Swedish Deep Medicine

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Research projects →

uu.se/awi uu.se/ai4research

prediction with AlphaFold Previous Al4Research seminars



Cautionary tale about a failure to replicate an (overfitted) ML algorithm



Features used







	Cohort 1: IQVIA holdout (ATTR-CM)	Cohort 2: Optum (ATTR- CM)	Cohort 3: IQVIA (cardiac amyloid)	Cohort 4: Optum (cardiac amyloid)
Sensitivity, %	87	90	56	61
Specificity, %	87	79	83	81
PPV, %	88	81	76	76
NPV, %	86	89	65	67
Accuracy, %	87	84	69	71
ROC AUC	0.93	0.95	0.76	0.78

Performance in Sweden

Metric	Value
PPV	0.200
NPV	0.970
Sensitivity	0.390
Specificity	0.920
Accuracy	0.890
AUROC	0.750
Brier	0.120





Swedish healthcare data are unbeatable



Swedish data sources leading globally

Data available and utilized

Data not available

Country		Belgiu	m		Canad	а	6	ierma	ıy		Israel		The Netherlands		lands	r	Norway		1	Portugal			Spain		Swee		n	Switzerland		and	U		
Level of care	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3
Registry coverage																																	
Nationwide full population																																	
A population with complete coverage																																	
Part of the population with complete coverage																																	
ta available																																	
Electronic medical records																																	
Claims data																																	
Quality-of-care registry data																																	
Drug prescription data																																	
Drug dispensed data																																	
Laboratory data																																	
Health care cost data																																	
Cause-of-death registry data																																	
Death registry data																																	
Level of patient identification																																	
Defined by laboratory measurements																																	
Defined by diagnosis																																	



Sundström et al, Lancet Reg Health Eur 2022;20:100438

Swedish mandatory registries*

Registry	Contents
Swedish Total Population Registry	Place of residency; country of own and parents' birth; marital status; date of death or emigration
Swedish Censuses	Socio-economic group; education; income; sick leave Sick leave; pensions
Swedish National Insurance Agency Swedish Education Registry	Highest education
Swedish 9th Grade Registry	Junior high school grades
Swedish Multi-Generation Registry	Number of children and siblings; identity of parents if born after 1932 and alive in 1961
Swedish Medical Birth Registry (since 1973)	Numbers of pregnancies and births; pregnancy outcomes
Swedish Prescribed Drug Registry (since 2005)	Pharmacy-expedited drug prescriptions
Swedish Inpatient Registry (since 1964, with complete national coverage since 1987)	Diagnoses of all hospitalizations; surgical and other procedures
Swedish Cancer Registry (since the 1950s)	All cancer diagnoses
Swedish Cause-of-Death Registry	Causes of death, including contributing factors
Swedish Out-Patient Registries (day-care surgery since 1997, all others since 2001)	All diagnoses. Hospital-based mandatory; primary care voluntary



National Quality Register for Bipolar Affe National Quality Registry for Cystic Fibros National Quality Registry for Intensive C National Quality Registry for Psychiatric Care Monitoring ("The Quality Star")

National Quality Registry for ADHD Treat National Quality Registry for Dementia (S) National Quality Registry for Internet-B; National Quality Registry for Psychosis Care (PsykosR)

National Quality Registry for Arkie Arthr National Quality Registry for Ear, Nose an National Quality Registry for Liver, Bile | National Quality Registry for Rehabilitation Medicine (SRR).

National Quality Registry for Behavioura National Quality Registry for Electroconvu National Quality Registry for Lung Canc National Quality Registry for Respiratory Diseases (RiksKOL+ NAR).

National Quality Registry for Better Man, National Quality Registry for Endovascula National Quality Registry for Macula National Quality Registry for Respiratory Failure

National Quality Registry for Bladder Car National Quality Registry for Enhancemer National Quality Registry for Malignant National Quality Registry for Rheumatic Diseases (SRQ)

Heart Disease (Swedeheart) <u>National Quality Registry for Brain Tumo</u>

National Quality Registry for Follow-up of National Quality Registry for Follow-up of National Quality Registry for Neonatal (National Quality Registry for Shoulder and Elbow Arthroplasty

National Quality Registry for Forensic Psy. National Quality Registry for Neurologic National Quality Registry for Sleep Apnoea

National Quality Registry for Fractures Registry) National Quality Registry for Cardiopulm

National Quality Registry for Gallstone Su National Quality Registry for Gallstone Su National Quality Registry for Neuromus National Quality Registry for Spine Surgery (SWESPINE)

National Quality Registry for Caries and Cholangiopancreatography (GallRiks) National Quality Registry for Obesity Su National Quality Registry for Stroke (Riksstroke)

National Quality Registry for Cataracts National Quality Registry for Gender Dys: National Quality Registry for Oesophage National Quality Registry for Systemic Psoriasis Treatment (PsoReg)

National Quality Registry for Catheter At National Quality Registry for Gynaecologis National Quality Registry for Paediatric National Quality Registry for Testicular Cancer (SWENOTECA)

National Quality Registry for Cervical Cat National Quality Registry for Gynaecologis National Quality Registry for Paediatric. National Quality Registry for Thyroid Cancer

National Quality Registry for Child and A National Quality Registry for Haemophilia National Quality Registry for Paediatric. National Quality Registry for Thyroid, Parathyroid and Adrenal Surgery (SQRTPA)

National Quality Registry for Child and A National Quality Registry for Hand Surger National Quality Registry for Pain Rehat National Quality Registry for Trauma

National Quality Registry for Child Preve National Quality Registry for Head and Ne National Quality Registry for Palliative C National Quality Registry for Ulcer Treatment (RiksSår)

National Quality Registry for Childhood (National Quality Registry for Heart Failure National Quality Registry for Pancreatic National Quality Registry for Vascular Surgery (Swedvasc)

National Quality Registry for Childhood I National Quality Registry for Hepatitis (Inf National Quality Registry for Penile Cancer

National Quality Registry for Childhood (National Quality Registry for Hernia National Quality Registry for Perioperative Care (SPOR)

National Quality Registry for Cleft Lip an: National Quality Registry for Hip Arthrophi National Quality Registry for Pituitary Disease

National Quality Registry for Colorectal (National Quality Registry for Hip Fracture National Quality Registry for Podiatric Surgery (RiksFot)

National Quality Registry for Congenital National Quality Registry for HIV (InfCare National Quality Registry for Pregnancy

National Quality Registry for Congenital National Quality Registry for Infectious Di: National Quality Registry for Preventative Care (Senior Alert)

National Quality Register Se/englishpages al Quality Registry for Inflammator National Quality Registry for Primary Immunodeficiency (PIDcare)

National Quality Registry for Cruciate Lig National Quality Registry for Inguinal Herr National Quality Registry for Prostate Cancer (NPCR)



Electronic health records





Cars et al, Basic Clin Pharmacol Toxicol 2013;112:392 & J Crohn's Colitis 2016;10:556

Electronic health records







Swedish healthcare is equal



Swedish healthcare is mostly driven by health needs



Trends in the *horizontal inequity index* (difference between observed health care utilization and that which would be expected given the individual's health needs)



Swedish healthcare is (was?) well governed



Sweden has among the highest health policy performances in Europe (a summary score of 27 indicators of success in 10 areas of health policy).





EmergAI: Enhancing emergency department safety, efficacy and costeffectiveness by artificial intelligence



Emergency department care is unsafe and costly



Clinical problems

- Bad statistical intuition of physicians
- Chaotic and stressful environment
- Inefficient documentation and processing of patient data
- Inefficient decision-making

The end goal of this program is a clinical decision support system for the ED, validated in a randomized clinical trial, ready for clinical implementation

Technical problems

- Hard to get into healthcare data systems,
- Hard to understand data structures and missingness mechanisms,
- Hard to get access to images, ECGs, etc.
- Demands on CE-marking according to the EU Medical Device Regulation prohibit fast development-testing cycles.



ML problems: Multiple kinds of massively missing data



Solution: Bayesian approaches





Produce underlying risk estimates for all and updated estimates for some

Novel data types



- Super-human-level performance in diagnosing heart attacks.
- The AI now teaches us humans to read ECGs.



Novel data types



- Heart failure?
- Chronic obstructive pulmonary disease?
- Stroke?
- Pulmonary embolism?
- Acute aortic syndromes?
- Gastric ulcer?
- Gallstones?
- Pancreatitis?



Novel data types







symptoms.se

The potential clinical gains by this research program are unequivocal:

• It has the potential to affect *rising costs* and *high misdiagnosis rates* in the ED, saving both money and lives.

The potential scientific gains are much more far-reaching:

- We will address two important developmental goals: handling missing data, and incorporating multiple kinds of data.
- Capturing entirely new varieties of patient-generated data, and using them to predict disease, is a massive developmental step for e-health (also outside of the ED). I propose calling it symptomics.



Ethical aspects



Ethical aspects raised by the ERC ethics panel

HUMANS

- 1. Detailed information on the informed consent procedures for research participants.
- Project-specific templates of the information sheets and informed consent/assent forms (in language and terms understandable to the participants) with all relevant information regarding the protection of personal data, including the DPO contact details for host institutions required to appoint a DPO under the General Data Protection Regulation 2016/679.
- 3. Description of procedures to assess the decision-making capacity of the research participants in order to ensure that the informed consent procedures are adapted to their capacity.
- 4. Clarification whether vulnerable individuals/groups will be involved, and, if so, adequate measures to protect them, prevent coercion and undue inducement, exacerbation of their vulnerability, and minimise the risk of harm and/or stigmatisation.
- 5. Description of incidental/unexpected findings procedures and related disclosure policy.
- 6. Copies of opinions/approvals by ethics committees and/or competent authorities for the research with humans together with the full application(s).
- 7. For each clinical study (as defined by the Clinical EU Trial Regulation), information about the registration of the clinical study in an EU clinical trial registry (within EU) or WHO ICTRP or ICMJE- approved registry (outside the EU).





Ethical aspects raised by the ERC ethics panel

PERSONAL DATA

- 8. Description of the technical and organisational measures to safeguard the rights and freedoms of the data subjects/research participants.
- 9. Description of the security measures to prevent unauthorised access to personal data or the equipment used for processing.
- 10. Description of the anonymisation/pseudonymisation techniques, and in case personal data are not to be anonymized/pseudonymized, a justification for not anonymizing/pseudonymizing the relevant data.
- 11. For personal data to be transferred from the EU to a non-EU country or international organisation, a justification that such transfers are in accordance with Chapter V of the General Data Protection Regulation 2016/679.
- 12. Detailed information on the informed consent procedures related to the processing of personal data.
- 13. For research involving profiling, an explanation on how the data subjects/research participants will be informed of the existence of the profiling, its possible consequences, and how their fundamental rights will be safeguarded.
- 14. For the further processing of previously collected personal data, documentation confirming that the beneficiary has the lawful basis for data processing and that the appropriate technical and organisational measures are in place to safeguard the rights of the data subjects.
- 15. Evaluation of the ethics risks related to the data processing activities of the project, together with an opinion if a Data Protection Impact Assessment (DPIA) should be conducted under art. 35 of the General Data Protection Regulation 2016/679, and if applicable, the DPIA.
- 16. Details on how patients' data using the "patient-centred technical platform" will be secured including clarifications on the role of ICT subcontractors vis-a-vis ethics issues.





Ethical aspects raised by the ERC ethics panel

ARTIFICIAL INTELLIGENCE

- 17. Human right impact assessment covering the development, deployment and post- deployment phases, including detailed information on how respect for fundamental human rights and freedoms will be ensured (human dignity, right to privacy and data protection, right to health, right to be free from discrimination).
- 18. Detailed explanation on the measures taken to prevent/avoid potential bias, discrimination and stigmatisation in input data and algorithm design and outcomes.
- 19. Detailed explanation on how the research participants and/or end-users will be informed about:
 - 1. their interaction with an AI system/technology;
 - 2. the abilities, limitations, risks and benefits of the AI system/technique;
 - 3. the manner in which decisions are taken and the logic behind them.
- 20. Assessment of the ethics risks related to the AI and the measures set in place (risk mitigation plan) to prevent/mitigate any potential negative personal impacts during the research, deployment and post-deployment phases.
- 21. Explanation on how humans will maintain meaningful control over the most important aspects of decision-making process in the use of the Visual clinical decision support tool.





Ethics Issue	Requirement	Category
Artificial Intelligence	A human right impact assessment (HRIA) covering the development, deployment and post-deployment phases, including detailed information on how respect for fundamental human rights and freedoms will be ensured, must be provided. Number of months to fulfill the requirement after the project starts: 18	Deliverable
Artificial Intelligence	A detailed explanation on the measures taken to prevent/avoid potential bias, discrimination and stigmatisation in input data and algorithm design and outcomes must be provided. Number of months to fulfill the requirement after the project starts: 18	Deliverable
Artificial Intelligence	The beneficiary must evaluate the ethics risks related to the AI and describe the measures set in place to prevent/mitigate any potential negative personal/social/environmental impacts during the research, deployment and post-deployment phases. Number of months to fulfill the requirement after the project starts: 18	Deliverable







