



Mental Wellbeing in Adolescence:  
Genes and Environment Study

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Lles Meddyliol Pobl Ifanc:  
Astudiaeth Genynnau ac Amgylchedd

# MAGES

## Mental Wellbeing in Adolescence: Genes and Environment Study

**Parent Information Sheet**  
**Please keep this copy**



## **Mental Wellbeing in Adolescence: Gene and Environment Study (MAGES)**

We are researchers from Cardiff University and we are inviting your child to take part in a new research study. Before you decide whether to give permission for your child to take part, it is important that you understand why the research is being carried out and what it will involve. Please take as much time as you need to read this information carefully and discuss it with others if you wish. You are welcome to contact us if anything is not clear to you, or if you would like further information. Our contact details are at the end of this information sheet.

Thank you for taking the time to read this.

### **What is the purpose of the study?**

Good mental wellbeing is extremely important. It enables children to reach their full potential at school, is linked with better relationships with friends and family, and it helps promote better health as children grow up.

Many children have some mental health difficulties from time to time. It is estimated that 1 in 5 young people experience problems such as depression or anxiety. Mental health problems can impact young people's education, relationships and wellbeing.

Genetic and environmental risk factors together contribute to the development of mental health problems. Protective factors, such as having supportive friends, family and teachers help to promote better mental health.

Nearly all genetic studies of mental health are based on adults, despite mental health problems typically beginning in childhood and adolescence. Our aim is to understand how genetic risk factors affect the development of mental health problems. This is important because it will allow researchers to better understand exactly how mental health problems develop, what risk factors are important and whether there are protective factors that can improve young people's mental health.

To achieve this, researchers would need to collect DNA samples from many thousands of young people. One way we could do this is by collecting data from children in secondary schools. Our aim in this project is to see if this is feasible. Therefore this study aims to:

- 1) explore parent, teacher and young people's views on the aims and procedures of this research;
- 2) test whether it is practical to collect saliva samples for the purpose of DNA analysis from children in school;
- 3) examine whether the samples obtained would be of sufficient quality for DNA analysis;
- 4) conduct group based DNA analysis on the saliva samples;
- 5) link DNA samples to information collected by the NHS and other public organisations (e.g. health and education records); and

- 6) link DNA samples to wellbeing data collected as part of the School Health Research Network (SHRN) survey.

### **Why has my child been chosen?**

Your child has been invited to take part because they are in Year 7 or Year 8. Your child's school is part of the School Health Research Network (SHRN) and has consented to be part of this feasibility study.

### **Does my child have to take part?**

It is entirely up to you and your child whether you would like them to take part or not. If both you and your child agree to take part then you will be asked to sign a consent form. Your child will still be free to withdraw from this study at any time without giving a reason.

### **What is involved if my child does take part?**

If your child is willing to take part in the study then we will give them a plastic tube and ask them to provide a small (about one teaspoon) saliva sample. The collection of the sample will not involve any discomfort for your child and will only take a short amount of time. Your child will be asked not to eat or drink anything for 30 minutes before giving the sample as this can affect the quality of the DNA in the saliva. With your permission, these samples will be stored and used for future ethically approved research examining genetic and social risk and protective factors related to mental health.

We would also like to ask your permission to securely link the DNA sample your child provides to:

- 1) Information collected by the NHS and other public organisations (e.g. health and education records); and
- 2) Information about health and wellbeing collected as part of questionnaire surveys completed in school, for example the School Health Research Network (SHRN) survey.

### **What will my child's saliva sample be used for?**

The saliva samples will be tested to make sure they are of adequate quality for DNA analysis. Our research uses the samples and information provided to improve our understanding of adolescent mental health. These saliva samples are valuable for research now, and in years to come when advances in technology can help us to answer questions that we cannot explore with current technology. Therefore the samples we collect may be used in the future by researchers in the UK and abroad undertaking ethically approved research which may include DNA analysis. Your child's sample will be anonymous and will not include their name. Researchers will need to get permission from Cardiff University to use your child's sample for their work.

### **Will you analyse my child's DNA?**

Yes, as part of this study we will carry out analysis of DNA. The types of analyses we will perform are for research purposes only, and therefore we will not be able to provide any individual feedback about your child's DNA and linked information to anyone.

If you request, any unused samples will be disposed of according to locally approved procedures at Cardiff University. Any results generated prior to the withdrawal of consent will continue to be used in this study.

### **Why are you asking for my permission to link my child's sample to other records?**

Giving permission to link your child's genetic information to other records allows us to build a much more complete picture and will ultimately help to improve the health and wellbeing of young people across Wales.

We plan to examine the links between genes, environment and children's health and wellbeing. To do this, we would use a process called 'data linkage' to anonymously and securely link other routinely collected data to your child's genetic information. The other data comes from organisations like schools and the NHS, which routinely collect information such as school student surveys, examination grades and reasons for visiting hospital. With your permission, the DNA sample your child provides for this study may be linked **securely and anonymously** to routinely collected information like these. For example, we work with the Secure Anonymised Information Linkage (SAIL) databank at Swansea University.

All data linkage is undertaken in line with the General Data Protection Regulation (2018) and University governance. Being able to link your child's sample to other education and health data will make their contribution even more valuable in terms of what we can learn through this research and its potential to help people in the future.

### **How would you link my child's genetic information to other records?**

In order to link your child's genetic sample with other data from public organisations (e.g. NHS) we will ask for your child's name, date of birth and postcode. This information will first be used to create an anonymous linkage file which allows different information to be linked together. This anonymous file will **not** include any of your child's identifying details, so no researcher who goes on to use it will ever know whose data they are looking at. Researchers will need permission to access this anonymous data and they will only be allowed to look at the information that they need for their specific study (for example whether your child has ever visited the GP for anxiety or depression).

### **If I allow my child to give a saliva sample will it automatically be linked to other information?**

No. You can choose which parts of the study you would like your child to be involved in. You can give permission for your child to provide a DNA sample, but not to have their sample

linked to other data. Or, you can choose for your child to take part in both parts of the study by consenting for them to provide a saliva sample and allowing us to link their sample to other publically held information (e.g. NHS and school records).

### **What happens if my child and I disagree about his/her participation?**

Your child will only be included in this study if parental permission is provided and if your child also agrees. They will not be able to participate if either you or they do not wish to.

### **Will my child's data be kept confidential?**

All information collected from your child during the course of this study will be kept strictly confidential in accordance with the General Data Protection Regulation (2018). Any information about your child's identity obtained from this research will be stored securely (we use identification numbers instead of names) and separately from any data collected from your child. Only the study team will have access to your child's identifiable data. There are strict laws that safeguard your child's privacy at every stage. Your child's name and identifying information will not be passed on to anyone.

To make the best use of the important information you provide, we will share data (which will be completely anonymous) with qualified researchers at other universities. No information will be supplied that will make it possible for other people to know your child's name or identify them in any way at all from any of the scientific reports that we publish.

### **What happens to the data and samples at the end of the study?**

All data will be anonymised meaning we will remove any identifiers that can identify your child from the data provided. This anonymous information may be kept indefinitely or analysed in support of the research. Other personal data we may have collected, such as your consent for your child to participate in the study will be kept for 20 years, as stipulated by the Medical Research Council's policy for data retention.

Your child's DNA sample will allow us to learn about the links between genes, environment and mental wellbeing so that we can help young people in the future. Therefore, at the end of the study, DNA samples will be retained by the MRC Centre for Neuropsychiatric Genomics and Genomics, Cardiff University for use in future ethically approved research. This allows us to use new techniques and technologies that are developed to continue this important research.

### **What do I have to do?**

If you and your child would like to take part then you will need to return the consent form to the researchers. Your child will have to complete an assent form to say they would like to take part before giving their sample.

## **Are there any risks?**

There are no risks associated with this research.

## **What will happen to the results of the research study?**

The results of the study as a whole will be written up in scientific papers. The results will be presented to professionals interested in young people's mental health. Nobody would be able to identify your child in any way from these results – we do not include names of children or ID numbers in these reports and presentations.

## **What if I decide I want to withdraw my consent?**

Your child's participation in this study is completely voluntary and you or they are free to withdraw at any time without giving a reason. If you wish to withdraw your consent, please contact us to let us know. Our contact details are at the end of this information sheet.

When you withdraw your consent we will remove your details from the database. The samples used or results generated prior to the withdrawal of your consent will continue to be used in this study.

## **Who is organising and funding this research?**

The research is organised by Professor Stephan Collishaw within the Division for Psychological Medicine and Clinical Neurosciences, Cardiff University. The research is currently funded by the Medical Research Council.

## **Data Protection**

We will process data in line with the General Data Protection Regulation and Data Protection Act 2018. In providing your personal data for this research we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards, and is in the public interest.

You have a number of rights under data protection law. Note that your rights to access, change or move your personal data are limited, as we need to manage your personal information in specific ways in order for the research to be reliable and accurate.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at:

[inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk). Further information about Data Protection can be found on the Cardiff University website: <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

## **Who has reviewed and approved the study?**

All research projects need to be reviewed by an ethics committee to ensure research is being carried out in an ethical way. This project has been reviewed by the School of Medicine Ethics Committee at Cardiff University.

If you are unhappy with the way you were treated or with something that happened during the course of the research project. In the first instance, contact the leader of the research project:

*Professor Stephan Collishaw*

MRC Centre for Neuropsychiatric Genetics and Genomics  
Cardiff University  
Hadyn Ellis Building  
Maindy Road  
Cardiff  
CF24 4HQ

**Telephone:** 029 20 688436

**Email:** [CollishawS@cardiff.ac.uk](mailto:CollishawS@cardiff.ac.uk)

Following this, if you are still unhappy, you can be advised on how to contact the relevant Ethics Committee.

## **Further information and queries**

If you or your child have any questions about this research then please contact the research team using the details on the next page.

## Contact for Further Information

**Website:** [www.cardiff.ac.uk/MAGES](http://www.cardiff.ac.uk/MAGES)

**Email:** [MAGES@cardiff.ac.uk](mailto:MAGES@cardiff.ac.uk)

**Telephone:** Sarah Rook (Research Assistant) 029 20 688392 / Naomi Warne (Research Assistant) 029 20 688473

**Post:**

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MRC Centre for Neuropsychiatric Genetics and Genomics  
Cardiff University  
Hadyn Ellis Building  
Maindy Road  
Cardiff  
CF24 4HQ

**Thank you for reading this information. This copy is for you to keep. We would like to thank you for considering to take part in this study. If you would like your child to participate, please return the parent consent form in the Freepost envelope provided.**