

Report of SUPERB Online Befriending Development

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This report summarises the adaptation of the SUPporting wellbeing through PeER Befriending (SUPERB) scheme for remote online delivery to individuals with aphasia. The work took place during the context of COVID-19 in the UK from July to October 2020. It was funded by The Stroke Association. City, University of London was the research sponsor.

Background

Depression is common after stroke. It reduces the effects of rehabilitation; impacts on long-term outcome and leads to higher mortality rates (Ferro et al., 2009; Hackett et al., 2008). Depression is persistent. There is a need for interventions that promote wellbeing and adjustment with stroke and aphasia and may prevent depression (Baker et al., 2018). We have completed a feasibility randomised controlled trial on supporting wellbeing through peer-befriending for people with aphasia (SUPERB trial, Hilari et al., 2019; Hilari et al., 2021). In response to the COVID-19 pandemic we explored the feasibility of delivering online the support intervention that had previously been carried out successfully face-to-face within the SUPERB trial.

Methods

SUPERB befriending materials (training, befriender manual) and processes (training, supervision, researcher team support, befriending visits) were adjusted for online delivery as detailed below. Eight people with aphasia worked with the research team, trialing out the online befriending scheme and sharing their views and experiences on how it worked.

User involvement

Four befriending pairs were recruited to trial four or five sessions of online befriending each. Both befrienders and befriendees with aphasia were identified through existing links with Aphasia Re-Connect. Two of four befrienders had previously taken part in the SUPERB face-to-face intervention. Two others were interested in doing more and supporting others and were familiar with Zoom, the platform used for online befriending.

Befriender Training in an Online Context.

Prior to undertaking online befriending sessions, befrienders received 5 group training sessions of 45-60 min each via the Zoom teleconferencing platform (4-5 hours in total). This compares to 2-3 face-to-face sessions of 2 hours each [4-6 hours over 2-3 days] for the face-to-face befriending trial. The same researchers delivered the befriender training for this online project as had delivered it previously for the face-to-face befriending trial. Training for online delivery was adapted from the face-to-face training programme by the researcher authors of the original training programme. Adaptations included:

- the shortening of training sessions (to limit duration of screen time for attendees),

- inclusion of a discussion of online safeguarding issues, and
- the addition of technical guidance regarding how to engage with key features of the teleconferencing platform Zoom. Technical guidance covered included how to join and leave a Zoom call, how to share a screen and how to use the whiteboard.

Technical demonstrations were supported with short screen recording videos available here:

- <https://loom.com/share/folder/56a0896e8dab415696f05283584bdcae>
- <https://youtu.be/ZVa41f3l1IQ>.

The manual shared with befrienders was also updated to include an additional section addressing online safeguarding and managing befriender meetings online.

Befriender Sessions in an Online Context.

Befrienders were each paired with a befriendee. Pairing allocations were based on sex (same sex pairings) and mutual interests, for instance, teaching or business interests. Befrienders were requested to aim to organise four or five meetings with their befriendee within a two-month period (August-September 2020).

Three researchers were assigned to support the four befriending pairs. (One supporting two pairs and the others supporting a pair each). The researchers took responsibility for setting up the video call for each meeting, technical troubleshooting and checking fidelity of befriender behaviour to SUPERB protocol. Sessions were not video recorded – instead the allocated researcher observed each session live. At the start and end of the call, the researcher would appear via video and voice, but they would switch off their camera and microphone during the main body of the session so as not to disturb the conversation between the befriending pair. Researchers were available as needed during the meeting to support technical challenges but other than this they did not intervene with the session except to check in at the beginning and end.

Supervision

Four online supervision sessions were offered to befrienders to accompany the intervention period. These were run by the researcher speech and language therapist who provided face to face befriender supervision sessions within the original SUPERB trial. One additional researcher from the team also attended to monitor fidelity. As for the main trial, supervision sessions served to provide a space for ongoing support, reflection and discussion with fellow befrienders and the supervisor once befriending sessions were underway.

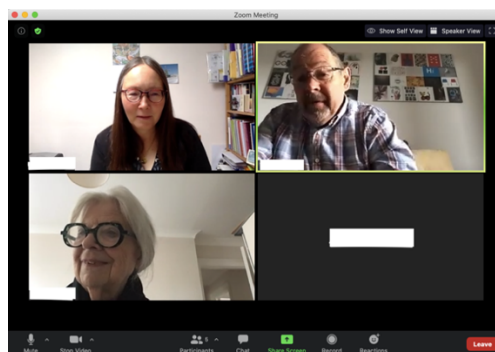


Figure 1: Example screenshot from befrienders' supervision session – shows supervisor & two befrienders in discussion.

Fidelity

Fidelity for training, befriending sessions and supervision was measured. *Training fidelity* was scored by reviewing videos of training meetings. Befriending and supervision sessions were scored via live researcher observation of sessions. For *befriending sessions*, the researcher scorer completed this with their camera and video off (i.e., discreet presence). For the *supervision session*, an observer researcher completed this during the session whilst leaving their camera and microphone on (i.e., being visibly and audibly present.)

Befriendees' experiences of online befriending: individual interviews

Following completion of befriending sessions, each befriender took part in a short one to one interview with a member of the research team to report on their experience of taking part in the online befriending visits. This interview was conducted via Zoom, supported with a PowerPoint slide show presented using screen sharing. Each interview question was presented verbally and with a supporting slide showing the question text (see Appendix 1). Where possible, this interview was conducted by a researcher separate to the one who had been assigned to support that befriender's pairing with organising their sessions. With permission, interviews were audio recorded and subsequently transcribed for thematic analysis. Befrienders each received a file summarising their responses to each question – presented as an annotated slide deck for the presentation shown in the interviews.

Befrienders' experiences of online befriending: focus group

Also following completion of the befriending sessions, befrienders took part in a focus group as a part of their final supervision session. All befrienders plus all three befriending pair researchers attended this group. One researcher facilitated the discussion – utilising the question series also presented to the befrienders (see Appendix 1). As for the individual interviews, each question was presented verbally and with a supporting slide showing the question text. Again, with permission, this was audio recorded and subsequently transcribed for thematic analysis. Befrienders received a summary of the outcomes of the focus group.

Results

Befrienders

Two male and two female befrienders took part. Ages ranged from 39 - 81 years old and time post onset ranged from 1.5 – 10 years. Befrienders all demonstrated mild – moderate aphasia based on observations and clinical judgement. Key clinical features were anomia (mostly mild) and some auditory comprehension difficulties. Reading and writing varied from mild impairment (spelling needs watching) to moderate / severe impairment. Further details are reported below using the pseudonyms Hapsa, Gerry, Diana and Simon to refer to befrienders.

Befriendees

Two male and two female befriendees took part. Ages ranged from 54 - 67 years old and time post onset ranged from 2 – 14 years. Befriendees demonstrated mild – moderate aphasia based on observations and clinical judgement. Key clinical features were mild to moderate anomia and some auditory comprehension difficulties. Reading and writing was also moderately impacted with some use of strategies to manage this. In several cases, writing was used to support spoken output. Further details are reported below using the pseudonyms Norma, Steve, Joanne and Dave to refer to befriendees.

Befriending Sessions

Pairs negotiated time and date for sessions together. Sessions were scheduled for a duration of 1 hour. A total of 21 sessions were scheduled and 15 took place as planned. Four sessions did not go ahead and 2 were partially but not fully completed. Reasons for no session / non-completion are reported below in table 1.

Pair ID	Total visits Booked	Number of visits fully completed	Number of visits partially completed	Number of visits not completed	Reasons for only partial completion / no session
1 Norma & Hapsa	6	4	0	2	Befriender cancelled due to ill health. Befriendee forgot the appointment.
2 Steven & Gerry	5	2	2	1	Befriendee experienced technical problems and was unable to get online (first meeting). 2 X Befriendee experienced audio difficulties preventing completion of full hour-long session
3 Joanne & Diana	5	4	0	1	Befriendee cancelled due to fatigue
4 Dave &Simo n	5	5	0	0	

Table 1. Visits scheduled, completed, partially completed or not completed plus reasons for partial or non-completion.

Technical Issues

Two befriending pairs experienced technical issues. These were Steven and Gerry and Dave and Simon. Steven and Gerry opted to finish one call 15 minutes early due to the appearance of technical issues with sound during the call. At first these were resolved with researcher assistance, but they subsequently reappeared after a further 5-10 minutes and the befriender decided to terminate the call. The same issue appeared again in a later session and again the befriender opted to end the call 10-15 minutes before allotted time rather than try and troubleshoot technical difficulties. Both Steven and Gerry were happy to manage the issue in this way.

Within Simon and Dave's pairing, Dave was unable to switch on his camera for the first session meaning the pair completed their first call without video. Before their next session, Dave visited a local computer shop and was advised how to resolve the issue. Within future sessions, Dave and Simon sometimes experienced difficulties with intermittent Wi-Fi signal. When these appeared, the pair addressed the problem by agreeing to both switch off their camera. This enhanced the audio quality by reducing the amount of data being used in the call.

The remaining befriending pairs, Norma and Hapsa and Joanne and Diana, did not experience any technical issues that disrupted their sessions.

Supervision

All befrienders attended four supervision sessions. Three took place whilst the pairs had their befriending sessions. Issues addressed included what to say when you've run out of ideas (how to expand a conversation), and how to respond when a befriender raises a difficult (e.g. emotionally challenging) topic. Session four took place after all befriending visits had been completed – serving as an opportunity for befrienders to provide feedback on their experience.

Fidelity Outcomes

Training session video recordings was reviewed and adherence of 100% was observed across the training.

Peer-befriending sessions: fidelity was monitored live for 15 of 15 sessions and adherence ranged from 93 – 100%.

Supervision sessions: fidelity was monitored live for 1 of 4 sessions and adherence of 100% was observed for this session.

Befriender and befriender experiences

Appendix 2 includes full analysis of interview and focus group data. Befrienders and befrienderes expressed a range of opinions when comparing the virtual scheme to an in-person visit. For example, Diana (befriender) noted it can be difficult to detect 'nuance' on a Zoom call which made it more difficult to have 'deep' conversations; similarly, Dave (befriender) pointed out that face to face it is easier to 'tell by their facial expressions if you've upset them.' Simon summed up the broad consensus across both befriender and befriender participants: 'It can't replace seeing someone in person, but it's the next best thing.'

Support for online befriending

Participants expressed gratitude that the research team set up their online meetings, describing this as 'a godsend' and adding that it would have been very difficult to do independently. Befrienders additionally emphasised the importance of the thorough training, saying this made the intervention 'easier' and 'more effective.' They felt the frequency of supervision, fortnightly, was ample, and though they knew they could contact the research team outside this setting, none of them felt the need to do so.

Benefits of online befriending

All participants appeared to be pragmatic about the impossibility of meeting face to face, and they were able to pinpoint some distinct advantages to virtual befriending. These included the capacity to visit someone who is geographically remote, the reduction in travel and associated fatigue and cognitive load, and the lack of need to arrange childcare.

Befrienders felt virtual meetings were 'a fantastic way of communicating, a godsend' and 'a lifeline'. Simon reported 'Zoom saved me from depression'; he felt that even when socialising restrictions are lifted, in his opinion some group meetings should continue virtually, to encourage higher attendance and participation.

All participants (befriendees and befrienders) felt strongly and unequivocally that the online befriending scheme had had positive effects on their mood, combating loneliness and boredom, and fulfilling a need for social interaction. Befriendees said it was 'all about hope' and appreciated the sense that someone truly understood their experience. Befrienders said it had left them feeling happy and motivated, and that they 'always finished the conversation on a high note.'

Destinations of Participants

After completion of the SUPERB online befriending programme, all four befrienders continued to offer online befriending. One offered two further sessions with her befriendee. The remaining three were allocated new befriendee pairings within Aphasia Re-connect. All additionally continued to engage with weekly online groups in Aphasia Re-connect.

All befriendees also continued engagement with Aphasia Re-connect services. One received additional befriending sessions; two continued to take part in weekly online groups. The final befriendee went on to deliver aphasia communication skills training to others.

Conclusions and Recommendations for the Future

It appears feasible to carry out befriending for participants with chronic aphasia using remote conferencing technology. All aspects of the befriending scheme (training, supervision, online sessions) were delivered with high fidelity. Both befrienders and befriendees reported positive effects on their mood. Befrienders emphasised the importance of the training and supervision received and indicated the benefit of having support to set up the scheduling and links for the online meetings. Technical issues were addressed resourcefully, pragmatically and collaboratively between befrienders and befriendees with minimal need for consistent researcher presence for technical support.

Future online befriending projects should look to provide comprehensive training and supervision for befrienders and assistance with the organisation and set up of online befriending meetings. Close observation of befriending meetings for the provision of technical support does not appear necessary, though it may be helpful to have a technology troubleshooting guide available to befriender and befriendee to try and self-resolve technology issues which arise during sessions (see appendix 3 for an example); and a contact person to get in touch with if the issues persist.

References

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Appendix 1: Question prompts for befriender interviews and befriender focus group

SUPERB virtual peer-befriending visits – your **feedback** please



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Tell me **what you thought** about the befriending visits?



Comments:

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What was the **best thing** about the befriending scheme?

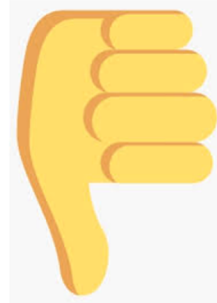
Comments:



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What **didn't** you like about befriending?

Comments:



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What were your **expectations** of befriending?

How well were they met?

Comments:



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Did the visits make any **difference** to how you are **feeling**?

Comments:



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What, if any, **difference** did you think there was between **virtual** befriending and **face to face**?

Comments:



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Tell us about your experiences with **Zoom**?

Comments:



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Tell us about your contact with the **research team**?

Comments:



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How would you **describe befriending** to someone else?

Comments:



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What **advice** would you give the team to take the scheme further?

Comments:



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Appendix 2: Qualitative outcomes from befriender interviews and befriender focus group

Befrienderes received 4-5 virtual visits from their befrienders. There were two male (Simon and Gerry) and two female befrienders (Diana and Hafsa). They were matched with two male (Dave and Steven) and two female befrienderes (Joanne and Norma) respectively.

Peer-befriending conversations

Befrienders reported a high level of satisfaction with the scheme. They particularly emphasised the importance of conversation flowing; Diana reported:

‘I found it incredibly easy because I was very lucky, I was paired with another teacher and we had lots to talk about, talked about learning to read, children, art and my befriender was very brave, she’d gone into schools and we talked about her returning to work, I mean I don’t think there were any gaps really, apart from thinking of words, and she was very good at writing things.’

The befrienders said that on occasion there were moments of silence, but that there was a sense that they had been resourceful in resolving these ‘lulls’, further supported in supervision with a document on facilitating deeper conversations. Some used tangible resources such as photographs, post-it notes and mobile phones to support their conversation. There were no instances where Zoom’s integral features such as the whiteboard were used, as this was not perceived to be necessary. However, one befriender did share her screen in order to give her befriender a recipe via YouTube.

Topics of conversation were wide-ranging, spanning interests and hobbies (e.g. cooking, football), former careers (including professional advice from a former midwife), family and everyday life, the global pandemic and more. Practical tips were also shared, including links to international meetings for people with aphasia, and invitations to join other Re-Connect groups. Humour was often present, sometimes linked to the current uncertain climate, for example when meetings were forgotten owing to not knowing the day of the week. The sense of being part of a community united by enforced isolation was a theme, and participants reported they had spent time ‘putting the world to rights.’

Building rapport

Some individuals in both groups said they had known - even if only by sight - their partner beforehand, and noted this was a helpful icebreaker, but not crucial to successfully building rapport. They also felt they had grown to know one another in a more genuine, less superficial, way through the one to one format. Befrienderes spoke of their partner’s character traits and how these were helpful: being kind, wise, funny, a positive person. Close bonds sometimes developed, for example when Norma was asked what was the best thing about her befriender she said: ‘Ohhhh she’s a good girl, I like it because she’s like my daughter.’ Befrienderes could not offer any aspects of the scheme they disliked, with one expressing a strong desire to be given another match at the beginning and end of their interview.

Dose

Asked to reflect on their expectations of the scheme before it commenced, one befriender explained they had been a befriender several times before, so knew roughly what it would entail. Two said they came with an open mind and no preconceived ideas, while one said it was 'definitely better' than she anticipated, adding she would have liked a daily visit if that had been feasible. Two befriendees told us they would have liked more visits than they received, with one suggesting six might be optimum. The length of each visit, approximately one hour, was judged to be appropriate. Befriendees reported that they were often surprised at how quickly the time had passed, but felt it was important to find a balance between appreciating the opportunity for conversation while also managing their fatigue.

Virtual peer-befriending

The befriendees were unanimous in their unequivocal support for the virtual befriending scheme. They reported one to one contact was preferable to group Zoom meetings, when it could sometimes be challenging to have a turn in conversation, which often led to them staying quiet or even discontinuing attendance. Most felt that the mutual experience of stroke and aphasia added value to the relationship, and favoured this over meeting with a volunteer or student. Steven felt ambivalent about whether mutual experience was a factor in the rapport owing to the length of time since his stroke.

Befrienders and befriendees expressed a range of opinions when comparing the virtual scheme to an in-person visit. For example, Diana noted it can be difficult to detect 'nuance' on a Zoom call which made it more difficult to have 'deep' conversations; similarly, Dave pointed out that face to face it is easier to 'tell by their facial expressions if you've upset them.' Simon summed up the broad consensus among both groups: 'It can't replace seeing someone in person, but it's the next best thing.' Steven's opinion differed from the other befriendees, and he felt there was no difference between either type of delivery. Hafsa went further and felt being a virtual befriender was easier, as it meant she could have a note of conversational prompts next to the screen.

All appeared to be pragmatic about the impossibility of meeting face to face, and they were able to pinpoint some distinct advantages to virtual befriending. These included the capacity to visit someone who is geographically remote, the reduction in travel and associated fatigue and cognitive load, and the lack of need to arrange childcare. They noted that being able to see one another's homes and other members of the household made visits more informal, and enjoyed commenting on items in the background, some even moving rooms for variation. Unexpected interruptions from children or pets were seen as an opportunity for entertainment and human connection rather than an inconvenience. Befrienders noted that this was a reciprocal experience, compared to the one-way experience of being a stranger in someone's home, and felt this made the relationship more equal.

Technical issues and research team support

Some of the pairs encountered technological problems with using Zoom. They described being resourceful in solving these independently, for example by visiting PC World before the next visit, turning cameras off to improve connectivity and moving nearer to the WiFi source. Consequently, very little intervention by the research team was required, though many

reported they felt reassured by their presence in case they were needed, and occasionally asked them to prompt their partner if they did not arrive at the meeting for the agreed time. Some described initially feeling slightly inhibited by the presence of a third party, albeit muted and off camera, but said they soon forgot they were there, to the extent it came as a surprise when they unmuted at the end of the visit. Participants expressed gratitude that the research team set up their meetings, describing this as ‘a godsend’ and adding that it would have been very difficult to do independently. Befrienders specifically emphasised the importance of the thorough training, saying this made the intervention ‘easier’ and ‘more effective.’ They felt the frequency of supervision, fortnightly, was ample, and though they knew they could contact the research team outside this setting, none of them felt the need to do so.

The befriendees explicitly welcomed the opportunity to give their feedback when the scheme ended. No participant from either group expressed any form of dissatisfaction with their contact with the research team, nor did they have recommendations to conduct the intervention differently in future, instead feeling the team should offer ‘more of the same.’ One befriender expressed concern for their befriender’s wellbeing now the scheme had ended, and was offered reassurance that there would be continued contact through Aphasia-Reconnect.

Perceived benefits and Impact on mood

When asked how they would describe befriending to people unfamiliar with the scheme, Diana said:

‘You may feel nervous contacting a stranger but it’s worth the risk, we all have to take, people living with aphasia are good at taking the odd risk, and I think it’s well worthwhile and you feel good about it.’

The befrienders’ group also noted that while they may also be perceived as therapeutic, the central purpose of the visits was to have a two-way, equal conversation. One befriender reported that she felt her own speech had improved as a result of the intervention.

Befrienders reported they had entered the scheme with an open mind and the hope that befriendees would benefit, but added they were surprised by how much they had also benefitted from the scheme. Hafsa explained:

‘I think when lockdown happened, so many people were lonely and this aphasia befriending scheme helped, it really did. Especially if they have a disability or something then they might not go out that much, or if they are lonely in the sense that their children or their siblings or husband or wife are not around.’

Finally, both groups were asked if the intervention had any impact on their mood. All felt strongly and unequivocally that it had positive effects, combating loneliness and boredom, and fulfilling a need for social interaction. Befriendees said it was ‘all about hope’, and appreciated the sense that someone truly understood their experience. Befrienders said it had left them feeling happy and motivated, and that they ‘always finished the conversation on a high note.’ They felt virtual meetings were ‘a fantastic way of communicating, a godsend’ and ‘a lifeline’. Diana summed up her virtual journey for the team:

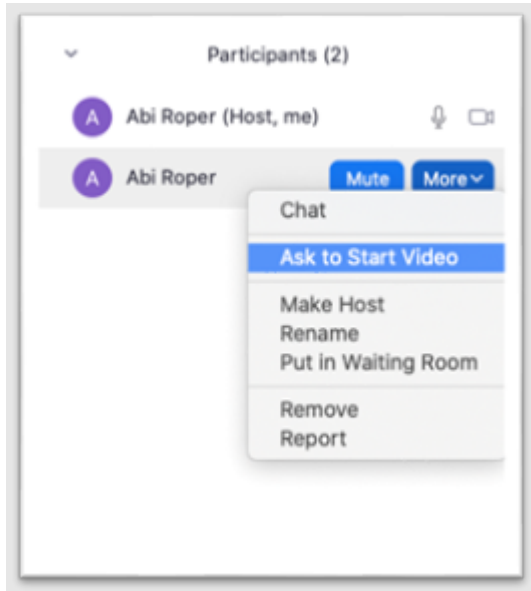
'Zoom is my friend now. When my daughters first introduced me to it, I thought "Oh I'm going to hate this, I can't be doing with it." Six months later I feel totally different.'

Simon reported: 'Zoom saved me from depression.' He added that even when socialising restrictions are lifted, in his opinion some group meetings should continue virtually, to encourage higher attendance and participation.

Appendix 3: Troubleshooting Sheet for Technical Difficulties During a Zoom call

Turning the camera on

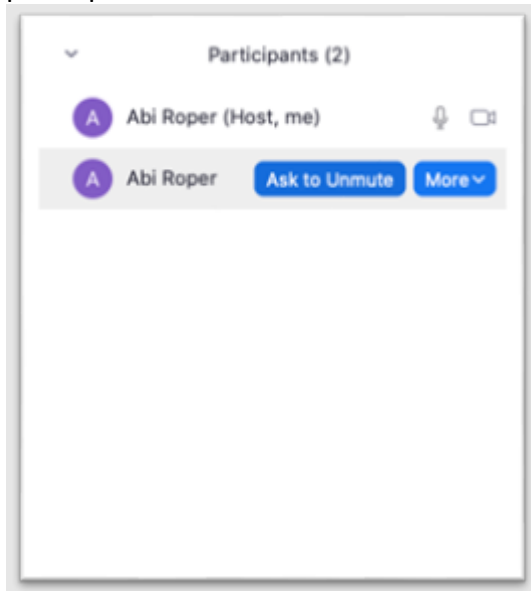
If a person in the call is finding it hard to turn the camera on, the host can click on the participant's name or window > more > Ask to start video.



This will create a prompt on the person's screen that they can respond to and may be easier than describing how to look in the settings.

Turning the mic on

If a person is finding it hard to turn the microphone on, the host can click on the participant's name or window > Ask to unmute.



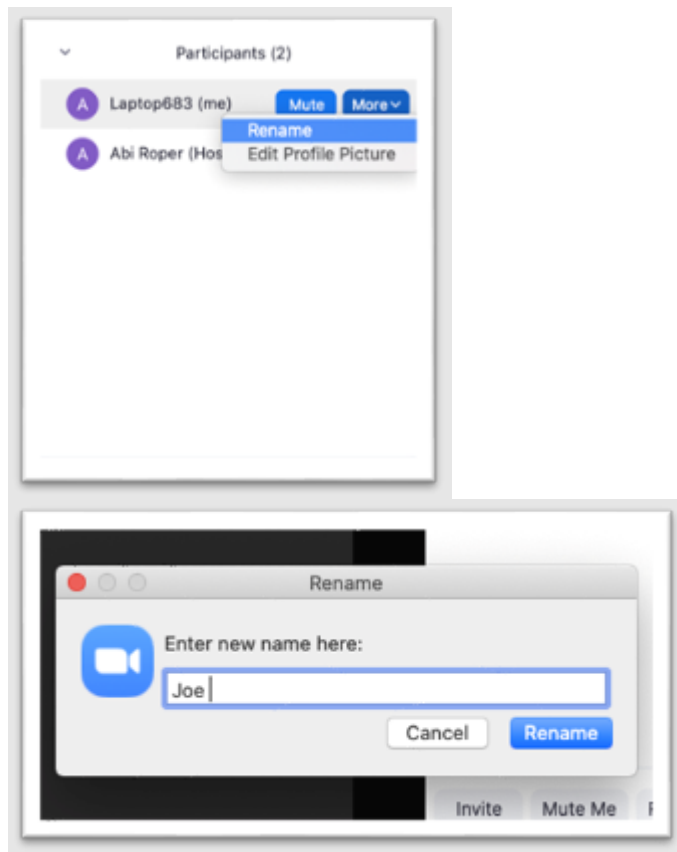
This will create a prompt on the person's screen that they can respond to and may be easier than describing how to look in the settings.

Renaming attendees.

If your name appears as a generic title (e.g. iPad/AcerInspire/Laptop683), you can rename yourself to show your given name.

Click on the “Participants” window > more > Rename > Enter the new name: > Rename

The host can also rename other members of the call using the same process.



If the sound or image fails for no clear reason try the following:

1. Press the camera button once or twice to turn the camera off and on again.
2. Press the microphone button once or twice to turn the microphone off and on again.
3. If this doesn't work, try leaving the call all together and re-joining via the original joining link

Ending the call:

If one person cannot leave the call independently, the host can end the call for everyone and re-start.