Hi, my name is Emily.

I am doing research at the University of Surrey.

I am interested in understanding what it is like being Black and getting older with a lifelong disability.

I would like to learn more about this by talking to you.

I would also like to learn more by talking to carers.

Why have I been invited to this study?
You have been invited because I want to hear about your experience of being Black and getting older with lifelong disability.

What do I mean by disability?

A lifelong disability is a difficulty that a person is born with or a difficulty that begins when a person is a child.

A lifelong disability affects everyone differently. It might make;
- Getting around on your own difficult
- Seeing or hearing difficult
- Learning or understanding complicated information difficult

Someone with a lifelong disability might have;
- Down’s Syndrome
- Cerebral Palsy
- Learning Disability
- William’s Syndrome
- Prader Will Syndrome
- Usher’s Syndrome
- Spina Bifida
- Congenital Rubella Syndrome
- Vision loss and Blindness
- Hearing loss and Deafness

What do I mean by older?

In this study, I mean someone who is 40 years old or older.

Do I have to take part?

No. You do not have to take part.

It is your choice to take part.

You can say “no” and that is ok.

What will happen if I say yes to taking part
I will find a day to come and meet you at a place of your choice.

You can ask someone you trust to be there if you want.

I will talk to you about my research.

You can ask me questions if you have any.

I will ask you questions about getting older.

If you would like, you can invite your family/key worker to sit with us.

I will use a voice recorder machine to help me remember what you tell me.
After you have told me all that you would like me to know and I will have to say “Goodbye”.

What are the possible good things about taking part?

I hope that this research will help understand how getting older can be made easier for Black older people with lifelong disability.

Are there any bad things about taking part?

Some people may feel upset when thinking about their disability or getting older.

You can ask a family member or carer to help with answering questions if this makes you feel better.

What if there is a problem?
You can talk to me or someone about the problem.

You can ask me questions.

You can tell me you don’t want to take part anymore.

What happens to what I tell you?

I will not use your real name in my work.

I will lock the information away.

This is to keep your information safe so that others can’t take it.

What will happen after?

I will talk to my teacher, who is called a supervisor about what I have learnt.

I will need to write a report about what I learnt.

This will take a long time.
If you like, I can send you information on what I have learnt from you.

Who has checked the study?

People from the University of Surrey have checked to make sure it is safe for me to collect this information.

What if I am upset by this project?

If you want to tell people that you are upset, you or your carer can contact the University of Surrey:

University of Surrey:
Phone: +44 (0)1483 683490
Email: rigo@surrey.ac.uk