



March 17, 2017

Vanderbilt REDCap Team  
Vanderbilt University  
1207 17th Avenue South Suite 105  
Nashville, Tennessee 37212

Ismael Gomez  
Fondation Voir et Entendre  
17 rue Moreau  
75012 Paris  
Email: [ismael.gomez@inserm.fr](mailto:ismael.gomez@inserm.fr)  
Phone: +33 1 53 46 26 80  
URL: <http://www.fondave.org/>

Dear Madam, Dear Sir,

My name is Ismael Gomez. I work as a data manager at the Voir et Entendre Foundation, a not-for-profit organization in close cooperation with the Pierre et Marie Curie (public) University (UPMC).

Our institution has been missioned by the public authorities to coordinate an observational research project on Usher's Syndrome which, as you know, is a rare disease caused by a genetic mutation resulting in a combination of hearing loss and visual impairment. This study is a part of a wider project known as Light4Deaf.

In the scope of this project, our department, under the direction of Mr. Marc LECHUGA, Project Manager, is responsible for the implementation of the corresponding eCRF, which we plan to deploy as soon as possible.

Our study is a multi-centric one, involving personnel from seven departments belonging to four public hospitals in Paris, monitoring an estimated 400-person cohort during a five-year period. Taking into account a five-year inclusion period, that means an overall timing scope of the project close to ten years.

We are truly impressed by the capabilities of REDCap and would be happy indeed to adopt it as the platform for our study. However, having read its Terms of Use document, we are aware of the risks that Section 2.5<sup>1</sup> and 2.6<sup>2</sup> could involve for our project.

We understand those events (unilateral Agreement termination / terms revision) would be rare by nature, but in our case they would mean whole project failure in case of advent, which we cannot afford. Our limited budget would not allow us to quickly deploy an open-source alternative to REDCap and so, it would all result in catastrophe.

Taking the above-mentioned elements into account, we would be very grateful if you could consider the possibilities of finding a workaround to our limitations that could help us become a Consortium Member under the scope of this project, as well as future ones.

Yours faithfully,

Ismael Gomez

---

<sup>1</sup>"Vanderbilt shall have the right, . . . , to amend, modify, or revise any term or terms of this Agreement at any time in its sole and absolute discretion".

<sup>2</sup>"Vanderbilt shall have the right to terminate this Agreement, at its discretion, for any reason upon providing Licensee with ninety (90) days advance notice."