Appendices

Appendix 1. Participant Information Sheets

PARTICIPANT INFORMATION SHEET: Patients Living with Sickle Cell Disease/ Carers of Children Living with Sickle Cell Disease (Survey)

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You are a person living with sickle cell disease, or a carer to a child with sickle cell disease, receiving care in the Liverpool catchment area. You therefore have very

important insights about your experiences of living with sickle cell disease or caring for someone with sickle cell disease.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. In no way will your medical care/your dependent's care be affected if you decline to participate. If you do decide to take part and later change your mind, that is absolutely okay. You can withdraw your participation at any time with no negative consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

We will like you to complete a short online survey about your experience living with sickle cell disease/caring for someone with sickle cell disease; and how a community resource centre or hub would be useful to you. Please go through this information sheet and if you wish to participate, sign (or initiate) the consent form before you start answering any questions. You have at least 1 week to make up your mind, during which you can ask any questions you might have. The questions will take a maximum of 30 minutes of your time.

5. Expenses and payments

There are no payments for participating and you will not incur any expenses.

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

This is a very low-risk study, as we are only asking you to reflect on your experiences and how you feel community resource centres or hubs for SCD patients will be helpful to you. However, if you have had some unpleasant experiences, this might be difficult for you to talk about. We are not asking about these experiences directly but if at any point the questions are upsetting to you, you can pause the survey or stop it altogether. You can decline to answer any questions you are not comfortable answering.

7. What are the possible benefits of taking part?

There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

8. Will my taking part in the study be kept confidential?

All survey data will be kept confidential. On the survey response itself, there is no identifying information—you will be given a unique number instead. As such, there will be no way to link your survey responses back to you. Signed consent forms will have your name but will be unlinked to your survey responses. These will be stored in a protected cloud server and only accessible to the principal investigators of this study.

9. Who is organizing and funding the research?

This study is being funded by the National Institute for Health Research in the UK. It is being led by the Liverpool School of Tropical Medicine (LSTM) supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT).

10. What will happen to the results of the research study?

Throughout the study, our key findings will be shared as part of a series of study dissemination meetings. A brief with key findings from this survey will be shared with the LUHFT for participants to view. We will also aim to publish our findings in scientific journals so that people in other contexts might benefit.

11. Who has reviewed the study?

This study has been reviewed and has been allowed to proceed by the Research Ethics Committee of the Liverpool School of Tropical Medicine (LSTM).

12. **Safeguarding**

The study team and data collectors are expected to behave ethically and responsibly at all times and follow the LSTM and LUHFT code of conduct. This means that they must not ask you for any financial, physical or sexual favours in return for taking part in this research. If you experience any abuse, harassment or neglect by a study team member you can contact the study Safeguarding Lead, Prof Imelda Bates on Imelda.Bates@lstmed.ac.uk. You may also raise a safeguarding concern directly with LSTM Designated Safeguarding Officer Philippa Tubb on +44 (0)151 705 3744/safeguarding@lstmed.ac.uk. LSTM's safeguarding commitment is described on LSTM Safeguarding webpage.

13. **What will happen to my data?**

All survey data will be anonymous. This anonymous data may be shared with specific members of the study team in the UK to support analysis. Study documents will be kept for 10 years, after which time they will be destroyed.

Other key points about how your data are handled:

- Your data will be handled in accordance with UK Data Protection Act 2018.
- You can find out more about how we use your information at https://www.lstmed.ac.uk/privacy-statement.
- The LSTM Data Protection Officer can be contacted if you have any concerns about the collection or storage of your personal data: dataprotection@lstmed.ac.uk
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CONTACT INFORMATION

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Liverpool School of Tropical Medicine Research Ethics Committee:

Telephone: +44(0)151 702 9551

Email: lstmrec@lstmed.ac.uk

If you have any questions, comments, or concerns about this study, now or at any point, you may contact the study principal investigator and co-investigator:

Study Principal Investigator:

Professor Imelda Bates

Telephone: +44 0151 705 3115

Email: Imelda.bates@lstmed.ac.uk

Study co-investigator:

Doctor Motto Nganda

Telephone: +44 0151 705 3276

Email: Motto.Nganda@lstmed.ac.uk

PARTICIPANT INFORMATION SHEET: Adolescent (15–17-year-old) Patients Living with Sickle Cell Disease/ Carers of Children Living with Sickle Cell Disease (Survey)

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You are a person living with sickle cell disease, or a carer to a child with sickle cell disease, receiving care in the Liverpool catchment area. You therefore have very important insights about your experiences of living with sickle cell disease or caring for someone with sickle cell disease. As an adolescent, you represent a very important group of sickle cell patients, as you transition out of paediatric care into adult care—this is a time when a lot of patients stopped engaging with healthcare services.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. In no way will your medical care/your dependent's care be affected if you decline to participate. If you do decide to take part and later change your mind, that is absolutely okay. You can withdraw your participation at any

time with no negative consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

We will like you to complete a short online survey about your experience living with sickle cell disease/caring for someone with sickle cell disease; and how a community resource centre or hub would be useful to you. Please go through this information sheet and if you wish to participate, sign (or initiate) the consent form before you start answering any questions. You have at least 1 week to make up your mind, during which you can ask any questions you might have. The questions will take a maximum of 30 minutes of your time.

5. Expenses and payments

There are no payments for participating and you will not incur any expenses.

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

This is a very low-risk study, as we are only asking you to reflect on your experiences and how you feel community resource centres or hubs for SCD patients will be helpful to you. However, if you have had some unpleasant experiences, this might be difficult for you to talk about. We are not asking about these experiences directly but if at any point the questions are upsetting to you, you can pause the survey or stop it altogether. You can decline to answer any questions you are not comfortable answering.

7. What are the possible benefits of taking part?

There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

8. Will my taking part in the study be kept confidential?

All survey data will be kept confidential. On the survey response itself, there is no identifying information—you will be given a unique number instead. As such, there will be no way to link your survey responses back to you. Signed consent forms will have your name but will be unlinked to your survey responses. These will be stored in a protected cloud server and only accessible to the principal investigators of this study.

9. Who is organizing and funding the research?

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10. What will happen to the results of the research study?

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11. Who has reviewed the study?

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Email: Imelda.bates@lstmed.ac.uk

Study co-investigator:

Doctor Motto Nganda

Telephone: +44 0151 705 3276

Email: Motto.Nganda@lstmed.ac.uk

PARTICIPANT INFORMATION SHEET: Patients (non-students) Living with Sickle Cell Disease

(Focus Group Discussion)

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You are a person living with sickle cell disease receiving care in the Liverpool catchment area. You therefore have very important insights about your experiences of living with sickle cell disease.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. In no way will your medical care be affected if you decline to participate. If you do decide to take part and later change your mind, that is absolutely okay. You can withdraw your participation at any time with no negative consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

You will be asked to take part in a group discussion with other people living with sickle cell disease. Before any discussion begins, we will ensure you have gone through an informed consent process. After this, as a group, you will be asked questions about experiences and expectations of sickle cell disease care, including reflecting on how a community resource centre or hub would be useful to you. This will take a maximum of 90 minutes of your time.

5. Expenses and payments

There are no payments for participating, but you will be given a transportation allowance to cover any expenses arising from coming to the discussion. There will also be refreshments (water and other drinks, biscuits, fruits) provided.

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

This is a very low-risk study, as we are only asking you to reflect on your experiences and what you feel some broader perceptions might be. However, if you have had some unpleasant experiences, this might be difficult for you to talk about. We are not asking about these experiences directly but if at any point the questions are upsetting to you, we can pause the discussion and you can step out, or you can withdraw your participation altogether if you do not wish to continue. You do not have to answer any questions you are not comfortable answering.

7. What are the possible benefits of taking part?

There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

8. Will my taking part in the study be kept confidential?

The study team will keep all responses entirely confidential. You will never be referred to by your name, but only by a unique study number. However, for group-based activities, it is not possible to guarantee confidentiality, though we will remind all participants to keep any discussions or admissions in the strictest confidence. Please refrain from mentioning anything that you do not wish the group to know—you can tell the facilitator separately at the end of the discussion if there is something important that you wish to raise privately. Signed consent forms will have your name, but will be unlinked to any of your responses in the discussion. These will be locked in cabinet in a secure office space to which only the study team principal investigators have access.

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PARTICIPANT INFORMATION SHEET: Patients (students) Living with Sickle Cell Disease

(Focus Group Discussion)

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You are a student living with sickle cell disease receiving care in the Liverpool catchment area. You therefore have very important insights about your experiences of living with sickle cell disease. As a student, you represent a very important group of sickle cell patients, as you face unique academic challenges — this is a time when a lot of patients stopped engaging with healthcare services.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. In no way will your medical care be affected if you decline to participate. If you do decide to take part and later change your mind, that is absolutely okay. You can withdraw your participation at any time with no negative

consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

You will be asked to take part in a group discussion with other people living with sickle cell disease. Before any discussion begins, we will ensure you have gone through an informed consent process. After this, as a group, you will be asked questions about experiences and expectations of sickle cell disease care, including reflecting on how a community resource centre or hub would be useful to you. This will take a maximum of 90 minutes of your time.

5. Expenses and payments

There are no payments for participating, but you will be given a transportation allowance to cover any expenses arising from coming to the discussion. There will also be refreshments (water and other drinks, biscuits, fruits) provided.

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

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8. Will my taking part in the study be kept confidential?

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Study co-investigator:

Doctor Motto Nganda

Telephone: +44 0151 705 3276

Email: Motto.Nganda@lstmed.ac.uk

PARTICIPANT INFORMATION SHEET: Adolescents (15–17-year-olds) Living with Sickle Cell Disease

(Focus Group Discussion)

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You are a person living with sickle cell disease receiving care in the Liverpool catchment area. You therefore have very important insights about your experiences of living with sickle cell disease. As an adolescent, you represent a very important group of sickle cell patients, as you transition out of paediatric care into adult care—this is a time when a lot of patients stopped engaging with healthcare services.

3. Do I have to take part?

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4. What will happen to me if I take part?

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There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

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9. Who is organizing and funding the research?

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10. What will happen to the results of the research study?

Throughout the study, our key findings will be shared as part of a series of study dissemination meetings. A brief with key findings from this survey will be shared with the LUHFT for participants to view. We will also aim to publish our findings in scientific journals so that people in other contexts might benefit.

11. Who has reviewed the study?

This study has been reviewed and has been allowed to proceed by the Research Ethics Committee of the Liverpool School of Tropical Medicine (LSTM).

12. **Safeguarding**

The study team and data collectors are expected to behave ethically and responsibly at all times and follow the LSTM and LUHFT code of conduct. This means that they must not ask you for any financial, physical or sexual favours in return for taking part in this research. If you experience any abuse, harassment or neglect by a study team member you can contact the study Safeguarding Lead, Prof Imelda Bates on Imelda.Bates@lstmed.ac.uk. You may also raise a safeguarding concern directly with LSTM Designated Safeguarding Officer Philippa Tubb on +44 (0)151 705 3744/safeguarding@lstmed.ac.uk. LSTM's safeguarding commitment is described on LSTM Safeguarding webpage.

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Study co-investigator:

Doctor Motto Nganda

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Email: Motto.Nganda@lstmed.ac.uk

PARTICIPANT INFORMATION SHEET: Parents of older (15–17-year-olds) transitioning children Living with Sickle Cell Disease

(Focus Group Discussion)

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You are a parent of a child living with sickle cell disease who is transitioning from paediatric to adult care (15–17-year-olds) in the Liverpool catchment area. You therefore have very important insights about your experiences caring for children with sickle cell disease transitioning from paediatric to adult care. Adolescents represent a very important group of sickle cell patients, as they transition out of paediatric care into adult care—this is a time when a lot of them stop engaging with healthcare services.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. In no way will the medical care of your adolescent child be affected if you decline to participate. If you do decide to take part

and later change your mind, that is absolutely okay. You can withdraw your participation at any time with no negative consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

You will be asked to take part in a group discussion with other parents of children living with sickle cell disease transitioning from paediatric to adult care. Before any discussion begins, we will ensure you have gone through an informed consent process. After this, as a group, you will be asked questions about experiences and expectations of sickle cell disease care, including reflecting on how a community resource centre or hub would be useful to you and your child. This will take a maximum of 90 minutes of your time.

5. Expenses and payments

There are no payments for participating, but you will be given a transportation allowance to cover any expenses arising from coming to the discussion. There will also be refreshments (water and other drinks, biscuits, fruits) provided.

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

This is a very low-risk study, as we are only asking you to reflect on your experiences and what you feel some broader perceptions might be. However, if you have had some unpleasant experiences, this might be difficult for you to talk about. We are not asking about these experiences directly but if at any point the questions are upsetting to you, we can pause the discussion and you can step out, or you can withdraw your participation altogether if you do not wish to continue. You do not have to answer any questions you are not comfortable answering.

7. What are the possible benefits of taking part?

There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

8. Will my taking part in the study be kept confidential?

The study team will keep all responses entirely confidential. You will never be referred to by your name, but only by a unique study number. However, for group-based activities, it is not possible to guarantee confidentiality, though we will remind all participants to keep any discussions or admissions in the strictest confidence. Please refrain from mentioning anything that you do not wish the group to know—you can tell the facilitator separately at the end of the discussion if there is something important that you wish to raise privately. Signed consent forms will have your name, but will be unlinked to any of your responses in the discussion. These will be locked in cabinet in a secure office space to which only the study team principal investigators have access.

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10. What will happen to the results of the research study?

Throughout the study, our key findings will be shared as part of a series of study dissemination meetings. A brief with key findings from this survey will be shared with the LUHFT for participants to view. We will also aim to publish our findings in scientific journals so that people in other contexts might benefit.

11. Who has reviewed the study?

This study has been reviewed and has been allowed to proceed by the Research Ethics Committee of the Liverpool School of Tropical Medicine (LSTM).

12. **Safeguarding**

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Study co-investigator:

Doctor Motto Nganda

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PARTICIPANT INFORMATION SHEET: Delphi process

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You have unique insights around sickle cell disease management, resource allocation or decision-making and how people living with sickle cell disease are supported in the Liverpool catchment.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. There are no consequences at all for declining to participate. If you do decide to take part and later change your mind, that is absolutely okay. You can withdraw your participation at any time with no negative consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

You will be asked to take part in a series of group discussion and reflections with other stakeholders in the Liverpool area. Before any discussion/reflections begin, we will ensure you

have gone through an informed consent process. After this, as a group, you will be presented with summaries from survey and group discussions on the experiences of people living with sickle cell disease and their carers; and on their reflections on how community resource centres would be useful to them. Based on this, you will be asked to reflect on how such community resource centres or hubs could be used to improve the wellbeing and resilience of people living with sickle cell disease and their carers. This will also include how such hubs would be funded and operated, what their functions would be and what measures should be put in place to assess their impact. This will take a maximum of 90 minutes of your time. We will re-contact you for 2 follow-up discussion/reflection sessions in 4- and 8-months time.

5. Expenses and payments

There are no payments for participating, but you will be given a transportation allowance to cover any expenses arising from coming to the discussion. There will also be refreshments (water and other drinks, biscuits, fruits) provided.

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

This is a very low-risk study, as we are only asking you to reflect on your experiences and the experiences of people living with sickle cell disease and their carers; and how you feel community resource centres could be implemented to improve wellbeing and resilience of people living with sickle cell disease. However, if you have had some unpleasant experiences, this might be difficult for you to talk about. We are not asking about these experiences directly but if at any point the questions are upsetting to you, we can pause the discussion and you can step out, or you can withdraw your participation altogether if you do not wish to continue. You do not have to answer any questions you are not comfortable answering.

7. What are the possible benefits of taking part?

There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

8. Will my taking part in the study be kept confidential?

The study team will keep all responses entirely confidential. You will never be referred to by your name, but only by a unique study number. However, for group-based activities, it is not possible to guarantee confidentiality, though we will remind all participants to keep any discussions/reflections in the strictest confidence. Please refrain from mentioning anything that you do not wish the group to know—you can tell the facilitator separately at the end of the discussion if there is something important that you wish to raise privately. Signed consent forms will have your name, but will be unlinked to any of your responses in the discussion. These will be locked in cabinet in a secure office space to which only the study team principal investigators have access.

9. Who is organizing and funding the research?

This study is being funded by the National Institute for Health Research in the UK. It is being led by the Liverpool School of Tropical Medicine (LSTM) supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT).

10. What will happen to the results of the research study?

Throughout the study, our key findings will be shared as part of a series of study dissemination meetings. A brief with key findings from this survey will be shared with the LUHFT for participants to view. We will also aim to publish our findings in scientific journals so that people in other contexts might benefit.

11. Who has reviewed the study?

This study has been reviewed and has been allowed to proceed by the Research Ethics Committee of the Liverpool School of Tropical Medicine (LSTM).

12. **Safeguarding**

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13. **What will happen to my data?**

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Other key points about how your data are handled:

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PARTICIPANT INFORMATION SHEET: Key-informant interviews

Study title: Exploring the design and operation of community health and wellbeing sickle cell hubs ('sickle hubs') to relieve pressure on GPs and hospital services

You are being invited to participate in a study in which we would like to understand how to best design sickle cell disease resource centres or hubs for improving SCD patients' wellbeing, resilience and interaction with health and social services, while also relieving NHS pressures. This study is being carried out by the Liverpool School of Tropical Medicine (LSTM), supported by the Royal Liverpool University Teaching NHS Foundation Trust (LUHFT) and SCD networks that include SCD patients and carers in the Liverpool health area catchment. This study will run from April 2025 to July 2026.

1. What is the purpose of the study?

We believe resource centres or hubs for people living with sickle cell disease will improve their wellbeing and resilience, thereby reducing hospitalizations or hospital visits while relieving pressure from the NHS. Therefore, we are trying to understand how the hubs will look like, where they will be located, what their key functions will be and how they will be run. Our findings will be used to subsequently test the hubs to determine how the hubs can be supported to function optimally.

2. Why have I been chosen?

You have unique insights around sickle cell disease management, resource allocation or decision-making and how people living with sickle cell disease are supported in the Liverpool catchment.

3. Do I have to take part?

You do not have to take part in this study if you do not wish to do so. There are no consequences at all for declining to participate. If you do decide to take part and later change your mind, that is absolutely okay. You can withdraw your participation at any time with no negative consequences at all—we will delete any recognizable data that we have collected from you at that point.

4. What will happen to me if I take part?

We will go through an informed consent process, after which we will begin an interview in which we will ask you several questions to reflect on how community resource centres or hubs could be used to improve the wellbeing and resilience of people living with sickle cell disease and their

carers. This will also include how such hubs would be funded and operated, what their functions would be and what measures should be put in place to assess their impact. This will take a maximum of 60 minutes of your time and will be carried out in a private location of your chosen, including in your office if you wish. However, if it is difficult to carry out this interview face-to-face, we will arrange a meeting online using Teams or Zoom. You will be provided with a link to that interview at least 24 hours before it is scheduled.

5. Expenses and payments

There are no payments for participating and you will not incur any expenses.

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

This is a very low-risk study, as we are only asking you to reflect on how you feel community resource centres could be implemented to improve wellbeing and resilience of people living with sickle cell disease. Though it is very unlikely, if, at any point, the questions are upsetting to you we can pause the interview or stop it altogether. You do not have to answer any questions you are not comfortable answering.

7. What are the possible benefits of taking part?

There will be no direct benefit to you but this study will help us to understand many things including key factors that will help to improve the wellbeing and resilience of people living with SCD, and how resource centres can help to realize this.

8. Will my taking part in the study be kept confidential?

All interview data will be kept confidential. However, as you are a “key informant”, this means that you occupy a unique position. We will make the greatest effort to ensure that no identifying information remains in any study materials, but this may not always be 100% possible. We will share with you any materials we intend to report to ensure you are comfortable with the information being shared. Signed consent forms will have your name, but will be unlinked to any of your responses in the discussion. These will be locked in cabinet in a secure office space to which only the study team principal investigators have access.

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