



Fondation VOIR ET ENTENDRE

Ismael Gomez

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Vanderbilt REDCap Team
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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) in Paris, France.

Our institution has been missioned by the public authorities to coordinate an observational research project on Usher Syndrome, a rare disease caused by genetic mutations 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 in charge of the implementation of a dedicated eCRF, which will be a key tool for this multi-centric study.

The project involves 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 time of ten years for the whole study.

We are truly impressed by the capabilities of REDCap and would be happy 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 2.5¹ and 2.6² 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.

Taking the above-mentioned elements into account, we would be very grateful if you could consider a win-win agreement that could help us become a Consortium Member under the scope of this project, as well as future ones, and guarantee the respect of the rules of use of REDCap.

We are, of course, willing to answer your questions if necessary.

Yours faithfully,

Ismael Gomez

¹"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".

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