

1 October 2013

To whom it may concern at (research organization),

(Research organization) conducts pharmaceutical research in my community and recruits members of my community to volunteer for this research as clinical trial participants. I myself am a supporter of clinical research and I want it to progress efficiently and in a collaborative way with the volunteers being empowered to be understand the research for which they volunteer. Right now, a major difficulty which impedes a community's understanding of research are the barriers which your organization maintains and which prevent people in my community from discussing your research - actually our research - among ourselves.

All clinical research has risks, and when a volunteer provides informed consent to join a clinical trial, this is not a private agreement between only the researcher and the volunteer. When a volunteer agrees to take risks, that volunteer distributes that risk among all members of their community, and any potential harm which may ever come to a volunteer is a harm to the entire community even if the researcher has committed to fix any problems which occur. Significant harms are uncommon; as I said, I am a supporter of clinical research and I believe in its institutions. However, I am writing to ask that you remove the barriers which prevent communities from getting basic public information about our research.

If I were to meet with you and ask you about any of your research I am confident that you would share all public information about it with me verbally. The things you tell me would be reflective of what is in the written public information about the research, and if I asked for that written public information I expect that you would share with me a copy of the informed consent document, because that is a layman document presented to all potential research participants and which presents among other things the study goals, a simple explanation of the research, and risks. I want no private information, or any information at all which is not already available on request. I am writing to request your informed consent documents.

I can only use these documents if you waive certain copyrights over them so that I can distribute them for discussion and remix them so that members of my community can understand them and use them as we like. Perhaps you have heard of an "open access" movement in research which has as its aim a similar demand for access to information - I need media licensing aligned with that movement, such as Creative Commons-Attribution licensing ("CC-BY").

Thanks for your reply in any case. If you can provide the ICD to me under these terms then I will share it broadly with everyone. If you are unable to share the document with me, then please also explain to me why you are unable to do so. I have shared the fact of my request with my community and a timestamped copy of it can be found at (hyperlink)

Thank you for your attention and thank you for conducting health research. I am the biggest fan of the advancement of open science!

yours,

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