

Template letter for GMCS to send to participants

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Dear X,

Taking part in the 100,000 Genomes Project

You may remember agreeing to take part in the 100,000 Genomes Project. You were under the age of 16 at the time, so your parent(s) or legal guardian(s) signed a consent form on your behalf. Now that you are over 16, it is up to you to decide whether you would like to carry on taking part in the project as an adult.

You may have already had results back from the project that could explain your condition, or you might not have had results yet. If you haven't had your main results back yet, the project team will still return them to your doctors or the team caring for you, even if you decide that you don't want to be part of the 100,000 Genomes Project after that.

If you decide that you **do** want to take part in the project as an adult, we will be able to contact you again after you have had your main results, and collect more information about you. This means that, through research in the future, if the project team find something that might be relevant to your health in the future we will be able to return these to you.

With this letter you will find a copy of an information sheet giving more information about the choices you can make. You can find more information at www.genomicsengland.co.uk and [any local GMC links].

If you would like to carry on taking part in the 100,000 Genomes Project as an adult, please fill in the form you were sent with this letter and send it back to [GMC address] in the enclosed SAE. If you DON'T want to carry on taking part in the 100,000 Genomes Project as an adult, please e-mail [GMC address] or ring [GMC phone number] to let us know.

You may find it difficult to make up your mind so if you have any questions at all or would like to talk this over with someone please e-mail [GMC address] or ring [GMC phone number].

Some young people have an adult who helps them make decisions about their healthcare. This could be a parent or other relative or friend. If your friend or relative contacts us at [GMC e-mail address] or rings [GMC phone number] we can send a form for them to fill in, to tell us whether you would like to carry on taking part as an adult.