Quality of Life Technologies Lab
University of Geneva (CH)
qol.unige.ch

Measuring Health and Life Quality Outcomes

'What is always speaking silently is the body'

Norman O. Brown, Love's Body 1966

Prof. Dr. Katarzyna Wac & QoL Lab

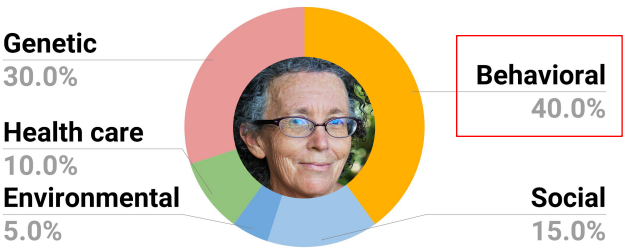
QooooL School 2024

A Patient (female, 73)

Type 2 Diabetes (1992)
Heart attack (2014), stroke (2024)
Hip fractures (2016, 2022)

Loves cooking
Much (too much) food (carbs)

Not the Only One



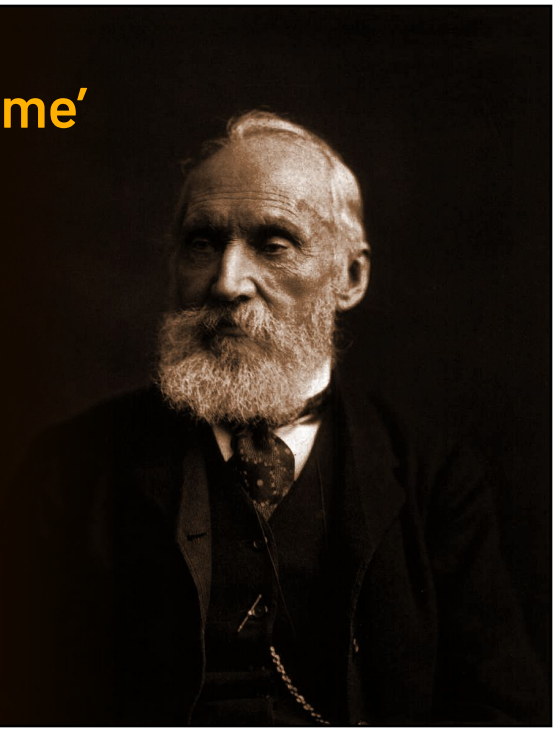
Behavioural patterns	Deaths
Tobacco intake	18.1%
Poor diet Physical inactivity	16.6%
Alcohol consumption	3.5%
...	

THE LANCET JAMA

Naghavi, M., Abajobir, A. A., Abbafati, C., Abbas, K. M., Abd-Allah, F., Abera, S. F., ... & Ahmadi, A. (2017). *Global, Regional, And National Age-Sex Specific Mortality For 264 Causes Of Death, 1980-2016: A Systematic Analysis For The Global Burden Of Disease Study 2016*. The Lancet, 390 (10100), 1151-1210.

Mokdad, A. H., Marks, J. S., Stroup, D. F., & Gerberding, J. L. (2004). *Actual Causes of Death in the United States, 2000*. Jama, 291 (10), 1238-1245.

‘Behaviour marker’, ‘Behaviome’ ‘Digital Biomarker’



If you can’t measure it, you can’t improve it.

William Thomson, 1st Baron Kelvin, 1824-1907

PROs: Example Activity Questions

1a. During the last 7 days, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling,?

Think about *only* those physical activities that you did for at least 10 minutes at a time.

_____ **days per week** ⇨

or

☐ **none**

1b. How much time in total did you usually spend on one of those days doing vigorous physical activities?

_____ **hours** _____ **minutes**

2a. Again, think *only* about those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

_____ **days per week** ⇨

or

☐ **none**

2b. How much time in total did you usually spend on one of those days doing moderate physical activities?

_____ **hours** _____ **minutes**

3a. During the last 7 days, on how many days did you **walk** for at least 10 minutes at a time? This includes walking at work and at home, walking to travel from place to place, and any other walking that you did solely for recreation, sport, exercise or leisure.

_____ **days per week** ⇨

or

☐ **none**

3b. How much time in total did you usually spend walking on one of those days?

_____ **hours** _____ **minutes**

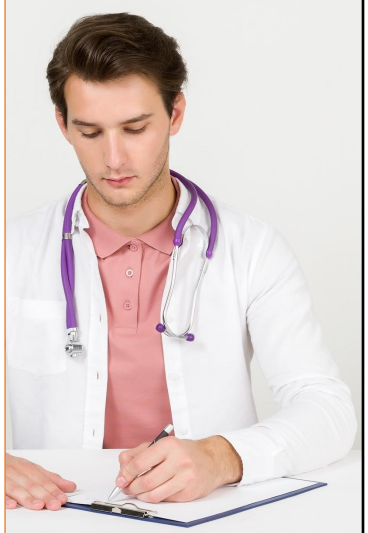
The last question is about the time you spent sitting on weekdays while at work, at home, while doing course work and during leisure time. This includes time spent sitting at a desk, visiting friends, reading traveling on a bus or sitting or lying down to watch television.

4. During the last 7 days, how much time in total did you usually spend *sitting* on a **week day?**

_____ **hours** _____ **minutes**

This is the end of questionnaire, thank you for participating.

This is the final SHORT LAST 7 DAYS SELF-ADMINISTERED version of IPAQ from the 2000/01 Reliability and Validity Study. Completed May 2001.



International Physical Activity Questionnaire short form (IPAQ-SF)

Assessing Quality of Life: Instruments

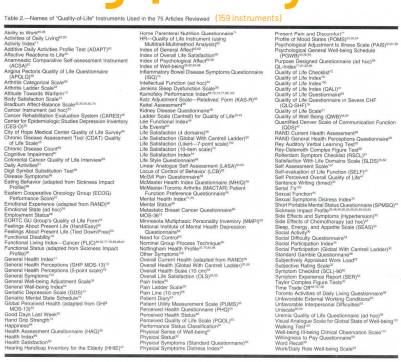
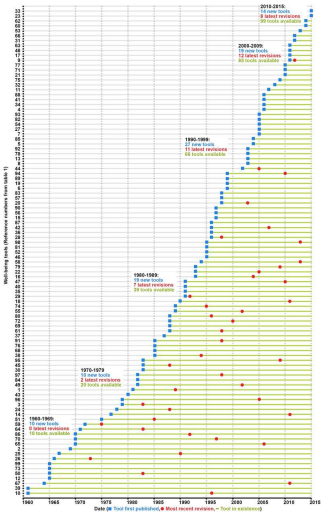


Table 2—Names of "Quality-of-Life" Instruments Used in the 75 Articles Reviewed. (159 Instruments)

Ability to Work[48,49]
Activities of Daily Living[47,50]
Activity Index[51]
Additive Daily Activities Profile Test (ADAPT)[52]
Affect Balance Scale[53,54]
Anamnestic Comparative Self-assessment Instrument (ACSA)[55]
Angina Pectoris Quality of Life Questionnaire (APQLQ)[56]
Arthritis Pathological Scale[48]
Arthritis Ladder Scale[48]
Attitude Towards Warfarin[57]
Body Satisfaction Scale[58]
Bradburn Affect Balance Scale[59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99,100,101,102,103,104,105,106,107,108,109,110,111,112,113,114,115,116,117,118,119,120,121,122,123,124,125,126,127,128,129,130,131,132,133,134,135,136,137,138,139,140,141,142,143,144,145,146,147,148,149,150,151,152,153,154,155,156,157,158,159]
Cancer Rehabilitation Evaluation System (CARES)[48]
Center for Epidemiologic Studies Depression Inventory (CES-D)[49]
City of Hope Medical Center Quality of Life Survey[48]
Cornell Medical Index Assessment Tool (COAT) Quality of Life Scale[48]
Chronic Disease Count[48]
Cognitive Impairment[48]
Colorectal Cancer Quality of Life Interview[48]
Daily Activities[48]
Digit-Symbol Substitution Test[48]
Disease Symptoms[48]
Emotional Behavior (adapted from Sickness Impact Profile)[48]
Eastern Cooperative Oncology Group (ECOG) Performance Scale[48]
Emotional Experience (adapted from RAND)[48]
Emotional Well-being[48]
Employment Status[48]
EORTC QLI Group's Quality of Life Form[48]
Feelings About Present Life (Hunt/Essay)[48]
Feelings About Present Life (Test Down/Heal)[48]
Functional Capacity[48]
Functional Living Index—Cancer (FLIC)[48,51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99,100,101,102,103,104,105,106,107,108,109,110,111,112,113,114,115,116,117,118,119,120,121,122,123,124,125,126,127,128,129,130,131,132,133,134,135,136,137,138,139,140,141,142,143,144,145,146,147,148,149,150,151,152,153,154,155,156,157,158,159]
Functional Status (adapted from Sickness Impact Profile)[48]
General Health Index[48]
General Health Perceptions (GHP MOS-13)[48]
General Health Perceptions (5-point scale)[48]
General Symptoms[48]
General Well-being Adjustment Scale[48]
General Well-being Index[48]
General Well-being Schedule (GDS)[48]
Geriatric Mental State Schedule[48]
Global Perceived Health (adapted from GHP MOS-13)[48]
Good Days Last Week[48]
Health Distress[48]
Happiness[48]
Health Assessment Questionnaire (HAQ)[48]
Health Index[48]
Health Satisfaction[48]
Hearing Handicap Inventory for the Elderly (HHIE)[48]
Home Theoretical Nutrition Questionnaire[48]
HR—Quality of Life Instrument (using Multitrait-Multimethod Analysis)[48]
Index of General Affect[48,49]
Index of Life Satisfaction[48]
Index of Psychological Affect[48,49]
Index of Well-being[48,49,50,51]
Inflammatory Bowel Disease Symptoms Questionnaire (ISQ)[52]
Interpersonal Function (ad hoc)[48]
Jenkins Sleep Dysfunction Scale[48]
Kornofsky Performance Index[48,49,50,51,52,53,54]
Katz Adjustment Scale—Relatives' Form (KAS-R)[48]
Kellet Assessment[48]
Kidney Disease Questionnaire[48]
Ladder Scale (Cantril) for Quality of Life[48,49]
Lee Functional Index[48]
Life Events[48]
Life Satisfaction (4 domains)[48]
Life Satisfaction (Cantril Self-with Control Ladder)[48]
Life Satisfaction (Likert—7-point scale)[48]
Life Satisfaction (10-item scale)[48]
Life Satisfaction Index[48]
Life Style Questionnaire[48]
Linear Analog Self-report Assessment (LASA)[48,49]
Locus of Control of Behavior (LCB)[48]
McGill Pain Questionnaire[48]
McMaster Health Index Questionnaire (MHQ)[48]
McMaster-Toronto Arthritis (MACTAR) Patient Preference Disease Questionnaire[48]
Mental Health Index[48,49]
Mental Status[48]
Miller-Powell Breast Cancer Questionnaire[48]
MOS-SF-36[48]
Minnesota Multiphasic Personality Inventory (MMPI)[48]
National Institute of Mental Health Depression Questionnaire[48]
Nottingham Health Profile[48]
Nominal Group Process Technique[48]
Nottingham Health Profile[48,49,50,51]
Other Symptoms[48]
Overall Current Health (adapted from RAND)[48]
Overall Life Satisfaction (Cantril Ladder)[48,49]
Overall Health Scale (10 point)[48]
Overall Life Satisfaction (OLS)[48,49]
Pain Index[48]
Pain Ladder Scale[48]
Patient Activity Card[48]
Patient Days[48]
Patient Utility Measurement Scale (PUMS)[48]
Perceived Health Questionnaire (PHQ)[48]
Perceived Health Status[48]
Performance Status Scale (POOL)[48]
Performance Status Classification[48]
Physical Sense of Well-being[48]
Physical Status[48]
Physical Symptoms (Standard Questionnaire)[48]
Physical Symptoms Distress Index[48]
Present Pain and Discomfort[48]
Profile of Mood States (POMS)[48,50,51]
Psychological Adjustment to Illness Scale (PAIS)[48,51,52]
Psychological General Well-being Schedule (PGWBS)[48]
Purpose Designed Questionnaire (ad hoc)[48]
QL-Index[48,51,52,53]
Quality of Life Checklist[48]
Quality of Life Index[48]
Quality of Life Profile[48]
Quality of Life Index (QALI)[48]
Quality of Life Questionnaire[48]
Quality of Life Questionnaire in Severe CHF (QLQ-SHF)[48]
Quality of Well Being Scale[48]
Quality of Well Being (QWB)[48,49]
Quantified Denver Scale of Communication Function (QDSF)[48]
RAND Current Health Assessment[48]
Rand Health Insurance Study Questionnaire[48]
Ray Auditory Verbal Learning Test[48]
Rey-Osterreith Complex Figure Test[48]
Rotterdam Symptom Checklist (RSCL)[48]
Satisfaction With Life Domains Scale (SLDS)[48,50]
Self-Anchoring Ladder[48]
Self-evaluation of Life Function (SELF)[48]
Self Perceived Overall Quality of Life[48]
Sentence Writing (timed)[48]
Social[48]
Social Functions[48]
Sexual Symptoms Distress Index[48]
Short Portable Mental Status Questionnaire (SPMSQ)[48]
Sickness Impact Profile[48,49,50,51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99,100,101,102,103,104,105,106,107,108,109,110,111,112,113,114,115,116,117,118,119,120,121,122,123,124,125,126,127,128,129,130,131,132,133,134,135,136,137,138,139,140,141,142,143,144,145,146,147,148,149,150,151,152,153,154,155,156,157,158,159]
Side Effects and Symptoms (Hypertension)[48]
Sleep, Energy, and Appetite Scale (SEAS)[48]
Social Activity[48]
Social Network Questionnaire[48]
Social Participation Index[48]
Social Participation (Global With Cantril Ladder)[48]
Standard Gamble Questionnaire[48]
Subjectively Appraised Work Load[48]
Symptom Checklist[48]
Symptom Checklist (SCL-)[48]
Symptom Experience Report (SER)[48]
Taylor Complex Figure Tests[48]
Time Trade Off[48,51]
Time Use Survey of Daily Living Questionnaire[48]
Unfavorable External Working Conditions[48]
Unfavorable Interpersonal Difficulties[48]
Urbanite[48,49]
Uremia Quality of Life Questionnaire (ad hoc)[48]
Visual Analogue Scale for Global State of Well-being[48]
Walking Test[48]
Well-being (Well-being Clinical Observation Scale)[48]
Willingness to Pay Questionnaire[48]
Word Recall[48]
Work/Daily Role Well-being Scale[48]



Health related QoL

EQ5D *mobility, usual activities, pain, anxiety/depression, self-care*

SF-36 *mobility, usual activities incl.social, pain, emotions, energy*

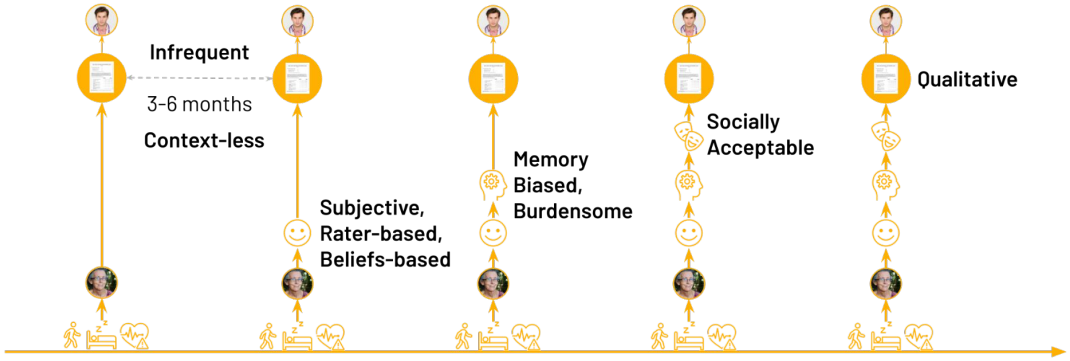
Gill, T. M., and A. R. Feinstein. "A critical appraisal of the quality of quality-of-life measurements." Jama 272.8 (1994): 619-626.

Linton M, Dieppe P, Medina-Lara, A Review of 99 self-report measures for assessing well-being in adults: exploring dimensions of well-being and developments over time, BMJ Open 2016;6:e010641

EuroQol Research Foundation. EQ-5D-5L User Guide, 2019. doi: 10.3109/07853890109002087

Hays RD, Sherbourne CD, Mazel RM. The RAND 36-Item Health Survey 1.0. Health Econ. 1993 Oct;2(3):217-27. doi: 10.1002/hec.4730020305.

Self-Reported Outcomes



The Big Picture

Smartphone

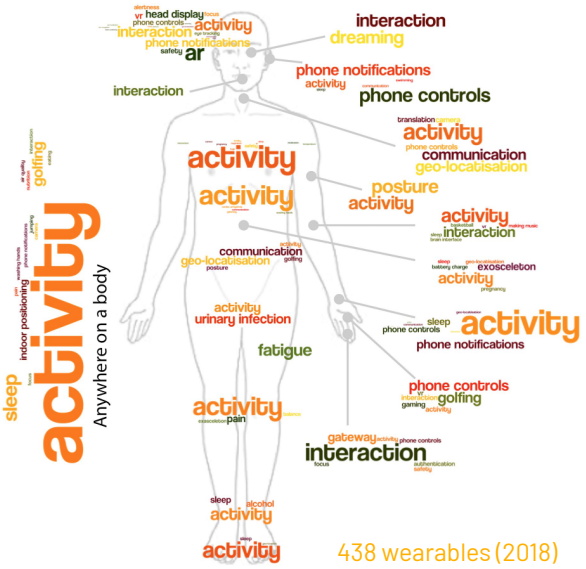
88%

of the time next to us

Dey, A. K., Wac, K., Ferreira, D., Tassini, K., Hong, J. H., & Ramos, J. (2011). *Getting closer: An Empirical Investigation Of The Proximity Of User To Their Smart Phones.* In Proceedings of the ACM UBICOMP.

who has a wearable?

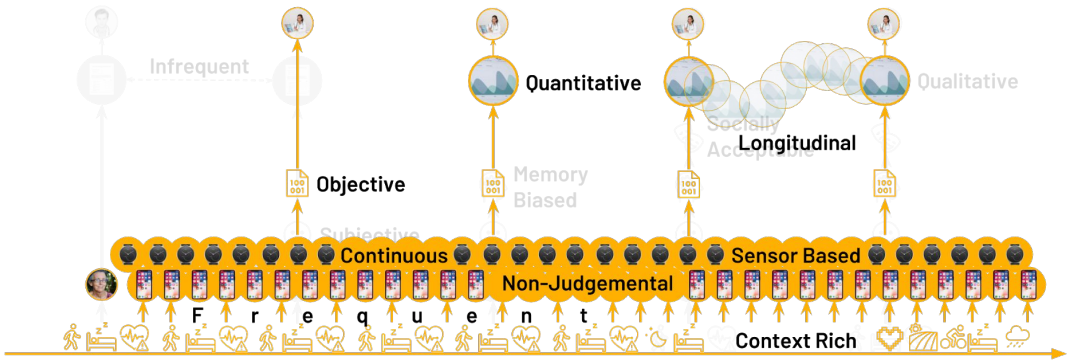
Smartphone & Wearables



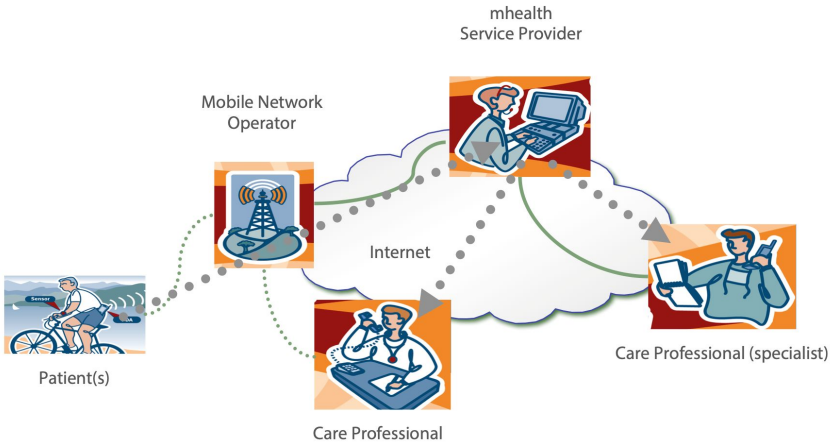
438 wearables (2018)

Wac, K. (2018). *From Quantified Self to Quality of Life*, Chapter in: Digital Health: Scaling Healthcare to the World, Series: Health Informatics, Springer Nature, Dordrecht, the Netherlands.
Annotated wearables dataset https://doi.org/10.6084/m9.figshare.9702122

TechRO-Reported Outcomes: A New Paradigm

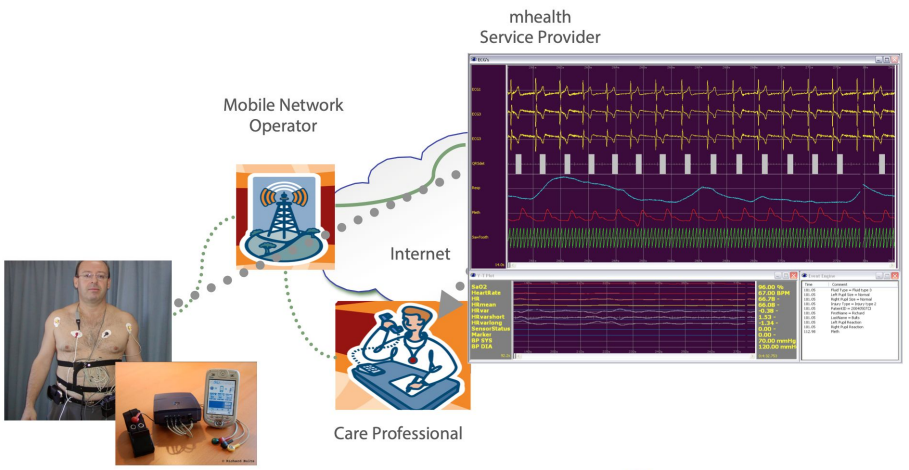


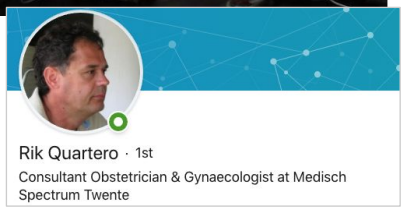
mhealth example (2003)



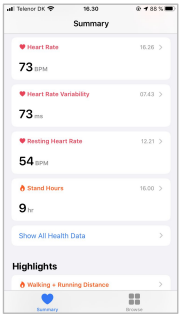
mhealth example (2003)

MobiHealth system
- HR, ECG
- Resp rate
- Sp02
- Activity
- GSR



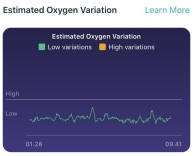


Apple Watch

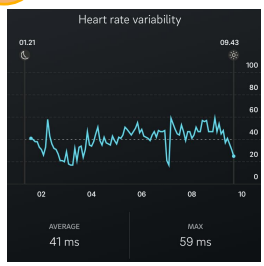


TODAY

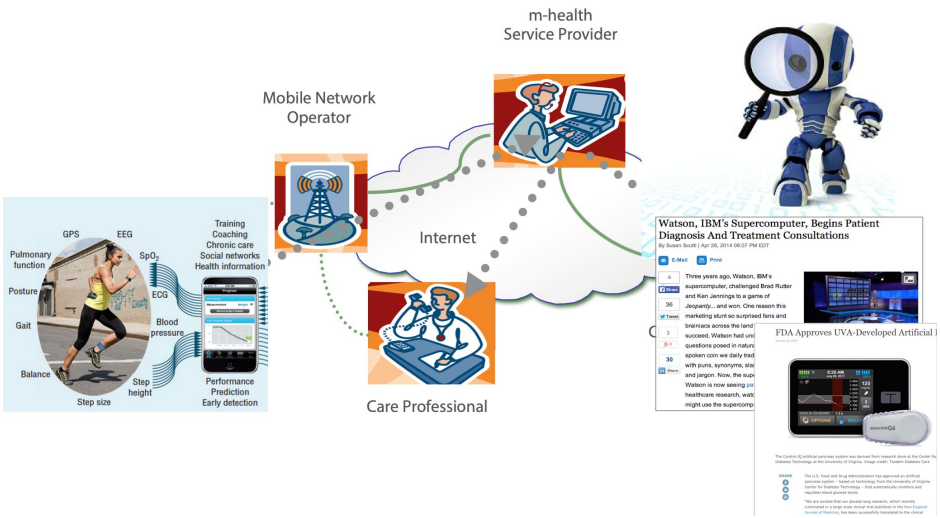
FitBit Charge 4



Oura Ring



mhealth example (2020)



At the Doctor's Office

Patient as the source

Other as the source

Patient-Reported Outcomes
(PRO)

Self-Reported Outcomes
(SRO)

PROs

Non-Patient-Reported Outcomes
(Non-PRO)

Observer-Reported Outcomes
(ObsRO)

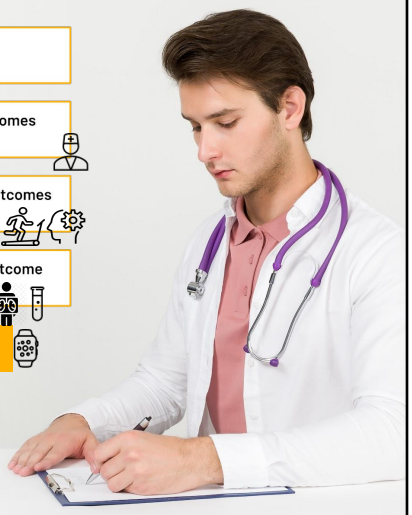
Proxy-Reported Outcomes
(ProxRO)

Clinician-Reported Outcomes
(ClinRO)

Performance-Reported Outcomes
(PerfRO)

Technology-Reported Outcome
(TechRO)

TechROs



JCE Mayo, N. E., Figueiredo, S., Ahmed, S., & Bartlett, S. J. (2017). *Montreal Accord on Patient-Reported Outcomes (PROs) use series–Paper 2: Terminology proposed to measure what matters in health.* Journal of clinical epidemiology, 89, 119-124.

How?

QoLife

Health

A state of <u>complete</u> physical, mental and social well-being and not merely the absence of disease or infirmity.

World Health Organization | www.who.int
Constitution of the World Health Organization, 22 July 1946
Callahan, D. (1973). The World Health Organization definition of 'health'. Hastings Center Studies, 77-87.

QoLife

Redefining Health

The ability to <u>adapt and self manage</u> in the face of social, physical, and emotional challenges.

BMJ

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., ... & Schnabel, P. (2011). How should we define health?. Bmj, 343, d4163.

QoLife

Quality of Life

QoL Domains	QoL Facets
Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory, and concentration
Social relationships	Personal relationships Social support Sexual activity
Environment	Financial resources Freedom, physical safety, and security Health and social care: accessibility, and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Individuals' <u>perception</u> of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.

World Health Organization | www.who.int
"The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties.," Soc. Sci. Med., vol. 46, no. 12, pp. 1569-85, Jun. 1998.

QoLife

www.qol.unige.ch

Bending the Curve

PROs

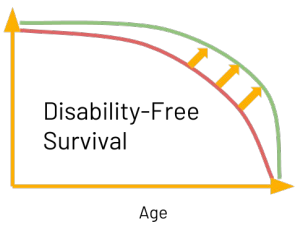
QoL Domains	QoL Facets (16*/24)
Physical health	**Activities of daily living** ✓ **Dependence on medicinal substances and medical aids** ✓ **Energy and fatigue** ✓ **Mobility** ✓ **Pain and discomfort** ✓ **Sleep and rest** ✓ Work capacity
Psychological	Bodily image and appearance **Negative feelings** ✓ **Positive feelings** ✓ Self-esteem Spirituality / Religion / Personal beliefs **Thinking, learning, memory, concentration** ✓
Social relationships	**Personal relationships** ✓ **Social support** ✓ **Sexual activity** ✓ CAS Sexologie clinique 2023
Environment	Financial resources **Freedom, physical safety, and security** ✓ **Health and social care: accessibility, and quality** ✓ **Home environment** ✓ Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities **Physical environment** (pollution / noise / traffic / climate) ✓ Transport

Self-management & Behaviour Change Facilitation

mQoL-Lab
Computational Modelling

Digital Measures / Biomarkers / Endpoints

TechROs



1000+ Participants
(mQoL Living Lab)
mqol.unige.ch

MobiSPC

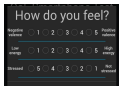
Fries, J. F. (2002). *Aging, natural death, and the compression of morbidity*. Bulletin of the World Health Organization, 80, 245-250.
Berrocal, A., Manea, V., De Masi, A., Wac, K. mQoL-Lab: Step-by-Step Creation of a Flexible Platform to Conduct Studies Using Interactive, Mobile, Wearable and Ubiquitous Devices, MobiSPC 2020

World Health Organization | www.who.int
"The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties.," Soc. Sci. Med., vol. 46, no. 12, pp. 1569-85, Jun. 1998.

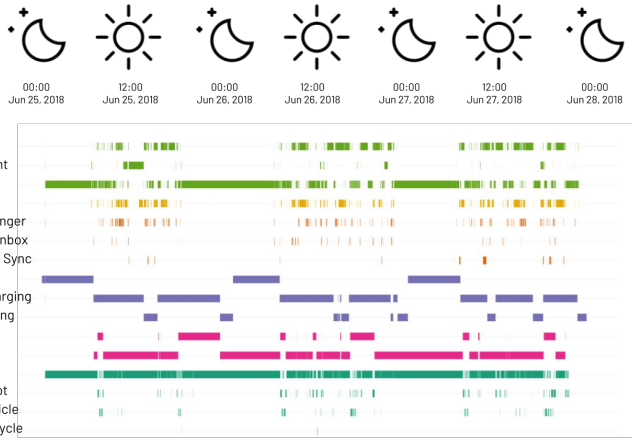
*✓In green: QoL facets actively researched in the lab; the rest: facets to be researched

QoLife

Context-based EMA/ESM



mQoL Log



6.6+ billion data points

MobiSPC

De Masi, A., & Wac, K. (2018). You're Using This App for What?: A mQoL Living Lab Study. Mobile Human Contributions: Workshop in conjunction with ACM UBICOMP, Singapore, October 2018.
Berrocal, A., Manea, V., De Masi, A., Wac, K. mQoL-Lab: Step-by-Step Creation of a Flexible Platform to Conduct Studies Using Interactive, Mobile, Wearable and Ubiquitous Devices, MobiSPC 2020.

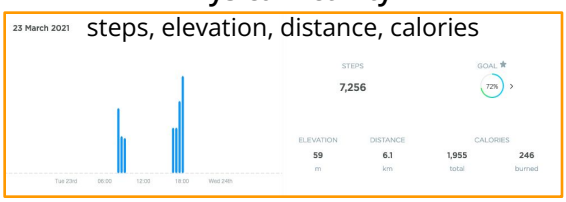
(since 2023)

carp

Time Series: Example Behaviour Data

Physical Activity

steps, elevation, distance, calories



Heart Rate

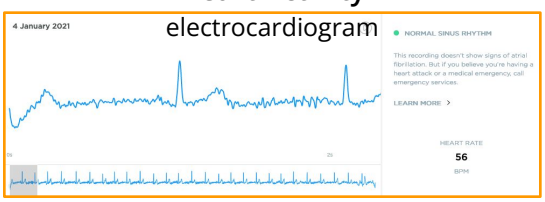
normal, moderate, fast, too fast

Sleep

total, in bed, score, interruptions, heart rate

Heart Activity

electrocardiogram

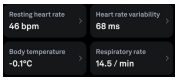


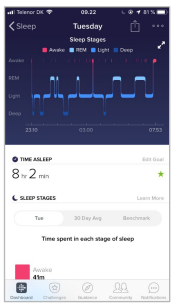
The same night of sleep

Fitbit Charge 2

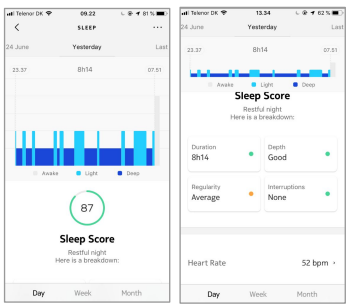
Withings Steel HR

Oura Ring

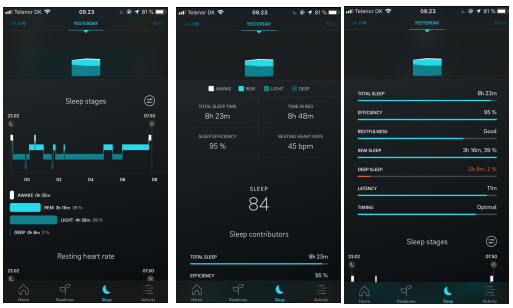




8h 2m



8h 14m



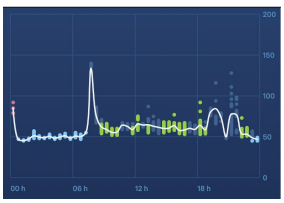
8h 23m

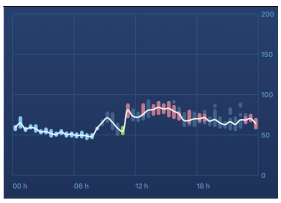
...a day in a life...

good day

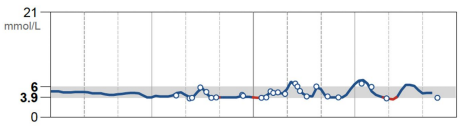
stressful day

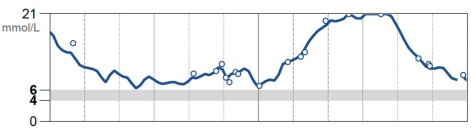
HRV
[ms]





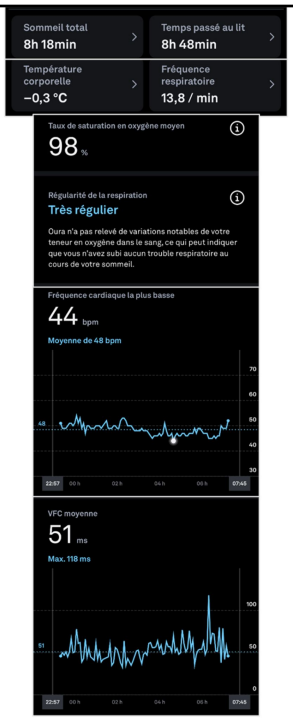
BG
[mmol/L]





...a night in a life...

good night

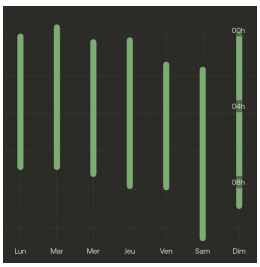


stressful night

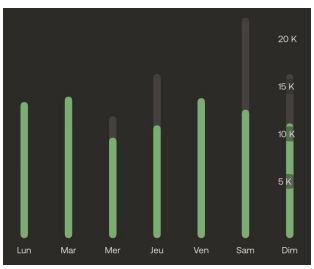
...a week in a life...

good week

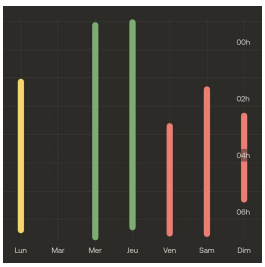
sleep duration/ placement [hrs]

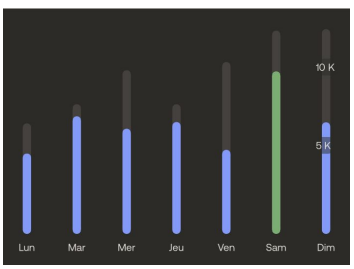


physical activity [steps]

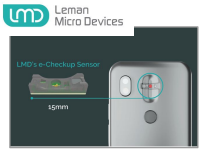


stressful week

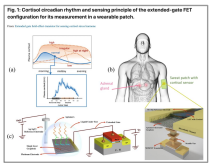




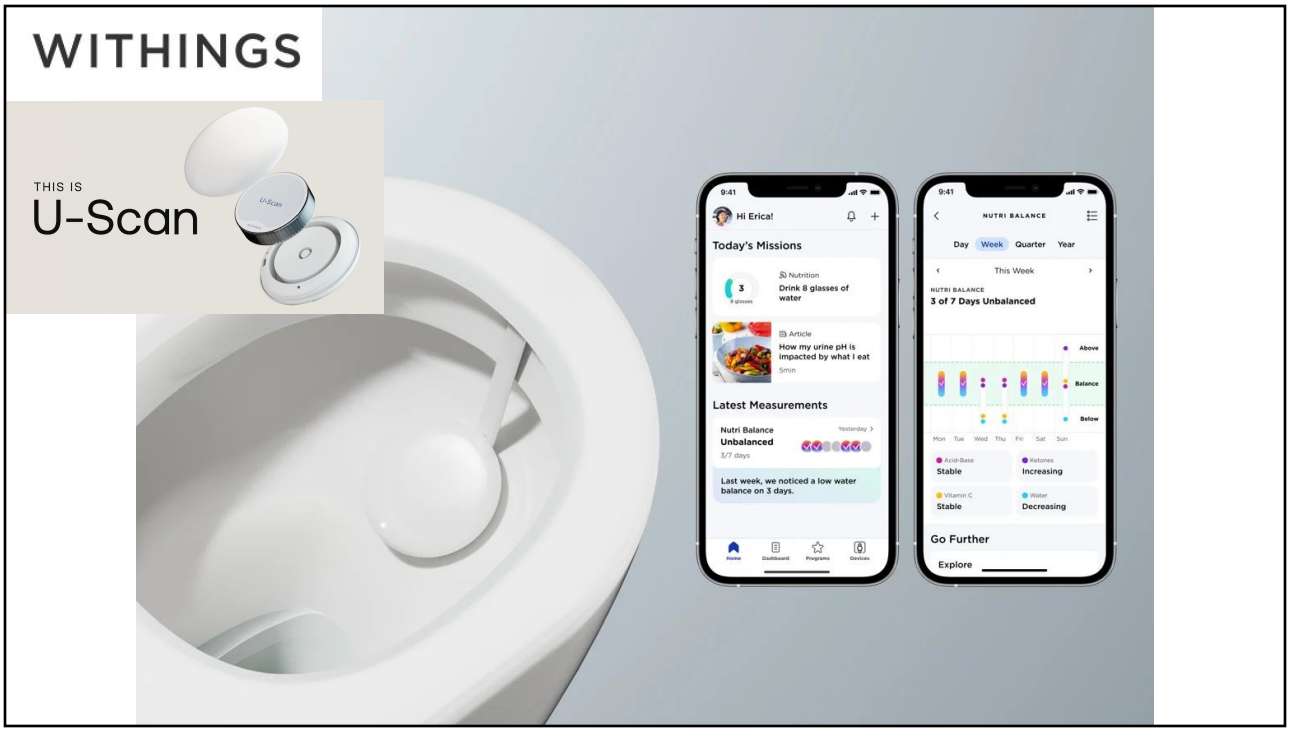
Add-ON examples of wearables & Apps



Ear (CellScope)
Eye (PEEK, eyeNetra)
Oral Health (OScan)



OMRON



QoL challenges and potential solutions...

QoL Domain	Facets incorporated within QoL domains
Physical Health 	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
Psychological 	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality/religion/personal beliefs Thinking, learning, memory and concentration
Social relationships 	Personal relationships Social support Sexual activity
Environment 	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure act. Physical environment (pollution / noise / traffic / climate) Transport

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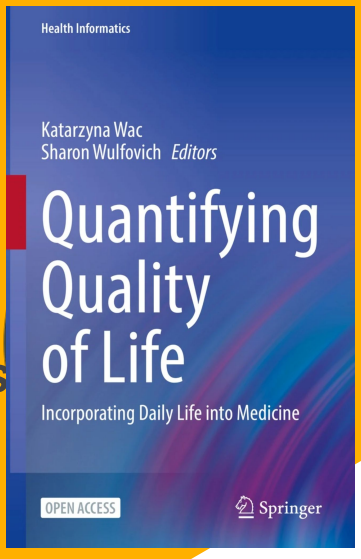
The Bigger Picture

qualitative summary
TechRO data-driven validations
research studies



Human Factors:

What about the Individual?

Human Factors

Q: Do you use technologies (smartphone/wearable) for your own health/care?

I don't!

I don't mix my smartphone with my health [visibly angry]
It's all in here [indicating own head]
I do not want a phone reminds me about my disease
I have got a [fitbit as a] gift and I dropped it

I would...

Privacy is an issue
It's complicated, I don't know how to use it, I am not a techie
It's inaccurate: I have compared [fitbit] to my husband's Garmin and I was disappointed" [and have dropped it]

I do...

Interface design
Too complex!
Passwords
Notifications

Performance
Slow!
No sync
Malfunctioning
Internet is touchy

Battery
Too short
Carry 2 batteries
Walked for free!

Social Sharing
I have enough people judging me offline
Doctor won't trust it

Accuracy
Not a medical accuracy
Accurate enough to recognize my efforts

Emotions
Keeps me entertained
I hate it when gained weight
I get addicted

Cost
Smartphone is a basis
Wearables: Too Costly!

Self-Efficacy
I like to see my progress
I try harder
I can always walk tomorrow

Routines
For me when I need it
Non-routine events most critical

Study details
N = 200 participants (US)
Affinity clustering of significant factors

Wac, K., Rivas, H., & Fiordelli, M. (2016). *Use and misuse of mobile health information technologies for health self-management*. Annals of Behavioral Medicine, 50 (Supplement 1).
Wac, K. et al., (2019). *"I Try Harder": The Design Implications for Mobile Apps and Wearables Contributing to Self-Efficacy of Patients with Chronic Conditions*, Frontiers in Psychology, SI: Improving Wellbeing in Patients with Chronic Conditions.

Current State of the Research

Can it Work?

Maybe, yes.