

Key facts and findings from our research so far:

- 3,364 children and adults have joined IMAGINE ID since it opened in October 2014.
- 1,504 (45%) are female and 1,860 (55%) are male.
- The average age of people joining the research is 10 years old, with the most common age of people joining the research (median) at 8 years old.
- 3,182 (95%) of children and adults that have joined IMAGINE ID live in the UK.
- The remaining 182 (5%) of children and adults live in a range of places including Australia, Brazil, Canada, France, Germany, Hong Kong, India, Republic of Ireland, Israel, Italy, Japan, Lithuania, Malaysia, Netherlands, New Zealand, Portugal, Saudi Arabia, South Africa, Spain, Scandinavia, Switzerland, Turkey, United Arab Emirates and the USA.
- 2,549 (76%) of children and adults were referred to the IMAGINE ID study by NHS Regional Genetic Services in the UK.
- The top three NHS Regional Genetic Services that referred the most families to IMAGINE ID are in Birmingham, St George's (South East London) and Leeds.
- 295 (9%) of children and adults were referred to the IMAGINE ID study by the charity, *Unique*.
- 2,336 (70%) of children and adults have completed the Development and Well-Being Assessment (DAWBA) and received their personalised summary report from University College London.
- 498 (15%) of children and adults have completed a further face-to-face assessment with the team at Cardiff University.
- 2,552 (76%) of children and adults registered in IMAGINE ID have a chromosome disorder called a copy number variant (CNV).
- 812 (24%) of children and adults registered in IMAGINE ID have a single gene disorder called a single nucleotide variant (SNV).
- For 1,378 children that registered in the study up until June 2018:
 - 56% attend mainstream school and receive additional help
 - 37% attend a special school
 - 7% attend mainstream school and receive no additional help
- For 1,650 children in the study that have a copy number variant (CNV) the average age they were diagnosed at was 6 years old.
- For 464 children in the study that have a single gene disorder (SNV) the average age they were diagnosed at was 8 years old.
- For 1,526 children whose parents and carers completed a DAWBA questionnaire which was professionally rated and given diagnoses using particular criteria (DSM-5) found that:

- 865 (57%) were found to have at least one or many psychiatric mental disorder diagnoses, which included:
 - 580 (38%) Autistic spectrum disorder
 - 358 (23%) Attention deficit hyperactivity disorder (ADHD)
 - 199 (13%) Conduct disorder or Oppositional defiant disorder (ODD)
 - 183 (12%) Emotional disorder (including anxiety)
- On the DAWBA questionnaire, over 95% of parents and carers reported their child had above average behavioural problems and over 70% of parents and carers reported these were extremely significant behavioural problems, compared to the national average.
- From our medical questionnaire, that over 700 parents and carers have completed so far, 94% reported their child had at least one significant physical health problem.
- The commonest medical problems were difficulties with sleep, muscle or movement disorders, and food and eating difficulties, but the range of additional medical problems was wide.
- 31% of children with completed medical questionnaires were reported to have seizures.
- 54% of children with completed medical questionnaires were reported to have feeding and eating problems.
- 69% of children with completed medical questionnaires were reported to have sleep problems; with the commonest being difficulty getting to sleep and multiple interruptions during sleep.
- It is clear lots of children and adults that are part of the IMAGINE ID study have multiple, complex needs that the healthcare, educational and social systems need to do more to support. We are working hard to raise the awareness of these needs and influence policy to better support changes in these systems.
- The IMAGINE ID team have published and presented lots of research so far (copies are in the science pack in the Avery craft bag). We are working hard to publish and raise further awareness of learning disabilities and the impact on mental health.

If you have further questions for any of the Principal Investigators of IMAGINE ID, please contact them:

- Professor Lucy Raymond: Lucy is Professor of Medical Genetics and Neurodevelopment at the University of Cambridge and Honorary Consultant in Medical Genetics at Cambridge University Hospital, Cambridge Biomedical Campus, UK. Lucy has led research on understanding the genetic basis of learning disability and has identified many new disease-causing genes, which have been rapidly translated into clinical service. flr24@cam.ac.uk
- Professor David Skuse: David is Professor of Behavioural and Brain Sciences at the University College London and Honorary Consultant in Developmental Neuropsychiatry at Great Ormond Street Hospital for Children, UK. Over the past 20 years, David has been a lead researcher in the field of neurodevelopment and autism. d.skuse@ucl.ac.uk
- Professor Marianne van den Bree: Marianne is Professor of Psychological Medicine at Cardiff University. Her research focuses on the development of behaviour, thinking and learning from childhood to adolescence to adulthood. Vandenbreemb@cardiff.ac.uk
- Professor Jeremy Hall: Jeremy is Professor, Director and Research Theme Lead at the Neurosciences & Mental Health Research Institute at Cardiff University. His overarching interest is in the role of genetic and environmental risk factors in the development of neurodevelopmental disorders such as schizophrenia, autism and related personality disorders. HallJ10@cardiff.ac.uk