**LIVING WITH SICKLE CELL OR THALASSAEMIA TRAIT**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please feel free to ask your family, friends, sickle cell or thalassaemia counsellor, or the researchers if there is anything that is not clear or if you would like more information.

**What is the study about?** We are interested in your experience of having sickle cell or thalassaemia trait. We would like to discuss how having a trait has affected your life and your relationship with people, such as family and friends. We would also like to chat about what kind of advice should be available to people like you. By taking part you will help those who provide support to better understand the needs of those who carry a trait for a genetic disorder.

**Why have I been approached?** During the study 20 people who carry a sickle cell trait and 30 people who carry a thalassaemia trait will be invited to talk about their experiences. If you have been given or sent this information sheet, no one would have told us your name or address or given any personal details about you.

**Who is involved in the study?** The study is led by researchers from the Department of Health Sciences, University of York and also involves DeMontfort University and Middlesex University. The study has the support of the Sickle Cell Society and the UK Thalassaemia Society, two major voluntary organisations. All the researchers who contact you have been checked out by the Criminal Records Bureau.

**Do I have to take part?** No**,** the study is entirely voluntary. Whether you choose to take part or not, will not affect your health or social care in any way. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you do decide to take part, you are free to withdraw from the study at any time and this includes during the interview. You do not need to give a reason. Withdrawing from the study will not affect present or future care.

**What is involved?** If you are willing, we would ask you about your experiences of having sickle cell or thalassaemia trait and whether or not carrying a trait has had much impact on your life. This interview would be audio-recorded, with your permission, and would take around 45 to 60 minutes. We will choose people to reflect a range of experiences. We could interview you at your home or at another venue of your choice. We are happy to talk to you in a language of your choice too. We will pay reasonable travel expenses.

**What happens to the information?** All the information is confidential. No one will be able to identify you from the study. Nor will we share what you tell us with health professionals or family members, including your partner or children. However, if you tell us something, which we believe place you or others at serious risk, we are obliged to tell the relevant authorities.

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The audio-files from interviews will be transcribed (listened to and written down in full). The notes taken by researchers, the audio-files and the transcripts will be kept safely in locked offices at the University of York. Only the research team can access them. Notes, audio-files and transcripts will be given a code to safeguard confidentiality. At the end of the research the audio tapes will be erased and the interview transcripts will be stored for five years. All data will be treated in accordance with the current Data Protection Act.

**What are the possible advantages of taking part?** There may be no personal benefit. By taking part you may gain some more knowledge about sickle cell or thalassaemia. At the end of the study you will be given a feedback sheet summarising the results of the study and what recommendations for improving practice are being made as a result of the research.

**What are the possible disadvantages of taking part?** You might become more anxious about being a carrier but you will be given verbal and written information explaining more about sickle cell. You will have the opportunity to speak further to someone from the NHS screening services should you wish.

**What if something goes wrong?** In the event that something does go wrong and you are harmed during the research there are no special compensation arrangements. If you are harmed and this is due to someone’s negligence then you may have grounds for a legal action for compensation against University of York (who have indemnity for negligent harm) but you may have to pay your legal costs.

**What if I wish to complain?** Please raise any difficulties or questions with Karl Atkin (01904) 321355 (8am to 5pm weekdays) or email [karl.atkin @york.ac.uk](mailto:another@york.ac.uk). If the research team are unable to give you a satisfactory answer, please contact Professor Hilary Graham (Head of Department, Department of Health Sciences, University of York) on (01904) 321934 or email [hilary.graham@york.ac.uk](mailto:hilary.graham@york.ac.uk)

**What will happen to the results of the study?** The results will be made available following the completion of the study in 2014. We will provide a summary and you will receive a copy of this if you wish. We will also hold workshops in several parts of the country to feed back our findings and to get ideas about what policies should be put into place to better support those who carry sickle cell or thalassaemia trait. You will be invited to one of these workshops, although it is up to you, whether you attend or not. You can also call members of the research team at anytime to discuss the progress of the research.

**Who is organising and funding the study?** The study is organised by researchers at University of York and

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De Montfort University. The University of Middlesex, University of West London, The Sickle Cell Society and UK Thalassaemia Society are involved in the research too

The study is funded by the Economic and Social Research Council (ES/1035508/1). The ESRC is the UK's largest organisation for funding research on economic and social issues. Its aim is to produce evidence to improve the economic, social and cultural life of people living in the UK (<http://www.esrc.ac.uk/>). The study has been reviewed and approved by the University of York Human Research Ethics and Governance Committee.

**Contact for further information** If you would like any further information about the study please contact Karl Atkin Tel: (01904) 321 355. Thank you for taking the time to read this information sheet. We are very grateful to you for considering participation in this study.

**Professor Karl Atkin, Seebohm Rowntree Building, Department of Health Sciences, University of York, York, YO10 5DD. Tel: (01904) 321 355** [**Karl.Atkin@york.ac.uk**](mailto:Karl.Atkin@york.ac.uk)**.**

Other members of the research team include: Professor Simon Dyson, De Montfort University (0116 257 7751, [sdyson@dmu.ac.uk](mailto:sdyson@dmu.ac.uk)); [Researcher tba]; Professor Waqar Ahmad (University of Middlesex); Professor Elizabeth Anionwu (University of West London). The Sickle Cell Society (<http://www.sicklecellsociety.org/>) and UK Thalassaemia Society (<http://www.ukts.org/>) are also offering advice and support.

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