

## Science Communication Interest Group Meeting - *Community Engagement: how to adapt a more patient-centric approach in AMR & TB research?*

15.03.23, Basel, Switzerland

### BACKGROUND INFORMATION

People affected with bacterial infections can and should be involved in every step of antibiotic drug development. They are too often considered as mere recipients of antibiotic treatments derived from research results, whereas they could be empowered as active partners contributing to the research. During this Science Communication Interest Group meeting, community engagement was explored on three levels:

- 1) the right language to use when communicating with people affected by infectious diseases like tuberculosis (TB);
- 2) involving the public in antimicrobial development research;
- 3) including community preferences in medical product decision-making.



Before considering engaging community in research, it is essential to know how to communicate with members of the community. To set the right tone, the meeting was opened by an introductory presentation on the appropriate language to use with TB-affected people. The presentation was delivered remotely by Patrick Agbassi, Chair of the Global Tuberculosis Community Advisory Board. A

second online presentation followed with Andy Gibson, Associate Professor in Public Involvement in Research, University of West England. The focus shifted from best linguistic practices to the concrete implementation of Patient and Public Involvement (PPI) activities in research. Prof. Gibson first explained what public involvement in research means in practical terms before highlighting the benefits of such activities for researchers. At the end of the presentation, evidence-based advice on how PPI activities can support trial design and research protocol development and how these can be monitored were provided. The last talk was given by Josepine Fernow, Communication Strategist, Uppsala University who reported to the participants a series of recommendations for patient involvement in research and

the inclusion of structured patient input in medical product decision-making from the IMI project [PREFER](#). She used the project outcomes to demonstrate how patient preference studies can be valuable tools for decision-making process throughout the trial continuum - all the way from the trial design to the Health Technology Assessment review. Each presentation was followed by several questions from the audience giving rise to discussions which key points have been summarised hereunder. The meeting was concluded with an invitation by Katharine Cresswell, NICE to the joint [ERA4TB-UNITE4TB webinar on community involvement in early-stage TB research](#).



## DISCUSSION OUTPUTS

### *Take-home message #1:*

**Stigmatising language should be avoided to the extent possible in all contexts, not only when communicating with people affected by a disease or a condition**

Language should be carefully used at all levels of interaction as related to medical research. Using the appropriate words that do not stigmatise and offend people affected by a disease or a condition and that do not place the blame on them is not recommended only when exchanging with the non-research communities, but also amongst healthcare professionals, scientists, and researchers themselves. Efforts should constantly be made so that the use of an appropriate language eventually becomes a natural reflex and not a constraint. For example, while the word 'patient' is a very common word in a clinical context, it wrongly underlies the passivity of the people in need of healthcare services who should be actively involved at the centre of the research. It also conveys a sense of unequal relationship between them and the healthcare and research professionals, while they should be working as healthcare and research partners.

### *Take-home message #2:*

**Plain language is a pre-requisite to communicate with people from outside your community**

Effective public engagement activities can only be done in a simplified language that is free of acronym and abbreviation, and understandable to all. Scientific notions, concepts, and

methodologies, even those that seem the most evident to you, need to be described with easy-to-understand, non-technical words in order to make your research as accessible and inclusive as possible. For example, saying “when germs stop responding to antibiotic medicines” would be a clearer alternative to systematically referring to antimicrobial resistance in public-facing communications. Never assume that members of the general public have an identical level of literacy.

*Take-home message #3*

**Use patient representation groups to leverage engagement of local communities in pre-clinical and clinical research**

Research does not always take place where there is a high disease prevalence (e.g. tuberculosis). In addition to the geographical distance, there may as well be linguistic, educational, and perspective gaps between healthcare professionals and the community affected by the disease. All in all, these gaps form a disconnect which helps explain the difficulty for researchers to reach out and get closer to the local communities. This proves especially challenging in countries with many different languages. Using advocacy groups or organisations representing local communities as intermediaries can mitigate these challenges and reduce the distance between researchers and communities. Local patient groups often work with the support of interpreters to facilitate communication and community engagement.

*Take-home message #4*

**Engage with people affected by the disease or condition in research as early as possible**

Early community engagement will yield multiple benefits for your research. Direct benefits include, for example, improving the quality and relevance of your study design, and ensuring that your research agenda is right and comprehensible by the general public. The sooner you will involve people affected with a condition or disease in your research, the sooner you will make sure that your research is ethical and meaningful to the community in need of the intended research outcomes. This will in turn help rightly define your endpoints, increase your recruitment rate in clinical trials, and enhance your communication and dissemination activities. Involving people affected by the researched disease or condition from the very beginning and empowering them with different roles (oversight, managerial, responsive, or decision-making) will make them excellent communication ambassadors able to explain your research results in a language that will be familiar enough to be in tune with the peer members of the community.

*Take-home message #5*

**Involve members of the general public in AMR research, not only people living with resistant bacterial infections**

One of the difficulties in the context of antimicrobial resistance is that there is not one well-defined target population affected by this burden. Antibiotic-resistant infections can be acquired in hospitals as they can be acquired in the community following an overuse or misuse of antibiotics. In addition, infectious diseases caused by Gram-negative and TB bacteria can easily be transmitted, for example, via surface or hand-to-hand contacts in medical care settings or through the air we all need to breathe. Everyone is at risk of contracting infectious diseases that may thereafter develop resistance to antibiotics. Therefore, an appropriate tactic when planning community engagement activities is not to focus only on the population in need of antibacterial treatments, but to involve the general public at large and raise awareness that no one is spared by this silent antimicrobial resistance pandemic.

*Take-home message #6*

**Foresee budget for community engagement activities in your future research projects**

Any expenses and time invested by the members of the community in contributing to your research should be reimbursed or even compensated. This requires the earmarking of a dedicated budget when planning the financial expenditures incurred in your research and drug development process. When applying for research grants, applicants should be making sure that budgets are thoughtfully allocated to foster meaningful and inclusive involvement of members of the general public with or without lived experiences of health issues. As demonstrated in this report, these will be well-spent resources that will yield more benefits than one may expect.

## USEFUL RESOURCES

- [Words Matter – Suggested language and usage for tuberculosis communications \(2022 edition\)](#), Stop TB Partnership
- [Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients?](#), International Union Against Tuberculosis and Lung Disease
- [Stop the Stigma: Eliminating stigmatizing language in TB](#), Heartland National TB Center
- [Patient and Public Involvement Toolkit on Antimicrobial Medicines Development Research](#), ND4BB COMBACTE-MAGNET project
- [Practical Guide on Patient and Public Involvement](#), ND4BB COMBACTE-MAGNET project
- [Patient Engagement Toolbox](#), PARADIGM project
- [The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research](#), Royal College of Nursing (UK), UK Clinical Research Collaboration, University of Warwick
- [Exploring Impact: Public involvement in NHS, public health, and social care research](#), UK National Institute for Health Research
- [Patient Involvement Guide](#), Innovative Medicine Initiative

**AGENDA**



# Scientific Interest Group (SIG) Event

**15 March 2023**  
**13:30-15:00 CET**

**Basel, Switzerland**

## Community engagement: how to adapt a more patient-centric approach in AMR & TB research?

**Moderated by**



**Clément Robijns**

BIOCOM AG

**Presentations by**



**Patrick Agbassi**

Global TB Community Advisory Board



**Prof. Andy Gibson**

University of West England



**Josepine Fernow**

Uppsala University



**Katharine Cresswell**

NICE

- 13:30** Welcome and introduction
- 13:35** Appropriate language use and continuous communication with TB-affected people - Patrick Agbassi, Global TB Community Advisory Board
- 13:55** Developing patient and public involvement in pre-clinical development and clinical trials - Prof. Andy Gibson, University of West England
- 14:15** Patient input to medical product development: lessons learnt from IMI Project, PREFER - Josepine Fernow, Uppsala University
- 14:25** Discussion with AMR Accelerator projects on planning, conducting, monitoring, and evaluating community engagement in their research
- 14:55** Invitation to Joint ERA4TB-UNITE4TB webinar on community involvement and engagement in early-stage TB research - Katharine Cresswell, NICE

For additional information please contact Frederik Deroose: [deroosefrederik@gmail.com](mailto:deroosefrederik@gmail.com)



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## PARTICIPANTS

First Name	Last Name	Organisation	Affiliated projects
Jonathan	Butcher	BioVersys AG	TRIC-TB
Katharine	Cresswell	NICE	ERA4TB
Raquel	Duarte Melo	Institute of Public Health University of Porto	UNITE4TB
Judith	Eckstein	LMU University Hospital Munich	UNITE4TB
Josepine	Fernow	Uppsala University	COMBINE
Timo	Jaeger	German Center for Infection Research - DZIF	UNITE4TB
Geraldine	Joanny	Innovative Health Initiative	(AB-Direct, COMBINE, GNA NOW)
Linda	Marchioro	Paul-Ehrlich-Institut	COMBINE
Marie	Olliver	Uppsala University	COMBINE
Kristina	Orrling	Lygature	GNA NOW
Fred	Peyrane	BEAM Alliance	COMBINE
Clément	Robijns	BIOCOM AG	COMBINE
Lily	Teitelbaum	BIOCOM AG	COMBINE

### About AMR Accelerator

The AMR Accelerator receives funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 853976 | 853967 | 853979 | 853932 | 853903 | 853800 | 853989 | 853932 | 101034420. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA. ERA4TB receives additional support from Global Alliance for TB Drug Development, Bill & Melinda Gates Foundation and University of Dundee.

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### About the Innovative Medicine Initiative

About the Innovative Medicine Initiative The Innovative Medicines Initiative (IMI) is Europe's largest public-private initiative aiming to speed up the development of better and safer medicines for patients. IMI supports collaborative research projects and builds networks of industrial and academic experts in order to boost pharmaceutical innovation in Europe. IMI is a joint undertaking between the European Union and the European Federation of Pharmaceutical Industries and Associations, EFPIA.

For more information on IMI, please visit <https://www.imi.europa.eu/>

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