Emotions and Personal Health Information Management. Some implication for Design

Enrico Maria Piras¹, Alberto Zanutto²

¹Fondazione Bruno Kessler; piras@fbk.eu;
²Università di Trento alberto.zanutto@unitn.it

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Cartella Clinica del Cittadino
An eHealth Living lab

Context research, design and prototyping and testing of a Personal Health Record

- On line access to medical records
- Structured health diary
- Communication platform
Research design (overall plan)

32 families (42 interviews)

Semi-structured interviews (1h aprox.) at respondents homes

Preliminary analysis with design group

Focus on common practices
Specific focus on (pediatric) booklets

Paper based-records (20x15 cm.; 70 pages approx)

- Information section
- Sheets to be filled in by doctors
- Sheets (fields) to be filled in by patients/caregivers

Practices built around the artefact
Dematerialization of documents
Family’s use of the booklet

The only medical record that always follows the child (e.g. on holidays)

Always carried with them when meeting doctors (pediatrician, emergency room, specialists)

Always at hand. Placed in easily accessible places at home
Booklet in clinical practices

Data inputted by parents becomes less and less after some time and after the first child (they perceive themselves as custodians of the booklet)

Pediatricians fill it in only occasionally (perceived as a surrogate of their system)

Little/no interest paid to booklet by other doctors
Appropriation: booklet-container

Discharge letters
Prescriptions
Vaccines certificates
Referrals
Blood test results

Medical cards

Business cards
Prints from the internet
Leaflets

NO bulky items (e.g. x-rays)
«Pediatric booklets are nearby the entrance door. Because the booklet is something... something you use not daily but... almost daily. »
[man, 45 anni]
Appropriation: booklet-symbol
[booklets are among] «their things they used when they were little kids. Just like, for instance, the bracelet they are wearing right after birth. Things with no value, only affective objects, not clinical, you know what I mean? The baptism candle, you know, one of those things... And there is where I placed my booklets»
[woman, 45 years]
Care practices, use practices

Relevance of booklet’s *affordances*
- Connecting it with other paper documents
- Keeping all the information in the same place (always accessible)

Relevance of the symbolic aspect of the booklet
- Connoted as symbol of care and affection
- “Takes part” to every important moment in child’s life
Implication for design

A personally controlled hub of information

- Personal-based vs. evidence-based (leaflets, prints from the internet, personal observation)
- Meaningful for the people that use it not (only) for the clinicians
- Controlled by the users (not automatically shared)
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