Virtual Therapy in Head&Neck cancer

Data collection and sharing for articulatory synthesis of patient speech

Rob van Son

Netherlands Cancer Institute, Amsterdam, The Netherlands R.v.Son@nki.nl

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Introduction



TAPAS: Training Network on Automatic Processing of PAthological 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 want to share

Collections of Patient Speech and PROs



Current practices regarding speech

Data of Head&Neck tumor patients

Protocols: Speech and Patient Reported Outcomes (PROs¹)

- Data pre- and post-treatment (6mnd+12mnd)
- Oral Cavity protocol (∼95)
 - Sustained a:-u:-i:; ei-qu-œy; word-list (36w); story[†] (75w); pa-ta-ka
 - PROs: SHI, SWAL QoL, EORTC QLQ-H&N35
- Larynx protocol (\sim 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,

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

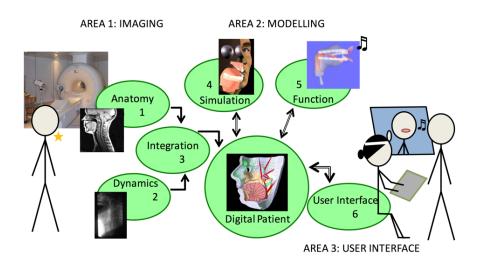
- All patients asked to consent
- Look for broad consent
 Unclear whether broad consent is possible

Virtual Therapy

Predicting and synthesizing plausible speech examples after oral cancer treatment



Demonstrating functional outcome of therapy



Data collection

Digital Patient

- 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 CTR² [1, 2]
 - GDPR: Consent must be specific [3, 4]
 - CTL: One-stop informed consent possible [5, 6]
- EU vs. National rules on health data and consent (CTR, [4])
- 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

Consensus: Privacy by design

Demands on shared data (under the GDRP)

- 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
- Encryption
- Security, computer and otherwise
- Data transfer agreements, NDA's, Promise of Confidentiality
- ⇒ Take the analysis to the data privacy-protecting 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 [7, 8]
- Platform enforces access rights, audit trails, and security

Biometrics Evaluation and Testing (BEAT)

[9]

- EU 7th framework program
- Part of European computing e-infrastructure for Open Science
- Solution for open access, scientific information sharing and re-use
- 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

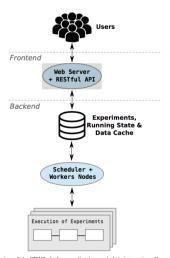
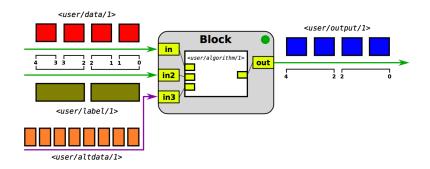


Figure 1: An overview of the BEAT platform applications and their interaction. Users use the web frontend to run experiments, search and combine results. A back-end handles the execution of experiments on dedicated hardware.

BEAT toolchain block



Individual Blocks are strung together into tool-chains

BEAT experiment configurator

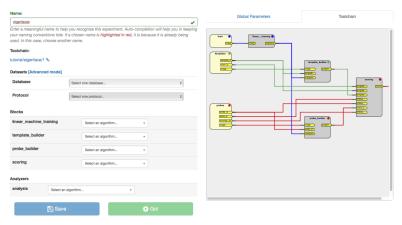
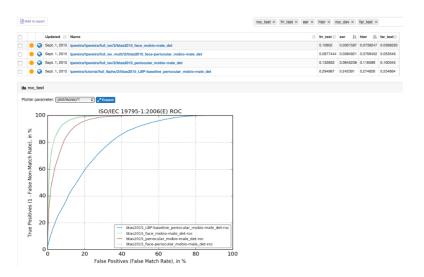


Figure 3: The BEAT platform experiment configurator allows the user to easily associate databases, algorithms and analyzers together to create the desired setup. As the user chooses components for the toolchain, choices of further components are restricted respecting data format compatibility between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

BEAT automatically generated tables



Thank You!





More information I

- [1] European Parliament and the Council of the EU, "Clinical trials regulation 536/2014." https://ec.europa.eu/health/sites/health/files/files/eudralex/vol-1/reg_2014_536/reg_2014_536_en.pdf, 2014.
- [2] C. K. Schneider *et al.*, "Deciphering the eu clinical trials regulation," *Nature biotechnology*, vol. 34, no. 3, p. 231, 2016.
- [3] European Union, "General Data Protection Regulation, GDPR." https://gdpr-info.eu/, 2016.
- [4] G. Chassang, "The impact of the eu general data protection regulation on scientific research," ecancermedicalscience, vol. 11, pp. 709, doi:10.3332/ecancer.2017.709, 2017.
- [5] A. Mende, M. Frech, and C. Riedel, "Principles of the eu clinical trials regulation no 536/2014: What will change?," *Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz*, 2017.
- [6] C. Dittrich, A. Negrouk, and P. G. a. Casali, "An ESMO-EORTC position paper on the EU clinical trials regulation and EMA's transparency policy: making european research more competitive again," *Annals of Oncology*, vol. 26, no. 5, pp. 829–832, doi:10.1093/annonc/mdv154, 2015.

More information II

- [7] M. Cernak, A. Komaty, A. Mohammadi, A. Anjos, and S. Marcel, "Bob speaks kaldi," in *Proc. of Interspeech*, no. EPFL-CONF-229211, 2017.
- [8] A. Gaye, Y. Marcon, J. Isaeva, P. LaFlamme, A. Turner, ..., and P. R. Burton, "DataSHIELD: taking the analysis to the data, not the data to the analysis," *International Journal of Epidemiology*, vol. 43, no. 6, pp. 1929–1944, doi:10.1093/ije/dyu188, 2014.
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- [10] A. Anjos, L. El-Shafey, and S. Marcel, "Beat: An open-source web-based open-science platform," arXiv preprint arXiv:1704.02319, 2017.



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