

# RESPECT Patient Needs

 [consortiapedia.fastercures.org/consortia/respect/](https://consortiapedia.fastercures.org/consortia/respect/)

## Research Areas



### Tool Development

Clinical Trial



### Basic Research



### Data-Sharing Enabler



### Product Development

Data

## At a Glance

- Status: **Completed Consortium**
- Year Launched: **2008**
- Initiating Organization: **European Commission's 7th Framework Programme**
- Initiator Type: **Government**

## Abstract

The European research project RESPECT (Relating Expectations and needs to the Participation and Empowerment of children in Clinical Trials), led by the Institute of Clinical Sciences at the Sahlgrenska Academy at Gothenburg University, Sweden, set out to identify the needs and motivations of children and their families who have participated or might participate in clinical trials in Europe.

They explored the issues raised by children's participation in medical research by speaking with pediatric patients and their parents, patient support organizations, pediatricians, ethical committees, and representatives of the pharmaceutical industry to gather their experience, insights, and suggestions. This enabled RESPECT to make recommendations for how to empower children such that medical researchers respect their interests and can motivate their participation in future clinical trials.

## Mission

The objective of the RESPECT project is to identify the needs of children and their families as related to outcomes in clinical trials. This will include the needs of children who have participated or who might participate in clinical trials in Europe. Secondly, to identify methods by which these needs can be translated into empowering and motivating participants in future clinical trials research.

RESPECT is also exploring the ethical issues involved in children's participation in medical research and contacting ethical committees, patient support organizations, pediatric patients, and their parents to gather their insight and suggestions.

## Structure & Governance

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The project coordinator is the Institute of Clinical Science at the Sahlgrenska Academy at Gothenburg University (Sweden)

## Financing

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Funded under the European Union's 7th Framework Programme

## Patent Engagement

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Patients and their parents were contacted to gather their insights, experience, and suggestion about their participation or potential participation in clinical trials.

## Impact/Accomplishment

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[Determinants of Decision-making and Patient Participation in Paediatric Clinical Trials: A literature review](#)

[Impact of the new European paediatric regulatory framework on ethics committees: overview and perspectives](#)

[Masters thesis: Beyond Informed Consent - Educating patients to empower them in the clinical trial process](#)

[Activity of ethics committees in Europe on issues related to clinical trials in paediatrics: Results of a survey](#)

[A European survey on ethical and legal framework of clinical trials in paediatrics: results and perspectives](#)

## Links/Social Media Feed

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Homepage

<http://www.patientneeds.eu/RESPECT.html>

## Points of Contact

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## Sponsors & Partners

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European Patients' Forum

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