

**BASELINE SURVEY (IN-DEPTH)  
Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We would like to invite you to take part in a research study. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it will involve. We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/ UVRI & LSHTM Uganda Research Unit and Makerere University, are conducting research in this location to understand the quality of life, health, and health services used amongst people with functional difficulties. The purpose of our research is to understand whether several activities we plan to implement in Luuka district change the health and quality of life of people with functional difficulties living in the area. At a minimum, in your area there will be training of healthcare workers about functional difficulties and assessment of whether healthcare facilities are accessible.

**Why have I been asked to take part?**

You have been invited to take part because you are living in one of the villages where this study is taking place, and your household head indicated that [*delete as appropriate*: you/ the person for which you are guardian for] may have difficulties with functioning.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part, we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you questions about [*delete as appropriate*: your/ the person for which you are guardian] health status, use of health services, quality of life, participation in society and attitudes. We will come back in two years' time, and with further

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A copy of this informed consent document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Baseline Survey (In-depth): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





written consent, ask you these questions again. In order to find your household in two years' time we will note down the location of your home but this location information will not be used for any other purpose in the study.

### Do I have to take part?

No. It is up to you if you decide to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect any services you or your household receive.

### What are the possible risks and disadvantages?

We perceive no risks or disadvantages to you in taking part, other than the time to answer all our questions. The questions we will ask should take approximately 45-60 minutes to complete. If you feel uncomfortable at any point during our questions, you are free to take a break or ask to stop entirely at any time without providing a reason.

### What are the possible benefits?

We cannot promise the study will help you or your household, but the information we get from the study will help our knowledge and understanding on how to improve the health and quality of life of people with functional difficulties. If you agree to participate, we will offer you UGX 15,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at Makerere University (Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect any care that you or your household gets in the future. If you withdraw from the study we will not ask any further questions

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of you and will not revisit you in two years' time. However, we may still use the information that we have already collected from you.

### What will happen to information collected about me?

All information collected provided by you, and if applicable the person for which you are guardian, will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at the information you provide.

We will keep all information you provide safe and secure. The storage of your data will be managed by the Medical Research Council Uganda. Personal details, meaning your name and if applicable the name of the person for which you are guardian, as well as any other identifiable information, will be kept securely and will be destroyed within 10 years of the end of the study.

Data may be sent to other study staff outside Uganda, to the United Kingdom, but this will be anonymised. This means that any information you provide will have names and detailed location information removed so that you cannot be identified, and your data will have a coded number instead.

We may share information that you provide to us with other researchers or on an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you, or if applicable the person for which you are guardian, will be removed before we put it on this site or share it with other researchers.

### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you and your household that we already have.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]
- by sending an email to [REDACTED]

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Virus  
Research  
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LONDON  
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HYGIENE  
& TROPICAL  
MEDICINE



Makerere University  
College of Health Sciences  
SCHOOL OF PUBLIC HEALTH

### What will happen to the results of this study?

The study results will be published in a journal so that other researchers and programme providers can learn from them. Any personal information provided to us will not be included in these journal publications, or any other study reports, and we will ensure there is no way that you can be identified from them.

### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for this research and they have full responsibility for the project including the collection, storage, and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Makerere University Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI) Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED].
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

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Medical Research Council



Uganda Virus Research Institute

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE



Makerere University College of Health Sciences SCHOOL OF PUBLIC HEALTH

**BASELINE (IN-DEPTH)  
Participant Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
<b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I understand that data about me may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data about me may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

Printed name of participant	Signature/Thumbprint* of household representative	Date

Printed name of person obtaining consent	Signature of person obtaining consent	Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

Printed name of impartial witness*	Signature of impartial witness*	

[\*Only required if the participant is unable to read or write.]



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**BASELINE (IN-DEPTH)  
Guardian Consent Form**

**Title of Project:** The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. <b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that the participation of the person for which I am guardian for is voluntary and my consent for their participation can be withdrawn at any time without giving any reason, and without any negative consequences.	
I understand that data about the person for which I am guardian may be sent to study staff in the United Kingdom, and that they (or I) will not be identifiable from this information.	
I understand that data about the person for which I am guardian may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree for the person for which I am guardian to take part in the above-named study.	

Name of participant (First, Last): \_\_\_\_\_

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Printed name of guardian

Signature/Thumbprint\* of guardian

Date

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Printed name of person obtaining consent

Signature of person obtaining consent

Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

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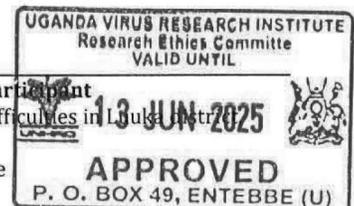
Printed name of impartial witness\*

Signature of impartial witness\*

Date

[\*Only required if the participant is unable to read or write.]

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**HEALTHCARE WORKER INTERVIEWS (PROCESS EVALUATION)****Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit, Makerere University, Women and Children First and Amref Health Africa in Uganda, are undertaking a study to determine how training healthcare workers on disability and conducting accessibility audits of healthcare facilities has affected practice in health facilities.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then [*delete as needed*: sign/thumbprint a document confirming you've been told about the study and that you agree to participate OR confirm you've been told about the study and that you agree to participate by being recorded agreeing to the study terms]. Once you have agreed to participate, we will ask you to speak with us [*delete as needed*: over the phone/in person] about your experience of the disability and audit training, including what you thought went well and where improvements may be needed, what you remember from the training, and your experiences treating people with disabilities since. We may also ask about any changes that have been made to your health facility in relation to the feedback received from the accessibility audit that was conducted. This interview will last about 45-60 minutes. If you agree to participate, we will also record the interview so that we can review it later.

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**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Healthcare Worker Interviews (Process Evaluation): Participant Information Sheet

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**Why have I been asked to take part?**

We are interested in speaking to healthcare workers who have been involved in the disability and accessibility audit training led by the MRC/ UVRI & LSHTM Uganda Research Unit, either as facilitators or recipients.

**Do I have to take part?**

No. It is up to you to decide if you would like to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect your job in any way.

**What are the possible risks and disadvantages?**

We perceive no risks or disadvantages to you for taking part. In the unlikely event you feel distressed or uncomfortable during the interview, you are free to take a break in the interview or stop the interview completely at any time.

**What are the possible benefits?**

We do not think the study will help you directly but the information we get from the study will help our knowledge and understanding on how to improve the provision of health services for people with disabilities. If you agree to participate, we will offer you UGX 20,000/= as compensation for your time spent with us.

**What if something goes wrong?**

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at the MRC/ UVRI & LSHTM Uganda Research Unit - Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED] [REDACTED]. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.



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**Can I change my mind about taking part?**

Yes. You can withdraw from the study at any time and this will not affect your job in any way. If you withdraw from the study we will not ask any further questions of you. However, we may still use the information that we have already collected from you.

**What will happen to information collected about me?**

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about you.

Shortly after the interview takes place we will make a written copy of the recording, with any identifying details about you removed. This means that any information about you will have your name, and any other identifying information about you, removed so that you cannot be recognised, and your data will have a coded number instead. After writing up the recording is complete and checked, all audio-recordings will be deleted.

We will keep all information about you safe and secure. The storage of your data will be managed by the MRC/UVRI & LSHTM Uganda Research Unit. Your personal details, meaning your name and other identifiable information on the consent forms, will be kept securely and will be destroyed within 10 years of the end of the study.

Written copies of the audio-recordings containing no identifying information about you will be shared with other study staff outside Uganda, in the United Kingdom. These written copies of the recordings may also be uploaded to an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you will be removed before we put it on this site.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]
- by sending an email to [REDACTED]

**What will happen to the results of this study?**

The study results will be published in a research journal so that other researchers and programme

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Makerere University  
College of Health Sciences  
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providers can learn from them. In these publications we will share quotes from interview participants. Your personal information will not be included in these publications or any other study reports and we will ensure there is no way that you can be identified from any quote.

### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI), Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED]
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED] or [REDACTED].

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**HEALTHCARE WORKER AND TRAINER WITH DISABILITY INTERVIEWS (PROCESS EVALUATION)**  
**Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit, Makerere University, Women and Children First and Amref Health Africa in Uganda are undertaking a study to determine how training healthcare workers on disability and conducting accessibility audits of healthcare facilities has affected practice in health facilities.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then sign/thumbprint a document confirming you've been told about the study and that you agree to participate OR confirm you've been told about the study and that you agree to participate by being recorded agreeing to the study terms].

Once you have agreed to participate, we will ask you to speak with us [*delete as needed*: over the phone/in person] about your experience of the disability and audit training, including what you thought went well and where improvements may be needed, what you remember from the training, and your experiences treating people with disabilities since. We may also ask about any changes that have been made to your health facility in relation to the feedback received from the accessibility audit that was conducted. This interview will last about 45-60 minutes. If you agree to participate, we will also record the interview so that we can review it later.

As part of the training, we will also introduce you to a tool called the Disability Awareness Checklist. This tool can be used to assess the accessibility of health facilities. At the end of the training, we will

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introduce DAC facilitators, who will organise to visit you at the facility you work in and complete the checklist together shortly after the training. Completion of the checklist together with the facilitators will take 1-2 hours.

### **Why have I been asked to take part?**

We are interested in speaking to healthcare workers and trainers with disabilities who have been involved in the disability and accessibility audit training led by the MRC/ UVRI & LSHTM Uganda Research Unit, either as facilitators or recipients.

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

No. It is up to you to decide if you would like to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect your job in any way.

### **What are the possible risks and disadvantages?**

We perceive no risks or disadvantages to you for taking part. In the unlikely event you feel distressed or uncomfortable during the interview, you are free to take a break in the interview or stop the interview completely at any time.

### **What are the possible benefits?**

We do not think the study will help you directly but the information we get from the study will help our knowledge and understanding on how to improve the provision of health services for people with disabilities. If you agree to participate, we will offer you UGX 20,000/= as compensation for your time spent with us.

### **What if something goes wrong?**

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at the MRC/ UVRI & LSHTM Uganda Research Unit - Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED] or + [REDACTED].

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### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect your job in any way. If you withdraw from the study we will not ask any further questions of you. However, we may still use the information that we have already collected from you.

### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about you.

Shortly after the interview takes place we will make a written copy of the recording, with any identifying details about you removed. This means that any information about you will have your name, and any other identifying information about you, removed so that you cannot be recognised, and your data will have a coded number instead. After writing up the recording is complete and checked, all audio-recordings will be deleted.

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### What will happen to the results of this study?

The study results will be published in a research journal so that other researchers and programme providers can learn from them. In these publications we will share quotes from interview participants. Your personal information will not be included in these publications or any other study reports and we will ensure there is no way that you can be identified from any quote.

### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI), Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED]
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

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A copy of this document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Healthcare Worker Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927

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## PLA-D GROUP FACILITATOR INTERVIEWS (PROCESS EVALUATION)

### Participant Information Sheet

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

#### Introduction

We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

#### What is the purpose of the study?

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit, Makerere University, Women and Children First and Amref Health Africa in Uganda, are conducting research to support the development of participatory groups to support the health needs of people with disability in the community. As part of this study, we have established one of these groups in your community for people with disabilities, their family members and other interested community members. We are conducting the current study to understand how these groups have benefitted people with disabilities in the community.

#### What will happen if I take part?

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you to share with us your thoughts and experiences of facilitating your group, including what you thought went well and where improvements may be needed. The questions will take about an hour to answer. If you agree to participate, we will also record the interview so that we can review it later.

#### Why have I been asked to take part?

You have been invited to participate because you are a facilitator of one of these groups.

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A copy of this document should be provided to the participant.

Study title: The Missing Billion: Community-based participatory learning and action groups to address healthcare access issues for people with disabilities in Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
PLA-D Group Facilitator Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





### Do I have to take part?

No. It is up to you to decide if you would like to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect your ability to facilitate group meetings in the future or any other services you or your household receive.

### What are the possible risks and disadvantages?

We perceive no risks or disadvantages to you for taking part, apart from the time required to answer our questions. In the unlikely event you feel distressed or uncomfortable during the interview, you are free to take a break in the interview or stop the interview completely at any time.

### What are the possible benefits?

We cannot promise the study will help you directly but the information we get from the study will help our knowledge and understanding on how to improve the participatory groups, to better support people with disabilities in addressing their health needs. If you agree to participate, we will offer you UGX 20,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at the MRC/ UVRI & LSHTM Uganda Research Unit - Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect your ability to facilitate the groups or any services you or your household may receive in the future. If you withdraw from the study we will not ask any further questions of you. However, we may still use the information that we have already collected from you.

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A copy of this document should be provided to the participant

Study title: The Missing Billion: Community-based participatory learning and action groups to address healthcare access issues for people with disabilities in Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Facilitator Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about you.

Shortly after the interview takes place we will make a written copy of the recording, with any identifying details about you removed. This means that any information about you will have your name, and any other identifying information about you, removed so that you cannot be recognised, and your data will have a coded number instead. After writing up the recording is complete and checked, all audio-recordings will be deleted.

We will keep all information about you safe and secure. The storage of your data will be managed by the MRC/UVRI & LSHTM Uganda Research Unit. Your personal details, meaning your name and other identifiable information on the consent forms, will be kept securely and will be destroyed within 10 years of the end of the study.

Written copies of the audio-recordings containing no identifying information about you will be shared with other study staff outside Uganda, in the United Kingdom. These written copies of the recordings may also be uploaded to an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you will be removed before we put it on this site.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]
- by sending an email to [REDACTED]

### What will happen to the results of this study?

The study results will be published in a research journal so that other researchers and programme providers can learn from them. In these publications we will share quotes from interview participants. Your personal information will not be included in these publications or any other study reports and we will ensure there is no way that you can be identified from any quote.

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Study title: The Missing Billion: Community-based participatory learning and action groups to address healthcare access issues for people with disabilities in Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Facilitator Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

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### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI), Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED].
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

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Study title: The Missing Billion: Community-based participatory learning and action groups to address healthcare access issues for people with disabilities in Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Facilitator Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



**PLA-D GROUP IMPLEMENTER INTERVIEWS (PROCESS EVALUATION)****Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit, Makerere University, Women and Children First and Amref Health Africa in Uganda, are conducting research to support the development of participatory groups to support the health needs of people with disability in the community. As part of this study, we have established groups in a number of villages across Luuka district for people with disabilities, their family members and other interested community members. We are conducting the current study to understand how these groups have been implemented to benefit people with disabilities.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you to speak with us about your experience of your role and the project, including what you thought went well and where improvements may be needed. This will last about 45-60 minutes. If you agree to participate, we will also record the interview so that we can review it later.

**Why have I been asked to take part?**

You have been invited because you have been involved in the wider implementation of the community groups.

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Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Implementer Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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### Do I have to take part?

No. It is up to you to decide if you would like to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect your ability to facilitate group meetings in the future or any other services you or your household receive.

### What are the possible risks and disadvantages?

We perceive no risks or disadvantages to you for taking part. In the unlikely event you feel distressed or uncomfortable during the interview, you are free to take a break in the interview or stop the interview completely at any time.

### What are the possible benefits?

The study is unlikely to help you directly but the information we get will help our knowledge and understanding on how to improve the participatory groups, to better support people with disabilities in addressing their health needs. If you agree to participate, we will offer you UGX 20,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at the MRC/UVRI & LSHTM Uganda Research Unit - Dr Femke Bannink Mbazzi, study Co-PI, Tel [REDACTED]. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect your role within the project or other project opportunities in the future. If you withdraw from the study we will not ask any further questions of you. However, we may still use the information that we have already collected from you.

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A copy of this document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Implementer Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about you.

Shortly after the interview takes place we will make a written copy of the recording, with any identifying details about you removed. This means that any information about you will have your name, and any other identifying information about you, removed so that you cannot be recognised, and your data will have a coded number instead. After writing up the recording is complete and checked, all audio-recordings will be deleted.

We will keep all information about you safe and secure. The storage of your data will be managed by the Medical Research Council Uganda. Your personal details, meaning your name and other identifiable information on the consent forms, will be kept securely and will be destroyed within 10 years of the end of the study.

Written copies of the audio-recordings containing no identifying information about you will be shared with other study staff outside Uganda, in the United Kingdom. These written copies of the recordings may also be uploaded to an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you will be removed before we put it on this site.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]
- by sending an email to [REDACTED]

### What will happen to the results of this study?

The study results will be published in a research journal so that other researchers and programme providers can learn from them. In these publications we will share quotes from interview participants. Your personal information will not be included in these publications or any other study reports and we will ensure there is no way that you can be identified from any quote.

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Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
PLA-D Group Implementer Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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### Who is organising and funding this study?

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### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI), Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED]
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].



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Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Implementer Interviews (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



**PLA-D GROUP PARTICIPANT FOCUS GROUP DISCUSSIONS (PROCESS EVALUATION)**  
**Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit, Makerere University, Women and Children First and Amref Health Africa in Uganda, are conducting research to support the development of participatory groups to support the health needs of people with disability in the community. As part of this study, we have established one of these groups in your community for people with disabilities, their family members and other interested community members. We are conducting the current study to understand how these groups have benefitted people with disabilities in the community.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you to participate in a group discussion where we will ask you to share your thoughts and experiences of the participatory groups for people with disabilities that have been established in your village. This will last about 1 hour 30 minutes and take place in a convenient location. We expect there will be around 8 persons with disabilities in the discussion in total (including yourself). If you agree to participate, we will also record the interview so that we can review it later.

The facilitator of the focus groups will ask you questions about:

- Yourself
- Your disability and quality of life



**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Participant Focus Group Discussions (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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- Your health and healthcare use
- Your participation in group meetings
- Your views on the group programme, for example what went well and where improvements may be needed.

### Why have I been asked to take part?

We are interested in speaking to people with disabilities who participated in the participatory group meetings in their village.

### Do I have to take part?

No. It is up to you to decide if you would like to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect your ability to attend group meetings in the future or any other services you or your household receive.

### What are the possible risks and disadvantages?

If you choose to participate in the focus group discussion, your identity will be known to the other persons with disabilities participating in the group discussion, who could tell other people that you took part. We will ask all focus group participants (including yourself) to agree not to tell any other people who participated in the discussions and remind participants of this before and after the discussion. In the unlikely event you feel distressed or uncomfortable during the discussion you are free to take a break in the interview or leave the discussion completely at any time.

### What are the possible benefits?

We cannot promise the study will help you directly but the information we get from the study will help our knowledge and understanding on how to improve the participatory groups, to better support people with disabilities in addressing their health needs. If you agree to participate, we will offer you UGX 20,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at the MRC/UVRI & LSHTM Uganda Research Unit - Dr Femke Bannink Mbazzi, study Co-PI, Tel 0417 704 000 or 0776102265. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED] or [REDACTED]. The London School of Hygiene and Tropical

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Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
PLA-D Group Participant Focus Group Discussions (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect your ability to participate in the groups or any services you or your household may receive in the future. If you withdraw from the study we will not ask any further questions of you. However, we may still use the information that we have already collected from you.

### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about you.

Shortly after the interview takes place we will make a written copy of the recording, with any identifying details about you removed. This means that any information about you will have your name, and any other identifying information about you, removed so that you cannot be recognised, and your data will have a coded number instead. After writing up the recording is complete and checked, all audio-recordings will be deleted.

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### Where can you find out more about how your information is used?

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- by sending an email to [REDACTED]

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Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Participant Focus Group Discussions (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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### What will happen to the results of this study?

The study results will be published in a research journal so that other researchers and programme providers can learn from them. In these publications we will share quotes from interview participants. Your personal information will not be included in these publications or any other study reports and there is no way that you can be identified from any quote.

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### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

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Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Participant Focus Group Discussions (Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





**PLA-D GROUP PARTICIPANT & NON-PARTICIPANT INTERVIEWS (PROCESS EVALUATION)**  
**Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit, Makerere University, Women and Children First and Amref Health Africa in Uganda, are conducting research to support the development of participatory groups to support the health needs of people with disability in the community. As part of this study, we have established one of these groups in your community for people with disabilities, their family members and other interested community members. We are conducting the current study to understand how these groups have benefitted people with disabilities in the community.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will interview you about your thoughts and experiences of the participatory groups for people with disabilities that have been established in your village. This will last about 1 hour and take place in a private and convenient location. If you agree to participate, we will also record the interview so that we can review it later.

During the interview we will ask you questions about:

- Yourself
- Your disability and quality of life



**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
PLA-D Group Participant & Non-Participant Interviews(Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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- Your health and healthcare use
- Your participation in group meetings
- Your views on the group programme, for example what went well and where improvements may be needed.

### Why have I been asked to take part?

We are interested in speaking to people with disabilities in the village, including those who participated in some or all of the group meetings and people with disabilities that did not participate in the groups at all.

### Do I have to take part?

No. It is up to you to decide if you would like to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect your ability to attend group meetings in the future or any other services you or your household receive.

### What are the possible risks and disadvantages?

We perceive no risks or disadvantages to you for taking part, other than the time it will take to answer our questions. In the unlikely event you feel distressed or uncomfortable during the interview, you are free to take a break or ask to stop entirely at any time without providing a reason.

### What are the possible benefits?

We cannot promise the study will help you directly but the information we get from the study will help our knowledge and understanding on how to improve the participatory groups, to better support people with disabilities in addressing their health needs. If you agree to participate, we will offer you UGX 20,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at the MRC/UVRI & LSHTM Uganda Research Unit - Dr Femke Bannink Mbazzi, study Co-PI, Tel [REDACTED]. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

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A copy of this document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Participant & Non-Participant Interviews(Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927

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The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect your ability to participate in the groups or any services you or your household may receive in the future. If you withdraw from the study we will not ask any further questions of you. However, we may still use the information that we have already collected from you.

### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about you. We will keep all information about you safe and secure in a password protected secure server. Shortly after the interview takes place we will make a written copy of the recording, with any identifying details about you removed. This means that any information about you will have your name, address and other identifying information about you removed so that you cannot be recognised. After transcription is complete, all audio-recordings will be deleted.

Your personal details, meaning your name and other identifiable information on the consent forms, will be kept in a different safe place to the other study information and will be destroyed within 10 years of the end of the study. Your name and other identifiable information will only be known to staff at MRC Uganda and will not be shared more widely, including with staff in LSHTM. Transcripts of audio-recordings will be shared with LSHTM staff and will contain no identifying information about you. Transcripts may be uploaded to the public domain via a data repository held at LSHTM.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED]
- 
- by sending an email to [REDACTED]

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**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Participant & Non-Participant Interviews(Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





### What will happen to the results of this study?

The study results will be published in a research journal so that other researchers and programme providers can learn from them. In these publications we will share quotes from interview participants. Your personal information will not be included in these publications or any other publicly available study reports and there is no way that you can be identified from any quote.

### Who is organising and funding this study?

London School of Hygiene & Tropical Medicine is the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Dr Femke Bannink Mbazzi, study Co- PI, Tel [REDACTED].

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI), Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED].
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

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**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

PLA-D Group Participant & Non-Participant Interviews(Process Evaluation): Participant Information Sheet

Version & Date: 1.2/13 March 2024

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Medical Research Council



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**FOCUS GROUP DISCUSSIONS (PROCESS EVALUATION)**

**Consent Form for Participants**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (13 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
<b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I understand that my identity will be known to other focus group participants and agree not to disclose the identity of other focus group participants to any other person.	
I agree to the interview being recorded and for the words spoken during the interview to be anonymously quoted.	
I understand that data about my household may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data from my household may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

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Printed name of participant

Signature/Thumbprint\* of participant

Date

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Printed name of person obtaining consent

Signature of person obtaining consent

Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

--	--	--

Printed name of impartial witness\*

Signature of impartial witness\*

Date

[\*Only required if the participant is unable to read or write.]

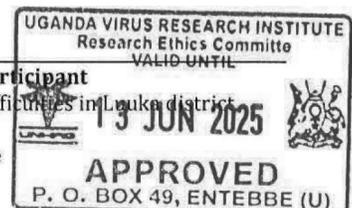
**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Version & Date: 1.2 (13 March 2024)

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





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**INTERVIEWS (PROCESS EVALUATION)  
Participant Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (13 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
<b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I agree to the interview being recorded and for the words spoken during the interview to be anonymously quoted.	
I understand that data about my household may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data from my household may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

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Printed name of participant

Signature/Thumbprint\* of participant

Date

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Printed name of person obtaining consent

Signature of person obtaining consent

Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

--	--	--

Printed name of impartial witness\*

Signature of impartial witness\*

Date

[\*Only required if the participant is unable to read or write.]

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.2 (13 March 2024)  
REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





**FOCUS GROUP DISCUSSIONS (PROCESS EVALUATION)**

**Parent/ Guardian Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (13 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. <b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my participation and the person for which I am a parent/ guardian for, is voluntary and my consent for my and their participation can be withdrawn at any time without giving any reason, and without any negative consequences.	
I agree to the interview being recorded and for the words spoken during the interview by myself or the person for which I am a parent/ guardian to be anonymously quoted.	
I understand that my identity and the person for which I am a parent/ guardian will be known to other focus group participants and agree not to disclose the identity of other focus group participants to any other person.	
I understand that data about myself and the person for which I am a parent/ guardian may be sent to study staff in the United Kingdom, and that they (and I) will not be identifiable from this information.	
I understand that data about myself and the person for which I am a parent/ guardian may be shared via a public data repository and that they (and I) will not be identifiable from this information.	
I agree for myself and the person for which I am guardian to take part in the above-named study.	

Name of participant : \_\_\_\_\_

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Printed name of parent/ guardian

Signature/Thumbprint\*

Date

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Printed name of person obtaining consent

Signature of person obtaining consent

Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

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Printed name of impartial witness\*

Signature of impartial witness\*

Date

[\*Only required if the participant is unable to read or write.]

**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda. Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.2 (13 March 2024)  
REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





**INTERVIEWS (PROCESS EVALUATION)**

**Parent/ Guardian Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (13 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. <b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my participation and the person for which I am a parent/ guardian for, is voluntary and my consent for my and their participation can be withdrawn at any time without giving any reason, and without any negative consequences.	
I agree to the interview being recorded and for the words spoken during the interview by myself or the person for which I am guardian to be anonymously quoted.	
I understand that data about myself and the person for which I am a parent/ guardian may be sent to study staff in the United Kingdom, and that they (and I) will not be identifiable from this information.	
I understand that data about myself and the person for which I am a parent/ guardian may be shared via a public data repository and that they (and I) will not be identifiable from this information.	
I agree for myself and the person for which I am a parent/ guardian to take part in the above-named study.	

**Name of participant:** \_\_\_\_\_

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Printed name of parent/ guardian

Signature/Thumbprint\*

Date

--	--	--

Printed name of person obtaining consent

Signature of person obtaining consent

Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

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Printed name of impartial witness\*

Signature of impartial witness\*

Date

[\*Only required if the participant is unable to read or write.]

**A copy of this document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.2 (13 March 2024)  
REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



**ENDLINE SURVEY (SHORT)**  
**Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We would like to invite you to take part in a research study. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it will involve. We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit and Makerere University, are conducting research in this location to understand the quality of life, health, and health services used amongst people with functional difficulties. The purpose of our research is to understand whether several activities we have implemented in Luuka district have changed the health and quality of life of people with functional difficulties living in the area.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you questions about [your/ or a member of your household/ or your neighbour's (*delete as appropriate, if original respondent cannot be found ask other household member and neighbour*)] health and well-being.

**Why have I been asked to take part?**

You have been invited to take part because you are living in one of the villages where this study is taking place. Two years ago, it was indicated that [you/ a member of your household/ your

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**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Short): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927

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neighbour] may have difficulties with functioning and we explained we would return again in two years' time to ask further questions about [your/their] health and well-being.

### Do I have to take part?

No. It is up to you if you decide to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect any services you or your household receive.

### What are the possible risks and disadvantages?

We perceive no risks or disadvantages to your household in taking part, other than the time to answer all our questions. The questions we will ask you should take approximately half an hour to complete. If you feel uncomfortable at any point during our questions, you are free to take a break or ask to stop entirely at any time without providing a reason.

### What are the possible benefits?

We cannot promise the study will help you or your household, but the information we get from the study will help our knowledge and understanding on how to improve the health and quality of life of people with functional difficulties. If you agree to participate, we will offer you UGX 15,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at Makerere University (Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED]

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect any care that you or your household gets in the future. If you withdraw from the study we will not ask any further questions. However, we may still use the information that we have already collected.

---

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Endline Survey (Short): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information about your household.

We will keep all information about your household safe and secure. The storage of your data will be managed by the Medical Research Council Uganda. Your personal details, meaning your name and other identifiable information, will be kept securely and will be destroyed within 10 years of the end of the study.

Data may be sent to other study staff outside Uganda, to the United Kingdom, but this will be anonymised. This means that any information about you will have your name and address removed so that you cannot be recognised, and your data will have a coded number instead.

We may share information that you provide to us with other researchers or on an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you will be removed before we put it on this site or share it with other researchers.

### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep the information that we already have.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]
- by sending an email to [REDACTED]

### What will happen to the results of this study?

The study results will be published in a journal so that other researchers and programme providers can learn from them. Your personal information will not be included in these journal publications, or any other study report, and we will ensure that there is no way that you can be identified from them.

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**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Short): Participant Information Sheet

Version & Date: 1.2/01 March 2024

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### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for this research and they have full responsibility for the project including the collection, storage, and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology (UNCST) has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Makerere University Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI) Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED]
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED]



**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Short): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927

**ENDLINE SURVEY (IN-DEPTH)  
Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We would like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it will involve. We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/UVRI & LSHTM Uganda Research Unit and Makerere University, are conducting research in this location to understand the quality of life, health, and health services used amongst people with functional difficulties. The purpose of our research is to understand whether several activities we have implemented in Luuka district have changed the health and quality of life of people with functional difficulties living in the area.

**Why have I been asked to take part?**

You have been invited to take part because you are living in one of the villages where this study is taking place. Two years ago, your household head indicated that [*delete as appropriate: you/ the person for which you are guardian for*] may have difficulties with functioning and at that time we asked you questions on the same topics we hope to ask you about today, and explained we would return again in two years' time.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you questions about [*delete as appropriate:*

---

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (In-depth): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





your/ the person for which you are guardian] health status, use of health services, quality of life, participation in society and attitudes.

### Do I have to take part?

No. It is up to you if you decide to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect any services you or your household receive.

### What are the possible risks and disadvantages?

We perceive no risks or disadvantages to you in taking part, other than the time to answer all our questions. The questions we will ask should take approximately 45-60 minutes to complete. If you feel uncomfortable at any point during our questions, you are free to take a break or ask to stop entirely at any time without providing a reason.

### What are the possible benefits?

We cannot promise the study will help you or your household, but the information we get from the study will help our knowledge and understanding on how to improve the health and quality of life of people with functional difficulties. If you agree to participate, we will offer you UGX 15,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at Makerere University (Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect any care that you or your household gets in the future. If you withdraw from the study we will not ask any further questions

---

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (In-depth): Participant Information Sheet

Version & Date: 1.2/01 March 2024

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of you. However, we may still use the information that we have already collected from you and your household.

### What will happen to information collected about me?

All information provided by you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information you provide.

We will keep all information you provide safe and secure. The storage of your data will be managed by the Medical Research Council Uganda. Personal details, meaning your name and if applicable the name of the person for which you are guardian, as well as any other identifiable information, will be kept securely and will be destroyed within 10 years of the end of the study.

Data may be sent to other study staff outside Uganda, to the United Kingdom, but this will be anonymised. This means that any information you provide will have names and detailed location information removed so that you cannot be identified, and your data will have a coded number instead.

We may share information that you provide to us with other researchers or on an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you, or if applicable the person for which you are guardian, will be removed before we put it on this site or share it with other researchers.

### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you and your household that we already have.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]
- by sending an email to [REDACTED]



### What will happen to the results of this study?

The study results will be published in a journal so that other researchers and programme providers can learn from them. Any personal information provided to us will not be included in these journal

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A copy of this informed consent document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (In-depth): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



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publications, or any other study reports, and we will ensure there is no way that you can be identified from them.

### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for this research and they have full responsibility for the project including the collection, storage, and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign/thumbprint the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Makerere University Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI), Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED].
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].



**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (In-depth): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



## ENDLINE SURVEY (VERBAL AUTOPSY- HOSPITALISATION) Participant Information Sheet

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

### Introduction

We would like to invite you to take part in a research study. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it will involve. We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

### What is the purpose of the study?

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/ UVRI & LSHTM Uganda Research Unit and Makerere University, are conducting research in this location to understand more about the lives of people with functional difficulties. The purpose of this part of the research is to investigate causes of hospitalisation among participants of the study.

### Why have I been asked to take part?

You have been invited to take part because you are living in one of the villages where this study is taking place. Recently, you completed a survey with us, during which you told us that [*delete as appropriate: you/ the person for which you are guardian for*] was hospitalised. We have selected a few people that told us they had been hospitalised, to understand more about why they were hospitalised.

### What will happen if I take part?

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you questions about:

1. Any medical conditions [*delete as appropriate: you/ the person for which you are guardian for*] had in the time before hospitalisation.

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Verbal Autopsy - Hospitalisation): Participant Information Sheet

Version & Date: 1.0/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927

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2. The health services attended by [*delete as appropriate: you/ the person for which you are guardian for*].

### Do I have to take part?

No. It is up to you if you decide to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect any services you or your household receive.

### What are the possible risks and disadvantages?

Talking about [*delete as appropriate: your/ the person for which you are guardian for's*] hospital experience may be difficult but the questions will be asked in a sensitive way. The other potential disadvantage is the time taken to complete the interview, which will be about one hour. If you feel uncomfortable at any point during our questions, you are free to take a break or ask to stop entirely at any time without providing a reason.

### What are the possible benefits?

We cannot promise the study will help you or your household, but the information we get from the study will help our knowledge and understanding on how to reduce emergency hospitalisations of people with functional difficulties. If you agree to participate, we will offer you UGX 15,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at Makerere University (Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED]

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect any care that you or your household gets in the future. If you withdraw from the study we will not ask any further questions. However, we may still use the information that we have already collected.

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**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Verbal Autopsy - Hospitalisation): Participant Information Sheet

Version & Date: 1.0/01 March 2024

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### What will happen to information collected about me?

All information collected about you will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information provided.

We will keep all information about your household safe and secure. The storage of your data will be managed by the Medical Research Council Uganda. Your personal details, meaning your name and other identifiable information, will be kept securely and will be destroyed within 10 years of the end of the study.

Data may be sent to other study staff outside Uganda, to the United Kingdom, but this will be anonymised. This means that any information about you will have your name and address removed so that you cannot be recognised, and your data will have a coded number instead.

We may share information that you provide to us with other researchers or on an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you or the deceased will be removed before we put it on this site or share it with other researchers.

### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep the information that we already have.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]
- by sending an email to [REDACTED]

### What will happen to the results of this study?

The study results will be published in a journal so that other researchers and programme providers can learn from them. Your personal information will not be included in these journal publications, or any other study report, and we will ensure that there is no way that you can be identified from them.

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A copy of this informed consent document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional disabilities in Luuka district, Uganda.  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine,  
Endline Survey (Verbal Autopsy - Hospitalisation): Participant Information Sheet  
Version & Date: 1.0/01 March 2024  
REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





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### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for this research and they have full responsibility for the project including the collection, storage, and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology (UNCST) has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Makerere University Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI) Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED]
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED]



**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Verbal Autopsy - Hospitalisation): Participant Information Sheet

Version & Date: 1.0/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



**ENDLINE SURVEY (VERBAL AUTOPSY- DEATH)  
Participant Information Sheet**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

**Introduction**

We would like to invite you to take part in a research study. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it will involve. We will go through this information sheet with you, and answer any questions you may have. Please ask us questions if anything is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not you would like to take part in the study. If you have any difficulties reading this information sheet, we can read it to you and invite someone that can read, who is separate to our work, to confirm that what we tell you matches what is written in this information sheet.

**What is the purpose of the study?**

The London School of Hygiene and Tropical Medicine, in partnership with the MRC/ UVRI & LSHTM Uganda Research Unit and Makerere University, are conducting research in this location to understand more about the lives of people with functional difficulties. The purpose of this part of the research is to investigate causes of death among participants of the study.

**Why have I been asked to take part?**

You have been invited to take part because you are the relative or household member of a person with functional difficulties who was recruited to take part in the study two years ago, but who has died since the start of the project.

**What will happen if I take part?**

After we have discussed the study, if you agree to take part we will first check you have fully understood the information provided and then ask you to sign (or thumbprint) a consent form. Once you have signed (or thumbprinted), we will ask you questions about:

1. The medical condition of the deceased in the time before death.
2. The health services attended by the deceased while they were alive.

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**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Verbal Autopsy - Death): Participant Information Sheet

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### Do I have to take part?

No. It is up to you if you decide to take part or not. We will discuss the study together and if you don't want to take part, that's ok. Taking part in this study will not affect any services you or your household receive.

### What are the possible risks and disadvantages?

Talking about a deceased relative is expected to be difficult but the questions will be asked in a sensitive way. The questions we will be using have been tested in many countries and recommended by the World Health Organization (WHO). The other potential disadvantage is the time taken to complete the interview, which will be about one hour. If you feel uncomfortable at any point during our questions, you are free to take a break or ask to stop entirely at any time without providing a reason.

### What are the possible benefits?

We cannot promise the study will help you or your household, but the information we get from the study will help our knowledge and understanding on how to reduce mortality of people with functional difficulties. If you agree to participate, we will offer you UGX 15,000/= as compensation for your time spent with us.

### What if something goes wrong?

If you have a concern about any aspect of this study, you can speak to the data collectors or their supervisor present today, or you can contact the researchers managing the data collection at Makerere University (Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED].

The London School of Hygiene and Tropical Medicine holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.

### Can I change my mind about taking part?

Yes. You can withdraw from the study at any time and this will not affect any care that you or your household gets in the future. If you withdraw from the study we will not ask any further questions. However, we may still use the information that we have already collected.

---

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Endline Survey (Verbal Autopsy - Death): Participant Information Sheet

Version & Date: 1.2/01 March 2024

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### What will happen to information collected about me?

All information collected about you and the deceased will be kept private. Only the study staff and authorities who check that the study is being carried out properly will be allowed to look at information provided.

We will keep all information about your household safe and secure. The storage of your data will be managed by the Medical Research Council Uganda. Your personal details, meaning your name and other identifiable information, will be kept securely and will be destroyed within 10 years of the end of the study.

Data may be sent to other study staff outside Uganda, to the United Kingdom, but this will be anonymised. This means that any information about you or the deceased will have your names and addresses removed so that you or the deceased cannot be recognised, and your data will have a coded number instead.

We may share information that you provide to us with other researchers or on an online data repository. A data repository is a site where other researchers outside this study team can look at data from different studies so that they can confirm our findings or use the data for other research. All information that could potentially identify you or the deceased will be removed before we put it on this site or share it with other researchers.

### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep the information that we already have.

### Where can you find out more about how your information is used?

You can find out more about how we use your information

- by asking one of the data collection team present today
- by contacting Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]
- by sending an email to [REDACTED]

### What will happen to the results of this study?

The study results will be published in a journal so that other researchers and programme providers can learn from them. Your personal information will not be included in these journal publications, or any other study report, and we will ensure that there is no way that you can be identified from them.

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

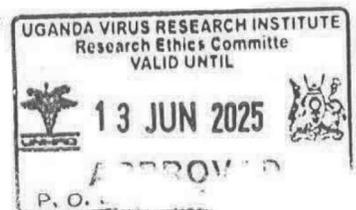
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Verbal Autopsy - Death): Participant Information Sheet

Version & Date: 1.2/01 March 2024

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### Who is organising and funding this study?

London School of Hygiene and Tropical Medicine is the sponsor for this research and they have full responsibility for the project including the collection, storage, and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.

### Who has reviewed this study?

All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The London School of Hygiene and Tropical Medicine Research Ethics Committee and the Uganda Virus Research Institute Research Ethics Committee. The Uganda National Council for Science and Technology (UNCST) has also reviewed the study and have agreed that it is okay for us to ask people to take part.

### Further information and contact details

Thank you for taking time to read/listen to this information sheet. If you think you will take part in the study, please read, and sign the consent form.

### Further questions about the research?

If you would like any further information, please contact:

Makerere University Dr Peter Waiswa, study Co- PI, Tel: [REDACTED]

### What if I have concerns about the study?

If you have any concerns about your or a member of your household's experiences of being involved in this research you can contact any of the following organisations:

- Uganda Virus Research Institute (UVRI) Research and Ethics Committee (REC) chairman, Dr Tom Lutalo, Tel [REDACTED]
- Research Governance and Integrity Office at London School of Hygiene and Tropical Medicine at [REDACTED]



A copy of this informed consent document should be provided to the participant

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.

Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine

Endline Survey (Verbal Autopsy - Death): Participant Information Sheet

Version & Date: 1.2/01 March 2024

REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927



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**ENDLINE (SHORT)  
Participant Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.  <b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I understand that data provided by me may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data provided by me may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

Printed name of participant	Signature/ Thumbprint* of participant	Date

Printed name of person obtaining consent	Signature of person obtaining consent	Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

Printed name of impartial witness*	Signature of impartial witness*	Date

[\*Only required if the participant is unable to read or write.]

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.2 (01 March 2024)  
REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





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**ENDLINE (IN-DEPTH)  
Participant Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
<p>I confirm that I have read and understood the information sheet version 1.2 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.</p> <p><b>OR</b></p> <p>I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.</p>	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I understand that data about me may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data about me may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

<b>Printed name of participant</b>	<b>Signature/Thumbprint* of participant</b>	<b>Date</b>

<b>Printed name of person obtaining consent</b>	<b>Signature of person obtaining consent</b>	<b>Date</b>

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

<b>Printed name of impartial witness*</b>	<b>Signature of impartial witness*</b>	<b>Date</b>

[\*Only required if the participant is unable to read or write.]

**A copy of this informed consent document should be provided to the participant.**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.2 (01 March 2024)  
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**ENDLINE (VERBAL AUTOPSY - HOSPITALISATION)  
Participant Consent Form**

**Title of Project: Addressing healthcare access issues for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.0 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.  <b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I understand that data provided by me may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data provided by me may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

Printed name of participant	Signature/ Thumbprint* of participant	Date

Printed name of person obtaining consent	Signature of person obtaining consent	Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

Printed name of impartial witness*	Signature of impartial witness*	Date

[\*Only required if the participant is unable to read or write.]

**A copy of this informed consent document should be provided to the participant**

Study title: Addressing healthcare access issues for people with functional difficulties in Luuka district, Uganda  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.0 (01 March 2024)  
REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





**ENDLINE (VERBAL AUTOPSY - DEATH)  
Participant Consent Form**

**Title of Project: Addressing healthcare access issues for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.2 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.  <b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without any negative consequences.	
I understand that data provided by me may be sent to study staff in the United Kingdom, and that I will not be identifiable from this information.	
I understand that data provided by me may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree to taking part in the above-named study.	

Printed name of participant	Signature/ Thumbprint* of participant	Date

Printed name of person obtaining consent	Signature of person obtaining consent	Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

Printed name of impartial witness*	Signature of impartial witness*	Date

[\*Only required if the participant is unable to read or write.]

**A copy of this informed consent document should be provided to the participant**

Study title: Addressing healthcare access issues for people with functional difficulties in Luuka district, Uganda  
 Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
 Version & Date: 1.2 (01 March 2024)  
 REC ref: UVRI: GC/127/904; UNCST: SS1348ES; LSHTM:29927





**ENDLINE (VERBAL AUTOPSY - HOSPITALISATION)**

**Guardian Consent Form**

**Title of Project: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.**

Statement	Please initial or thumbprint* each box
I confirm that I have read and understood the information sheet version 1.0 (01 March 2024) for the above-named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
<b>OR</b> I have had the information explained to me by study personnel in a language that I understand. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that the participation of the person for which I am guardian for is voluntary and my consent for their participation can be withdrawn at any time without giving any reason, and without any negative consequences.	
I understand that data about the person for which I am guardian may be sent to study staff in the United Kingdom, and that they (or I) will not be identifiable from this information.	
I understand that data about the person for which I am guardian may be shared via a public data repository, or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I agree for the person for which I am guardian to take part in the above-named study.	

Name of participant (First, Last): \_\_\_\_\_

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Printed name of guardian

Signature/Thumbprint\* of guardian

Date

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Printed name of person obtaining consent

Signature of person obtaining consent

Date

The participant/representative is unable to sign. As a witness, I confirm that all the information about the trial was given and the participant/representative consented to taking part.

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Printed name of impartial witness\*

Signature of impartial witness\*

Date

[\*Only required if the participant is unable to read or write.]

**A copy of this informed consent document should be provided to the participant**

Study title: The Missing Billion: Addressing healthcare access needs for people with functional difficulties in Luuka district, Uganda.  
Principal Investigator: Professor Hannah Kuper, London School of Hygiene and Tropical Medicine  
Version & Date: 1.0 (01 March 2024)  
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