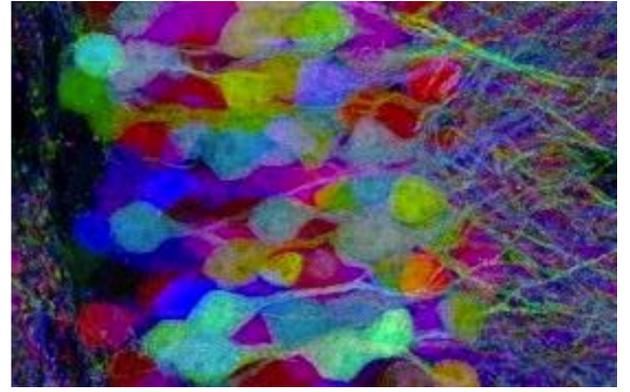


iMAGINE iD

Intellectual Disability and Mental Health:
Assessing Genomic Impact on Neurodevelopment



Chromosomes



Nerve cells in the brain

About iMAGINE ID

When a child is diagnosed with a rare genetic change there is often limited knowledge available to help doctors to answer parents' next question: "So what does this mean for my child?" Our study aims to help expand the knowledge available by investigating the relationship between genetic changes, development and behaviour in children with intellectual disability (ID).

Taking part

The study involves parents or carers filling out an online questionnaire about your child's behaviour in your own home. This will take approximately 2 hours in total but for ease may be done in short sessions over a period of time. After participating you will receive a report which you may find useful when your child is undergoing assessment for services, benefits or specialist treatment. If you wish, we may also visit you at home to complete further puzzles and tasks with your child.

We would love to hear from you if your child:

- Is 4 to 18 years old
- Has been diagnosed with ID, learning problems or developmental delay
- Has a genetic change (e.g. deletion or duplication)

More Information

For more information please contact the Study Recruitment Team:

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W: www.imagine-ID.org

T: 01223 254633

M: 07711 500477

Address: Dr F L Raymond

IMAGINE ID Study
Cambridge Institute for Medical Research
University of Cambridge
Wellcome Trust/ MRC Building
Hills Road
Cambridge | UK | CB2 0XY

If you do get in touch, this does not mean you have to take part!



1. Is my child eligible for the study?

If your child is between 4 – 18 years old and has a genetic change that is likely to be the cause of his or her developmental delay, intellectual disability (ID) or learning problems then they are eligible and welcome to take part in the IMAGINE ID Study.

2. My child is too young for the study

If your child is too young to take part in the study now please get in touch with your contact details anyway so that we can re-contact you once your child has turned 4.

3. My child has learning problems would he/she be eligible for the study?

Yes. If your child has learning problems or developmental delays then he or she would be eligible for the study. This is provided your child also has a genetic change that is likely to be the cause of the problems.

4. I do not live in the UK, can I still participate?

Yes. Families who do not live in the UK can still take part in the IMAGINE ID Study. In order to complete the questionnaire component of the study, you need to have internet access and you can complete the questionnaire online at home. We can arrange Skype face-to-face sessions for those who are happy to do this too.

5. Do I have to have a face-to-face interview?

No. This is an option on the consent form and face-to-face interviews will only be carried out with families who are happy for us to contact them about this. You can of course either way change your mind at any time.

6. I do not have internet access/ I am not good with computers, how would I complete the online questionnaire?

Don't worry, just let us know you need help. You can still complete the online questionnaire either over the phone with a member of our Research Team or someone from our team can visit you at home with a laptop to complete the questionnaire if you wish. Please remember you will still be able to take regular breaks during this process.

7. How long does the online questionnaire take?

We estimate completing the online questionnaire will take 1-2 hours in total but this does not have to be done all at the same time as the information will be saved and stored as you go along.

8. What are the benefits of taking part in the IMAGINE ID Study?

After completing the questionnaire you will be provided with a report which draws your child's strengths and weaknesses and you can use this report in the future with healthcare professionals and places like your child's school.

9. Can I withdraw from the study when I wish?

Yes. You can withdraw from the study whenever you wish without giving us a reason however we would like you to contact us to tell us you no longer wish to take part.