



Patient and Audio Data in Clinical Speech Therapy

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Motivation

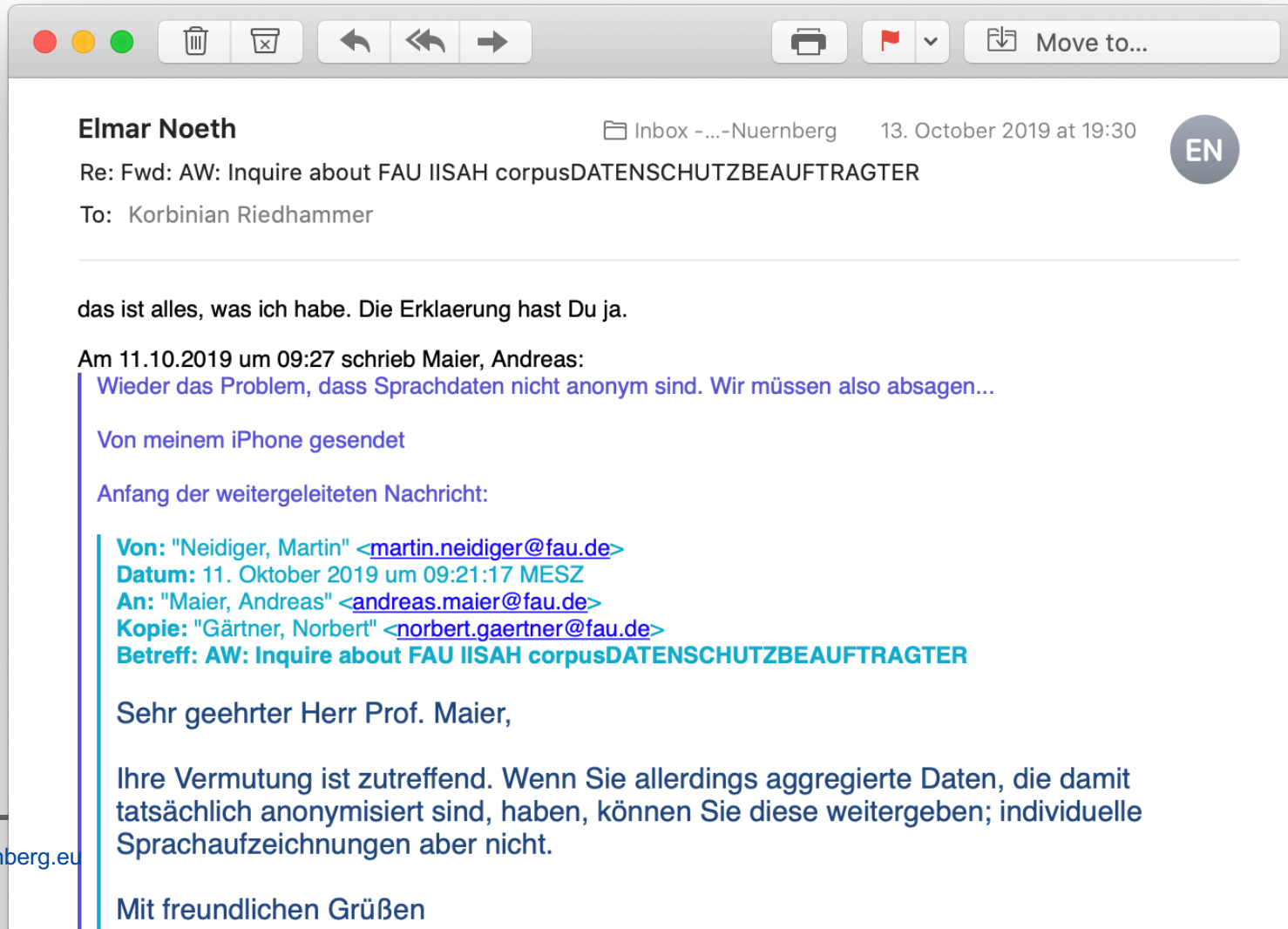
- Speech corpora collected at the Pattern Recognition Lab (FAU Erlangen)
 - FAU Aibo Emotion Corpus (9h audio/video, 51 children aged 10-13)
 - FAU IISAH (8h multi-channel audio, 31 seniors aged 61-78)
- Even more "medical" audio collected in DFG and BMBF projects using PEAKS
 - Laryngectomy; shut valves (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



The screenshot shows an email client interface. At the top, there are standard window controls (red, yellow, green buttons) and a toolbar with icons for deleting, moving, and navigating. The email header shows the sender as Elmar Noeth, the subject as 'Re: Fwd: AW: Inquire about FAU IISAH corpusDATENSCHUTZBEAUFTRAGTER', and the date as 13. October 2019 at 19:30. The recipient is Korbinian Riedhammer. The main body of the email contains a message in German, a quoted message from Andreas Maier, and a forwarded email header.

Elmar Noeth Inbox -...-Nuernberg 13. October 2019 at 19:30 

Re: Fwd: AW: Inquire about FAU IISAH corpusDATENSCHUTZBEAUFTRAGTER

To: Korbinian Riedhammer

das ist alles, was ich habe. Die Erklaerung 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>
Datum: 11. Oktober 2019 um 09:21:17 MESZ
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



Collaborators
(external)



Faculty/Staff
(internal)



Patient/Subject



Researcher



Students



Doctor



Nurse



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?

Proposed Architecture

Proposal Under Review
Please Do Not Share

