eHealth and patients’ rights in Sweden.

Win – win?
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Bengt von Zur-Mühlen MD PhD
Arlanda airport this very morning

Advertisement for appointments in your smartphone
WHO defines empowerment as:

“a process through which people gain greater control over decisions and actions affecting their health”

and should be seen as both an individual and a community process.
Four components are fundamental to the process of patient empowerment:

1) understanding by the patient of his/her role;

2) acquisition by patients of sufficient knowledge to be able to engage with their healthcare provider;

3) patient skills; and

4) the presence of a facilitating environment
The Swedish patient act

- Earlier patient rights in Sweden where protected in many different laws but in 2015 Sweden became a specific patient act.

- The purpose is to protect rights and interests as a patient.

- Patients are to be informed about their illness and the kinds of treatments that are available.

- Patients have the right to participate in all decisions about the care they will be receiving.

- They must also be told where they can obtain the care that they need.
Healthcare is under pressure

- Around the world populations are becoming older, sicker and increasingly overweight
  - In Sweden 24 % are aged above 60,
  - 20 % are obese
  - 44 % live with at least one chronic disease.

- All of this contributes to put healthcare under pressure – and costs are estimated to grow to 16% by the year of 2050
There is an increasing desire to be independent, while being involved and having influence and control over decisions that impact their health and situation in life.
Swedes have healthy lifestyles.

Sweden has the lowest smoking rate of any OECD country, below average alcohol consumption and low rates of obesity.

Rates among adults (aged 15 and over) in 2013:

- Daily smoking: Sweden 11%, OECD 20%
- Alcohol consumed: Sweden 7.4 litres, OECD 8.8 litres
- Obesity: Sweden 11%, OECD 19%

Life expectancies are above the OECD average, especially for men.

Life expectancy at birth, 2013:

- Sweden: 80.2
- OECD: 77.8
- Sweden: 83.8
- OECD: 83.1

To read more about our work:

- Health at a Glance 2015: OECD Indicators
- Tackling Harmful Alcohol Use: Economics and Public Health Policy
- Obesity Update 2014
Sweden has high health care quality

13 Indicators – comparison

1. Mortality 30 days after AMI
2. Mortality 30 days after ischemic stroke
3. Proportion operated 48h after hip fracture
4. 5 year survival breast cancer
5. 5 year survival colorectal cancer
6. Amputation due to diabetes per 100,000
7. Neonatal mortality
8. DTP vaccination
9. Morbilli vaccination
10. Lost life years before age 70
11. Proportion with elevated blood glucose
12. Proportion with hypertension – untreated
13. Antibiotic usage DDD per 100,000
Health spending in Sweden 2013

GDP

* Excluding capital expenditure.
Source: OECD Health Statistics 2015
Sweden has excellent health care ... 

... but must improve care co-ordination, 
says OECD
Our patients will be given comprehensive information to enable them to make informed decisions about their health care.
Digitalisation can make the patient move from **Compliance** to **Adherence**

- **Follow orders**
- **I want to take my medication**
But what is digitalisation

The process in which an analogue model is transformed into digital information. This means that the information can be structured, searchable and accessible through digital channels.
Sweden second best in the EU for digital performance

Denmark in top but Sweden on second place
Swedes are digitally mature

- In 2015 90% of Swedes had access to computers and the internet
- 8 of 10 used internet at home on a daily basis
- 6 of 10 owned a tablet
- 3 out of 4 had a smartphone
Healthcare personnel even more digitally mature

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<tr>
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<th>In your private life</th>
<th>At work when interacting with patients</th>
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<tr>
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<td>Videocalls</td>
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But not at work interacting with patients!!
Digitalisation

Digitalisation has impacted the way of interaction with customers in other industries such as banking, retail, travel, information seeking, news papers ... ...

The digital patient is here – but is healthcare ready?
National strategy for eHealth

- In 2005 Swedish central government and health authorities established cooperation in order to create better information and communication technologies (ICT)
- The National Strategy for eHealth was adopted in 2006 and revised in 2010
- In 2016 came the next step - vision for eHealth
The eHealth vision states

“By 2025, Sweden will be the best in the world in leveraging the opportunities that digitalisation creates,

with the aim of enabling people to achieve good and equitable health and welfare

as well as develop and strengthen their own resources for increased independence and participation in society.”
Sweden has vastly adopted ICT in their health care.

- E-prescription and a national database for all pharmacies
- Fully digitalized patient health records but not a common system
- E-services for clinical information and appointment booking online
- National identity cards (SIHTS)
- National patient summary (NPÖ) (prescriptions, laboratory results)
- Clinical decision support systems
Patient records on line

In 2002 - a pilot study in Uppsala for providing all of the citizens online access to their personal health record, but it failed due to legal issues.

In 2008 - The Patient Data changed this by allowing patients the right to access their EHRs.

In 2013 all patients of the Uppsala County in Sweden were given online access to their personal health records and over 18,000 patients out of the population of 200,000 people had read their EHR in a total of 67,102 sessions the first year.

In 2017 online records for all citizens will be implemented in all other Swedish regions.
Introducing Patient records on line

The opinions of healthcare professionals and patients are divided

where some have a positive attitude towards this implementation, while others are concerned with

• patient anxiety due to misinterpreting the information – also unsigned information is readable
• security of the service
• unauthorized access or misuse of data
Health apps

- 44% of Swedes have at least one app on their smartphone or tablet that relates to health
- Clearly higher proportion than in the US with 28% and the UK with 25%
- Despite this only 1 out of 10 healthcare personnel recommended patients to use apps as part of their treatment
Proportion recommending future health app
Telehealth increase access but does not decrease spending

Direct-to-consumer telehealth was studied in California, US

Comparison of 300 000 patients in the years 2011-2013 and the spending for acute respiratory illnesses

Tele-health contacts increased from 0 to 85/100 individuals. Regular visits increased from 61 to 78/100 individuals.

The authors concluded: Telehealth showed 88 % new utilization. Although telehealth visits were cheaper the net annual spending increased 45 USD

JS Ashwood Health Affairs 2017;36:485-491
Three keypoints to reach the eHealth vision

I. Laws and regulatory frameworks
   • The new Patient Data Act from 2008 enabled integrated health records

II. Standardisation
   • Terms and vocabulary

III. Technical standard
   • Interoperability
How to go on

- E-Health is not an IT project - it is about development in health care.
- End users, meaning staff (and patients) should always have a clear role in all development projects.
- This requires employers to ensure that clinical (active!) staff can allocate time and participate fully. For real!
- Those who do not work clinically need to come out and see the reality to create understanding