RECAP with the RBDCOV Community Advisory Panel | Considerations on Accessibility in Clinical Trials and EU-funded projects

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 are Mona Sundnes, Patient Advocate, and Jenny Camaradou, Grants Writer/Knowledge Exchange & Patient engagement, and members of the Community Advisory Panel for the RBDCOV project.

Let's take a deep dive into making clinical trials and EU-funded projects more accessible. A big thank you to Mona and Jenny for sharing their lived experiences and for accepting the invitation to exchange views, expertise, and knowledge with us. Let's get started!

Interviewer: *Hi Jenny and Mona, thank you for taking the time to be here with us today. Let's start from the beginning. What does accessibility mean to you?*

Jenny: For me, access and accessibility are two different but related things. The former describes more concrete concepts, like physical access to a building, a car parking space, a toilet, or a transport modality such as a train. The latter involves employment and organizational attitudes, which can be influenced by cross-cultural issues as well as general disability accommodations.

A lot of disabilities are not visible. Often, people living with a range of autoimmune conditions or who are immunosuppressed experience symptoms that affect their quality of life but are not immediately apparent, such as pain and fatigue. They may not appear to have immediate access needs because they aren't using a walking aid or wheelchair. However, this doesn't mean they have the same capacity to walk as far as others. Their condition may fluctuate—one day they can manage, and the next, they can't be due to flare-ups. For example, they may need a cab to get from point A to point B, assistance carrying a suitcase, or more time to rest before reaching a venue. If a patient is asked to attend an event or meeting, such as for the RBDCOV project, they may need additional time and accommodations to conserve energy. This would be classified as disability accommodation under the UK Equality Act 2010.

Mona: If someone requires specialist equipment or prefers certain transportation modalities, such as fewer travel changes, that could also count as disability accommodation. Continuing from Jenny's points, in a project like this, it's crucial to recognise that traveling to meetings can be challenging. Providing funding for participants to bring an assistant can reduce stress and ensure they have the necessary help, especially when navigating unfamiliar environments or managing health challenges. Long journeys can be physically and emotionally exhausting, so offering extended stays or accommodations prior to meetings allows participants to rest and arrive in better shape to contribute meaningfully.

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For participants who are also caregivers, childcare support during meetings can be a game-changer. Flexibility in transportation options is equally important. For example, if someone prefers a train over a long bus ride or flying from a different departure point because of convenient timing, funding should reflect this choice to ensure comfort and well-being.

Interviewer: *Thanks a lot for your answers. Now that we've explored what accessibility means, how would you define accessibility in the context of clinical trials and, more broadly, in research and development?*

Jenny: One way to make clinical trials more accessible is by offering hybrid trials, where patients can access therapies or medications at their local GP practice, hospital, or even at home through platform trials. Additionally, trial sites should reimburse travel expenses, including hospital car park fees, train fares, and other associated costs. Many patients may not have the financial means to travel far outside their community.

Interviewer: *And how do you think we can improve accessibility in this field?*

Jenny: I'd recommend providing information on trial advertisement materials in multiple formats—online, in posters, and in leaflets. If the budget allows, include QR codes linking to short video clips with auditory information and braille format for those with visual or hearing impairments. Patient information leaflets should also be available in different languages to reflect diversity across the EU and beyond.

Communication platforms about trials need to be accessible. Websites and apps should be compatible with screen readers, offer adjustable font sizes, and incorporate text-to-speech functionality. Invisible disabilities, such as chronic pain, mental health challenges, or sensory sensitivities, require accommodations to enable participation. Recognizing and respecting these needs is crucial for true inclusivity and it is best to work with people with lived experience of such matters to get the design of the study right first time!

Mona: As Jenny mentioned, hybrid trials are essential. Digital tools like telemedicine, remote monitoring, and home healthcare services make trials more accessible, especially for people in rural areas. Accessible transport options should also be provided, ensuring safe travel for participants with disabilities or the elderly. Flexible scheduling, including evening and weekend visits, is another key aspect, as it accommodates working participants, students, and caregivers.

Expanding trial eligibility criteria to include diverse patient groups, such as the elderly, people with disabilities (visible and invisible), and those with multiple health conditions, is crucial. These groups are often excluded due to the complexity of their needs, but their inclusion is vital for equitable research.

Interviewer: *When designing and conducting accessible clinical trials, what aspects should be taken into account to address potential barriers for underrepresented groups?*

Jenny: Building partnerships with organizations that represent marginalised communities is essential. Examples include charities supporting refugees, migrants, the homeless, and interfaith

communities. Trust is crucial and takes time to develop. These partnerships should be based on mutual respect and learning.

Inclusion is a part of Equality, Diversity, and Inclusion (EDI). In the UK, research funders emphasize that every eligible person should have the same opportunity to participate in research, regardless of geographical location, age, disability, ethnicity, gender, or socioeconomic status. So, there is a requirement when researchers apply for funding for both trials and research for them to complete a section on how their work benefits patients and how they have involved the public in designing it.

Mona: Jenny's points are spot-on. Additionally, understanding cultural differences and historical distrust of healthcare systems is vital. Some communities may be hesitant due to past exploitation or negative experiences. Trial sites should be easily accessible, and study materials must be available in multiple languages and written in clear, simple language. Flexibility, reimbursement, caregiver support, and accessible digital platforms—as we discussed earlier—are equally relevant here.

Interviewer: *Given your experience as CAP members in the RBDCOV project, what lessons have you learned so far about accessibility in this project?*

Jenny: Accessibility is constantly evolving. One important practice is asking people how they prefer to receive communication. Some may prefer writing online over voicing opinions in a group. Supporting less experienced patient advocates through mentoring or a buddy system can also make a difference. This is something that is being done a lot in regulatory bodies e.g in the UK with NICE.

Patient needs vary widely based on their conditions. For example, preferences for trial design can differ between children and adults or across cultural contexts. In the RBDCOV project, we've seen how crucial it is to consider such factors, like ensuring vaccine components are halal in Turkey.

Interviewer: *What recommendations would you give to other EU projects aiming to improve accessibility in clinical trials?*

Jenny and Mona:

We think these should be prioritised:

- Consult existing resources on best practices for EDI and patient involvement frameworks.
- Engage with patients and communities early to build trust and establish long-term partnerships.
- Recognise that accessibility is not one-size-fits-all; adapt and learn.
- Involve diverse patient groups from the beginning to identify barriers and ensure inclusivity.
- Provide flexible scheduling, transportation support, and resources like childcare to accommodate varying needs.
- Train research staff in cultural competence and inclusivity to create a welcoming environment.

Jenny: In conclusion, involving patient representatives or user participation in clinical trials and EU-funded projects like RBDCOV is essential. Early engagement helps make trials more relevant and patient-friendly. Patients' insights can highlight challenges and suggest accommodations that researchers might overlook. This approach ensures the trial meets the real needs of participants, particularly those with chronic conditions or disabilities, and ultimately leads to better, more inclusive research outcomes.

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