User Needs - Augmentative Communication Devices

Consent
Understanding user needs for augmentative communication devices - research study
Thank you for your interest in our research study! The goal of this study is to understand user needs for augmentative communication interfaces. The outcomes of this survey will help drive the design of an early-stage research project to design new augmentative communication interfaces that utilize technological advancements in neuromuscular sensing and artificial intelligence. We estimate that this survey will take approximately 30 minutes to complete.
The information you provide in this survey will not be presented in a way that can be identified to you. Please contact Jaya Narain (jnarain@mit.edu) with any questions.

☐ I would like to take the user needs for communication devices survey

1. How old are you in years? (Please enter your age here, even if you are filling out this form on behalf of someone else)
2. Are you filling out this form on behalf of someone else?
   ○ Yes
   ○ No

*NOTE*: If the person answered “No” to Q2, then Q3 and Q5 were not shown. Other questions were displayed with the text “you” instead of “your loved one” (e.g., for Q4: “What condition do you have?”)

3. What is your relation to the person you are filling out this form on behalf of?
   ○ Parent
   ○ Child
   ○ Sibling
   ○ Professional caregiver
   ○ Other ____________________________________________________________

4. What condition does your loved one have?
   ○ Amyotrophic lateral sclerosis (ALS)
   ○ Cerebral Palsy (CP)
   ○ Stroke
   ○ Autism spectrum disorder (ASD)
   ○ Multiple sclerosis (MS)
   ○ Spinal cord injury
   ○ Other ____________________________________________________________

5. How old is your loved one in years?
   __________________________________________________________________
6. Does your loved one have a intellectual disability?
   - Yes (1)
   - No (2)
   - Other response (3) ______________________________________________________

Display This Question:
If What condition does your loved one have? = Autism spectrum disorder (ASD)

7. What activities does your loved one find most challenging as a person living with ASD?
   ______________________________________________________________________

Display This Question:
If What condition does your loved one have? = Amyotrophic lateral sclerosis (ALS)

8. When was your loved one diagnosed with ALS?
   ______________________________________________________________________

Display This Question:
If What condition does your loved one have? = Multiple sclerosis (MS)

9. When was your loved one diagnosed with MS?
   ______________________________________________________________________

Display This Question:
If What condition does your loved one have? = Stroke

10. When did your loved one have a stroke?
    ______________________________________________________________________

Display This Question:
If What condition does your loved one have? != Autism spectrum disorder (ASD)

11. Is there any other information about your loved one’s condition you would like to share? (e.g. sub-condition type, what activities are affected most by the condition)
    ______________________________________________________________________

12. Does your loved one experience spasticity, tics, or sudden jerking motions?
    - Yes
    - No

Display This Question:
If Does your loved one experience spasticity, tics, or sudden jerking motions? = Yes

13. How often does your loved one experience spasticity, tics, or sudden jerking motions?
    - Every few minutes
    - Every hour or so
    - Daily
    - Weekly or monthly
    - Other ________________________________________________________________

Display This Question:
If Does your loved one experience spasticity, tics, or sudden jerking motions? = Yes
14. Where does your loved one experience spasticity, tics, or sudden jerking motions? You can select multiple options.
- Eye gaze
- Facial muscles
- Head and/or neck
- Hands
- Arms
- Legs
- Trunk
- Other

15. Do your loved one's speech and/or motor abilities change with time?
- Abilities improve
- No change
- Abilities worsen

16. How frequently do you notice changes in your loved one's speech and/or motor abilities?
- Daily
- Weekly
- Monthly
- Every few months
- Yearly
- Other

17. Which of the following better describes your loved one's speech abilities?
- Used to be able to speak, but lost speech ability
- Have never been able to speak

18. Which of the following applies to your loved one's verbal speech? You can select multiple options.
- No auditory speech
- Can speak in short phrases, not complete sentences (e.g. "milk: instead of "I want some milk")
- Can speak in sentences with full clarity
- Can speak in sentences, with reduced clarity (still understandable by most people)
- Can speak in sentences, with reduced clarity (only understandable by close friends and family)
- Other

19. Which of the following applies to your loved one's communication practices? You can select multiple options.
- Has more difficulty communicating in unfamiliar settings
- Hand gestures have consistent meanings when communicating
- Non-word vocalized sounds have consistent meanings when communicating
- Primarily communicates through crying/yelling when unhappy
- Assistive device used to aid communication
- Communication speed is significantly reduced
- Communication is often misunderstood
- Other
20. Would you like to provide any more information on how your loved one communicates (optional)?

_____________________________________________________________

21. Can your loved one do the following tasks?

<table>
<thead>
<tr>
<th></th>
<th>Can do independently with no difficulty</th>
<th>Can do independently with some difficulty</th>
<th>Can fully do with help or prompting (e.g. from a device or person)</th>
<th>Can somewhat do with help or prompting (e.g. from a person or device)</th>
<th>Cannot complete task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talk (to friends and family)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talk (to strangers)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Write</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type (physical keyboard)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouth words (without producing sound)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answer yes or no questions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make hand gestures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make facial expressions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express emotions and/or feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Push physical buttons</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Push touch screen buttons</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use a computer or tablet to send a text or email</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make a purchase at a store</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ask for food when hungry    ○    ○    ○    ○    ○    ○
Let people know when in pain    ○    ○    ○    ○    ○    ○
Express need for sleep    ○    ○    ○    ○    ○    ○

22. Tasks more info If you would like, please use this space to provide more information about how your loved one does the tasks above (optional).
_________________________________________________________________

23. What communication related tasks does your loved one find most difficult or frustrating?
_________________________________________________________________

24. What, if any, devices does your loved one use to help with communication? You can select more than one option. If you do not use a device, please select “Other” and write that you don't use a device in the associated text box.

If you use a specific product, please list the product name (if applicable).
☐ Tobii
☐ Other gaze tracking device
☐ Head motion tracking device
☐ Proloquo2Go app
☐ Other tablet app
☐ Non-electronic word board
☐ Physical keyboard
☐ Stylus/pen + writing surface
☐ Buttons that produce audio messages (e.g. GoTalk 9+, BigTalk)
☐ Other
☐ Other
☐ Other

Display This Question:
If What, if any, devices does your loved one use to help with communication? You can select more than one option. If you do not use a device, please select “Other” and write that you don't use a device in the associated text box.

25. What difficulties does your loved one have with Tobii?
_________________________________________________________________

26. What does your loved one like about Tobii?
_________________________________________________________________

Display This Question:
If What, if any, devices does your loved one use to help with communication? You can select more than one option. If you do not use a device, please select “Other” and write that you don't use a device in the associated text box.

27. What difficulties does your loved one have with the gaze tracking device?
_________________________________________________________________

28. What does your loved one like about the gaze tracking device?
_________________________________________________________________

Display This Question:
If What, if any, devices does your loved one use to help with communication? You can select more than one option. If you do not use a device, please select “Other” and write that you don't use a device in the associated text box.
29. What difficulties does your loved one have with the head motion tracking device?

30. What does your loved one like about the head motion tracking device?

31. What difficulties does your loved one have with Proloquo2Go?

32. What does your loved one like about Proloquo2Go?

33. What difficulties does your loved one have with the tablet app?

34. What does your loved one like about the tablet app?

35. How does your loved one select inputs to your word board?

36. What difficulties does your loved one have with the word board?

37. What does your loved one like about the word board?

38. What difficulties does your loved one have with the keyboard?

39. What does your loved one like about using the keyboard?

40. What difficulties does your loved one have with the stylus/pen + writing surface?

41. What does your loved one like about the stylus/pen + writing surface?

42. What difficulties does your loved one have with the physical buttons that generate audio messages?

43. What does your loved one like about the physical buttons that generate audio messages?
44. What difficulties does your loved one have with the device you listed in other (box 1) - 

45. What does your loved one like about the device you listed in other (box 1) - 

46. What difficulties does your loved one have with the device you listed in other (box 2) - 

47. What does your loved one like about the device you listed in other (box 2) - 

48. What difficulties does your loved one have with the device you listed in other (box 3) - 

49. What does your loved one like about the device you listed in other (box 3) - 

50. Use this space to provide any other information you would like to share about the assistive devices your loved one uses (optional).
51. Would your loved one be interested in using a device with the following outputs?

<table>
<thead>
<tr>
<th></th>
<th>Extremely interested</th>
<th>Very interested</th>
<th>Moderately interested</th>
<th>Slightly interested</th>
<th>Not at all interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer generated speech</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Written text</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private auditory prompting to device user (e.g. device suggests a word or phrase)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlling a tablet or computer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlling a mobile phone</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Calling a caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlling the lights in a room</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlling a television</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about user's physical state (e.g. pain, emotions, hunger, tiredness)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Display This Question:**

If Would your loved one be interested in using a device with the following outputs? = Information about user's physical state (e.g. pain, emotions, hunger, tiredness) [Extremely interested]

Or Would your loved one be interested in using a device with the following outputs? = Information about user's physical state (e.g. pain, emotions, hunger, tiredness) [Very interested]

Or Would your loved one be interested in using a device with the following outputs? = Information about user's physical state (e.g. pain, emotions, hunger, tiredness) [Moderately interested]
52. If a device had the capability to send physical state information to designated people, what information output would be useful for your loved one?
- Hunger
- Presence of pain
- Location of pain
- Tiredness
- Need to urinate
- Need to defecate
- Emotions (e.g. sadness)
- Excitedness
- Stress

53. Are there any device outputs not listed above your loved one would find useful?

54. How would you rate the difficulty of the following input mechanisms for an assistive device for communication for your loved one?

<table>
<thead>
<tr>
<th>Input Mechanism</th>
<th>Not difficult at all</th>
<th>Slightly difficult</th>
<th>Moderately difficult</th>
<th>Very difficult</th>
<th>Cannot do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouthing words (without producing sound)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pushing tactile buttons</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pushing touch screen buttons</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving facial muscles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving fingers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moving eye muscles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Moving wrist</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Moving foot</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

55. Are there any device input mechanisms not listed above your loved one would find useful?
56. How important are the following characteristics for an assistive device to augment communication for your loved one?

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Extremely important</th>
<th>Very important</th>
<th>Moderately important</th>
<th>Slightly important</th>
<th>Not at all important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Input speed</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Output accuracy</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Device is wearable</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>No tablet needed</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Can be used outside</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Does not take long to train device</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Aesthetics</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Device is robust to being dropped and treated roughly</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Device does not take long to set up</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Data privacy</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
57. Please rate the likelihood your loved one would be willing to wear an assistive devices with the displayed form factors:

<table>
<thead>
<tr>
<th></th>
<th>Very likely</th>
<th>Moderately likely</th>
<th>Neither likely nor unlikely</th>
<th>Moderately unlikely</th>
<th>Very unlikely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headphones</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glasses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wristband</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Armband</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Device on wrist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Worn under clothes)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headset on face</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cap</td>
<td></td>
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</tr>
</tbody>
</table>
58. Consider the following potential device architectures:

*Trained Speech Generation:* Imagine a wearable headset-like device that can generate speech and text. The user trains the device to recognize the intent of facial muscle movements. When he/she makes a facial motion the device recognizes, it outputs the corresponding word as auditory speech, or as text input to a device (e.g. a phone or tablet). The user can choose to only have the device output messages after they have been checked and approved. The device can only be used to output messages it has been trained for.

*Context-based Speech Generation:* Imagine a goggle-like device. The user trains the device to recognize certain facial muscles, and the device has a camera, microphone, and other sensors to help interpret context. The device can process the speech of other people in a conversation, and understand basic information about the user’s setting (e.g. restaurant, home). The device uses the context to suggest words or phrases to the user, who can accept, deny, or edit the suggestions. When the user approves a message, it is output as auditory speech or as text input to a device (e.g. a phone or tablet).

*Speech Prompting:* Imagine a headset-like device that can prompt the wearer in conversations. The device can recognize simple speech phrases, and also has a camera and microphone to interpret the context. For instance if he/she says the word "sandwich" and they are in a kitchen, the device will ask them easy yes/no questions to better understand their goals (e.g. Do you want a peanut butter sandwich? Do you want a sandwich now?). The device will process the given information and will prompt them to say a more complex thought, like "Can you please make me a ham sandwich now?")

*Physical State Messaging:* Imagine a glove or armband that records basic physiological data that can be correlated to physical states like pain, tiredness, excitement, or hunger. When the glove a change in physical state, it can help the wearer communicate how they may be feeling (e.g. excitement, sadness) and/or provide information on the wearer's physical state (e.g. pain or hunger). The device can be programmed to communicate with pre-designated family members or carers and/or with individuals in the wearer's vicinity. If desired, the device can be set-up to share information only with the wearer's permission.

59. How helpful would each of the devices described above be for your loved one?

<table>
<thead>
<tr>
<th></th>
<th>Extremely helpful</th>
<th>Very helpful</th>
<th>Moderately helpful</th>
<th>Slightly helpful</th>
<th>Not at all helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trained Speech Generation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Context-based Speech Generation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Speech Prompting</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Physical State Messaging</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

60. Do you have any other comments or suggestions?

________________________________________________________________