Number	LANCS-D4.1-RN-A-Flagship.1	A-PI--

Title	Research Note (RN) for D4.1
Subtitle	Ethical aspects of development **A : Flagship Development** : *Personal Health System*

PROBLEM		SOLUTION			Research Note	X		Selected Annotation	

Categories: | | |

Summary: This note addresses the European eHealth Action Plan and lists some of the ethical issues surrounding personalized systems for healthcare and health monitoring.

CONTEXT

The European eHealth Action Plan was first put into effect in 2004 with the aim to encourage EU-wide development and deployment of electronic health records and information networks, telemedicine, personal wearable and portable sensory / communication systems, and eHealth service portals. The Framework Programmes have funded research and development projects, many of which focus on remote health monitoring of chronic illnesses and healthcare services to elderly and frail persons (key reading: Commission of the European Communities, 2004).

FACTS

Scenario exercises like *Being Diabetic in 2011* (ENISA, 2009) foreground common concerns about the dynamic recording of health conditions – issues about access, mission creep, vulnerabilities, security, unintended consequences of interoperability and risk relating to the (in)accuracy of data. The work of ENISA has also explored the generational gap in sentiments about what counts as invasion of privacy or if/how the dignity of persons is challenged with remote monitoring systems which are personalized to assist the individual (see also Brey, 2005; Crump, 2005; European Commission, 2011; Friedewald et al, 2007; Sparrow and Sparrow, 2006; Van De Garde-Perik et al, 2008).

COMMENT

The key problem is centred on adequate management of personal and sensitive health-related data, as well as how to manage the accumulation of behavioural and other data which may not be relevant to a person's everyday care. Even if informed consent is obtained for the use of a remote monitoring system, there are still significant issues unresolved with respect to data collection and use, stemming from sensory systems, highly distributed protocols for data transmission, processing and (in)adequate responses to the person's change in condition.

eHealth systems and services rely on resolving particular technical challenges, such as:

1. correctly capturing of the identity of persons
2. correctly capturing of the identity and state of objects/devices
3. correctly capturing of the state of bodies
4. correctly processing information in order to 'know' what to do next

Organisational challenges need resolving as well:

1. Who is responsible for adequate and timely response?
2. Who owns the data?
3. Who / what accesses the data?
4. What are the risks when data propagate through constellations of service systems or get lost in the infrastructures?

The very conception of how eHealth technologies are supposed to work as part of 'intelligent environments', is also problematic:

1. Privacy, identity and security are challenged.
2. What happens when 'smart' applications go wrong or do not function as expected?
3. What if healthcare-related data are misused or incompletely processed?
4. What if people are excluded from services due to lack of interoperability, inadequate monitoring profiles and data mismatches?
5. To what extent do eHealth technologies represent surveillance and sophisticated personal and activity profiling?
6. How is equal access and fair distribution of potential benefits guaranteed?

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