

# Selecting Futures: The Social and Ethical Implications of Genetic Screening

<https://neurodegenerationresearch.eu/survey/selecting-futures-the-social-and-ethical-implications-of-genetic-screening/>

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United Kingdom

## Title of project or programme

Selecting Futures: The Social and Ethical Implications of Genetic Screening

## Source of funding information

ESRC/MRC

## Total sum awarded (Euro)

€ 225,163

## Start date of award

01/05/2013

## Total duration of award in years

3.8

## The project/programme is most relevant to:

Spinal Muscular Atrophy (SMA)

## Keywords

### Research Abstract

This study explores the social and ethical implications of the potential introduction of genetic screening for conditions with variable presentations and focusing on the condition Spinal Muscular Atrophy (SMA). The study aims to explore what families living with SMA think about genetic screening and testing in order to understand the role and value of direct 'experiential knowledge' in reproductive decision-making. The study also aims to explore whether families

living with genetic disease approach screening decisions in a different way to pregnant women from the general population without such 'experiential knowledge' of the condition being screened for.

The research will be conducted in three phases: the first phase comprises 30 in-depth interviews with family members and individuals living with SMA to explore their views around SMA screening, the second phase involves a questionnaire (developed from the interview data) to be administered to a much larger sample of families living with SMA in the UK (aprox 2,000) and the third phase involves a comparative analysis of the survey data with a pre-existing survey dataset exploring the views of 996 women from the general population undergoing screening for Down's Syndrome.

### **Lay Summary**

**Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

United Kingdom

#### **Diseases:**

Spinal muscular atrophy (SMA)

#### **Years:**

2016

#### **Database Categories:**

N/A

#### **Database Tags:**

N/A