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# Community-based participatory research in travel medicine to identify barriers to preventing malaria in VFR travellers

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The use of participatory approaches involving community stakeholders is novel in travel medicine research. We describe various community-based participatory methods, using the examples of community advisory boards (CABs), community-based organisations (CBOs), and focus groups as mechanisms for achieving a desired interventional outcome. While these methodologies can be applied to many settings, we used them to investigate barriers to malaria prevention in travellers visiting friends and relatives (VFRs) and to implement interventions targeting VFRs.

### Establishing community partnerships

An important first step in any community-based intervention is determining whether the affected community is concerned about the condition targeted for intervention.<sup>1</sup> Through communicat-ing with local leaders and public health partners, we determined that malaria was a concern in US-based West African immigrant communities in the Bronx (NY) and

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E.W., D.W., A.A., H.V., J.G., K.A., C.C., S.D. and W.S. made substantial contributions to the conception or design of the work. E.W., D.W., A.A., A.E.B. and C.C. participated in data acquisition, analysis or interpretation of data for the work. E.W. and D.W. drafted the manuscript, and all authors participated in revising it critically for important intellectual content.

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Minneapolis-St. Paul (MN). Once it is determined that an intervention is needed or desired, researchers solicit expertise from established CBOs in the community and form a CAB, a group of representatives from a target population that works with a research team to develop solutions to a problem.<sup>1,2</sup> A CAB can help in soliciting community insights in target populations,<sup>3</sup> developing and disseminating culturally appropriate materials and measures, and promoting project activities and subsequent interventions. A CAB was established in both MN and NY, comprising West African local community members. Each site (NY and MN) invited respected representatives of the largest West African immigrant groups to participate. The CABs were gender-balanced, represented eight countries and each comprising 8–10 members to facilitate productive conversations.

Establishing expectations for CAB members and study staff at the onset creates realistic expectations for time commitment and fosters mutual respect. In our project, CABs were given a monthly stipend and, in return, provided input on survey questionnaires and cultural risk factors, reviewed focus group question guides for clarity, and refined language used in research documents. CAB members helped develop educational materials, served as key informants for qualitative data analyses (a process known as member checking<sup>4,5</sup>) and helped identify local organisations representing West African community interests. Four community-based non-profits serving West Africans in MN, recommended by the CAB, collaborated on study design and implementation. These relationships were important in focus group recruitment and ensured interventions were effective and sustainable.

Community groups often have small budgets and rely on volunteer staff. CAB members and CBOs identified capacity gaps for their organisations. We hosted workshops on focus group guide creation and facilitation, qualitative analysis methods, use of logic models, monitoring and evaluation strategies, and survey design, which met partner organisations' needs and strengthened their participation in and goodwill toward the project.

#### Creating and conducting focus groups

Focus groups allow community members to participate in research in a manner that allows individuals to express their perceptions, experiences, and preferences in their own words. Focus groups represent a model for reaching the historically difficult-to-reach population of VFR travellers. A key tenet of focus group methodology is to foster an environment for discussion that minimises judgement, stigma and shame.<sup>4,5</sup> Our partnership with trusted community members and organisations was essential in gaining confidence and maintaining cultural sensitivity.

Choosing an appropriate location and group makeup is also important to focus group success.<sup>4</sup> Partner organisations recruited participants via purposive sampling (i.e. recruitment based on ability to provide relevant information).<sup>4</sup> We emphasised selecting individuals from a range of ages, education levels and occupations, and balancing genders in each session.

Each focus group session lasted 1.5–2 h and used a question guide developed in collaboration with the CABs. All sessions were audio-recorded, de-identified and

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transcribed. Non-verbal cues (e.g. gestures, nods of agreement) and other interactions were added to the transcript by the note taker observing the session. In NY, a study staff member of West African descent facilitated all sessions for consistency. In MN, a facilitator from each recruiting CBO was trained and moderated the focus groups.

The supervising institutional review boards at the Minnesota Department of Health and Albert Einstein University approved this study. Participants provided written consent and received a copy of the form. Participants received a meal and gift card as compensation.

#### Data analysis from focus groups

Grounded theory<sup>6</sup> is a well-recognised, scientifically rigorous analytical framework in which researchers review data with as few preconceptions as possible while attempting to mitigate personal biases or assumptions.<sup>4</sup> Thus, transcripts obtained in focus groups were reviewed using an inductive process known as open coding to tag raw data (phrases or dialogue) and group key concepts, themes and recurring ideas.<sup>7</sup> Selective coding, or employing defined codes derived from previously analysed focus group sessions, was used to narrow, expand or provide hierarchy within the working definition of a code.

Data were analysed with Atlas.ti Ver. 8.0 (Scientific Software Development, Berlin, Germany). Transcripts and code structures were reviewed to identify higher-level recurring categories or themes.<sup>4</sup> Four staff members analysed the transcripts to ensure reliability and objective coding. Two or more individuals coded transcript selections; inter-coder reliability (kappa) was >0.90, signifying that code definitions and structures were similarly interpreted. Subsequently, all codes were analysed by one scientist to collect major themes present in multiple groups.<sup>7</sup>

Validity of findings was verified using three tactics: triangulation of findings, peer debriefing and member checking.<sup>8</sup> The process of finding concordant themes between multiple data sources is known as triangulation of findings. To help with triangulation, most coders attended focus groups, engaging with study participants. These interactions allowed coders to reference both in-person experiences and written transcripts when interpreting the potential meaning of a statement. To limit misinterpretation of underlying meanings during discussions, study staff and community partners debriefed with the moderator immediately after each focus group to clarify any unknown terms used by participants (e.g. names of specific folk medicines), a process known as peer debriefing.<sup>5</sup> Feedback from CBOs led to the planning of community forums at each study site, which allowed community members (including past focus group participants) to review major themes and provide input on what may have been missed or misrepresented.

Finally, ensuring that participants represent diverse perspectives in the community is important to limit overgeneralisations of community views. This diversity can be accomplished in focus groups by continuing to sample (i.e. recruit and host discussion groups) until no new information emerges from the transcripts, a phenomenon known as saturation of themes.<sup>5</sup> Before the study's conclusion, saturation was achieved.

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#### Closing the loop in community research

In community-based participatory research, the impact extends beyond contribution to the scientific literature. Focus group findings will be published for scientific audiences; however, CAB member participation was essential to dissemination of study findings and subsequent programme interventions to the affected population, through social media postings, culturally appropriate handouts and participation at religious and community events.

#### Conclusion

Community-based participatory research is an iterative process in which the research team is intimately involved with study participants and their community. While the use of CABs,<sup>1,3</sup> focus groups<sup>9</sup> and community organisation capacity building<sup>2</sup> have been successfully implemented in public health and other related fields, the use of such methods in travel medicine is relatively novel. Through active involvement of community stakeholders in all aspects of the research process, we were able to enhance data collection, identify interventions and ensure the success and sustainability of preventive efforts in travellers' health. These methods allowed us to hone our focus on previously reported and unreported barriers<sup>10</sup> to malaria prevention in VFR travellers by leveraging assets in affected communities. The use of these novel methods should be considered for future research involving VFR travellers.

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