RECAP with the RBDCOV Community Advisory Panel | How can we engage youth in Research & Development initiatives?

ReCAP is a series of interviews with the members of the RBDCOV Community Advisory Panel that will explore the world of community engagement in EU projects and the importance of including people living with immunocompromising conditions in clinical trials. Our guests for this interview Lungile Jafta, Youth Engagement Consultant at PENTA and Maka Gogia, EATG member and member of the Community Advisory Panel for the RBDCOV project.
Let's read this interesting conversation about youth engagement in R&D and clinical trials. Thanks to Maka and Lungile for having accepted this exchange invitation and for sharing their expertise and knowledge with us. Let's get started!

LUNGILE
Good morning Maka. Nice to be here with you. Could you start by telling us more about the RBDCOV project and the role of the CAP in it?

MAKA
Good morning, Lungile. Likewise, it is a pleasure to exchange with you about such a relevant topic!

Within the RBCOV project, we, as community members, were part of the Community Advisory Panel (CAP). We were actively involved in developing research protocols. We had intensive online and face-to-face meetings about ethical issues, participant safety, data collection methodology, data protection, and community-informed decision-making before involvement in the study. We reviewed questionnaires, follow-up forms, and contributed to drafting participants' information materials and consent forms to ensure accessibility. CAP members provided individual comments and suggestions, which were collected and sent to the study organisers.

I think that our involvement as community representatives is very important and that we can divide it into two components or steps:

The first step is educating people about the advantages and disadvantages of participating in clinical research. RBDCOV is one example where we provided information in an easily understandable way through communication materials. The second step was for clinical trial sponsors to effectively communicate their work, how it will benefit the entire community, and how to invite the designated population needed for a particular study. I think the roles of community members during the development of new vaccines and medicines should include setting priorities, defining the study population, and explaining why certain populations, such as those with chronic conditions or young people, are needed.

Horizon2020
European Union Funding
for Research & Innovation

Community members should participate in the broader dialogue happening between authorities, researchers, and patients during study preparation, before study initiation, during study implementation, and even in providing feedback about the study results. Even if the clinical trial product is not successful, participants should get feedback about the trial's outcomes.

Furthermore, we should also ensure the confidentiality of participants, whether they are considering taking part, have completed the study, or have quit. This is an important component from the community perspective. Additionally, the study organisers and the supervising committee should ensure informed decision-making throughout the study, sharing first-person patient experiences, identifying risks and benefits, and understanding the patient-relevant added value.

LUNGILE
Thank you, Maka. That was very interesting. I can see that you've done a lot of work in the RBDCOV project.

But from the perspective of youth engagement, we find that clinical trials in the past have only included youth and children as participants. This has eliminated or blocked much influence from young people and their opinions about clinical trials. This might be because young people are considered non-professionals, so it is assumed they wouldn't have much impact or information to help build or influence the trial. But we have found that if you engage and educate young people correctly, they can provide input that is very beneficial to the trial.

One key thing Maka spoke about is education. It is crucial to educate children and adolescents about what they are engaging in. I know it's challenging because when you're talking about youth, adolescents, and children, you're dealing with a vast age group. Their maturity levels and understanding vary. What you say to a seven-year-old, a 14-year-old, and an 18-year-old can differ. You always have to find a middle ground so that the information is clearly understandable to a seven-year-old but also comprehensible to an 18-year-old.

In my opinion, once you've educated young people to understand what a clinical trial is, they may have valuable input at the beginning of the trial, which can benefit other young people. They have lived experiences that clinical trial managers do not have. Young people bring a unique perspective, especially those living with immunocompromising conditions like HIV who have participated in trials. Equipping and empowering them can bring a lot to the table. Therefore, they should be involved not just as participants but also as youth trial board members or even trial steering committee members, where their input can be very beneficial.

MAKA
Thank you, your perspective as a youth engagement consultant is really interesting for projects like RBDCOV.

I will add that RBDCOV was the first serious study I reviewed that included children and adolescents in clinical trials. While reviewing this protocol, I wanted to highlight the importance of the rights of young people and adolescents, ensuring they were informed about the project and made informed decisions without being coerced. Like the community, they should also receive feedback on how the study is proceeding.

In terms of recruitment, different strategies can be used. One strategy I used in my research was a peer-driven intervention, where peers provided information about the trial and conducted mini-trainings on the pros and cons of participation. They could recruit other peers and supervise their involvement. This method works well for key populations, marginalised groups, and vulnerable groups and can be applied in studies like the RBDCOV project.

LUNGILE
In this regard, what challenges did you experience, Maka, involving youth in a clinical trial, especially since it was your first time working with them?

MAKA
The biggest challenge was the lack of interest in participating in clinical trials. Young people often think trials are only for older populations with serious health problems. They have different interests and lack the lived experience to understand the importance. This lack of information and properly provided information can result in barriers to engaging young populations in clinical trials.

LUNGILE
Can I ask, what languages were you using locally? Most scientific information and clinical trials are written in English. Did you translate the materials? Was the translation easy? And I'm asking you this because with our local languages, when you translate from English to our local language, it's so difficult. And some of the words are not usually used, so it doesn't translate very easily. How did you find that?

MAKA
I must say that the language barrier is crucial. It becomes a significant hurdle when only one language is offered for study participants. Local context, including minority groups, ethnic minorities, and migrants, must be considered when planning studies for all populations, especially young people who may lack the motivation to read designated information on the internet. Time constraints are also a factor. Therefore, information should be presented in an easily understandable manner, ensuring clarity and comprehension for all participants.

In addition, it's essential to consider participants with cognitive challenges who may struggle to process provided information. Caregivers must ensure that information is conveyed in a way that respects participants' rights and facilitates informed decision-making.

LUNGILE
We face similar challenges in South Africa, where we have 11 official languages. I work with youth trial boards across Africa, including Uganda, Kenya, and Zimbabwe. The local languages are significantly different from English. Translating even simple terms from English into local languages often results in lengthy explanations. Unlike fluent English speakers who understand scientific terms in informed consent documents, youth often require simplified language. This simplification process involves not only translation but also ensuring that no information is lost. Youth must be educated about clinical trials, including basic concepts like injection or side reactions, which they may not understand initially.

The scientific jargon used in information sheets and patient leaflets, often extensive and complex, poses challenges. These documents, which can span 20 or 30 pages, are overwhelming for young people, regardless of age. Therefore, it's crucial to not only summarise and translate but also make them youth-friendly. Communication methods such as Zoom or WhatsApp are vital for engaging young participants, particularly in regions with limited internet access. Providing alternative ways to access information, aside from traditional contact methods, ensures inclusivity and participant safeguarding.

In some countries, cultural norms discourage youth from questioning authority figures, such as doctors or nurses. This can be an obstacle to participation in clinical trials. Educating young people about their rights as trial participants is essential to empower them to ask questions and make informed decisions about their involvement.

Moreover, access to technology remains a challenge in many regions, limiting young people's ability to access trial information via websites or phone numbers. Tailoring information delivery to local contexts and ensuring accessibility are crucial steps in bridging this gap.

MAKA
When you mention access to technology, are you referring to gadgets that people can use to enter information themselves while participating?

LUNGILE
For example, sometimes, on an information sheet, they'll provide a phone number or website for queries or reports. However, in our third-world countries, many people lack internet access. When drafting these clinical trials, we must customise them for each country to ensure that even young people in less-developed regions can access the same information. This might include providing toll-free numbers or setting up a system at clinics where they can leave a note and receive a callback. It's crucial to make information easily accessible without assuming access to technology.

And from your side, Maka, how do you bridge the gap of language? How do you adapt scientific language for the young population in your country?

MAKA
In my country, we consider language barriers when planning studies in specific geographic areas with minority populations. We use local languages and create informational materials that are accessible to ethnic minorities. These materials include contact information for questions, making it easier for them to follow up.

LUNGILE
We also simplify complex scientific language in our information leaflets for adolescents and young adults. Rather than simply translating, we ensure the content is understandable to younger audiences by using clear, straightforward language. For instance, we refer to ARTs as "HIV medicine" to enhance understanding among young participants, because a seven-year-old doesn't need to know what ART or ARV is but if you use HIV medicine, they know what you're talking about. By summarising and simplifying lengthy information sheets, we ensure that young

people grasp essential details about the trial. This approach respects their need for clear, concise information to make informed decisions about participation.

MAKA
Absolutely, you are right. Simplifying language and avoiding jargon are critical to ensuring broad comprehension, not just among young people but also across diverse audiences.

As we have mentioned, information needs to be clear and accessible for young people but also for their parents and guardians. I would be interested in knowing a bit more about the strategies you usually use to share information about clinical trials or vaccine trials.

For instance, children and adolescents should receive tailored information on the specific diseases and treatments targeted by clinical or vaccine trials. This information should be presented in clear, simple language, avoiding medical jargon and abbreviations. Typically, we print such materials and distribute them directly during our training sessions. These brochures also include contact information for further questions or queries. And you? What would be your strategies?

LUNGILE
Thanks for your question, Maka.

In our approach, through consultations with young people, we have implemented several strategies to simplify information and enhance accessibility. Here are our initiatives:

- Simplified patient information sheets: We've simplified the language to make it less scientific and more understandable for children and young people. We also use cartoons to illustrate complex concepts.
- Posters: We've created concise, youth-friendly versions that summarise trial information or results.
- Videos: We've developed various videos for sharing results on social media platforms and educational videos to explain complex concepts such as PK (Pharmacokinetics) day.
- Pamphlets: Our colorful pamphlets engage young people with simplified language and concise content.

And last but not least, I would like to know, in your opinion, what kind of considerations are needed to set up a Youth Advisory board with children and adolescents?

MAKA
I believe you could provide a more comprehensive answer, but in my opinion, it's crucial to consider diversity within the youth board—including ethnic groups, genders, and individuals with disabilities. Caregivers and psychologists should also be included on the board. Additionally, board members should undergo thorough training to enhance their expertise in this specific area.

In your opinion, what factors should be taken into consideration?

LUNGILE
I agree with you that the Youth Advisory Board should reflect the diversity and demographics of the local region. It's also crucial to consider age; we work with young people aged 15 to 19,

allowing them to serve until they turn 21. We exclude young adults aged 21 and older because their challenges differ significantly from those in mid-teens.

Accessibility for young people is another important factor. We employ a hybrid model, with some meetings held in person and others online. Physical meetings are scheduled during school holidays to facilitate attendance. Digital meetings are reserved for global gatherings involving youth from various countries.

However, access to digital technology remains a challenge for youth in middle to low-income countries. To address this, we provide tablets and data plans so they can participate in online meetings. Although there's a risk of theft, damage, or misuse of these devices, the benefit of their participation far outweighs these concerns. When working with underage youth, obtaining parental permission is essential. It's also critical to educate recruited youth about clinical trials so they can effectively represent their peers.

MAKA
Thanks a lot for your insights on how to make clinical trials more youth-inclusive, it has been a really interesting exchange!

LUNGILE
Same here, it has been a pleasure, Maka. Thanks for your time!

Disclaimer: This activity was developed under the RBDCOV Project, which has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101046118.