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# Prototyping a Personal Health Record taking *social* and *usability* perspectives into account

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# Background



The Autonomous  
Province of Trento



The Department  
of Health

The *Department of Health*  
and the *Department of Research and Innovation*  
of the *Autonomous Province of Trento* (NE Italy)  
sponsored a feasibility study of a  
**Personal Health Information Management (PHIM) System**  
for the citizens living in the Province.

# Talk's topic



An ideal PHIM system should support the individuals in their health-related activities through all their lives, adapting to their evolving needs.

## STATE OF THE ART:

At the present there is a growing production of different PHR prototypes.

To our knowledge, few of them have been designed after an analysis of what people actually do to manage their own health at home.

## OUR STARTING POINT:

**Like EMRs are designed having in mind the workflow and the needs of the medical personnel, PHRs need to take into account the multifarious ways and settings in which the individuals are more like to use them.**

At the same time, these systems need to be easily usable by anyone.

# The sociological study



GENERAL AIM | Eliciting the real activities carried out by people to take care of themselves and their perceived hierarchy of relevance.

PURPOSE | **To identify the strategies (if any) commonly adopted for health information (i.e. paper documents) management.**

METHODOLOGY | 30 families  
In-depth interviewing + ethnographic observations  
Interviews of 50-80 minutes were audio recorded and transcribed  
Grounded theory method were used to code transcripts  
Data were analyzed by using Atlas T.I 5.5 software

# Health information management in the household



\* 30 Families, in-depth interviews with ethnographic observation.

4 dimensions



(*)			
<b>Classification system</b>			
<b>Use of information</b>			
<b>Perceived importance</b>			
<b>Network of caregivers</b>			

Common elements people use to justify the ways they keep medical archives.

# Health information management in the household



\* 30 Families, in-depth interviews with ethnographic observation.



(*)	Zero-effort strategy		
Classification system	Random and long lasting		
Use of information	Rare/null		
Perceived importance	Low/null		
Network of caregivers	One doctor		

# Health information management in the household



\* 30 Families, in-depth interviews with ethnographic observation.



(*)	Zero-effort strategy	Erratic strategy	
<b>Classification system</b>	Random and long lasting	Analytical and mutable	
<b>Use of information</b>	Rare/null	Frequent	
<b>Perceived importance</b>	Low/null	High	
<b>Network of caregivers</b>	One doctor	More than one professional caregiver	

# Health information management in the household



\* 30 Families, in-depth interviews with ethnographic observation.



(*)	Zero-effort strategy	Erratic strategy	Networking strategy
<b>Classification system</b>	Random and long lasting	Analytical and mutable	Analytical and long lasting
<b>Use of information</b>	Rare/null	Frequent	Medium
<b>Perceived importance</b>	Low/null	High	High
<b>Network of caregivers</b>	One doctor	More than one professional caregiver	A network of informal caregivers

# Health information management in the household



\* 30 Families, in-depth interviews with ethnographic observation.

The strategies are not mutually exclusive.

**Many people adopt more than one at time for different records.**

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<b>Classification system</b>	Random and long lasting	Analytical and mutable	Analytical and long lasting
<b>Use of information</b>	Rare/null	Frequent	Medium
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# Implications for system design



- Flexibility

The users decide which information are relevant and how to create connections between documents.

- Customization

The users need to adapt the system to the need of the moment as they do with their paper records.

- Pervasivity

Information should be made available where it is needed and used.

# Architectural paradigm



Three levels of abstraction for information organization:

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## **CONTROL LEVEL.**

It defines the rules a configuration must satisfy and describes how evolution from a configuration to the next one is carried on.

**Example:** people privacy is a priority; customizability.

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## **CONFIGURATION LEVEL.**

A configuration is a collection of functionalities which act together in order to realize a use case and respond to specific health needs.

**Example:** the set of services for the management of a chronic disease.

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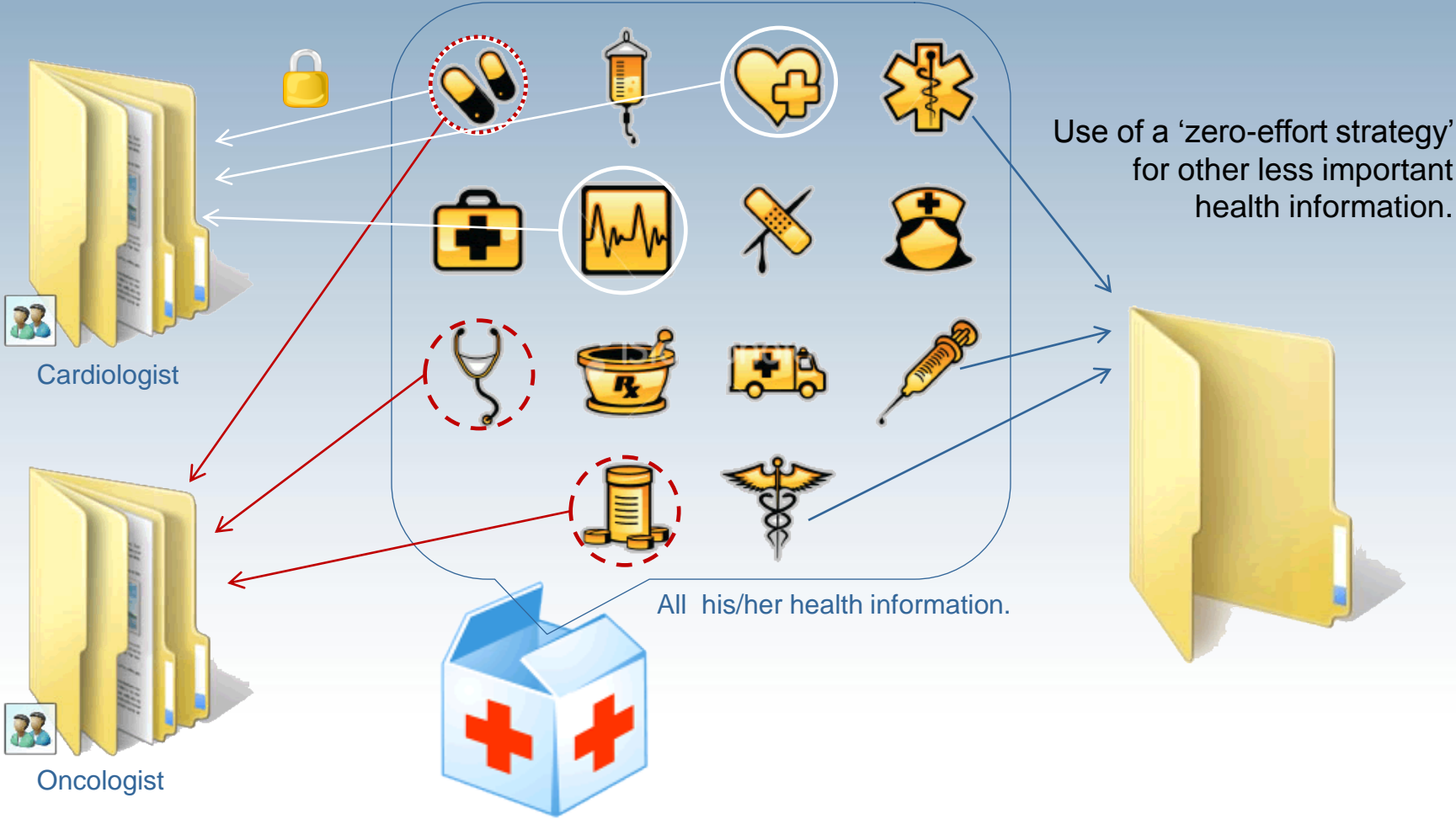
**BASE LEVEL.** Basic “agnostic” “brick” functionalities which can be assembled to build more complex functionalities.

**Example:** a web service with a Create-Read-Update-Delete (CRUD) interface  
Managing the list of currently taken drugs.

# Architectural components



An example of using an 'erratic strategy' for a person suffering from cancer.





# Future work



**To design the user interface so that not to compromise the user's acceptability, strongly influencing the use of the system.**

A system's usability evaluation:

*How well does the system communicate with and support the functional needs of the users?*

The target users: older and disabled people;

*“in terms of their abilities, design which is appropriate for older people will be appropriate for most of the population, whereas design for younger and middle aged people will exclude significant numbers of older people.”*

[Newell Alan F., Older people as a focus for Inclusive Design. March 2006, 4(4): 190-199

Available at: <http://gerontechjournal.net> -1 may 2009]



Thank you  
for your attention

→ <http://ehealth.fbk.eu>

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