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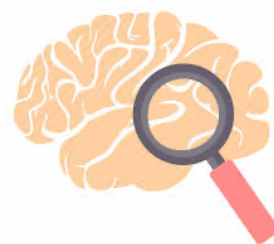
PARTICIPANT KEY POINTS DOCUMENT

**Study title: Alzheimer's Biomarker Consortium for Down Syndrome (ABC-DS)
29 March 2023 (Version 1.0)**

ABC-DS Key Points:

This sheet should tell you everything you need to know about the study and taking part in it. If you would like further information or are interested in taking part, please get in touch with us.

1. People with Down's Syndrome are much more likely than other people to get Alzheimer's Disease when they are older.
2. In our study, we are looking at proteins in the brain (amyloid and tau) to help us understand how Alzheimer's Disease develops in Down's Syndrome and to try and develop medicines that could help.
3. If you take part, you will come to Cambridge 4 times over 5 years. When you visit Cambridge, you might stay in a hotel. You will not have to pay to travel to Cambridge or to stay overnight.



4. The first day of the study lasts from roughly 11am - 5pm. The second day lasts from roughly 9am - 4pm. Across these two days you will:

- *Do some puzzles for about 4 hours. We will videotape these unless requested not to.*



- *Have a check-up, like you would have at the doctors.*



- *Have a CT scan which takes 3-4 minutes.*



- *Have a blood test where we will take just over 4 tablespoons of blood.*



- *Have two PET-MRI brain scans to look for amyloid and tau protein. For each one, you will be lying down in the scanner for about 45 minutes.*



5. You must lie very still during the CT and PET-MRI scans. The space you lie in for the CT and PET-MRI scans is small. You might not like this if you don't like small spaces.



- The PET-MR scanner is very noisy. You will hear loud buzzing and knocking sounds but won't feel anything. It does not hurt.
- We will put some soft earplugs in your ears to help protect them from the noise and you can listen to some music that you like.



6. For the PET-MRI scans, a small needle will be put in your arm to put some of radiation into your body. Radiation is a chemical that helps us to see if there is any amyloid or tau in your brain.



- Radiation may cause cancer many years later, but we will only give you small amounts. 50% of the general population will develop cancer during their lifetime. Taking part in this study may increase the chances of this happening to you to about 50.09%.
- Because of this radiation, you will not be able to take part if you are pregnant, or if the person coming with you to Cambridge is pregnant.



7. For the PET-MRI and blood test you will have a small needle put in your arm. This is done by someone who has done this lots of times before. Your arm may be a bit sore afterwards, but we have never had anyone seriously hurt before.



8. We tell your doctor that they are taking part unless you don't want us to.



9. If you decide to take part, you can withdraw from the study, at any time, without giving reason. This will never affect any medical treatment that you get.



If you are interested in hearing more about the study, please send an email to [**ciddrg@medschl.cam.ac.uk**](mailto:ciddrg@medschl.cam.ac.uk)



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