

# Children's Voices in Rare Diseases

## Sand Play, Arts, Music, Photo Voice, and Interviews

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### Background

Rare Disease is defined as any disease affecting fewer than 5 people in 10,000 in the EU is considered rare (EU, 2018). Individually this numbers might appear small, it translates into approximately 246,000 people currently living with a rare disease in Europe (EU, 2018). The rare disease research community is fragmented in Ireland/EU due to large heterogeneity of rare conditions.

The SAMPI project is funded by the Temple Street Foundation to "Give a voice to the children and their families with Rare Diseases through Sand Play, Art, Music, Photovoice and Interviews. This project aim to answer a simple research question "what is it like for a child to live with a rare disease and how can children be best supported to express this?".

### Aim and Objectives

#### Aim:

To explore children's and young people's and their families experiences of living with rare diseases

#### Objectives:

1. To explore the factors which enhance, inhibit and impact on the lives of children and young people living with a rare condition.
2. To explore children and young people understanding of a rare diseases.
3. To explore day-to-day parenting of a child and young people with a rare disease
4. To examine knowledge, understanding of rare diseases from the perspective of fam

### Methodology

Participatory Research approach utilising Multiple methods

Data collection will comprise of qualitative multiple methods utilising Sand Therapy, Music Therapy, Arts Therapy, Photo voice and Interviews with children.

A quantitative element will be added as questionnaire different perspectives are captured from parents.

### Sampling

#### Purposeful sampling

A minimum of 30 children (aged from 4-16 years of age) will be recruited across all rare disease speciality who is currently attending Children's Health Ireland at Temple Street will be recruited for the study.

The children will be purposefully selected to ensure that there are broad representations from each age group (4-7 years) (8-11 years) (12-16 years) and various rare diseases categories.

#### Inclusion Criteria

The child aged from age 4 to 16 with a RARE DISEASE (In Europe, a disease is considered to be rare when it affects 1 person per 2000(Orphanet, 2016)

Children who attend Temple Street Children's university Hospital

### Research Approaches



**Sand Play:**  
Dr Sandra McNulty  
Senior Clinical and  
Counselling Psychologist

#### Art Therapy:

Aimee O'Neill  
Art Therapist



**Music Therapy :**  
Alison Sweeney, Music  
Therapist

#### Photovoice:

Shirley Bracken, Craniofacial  
Research Assistant



#### Interview:

Yvonne Rogers, Senior  
Clinical Psychologist  
Interview & Doris O'Toole,  
Clinical Placement Co-  
ordinator

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For more information or if you are interested in joining the study, contact: Dr Suja Somanadhan, Researcher at University College Dublin

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