Patient and Audio Data in Clinical Speech Therapy

Korbinian Riedhammer
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Motivation

• Speech corpora collected at the Pattern Recognition Lab (FAU Erlangen)
  • FAU Aibo Emotion Corpus (9h audio/video, 51 children aged 10-13)
  • FAU IISAH (8h multi-channel audio, 31 seniors aged 61-78)
• Even more “medical” audio collected in DFG and BMBF projects using PEAKS
  • Laryngectomy; shut valves (40+ patients)
  • Cleft lip and palate (~400 affected children, ~800 control; PLAKSS test)
  • Cancer of the oral cavity (46 patients aged 34-80)
  • Dementia, stroke, …
  • …and tons of annotations (transcriptions, intelligibility ratings, etc.)
• Some data we shared publicly (eg. Aibo, IISAH)
• …some we shared only with partners
• …some we only used locally
Collecting Speech Data in the Medical Domain

...prior to GDPR

- Implemented PEAKS tool (originally: Java Plugin; later standalone)
- Server hosted (with SSL cert) at our lab or at partners’ sites
- User (=staff) accounts to administer recordings and annotations
- Patient database (parallel to HIS; mostly name/dob/pathology)
- Cohorts and basic access rights
- Server accessible to any sysadmin at the lab, files/mysql to anyone with access to the server (mostly sysadmin, but also sort-of open via NFS shares)
Motivation

das ist alles, was ich habe. Die Erklärung hast Du ja.

Am 11.10.2019 um 09:27 schrieb Maier, Andreas:
Wieder das Problem, dass Sprachdaten nicht anonym sind. Wir müssen also absagen...

Von meinem iPhone gesendet

Anfang der weitergeleiteten Nachricht:

Von: "Neidiger, Martin" <martin.neidiger@fau.de>
An: "Maier, Andreas" <andreas.maier@fau.de>
Kopie: "Gärtner, Norbert" <norbert.gaertner@fau.de>
Betreff: AW: Inquire about FAU IISAH corpusDATENSCHUTZBEAUFTRAGTER

Sehr geehrter Herr Prof. Maier,

Ihre Vermutung ist zutreffend. Wenn Sie allerdings aggregierte Daten, die damit tatsächlich anonymisiert sind, haben, können Sie diese weitergeben; individuelle Sprachaufzeichnungen aber nicht.

Mit freundlichen Grüßen
Motivation

GDPR §17: request to delete data

v.

DFG/EU: research data must be archived 10 years
Who does recordings and subsequent evaluation?

- Speech recognition research 😊
- Speech and language understanding research
- Medical speech processing
- Psychology (generations of students transcribing their *** off…)
- Psychotherapy
- Social sciences (eg. street workers)
- UX
- Market research
- …
Medical Speech Data: Stakeholders

Patient/Subject

Researcher
Medical Speech Data: Stakeholders

- Guardian
- Patient/Subject
- Doctor
- Nurse
- Collaborators (external)
- Researcher
- Students (internal/external)
- Faculty/Staff (internal)
- Annotator (internal/external)
Patient/Subject

- Static data (→ HIS)
  - Name
  - DoB
  - Contact info? Unique identifier? (eg. to map to HIS)
- Transient data (→ partly HIS)
  - Diagnosis/pathology
  - Treatment/therapy details (→ cohort?)
  - Responsible clinician(s)
- Data typically not in HIS
  - Dialect/accent
  - Education level
  - …
Acquiring Data: Recording a Subject

• We need consent. But what data are we capturing?

• If it’s a dial-in or remote session
  • Phone number, IP, username

• Subject
  • voice (video) data
  • Age, state, impediments, …

• Typically: Clinician’s voice data

• Sometimes: 3rd person entering the room (after all, we’re in a clinical env.)
What do we need the consent for?

• Analysis of the data (feature extraction, training, eval)
• Aggregation of data (of single and multiple subjects)
• Annotation of data (usually by medical experts)
• Publication of
  • aggregated data (usually anonymized)
  • snippets of raw data (transcripts, spectrograms)
  • individual or aggregated meta-data
• Use in machine learning aka. model training
• …sharing of trained models? (= sort of aggregated data?)
Who do we need the consent for?

• “Institutional” use of the data:
  • faculty and staff (usually covered under employment)
  • Students (GSR → employed, thesis work → not employed)
  • (Academic) visitors (often not employed)

• Partners inside the org
  • Projects are typically in cooperation with university hospital or alike
  • Typically automatically ”institutional” if same entity

• Partners outside the org
  • Associated clinical partner or research lab
  • What about future ones?
Technical Caveats

• User journal
  • document recordings, annotations, access

• Data access
  • Is the data stored locally or remote?
  • Is the data access ”channel” encrypted? (SSL, encryption at rest)
  • Is there access control both in recording app and on filesystem?

• Sharing: how can you prevent unauthorized copies?
  • We need to keep track who has access!
Open Questions

• How do you track subjects in collections to
  • provide complete account of data
  • delete data on request
• Who’s data are annotations and other derived data?
  • Or: Which data is actually owned by the subject?
• Is it possible to formulate a “permanent/irrevocable data donation”?
• How can we make ”old” data available?
  • Getting consent forms again is (close to) impossible
• How can we vet partners for trustworthiness?