



## PARTICIPANT INFORMATION SHEET

### How does the brain develop through adolescence into adulthood?

#### What is the purpose of the research?

To look at how the brain develops and changes between adolescence and adulthood and to see if differences in brain structure can affect health and behaviour. A brain MRI scan shows up the detailed structure of the brain and can distinguish between different types of brain tissue including grey matter, white matter, blood and cerebral vessels. We will conduct a new Brain MRI scan to look at how differences in brain structure might have an impact on health and behaviour. We are also interested in seeing how the brain works. While you are doing simple tasks, for example, such as identifying projected letters of the alphabet, the scan can show us how your brain is working.

You have been asked to participate in this study because you took part in a brain scan study a few years ago and your new brain scan will be compared to the previous scan, to see how your brain has changed and developed.

#### Do I have to take part?

No. It is up to you to decide if you wish to take part. If you choose to take part, you can still withdraw at any time. This will not affect your involvement in other Children of the 90s studies.

#### If I decide to take part, what will I have to do?

##### Before the Visit

- First, let us know if you'd like to take part by completing and returning the attached form in the freepost envelope provided.
- Once we have your form, we will contact you to check you can take part. We will ask you about your medical history and some screening questions to check that you are eligible to take part in the MRI scan.
- If you're eligible, we will book an appointment for you in Cardiff at the Cardiff University Brain Research Imaging Centre (CUBRIC).
- Before you go to CUBRIC, we will ask you to complete a questionnaire on-line at home. This will take around 20 minutes and we will send you a unique log-on user name and password with your appointment confirmation letter.

##### On the day of the visit

- On arrival at CUBRIC, you will be met by a Children of the 90s fieldworker who will ask you some questions to check there have been no changes to your eligibility for the study since we spoke to you on the phone. You will be asked to look at this Information Sheet again and provide consent for the study.
- In Cardiff, we will scan your brain in an MRI scanner. This will take about 90 minutes. You will be positioned comfortably on a scanning bed that slides into the tunnel-shaped magnet. When the

scanner is turned on, it makes loud humming and knocking sounds. Earplugs will be provided. An intercom system allows you and the radiographer to speak to each other. The procedure is not painful, just noisy.

- We will also ask you to complete some psychological questionnaires and cognitive exercises.
- During the first part of the brain scan you will be asked to lie still but you may wish to watch a DVD or just rest. During the second part we require you to perform a simple task, for example identifying letters of the alphabet projected onto a screen one after another. Following on from this will be a sequence where you will again be asked to lie still. The tasks will be fully explained to you beforehand. The whole session will last about 90 minutes, including time to set up the scanner.
- During your visit you will be asked to complete some interviews and exercises. Our Children of the 90s Fieldworker will ask you some questions about unusual psychological experiences that you may have had, which will take 20-40 minutes to complete. We will also ask you some questions about your work/education, family and friends which take about five minutes, and we will ask you a few questions about your medical history. You may have been asked these questions previously, but we need to ask them again at the same time as the scan. Lastly, you will be asked to spend about 20-30 minutes doing some simple tests of memory, knowledge and concentration – again you will have done similar tests in the past. For example, defining the meaning of words, and remembering a list of numbers.
- With your written consent, your interviews and cognitive exercises will be audio recorded for data quality and training purposes by the research team. All the answers you give will be completely confidential and no researcher will be able to link your answers back to you. Recordings will be stored indefinitely and securely by Children of the 90s with only a study ID attached. No transcripts will be made of your interview.
- With your consent, the data collected in this visit will be linked with other data that we have collected about you. In recent years we have sent you a 'play your part' pack. It explained your role in Children of the 90s now you are an adult. It also asked whether you would allow us to use your health (NHS) and other official records (education, benefits, earnings and any criminal conviction or caution records you may have) – including linked primary care (GP) and secondary care records. Many participants have filled in a form and let us know their decision about these questions. If you haven't yet completed a form, we will discuss this with you during your study visit and ask you to complete the consent form. With participants' consent, this study will access secondary care mental health records, where they exist, to gain further information about contact with the NHS mental health services.

If you haven't yet completed the consent form and would like to look at the pack in advance, you can download it here: <http://www.childrenofthe90s.ac.uk/participants/playingyourpart>

- Altogether your visit will take just over 3 hours, plus travel time to and from Cardiff. You will be given time for breaks during your visit and light refreshments will also be provided.

### **You won't be able to take part if you:**

- Have a known brain condition, including frequent migraines and epilepsy
- Are pregnant or think you might be
- Have a medical implant such as a pacemaker
- Have stents, metallic dust in your eyes, metal prostheses, surgical clips or have ever worked with metal without eye protection
- Have non-removable body piercings
- Have a contraceptive coil with metal in it fitted (we can check this by knowing the make of the coil)
- Are claustrophobic (afraid of small or closed spaces)
- Have Type 1 diabetes

- Have ever had a serious head injury

Before you participate in the study, we will ask you some questions to make sure that you are eligible to take part in the scan.

If you're in any doubt about whether you're able to take part, please call us on 0117 3310010

### **Will I receive any compensation?**

Yes, we will give you £40 as a thank you for taking part. This can be provided in either shopping vouchers or as a bank transfer, depending upon your preference. We will also reimburse your out-of-pocket travel expenses (either via cash on the day, if less than £50, or via a fee form). We can also book overnight accommodation if you need us to. Please keep all your receipts and we'll pay you back on arrival in Cardiff. We'll also give you a letter for your employer asking them to give you paid time off work. On the day, there will be hot and cold drinks, and snacks.

### **Are there any benefits if I take part?**

By taking part you are helping us with research that we hope will help people in the future but there are no known benefits for you as an individual.

### **Are there any disadvantages to taking part?**

Some people find the MRI scanner claustrophobic. Very rarely, some people feel dizzy, queasy or get a tingling sensation in their limbs. If you experience any of these symptoms or just don't like the experience, tell us straight away. We'll stop the scan immediately.

### **What exactly is MRI?**

MRI or magnetic resonance imaging takes pictures of the inside of the body using magnetic fields and low-energy radio waves. There is no exposure to x-rays or other forms of ionising radiation.

You will be asked to lie inside a large, cylinder-shaped magnet. When switched on, the scanner produces a strong magnetic field which you cannot feel. This can detect radio waves which are produced by water atoms inside the body. The scanner picks up these radio-wave signals and a computer turns them into a picture.

### **What happens if you see something unusual on my scan?**

Although this is not a diagnostic scan, rarely, something unusual may be detected on your scan. CUBRIC is required to forward information about anything unusual on your scan to your GP. When you visit CUBRIC, therefore, we will ask you to consent to receive feedback regarding any unusual findings seen on your scan. Without your consent to this feedback, and notification of your GP details, unfortunately you will not be able to take part in the study. If we notice something on your scan, we will promptly obtain a radiological review and report of the scan. If further investigation is required, we will:

- contact you and tell you that you need to see your doctor (GP)
- check your GP's details with you
- contact your GP and forward the report to your GP

### **Do I have to wear special clothes?**

The scanning room can be quite cold, so please bring a warm jumper or cardigan. We cannot have metal in the MRI scanner room, so we will ask you to change into clothes which we will provide (scrubs), and which we know do not contain metal. We have a private room where you can change. We will ask you to remove any piercings, bars and studs prior to scanning.

### **Do I have to fast before the scan?**

No, you can eat and drink as normal.

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

If you'd like to take part, please complete the attached form and return it in the enclosed pre-paid envelope.

## **Confidentiality and data protection**

Any data we collect from you will be stored with an individual ID number but with no personal information (your name, address or date of birth) attached. Files that link this ID number to your personal details will be securely stored. As mentioned earlier, the data will be used for research purposes only and will only be analysed by researchers who have been approved by the Children of the 90s executive committee. None of these researchers will have access to your personal information. We will keep your personal details confidential and separate from your research data. Your personal details will not be shared with third parties except for certain service providers working on our behalf, for example VCars if you ask us to book a taxi for your visit.

Children of the 90s is compliant with GDPR (General Data Protection Regulation) and with the Data Protection Act (2018) regarding the collection, processing, storage and disclosure of personal information. If you would like to find out more, please see our privacy notice here:

<http://www.bristol.ac.uk/alspac/participants/privacy/>

The results of the study will be published in scientific journals and a summary of the results will be provided to all study participants. No individual information or names will be published.

## **What if I have any concerns?**

Speak to any member of staff when you attend who will do their best to answer your questions. You can also contact the Children of the 90s team, or the Children of the 90s executive committee.

If you want to make a complaint, please contact the Children of the 90s team using the contact details below.

- 0117 331 0010
- [info@childrenofthe90s.ac.uk](mailto:info@childrenofthe90s.ac.uk)
- Children of the 90s, Oakfield House, Oakfield Grove, Bristol, BS8 2BN

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

This research is organised by Children of the 90s and is funded by the UK Medical Research Council (MRC).

In addition, Children of the 90s receives core funding from the Wellcome Trust, the UK Medical Research Council and the University of Bristol.

## **Who has reviewed this research project?**

All research is looked at by an independent group of people, called a Research Ethics Committee. Their role is to protect your safety, rights, wellbeing and dignity. In this case, the research has been reviewed and approved by:

- Children of the 90s executive committee
- Children of the 90s ethics and law committee (ALEC)
- Children of the 90s original cohort advisory panel (OCAP)

## **Who do I contact for further information?**

Children of the 90s

Tel: 0117 331 0010

Email [info@childrenofthe90s.ac.uk](mailto:info@childrenofthe90s.ac.uk)

Web: [www.childrenofthe90s.ac.uk](http://www.childrenofthe90s.ac.uk)