



European Reference Network

for rare or low prevalence complex diseases

 **Network**
Hereditary Metabolic Disorders (MetabERN)

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Object: Survey Patient's perspective on clinical trials

Dear All,

Clinical trials are very important for the advancement of medicine. To be effective and useful they suppose excellent interaction and collaboration between medical teams and patients during the entire study process.

There is a clear need to improve the realization of clinical trials and better adapt study protocols to patient's expectations. With that purpose in mind, MetabERN, the European Reference Network for Metabolic diseases, has prepared a survey to learn about patients' perception of clinical trials. We are inviting you to forward this questionnaire to the members of your community.

The survey is meant for ALL rare metabolic patients and/or their caregivers, including the persons who have never been approached to participate in a clinical trial.

We would strongly appreciate if you could circulate the link below as broadly as you can among patients and families in your community, emphasizing the importance of taking part to this initiative with regards to the challenging issues raised by clinical trials:

<https://www.surveymonkey.com/r/Patientsperspectiveclinicaltrials>

The deadline to completing the surveys is March 31st 2019

Answers are anonymous. Data will be collected and analysed by the MetabERN central office and will not be communicated to anyone outside. At the end of the analysis, the conclusions will be returned to participants and communicated to health care providers in the MetabERN network. If the study is conclusive enough, a report will be posted on the MetabERN web site and shared with other ERN teams and European Commission officers (DG santé).

Please do not hesitate to ask for further information from Cinzia Maria Bellettato (cinzia.bellettato@metab.ern-net.eu)

Thank you in advance for your precious collaboration,
Best regards

Prof. Maurizio Scarpa

MetabERN Coordinator