



UiO : Faculty of Medicine

Patient Generated and Reported Data Real Work Data



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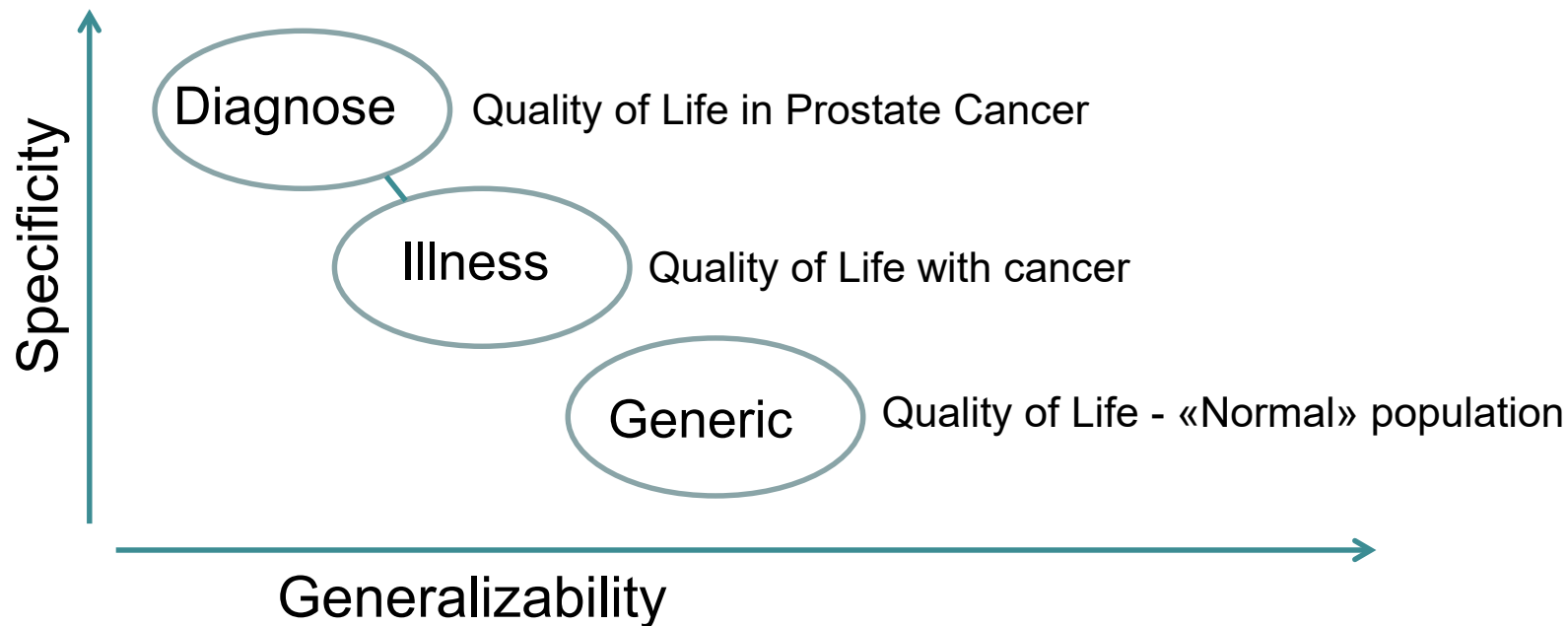
Professor II, Norwegian Centre for eHealth Research, Tromsø, Norway

Focusing in

- Patient Generated Data – PROM, IoT, patient facing apps
 - Standardized and unstructured data complement expanding repositories
Observations in Daily Living and Patient Reported Outcomes
 - Data Science analytics, NLP, ML
- Meaningful Health Data Use – Real World Data / Trial
 - Innovation supported by real evidence or high expectations ?

Types of PROM

Generic - illness (diagnosis)



Examples – patient reported data

- Symptom management
 - Palliative Home Care – ESAS
- R-Outcomes: howRU and wellbeing
 - credit Tim Benson,
- Citizen empowerment - CAPABLE
 - “Empower citizens to active use of their health information”
 - Medication List
 - Sleep Diary

Remote monitoring – palliative care

- ESAS
Edmonton Symptom Assessment Scale
 - Person rate their symptoms
-
- Change over time
 - Personalize care, symptom mgt
 - System level improvement

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety (Anxiety = feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem (For example constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Reference:

Steindal, S. A., Nes, A. A. G., Godskesen, T. E., Dihle, A., Lind, S., Winger, A., & Klarare, A. (2020). Patients' Experiences of Telehealth in Palliative Home Care: Scoping Review. *J Med Internet Res*, 22(5),

Measure what we want

Tim Benson (UK)

Quality of Life	Individual Care	Community	Care Provided	Provider Culture	Innovation
Health status	Health confidence	Loneliness	Patient experience	Patient safety	Digital confidence
Person-specific outcome	Self care	Social determinants	Service integration	Staff relationships	Product confidence
Well-being	Share decisions	Loneliness (ONS)	Service provided	Share decisions	User satisfaction
Sleep	Behaviour change	Neighbour relationships	Patient confidence	Staff safety	Digital readiness
Fatigue	Adherence	Personal safety		Privacy	IT capability
Work wellbeing	Acceptance of loss				Innovation process
Accessed need	Job confidence				Training

Reported by: Patients, Staff, Both

Reference:

Benson T. Measure what we want: a taxonomy of short generic person-reported outcome and experience measures (PROMs and PREMs). *BMJ Open Quality* 2020; 9: e000789

Format

R-OUTCOMES

Personal Well-being

How are you feeling in general?

Strongly agree

Agree

Neutral

Disagree

I am satisfied with my life

😊

🙂

😐

😞

What I do in my life is worthwhile

😊

🙂

😐

😞

I was happy yesterday

😊

🙂

😐

😞

I was NOT anxious yesterday

😊

🙂

😐

😞

NEXT

Health Status

How are you today? (past 24 hours)

None

A little

Quite a lot

Extreme

Pain or discomfort

😊

🙂

😐

😞

Feeling low or worried

😊

🙂

😐

😞

Limited in what you can do

😊

🙂

😐

😞

Require help from others

😊

🙂

😐

😞

Patient Experience

How are we doing? (our recent care)

Excellent

Good

Fair

Poor

Treat you kindly

😊

🙂

😐

😞

Listen and explain

😊

🙂

😐

😞

See you promptly

😊

🙂

😐

😞

Well organised

😊

🙂

😐

😞

Measures have a common layout with 4 items and 4 options using coloured emojis. Positive wording.
Results on 0-100 scale. Item and summary scores. High scores are good.

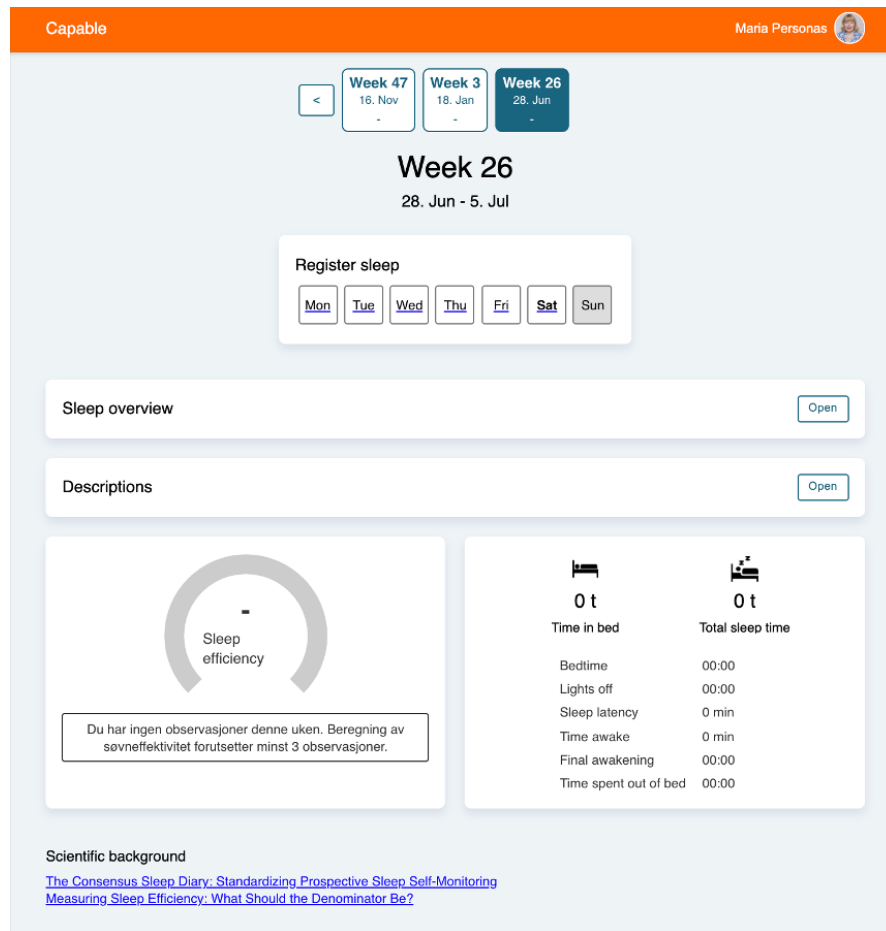
<https://r-outcomes.com/r-measures/all-measures>

Patient reported data, ongoing trial



Reference:

Thorshov, T.C et.al (2020) "Jeg får ikke sove", Poster, eHelsekonferansen 2020, Oslo



Capable Maria Personas

Sleep diary

< 30.06.2021 >

How did you function yesterday?

Choose from list...

Write down any activity you did yesterday to function better

Write keywords

Did you take sleeping pills, consumed alcohol and/or illegal drugs 5 hours prior to getting to bed?

Yes No

When did you go to bed? This does not have to be the same time as you tried to sleep (such as looking at a screen, read a book or other activities)

Choose time, round off to closest half hour

Choose from list...

When did you try to sleep?

Choose time, round off to closest half hour

Choose from list...

How long time did it take you to fall asleep?

In minutes

How many times during the night did you wake up (not counting the final awakening)?

Number of time

During the night, how much time was spent awake?

Note number of minutes you were awake after you fell asleep the first time. For instance, if you were awake 3 times for 20 minutes, 35 minutes and 15 minutes, you summarise all these into one number (20+35+15=70 min or 1 hour og 10 min)

In minutes

Capable Maria Personas

Sleep diary

< 30.06.2021 >

How did you function yesterday?

Good

Write down any activity you did yesterday to function better

relaxed less, went for a walk

Did you take sleeping pills, consumed alcohol and/or illegal drugs 5 hours prior to getting to bed?

Yes No

What kind of sleep aids and/or other substances did you take 5 hours prior to getting to bed?

walk

When did you go to bed? This does not have to be the same time as you tried to sleep (such as looking at a screen, read a book or other activities)

Choose time, round off to closest half hour

23:00

When did you try to sleep?

Choose time, round off to closest half hour

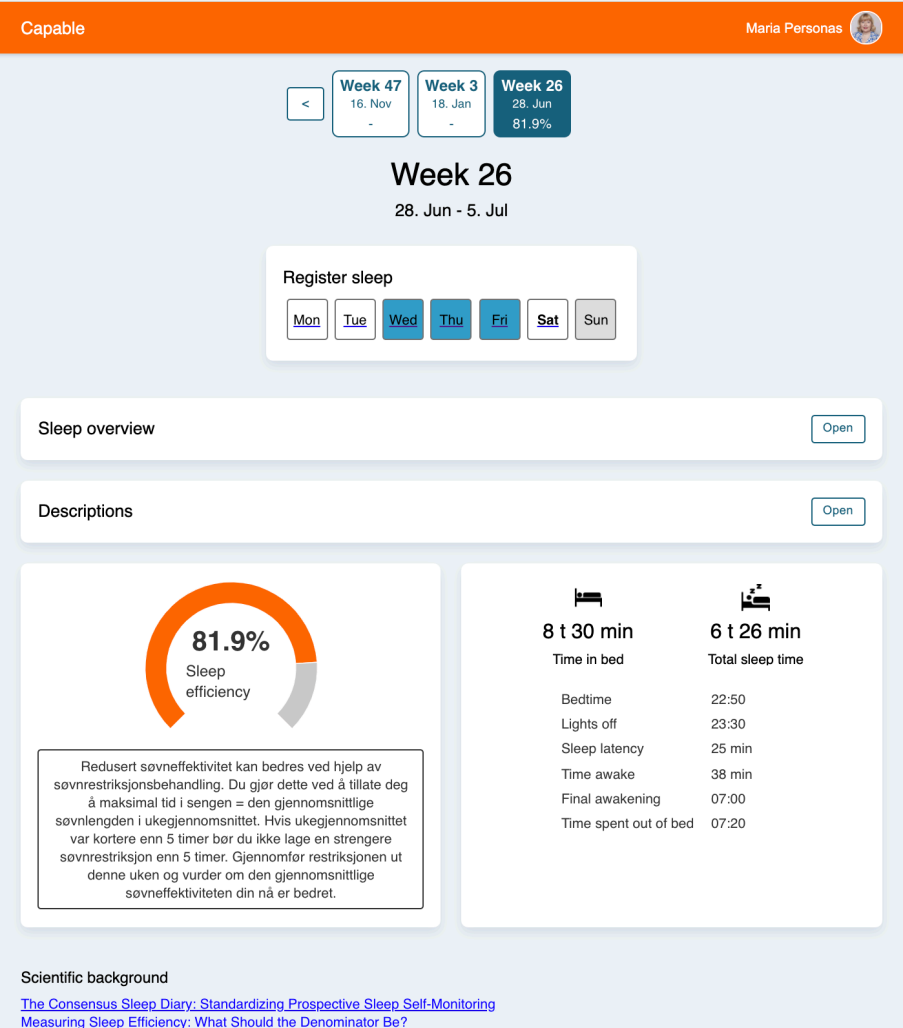
23:30

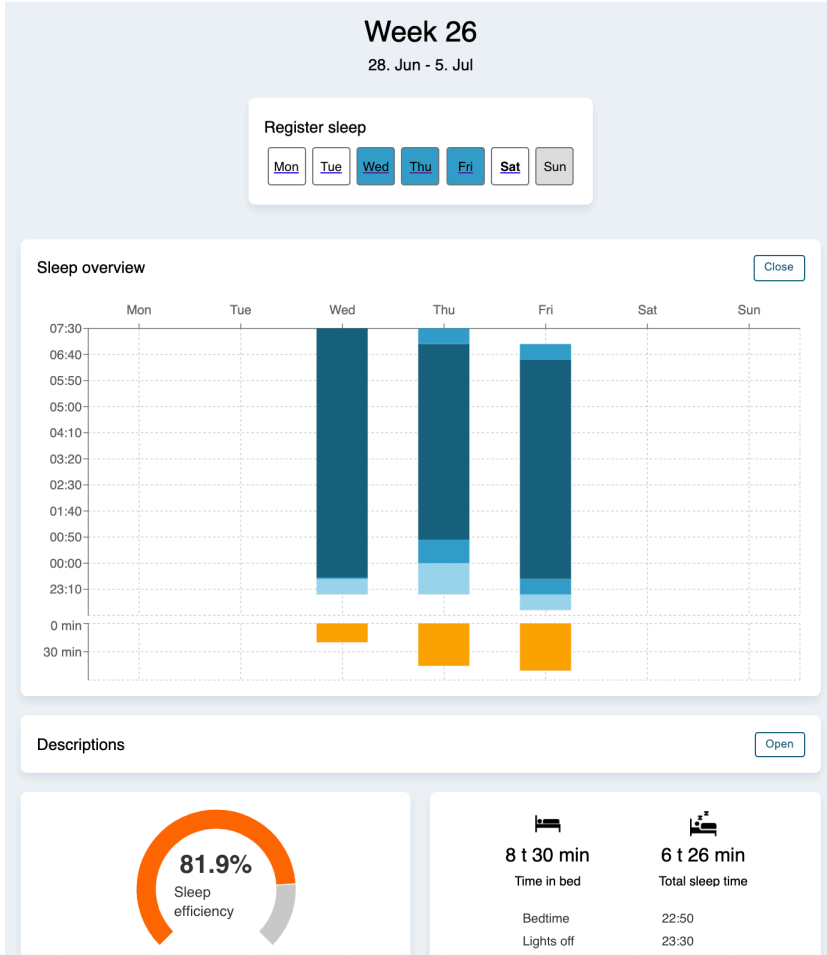
How long time did it take you to fall asleep?

2

How many times during the night did you wake up (not counting the final awakening)?

4





Register sleep

Mon

Tue

Wed

Thu

Fri

Sat

Sun

Sleep overview

Open

Descriptions

Close

Mon

Tue

Wed

Thu

Fri

Sat

Sun

Sleep efficiency

0%

0%

95.4%

73.3%

77.1%

0%

0%

How did you feel yesterday?

Bra

Verken bra eller dårlig

Dårlig

What about your function was bad?

tiered all morning

Measures taken to improve function

relaxed less, went for a walk

small nap around noon

Sleep aid and/or other substances

walk

a glass of wine

Sleep quality

God

Grei

Grei

Comment

a lot of noise outside bothered me

PROM resources

- Calvert, M., Brundage, M., Jacobsen, P.B. *et al.* The CONSORT Patient-Reported Outcome (PRO) extension: implications for clinical trials and practice. *Health Qual Life Outcomes* **11**, 184 (2013).
- Calvert M, et.al. Guidelines for Inclusion of Patient-Reported Outcomes in Clinical Trial Protocols: The SPIRIT-PRO Extension. *JAMA*. 2018 Feb 6;319(5):483-494. PMID: 29411037.
- Hamilton DF, Giesinger JM, Giesinger K. Technological developments enable measuring and using patient-reported outcomes data in orthopaedic clinical practice. *World J Orthop*. 2020 Dec 18;11(12):584-594 PMID: 33362994
- Hertler C, Seiler A, Gramatzki D, Schettle M, Blum D. Sex-specific and gender-specific aspects in patient-reported outcomes. *ESMO Open*. 2020 Nov;5(Suppl 4):e000837. PMID: 33184099;

Real World Data collection – references

- Makady A, de Boer A, Hillege H, Klungel O, Goettsch W; (on behalf of GetReal Work Package 1). What Is Real-World Data? A Review of Definitions Based on Literature and Stakeholder Interviews. *Value Health*. 2017 Jul-Aug;20(7):858-865. PMID: 28712614.
- Wise J, Möller A, Christie D, Kalra D, Brodsky E, Georgieva E, Jones G, Smith I, Greiffenberg L, McCarthy M, Arend M, Luttringer O, Kloss S, Arlington S. The positive impacts of Real-World Data on the challenges facing the evolution of biopharma. *Drug Discovery Today* 2018 (23), 4, April 2018, pp 788-80. <https://doi.org/10.1016/j.drudis.2018.01.034>
- Collins R, Bowman L, Landray M, Peto R. The Magic of Randomization versus the Myth of Real-World Evidence. *N Engl J Med*. 2020 Feb 13;382(7):674-678. PMID: 32053307.