



Faculty of Wellbeing, Education and Language  
Studies  
118, Horlock Building  
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Walton Hall  
Milton Keynes, MK7 6AA

Participant Information Sheet

Healthcare Professionals

Further information about the research project:

**Title of the project:** Diabetes appointments for people with learning disabilities

IRAS ID: 216015

OU HREC Reference: HREC/2017/2522/Rouse/1

### **What is the aim of this research?**

This study aims to improve understanding of the experience of diabetes care appointments for adults with mild-to-moderate learning disabilities, their supporters and healthcare professionals. This study will focus particularly on how 'quality' care is described in relation to primary care diabetes appointments for adults with learning disabilities.

### **Why this project?**

- People with learning disabilities are more likely to be diagnosed with type 1 or type 2 diabetes than people without learning disabilities.
- Audits & surveys have so far provided a mixed picture of the quality of diabetes care for people with learning disabilities. These studies use varying definitions of 'quality care'.
- No studies have explored what is considered a quality diabetes care appointment for people with learning disabilities by the key stakeholders in these appointments (e.g. diabetes patients with learning disabilities, those who support their diabetes management and healthcare professionals who provide diabetes care for adults with learning disabilities).

### **Invitation to participate**

You are invited to participate in this research if:

- Have been involved in the provision of diabetes primary care services for a patient with mild-to-moderate learning disabilities within the last 6 months.
- Have provided this support located within Cambridgeshire & Peterborough CCG geography.

### **What should I do if I think I would like to take part?**

- Read the rest of this Participant Information Sheet
- Contact the researcher expressing your interest and ask any questions you may have (contact details are provided at the end of this document).



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### **Who is conducting the research and who is it for?**

Lorna Rouse is carrying out this research as part of her PhD project funded by the Open University.

### **What will happen to the information I give?**

Your interview will be audio recorded using a digital voice recorder. The audio recording will be typed into a transcript by the researcher who interviewed you. Any personal information given will be confidential to the research team. Anonymity will be maintained within the report so individuals are not identifiable. The researcher will then analyse your transcript and the transcripts of interviews from other people in the study and write a report for their PhD thesis. They may also write a paper and give presentations. The report, paper and presentations will contain anonymous quotes from the interviews. Therefore what you have said will be made public but your name will not. If you wish, we can send you a summary of findings from the research.

### **Your participation in the research project**

#### **Why am I being invited to participate in this research?**

You have been invited to participate in this research because you have told us that you are part of a care team that provides diabetes primary care services to at least one adult with mild-to-moderate learning disabilities. For example, this may be through your role as a diabetes nurse, GP, dietician or healthcare assistant.

#### **Whether I can refuse to take part**

Participation is entirely voluntary; you do not have to take part. You can refuse to take part in this study at any time before during or after the study up until the final report has been written. Your choice to participate will not impact on you job.

#### **Whether I can withdraw at any time, and how**

You are free to withdraw from this project at any time until the final report has been written (predicted to be December 2018) without explaining the reasons why. If you decide to withdraw from the study your interview (audio file and transcript) and any other information relating to your involvement in the study will be destroyed.

To withdraw you can: talk to the researcher before, during or after the interview, contact the researcher by phone or email (contact details below), complete and return the withdrawal slip attached to the consent form.

#### **If I take part in this research, what will be involved?**

One-to-one interviews will be conducted during January 2018 - May 2018. The interviews will take approximately 30 minutes to 1 hour and would be conducted at your workplace or another location (e.g. community venue) or via Skype/phone if you prefer, at a date and time that is convenient to you. To ensure your safety, all our researchers carry photographic identification. Reimbursement will be available for reasonable travel expenses to interview venues. Travel expenses will be paid at 37.5 pence per mile or public transport rates. All claims must be accompanied by relevant receipts.

### What will the interview be like?

If you agree to take part the researcher will arrange a convenient time and place to meet with you and carry out an interview. The interview will be about your experience of providing diabetes care to someone who has mild-to-moderate learning disabilities within primary care settings. We want to hear about your views in your own words so although the interview will be guided by a schedule there will be no set questions and answers and there are no right or wrong answers. The interview will last for around 30 minutes to 1 hour and will be audio recorded using a digital voice recorder. This will allow you to talk in-depth about your experiences.

### What will we be talking about?

We are interested in your experience of all aspects of providing diabetes care to people with learning disabilities in primary care including before, during and after the appointments.

The kinds of topics we will be asking you about include: your experiences of making preparations for appointments, your experiences of communicating with people with learning disabilities and their carers, your views on what makes a good/poor quality appointment for adults with learning disabilities.

### Is it confidential?

Your participation will be treated in **strict confidence** in accordance with the Data Protection Act. No personal information will be passed to anyone outside the research team. The researcher will write a report of the findings from this study, but no individual will be identifiable in published results of the research.

Confidentiality would only be broken if you are at serious risk of harming others then we will have to share your information with appropriate agencies, this may be without your permission. In this unlikely event we would discuss it with you first.

### How your participation in the project will be kept confidential

In order to protect your anonymity your name and the names of any people or places you mention will be changed when your interview is transcribed. This means that your name will only be known to the researcher who interviews you. Any information which may make you easy to identify will also be changed e.g. your workplace. Your name will not be connected to any information stored for the project. The interview transcript will be seen by the researcher and their supervisors at The Open University. Electronic and hardcopy files relating to your interview will be stored securely. Once the project has been completed the audio recording of your interview will be destroyed.

### Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety

A potential risk involved in taking part in this study is that it is possible you may find talking about some experiences upsetting. If this happens you can:

- tell the interviewer that you would like to take a break at any time
- choose not to answer any questions without giving an explanation
- stop the interview without giving an explanation.



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### Whether there are any benefits from taking part

There are no direct benefits to you of taking part but the study may help to improve understanding of diabetes care appointments for people with learning disabilities.

### What happens now?

You should take at least 24 hours to consider whether you would like to take part in this study and discuss your decision with other people if you wish. Please contact the researcher using the contact details below if you think you would like to take part in the study. The researcher will ask you a few questions about yourself. Your participation is entirely voluntary. If you have any questions about the study I would be very happy to answer them.

### Contact details

**If you have any questions or would like any further information about the study please use the contact details below to get in touch with the researcher Lorna Rouse.**

<b>Researcher</b>	<b>Project Supervisor</b>
Lorna Rouse	Dr Elizabeth Tilley
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