Healthcare data from a patient perspective

Hanna Svensson, e-patient och RISE Mättenik
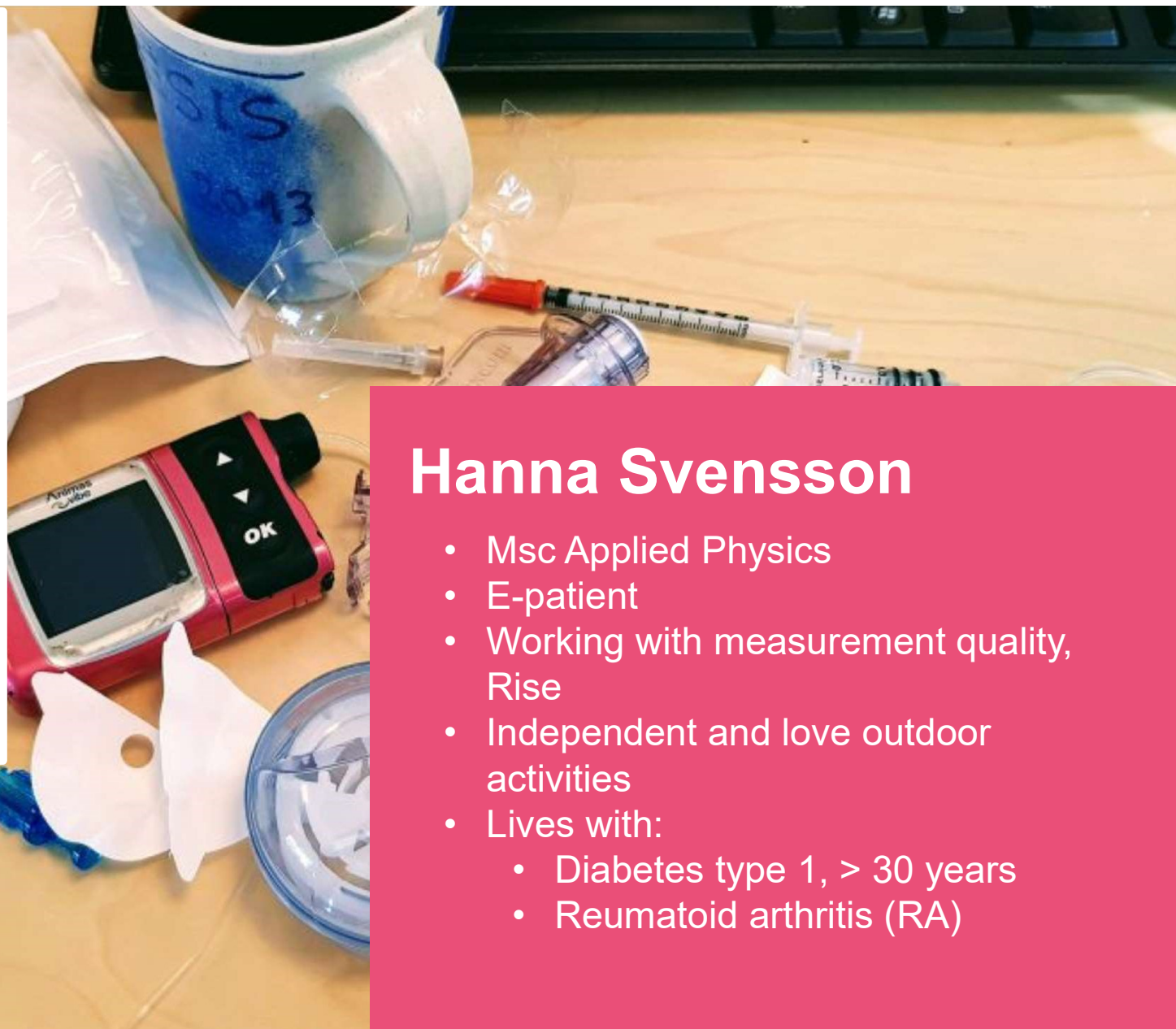
RISE

Health~~car~~e data from a patient perspective

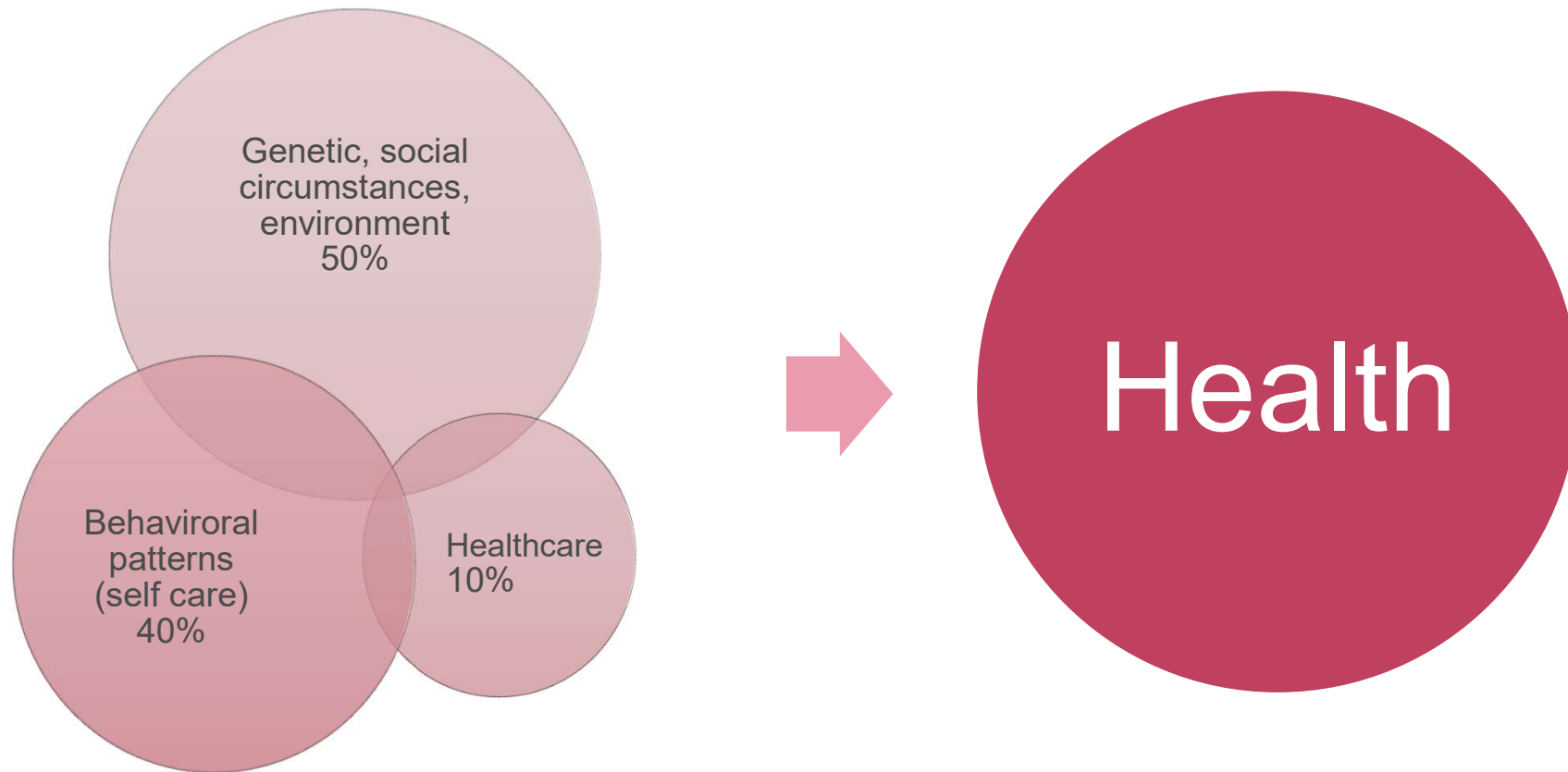Hanna Svensson, e-patient och RISE Mättenik

Agenda

> **Introduction**

> **My health data**

> **Health data**
  > Different variables
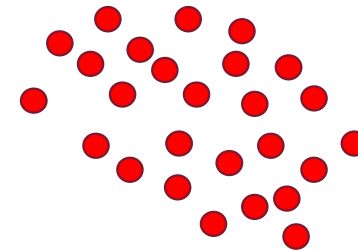 > Structure of health data
  > Data sharing

Hanna Svensson

- Msc Applied Physics
- E-patient
- Working with measurement quality, Rise
- Independent and love outdoor activities
- Lives with:
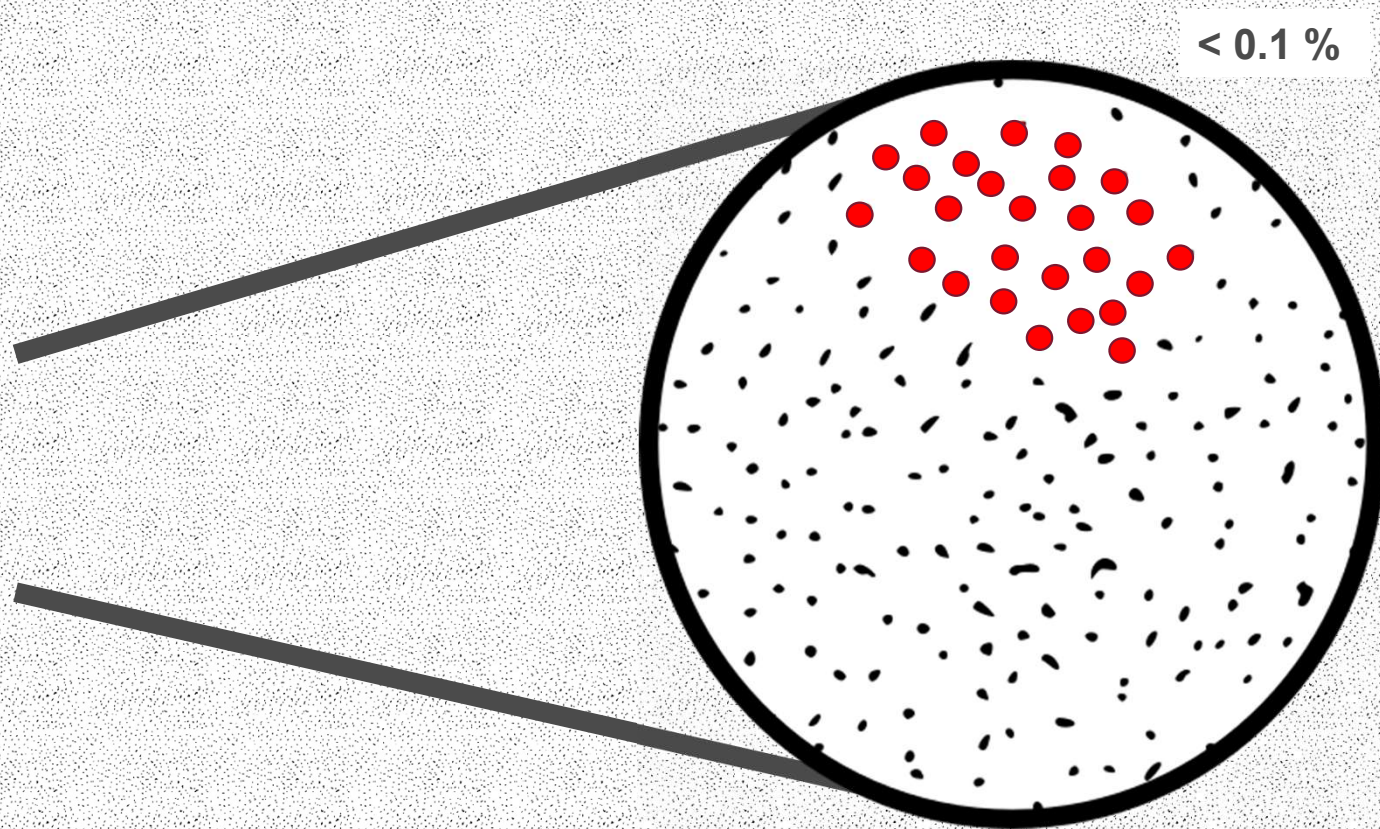 - Diabetes type 1, > 30 years
  - Reumatoid arthritis (RA)

Från: S. A. Schroeder, "We Can Do Better - Improving the Health of the American People," N. Engl. J. Med., vol. 357, no. 12, pp. 1221–1228, 2007. (anpassad)

2017

EMR notes
Lab result
26 points

SWElife

95 600 point

< 0.1 %

Data in self-care

SWElife

Data in self-care
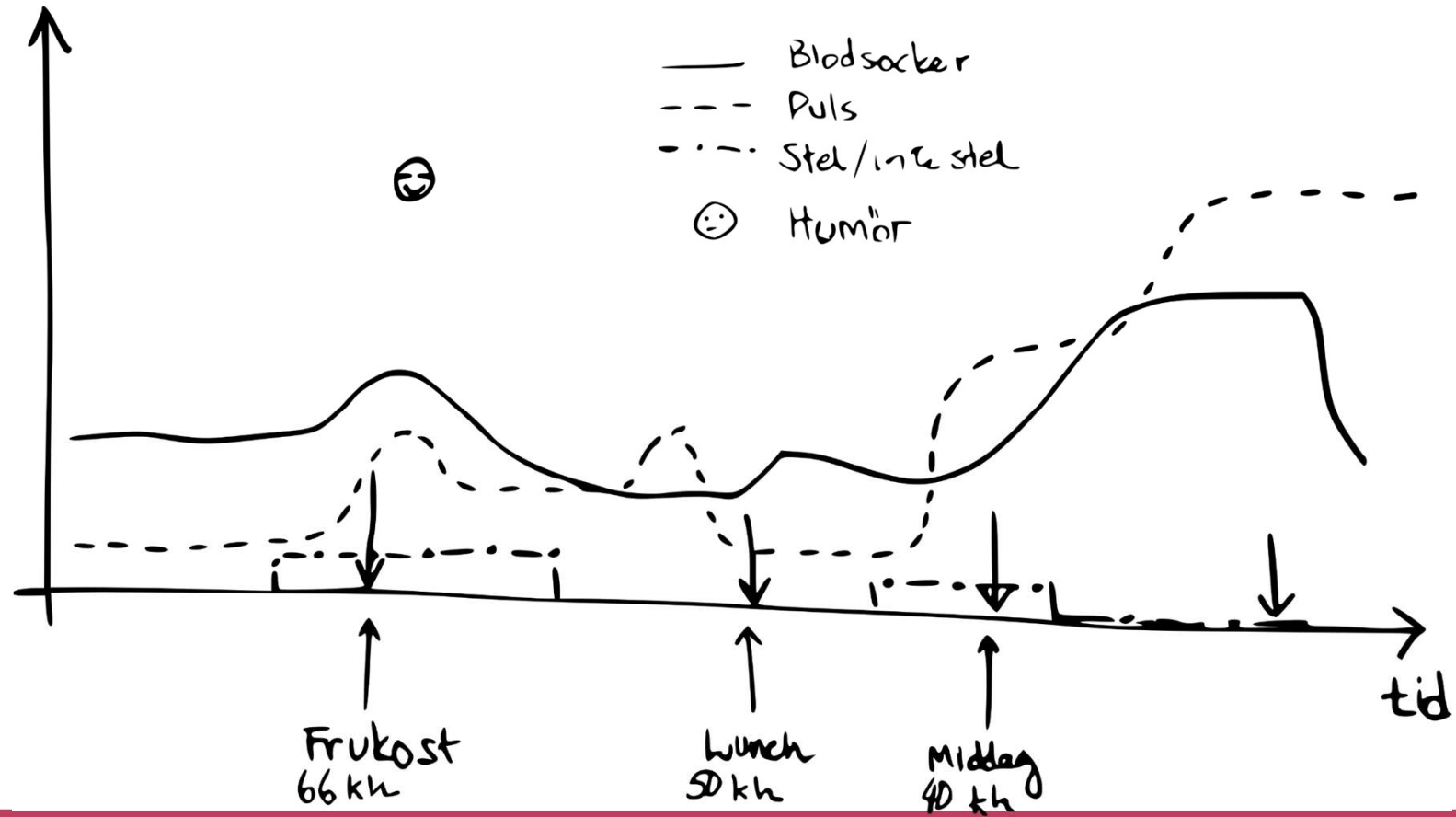
Healthdata from an indivual and self-care perspective

> **Questionnaire**

> **Interviews**

> **Academic articles**

HÄLSODATA UR ETT INDIVID- OCH EGENVÅRDS-PERSPEKTIV

Av Hanna Svensson

Health data variables

> **Measurements – variables measured with availble products**

> **Assessments – variables assessed by the indivdual that are not measureable**

> **Estimation of measurements – estimation of measureble variables**

> **Self-developed tests – variables measured with tests developed by the individual (sometimes with inspiration from research or other individuals)**

Variables - exemples

Assessment

> Fatigue

> Pain

> Stiffness

Estimation of measurements

> Diet and foodintake

> Exercise

Measurements

> Glucose levels

> Body temperature

> Pulse

Self-developed tests

> Shaking

> Tapping test

> Inflammotory bowl test

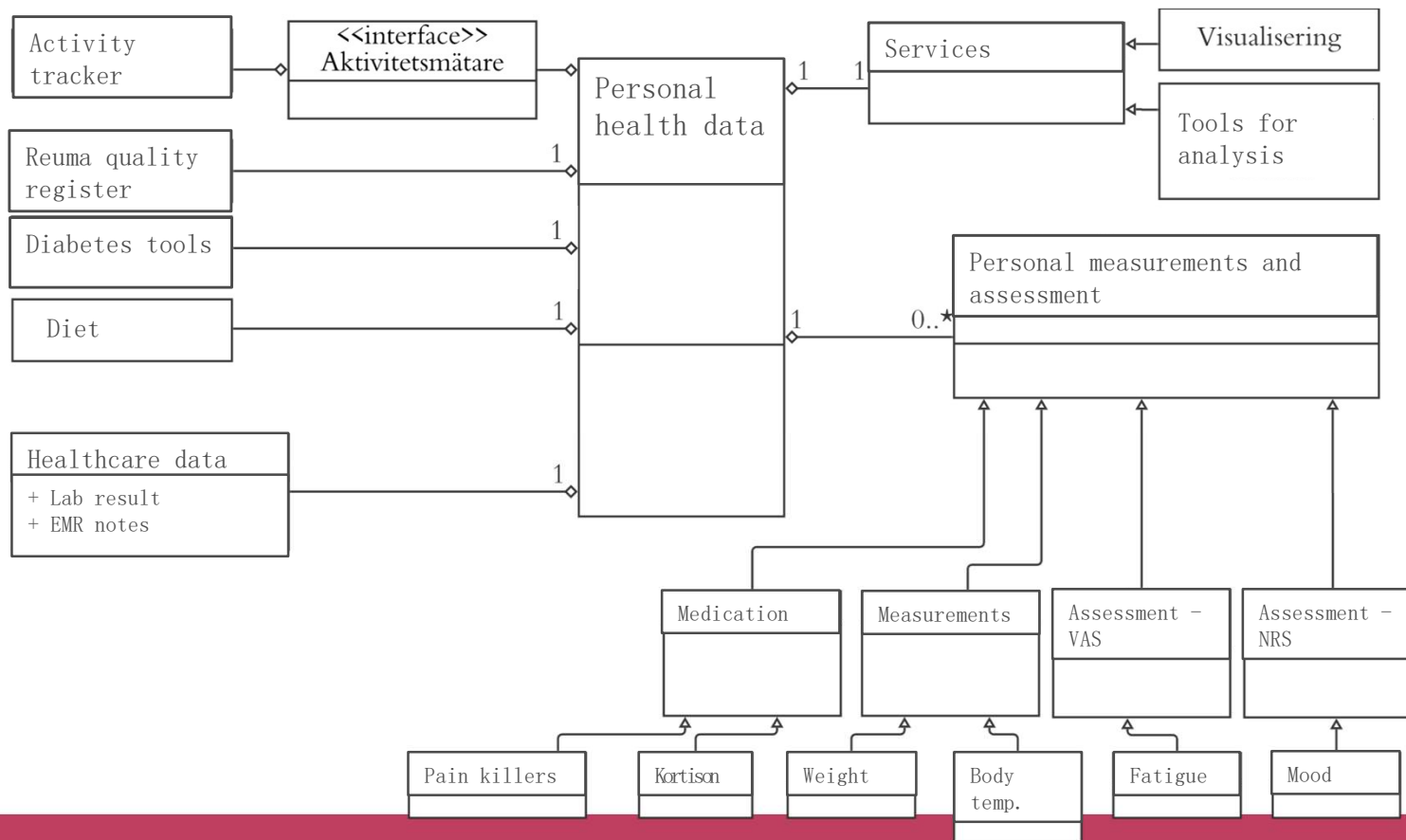# Result

> **Data structure for self-collected data**

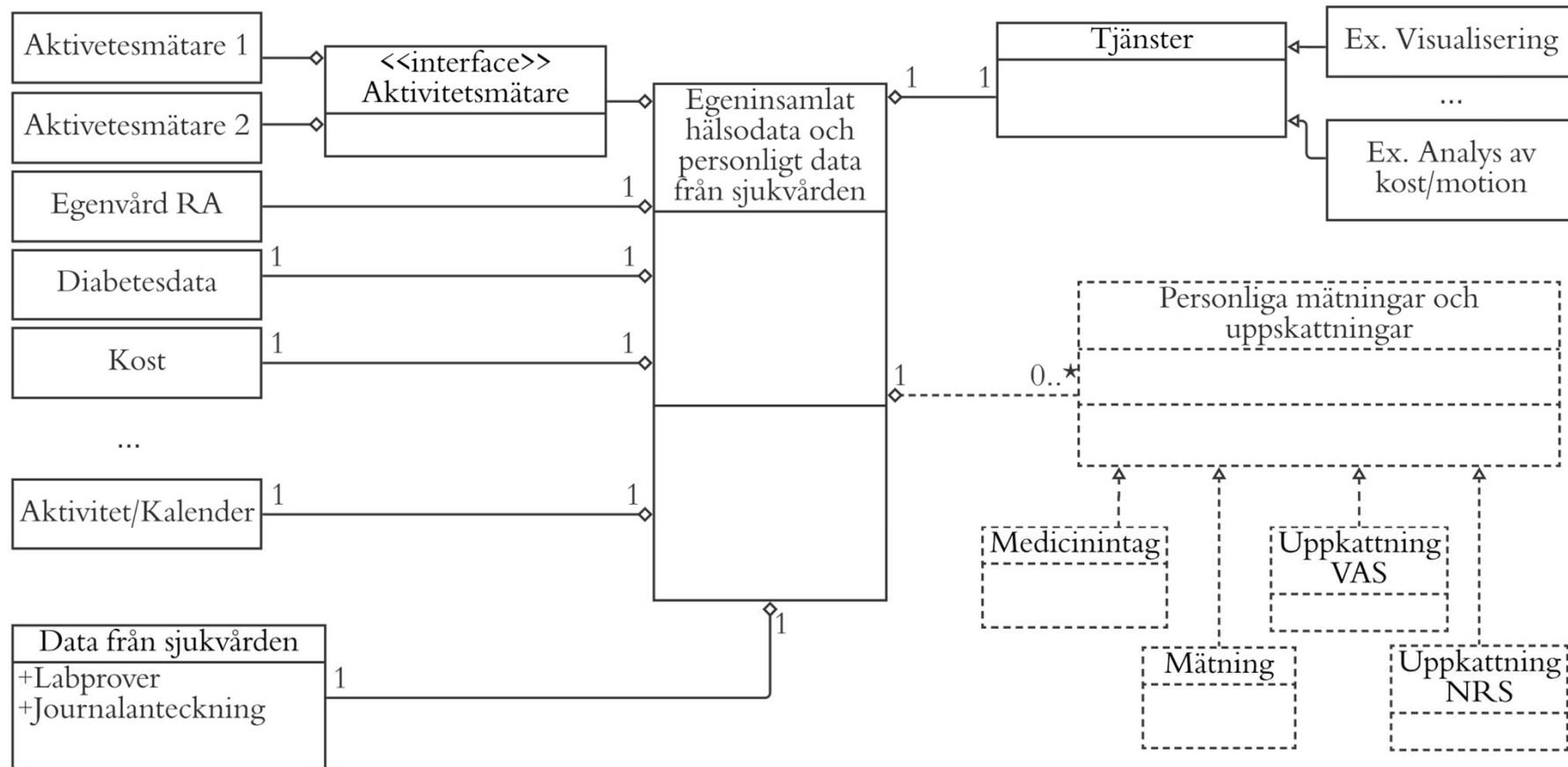Generalized model → What is important for the person → Configuration → Personal model

Structure – personal health data

Generalized structure – personal health data

Personal health data

Personliga mätningar och uppskattningar

Personlig mätning eller uppskattning
+Tid
+Tid vid loggning

1   0..★

Medicinintag
+ Medicin
+ Mängd

Mätning
+Mätvärde
+Osäkerhet
+Enhet
+Källa
+Mätt eller uppskattat

Uppskattning VAS
+Värde kontinuerligt
+Benämning min
+Benämning max
+Källa

Uppskattning NRS
+Värde diskret
+Benämning min
+Benämning max
+Källa

Structure – personal healthdata

Modeller från andra produkter
+ Aktivitetsmätare
+ Egenvård RA
+ Diabetesbehandling
+ Kost
+ Kalender/Aktivitet

Egeninsamlad hälsodata och personligt data från sjukvården

Personliga mätningar och uppskattningar
+ Mätningar
+ Uppskattningar VAS
+ Uppskattningar NRS
+ Medicinintag

Data från sjukvården
+ Provresultat
+ Journalanteckningar

Tjänster
+ Visualisering
+ Analys av samband

SWElife

Data-sharing – health-data

Share self-collected health data with healthcare for my own care	84% / 10% / 6%
Share self-collected health data with research	84% / 10% / 6%
Share EMR data with research	67% / 12% / 21%
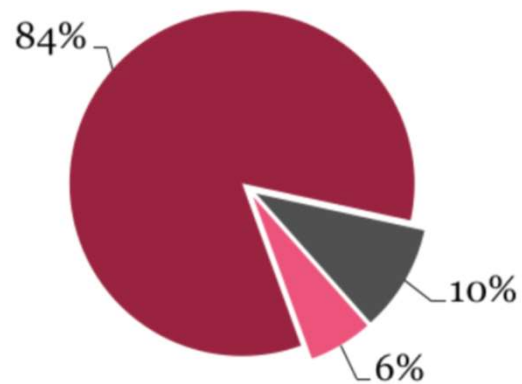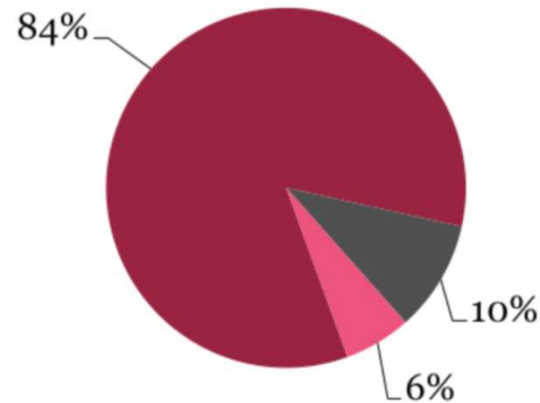
■ - Ja   ■ - Nej   ■ - Vet ej

SWElife
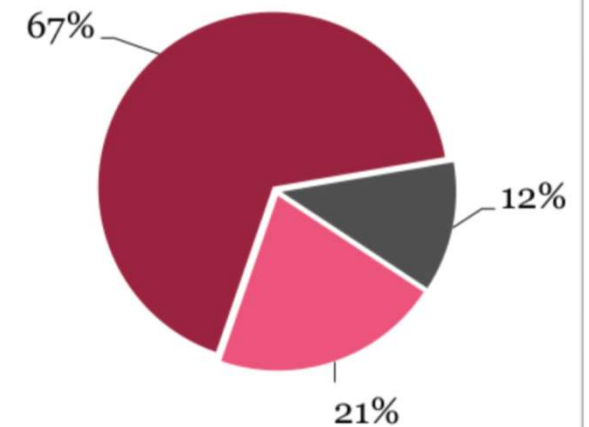
Conclusions

> **Odontology och structure for self collected health data is lacking**

> **Healthcare data is a minority of all health data**

> **To understand health and health data citizien and patients needs to be involved, for real**

Thank you!

Hanna Svensson
hanna.svensson@ri.se
+46 10 516 50 67

hanna.svensson@ri.se