Boston Children's Hospital
ALS Augmentative Communication Program

The Jay S. Fishman ALS Augmentative Communication Program @ Boston Children's Hospital

Guiding Principles on Voice Cloning and Integration into Augmentative Communication Technologies

Purpose

This document outlines the ethical and clinical guidelines for implementing voice cloning technology in augmentative and alternative communication (AAC) devices at our hospital's augmentative communication clinic. Our aim is to enhance patient communication while protecting patient autonomy, ensuring professional integrity, and maintaining the clinic and hospital's reputation.

Scope

This document applies to all speech-language pathologists (SLPs), clinicians, and staff involved in the assessment, implementation, and management of AAC solutions incorporating voice cloning technology.

Guiding Principles

1. **Patient Autonomy and Control**
    - Patients have the right to make informed decisions regarding the creation and use of their voice clone.
    - Comprehensive information, including potential risks and benefits, must be provided to ensure informed consent.
    - Patients shall have the ability to dictate who can access their cloned voice and how it may be used, both during their lifetime and posthumously (see handout A).
2. **Ethical and Professional Conduct**
    - SLPs must adhere to ethical guidelines established by the American Speech-Language-Hearing Association (ASHA).
    - All procedures will align with hospital ethics policies, emphasizing patient welfare, privacy, and autonomy.
3. **Privacy and Data Protection**
    - Secure storage and encryption will be employed to protect voice data from unauthorized access or misuse.
    - Access to voice data shall be limited to authorized personnel, with patient consent governing its use and distribution.
    - This clinic will protect a patient's privacy, control and autonomy and will not support integration of a voice clone in technology that is not owned by and fully in control of the patient and patient delegate. In the instance whereby a patient requests/consents to have personal voice clone integrated into technology that is not owned by the patient, this clinic may support this only if, at the time the technology is no longer used or desired, it is returned to this clinic (regardless of the origin of the equipment loan) to fully remove the voice clone and re-set the technology to the endemic system voice. This plan needs to be provided by patient or delegate in writing and will be put in the hospital medical record with the clinical notes.

4. **Informed Consent Process**
    - The informed consent process will include discussions about data ownership, usage rights, and the patient's preferences related to posthumous voice management.
    - Consent documentation must be reviewed annually or upon significant changes in the patient's health status.
5. **Clinical Best Practices**
    - Implement standardized and customized protocols to ensure the effective and ethical integration of voice cloning into AAC devices, tailored to meet each patient's evolving needs.
    - Ongoing training and education will be provided to SLPs to keep abreast of technological advancements and ethical practices.
6. **Protection of Professional Licensure**
    - SLPs must engage in continuous professional development to maintain and enhance their competencies related to voice cloning technologies.
    - All practices and procedures shall comply with licensure requirements and healthcare regulations to safeguard professional standing.
7. **Institutional Integrity and Reputation**
    - The clinic is dedicated to upholding the hospital's values by prioritizing patient-centered care and innovation within ethical boundaries.
    - Continuous improvement initiatives will be pursued to foster trust and excellence in patient care and protect the clinic and hospital reputation within the community.
8. **Equity and Access**
    - Strive to make voice cloning technology accessible to all patients, irrespective of financial, linguistic/dialectal (within the structure of available technology options) or geographical barriers, through advocacy and partnerships.

Review and Compliance

This document will be reviewed regularly and updated to ensure compliance with emerging best practices and regulatory changes. Non-compliance with this policy will subject staff to disciplinary action consistent with hospital procedures.

Through these guidelines, the clinic commits to supporting voice cloning in AAC with integrity, ensuring patient dignity, and safeguarding the interests of all stakeholders involved.

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Attachment A

Here is a list of **considerations** for you/our patient to review regarding the management and access of your personal voice clone in the event of incapacitation or death. One should feel free to supplement with additional considerations as these are only suggestive. Although you may update this at any time, you are encouraged to do the following:

1. **Primary Custodian**:
    - Designate a primary custodian who will have the legal right to manage the voice clone in the event you are not able to do so.
2. **Access Rights**:
    - Specify who (if anybody) can access the voice clone, including family members, caregivers, or partners.
    - Determine if access differs between incapacitation and death.
3. **Usage Permissions**:
    - Outline specific permissions for how the voice clone can be used by others such as simulating novel conversation or only playing pre-recorded messages.
4. **Discontinuation Options**:
    - Decide if the voice clone account should be deactivated immediately upon incapacitation or death.
    - Provide options for conditions under which the voice clone account should be permanently deleted.
5. **Posthumous Use**:
    - Set parameters on whether the voice clone can be used including for memorial purposes or if it should cease operation entirely.
6. **Message Management**:
    - Include instructions on whether previously recorded messages can be accessed or if creation of new messages should be disabled.
7. **Transferability**:
    - Clarify if the voice clone can be transferred to a different device or owner, and under what conditions.
8. **Consent Documentation**
    - Provide your feedback through the hospital email portal so all your decisions are documented for inclusion in clinical report/medical record.
9. **Review and Updates**:
    - Establish regular intervals for review and updates (suggested at clinic visits) to preferences and ensure they reflect the current state of mind and relationships. This will be documented in the clinical note and stored in the medical record. You may also provide this in writing, and we will scan to the record.
10. **Third-party Agreements**
    - Refer to the Terms, Privacy Policy and Data Use statement in their Voice Clone Technology on-line application. Individuals should ensure they align with wishes.

This is a living document with more added as provided.

These are statements from patients/families regarding voice clone when asked about legacy. These are shared with patients to give a sense of context for the discussion in clinic.

“We would like to use his voice to deliver a message to everyone {that we wrote} at his memorial service”

“I know that he would want to give a toast at our daughter’s wedding and I can make sure he does, even if he is not with us”

“I don’t want messages created in my voice that I never really said; it feels creepy”

“This is great, I don’t care if my family has this after I die. They will have lots of laughs at my expense and that feels good to know”

“Hey, if someone can’t create their own voice, you should give them mine if I can’t use it any more….as long as they don’t mind sounding like a bozo south shore guy”

“My son has mental illness and I would never want him to be able to get this and create messages with my voice if I wasn’t here”

“I need to think a lot more about this; it is a really big deal and with lots of things I have not considered”

“I am thrilled we are talking about this, and I feel even better cared for since you are taking the lead on this conversation. All of my banking accounts have voice identification access. I really want to make sure I protect myself and my family if I am not here by having rigid control over the voice clone access.”

“I was afraid to ask about this. It has been on my mind, but I really want my own voice. The fact you are thinking about this really comforts me when pretty much there is little comfort with ALS”

“I would like to have the credentials deleted when I die. People can listen to old recordings of me if they want to hear my voice”

“ALS has changed our lives. He used to say ‘I love you babe’ all the time’. He doesn’t any more but I need to hear it. I want to be able to create that sentence and listen to it”

“I approach the question of a preserved voice as I do photographs, videos, and films of me. They were created in the context of specific moments in time. So with statements I’ve recorded, they may be preserved. But as much as I’m uncomfortable with the thought of photoshopped images of me doing things I didn’t do, I feel the same about someone expressing their thought with my voice and passing them off as mine.”

“Patients should understand that it’s their voice, their choice. They may consult with family if they choose, but are under no obligation to do so.”

“It is important to give this handout to patients to start the wheels turning on the issues of having a cloned voice that has the potential to outlive its creator”.

“This document is thought provoking in the best sense of the phrase”.