



What do patients expect from eHealth – let the patients tell us

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Outline of the workshop

- 0 - 5 min: Presentation of patients, organizers and aims of the workshop
- 6 -15 min Ole Stangegaard: What do patients expect.
Ilkka Kunnamo: EQuIP Policy Paper on eHealth and survey of patient's expectations
- 15 - 30 min Two more patients tell about their own experiences and expectations
- 30 - 40 min Clearing questions
- 40 - 45 min Introduction to group work
- 45 - 65 min Group discussion
- 65 - 75 min Summing up

Presentation by Ole Stangegaard: What do patients expect from eHealth

<https://dl.dropboxusercontent.com/u/14785933/Presentations%20in%20English/WONCA%20Europe%202016%20workshop.%20OS%20presentation.%20v.1.1%20.pdf>

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WONCA Policy Statement on eHealth 2016



1. The primary aims of Health Information Systems (HIS) should be to empower patients and health professionals by
 - **supporting patients' self-management, shared decision-making, easy communication with the primary care provider, and data entry into personal health records which patients can share with their care providers;**
 - supporting professionals in delivering care that has high quality and is safe.Health Information Systems should also **provide patients with reliable information on health, disease and relevant care.**
2. Each patient should have one record containing essential coded data including, as a minimum: problems, medication list, test and examination results, procedures and management plans; across all levels of health care and social care when needed, in order to promote continuity, patient-centeredness, team work, integrated care, and care coordination by the family doctor. **Patients should have access to their records and control over who can access their data.**
3. Family doctors and **patients should have the right to use information technology tools that are tailored to their needs.** This can be accomplished by making the data interoperable and shareable by different tools, including **mobile applications.**
4. Health Information Systems should enable and facilitate the coding of high-quality data in a standardized manner so as to allow processing by computer, clinical decision support, personalised medicine, automation of tasks, and patient-oriented service provision.
5. Health Information Systems should enable the family doctor to analyse the health data of the whole population for which he or she is responsible, in order **to identify care gaps in people who would benefit** from health care interventions, and to **serve the people with the greatest health care needs.**

6. Health Information Systems developers should engage family doctors and patients in the development of tools that support the care of people with multiple morbidities and polypharmacy; facilitate **care coordination** and promote evidence-based practice, while preventing fragmentation of care, overdiagnosis, overtreatment and medicalization.
7. Health Information Systems should help primary care providers to learn from every patient, every intervention and its outcome. Health Information Systems should enable the **capture of coded data from electronic health records and personal health records** in a standardised manner, and the deposit of such coded data into repositories controlled by the primary care unit that has generated the data, for use at the unit, and for **sharing standardised data reports for quality improvement and benchmarking**.
8. Health Information Systems should enable the **sharing of anonymised or encrypted data through safely maintained and publicly controlled repositories for the generation of new knowledge via research and big data analysis**. The primary care units should **make their participation in data sharing known to patients, and patients should be granted the choice to opt out from sharing their data** or to pose restrictions on the ways in which their shared data can be used.
9. Governments, in close collaboration with health care professionals, should endorse and implement eHealth strategies and infrastructures that include standardisation and interoperability, and develop their regulations to facilitate the use of data for research, development and innovation in a secure and safe manner, so as to guarantee the rights of the individual.
10. Governments should ensure access for professionals and **patients to the best available health information systems and continuously updated clinical knowledge** in primary care, education and training in health literacy and in the use of IT tools. Governments should also ensure the availability of aggregated data for decision making and management.

WONCA Working Party on eHealth April 2016

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Table 6 Electronic services needed by respondents

The most important electronic functionalities in future	Important (Grades 4+5)	Not important (Grades 1+2)	Mean	No response
Access to laboratory and imaging results	70%	15%	3.92	4%
Access to own EPR (electronic patient record)	67%	16%	3.86	5%
Access to view and renew prescriptions	67%	16%	3.82	4%
SMS-reminder of an appointment	66%	16%	3.81	4%
Electronic booking of health care services	65%	17%	3.79	4%
Reliable information on health, illnesses and self-care	61%	18%	3.67	4%
Service directory	59%	19%	3.59	5%
Possibility to apply for services via internet	57%	23%	3.55	5%
Giving consent/refusal to use own EPR-data	52%	22%	3.53	5%
Possibility to make and store a living will	52%	20%	3.52	5%
Possibility to mediate own measurement data and get care instructions online	52%	23%	3.45	5%

Hannele Hyppönen, Päivi Hämäläinen, Jarmo Reponen (eds.) E-health and ewelfare of Finland. Checkpoint 2015. National Institute for Health and Welfare (THL). Report 18/2015, 155 pages. Helsinki, Finland 2015

Secure communication with professionals	50%	24%	3.36	5%
Personal health record to store own measurement and life style data	50%	24%	3.36	5%
Electronic feedback on services	50%	23%	3.39	5%
Monitoring own measurements (e.g. RR)	47%	26%	3.29	4%
Reporting patient safety incidents	45%	24%	3.3	5%
Access to own social care data	43%	34%	3.1	5%
Monitoring own life style (e.g. food and exercise)	38%	33%	3.02	4%
Electronic booking to social care	37%	39%	2.89	5%
Filling in client satisfaction and impact-surveys	35%	31%	3.02	5%
Making risk tests to assess need of care and to get self-care instructions	29%	36%	2.82	5%
Participation in making a care plan	27%	39%	2.75	5%
Electronic voucher for e-health and e-welfare services	23%	39%	2.66	6%

Wearables



Sleeping

On average, how many hours do you sleep per night?

hours

Stress

Have you felt yourself tense, stressed or under a lot of pressure during the last month?

- not at all
- yes, to some degree but not more than most people
- yes, considerably more than most people
- yes, my life situation is almost intolerable

Satisfaction

How satisfied are you with what you have achieved in your life?

- very satisfied
- satisfied
- somewhat satisfied
- unsatisfied or very unsatisfied

Do you agree with the following statement?

During the last month I have felt sad.

- agree
- somewhat agree
- somewhat disagree
- disagree

Do you agree with the following statement?

During the last month I have felt that all the joy in my life is gone.

- agree
- somewhat agree
- somewhat disagree
- disagree

Strain related to work and studies

How often do you feel annoyed for having to push yourself to the limit in order to cope with your present job or workload?

- I do not work or study
- rarely or never
- sometimes
- fairly often
- most of the time

Patients performing their own health checks

- somewhat disagree
- totally disagree

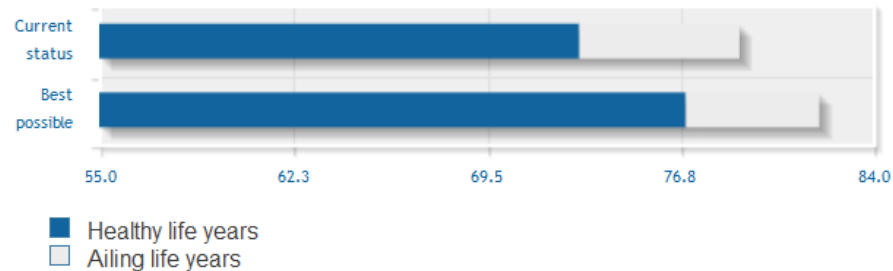
VIRTUAL HEALTH CHECK - REPORT



Your lifestyle and living conditions influence your life expectancy. According to estimates, men in your age group with similar lifestyles achieve on the average about the age of 79.

The chart below shows estimated life expectancy and also the average remaining healthy life years and ailing years.

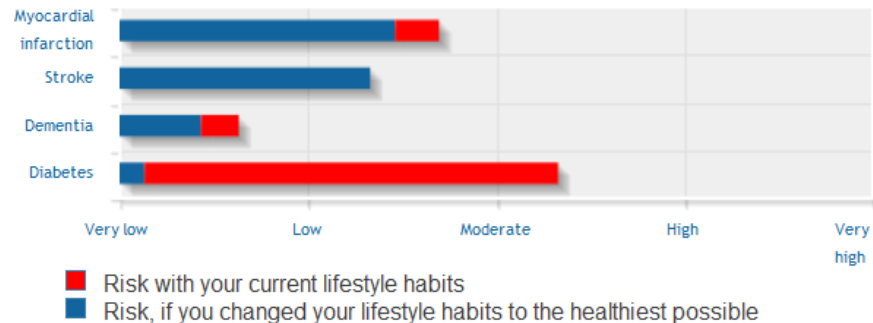
Life expectancy



If you were to change your lifestyle to most favorable, you might increase your healthy life years by **4**.

Ailing years are characterised with sicknesses, the likelihood of which can also be estimated from your health habits. The chart shows the risk during your lifetime of suffering a heart attack, stroke, dementia or diabetes. At the same time the chart shows your disease risk, if your lifestyle were as healthy as possible.

Disease risk





Alcohol

Alcohol

Reducing your alcohol consumption will reduce the risk of several cardiovascular, liver, and neurological diseases and cancers. Moderate alcohol consumption is 7-14 standard bar measures per week. For women, the limit is closer to seven, for men, fourteen.

Read more

- ▶ [Alcohol dependence](#)
- ▶ [Alkoholiriippuvuustesti in Finnish only](#)
- ▶ [Päihteet ja riippuvuus in Finnish only](#)



Smoking

Smoking

Healthwise, that you do not smoke is splendid.



Sleep

Sleep

Sleep requirements are individualistic, but your entered amount of daily sleep doesn't feel sufficient, especially if waking up in the mornings is difficult or you experience feelings of tiredness during the day. Continuous lack of sleep can predispose arterial disease, increase harmful stress, weaken the immune system, predispose accidents and lead to over eating, weight gain and also related difficulties. Sleep problems can stem from, among other things, being significantly overweight, excessive amounts of stress, little exercise or excessive alcohol consumption.

Read more

- ▶ [Insomnia](#)

... and getting individualized advice



Stress

A reasonable amount of stress is part of life, but continuous stress lowers quality of life and increases the risk of developing cardiovascular disease. Excessive stress connected to daily life can be reduced by relaxing exercise, healthy diet and many other actions. If you want to develop your stress tolerance you can choose a training program for that.

Automatic reminder to patient

According to your health records you have recently got a prescription (enalapril, [trade name X]) for high blood pressure, and you are regularly using diclofenac [trade name Y] for pain. Painkillers like diclofenac may contribute to high blood pressure. Consider if you could use another type of painkiller ([paracetamol](#)) that does not increase blood pressure, or [treatments other than drugs](#). Contact your GP if necessary.

Symptom checkers

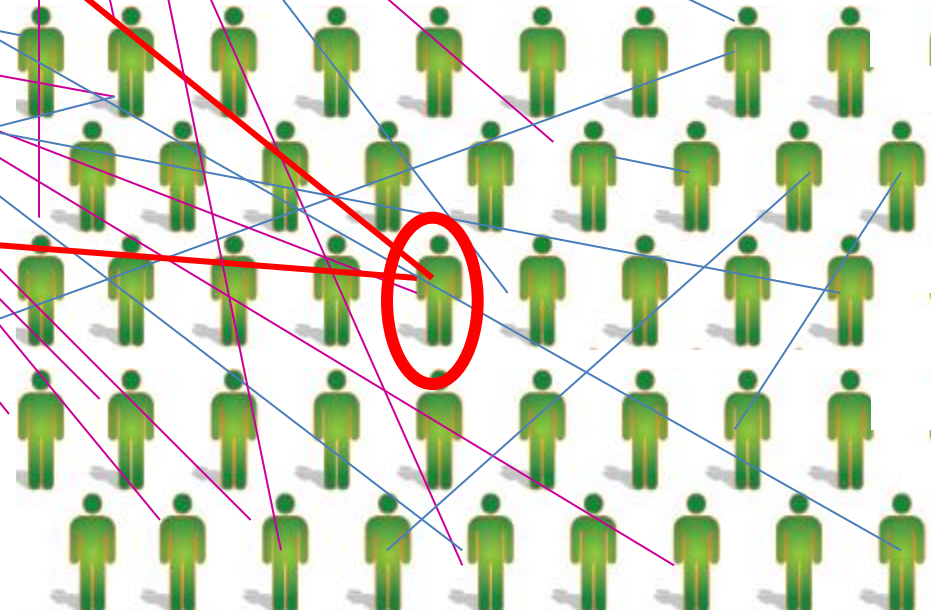
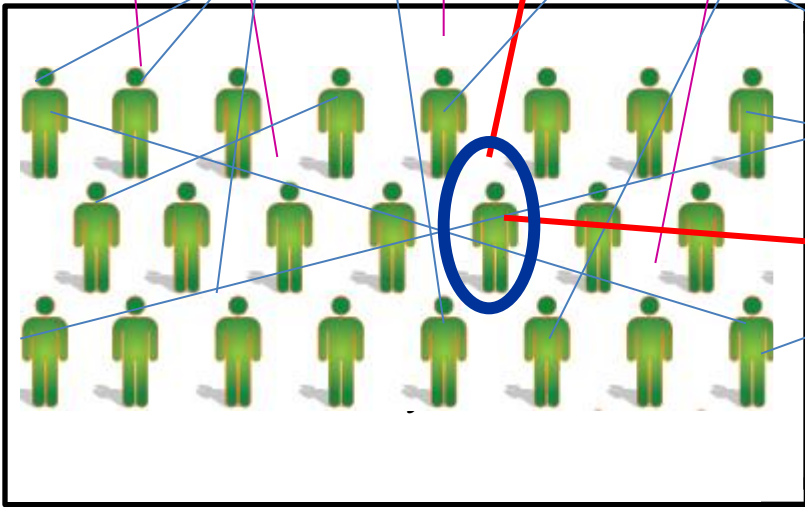
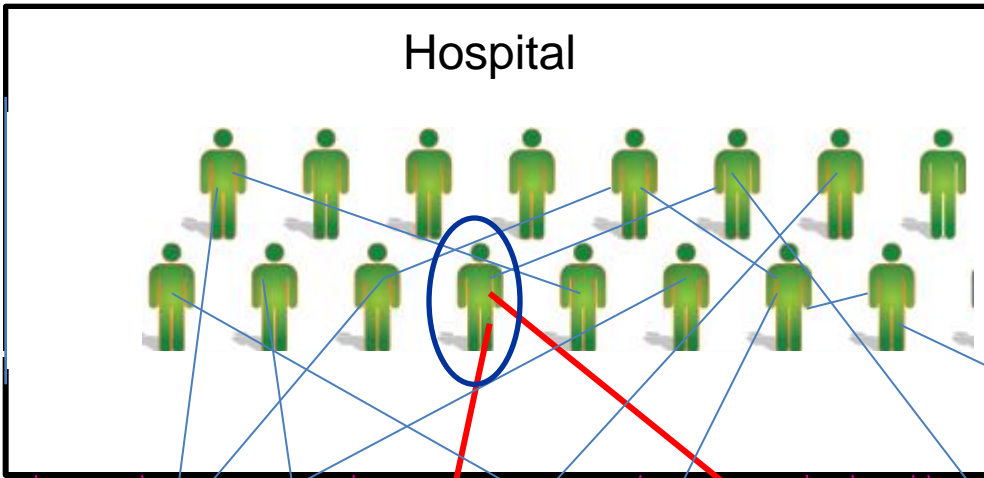
- Sore throat:

<http://www.surveygizmo.com/collab/2838100/Sore-throat-and-pharyngeal-symptoms-DEMO>

- Symptoms of urinary tract infection:

<https://www.surveygizmo.com/collab/2824045/UTI>

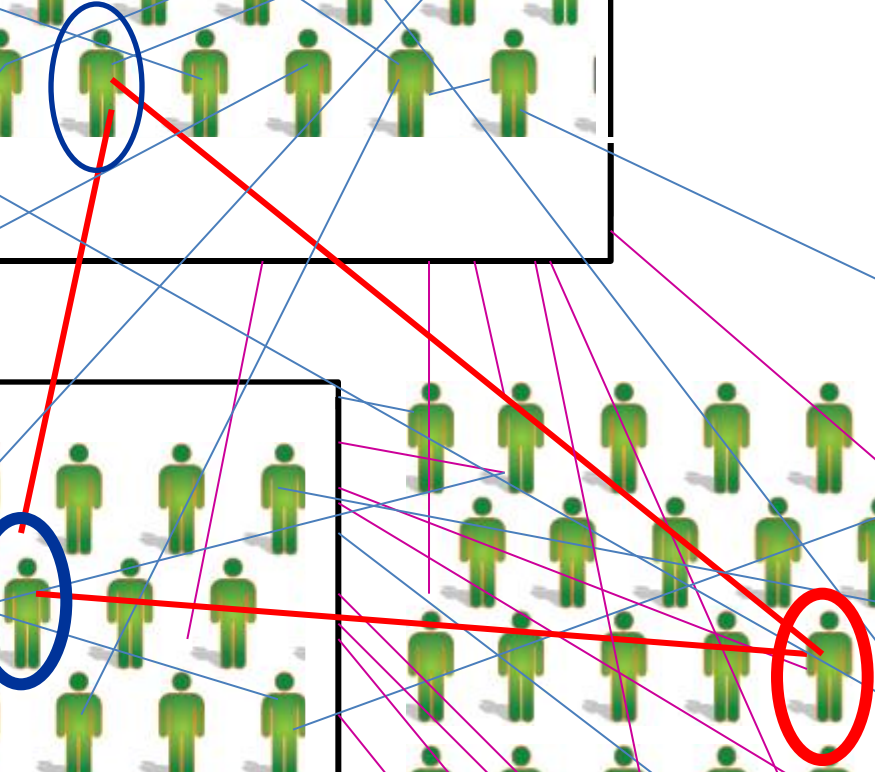
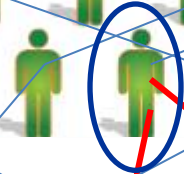
Health network of the future



Primary health care

Home

Hospital



Small group discussion topics

1. **What (information) do I miss in the current system and would sharing full health records with patients help**
2. **Getting direct advice from the computer**, replacing some face-to-face or telephone encounters, and managing booking of appointments with the computer etc
3. **Using** (some new type of?) **social media** for communicating with professionals and other patients

Thank you!

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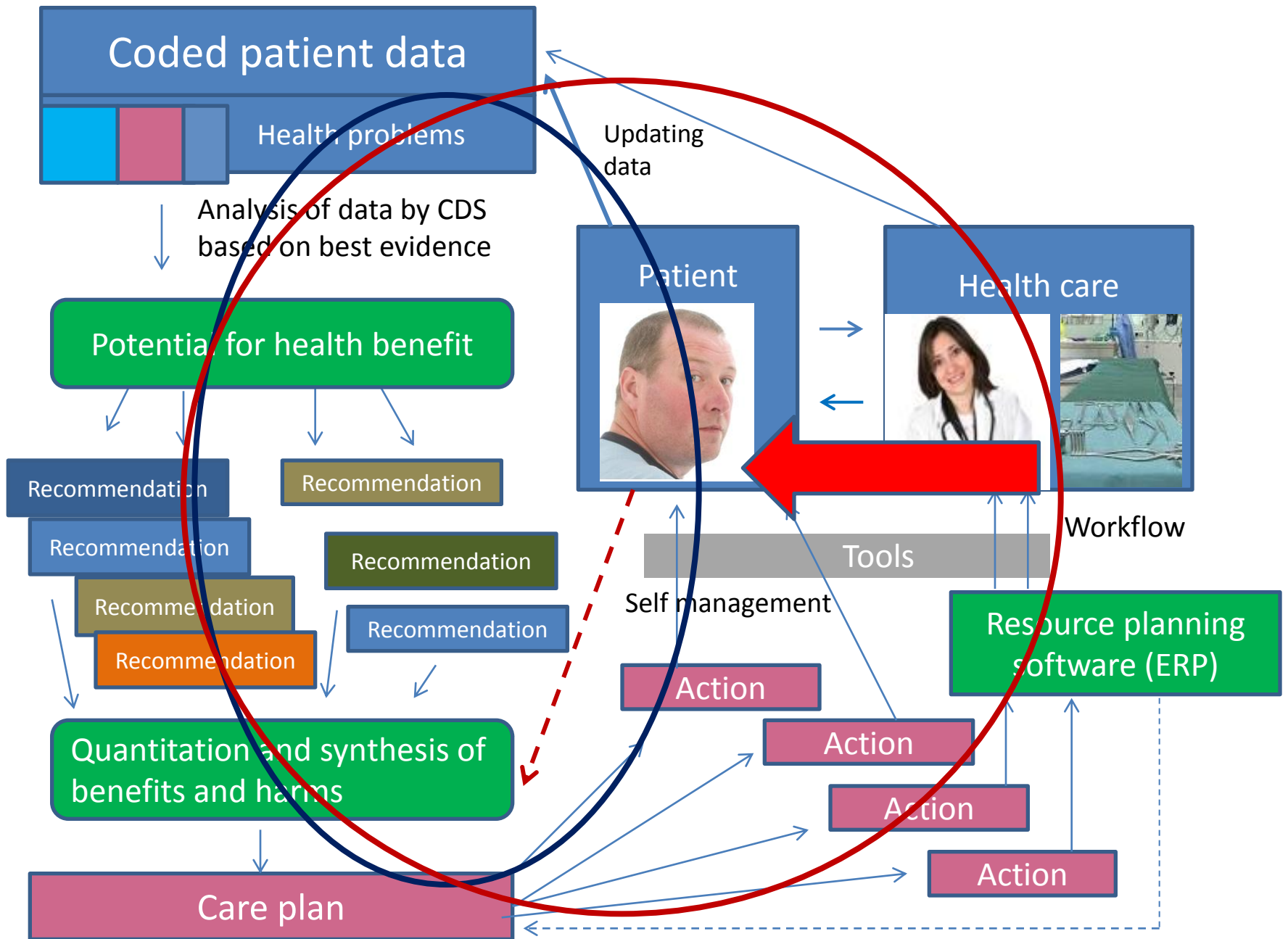
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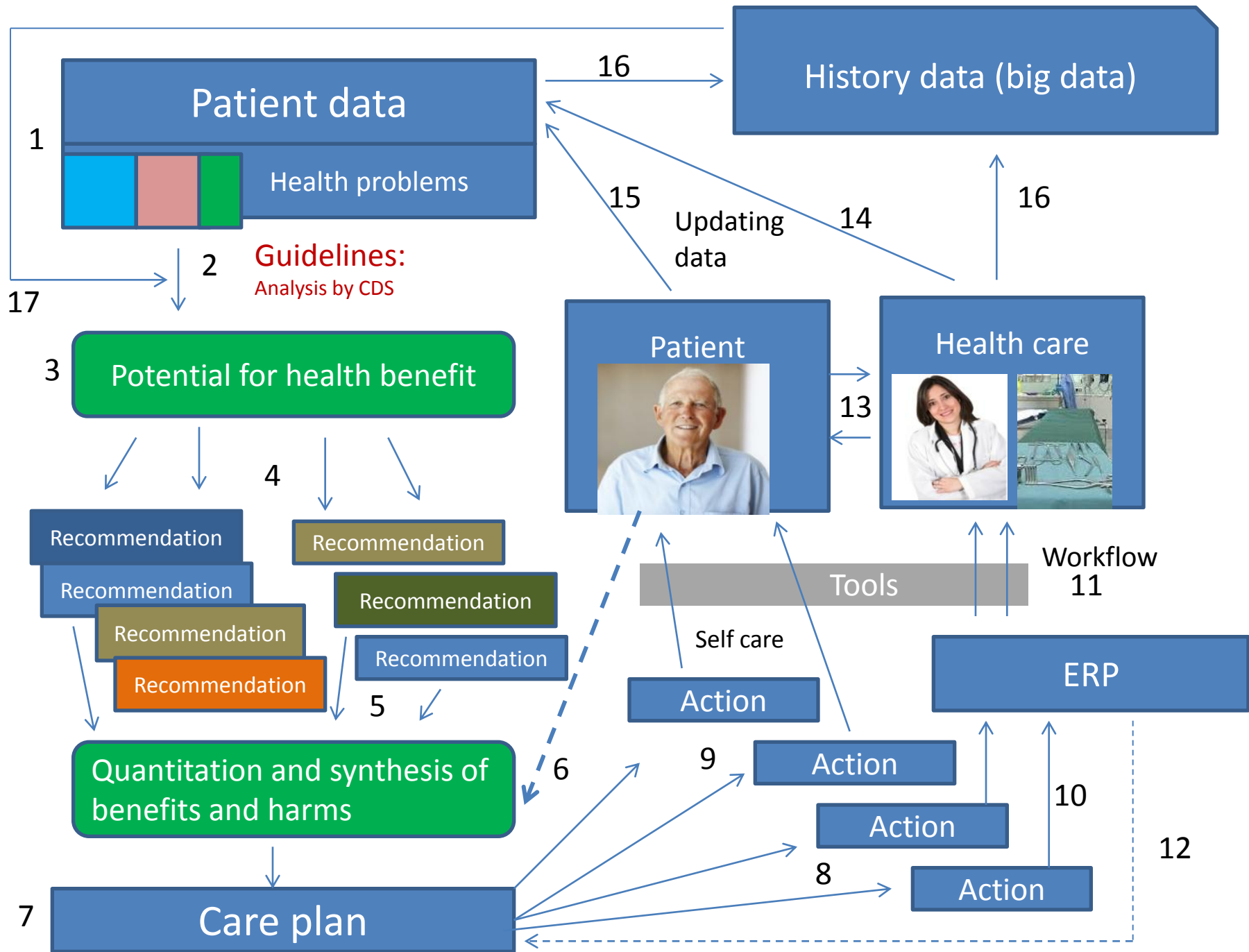
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The Vasco da Gama Movement Compass: Navigating the Sea of Soci@l Media



bit.ly/1OLEjPD





1. All data about the patient (from the EHR, PHR, wearable devices, national eHealth Archive, biobanks) is the starting point in making a care plan.
2. Clinical decision support based on trustworthy guidelines analyzes the data by using evidence-based rules, risk calculators and databases (including big data and genomic databases). A PICO ontology links evidence to the health problems and characteristics of the individual patient.
3. Clinical decision support identifies care gaps and interventions that could improve health outcomes of the patient.
4. Recommendations are constructed to fill the care gap. If the patient has many health problems, individual recommendations from many clinical practice guidelines and care pathways will be listed.
5. Clinical decision support tools that utilize risk calculators, prognostic models and interactive summary of findings tables of research evidence are used to quantify benefits and harms individually for the patient, so that the interventions that would benefit the patient most are on top. Interactions of interventions (such as drug-drug interactions), and concordant and discordant recommendations are taken into account at this stage.
6. The recommendations are shown to the patient, using decision aids that make the benefits, harms and burdens of interventions easier to understand. The patient chooses which interventions he or she is willing to use. The patient defines his or her individual targets (together with the professional) according to the principles of the chronic care model.
7. The interventions that have been chosen to be performed are recorded in the structured care plan. Care protocol templates can be used for recording bundles of interventions.
8. The actions recorded in the care plan have codes that can be analyzed to guide the process of care and the provision of care for the whole population.
9. The patients are offered self-care interventions and tools and on-line health coaching.
10. Actions needed from health care professionals serve as input to resource planning tools that link the actions with the competencies, equipment, rooms, and other resources needed for their completion. Bookings can be automated and can also be made by the patient.

11. The resource planning tools place the actions on the task list and schedule of professionals. Tools are provided that make the work easier and faster. The right thing is made the easy thing to do.
12. The resource planning tools have access to all care plans of all people in the population. In this way the volume of care needed, and the availability of resources is known when the care plans are made for individual patients. If overuse of resources threatens, the care plan can be modified. When prioritizing actions for individual patients in the population, the conclusions from steps 5 and 6 are used as guidance.
13. The patient and the professional meet face-to-face or virtually.
14. The professionals record observations and interventions in the structured EHR from where they are forwarded to the national eArchive and big data repository.
15. The patient records his or her health data, symptoms, and functional ability, as well as measurements from home monitoring into the PHR from where they are available for analysis by CDS.
16. The data recorded by the professionals, patients, and devices are anonymized and stored in a big data repository where they are used for the creation of new knowledge and for developing prediction models. The big data repository can also receive data from the patient's environment, and position data can be linked with patients.
17. CDS uses both individual patient data and big data for determining the patient's baseline risk for events, and making recommendations ("search from history earlier patients that are similar to the index patient and see what happened to them"). In a learning health care system every single data item (such as a single blood pressure measurement) contributes to knowledge. Similarly, every path of the patient can be analyzed for finding shortcuts in the care of future patients.

Future: a learning health care system

- Every data item in the electronic health record and personal health record contributes to the body of medical knowledge and becomes a part of a prediction tool.
- Every series of actions of the EHR user and every path of the patient in the IT system helps to understand workflows and find shortcuts.