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QoLife

Quality of Life Technologies Lab
University of Copenhagen (DK) & University of Geneva
qualityoflifetechnologies.org

European Network of Living Labs

AI@CARE: Algorithmic Bias, Laws and Ethics in Healthcare (*ProjektTOF.dk*)

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Patient (female, 69)

Type 2 Diabetes (1992)
Heart attack (2014)
Hip fracture & replacement (2016)

Loves cooking
Much (too much) food (carbs)

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Chronic Disease Risk (CVD, T2DM, COPD)

Genetic 30.0%
Health care 10.0%
Environmental 5.0%

Behavioral 40.0%

Social 15.0%

Behavioural patterns	Deaths
Tobacco intake	18.1%
Poor diet Physical inactivity	15.2%
Alcohol consumption	3.5%
…	

THE LANCET · JAMA

Naghavi, M., Abajobir, A. A., Abbafati, C., Abbas, K. M., Abd-Allah, F., Abera, S. F., ... & Ahmadi, A. (2017). Global, Regional, And National Age-Sex Specific Mortality For 264 Causes Of Death, 1980-2016: A Systematic Analysis For The Global Burden Of Disease Study 2016. The Lancet, 390(10100), 1151-1210.
Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). Actual Causes of Death in the United States, 2000. JAMA, 291(10), 1238-1245.

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Chronic Disease Risk

Diabetes (T2DM): *race/origins, family history, age, gender, cholesterol (TC), blood pressure (BP), diet, physical activity*

DIABETIC STUDIES

Janghorbani, M., Adineh, H., & Amini, M. (2015). Evaluation of the Finnish Diabetes Risk Score (FINDRISC) as a screening tool for the metabolic syndrome. The review of diabetic studies : RDS, 11(4), 266-292. doi:10.1900/RDS.2013.10.252

Slide 5

tof · SDU

Vision: Can we leverage EHR for health of Danish citizens?

Danish Context
- tax-funded state-run universal health care system, unified EHR
- obligatory unique citizen ID (CPR), obligatory use of e-box
- Statistics Denmark (DST) as a research stakeholder ♔ DST

TOF Research Project (since 2016)
- Research Unit of General Practice
- primary EHR data use, behavioural intervention study (non-randomized)
- ethics/informed consent, The Committee on Health Research Ethics for the Capital Region of Denmark, Danish Data Protection Authority (Datatilsynet)
- DST licenced
- Pilot: Random N=9400 30-59 years old from two municipalities ♔ DST

Bruun Larsen, L., ... Lønsdale Søndergaard, A., Søndergaard, J., Lauat Thomsen, J., Halling, A., Hvidt, N. C., ... Thilsing, T. (2018). Targeted prevention in primary care aimed at lifestyle-related diseases: a study protocol for a non-randomised pilot study. BMC Family Practice, 18(1 (p.)+e27).
Larsen, L. B., Sønderaard, J., Thomsen, J. L., Halling, A., Sønderlund, A. L., Christensen, J. R., & Thilsing, T. (2019). Digital recruitment and acceptance of a stepwise model to prevent chronic disease in the Danish primary care sector: cross-sectional study. Journal of medical internet research, 21(1), e7953.

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tof · SDU

Vision: Can we leverage EHR for health of Danish citizens?

Population register
age, gender, family, if immigrant, (un)employment, income, education, ...

Self-reports
(diet, physical activity, smoking, alcohol, stress, social support, ...)

EHR
(healthcare use, diseases, labs, ..., weight, height, TC, BP, ...)

Medication

Slide 1

Vision: Can we leverage EHR for health of Danish citizens?

N=2661 (/9400) consented (female, higher age, Danish, income, education, less sick)

min SUNDHEDSMAPPE

26%   22%   23%   29%
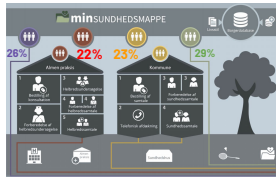
Almost half
of the sample population
qualifies for an
intervention!

Slide 2

Algorithmic Bias, Laws and Ethics in Healthcare (Project)

AI@CARE Project (2020-2023)
- Computer science & law
- Secondary EHR data use: TOF data access
- Goal
  - Evaluate EHR-based predictive disease risk models
  - Introduce intentional biases (age, gender, immigration status, …) and evaluate consequences → policies, law, healthcare costs
- Ethics, The Committee on Health Research Ethics for the Capital Region of Denmark, Danish Data Protection Authority (Datatilsynet)
- SDU: data controller, UCPH: data processor
- DST licenced

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AI@CARE Discussion Points

- Algorithmic Bias
- Law
- Ethical considerations

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AI@CARE: Algorithmic Bias

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AI & Unintentional and Intentional Biases

Datasets Inputs
- SDU: TOF design choices
  - Sample selection bias (e.g., study inclusion age, study invitation channel, info in Danish)
  - Variables/models selection bias (e.g., asked for stress, yet sleep is missing)
- EHR data structure (e.g., data model, missing data, free notes/text to be coded)
- Patient self-report bias (e.g., response-bias, summary of behaviours, memory bias, social desirability bias)
- …

Algorithm & Risk Assessment Output Biases
- Algorithm (e.g., risk outputs (3), statistical biases, data distribution assumptions, timeframes for vars)
- Fairness criteria - performance for subgroups (e.g., gender, immigrant status) and across subgroups
- Overgeneralization of results
- Correlation vs. causation (e.g., moderating variable: stress)
- …

Slide 6

Law: The Right To Health

AI & 'Right to Health'

1996: European Social Charter Article 11 & EU Charter of fundamental rights (Article 35) protects the *right to health*, including *everyone's right of access to preventive health care*
- Article 12(2)(c) requires States to take steps to ensure *[t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases*

TOF/UCPH project
- information availability, non-discrimination, transparent data processing, ...

Ethics:
Self-governance
& Autonomy

Individual Autonomy

- Who owns the citizens' data?
- Is citizens' data secure?
- Who can access citizens' data and for what?
  - data literacy
  - social acceptability 👑DST
  - privacy protection
- ....

Quality of Life Technologies Lab
www.qol.unige.ch

Digital Health

2021 Quantifying Quality of Life

European Network of Living Labs

Thank You

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