

HELIUS participants give advice

How can the HELIUS study be improved?



Nine participants of the HELIUS study participated in a group interview. The participants all had a migration background (Surinamese, Turkish and Moroccan). We were curious about their experiences with the HELIUS study, possible areas for improvement and their ideas on how to better involve people with a migration background in research.

Motivation

Participants gave two reasons for participating in the HELIUS study: 1) More medical research and knowledge is needed about/with people of different ethnic backgrounds; 2) Participants get more information about their own health through independent research.



People with a migration background

may participate less often in research because they are not focused on their health, are afraid of negative results or do not know why research is important. Recruiting people requires customization. Participants advise to use appropriate channels for this and key figures of different communities.

Study design

It is nice that HELIUS examines multiple aspects of your health and that there are multiple measurements; this keeps you informed about how you are doing. The status and importance of the study could be shared more often. Then participants can also better explain to others what HELIUS does.



Organization

The HELIUS study is well organized: travel expenses are reimbursed, there is always food/drink available, you get clear information in advance and the guidance during examinations is very pleasant. A major point for improvement is the directions to the HELIUS location at the AMC, which are very unclear.

Feedback of results

Participants appreciate receiving their own research results. Just make sure the results are presented in a way that is understandable to people without medical training. The same goes for the online meetings. Less medical words, more visualizations!



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