

Marianne Cohort: Humanities and participatory research

Scientific coordinator: H. Peyre (CHU Montpellier)

Our participatory research project is part of the national multicenter prenatal cohort MARIANNE whose goals are descriptive (clinically identifying and characterizing ASD and NDD cases and their evolutions for example), aetiological (identifying the prenatal and perinatal risk factors for NDDs linked to the external exposome for example) and economical and social (evaluating the medico-economic impact of NDDs for example).

A work group is entirely dedicated to participatory research and research in humanities. Therefore the study has enabled to bring together family representatives and autistic people in helping:

- To write the call for project and the various documents of the study
- To define the language elements
- To proofread the Marianne cohort website
- To seat on the boards: strategic committee, steering committee, scientific and ethical committee.

A researcher's group is constituted around several axes:

- Research on the humanities variables (parents scale, stress, QDV...)
- Proposal for the focus group
- Discussions with autistic adults (head of the Strasbourg GEM for example)
- Proposal of a PhD to an autistic person within a research university degree
- Qualitative research on the parental experience of a child at risk of an NDD

Our participatory research has the following projects:

- Developing programs: ETP, parental education and parental training
- Raising awareness (webinar on the cohort, day on participatory research)
- Naming one or several MARIANNE ambassador families
- Supporting professional environments for early childhood.