Reconsenting for Data Sharing  TISLR12
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Introduction
Sign language acquisition research depends on videos of signing children, often collected longitudinally and in intimate settings. In the last 40 years, researchers have amassed at least hundreds of hours of such video footage, representing enormous potential for scientific investigation, yet most videos are kept private and have never been shared. Also, video data must be catalogued, tagged, and transcribed to maximize usefulness in research, but doing so requires a community of users. We are currently building an archive for sharing previously-collected video data, in hopes that current technology will enable growth in linguistic analyses and more efficient processing. However, we must first establish guidelines for sharing sign language video data and obtaining consent from former research participants. Many important issues of privacy and trust must be addressed first.

Focus Group
We convened two focus groups at Gallaudet University (DC) and at the American School for the Deaf (CT) including individuals in these categories:
- Deaf of Deaf adults who participated or could have participated in longitudinal video collection for research purposes when they were children
- Signing family members of Deaf or Coda children
- Researchers interested in sign language video data
- Current and former research assistants on projects related to sign language

Discussion of select complex and multi-faceted issues related to video data sharing. These issues and responses are shared below.

To see a copy of the questions asked at the focus group, please ask the authors of this poster.

General comfort with sharing videos on the internet
There were clear age-related differences among focus group participants on this issue, with younger individuals expressing less concern with videos of themselves being posted online than older individuals, particularly those with children.

"It's an exchange. We as research participants give up our privacy in allowing ourselves to be 'posted online' more than older individuals, particularly those with children.

Measures that would increase comfort level with video data sharing

Sharing longitudinally collected spontaneous video data
Sharing with other researchers (but not general public) should occur. Such sharing should be restricted in ways to increase the likelihood of responsible use.

Impossibility of fully controlling how others use shared video data
One possibility that found favor is the use of a board with Deaf and hearing researchers to evaluate requests for access. Another is to receive input from "whistle-blowers" with consequences for violations of acceptable use guidelines.

"It's true that researchers can't guarantee that shared video data won't be misused. So it's important that researchers inform families of this fact before they agree to participate in research.

"Hearing a parent of a Deaf child, 46 or older"

Collecting consent from research assistants appearing in video footage.

"My data is out there. It’s there. There may be sticky issues but the Deaf community is so small, we have to think about it. And talk about it.” - one of the focus group participants, a Deaf man in his twenties

"My son is 15, still a minor. But if he tells me he no, then I will respect his wishes, regardless of what his reasons are.”

Collecting consent from incidental appearances in video footage.

Very incidental appearances (for example, a neighbor appearing briefly on video) were generally deemed to not warrant consent/reconsent. However, the decision is much less clear-cut for longer incidental appearances by classmates, teachers, siblings and other relatives. People agreed that researchers have a serious obligation to respect the wishes of the people they film.

Potentiality uncomfortable scenes
Potentially uncomfortable scenes should be evaluated for research value and if not useful perhaps be edited. Participants expressed trust the in researchers’ judgment.

Appropriate age for former child research participants to re-consent
Participants stressed that preferences of children who were research participants should be solicited and respected. However, they were in favor of parents making decisions about consent for their children while they were still minors.

"My son is 15, still a minor. But if he tells me he no, then I will respect his wishes, regardless of what his reasons are.”

Freedom for former research participants to change preferences
Both focus groups stressed that researchers must always respect the wishes of former research participants if they decide to withdraw consent, even if this change occurs many years after filming. This requires much more active and sustained contact between researchers and former participants than is currently standard.

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Conclusion
The major take-away points from discussions:
- Focus group participants generally supportive of research using videotaped sign data, but stress importance of sustained and transparent communication between researchers and research participants, something that many felt has been neglected in the past.

- Critical importance to continue this dialogue more broadly and establish new and clear guidelines prior to any large-scale archiving and sharing, and crucially, with significant input from stakeholders in the community.

- Some important differences depending on age group and location that must be explored in more detail.

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