



# iMAGINE iD

A study of intellectual disability, mental health and genetics

Invitation to take part



“ IMAGINE ID is a brilliant initiative and should really help us to gain a much deeper understanding of how rare genomic disorders affect children’s learning ability and behaviour. I encourage families to join this study ”

*Beverly Searle, Unique CEO*

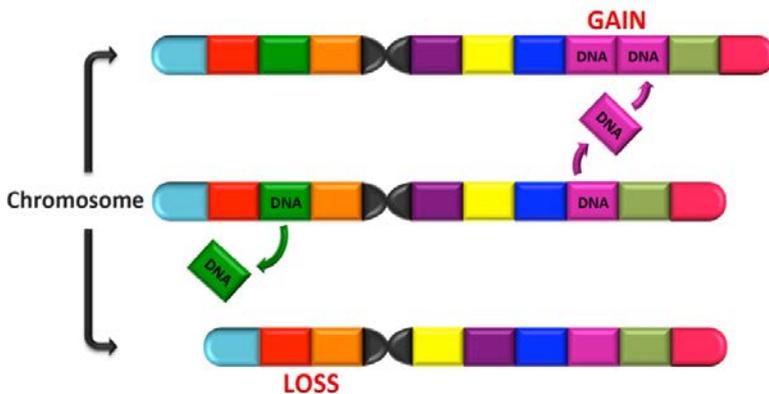


## What is intellectual disability?

Intellectual disability (ID), learning difficulties or developmental delay are terms used to describe people who struggle with some everyday activities and learning. This often means it will be more difficult for them to understand complex information, develop new skills, and cope with unfamiliar situations.

Intellectual disability often has a genetic cause and many children with ID are born with genetic changes. These changes in the genetic code (DNA) are very complex. This means that people with ID rarely have the same genetic changes. Examples of genetic changes include gains or duplications of DNA, losses or deletions of DNA and changes of the letters of the DNA code.

Changes in DNA can affect genes that are important in brain development. This can lead to intellectual disability or difficulties with development and behaviour. We do not understand exactly how and why this happens yet. To really help people with ID we need to do much more research.





## What is the IMAGINE ID study?

Our Study, IMAGINE ID stands for **I**ntellectual Disability and **M**ental Health: **A**ssessing the **G**enomic **I**mpact on **N**eurodevelopment. Our study aims to answer one of the questions parents often ask when their child has a genetic condition: *“So what does this mean for my child?”*

To answer this question we are collecting lots of information about a large group of children and young adults with intellectual disability. This will help us understand the impact of genetic changes on their behaviour. We hope this will help families and children now and in the future.





## Why have we been invited to take part?

You have been invited to join IMAGINE ID because you/your child has been diagnosed with a genetic condition. By getting involved, you have the chance to help us understand the links between rare genetic changes and children's development and behaviour.

We hope this will improve the care and support parents and professionals can offer children and young people with intellectual disabilities.





## What are the benefits of taking part?

Joining IMAGINE ID gives you a chance to help learn more about children and young adults living with rare genetic conditions. Your contribution will help other families to gain better information about their child's development and behaviour.

 <p>International Genetic and Genomic Researching Rarely Occurs in the UK</p> <p><b>Dear Sirs,</b> Dear Sirs, I am writing to you on behalf of the IMAGIN team. We are pleased to hear that you have agreed to participate in the IMAGIN study. This report will be generated only after we have received your consent and you have agreed to participate in the study.</p> <p>This report will be generated only after we have received your consent and you have agreed to participate in the study.</p> <p>The IMAGIN study is a collaborative effort of researchers from across the UK and internationally. We are pleased to hear that you have agreed to participate in the study.</p> <p>What genetic and physical characteristics of your child will be included in the study? This is a summary of the genetic and physical characteristics of your child that will be included in the study.</p> <p>The IMAGIN study is a collaborative effort of researchers from across the UK and internationally. We are pleased to hear that you have agreed to participate in the study.</p> <p>What genetic and physical characteristics of your child will be included in the study? This is a summary of the genetic and physical characteristics of your child that will be included in the study.</p>	 <p>International Genetic and Genomic Researching Rarely Occurs in the UK</p> <p><b>How to interpret the report?</b></p> <p>This report will be generated only after we have received your consent and you have agreed to participate in the study. It will provide you with information about your child's genetic and physical characteristics. The report will be generated only after we have received your consent and you have agreed to participate in the study.</p> <p><b>How to interpret the report?</b></p> <p>This report will be generated only after we have received your consent and you have agreed to participate in the study. It will provide you with information about your child's genetic and physical characteristics. The report will be generated only after we have received your consent and you have agreed to participate in the study.</p> <p><b>How to interpret the report?</b></p> <p>This report will be generated only after we have received your consent and you have agreed to participate in the study. It will provide you with information about your child's genetic and physical characteristics. The report will be generated only after we have received your consent and you have agreed to participate in the study.</p>	 <p>International Genetic and Genomic Researching Rarely Occurs in the UK</p> <p><b>What is the IMAGINE ID study?</b></p> <p>The IMAGINE ID study is a collaborative effort of researchers from across the UK and internationally. We are pleased to hear that you have agreed to participate in the study. It will provide you with information about your child's genetic and physical characteristics. The report will be generated only after we have received your consent and you have agreed to participate in the study.</p> <p><b>Strengths and Difficulties Questionnaire (SDQ)</b></p> <p>The Strengths and Difficulties Questionnaire (SDQ) is the first question you completed when you started the IMAGINE ID study. It is a questionnaire that asks you to describe your child's behaviour, based on your own observations. It is a questionnaire that asks you to describe your child's behaviour, based on your own observations. It is a questionnaire that asks you to describe your child's behaviour, based on your own observations.</p> <p><b>Your child's ratings:</b></p> <ul style="list-style-type: none"> <li>Score for total score is <b>10/25 (40%)</b></li> <li>Score for emotional difficulties is <b>4/25 (16%)</b></li> <li>Score for conduct difficulties is <b>2/25 (8%)</b></li> <li>Score for hyperactivity-inattention difficulties is <b>3/25 (12%)</b></li> <li>Score for peer problems is <b>1/25 (4%)</b></li> <li>Score for prosocial behaviour is <b>10/25 (40%)</b></li> </ul> <p>The IMAGINE ID study is a collaborative effort of researchers from across the UK and internationally. We are pleased to hear that you have agreed to participate in the study. It will provide you with information about your child's genetic and physical characteristics. The report will be generated only after we have received your consent and you have agreed to participate in the study.</p>
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You will receive a personal summary report of your child's strengths and difficulties. You may find it a useful summary if your child has assessments for services, school or specialist treatments.

Below are some comments we have received from parents who are taking part in IMAGINE ID:

“ I am very happy with the summary report. It will be very useful when my son is changing from one school to another as it summarises all his difficulties. ”

*Nieves from Sleaford*

“ It was great to receive the report. I have shown it to the Educational Psychologist and we are using it to apply for extra help. ”

*Nicola from Coventry*

“ It will be very helpful when asking and pushing for further help. I will bring it everywhere we go. ”

*Sarah from Kent*



## What will happen if we take part?

If you would like to take part we would be delighted. In order to join you will be given a detailed information sheet about the study and a consent form for either you to sign for yourself or on behalf of your child.

Once you have joined, we will arrange for you to complete online questionnaires through a secure internet connection. The questionnaires ask about your family's medical history and about your child's development and behaviour. Both you and your child will be asked to complete an online puzzle. The assessments will take approximately 3-4 hours in total, but you do not have to complete them all in one go. Your responses will be saved as you go along. If you do not have access to the internet the IMAGINE ID team are happy to complete the questionnaires with you in person or over the phone. We will send you a personalised summary report based on the information you have given us.

We will also visit some families to complete further assessments and puzzles at home. You can choose whether or not to sign up to these home visits on the consent form.

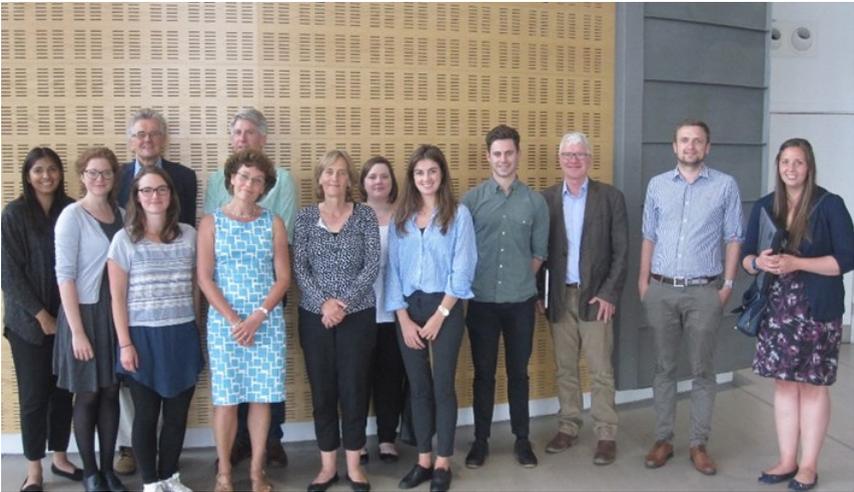


To see a list of frequently asked questions please visit: [http://imagine-id.org/page\\_id=149](http://imagine-id.org/page_id=149)



## Who is the IMAGINE ID team?

The IMAGINE ID team is a group of doctors and researchers who are experts in Clinical Genetics and Mental Health. We are based at University of Cambridge, Cardiff University and University College London. We also work closely with the charity Unique who support thousands of individuals affected by rare chromosome disorders.



# Get involved!



Is your child aged 4 and over?



Does your child have an intellectual disability, learning difficulties or developmental delay?



Does your child have a genetic change?



## Get in touch

01223 254631 or 07711 500477

[imagineID@cimr.cam.ac.uk](mailto:imagineID@cimr.cam.ac.uk)



## Sign up

Receive and return your forms



## Get started!

We will send you login details to the online questionnaires

# Where can I find more information?



The IMAGINE ID Team:

[imagineID@cimr.cam.ac.uk](mailto:imagineID@cimr.cam.ac.uk)

[www.imagine-id.org](http://www.imagine-id.org)



Unique:

[info@rarechromo.org](mailto:info@rarechromo.org)

[www.rarechromo.org](http://www.rarechromo.org)



Speak to your clinical geneticist or genetic counsellor

# iMAGINE iD

Intellectual Disability and Mental Health:  
Assessing Genomic Impact on Neurodevelopment

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