillance mechanism so that treatment outcomes are documented? Samvel, I know you and Tamara had experiences in that. Maybe you could talk about that.

TAMARA GVARAMADZE: There is activities through our two projects, included advocacy among, if you remember I mentioned we had two targets, service providers and those who use these

services. So among communities we identified specific groups that we focused our activities on. These were militaries, injecting drug users and prisoners. And we have the figures of increased voluntary testing among all those groups.

We reached militaries after a series of lectures and we distributed booklets about the TB itself, the transmission, the symptoms, the treatment and so on and the TB/HIV co-infection, the other one was. We distributed those booklets in prisons also but we did not have access to prisons and we used our collaboration with other NGO HIV-AIDS service providing NGO who had this access. And this was our first project. And for the second project, we had such activities aimed to injecting drug users.

In Georgia, they represent the majority of HIV-positive people, 68-percent other sources say 70 or 71 so it is more than half, about two-thirds. So this is a really at-risk group that we identified, and needs to be advocated. But I do not know how many of TB patients were among those, we do not have these figures. But some of them, of course, were TB patients who voluntarily tested on HIV. In the five-year TB National Plan, one of the objectives is to test all of the TB patients on HIV because the officials in this field, they understand that this is a key point in identifying [inaudible] about co-infection.

But there is currently, unfortunately, there are no sufficient resources to test all TB patients on HIV. And if they were available, there is another issue of this voluntary thing, because you cannot make anyone to be tested on HIV. If the patient does not want it, then they will not test. So we have much more referrals from the HIV field to TB to test on TB than vice versa. This is the current situation in Georgia.

SAMVEL GRIGORYAN: According to approved policy in Armenia, VCT [misspelled?] are integrated into the existing health care services. So we can state that for the last two years, there is a significant increase in HIV VCT provision for TB patients. But of course, we can state also that this is not enough countrywide.

So our organization advocated inclusion of TB/HIV joint and collaborative activities into the country proposal submitted to the Global Fund last year and approved consequently and it is already signed agreement between Global Fund and the National TB Program as a principal recipient. And this program will be started at the end of this year and there is a separate objective of TB/HIV collaborative activities in the program. And the [inaudible] this objective all TB patients will be [inaudible] VCT services will be advised and it will be created universal access to HIV VCT services with further [inaudible] treatment maybe from the non-medical care and support provision to all people who are in need. And

surveillance system will be improved, referral system will be improved and everything is included in the program. So we hope that next year, we will complete this activity.

ELEONORA JIMENEZ: Thank you, Samvel. Carlos.

CARLOS GARCIA DE LEON: I want to comment about this issue I think it is really related with the last question that you make because it is not only an issue of testing. It is not an issue only [inaudible] from the TB program to the AIDS, People Living with HIV AIDS, and the other way. I think the [inaudible] discrimination is part of the context of both situations.

What I think is that TB is a forgotten problem, something that is admissible. That people that are living with HIV AIDS do not want to know about that issue. Because it is another kind of stigma, it is related more with poverty and with a lot of myths around the illness. So, that situation put them so far from testing from the TB issue. And for the people who are living with [inaudible] HIV/AIDS, it is [inaudible] of Latin America, sexual issues.

So this is another kind of stigma related with that. So they are people who are not perceiving themselves in any kind of risk. So these it is [inaudible] patient. Of course, the national programs are impacting them. For example they have mobile laboratories going to many cities around the country and they are testing not only for TB, also for HIV.

But those issues made us a need that is why we are thinking, work together because they should know the social perspective and we should know the medical issues that are related with that. And finally I do not know about the [inaudible] making in the bi-national [misspelled?] cart that works in the U.S. side and the cross-boarding [misspelled?] issues but there [inaudible] of that program are backward so go an attack them at the end of the presentation.

ELEONORA JIMENEZ: Thank you. Lillian.

LILLIAN MWOREKO: Before you go, thank you for your question and I just wanted to say that I think your question brings us to the fact that it is important that we have community involvement. And by community involvement, we are aware that there are people who go to HIV/AIDS [inaudible] and they do not go to TB clinics but we are also aware that there are those who attend TB clinics and are not aware of HIV. And what we are advocating for and what we are struggling to ensure that is empress [misspelled?] is to make sure that if somebody goes to a TB clinic, then NEFF [misspelled?], somebody who is attending to this person is able to bring up the information [inaudible] HIV.

To make this person aware that there is a possibility that this person could be having HIV and therefore even if they are not willing to be tested at that moment or they are not finding it comfortable to do the tests within that facility,

they can get the services somewhere else. So this is what we are trying to ensure that is in place such as that this health care worker who is dealing with TB has got information, has got knowledge about HIV. And second we are also struggling and in some— for example in our country, we have come up with community mobilization activities.

We have one of our groups called Mama [misspelled?] Club which goes out conducting drama [misspelled?] activities and they have come up with drama programs that bring out issues of TB in the communities and we believe that knowledge is power. So if members of the community level, have knowledge about what is happening, [inaudible] for example would be [inaudible] if I have TB, probably there is a possibility that I could be HIV infected, then they would sit for the services. So we are trying by all means to ensure that the communities, people themselves are empowered, have knowledge, have information and we believe that with information, with knowledge than they can be able to seek [misspelled?] for services. Thank you.

ELEONORA JIMENEZ: Thank you, Lillian. You know, in listening to your response right now it makes me think about, what are we doing in the near future and how are we going to promote this advocacy moment? And particularly with the new generation of activists, and I want to ask the panel, what are their recommendations for marinating this momentum and

promoting among the new generation of young activists in your country? What are you doing to promote the advocacy participation around TB and HIV? You can start, Pervaiz.

PERVAIZ TUFAIL: I think this is, again, an important issue, we are not having much activists, especially at the local level. And it is very much needed especially with reference to the TB patients and we have some very active people with reference to the HIV. But we did not have any TB activists and I am very much ashamed that I am the only one who is trying to raise this issue everywhere.

What I have learned from my experiences like having more and more people who can raise a voice and within that, I was as earlier said, I had a discussion with my National TB Control Program Manager and he was very much inspired the discussion and he has had that [inaudible] to come to us. We have registered patients who are suffering with TB and he said he can share that [inaudible] with me and he also suggested that I can go to the patients at the grassroots level and I can also visit different hospitals and share this information with the people.

And second level, but at the organization level, that National Group of TB People, what we are trying to do is, we are trying to find all of the patients who are willing to come out and give their [inaudible] and we are trying to develop different kinds of groups at grassroots level in different

regions in my country. Currently we are able to identify 50y TB patients who are ready to give their [inaudible]. As an organization, we are building their capacity, on three issues particularly, what advocacy is, what TB and HIV is and how they can advocate for their rights and responsibilities. And we are doing different kinds of activities currently.

What I am doing is I am traveling nationally, I am visiting different hospitals and I trying to find a person within the hospital, who is there at the hospital and want to spend his or her time, like when other people come into the hospital, he is agreed to advocate and share the information with the people. And secondly, what we are trying to do within this group of 50 TB people, we are trying to identify a co-lead person who can be a peer leader and I am trying to build a capacity of that person to work as an activist. And within this group, we are trying to have 10 active people and linking this group of 10 people with the National TB Control Program and particularly at the prevention TB programs and district level control programs so they can be involved in all this kind of activities.

And the next step which we are taking is we are trying to have our meeting with the policy makers and giving our perspective that this is the patients and community perspective, particularly the TB patients' perspective. And we are looking to have these activities, and the good thing is

that my TB Control Program Manager likes this very much and when I get back, I will try to find the time and I hope he will also be able to manage his time and we will sit together and we will be sharing, the [inaudible], with him and he is also showing his [inaudible] with me. And within that, we are trying to start a capacity building exercise at grassroots level.

And the second thing is again, I am focusing on the patients [inaudible] this is a good document if [inaudible] and [inaudible] did not know what our rights are and where are the services and where we can get these services from. This [inaudible] not be achieved and the people at the grass root level, I think one of the great problems is that the sources are there, the services are there but people did not know where the services are especially, again, focusing on the people who come from [inaudible] in my country, there are different systems— our system structure is not very much well established.

People have to stay in [inaudible] for long, long hours, waiting for their turn to get medicine. And at the end when one o'clock comes, the doctor says it is off time, you can go back and he or she has to go back. So this is another advocacy [inaudible] where and how we can establish and this development of the local activists will be definitely contributing to National Group of Advocates and then the

Regional Group of Advocates then the global level advocates. And I hope the next year, I will be coming with a team of activists from Pakistan. Thank you so much.

ELEONORA JIMENEZ: Thank you, Pervaiz.

LILLIAN MWOREKO: Thank you very much, advocacy is about [inaudible] advocacy is about having a strong voice and a recommendation for all of us is that if we have to have a strong body of activists and advocates, we need to form partnerships. And these partnerships range and should be at different levels. So we have to have partnerships with the patients, we have to have partnerships with community based organizations, non-government organizations, devotement partners and everybody. And to me this is [inaudible].

And secondly, you cannot advocate, you cannot be an activist unless you have information unless you are talking from an informed position, and therefore it is very, very important that we get out and give skills, give knowledge to especially patients or those people who are going through TB so that they can join our team. And of course, it is also important that we get these facts about TB and therefore these people need to be knowledgeable about the facts so that we are speaking with one voice but from an informed position.

CARLOS GARCIA DE LEON: I think that we are a little bit far to have TB activists, at least in our region. I think that trying to share the model from the HIV/AIDS world to the

TB world is not exactly the same thing. But what we think that we can do is to promote that more HIV activists are related and work together with the TB issues. Because I agree with some question, the TB people they feel that they are far from the illness, they will go so far, they should not make [inaudible] their lifestyle.

In the HIV/AIDS situation, it is absolutely different because of palatization of the situation because there are some kind of rewards when you are HIV positive. There are a lot of good things, being positive because of a lot of social things that are related with the illness. So I do not think that we should make the same exact thing. The other thing that I think is that empowerment is a key word in this. We have to empower people living with any other diseases. But that should create before a human rights culture, and we do not have that.

If we can change our cultures to a human rights based cultures, we will not need many activists. Because everybody can raise their hands and say I have the right for medicine and have enough awareness and empowerment and ownership of my own situation so I can raise my hand by myself. But with the young activists, that it is a very good question because most of the new cases in my country are happening in very, very young people.

So we are trying to empower them, we are trying to inform them to have the evidence-based advocators. But most of

that we have to change a little bit more of that culture. For example, changing words like patient to people living with TB, that it is obviously a need, because for example for us, people living with HIV AIDS, it is a word that – the first thing that you are a person, not someone – it is only related with AIDS. You are a person with all of your values. And finally I want to say that we have a lot of challenges and I think that people living with HIV/AIDS and the NGOs related with AIDS work are a little bit overrepresented with all of the other illnesses.

So what we have to do is to begin to speak from the health perspective, not only speaking about AIDS, not only speaking about TB, there are a lot of other co-infections, Hepatitis for example. There are a lot of issues that we have to rise. So I think that we have to continue this work, we are in the first stages – the first steps and to make social modelization [misspelled?], but I think in the human rights perspective.

TAMARA GVARAMADZE: I very much share what Carlos just said and, unfortunately, I can not be so optimistic as Pervaiz is. Coming from Georgia, where stigma for TB is so high, higher than for HIV or anything else. We can not expect creation of the TB community organization in Georgia in the foreseeable future. But, how to maintain [inaudible] momentum, it is possible still because other organizations, other forces, other people can also be very much interested in moving TB

agenda forward. Because TB is something based on the nature of the disease, it is something that may affect all of us, everyone, so civil society organizations maybe very active.

If they are made aware of the problem, some other, like I mentioned, other individuals as a TB Ambassador in our country, such in though individuals can make a huge difference in it. And also we should not forget that HIV activists, HIV community can be a driving force in this process because they have this experiences of advocacy, of community activism. And they can take on this TB/HIV issue and TB/HIV co-infection is one of the major challenges of addressing TB as a whole. So it somehow will contribute to fighting TB as a whole. So these are the ways that I can now see how we can support TB movement.

ELEONORA JIMENEZ: Thank you, Tamara.

SAMVEL GRIGORYAN: If it is already five years since [inaudible] community activists are important to the national based program the development and realization process in Armenia. TB activism is not such revealed. And there are no advanced TB activists in our country. There are no advanced community based organizations, non-governmental organizations dealing with TB issues compared with organizations HIV AIDS activists.

So our TB/HIV project was the first one which has created a link between these two issues, the community level

and [inaudible] for future TB/HIV activism in our country.

Thank you.

JAVID SYED: There are so many interesting comments, [inaudible] please come to the microphone. I did want to engage in two of those comments. One was Carlos' comment about HIV/AIDS having so many social positive things that come out of it, that maybe we should see how we can actually create those positive things for the TB community.

I personally have a person living with HIV have a hard time understanding all of the positive things and weighing it with all the things that as an immigrant I have had to also face that have not been so positive. So that is just your personal reflection perhaps and then the other thing was that TB/HIV activists can be the driving force of TB activism and just from someone who has been doing TB/HIV as the primary area of my work, I have always come to it as – from the perspective of a partnership, I feel like TB/HIV - because most of the people globally living with TB are not actually TB/HIV people.

We should figure out what is the way in which TB/HIV can contribute to this conversation but not also use [inaudible] the space so that people who are "mono-infected" with only TB do not have access to those advocacy spaces, yeah it is something that we should think about more, as to how we can contribute to create a movement that enhances supports, increases the participation of people with TB into this

conversation as opposed to only having people living with TB/HIV in this conversation. Please.

FEMALE SPEAKER: Thank you very much. I'm sorry I was not here during the presentations, but since I did not hear any of the discussions and I wanted to allude to the fact that when he talked of community involvement it is very critical, but it has to be at all levels, right from the program level because if you don't provide them with the environment, a conducive environment, or the platform for that involvement, they will just [inaudible] and what we have seen in our country. I come from Botswana with a very high range of co-infection, between 60- and 80-percent. In that situation, of course, HIV organizations are always there to advocate for TB patients because, after all, they are the majority who experience the TB.

But, I do not see a situation where it is very possible to have separate TB advocacy groups from HIV advocacy groups. Because what we are really calling for right now is the integration of the two. And it is very difficult. We eventually moved forward with a collaboration between TB and HIV in our country. But the most difficult thing is where to start.

We started with establishing a TB/HIV advisory committee at the national level, but then it was we, the TB people, or the program people, who initiated and enforced that.

The HIV site is the least bothered about TB because even when you go to them and want records of those people who are on [inaudible] who have TB, they won't even have those numbers. They will say go to the TB program.

And yet, TB is one of the defectors or causes of death among their people. So it is very important that we the TB program, we stand up and make sure that this strong collaboration which trickles down to the district level and even to the facility and community level. Thank you very much.

JAVID SYED: Thank you very much for that comment and for your leadership on the country level. That is really amazing. Do people have any response to the comment? Yes, Lillian?

LILLIAN MWOREKO: Thank you very much for that comment and I think the [inaudible] on that is that, that is the reason why we need to have the communities mobilized. That is why we need to have people who can advocate, people who can [inaudible] to the HIV community to work together with the TB community.

Because evidence has shown that when people demand, when people push, when people force, especially their recipients, there are good results, and that is where we need to come in as activists, as people who are living with the diseases, to demand that basic collaboration, to demand that

there is an integration at different levels. So that is where our role becomes very, very critical.

PERVAIZ TUFAIL: I think having a collaborative board is a good idea, but, before that, we have to have people who can give their faces and what we are missing at the grass root level is the patient suffering with TB. Especially in my country, we did not have any face, and until and unless we have face, we can not make the momentum. And for building the momentum, we need activists.

We need people who can work as an active person who can advocate for their rights. And again, focusing awareness is not there, stigma is attached and we are not having very much collaboration. There is a gap between the community people and the policy people. And the National TB Control Program is doing their own. Their voice is not there. The community voice is not there. Patients' voice is not there. Patients' perspective is not there, and until and unless [inaudible] we did not have an active group of people who were ready to advocate for their rights. We were not getting that same momentum. And the need is very much there that we should have the people.

Identification of the people, for me, this is very important, identify the group of people and making them aware that, look, this is our cause, our disease and until and unless we do not get together, we will not raise our voice. We will

not demand our rights. We will not demand for medicine. We will not demand for health services. There has been no, no, and no change. And, unfortunately, there is no TB/HIV policy in my country. There are no community involvement guidelines there. There is no community perspective there, so as an activist, we have to do a lot. And as an active advocate, or activist, I am a role model for so many people. And what I am doing is a great example for others, like we all are a great example.

We have many people around here and the thing is we should come up with some kind of joint strategy which goes straight to the grass root level in getting people at grassroots level and keeping them there; getting momentum, focusing on TB first, then going to TB and HIV, then going together, then having collaborative bodies; then starting movement at grassroots to national to global level.

And this is very much important. We need more people. We need more faces asking and demanding for rights and services. Thank you so much.

JAVID SYED: I also have a disagreement with that comment, because I actually think we need to work concurrently where the problems arise. I do not feel like we have to focus first on TB, then on TB/HIV, and then first start from the local, then the national, then the global. I think one of the realities is that there are various opportunities that arise in

different places and there are issues that arise in different communities.

One of the ways we have come to TB/HIV is just from realizing that TB is the major cause of death among people living with AIDS. Are we going to wait for a TB movement to happen before we start doing TB/HIV work? It does not make sense, and, actually, your example is the prime example of how without a grass roots movement we still can engage on a global level of advocacy and use the credibility that we build as advocates on the global level to leverage and create that kind of greater momentum for TB on the grass roots.

I do feel like we have to be more – even opportunistic in some ways, but just more responsive to what the issues are and where we can ensure that people who are infected and affected by either TB or TB/HIV get the services as soon as possible. Prevaiz, you had a response, and then Lillian.

PERVAIZ TUFAIL: With due respect, I am not agreeing with this approach. Like I do agree with that, if I call myself a global activist, whatever am I doing? I am trying to get more and more people at the grass root level and my approach is that until and unless TB people are not visible, there will be no desired results. And the force is there at the ground level. Definitely we can not work alone. We need global people. We need grassroot people. We need national people. But the most important people are the community

people, and the people who are suffering with the disease. If they are not active, they are not involved, there will be no result.

JAVID SYED: Lillian.

LILLIAN MWOREKO: Thank you very much. I think the approaches and strategies have to be different depending on different countries, different regions, and also looking at where each country is. But, of course, one of the things that I've been reflecting on is that, why we talk about all of this? To some people it is a job. To some people it is an accomplishment. To some people it is a duty. But when it comes to the person who is living with the disease, it is the passion. It is a commitment, and I just want to give an analogy so that you can understand what I am talking about.

At one time we had a chicken and a goat and they were asked to make a contribution at someone's wedding. And when it came to the chicken, it gave an egg, and that was a contribution. But when it came to the goat, he didn't have an egg to give, but it had to give its own life, and this is what it had to say, "[inaudible] is a contribution. To me, it is a total commitment." And this is what we are going through, so to that person who is living with the disease, to that activist, to that advocate, and to you who are seated here, it would be the passion that is driving you. It could be the commitment, and a total commitment, but to some, it would just

be a contribution. And, therefore, we need to be guided by all of this. We need to understand as we engage, as we get involved, that we are getting to a world where somebody needs to first of all understand, whether it is going to remain a contribution or do they have to offer the total commitment probably by [inaudible].

So, these are issues that we need to be guided by as we get engaged and as we [inaudible] advocate for integration, as we [inaudible] and advocate for collaboration. And that is why at the beginning I said that it is very, very important to give people opportunity to discuss amongst themselves how, and when, and which strategy they want to use in looking at all of these issues.

JAVID SYED: Thanks, Lillian. Are there questions from the floor? I was also wondering if [inaudible] or Lillian was saying, if the panelists had any questions for the audience?

PERVAIZ TUFAIL: It is not a question. It is a suggestion. When you go back, take this [inaudible] with you. Copy [inaudible] around, I hope, and try to translate this into local languages and disseminate more and more information to the people at the grassroot level. So this is one way forward that we can create more activists within the community. Thank you.

LILLIAN MWOREKO: My question goes to if we have any national TB program manager or AIDS manager, I would like to

find out how and what are your expectations of us as representatives of the communities living with the diseases. How would you want us to get engaged so that at the end of the day we can all achieve our common destiny, our common goal?

JAVID SYED: Any NTP [misspelled?] managers? Martine, do you want to answer the question? Okay. The question was, Lillian, you can ask the question.

LILLIAN MWOREKO: My question is that from my own prospective, we are all striving to achieve a common goal. We all have a common destiny. So as a program manager, what do you expect of us as communities or representatives of communities living with HIV and AIDS, what do you see as our role, and how do you envision us working together in partnership with you so that we can get where we want to get?

MARTIN [MISSPELLED?]: As I told you before, it is not possible to the government to solve the problem from the government perspective, so we need to work together. Fortunately, Mexico will have a lot of NGOs working with AIDS. I think all your countries have groups like that, but we need to share experience, to see the plan, because a lot of her workers do not know of the magnitude of the HIV/TB problem. So even the bi-nomial [misspelled?] HIV and TB together.

So that's why we started two years ago with the initiative, Stop TB partnership in Mexico. What group is the TB/AIDS where Carlos Garcia de Leon is working in? So from the

government, we have started an initiative to install the Stop TB partnership and the Stop partnership has at least 5 working groups and each working group works hard separately and at least twice a year we [inaudible] the experiences in the working world as a money [inaudible] and immigration. So that is why we can do it, because we delegate the problem in different kinds to the different working groups.

And the working groups it is essential to work with the NGOs. So [inaudible] to the people who know about it and NGOs, the activists, they know a lot of how to empower people living with HIV and TB, mostly HIV people is empowered us, everybody says this morning. But we need to empower TB people in working groups and we are thinking when we are going back to our country to do it. Of course, I think in the next conference, we are going to bring some experiences about working groups of TB patients empowered.

JAVID SYED: Thanks, Martin. And also, from Mexico it would be great for the next AIDS Conference, which is going to happen in Mexico, to also have a much stronger visibility of TB/HIV. So that another part that Mexico can contribute to. Go ahead.

AZIR [MISSPELLED?]: I would like to just share the experience that we had a couple of years ago in Rio when the head of the TB program asked me to try to create a strategy to mobilize society for TB and I made a mapping of the

organizations and the populations most affected in the State of Rio and then I invited most of these organizations people who were working with this population to a series of workshops. And it was incredible, because the participants sometimes vary from 60 to 85 participants each and there was not a single person, not a single person or a participant meaning groups of women, sex workers, prisoner population, street population, street children, [inaudible] HIV and AIDS, the State of Rio's [inaudible] the worst situation in Brazil. And we had a huge number of organizations, only black women organizations, all sorts of communities and many in slums, associations of people living in slums, [inaudible].

It was incredible because everybody had stories of people who work with them, most of them had stories of people in the families, and despite the incredible quantity of cases and experiences, TB continued to be invisible. I don't know, how can that be invisible? But since we started this workshop in 2003, the spread of information went in such a way and we built a form of NGOs fighting to be in the State of Rio which has over 80 organizations and it works incredibly fast and with diverse populations, with prison populations, street children, in many slums they have diverse strategies to mobilize society, identify cases, bring them to the services, and try to help in the treatment of [inaudible].

And this initiative, which has a real community participation, and the meetings, there is a monthly meeting of all of the organizations, and they are boiling with information and people in participation, it is very, very exciting. The forum of AIDS, it was without any money, it was without any support. It is incredible because sometimes I get astonished at myself, because it doesn't have financial support from anybody, but they just work together. It is incredible.

It is a real community initiative and it has started from an initiative from the state, under the state program of TB. They have decided to make this mobilization. What we have to do first of all is raise consciousness. Because populations sometimes have a problem and they can see the impact of the problem. I mean, the majority of people with AIDS do not acknowledge that TB is the number-one cause of their death. And you have to face the problem. And it is extremely productive to work with TB and it is extremely cost effective because it is a cheap treatment. It is very cheap. And then you reduce morbidity and mortality on an incredible scale.

So, it only has advantages of doing that, but sometimes it is simple, the fact that you bring awareness and then things go by itself as it happened in Rio.

JAVID SYED: Thanks, Azir, for that really sort of practical demonstration of how we can do community building.

MOSABI JALLO [MISSPELLED?]: Right, I am just trying to respond to [inaudible] or from you [inaudible]. Of course, looking at the magnitude of the TB and HIV, especially in our sub-region, I can say for sure it has gone beyond the scope of MPP or MSEP's, hence the need for partnership, the need for involvement and participation of all state [inaudible] especially activists or advocates, socio-groups like you. You can play a very, very big role...very significant role.

Of course, we have seen from your experiences you have shared with us that, but what we expect from you, speaking from a point of MTP Manager or senior personnel, is to intensify your advocacy activities. Right? This [inaudible] calls for partnership, of course, you can play a big role especially in relation to promoting (inaudible) awareness, promoting awareness among people who are affected. Right? Of course, you can also improve the [inaudible] rates, especially in relation to TB and, of course, HIV, as well as the uptake of where it is.

We have seen in some settings that this would be provided but the uptake still remains low so it goes beyond advocacy to raising awareness. But tell them that the services are there, and if you get tested, the benefits are there. [inaudible] are there. Other [inaudible] are there, such as

[inaudible]. My only worry is, as I have seen in some settings is the division that we have seen among advocacy groups. It is very, very important for you to ask to speak on behalf of the faces. To give them faces, to make their voices heard, to advocate for them so that they can access quality service. You should also come together, avoid forming so many groups, because this can be what we call "infighting" or "conflict interest" as we have seen in some settings.

It is very important for you to come as groups or [inaudible] has already said that you can [inaudible] alone. Make sure you come as groups. Get all that you need from NTPs or NSCPs in times of support. It is [inaudible] as possible very important for you to get involved, to get relevant information, to be updated with what is going on, because you are presenting the people at the grassroots. Right? So that if you are in one voice, if you speak in one voice, avoid division, you can always get what you want from MPPs [misspelled?]. But if you are divided, MPPs[misspelled?] or NSCPs will be confused in terms of who to support.

Hence, it is very important for you to come in a single file, in one voice, with common interest, with common focus, with a common goal, so that MPPs[misspelled?] or NSCPs better understand you as a group.

JAVID SYED: Could you also please identify yourself?

MOSABI JALLO: Oh, sorry, I am Mosabi Jallo. I am representing the NTP of the Gambier.

JAVID SYED: Of Gambier?

MOSABI JALLO: Right, the Gambier.

JAVID SYED: Thank you so much. Carlos, you had a question?

CALOS GARCIA DE LEON: It is common around what you are saying. I understand I do NOT want to be a personal of the government, to all the NGOs and all their thinking ways that we have. I understand clearly the need that you have. But on the other hand, there is another way to read that. I believe a lot in diversity, diversity OF thinking, diversity of understanding a problem or situation or something like that. So I know that it is more complicated. But sometimes it is impossible to have only one voice. I want to be clear that I do not represent the Mexican grass roots living with HIV/AIDS and probably TB. I am representative of some groups, but all the gender issues that are affecting more women, for example, I understand them, but I can not talk about them.

So I understand that for the national programs in TB and also from AIDS, it is so difficult to hear many voices, but that is the way that we have to understand our communities. Our countries are complicated, are complex, so there is a lot of diversity in them. Many times you have to hear many, many voices to understand it, and with a little bit of the passion

that she was talking about, work will be easier. Of course, sometimes NGOs and organizations and movements should find a way to have a good dialogue and have a lot of dialogue, probably putting all together their needs, and that is the best way.

We have extraordinary examples, for example, from Brazil in a region in Latin America. They have a national forum of NGOs and they discussed this and finally they went to the government with one position. Many voices, one position. That is how it comes.

JAVID SYED: Thanks, Carlos.

TAMARA GVARAMADZE: One thing you were very right that you mentioned that we should provide information to our constituencies to communities about where they can get services, tests and what is the procedure? We did exactly these within the frame of our first project and one of the booklets provided the addresses and telephone numbers of the centers where people can go and get free TB testing and other services that they need and care. So this was really very useful.

Because when you talk about the co-infection and the threat of co-infection involving other negative things that may follow this, you should give some practical advice on what you do if you discover, or if you even suspect having TB, what are you practically doing in your life? And to seek this

information, we went to NTP managers and got this information from them.

JAVID SYED: Thanks, Tamara. One thing, just in doing this work, one of the things that we have experienced is that oftentimes communities contribution to decentralization of DOTS which is increasing uptake, early case finding, increasing communities' understanding of the services, is the safer area that entities seem to understand the role of communities significantly. But when you talk about communities being significant contributors to policy formulation, for example, or sitting around the table to decide on how resources need to get allocated, or evaluations need to get prioritized, that is when some of the challenges really come up.

Because then, you know, in our history, that has been more difficult for NTP managers to understand the contributions of communities on that level. So, one of the things that I would like to offer to all of the NTP managers as well as for us is to be clear about how we can contribute to that process as well. You had a question?

BEATRICE STICKERS [MISSPELLED?] My name is Beatrice Stickers from the [inaudible] Tuberculosis Foundation and my question concerns the Eastern European and Central Asian regions, so I would like to address my question to those people. And, in that region, I think the advocacy ought to be

pointed as much towards the professionals more than perhaps even the politics.

I mean, if the professionals are not yet convinced in many countries about DOTS strategy – I am sorry, I was not able to attend the presentation, so if that was already addressed then please tell me not to. I would like to ask you specifically how the role of civil society can be most forceful and then the role of patient groups. How they can most address these professional people to change their ways of thinking about TB treatment?

JAVID SYED: Thanks, Beatrice. Recognizing that we only have five more minutes left, why don't we respond to Beatrice's question and all of the presenters also use the stand to give your closing remarks and thoughts because her question actually creates a platform around how can communities actually contribute to increasing, not just the political awareness, but also the health care services resistance to doing better around TB/HIV?

TAMARA GVARAMADZE: With regards to Georgia, I would not say that there is a resistance on the part of medical professionals because I witnessed that they have continued training of medical staff for DOTS parts and the coverage of DOTS is almost 100-percent in Georgia and we have very good results of treatment successful. So, however case detection is not as good as it could be at this time. What was the next...

[INAUDIBLE]: Closing remarks-

JAVID SYED: Actually, let's answer that question because there was another question and then we can do the closing remarks. Does anyone else have a response to that question? Samvel?

SAVEL GRIGORYAN: You know, a country for TB patients or strategy for TB patients is widely accessed and there are TB treatments that are not such widely exist, but we plan to create a wide access for an [inaudible] TB treatment in the French and global fund supported program for TB/HIV co-infected people HIV [inaudible] treatment is available through a global fund and state budget-limited resources, and so, that is all I have.

JAVID SYED: The final question and then quick wrap-up remarks. And keep it short please, because we have only one (1) minute.

JUAN FRANCO [MISSPELLED?]: Thank you very much. I am Juan Franco [misspelled?] from Uganda. I have a question directed to Pervaiz and then one to Lillian. First of all, Pervaiz, I know I believe in patient perspective, but listening to the debates that have been going on, especially [inaudible] Carlos' discussion, emphasizes various perspectives. He talks about human rights perspective, health perspective. Is it possible for you to strike a balance between provider perspective and the patient perspective? Yesterday, we

listened to a speech where they said, for instance, that some of the providers have to have HIV. Thirty-percent of them did not test. There is that kind of need to strike a balance because if you advocate for only balancing towards the patients, I see a problem, personally as a research [inaudible]. To Lillian, my question is simple. You talked about mama clubs, those mainly the women. I am wondering whether it is not just tuition. Whether there are father clubs, dada clubs? Thank you very much.

JAVID SYED: Thanks.

PERVAIZ TUFAIL: A short answer due to lack of time. I think this question is very much linked to the previous question and the patients' perspective and health care providers' perspective; both are very important. And the focus of the patients' perspective is that they are the end commodity I would say. They are the end result. And until and unless patient [inaudible] understand, they will not demand [inaudible]. And with the health care providers' perspective, I will share the experience with my country.

In my country the doctor did not understand what the medicines are, especially when the child with TB comes. They did not have prescribed medication; they divide a tablet into 4 halves and say OK this is yours. So they did not understand what the prescription for the children is, and they did not [inaudible] and the need is always there.

Coming to your question, the patients' perspective is very much important for me because until and unless the patient did not understand what [inaudible] are, they can not advocate; they can not ask for information if they did not know what the disease is when they go to the doctors, health care providers, they can say, they can demand, okay this is our right, you have to give this, this, and this. Is this the right prescription or not?

The lack of information is still there and until and unless we did not work on the lack of information, we will not get even patients' perspective or even health care providers perspective. But the need is very much there as Javid said and everybody is saying, the need is there to work together. But the focus [inaudible] and if [inaudible] it should be our focus. Whether it should be the patients are focused or the health care providers' are focused or whether the community people are focused. So getting together is very important and the results should be the desire when we go together, work together, and do the same thing. And until and unless we do not go together, we will not get the desired affect.

JAVID SYED: Thanks, Pervaiz. Lillian?

LILLIAN MWOREKO: Thank you very much. Why I mentioned mama's club, is these are the groups that we have started with to look at issues of TB and TB/HIV. But of course, again I realize that even globally we don't have so many men

associations. And we are encouraging men to come up with their groups and associations and I am happy that in Uganda we already have one for men who are living with HIV and AIDS which is called [inaudible] Men's Union. But we call upon everybody, especially the men, to come up with their groups, because these are issues, the reason I think why we are having all these challenges is that men are not getting involved. So we need to have men involved and the way is to have them form groups.

JAVID SYED: So with really brief closing remarks because we are running already overtime, and so if you do not have closing remarks, that would be lovely, but if you do have closing remarks, we would want to give the panelists a second to do it.

PERVAIZ TUFAIL: Just very short, just one comment. Involvement or engagement of people with TB and TB/HIV, both are very much needed and we all are focusing with reference to the patient's perspective and until and unless they are not involved in policy, our program designing, implementation and monitoring, they will not be the desired result. The need is there to get community and TB patient and TB/HIV patient perspective and in collaborating with all kinds of ongoing activities, there would be definite [inaudible] result.

JAVID SYED: Thanks, Pervaiz.

TAMARA GVARAMADZE: A continuation of this. I would say that nothing is as important as raising the awareness of

the general population and reaching as wide as possible. Because everyone needs to be aware of this problem of TB and HIV and co-infection of this kind of global problem need to be discussed at various levels and it should be made as inclusive as possible starting from schools, youth, and other kinds of population, TV and radio and other media is a very good source of it and they should be widely used. And maybe for advocacy there is a good chance to always remember these kinds of things would be included in their project and their activities.

JAVID SYED: Thanks Tamara. Samvel.

SAMVEL GRIGORYAN: TB is the leading killer among HIV infected people. Therefore, TB/HIV programs must be collaborated. So my message to future activists is to be active, work hard, and make decision-makers promises and the voice of afflicted infected communities and people who are in need of real actions. Thank you.

JAVID SYED: Thanks, Samvel. Carlos.

CARLOS GARCIA DE LEON: Just a few words about, once again, diversity. I agree that we disagree so we can debate many, many other things. But the point is we have a lot of common things, a lot of common issues in the HIV AIDS situation and the TB. For example, [inaudible], so we have to share a lot of our information and to share the table of decision/policy making process. So, let's try to put their

communities, professionals, policy-makers, and, of course, enough funds to be efficient in this fight.

JAVID SYED: Thanks a lot, Carlos. Lillian?

LILLIAN MWOREKO: We thank you so much for all of the contributions that you are making at different levels. Of course, we need each other, we need to work together, and the challenge is big, but together we can make a difference. Thank you.

JAVID SYED: Thanks a lot, Lillian. The last thing I wanted make was, this report, it is around resource mobilization, which is another aspect of community contribution to TB. And this one is a documentation of how much research for TB R&D got funded for 2005 and it is less than \$400 million globally. So with that, I want to give a round of applause to all of our panelists and to all of our participants. Thanks very much for coming on this beautiful-

[END RECORDING]