# Outcomes that matter to patients

The importance of outcomes measurement in clincal practice



Stefan Larsson, MD, PhD

11 TH OF OCTOBER, 2019

## An admired teacher and leader



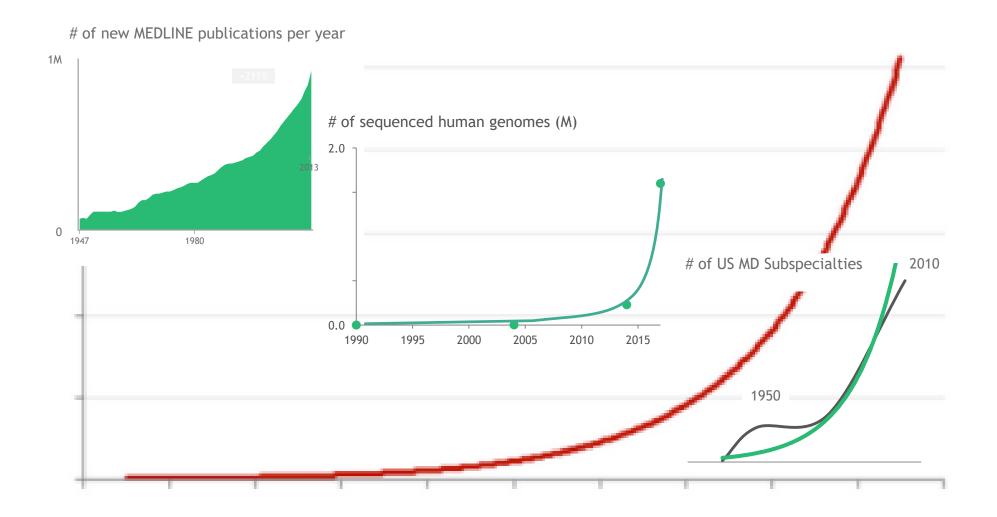
Prof Jan Lindsten

## **Clincal Genetics**

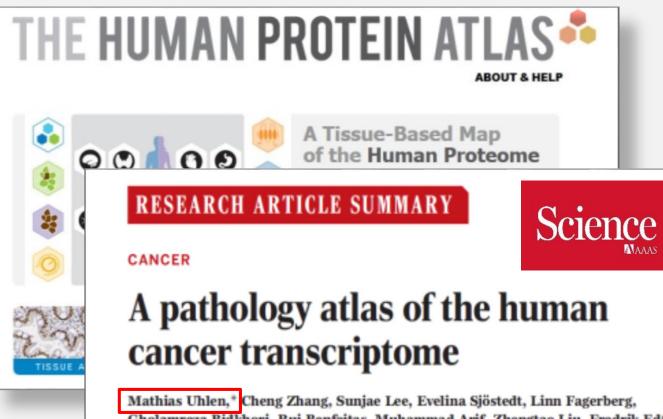
## Evidence based medicine

Process improvements

# Health care development is exponential



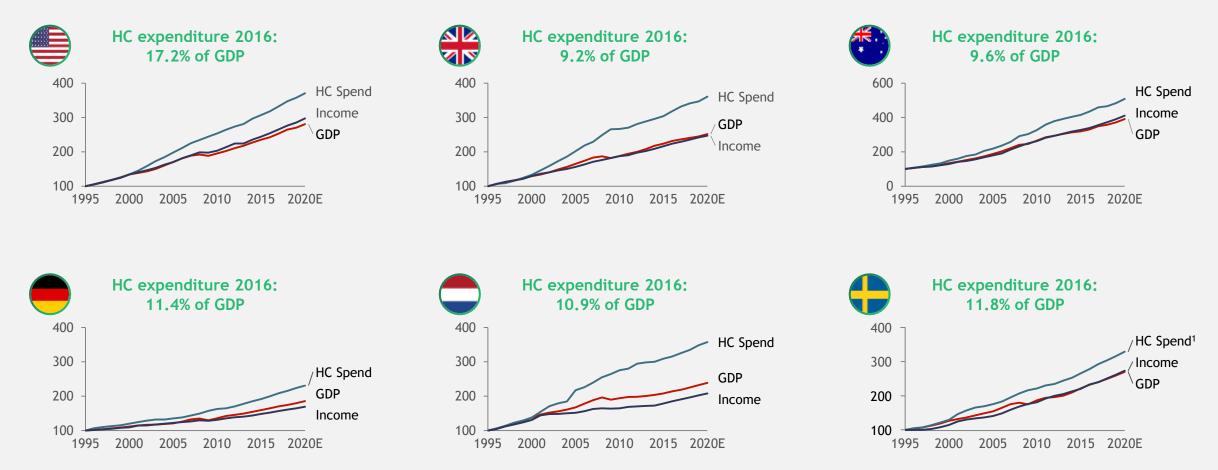
# Science is exploding - eg. human proteomics



Gholamreza Bidkhori, Rui Benfeitas, Muhammad Arif, Zhengtao Liu, Fredrik Edfors, Kemal Sanli, Kalle von Feilitzen, Per Oksvold, Emma Lundberg, Sophia Hober, Peter Nilsson, Johanna Mattsson, Jochen M. Schwenk, Hans Brunnström, Bengt Glimelius, Tobias Sjöblom, Per-Henrik Edqvist, Dijana Djureinovic, Patrick Micke, Cecilia Lindskog, Adil Mardinoglu,† Fredrik Ponten†



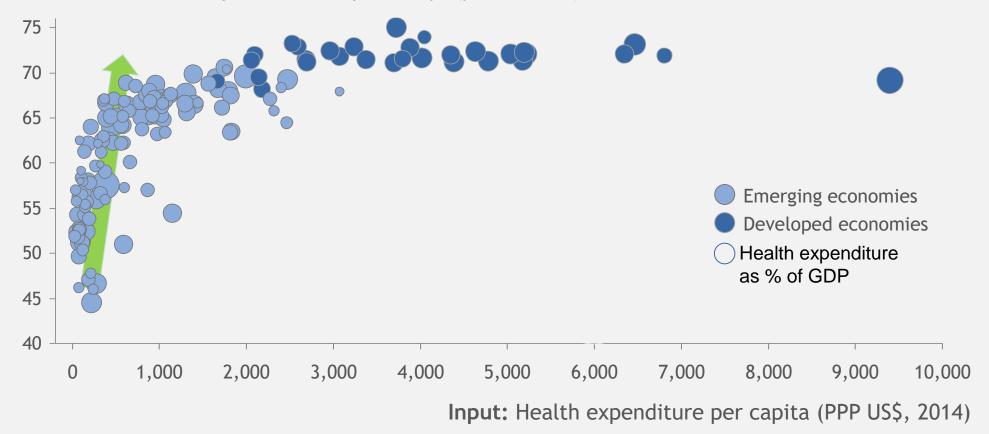
# Health care costs rising globally at unsustainable rates



Notes: Index 100 at 1995, based on local currencies; Income = Personal Disposable Income Source: WHO; EIU (May 2017); BCG analysis

## Health care with diminishing returns

**Outcome:** Health-adjusted life expectancy<sup>1</sup> (years, 2015)

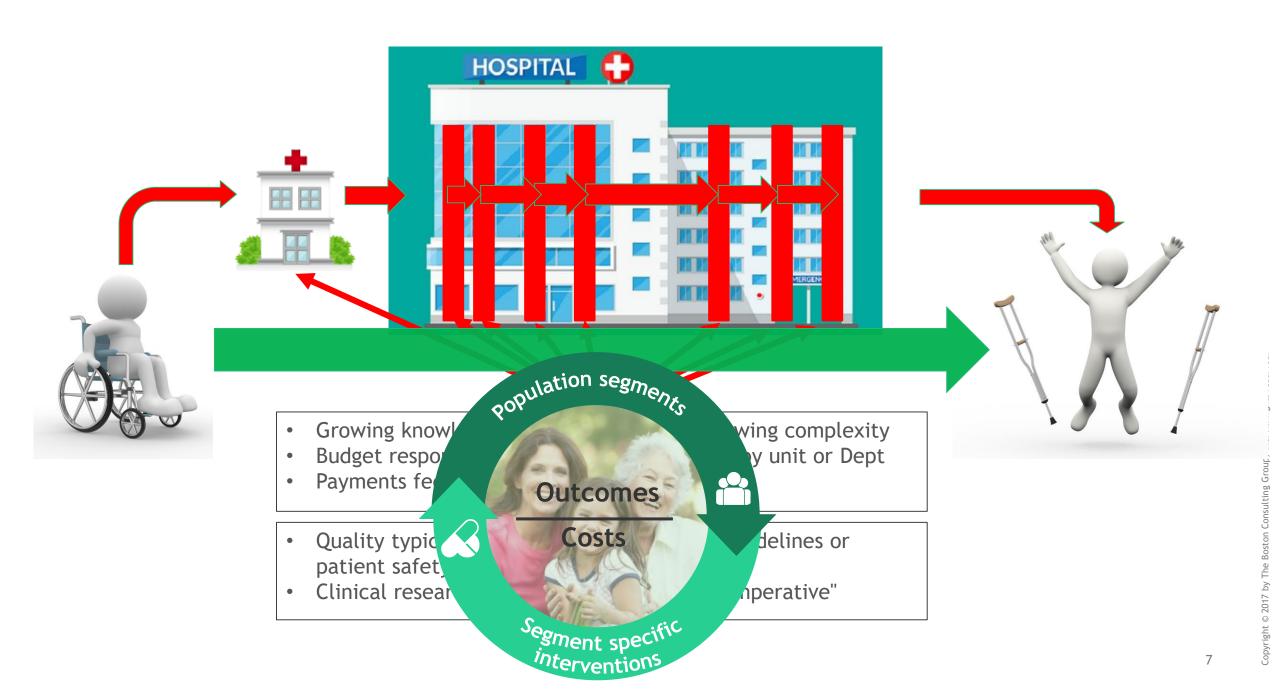


1. Health-adjusted life expectancy: Estimates the number of years in full health an individual is expected to live at birth by subtracting the years of ill health (weighted according to severity) from overall life expectancy. Sources: WHO, BCG

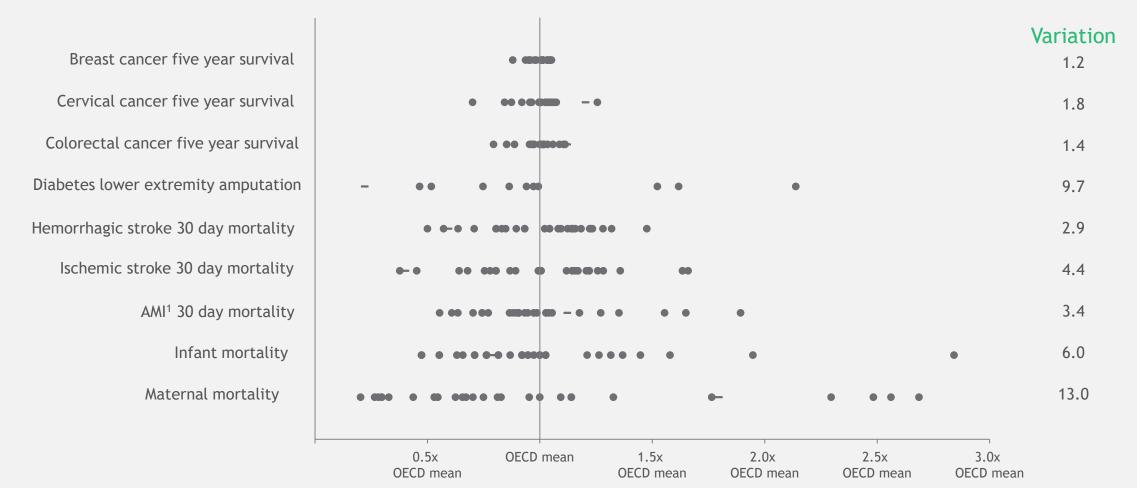
# Healthcare systems with significant challenges



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# Massive variation in health outcomes across OECD



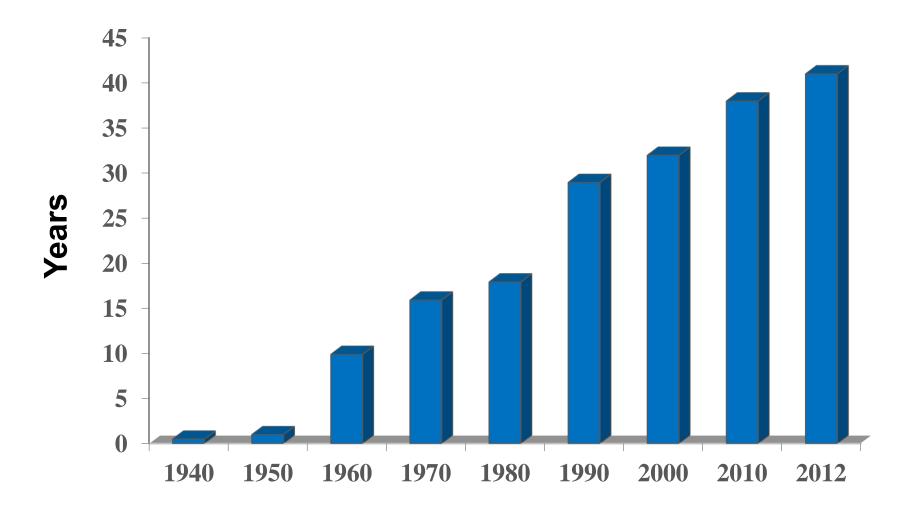
1. Acute Myocardial Infarction

Note: Most recent data from 2011-13 used. Mexico and OECD candidate countries not included Source: OECD Health May 2016, BCG analysis

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Vhat gets measured, gets done" - if we don't measure outcomes, do we know what we are doing?

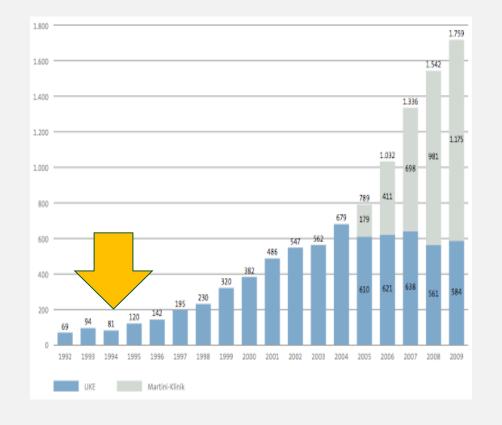
## Median Predicted Survival Age



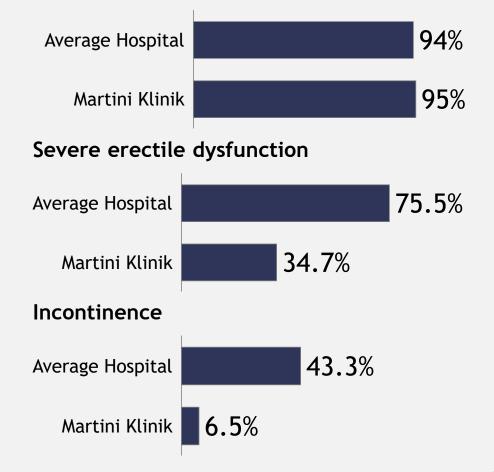
Source: CF Foundation Patient Registry

## The Martini Klinik world's largest Prostate Ca hospital

Martini Klinik does over 2k prostatectomies /year - largest in EU

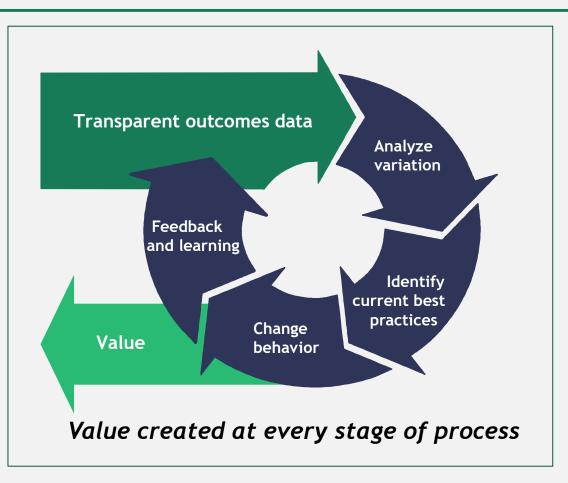


#### 5 year disease-specific survival



# Outcomes measurement and transparency the basis

Value cycle: starts with reliable outcomes data...



...to deliver superior patient value

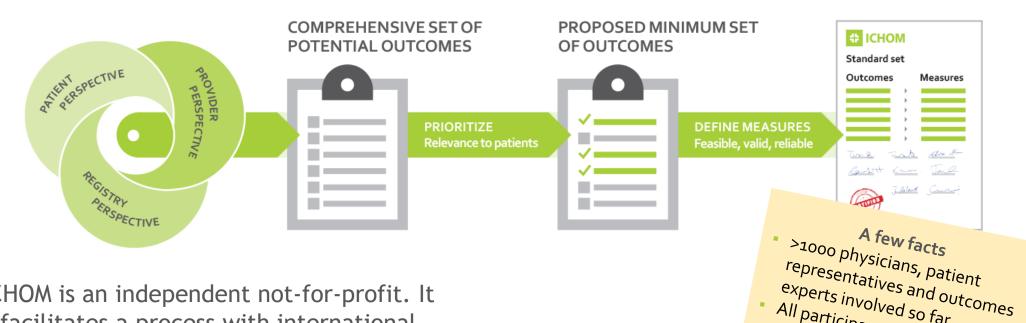


- Improved outcomes
- Reduced variation
- ✓ Reduced medical cost
- Continuous improvement

Improved health care value

## ICHOM organizes international working groups to define standard outcomes





ICHOM is an independent not-for-profit. It facilitates a process with international physician and registry leaders and patient representatives to develop a global Standard Set of outcomes that really matter to patients experts involved so far

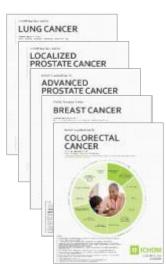
time, 2-3 hours per month 8-10 months to develop a

Standard Set

All participants volunteer their

## Currently 28 Open access Standard Sets published

#### Published sets cover >50% of global disease burden











HIP & KNEE OSTEOARTHRITIS

INFLAMMATORY

LOW BACK PAIN

Brann.

ICHON

ARTHRITIS



CHON

11111

OLDER PERSON

DEMENTIA

PARKINSON'S

DISEASE





#### In progress

Primary/preventative care

- Adult overall health
- Paediatric overall health
- Oral health

#### Mental health

- Personality disorders
- Depression and anxiety for children and young people
- Psychotic disorders
- Disorders related to substance use and addiction
- Personality disorders

#### Musculosketal

• Hand and wrist conditions



## Many leading institutions around the world are using the ICHOM standards



### Germans represented in ICHOM working groups



Andreas Bollmann UNIVERSITAT



**Andreas Schmitt** Diabetes Zentrum Mergentheim 🛕

**Axel Dignass** 

AGAPLESION MARKUS KRANKENHAUS

**Claudia Bausewein** 

**Michael Froehner** 

Universitätsklinikum Carl Gustav Carus



Markus Ketteler 



**Richard Dodel** Philipps Universität Marburg



**Thomas Steuber** Universitätsklinikum Hamburg-Eppendorf







Hartwig Huland Martini-Klinik



Markus Graefen • Martini-Klinik



**Thomas Wiegel** 

UNIVERSITÄTS KLINIKUM Ulm







Corinna Langelotz CHARITÉ



Sandra Nolte CHARITÉ



Alexander Obbarius

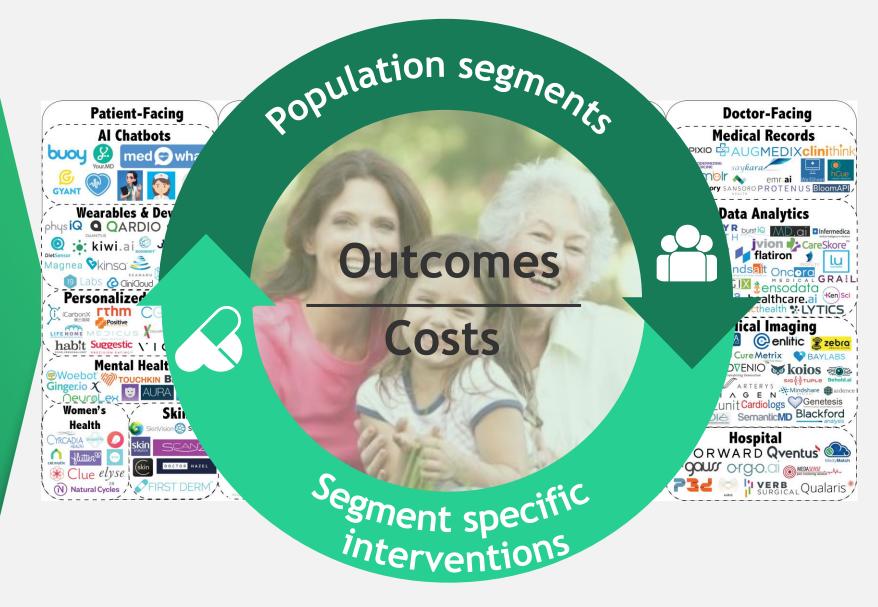
CHARITÉ



**Matthias Rose** CHARITÉ



Precision medicine will require the application of AI and deep learning



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TASTE

## Registry based randomized clinical trials

