

Communicating in stroke care and rehabilitation (COM-STAR)

Standard Participant Information Sheet

1. Project Title

COMmunicating in STroke cAre and Rehabilitation (COM-STAR): Improving staff communication skills for better access to and inclusion in care and rehabilitation for stroke survivors with communication impairments

2. Invitation

- You are being invited to take part in a research project.
- The project aims to understand the communication experiences of:
 - stroke survivors,
 - their families,
 - and stroke staff,
 - during stroke care in order to develop training for staff working in stroke care.
- Please take the time to read this information carefully and discuss it with others (family/ friends/ colleagues) if you wish.
- Ask us if there is anything that is not clear or if you would like more information (see contact details below).
- Take time to decide whether or not you wish to take part - you have up to one (1) week to decide.
- Thank you for reading this.

If you would like to read this Participant Information Sheet in a different language, please tell the researcher.

How to contact us

If you have any questions about the study or if you would like to take part, please contact Madeleine Harrison on 0114 2220723 or email: comstar@sheffield.ac.uk

3. What is the project's purpose?

- Almost two thirds of stroke survivors admitted to hospital have communication impairments affecting:
 - their ability to talk,
 - understand what is said,
 - read or write.
- Research shows the negative impact of not being able to communicate with stroke care staff.
- We plan to develop a new training programme for staff working with stroke survivors with communication impairment.
- As part of developing the training we will invite people to share their experiences of successful and unsuccessful communication during stroke care.
- We will conduct interviews with:
 - stroke survivors,
 - family members,
 - and healthcare staff
 - to gather their experiences and opinions.
- We will video record the interviews.
- Clips from the videos will be used to get the people who design the training to think about :
 - how communication impacts
 - stroke survivors,
 - their family members,
 - and the staff working with them.
- Clips will show how positive and negative communication experiences affect stroke survivors, family, and staff.

4. When is the project taking place?

- The interviews will be taking place from June to December 2024.
- The whole project, including designing and evaluating the training will finish in February 2027.

5. Why have I been invited?

- You have been invited to take part because you are either:
 - a stroke survivor who has a communication impairment,
 - a family member or close friend of someone who has had a stroke,
 - or a staff member who works with stroke survivors.

- We hope to include people of:
 - different ages,
 - types of communication impairments,
 - ethnicities
 - and first languages.
- In total, we plan to interview 10-15 people with communication impairments and/ or their family members/close friends.
- We will also interview 10 staff who provide care and rehabilitation to stroke survivors.

6. Do I have to take part?

- It is up to you to decide whether or not to take part.
- Your participation is voluntary.
- If you do decide to take part, you will be given this Participant Information Sheet to keep (and be asked to sign a consent form or provide recorded verbal consent).
- You can choose to stop taking part in the interview at any time, without any negative consequences. You do not have to give a reason.
- If you change your mind, you have one week from the date of the interview to decide that you do not want the information you have provided to be included in the study.

If you wish to stop taking part, you can let the researcher know during the interview or by contacting Madeleine Harrison on 0114 2220723 or email: comstar@sheffield.ac.uk.

Please note that by choosing to participate in this research, this will not create a legally binding agreement, nor is it intended to create an employment relationship between you and the University of Sheffield.

7. If I take part, what will I have to do?

- You will be invited to take part in an interview.
- The interview will be carried out by:
 - a researcher in person (you can choose the location)
 - or by videocall (e.g., Google Meet).
- The interview will last up to one hour. The interview will be video recorded so clips can be shown to the people developing the staff training.

If you are a stroke survivor or family member:

- The researcher will ask you to provide some information about you (age, gender, ethnic group, languages spoken, etc). This information will help us to know whether we have included a diverse group of people in the interviews.
- The researcher carrying out the interview will ask you to describe positive and negative experiences of communication
 - between you and the staff who provided care and rehabilitation after your stroke (or your family member's stroke.)
- The researchers carrying out the interviews are experienced in supporting stroke survivors to communicate during interviews.

If you are a member of staff providing care to stroke survivors:

- The researcher carrying out the interview will ask you to describe the successes and challenges that you have experienced whilst communicating with stroke survivors and their families.
- They will also ask about what communication strategies you have used or training you think you might benefit from.

If you take part in an interview, you will receive a £20 Love2shop or Amazon voucher to thank you for your time.

If your interview is held at the University of Sheffield or City, University of London, you will be reimbursed for your travel expenses.

If one or more clips from your video are selected to be shown to the team designing the training, we will send them to you to look at to check you are happy with them.

8. Will I be recorded, and how will the recorded media be used?

The interview will be video recorded. How it is recorded will depend on whether the interview is conducted:

- In person: it will be recorded using a video camera
- Videocall: it will be recorded using the record function within the videocall (e.g., Google Meet)
- The video recording will be watched by members of the research team and our patient and public involvement group to identify patterns across different people's experiences.
- Clips from the recordings will be shown to the people involved in designing the training.
 - This will include:
 - other stroke survivors,

- family members
 - and staff working in stroke care (approximately 18 people).
- We would also like your permission to use clips from your video recording for wider purposes, including:
 - in the training programme we are developing,
 - and in conference presentations or teaching students
 - to raise awareness of the impact of communication disorders.
- This is optional and you can still take part even if you do not want the clips shared beyond the team designing the training.

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

- In total, the interview will take up to one hour of your time.
- Talking about the stroke care you have received (or delivered) during the interview may bring up difficult memories or experiences. In order manage this possibility:
 - You will not be asked to discuss anything you find too sensitive.
 - You can choose to not answer a question.
 - You can take a break or stop at any point during the interview.
 - You can also bring someone else for moral support if you would like.
 - You can also ask to chat to the researcher after the interview is finished.
 - If the interview brings up difficult issues you wish to discuss further, we will provide contact details for support services in your area.
- As we will share the video recordings with others involved in the research and training design process it is possible that you will be identified.
- We will discuss this immediately before the interview to ensure you only provide information you are happy to share.
- We will also check if there is anything you do not want to be shared at the end of the interview.
- If you agree to your video being shared more widely
 - in the training programme, conference presentations or teaching,
 - you and the experiences that you share will be viewed by a wider audience.
- You can still take part even if you do not want your video to be shared more widely.

10. What are the possible benefits of taking part?

- If you take part in an interview, you will receive a £20 Love2shop or Amazon voucher to thank you for your time.
- If you complete your interview at the university, your travel expenses will be reimbursed.

- Many people value the opportunity to talk about their experiences
 - In receiving stroke care and rehabilitation,
 - Or in providing stroke care and rehabilitation, if you are stroke staff.
- Taking part will help with:
 - designing new communication training for staff working with stroke survivors
 - and improve communication practices in stroke care,
 - ultimately enhancing patient experience and outcomes.

11. Will my taking part in this project be kept confidential?

- We will share clips from the video recordings with:
 - the research team,
 - stroke survivors,
 - family members,
 - and stroke care staff
 - involved in designing the training.
- They will see your face and hear your voice.
- We will not identify you by name or include any other identifiable (personal) information with the video recording:
 - this means information like your name, your address, your phone number
- If you give permission for us to use clips from your video recording when we share the study findings more widely (for example in the training programme, at conferences, or in teaching),
 - we will also not identify you by name or include any other identifiable (personal) information.
- All information collected will be strictly confidential and accessible only to the research team.
- Your identity will remain anonymous unless you explicitly consent to being identified.
- Your data will be securely stored.
- Data will be transferred at the earliest possible opportunity from the video recorder
 - onto a password protected and encrypted device (e.g., computer)
 - and then transferred to a secure computer drive at the University of Sheffield.
- Video-recordings will be retained for 10 years.
 - After this time, video-recordings will be electronically destroyed, following University of Sheffield's policy.

12. What is the legal basis for processing my personal data?

According to data protection legislation, we are required to let you know that the legal basis we are applying in order to process your personal data is that:

- 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).
- Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general.>

As we will be collecting some data that is defined in the legislation as more sensitive (information about health), we also need to let you know that we are applying the following condition in law:

- that the use of your data is necessary 'for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)).

13. What will happen to the data collected, and the results of the research project?

- The data collected will be analysed directly from the recording by members of the research team
 - to identify patterns across people's experiences.
- The findings will be used to improve stroke care practices and will be shared in research publications and presentations.
- Your participation will be acknowledged but kept anonymous.

14. Who is organising and funding the research?

The research is funded by the National Institute for Health and Care Research through the Health and Social Care Delivery Research programme. The grant number is NIHR 155921. More information is available on the internet: <https://fundingawards.nihr.ac.uk/award/NIHR155921>.

15. Who is the Data Controller?

- The University of Sheffield will act as the Data Controller for this study.
 - This means that the University is responsible for looking after your information and using it properly.
- City, University of London will act as a Data Processor for this study.
 - This means City, University of London will collect some data for this study, and collect and store this in line with the requirements of the University of Sheffield.

16. Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the School of Population Health. This project and ethical approval has then been ratified by and registered with the School of Health and Psychological Sciences Research Ethics Committee at City, University of London.

17. What if something goes wrong and I wish to complain about the research or report a concern or incident?

- For complaints or concerns, please contact the Chief Investigator (Rebecca Palmer; r.l.palmer@sheffield.ac.uk) in the first instance.
- If you feel your complaint has not been handled in a satisfactory way you can contact the Head of the School of Population Health (Louise Preston; l.r.preston@sheffield.ac.uk).
- If the complaint relates to how your personal data has been handled, you can find information about how to raise a complaint in the University's Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.
- If you wish to make a report of a concern relating to potential exploitation, abuse or harm resulting from your involvement in this project, please contact the project's Designated Safeguarding Contact (Rebecca Palmer; r.l.palmer@sheffield.ac.uk).
- If the concern or incident relates to the Designated Safeguarding Contact, or if you feel a report you have made to this Contact has not been handled in a satisfactory way, please contact the Head of the School of Population Health (Louise Preston; l.r.preston@sheffield.ac.uk) and/or the University's Research Ethics & Integrity Manager (Lindsay Unwin; l.v.unwin@sheffield.ac.uk).

18. Contact for further information

For further information, please contact Madeleine Harrison on 0114 2220723 or email: comstar@sheffield.ac.uk

Thank you for reading this participant information sheet. If you decide to participate, you will receive a copy of this participant information sheet and a consent form for your records.

