Making Environments Work for People

A Novel Approach towards Personal Lifestyle Management Informatics

Position Paper #92

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change of paradigm

from reactive
to preventive

from treating at the hospital
to home care and self-management

from one solution fits all
to personalized medicine
lifestyle related diseases

non-communicable diseases
caused by non-physiological lifestyle factors such as unhealthy diet, physical inactivity, tobacco use, excessive use of alcohol, psychosocial factors, e.g. chronic stress and depression

diabetes  WHO estimates 366 million diabetes patients in 2030 – global epidemic

cardiovascular disease causes 30% of global deaths per year

cancer  40% of deaths due to cancer could be prevented by lifestyle modification

chronic kidney disease end stage renal disease > 2% of total healthcare costs

patient empowerment

a process where

patients are encouraged to think critically and act autonomously

promotes self-regulation, self-management and self-efficacy
in order to achieve maximum health and wellness

(virtual) coaching

a process that aims to

improve performance and focuses on the 'here and now'
“why”

- **sustain** good health and **prevent** health deterioration
  - lifestyle related disease, e.g. cancer, cardiovascular and respiratory chronic disease

- **recognize** early signs of disease
  - new disease or disease progression or transition to comorbid situation

- **manage** every day practical issues
  - manage a common, chronic, progressive, costly, health burden at home

- **gain** control and **co-decide** on treatment and disease management options

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*E. Kaldoudi, HealthInf 2017, slide #5*
“who”

- **healthy citizens**
  - to adopt and sustain a healthy lifestyle and detect disease early

- **chronic patients**
  - autonomously manage everyday practical issues
  - adhere to therapy and monitoring
  - detect disease progression and transition to comorbidities

- **all patients**
  - cope with disease
  - co-decide on treatment and disease management

also involved

- **family** and social environment: to cope and to be able to care
- healthcare providers: to be aware and support when needed
“how”

input data ➔ processing ➔ delivery
“how”

input data ➔ processing ➔ delivery

- Educational resources for patients
- Medical evidence

knowledge

quantified self

personal sensors
personal health records

- Data integration
- Analytics
- Semantics
- Predictive systems
- Decision support systems

intentions, plans, beliefs, etc.

- Web pages
- Social media
- Personal health applications
- …
so, we have a good grasp of...

the context

❖ who: healthy citizen, chronic patients, all patients, family, healthcare providers
❖ why: prevent, detect, manage, decide

the process:

❖ how: educational content, medical evidence, sensors, personal health and other systems, data integration, semantics analytics, predictive systems, decision support systems, web technologies, mobile devices, smart phones, ...

but, it is still unclear...

the content:

❖ what is to be designed and evaluated
  in a lifestyle management intervention

Symons’ evaluation onion, Context-Process-Content (Symon 1991 & Pettigrew 1985)
R. Bengoa, Regional Minister for Health and Consumer Affairs for the Basque Country of Spain (2012):

“Suppose I am a patient:

I have 12,000 apps about chronic disease, access to my records and a battery of gadgets for home support.

Am I more empowered?”

The WHO, Empowering Patients, 17-4-2012
attempts so far ...

1. Health education for the public

2. Customization for relevant and meaningful health information

3. Medical evidence

- Self awareness for engagement & control in health and disease prevention & management

quantified self

personal decision support system

E. Kaldoudi, HealthInf 2017, slide #11
CARRE
Cardiorenal comorbidity management via empowerment and shared informed decision

FP7-ICT-2013-611140
consortium: 6 partners from 4 EU countries
coordinator: Eleni Kaldoudi (DUTH)
budget: 3,210,470€

http://carre-project.eu/
CARRE approach

- quantified self
- medical evidence aggregation
- personal health information
- social media
- evidence based medical literature
- healthInf
- private
- public
- data harvesting & interlinking
- LOD
- comorbidity model visualization (generic and personalized)
- patient empowerment & decision support services
- weight
- physical activity
- blood pressure
- glucose
- evidence based
- medical literature
- PubMed
- MedlinePlus
- Educational resources

Intention extraction: G. Drosatos, A. Arampatzis, E. Kaldoudi, IUPESM WC2015

E. Kaldoudi, HealthInf 2017, slide #13
interactive risk prediction and planning

- patient’s personal data
- healthlines
- personal risk graph
- interactive planning
- personalized alerts

decision support

services for the patient

- establish self-monitoring regime
- adhere to a self-monitoring regime
- inform on a potential health status change
- inform on a change in personal risk factors
- and guide educational material retrieval
deployment

patient application in 2 different pilot installations

- DUTH (Greece)
- VULSK (Lithuania)

risk factor repository & system

https://www.carre-project.eu/
evaluation

- 2-site randomized control trial (Greece & Lithuania)

- two different patient groups
  - metabolic syndrome
  - heart failure or chronic kidney disease

- assessment for impact
  - health literacy
  - empowerment
  - quality of life
  - user satisfaction

Demographics of pooled study population for both pilot sites.

<table>
<thead>
<tr>
<th>Total Population</th>
<th>Control</th>
<th>CARRE</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>43</td>
<td>55</td>
</tr>
<tr>
<td>Age (yrs)</td>
<td>52.5 ± 7.1</td>
<td>48.9 ± 10.6</td>
</tr>
<tr>
<td>Female</td>
<td>12 (28%)</td>
<td>21 (38%)</td>
</tr>
</tbody>
</table>

Educational level

<table>
<thead>
<tr>
<th></th>
<th>Control</th>
<th>CARRE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary education</td>
<td>27 (63%)</td>
<td>32 (58%)</td>
</tr>
<tr>
<td>Tertiary education</td>
<td>16 (37%)</td>
<td>23 (42%)</td>
</tr>
</tbody>
</table>

study duration

phase 1: ~6 weeks

phase 2: ~6 months
system usability

SUS mean score of 67.7/100.0 ± 12.8 → acceptable
## results from phase 1

Mean differences between the two visits, calculated as a percentage of the value at baseline.

<table>
<thead>
<tr>
<th>Visit 2 – Visit 1: E2 – E1*</th>
<th>QoL physical</th>
<th>QoL mental</th>
<th>health literacy</th>
<th>empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td>[(E2 - E1)/E1]*100%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pooled data from two sites:**

<table>
<thead>
<tr>
<th></th>
<th>QoL physical</th>
<th>QoL mental</th>
<th>health literacy</th>
<th>empowerment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population</td>
<td>1.7%</td>
<td>1.0%</td>
<td>9.8%</td>
<td>8.0% #</td>
</tr>
<tr>
<td>Metabolic Syndrome</td>
<td>-0.6%</td>
<td>0.4%</td>
<td>3.7%</td>
<td>12.4%</td>
</tr>
<tr>
<td>HF or CKD</td>
<td>5.7%</td>
<td>1.8%</td>
<td>21.3%</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

* E2 = CARRE arm after (visit 2), E1 = CARRE arm at baseline (visit 1)

# bold red lettering highlights significant differences (p<.05), p values obtained by comparing values within each arm using paired samples t-test
health status case report 1 – ID001

body weight reduced by 7 Kg
blood pressure stabilized
health status case report 2 – ID216

blood glucose reduced
blood pressure stabilized
still, people have difficulty sustaining a healthy lifestyle...

- health campaigns and restrictions during the last 2 decades
  - but, prevalence of lifestyle related diseases increases
- studies show that
  - health reminders help adopt and sustain a healthy lifestyle
  - environmental factors play a crucial role

so, recently proposals to

- use smart cities infrastructure to help people sustain healthy lifestyle
  (Solanas 2014)
- create a healthy environment (WHO, Pruss-Ustun, 2006)
change of paradigm: make environments work for people

medical evidence

quantified self

personal decision support system

health content of the environment

via life context descriptions & participatory sensing

E. Kaldoudi, HealthInf 2017, slide #24
lifestyle related environmental context

- food
  - ingredients, nutritional and calorific content, allergens, salt

- recreational activities
  - work load, difficulty, special requirements, indications and contra-indications for the healthy person at different ages and capacities and when suffering from different health conditions and disease

- ambient environment
  - temperature, meteorological conditions, noise level, air pollution, airborne allergens, meteorological conditions
integrated services to realize personalized healthy living spaces

**Virtual Coach**

- **Person**
  - Sensors
  - Social networks
  - Sensors data extraction
  - Data extraction
  - Profiling
  - Sentiment analysis

**Personal, Private Data**

- **Environment**
  - Data harvesting and enrichment
  - Harvesting
  - Information extraction

**Health Content of the Environment**

- **Decision Support**
  - Real behaviour tracking
  - Goal setting, action planning
  - Motivational sustained behaviour change

- **Personalized Behaviour & Behaviour Change Model**

**Medical Evidence**

www, LOD

E. Kaldoudi, HealthInf 2017, slide #26
medical evidence

- structured representation of textual medical evidence
- public medical evidence repositories, interlinked and semantically integrated
- data curation and preservation of timestamped data snapshots

ontologies to efficiently capture medical evidence policies and tools to ensure evidence data is provided in structured form medical evidence timestamped ledgers (blockchains?)
personal status & needs

- real time, continuous assessment, as a person is evolving and changing over time, and from one moment to the next
- meaningful integration from multiple and variable sensors and inputs, including social life, sentiment and cognitive function
- streaming data analytics to make sense of personal data

major issue:

preserve privacy

consider the “no aggregation” approach and take computation to the client

secure multi party computation techniques?
health potential of the environment

- analysis of opportunities and limitations for each environment (urban and natural) to promote healthy lifestyles

- tools to massively create critical mass of environmental health content descriptions

- different types of accessing health content descriptions:
  - via programming interfaces for seamless integration with decision support
  - intuitive novel presentation approaches (including augmenting reality) for the user

ontologies to efficiently capture health content of the environment

(privacy preserving) participatory sensing, crowd based approaches

novel visualization modes

E. Kaldoudi, HealthInf 2017, slide #29
virtual coaching

- analysis of **coaching** elements for mindchange
- research **specific** to age, gender, culture, societal context, personality type, emotional status, health condition
- **unobtrusive** delivery and support
ultimate goal

- help citizens manage actively health and eventually adopt and maintain a healthy behaviour

- make stakeholders in food, commerce, retail, leisure, workplace and community level aware of the healthy (or non-healthy) aspects of the environment they offer to the public and support them to promote what is healthier for each citizen
acknowledgment

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7th Framework Programme
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CARRE: Personalized patient empowerment
and shared decision support
for cardiorenal disease and comorbidities

http://www.carre-project.eu/
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