

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.

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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 filmed, but in return, the researchers must respect our preferences and wishes."

- Deaf woman, 46 or older

Measures that would increase comfort level with video data sharing



Access protocol

U	R	C	S	(646)
U	R	C	S	(451)
U	R	C	S	(2)

3. May we show short clips of video footage including you as part of scientific publications resulting from this research?
 Yes, you may do so without further approval from me.
 Yes, but only with my prior approval of each clip that you plan to share.
 No.



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.

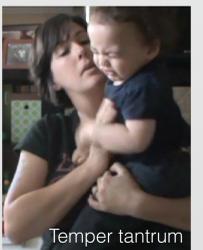
Another is to receive input from "whistle-blowers" with consequences for violations of acceptable use guidelines.

"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 parent of a Deaf child, 46 or older

Potentially uncomfortable scenes

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



Appropriate age for former child research participants to re-consent

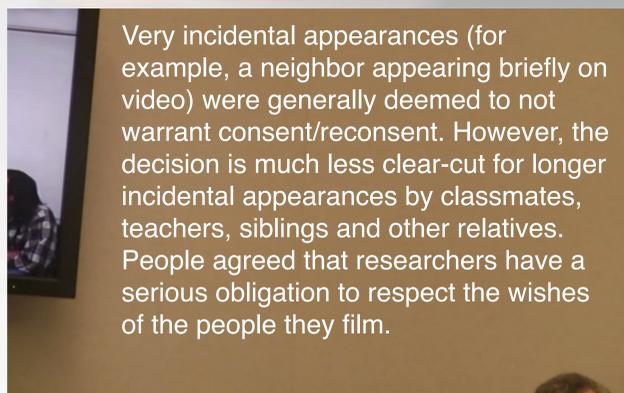
Participants stressed that preferences of children who were research participants should be solicited and respected. However, they were in favor of parents making decisions about consent for their children while they were still minors.

"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."

- Hearing parent of a Deaf child, 46 or older

"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

Collecting consent from incidental appearances in video footage.



Collecting consent from research assistants appearing in video footage

There were differences of opinion across the focus groups on whether research assistants should be treated the same way as former participants with respect to re-consent (CT), or whether being on video is an automatically assumed part of a research assistant's job, and thus does not require re-consent (DC).

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.

"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."

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 the past.

- Critically important 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.

"On the consent forms, I checked "Yes, yes, yes..." straight down the whole page, everything was fine with me. But I expect to be contacted every now and then with updates. Don't come and film us then just disappear."

- Deaf woman, 46 or older

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