

Virtual Therapy in Head&Neck cancer

Data collection and sharing for articulatory synthesis of patient speech

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Introduction



TAPAS: Training Network on Automatic Processing of PAtiological Speech

EU promotes Open Data and Open Science

- TAPAS will collect unique data on speakers and pathological speech
- Speakers are “vulnerable”: patients and children
- Most stringent requirements on privacy protection (GDPR&CTR)
- But we still want to share

Collections of Patient Speech and PROs



Current practices regarding speech data

NKI-AVL (hospital), ACLC (University)

Data of Head&Neck tumor patients at NKI-AVL

Protocols: Speech and Patient Reported Outcomes (PROs¹)

- Data pre- and post-treatment (upto 12mnd)
- Oral Cavity protocol (~95)
 - Sustained a: u: i:; ei-ou-œy; word-list (36w); story[†] (75w); pa-ta-ka
 - PROs: SHI, SWAL QoL, EORTC QLQ-H&N35
- Larynx protocol (~150)
 - a: Longest/high/low/loud/soft/sweep; story[†]
 - PROs: LASA, EAT-10, VHI, EORTC QLQ-C30/H&N35
- Tracheolaryngectomy (TLE) protocol (~25)
 - a: Longest/high/low/loud/soft/sweep; story[†]; 3 voiced sentences*
 - PROs: EQ-5D-5L, SOAL, VHI-10,

¹PROs are questionnaires asking about health and QoL

Secondary use of patient data

Currently *opt-out*

- Health care data, will switch to *opt-in* (informed consent)
- Restricted use (*severely* restricted under opt-out)
- IRB approval needed for *each* project
- Can we create a speech “Biobank” from secondary use data?
Probably not

Switch to *Informed Consent*

- All patients asked to consent
- Look for broad consent
Unclear whether broad consent is possible

pre-2000 longitudinal research of speech development at the ACLC²

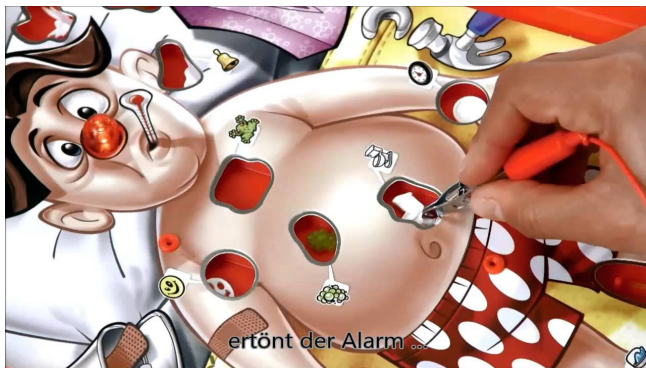
Recordings of mother-child interactions

- Video of 12 Cleft Palate + 6 normal babies during first 2 years [1]
- Audio of 5 Hearing impaired and 5 normal hearing babies [2, 3]
- Informed consent of parents for research
- Video material digitized, text files are now digitized
- Intention to make them available to researchers
- Access policies not yet known

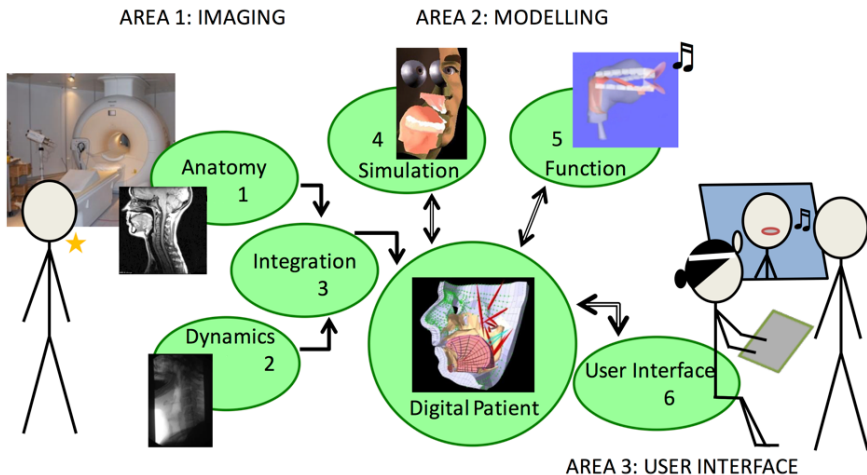
²Amsterdam Centre for Language and Communication, Fac. Hum., Univ. of Amsterdam

Virtual Therapy

Predicting and synthesizing plausible speech examples after oral cancer treatment



Demonstrating functional outcome of therapy



Data collection

Digital Patient

1 Anatomy & Physiology

MRI, DTI-MRI, Shear-Wave US elasticity
3D Photo of tongue shape and resection

2 Dynamics

dynamic MRI, Tongue mobility&strength,
3D video, sEMG

3 Integration

ArtiSynth bio-mechanical model

4 Simulation

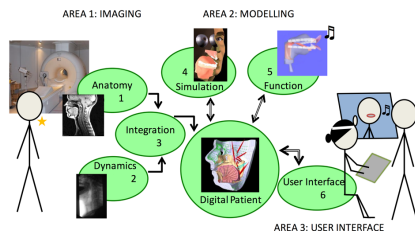
Forward and inverse model training

5 Function (Speech)

Real Speech & Articulatory synthesis

20 patients + 5 healthy

- 10 small tumors in oral tongue (surgery)
- 10 larger tumors in base of tongue (radio-therapy)



Data Sharing



What can be shared, when, and with whom?

Talk to:

MEC, Privacy Officer, Biobank organizers, Privacy lawyers

Confusion about *Informed Consent* (IC) in Open Data/Science

- IC determines what can be done with the data, i.e., cover all uses
- Confusion: IC covered by GDPR and CTR³ [4, 5]
 - GDPR: Consent must be specific [6, 7]
 - CTR: One-stop informed consent possible [8, 9]
- EU vs. National rules on health data and consent (CTR, [7])
- What health data fall under the research derogation of GDPR, if any?
- What research is “in the public interest”?
- Open data is international, the GDPR restricts cross-border exchange

³Clinical Trials Regulation (536/2014)

Consensus: Privacy by design

Demands on shared data (under the GDPR)

- Data minimization *what is not there, cannot be exposed*
 - Coarse-graining: age-brackets, truncate zip codes, etc.
 - Strip metadata from images, movies, MRI
 - Censor bars in pictures, movies, MRI
- Anonymization *if data is useful, it is not anonymous*
- Pseudonymization *is effort needed to re-identify relevant?*
- Encryption
- Security, computer and otherwise
- Data transfer agreements, NDA's, Promise of Confidentiality
- ⇒ Take the analysis to the data *privacy-preserving platform*

Take the analysis to the data

On-demand analysis from a web browser

- Only a single DTA contract between data-owner and platform owner
- Analyse data without access to micro-data
- Users only see the outcome of the certified analysis
- Platform supplies tools: e.g., [R](#), [Bob and Kaldi](#) [10, 11]
- Platform enforces access rights, audit trails, and security

The BEAT platform

[13]

Biometrics Evaluation and Testing (BEAT)

[12]

- EU 7th framework program
- Part of European computing e-infrastructure for Open Science
- Solution for open access, scientific information sharing and re-use
- Sharing access to data and source code
- Protecting privacy and confidentiality
- Data from different experiments can be easily compared and searched
- Challenges and education
- Attestation mechanism for reports

⇒ Chosen as the data platform for TAPAS

Anjos et al. (2017). *BEAT: An Open-Source Web-Based Open-Science Platform*. arXiv preprint arXiv:1704.02319.

BEAT overview

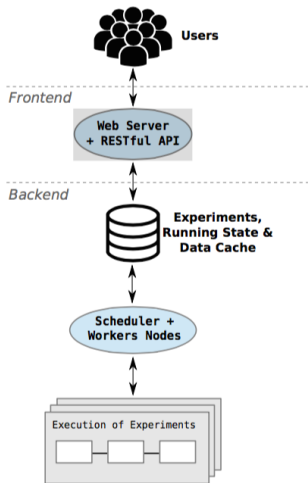
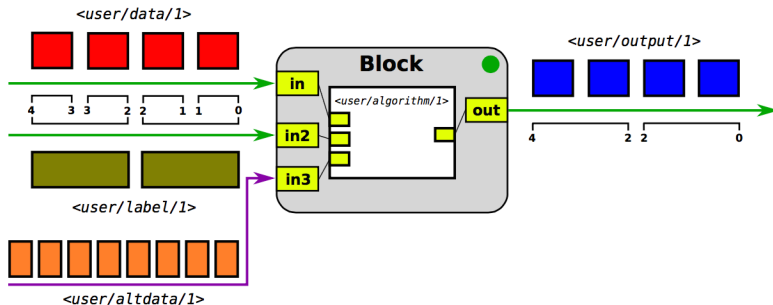


Figure 1: An overview of the BEAT platform applications and their interaction. Users use the web front-end to run experiments, search and combine results. A back-end handles the execution of experiments on dedicated hardware.

BEAT toolchain block



Individual Blocks are strung together into tool-chains/experiments


BEAT experiment configurator

Name:

eigenfaces


Enter a meaningful name to help you recognize this experiment. Auto-completion will help you in keeping your naming conventions tidy. If a chosen name is **highlighted in red**, it is because it is already being used. In this case, choose another name.

Toolchain:


tutorial/eigenface/1 

Datasets [\[Advanced mode\]](#)

Database


Select one database... 

Protocol


Select one protocol... 

Blocks


linear_machine_training

Select an algorithm... 


template_builder

Select an algorithm... 

probe_builder


Select an algorithm... 


scoring


Select an algorithm... 

Analyzers

analysis

Select an algorithm... 

 Save

 Go!

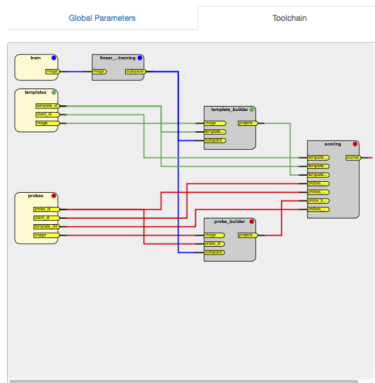
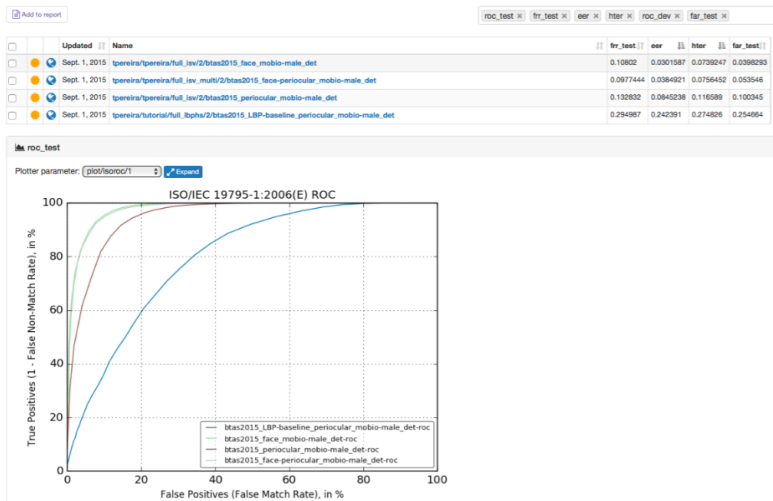


Figure 3: The BEAT platform experiment configurator allows the user to easily associate databases, algorithms and analyzers together to create the desired setup. As the user chooses components for the toolchain, choices of further components are restricted respecting data format compatibility between the blocks.

BEAT automatically generated tables



Conclusions

TAPAS: Sharing data

- Not clear what will be allowed under the GDPR&CTR
 - “International” sharing could be a problem (outside EU)
 - In the mean time: use Privacy Preserving Platform
- ⇒ TAPAS will use BEAT platform

Thank You!

?

More information I

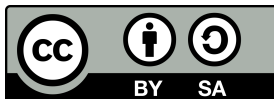
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More information III

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