

# INFORMATION SHEET

*(Interview Participant)*

## **Project Title:**

### **Access to Justice for People with Mental Health Conditions and Learning Disabilities in England and Ireland**

(Version 2, 4 February 2021)

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#### **1. Invitation**

My name is Edmore Masendeke. I am a disabled Early-Stage Researcher on the DARE (Disability Advocacy Research in Europe) Network and a PhD student at the University of Leeds School of Law in the UK.

I am contacting you because I need your kind assistance on the research I am conducting as part of my PhD thesis. However, before you decide to do so, it is important that you understand why the research is being conducted and what it will involve.

Please take time to carefully read everything on this information sheet. It will give you the basic information that you need to know before deciding if you want to participate in my research.

In addition to reading this information sheet, you may also ask me any question that you think will help you in deciding if you should take part in this research. Also, feel free to let me know if you want me to go through this form with you for any reason.

Also, feel free to discuss it with others if you wish. The most important thing to me is that you understand what the research is about and what your involvement means before deciding to take part in this research.

#### **2. What is the purpose of this research?**

This research is about the communication support which is available to defendants with mental health conditions or learning disabilities during court proceedings in England and Ireland. In this research, I am interested in finding out how consistent is this kind of support with international human rights standards, how well it is working in practice and what could be done to make it more effective.

### **3. Who am I expecting to hear from?**

I am expecting to hear from people with mental health conditions or learning disabilities who have experience of receiving communication support as defendants – at either the Magistrates’ and/or Crown Court – in the past 4 years. This includes people who have direct experiences of being supported by intermediaries, advocates, communication specialists, family members or friends, and understand the benefits, challenges and demands of such support provision.

### **4. Do I have to take part?**

You do not need to take part in this research if you do not want to. It is entirely up to you to decide. You do not also need to decide immediately. Please take time to carefully read this information sheet and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

### **5. What will my involvement be?**

I am interested in finding out from you what communication support is available to defendants with mental health conditions or learning disabilities in England, how well this support is working in practice and if there is anything that could be done to make it more effective. The key themes arising from all the interviews will be used as discussion points in focus group discussions with support providers in a later stage of this project.

If you agree to take part in this research, I will have interview with you. The interview will be more like a conversation. Basically, you will be having a conversation with me on your experience of being supported with communication in court; and all you need to do is to help me with answers to the questions I will be asking you. However, you do not need to answer a question or say anything that you do not wish to say to me during the interview.

If you decide to take part in this research, I will ask you to confirm that you have fully understood the research and the role you will play in it at the start of the interview.

Depending on your preferences, the interview will be conducted via telephone or on Zoom, Microsoft Teams, Microsoft Skype for Business or Blackboard Collaborate, which are externally hosted cloud-based services. You may use the following links to view these platforms privacy policies:

Zoom: <https://blog.zoom.us/zoom-privacy-policy/>),

Microsoft Teams: <https://www.microsoft.com/en-ww/microsoft-365/microsoft-teams/security>

Microsoft Skype for Business: <https://support.microsoft.com/en-us/office/privacy-supplement-for-microsoft-skype-for-business-f2100fe5-20f2-4f87-a986-2a823b013b41>

Blackboard Collaborate: [https://help.blackboard.com/Privacy\\_Statement](https://help.blackboard.com/Privacy_Statement)

Written notes of the interview will also be taken. The interview will last for about 1 hour.

You may make any requests for reasonable adjustments.

If you want somebody to be with you, please make sure they know that they are not being interviewed. They should not answer for you and should speak to us only if that helps you. I will ask them to promise not to tell anybody else what you say in the interview.

I will be interviewing you. However, as some people may find my speech to be unclear, my personal assistant, Parth Shah, may sometimes help us by repeating what I say to you. Parth will also help me take you through the consent form. Parth will respect your privacy by not disclosing any content discussed during the study.

## **6. What are the possible disadvantages and risks of taking part?**

No physical risks are anticipated. Should you become distressed at any point during the interview, or need a break, please let me know. I will also send you a list of organisations providing emotional support, and organisations working to improve access to justice for disabled people.

## **7. What are the possible benefits of taking part?**

This is purely an academic research. There are no immediate or direct benefits for participating in it. However, I hope that the findings from this research and the lessons which I may learn from these results will go some way to improve the support which is available for defendants with mental health conditions or learning disabilities.

## **8. How do I withdraw from the study?**

The fact that you have initially agreed to take part does not mean that you should be part throughout. You can still withdraw from the study at any point, even up to 60 days after the interview. After 60 days, I intend to have started my data analysis and it will be difficult to separate your data from the rest at this point.

You do not have to give me a reason for withdrawing. Withdrawing from the study will have no effect on you.

If you withdraw from the study, I will not retain the information you have given thus far, unless you give me permission to do so.

## **9. Will my taking part and my data be kept confidential?**

All the data which collected in this project will be treated in accordance with the UK Data Protection Act 1998. The records from this study will be kept as confidential as possible. Only my supervisors, my personal assistant, transcribers and I will have access to the files and any audio files. Any supervisors, transcribers or personal assistants, who have access to what you say during the interview, will also agree to maintain the confidentiality of the interview.

If you need somebody to be with you to help support you to take part, please let us know in advance. I will need to check they understand that their role is to support you, and not to take part on your behalf. I will also need to ask them to sign a confidentiality agreement in which they promise not to tell anybody anything about what was said during the interview.

As part of the measures needed to keep what you say during the interview confidential, I kindly ask you or your support person not to make your own recording of the interview.

Your name will not be used in any reports or publications resulting from the study. All digital files, transcripts and summaries will be given codes and stored separately from any names or other direct identification of participants. Any hard copies of research information will be kept in a safe at my university residence.

## **10. Limits to confidentiality**

Confidentiality will be maintained as far as it is possible, unless you tell us something which implies that you or someone you mention might be in significant danger of harm and unable to act for themselves; in this case, I may have to inform the relevant agencies of this, but I would discuss this with you first.

## **11. Will I be recorded, and how will the recorded media be used?**

Because I want to retain the information you give me as accurately as possible, I will use audio recording software which has been installed on my computer to record your voice during the interview. So that you are aware of when I am recording, I will advise you at each moment that the recording starts or ends so that you know.

The audio recording of your interview will be used only for analysis. No other use will be made of the recording without your written permission, and no one outside the project will be allowed access to the original recordings. I will keep the audio recording safely and securely from persons who are not part of my research team. I will upload password-protected audio files of the interview on a university drive. The recordings will however be finally destroyed 6 months after I am awarded my PhD.

## **12. What will happen to the results of the research project?**

I will publish the results of the research in my PhD thesis which will be available from the University of Leeds, UK. However, it is important that I remind you that you or any persons you refer to in your interview will not be identified in any such report or publication.

## **13. What if I have a question or concern?**

If you have any questions regarding this study, please contact me directly using the following details:

Edmore Masendeke  
School of Law, Liberty Building  
University of Leeds  
Leeds LS2 9JT  
Email: lw12etm@leeds.ac.uk  
Telephone: +44 07810 308 216

If you have a concern which relates to the conduct of the project in the first instance you can contact me directly through the contact information I have provided above. If you feel, however, that I have not adequately addressed your concern, you may contact my supervisors at the University of Leeds School of Law for further assistance. I will provide my supervisors' contact details in the consent form.

## **14. Who is organising or funding this study?**

The study is funded by the Commission of the European Community.

## **15. Who has ethically reviewed the project?**

This research has been ethically approved by the University Research Ethics Committee (UREC) of the University of Leeds, United Kingdom.

## **16. What do I do now?**

If you are interested in participating in this study, please contact me on +44 07810 308 216 or lw12etm@leeds.ac.uk for further information.