

A journey unfolded by Iannis Drakos, PhD

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Region of Zealand, Denmark



OHDSI in Denmark

from Ithaca to bedside



REGION SJÆLLAND
PRODUKTION, FORSKNING OG INNOVATION



- vi er til for dig

OHDSI in Denmark: from Ithaca to bedside

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6. Region Zealand Biobank, Zealand, Denmark
7. Biochemistry, Zealand University Hospital, Denmark
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9. Harvard Medical School, Boston, USA
10. Odysseus Data Services, Cambridge, Massachusetts, USA

The Danish health data scene

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Personal Identification Number

Nationwide since 1968 (used to be regional)

National Electronic Health Record

Health data produced at any healthcare level and source is digitally stored and available both to the citizen and the treating MD.

National Health Quality Databases (RKKP)

Data from the national EHR, via thorough curation and QC pipelines are forming the domain specific National Health Quality Databases.

Research and Precision Medicine

Data from RKKP may become available for research or clinical use, after a strictly governed application process.

Data lifecycle

Quality improvements performed at any stage of the health data lifecycle are reported back to all national data storage locations.

The Danish health data scene

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#	Register & Database	Since			
1	The Danish Register of Causes of Death	1875	21	The National Health Insurance Service Register	1990
2	The Cancer Registry	1943	22	Donor Register	1990
3	The Cancer Register - Other neoplasias	1943	23	Database for chronic kidney failure	1990
4	The Cancer Register - Cancer survival	1943	24	The Accident Register	1990
5	The Cancer Register - New occurrences of cancer	1943	25	Health Insurance Register	1990
6	The Danish Nephrology Society Land Register	1964	26	The Danish Vascular Registry	1993
7	The Family Relations Database	1968	27	IVF-register (fertility)	1994
8	The Pathology Register	1970	28	Medicines Register	1994
9	The Medical Birth Registry	1973	29	The Drug Statistics Register	1994
10	The Register of legally induced abortions	1973	30	The Register of Medicinal Product Statistics	1994
11	The Children's Death by Accident Register	1975	31	The Register for Selected Chronic Illnesses	1995
12	The National Patient Registry	1976	32	GP Register (doctors, dentists, physiotherapists etc.)	1995
13	National Patient Register - Activity on diagnosis group	1976	33	The Danish Diabetes register	1996
14	National Patient Register - Activity on diagnosis level	1976	34	The Danish Register of Child and Adolescent Diabetes	1996
15	National Patient Register - Operations	1976	35	Danish register for child and youth diabetes	1996
16	National Patient Register - Radiological services	1976	36	Drug addicts in treatment Register	1996
17	Blood spots from all new-born Danes since	1976	37	Danish Transfusion Database	1997
18	The Danish Neonatal Screening Biobank	1982	38	Danish Hernia Database	1998
19	The Danish National Biobank	1982	39	The Registry of Coercive Measures in Psychiatric Treatment	1999
20	Danish Melanoma Database	1985	40	The Danish Adult Diabetes Database	1999

The Danish health data scene

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41	Coercive Psychiatry Register	1999	61	The united orthopedics Database - Danish hip arthroplasty	2005
42	Danish Heart Register	2000	62	The united orthopedics Database - Danish knee arthroplasty	2005
43	Danish Colorectal Cancer Database	2001	63	The united orthopedics Database - Danish cruciate ligament	2005
44	DUSAS (Danes treated at foreign hospitals)	2002	64	The united orthopedics Database - Danish shoulder arthropl.	2005
45	MiniPas - LPR	2002	65	Alcohol treatment register	2005
46	Danish Head and Neck Cancer Group	2002	66	The Army Register	2005
47	Danish Hysterectomy and Hysteroscopy Database	2003	67	The Conscription Register	2006
48	Emergency Surgery Database	2003	68	Database for treatment of rheumatologic patients	2006
49	Danish Stroke Register	2003	69	Danish urogynaecological database	2006
50	Danish Childrens Cancer Register	2003	70	The Rehabilitation Register	2007
51	Danish Esophagus, Gastroesophageal transitional cancer	2003	71	Rehabilitation Register - All services	2007
52	Danish Interdisciplinary Register for Femoral Thigh Break	2003	72	Rehabilitation Register - Plans	2007
53	The Nationwide Database of Geriatrics	2004	73	Rehabilitation Register - Services on hospital	2007
54	The Tissue Register	2004	74	Danish Ultrasound scannings during pregnancy database	2008
55	Danish Anaesthesia Database	2005	75	Danish intensive database	2008
56	Danish Gynaecological Cancer Database	2005	76	Danish Quality Database for cervix screening	2008
57	The Hematologic Common Database - Acute leukemia	2005	77	Danish Quality Database for Mammography Screening	2008
58	The Hematologic Common Database - Chronic myeloid disorders	2005	78	Danish Sarcoma Database	2009
59	The Hematologic Common Database - Lymphoma	2005	79	The Children's Database	2009
60	The Hematologic Common Database - Multiple myeloma	2005	80	The Child Database (Children's health) - First living year	2009

The Danish health data scene

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81	The Child Database (Children's health) - Early and late primary school	2009
82	Danish Breast Cancer Operative Group	2010
83	Danish Database for Bariatric Surgery	2010
84	Danish Quality Database of Birth	2010
85	The Organ Donation Database	2010
86	Danish Palliative Database	2010
87	National database for Sleep Apnea	2010
88	Follow-up Program for Cerebral Palsy	2010
89	Attention Deficit Hyperactivity Disorder Database	2011
90	Danish Depression database	2011
91	Danish Liver and Biliary Cancer Database	2011
92	Dansk Pancreas Cancer Database	2011
93	DRG (diagnosis related groups)	2013
...

The Danish national strategy for Precision Medicine



Research

Create a common infrastructure with advanced analysis and collaboration options for research. Accelerate the translation from research to precision medicine.

Healthcare

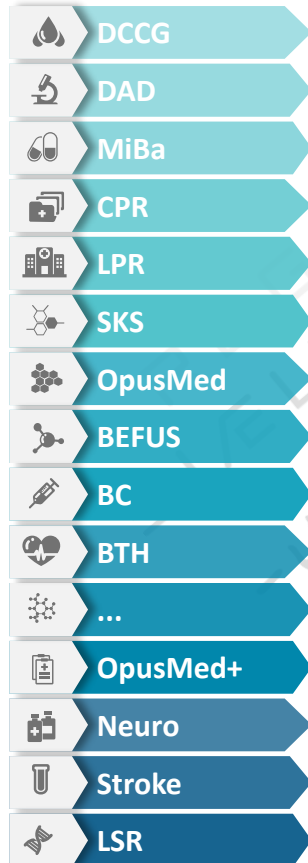
Provide bioinformatics as a service to support the clinical decision-making process (data warehouse classified as a clinical database).

Safety & Security

Build a strict IT governance that ensures who can access what, when and why. The data governance system will handle both clinicians' access to own patient data and authorizing others to perform specific tasks on specific datasets for specific period of time.

Using OHDSI OMOP CDM and community tools as part of the PM infrastructure

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Colorectal Cancer

Detailed description of all pathology aspects

Pathology

Hospital admissions, procedures and treatments during admission

Medication

Prescriptions and administrations

Biochemistry

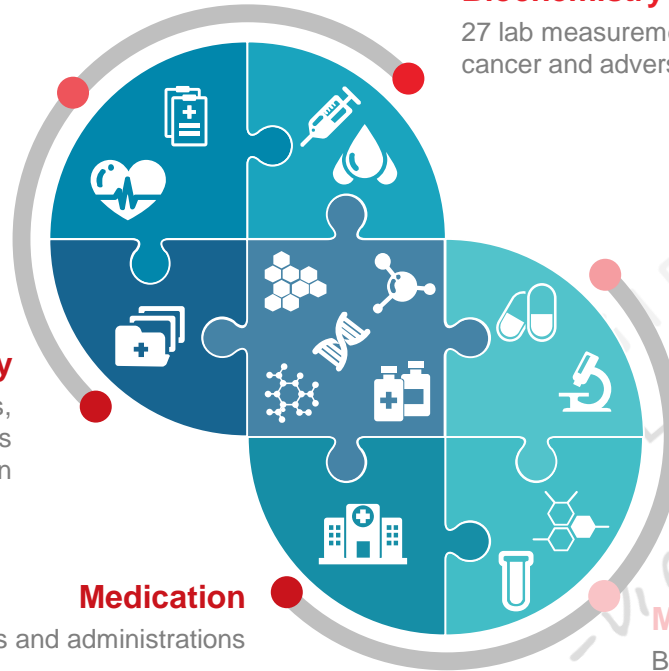
27 lab measurements targeting cancer and adverse drug reactions

Anesthesia

Detailed information for colorectal cancer operations

Microbiology

Blood analysis results 180 days after surgery



First wave of CDM data sources

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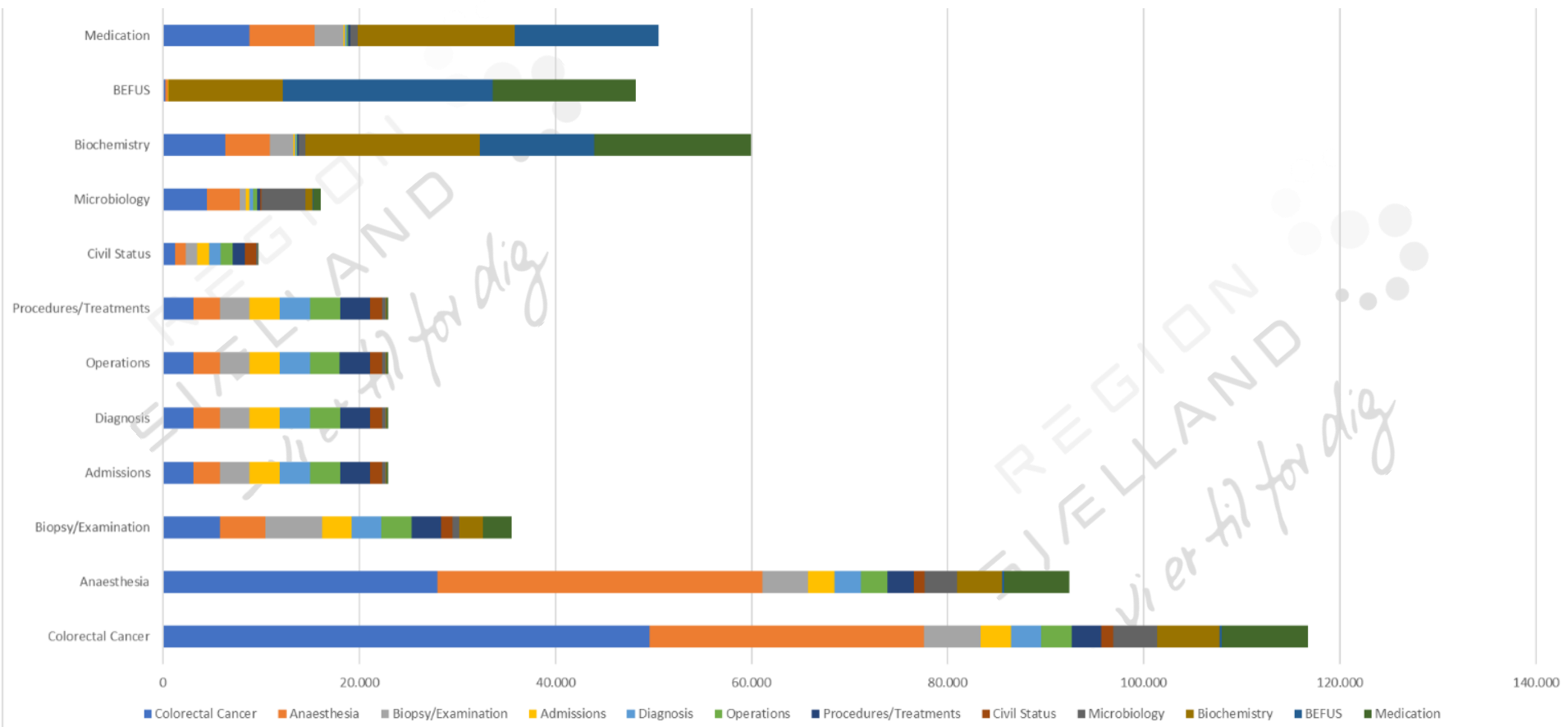
- **Danish Colorectal Cancer Group (DCCG) database**
 - 191 concept categories
- **Danish Anaesthesia Database (DAD)**
 - 114 concept categories
- **Civil Registration System (CPR)**
 - 22 concept categories
- **National Patient Registry (LPR)**
 - 46 concept categories
- **Microbiology Database (MiBa)**
 - 35 concept categories
- **Healthcare Classification System (SKS)**
 - 11 concept categories
- **Drug prescriptions and administrations**
 - 134 concept categories
- **Biochemistry LIMS**
 - 16 concept categories
- **BEFUS population study**
 - 270 concept categories

19 565 concepts in total

describing 75 000 persons



Data sources overlap



Colorectal cancer - clinical research

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Current challenges in Colorectal Cancer treatment

- **Postoperative complications** (1 in 4 patients)
- **Disease recurrence** (1 in 3 patients)
- **Mortality** (2 % after elective surgery and 20 % in emergency surgery)

How can we improve clinical outcomes?

- Develop an evidence base to inform shared decision-making for potentially curative therapies
- Establish optimum peritherapeutic interventions to improve outcomes and to demonstrate appropriately robust clinical and cost-effective outcomes
- Develop evidence-based approaches utilizing multimodality treatment for patients with CRC to improve outcomes
- Establish robust prognostic and predictive biomarkers to stratify patients to ensure every patient receives treatment, relevant to their particular disease trajectory

C·S·S**Center for Surgical Science**

Improving Patient Care

Prediction of Respiratory insufficiency among Patients operated for colorectal cancer

Resulting model

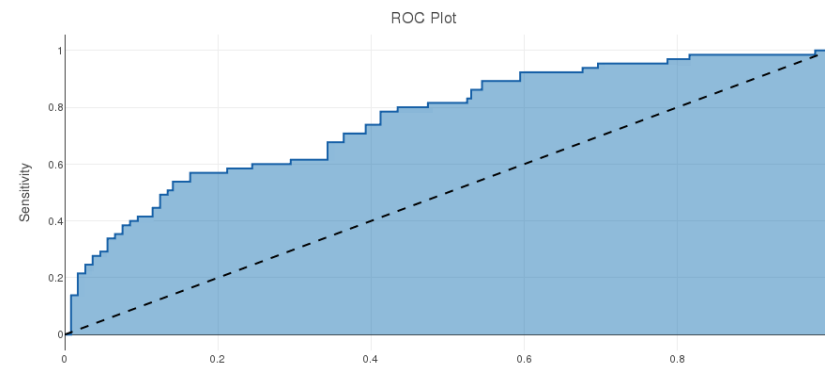
Evaluation Summary

Show entries

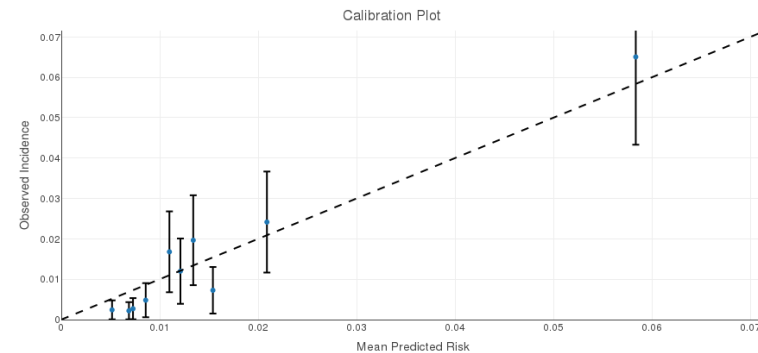
Search:

	Metric	test	train
1	AUC	0.7625	0.79339
2	AUC_lb95ci	0.7026	0.76235
3	AUC_ub95ci	0.8224	0.82443
4	AUPRC	0.1019	0.09558
5	BrierScaled	0.0505	0.03742
6	BrierScore	0.0149	0.01502
7	CalibrationIntercept.Intercept	-0.0031	-0.00633
8	CalibrationSlope.Gradient	1.1820	1.40117
9	outcomeCount	65.0000	197.00000
10	populationSize	4142.0000	12428.00000
11	Incidence	1.5693	1.58513

Test



Test





Ny datamodel skal forudsige den mest personlige kræftbehandling

De sjællandske regioner tester et system, som hjælper lægen frem mod den mest optimale behandling ved at finde 'patients like me'.

Af Mie Stage
mst@ing.dk

Når en patient med tyktarmskræft ligger klar på operationsbordet, hvilken bedøvelse skal han så have? Hvor omfattende skal indgrebet være, hvilken medicin skal der gives bag efter, og hvordan skal der følges op?

Den slags beslutninger kræver masser af data, og hvis man vil skræddersy et forløb bedst muligt til den enkelte, så skal man på en overskuelig måde kunne udnytte de mange data fra tidligere patientjournaler og internationale publikationer.

Det fortæller forsknings- og innovationschef i Region Sjælland Jesper Grarup, som ved konferencen High Tech Summit på DTU 10.-11. oktober fortæller om erfaringerne med brug af en ny datamodel, som siden 1. august har været testet i tre forskellige kliniske miljøer.

»Personlig medicin handler om at bruge data til at give den bedste

behandling for den enkelte. Ved at få alle eksisterende data i spil kan vi spejle patienten op mod en hel befolkning og se, hvad der har virket for de patienter, der ligner den pågældende mest.« forklarer Jesper Grarup.

Datamodellen hedder OMOOP (Observational Medical Outcomes Partnership) og er open source. Den oversætter patientdata, forskningsrapporter og indtastede observationer til et fælles sprog og gør det dermed muligt for lægen at analysere og visualisere relevante data.

I dag har lægerne masser af databaser, opslagsværker og erfaringer at støtte sig til ved planlægningen af et forløb, men hvad der har manglet, fortæller Jesper Grarup, er et system, som kan samle alle disse data og pege lægen i en konkret retning.

Finder lignende patienter

Med OMOOP kan lægen indtaste alle relevante oplysninger om patienten: højde, drøjde, sygdomshistorie, diæt og generel livsstil, og så kan systemet finde frem til de patienter, der ligner den pågældende mest muligt, og fortælle, hvilken form for behandling der har virket bedst.

»Der er evidens for, at det betyder noget i forhold til tilbagefald, om man f.eks. er i dårlig form, er overvægtig eller har sukkersyge. Hvor meget kombinationen af alle

de mange kendte faktorer betyder for den enkelte, kan det være svært at få et overblik over,« siger Jesper Grarup og fortsætter:

»Nu har vi en stor pulje af data, hvor vi kan beregne risikofaktorerne fra hele vores eget bagkatalog af data fra klinikken, så vi til sidst får de mest præcise forudsigelser, vi kan bruge i behandlingen.«

Jesper Grarup understreger, at det selvfølgelig ikke er datamodellens konklusioner, der skal ende som den endelige køreplan, men at

den er et enormt godt værktøj som beslutningsstøtte.

»Måske viser modellen, at tiden lige efter operationen er mest kritisk for denne type patient, eller at han kan få gavn af genoptræning. Vi skal jo følge op, hvor det giver mening, så vi bruger pengene de rigtige steder, og der kan modellen give os nogle tydelige fingerpeg,« siger han.

Region Sjælland er gået sammen med Region Hovedstaden i udviklingen af personlig medicin og

bidrager med test af datamodellen. Foreløbig er tiden gået med at få 'mappet' data korrekt i systemet. I første omgang er data lagt ind for tyktarmskræftpatienter, fra bivirkningsdatabasen samt fra en større befolkningsundersøgelse i Næstved Kommune.

Armene i vejret

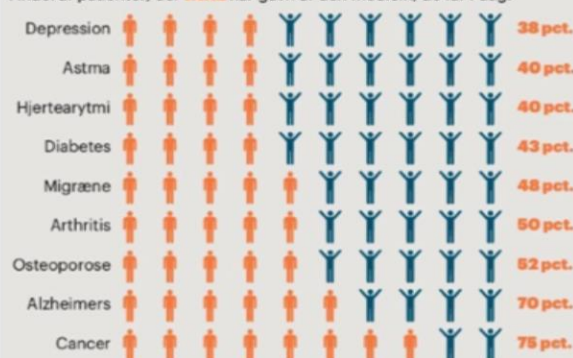
»De kliniske grupper, der arbejder med databasen lige nu, kan slet ikke få armene ned. De synes, det er fuldstændig fantastisk, at man så let kan få indsigt i sine data, lave prædiktioner og inddеле patienterne i så præcise risikogrupper,« fortæller Jesper Grarup, som også er vild med de muligheder, systemet giver for at få publikationer hurtigere ud i verden.

»Når man laver forskningsprojekter og skal kombinere data, har man et hyr med at lave scripts, der kan ekstrahere og integrere data på den rigtige måde. Her er der en masse supersmarte genveje til hurtigt at få resultater ud og – ikke mindst – til at kunne validere resultaterne,« understreger Jesper Grarup. ■

Jesper Grarup fortæller om 'A multi-data perspective on personalized medicine' på konferencen High Tech Summit på DTU i Kgs. Lyngby, 11. oktober kl. 13.50 – 15.50. Se mere på hihightechsummit.dk.

PERSONLIG MEDICIN

Andel af patienter, der IKKE har gavn af den medicin, de får i dag.



Kilder: FDA. Grafika: LGJ



A multi-data perspective on personalized medicine

13:50 - 15:50

Smart Healthcare & Food

Building 101 – M1

Genomic data are key to the development of personalized medicine. However, in the future, data about behavior, lifestyle, diet, and environmental exposure will also become part of the equation, influencing societal and clinical decision making. From this follows an exciting landscape with unattended challenges.

Program

Introduction: Mads H. Odgaard, Senior Executive Officer DTU

Tech Talk: "A multi-data perspective on personalized medicine. General observations and two use cases", Ramneek Gupta, Associate professor, DTU Bioinformatics


Business Talk: "Real World Data: The importance of Health Informatics in Pharma", Mishal Patel, Head of Health Informatics, AstraZeneca

Business Talk: "The digital behaviome: the key to personalized treatment of diabetes?", Morten Lind Jensen, MD Ph.d., International Medical Director, Medical & Science, Devices and Titration, Novo Nordisk A/S

Business Talk: "Bringing multi-data to the bedside through "patients like me"-tools. Three case studies from Region Zealand", Jesper Grarup, Head of Research & Innovation, Region Zealand

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h Tech Summit 2018

 [Download programme](#)

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g by Prime Minister Lars Løkke Rasmussen – Welcome Talks

e session - How Digital DNA could improve your health



Biotech manufacturing - Cutting-edge technology by leading startu...

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Thank you OHDSI

you are an awesome community !!!



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