The PROGRESSIVE Project

Approach, Ethos and Issues for ‘Key Terms and Phrases’ and around ‘Interoperability’ in the World of Standards

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The PROGRESSIVE Project

Progressive Standards around ICT for Active and Healthy Ageing

This Project has received funding from the European Union’s Horizon 2020 Research and Innovation Programme under Grant Agreement no. 727802
About the PROGRESSIVE Project?

• Horizon 2020 Coordination and Support Action funded by the European Commission (DG CNECT).
• Responds to Call H2020-SC1-2016 re. Standardisation Needs in the Field of ICT for AHA.
• Operates from 1st October 2016 to 30th September 2018.
• Contract Sum €905,781.
• Led by De Montfort University, Leicester (UK)
  • 10 Partners
PROGRESSIVE Project: Primary Objective

... to set in place a dynamic and sustainable framework where the contribution of standards and standardisation for ICT can be maximised for Active and Healthy Ageing
Who are the PROGRESSIVE Partners?

- De Montfort University – UK
- The Open University – UK
- Age Platform Europe AISBL – BE
- European Health Telematics Association (EHTEL) – BE
- Telehealth Quality Group EEIG – UK
- Consiglio Nazionale delle Richerche (CNR) – IT
- Asociacion Española de Normalizacion y Certificacion (UNE) - ES
- DIN Deutsches Institut fuer Normung E.V – DE
- Stichting Nederlands Normalisatie – Instituut (NEN) – NL
- UNINFO Associazione di Normazione Informatica – IT
Supporting the PROGRESSIVE project? Most on Advisory Group

- ANEC - The European Consumer Voice on Standardisation, BE
  - CEN / CENELEC, BE
  - ETSI, FR
- International Society for Telemedicine & eHealth, CH
  - UC Leuven Limburg, BE
- CRETECS Centre of Expertise in Care Technology, BE
  - British Standards Institution, UK
- EASPD European Association of Service Providers for People with Disabilities, BE
  - Stëftung Hëllef Doheem, LU
  - Mextel, NL
- Debrecen University, HU
What is ‘Active and Healthy Ageing’?

Process of optimising opportunities for health, participation and security in order to enhance quality of life as people age

WHO Definition
What is a Standard?

Criterion used as a rule, guideline or definition by which materials, products, processes and services can be determined as fit for purpose

Amended ISO Definition
PROGRESSIVE Response: Interactive Platform via www.progressivestandards.org

Interactive Platform for
... documenting relevant standards
- Filtered to ensure ‘relevance’
- Searchable by topic
- Abstract and description
- Other detail regarding currency of standard

PTO
<table>
<thead>
<tr>
<th><strong>Name</strong></th>
<th>Services para la promoción de la autonomía personal: Gestión del servicio de teleasistencia [Services for the Promotion of Personal Autonomy: Teleassistance (Telecare) Service Management Requirements]</th>
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<tr>
<td><strong>Number</strong></td>
<td>UNE 158401 / PNE 158401</td>
</tr>
<tr>
<td><strong>Country</strong></td>
<td>Spain</td>
</tr>
<tr>
<td><strong>Website</strong></td>
<td><a href="http://www.aenor.es">www.aenor.es</a></td>
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<tr>
<td><strong>Type</strong></td>
<td>Standard</td>
</tr>
<tr>
<td><strong>Issue Date</strong></td>
<td>2007</td>
</tr>
<tr>
<td><strong>Forward Review Date</strong></td>
<td>Not known</td>
</tr>
<tr>
<td><strong>Intended Audience</strong></td>
<td>Governmental and Public Sector bodies; Private Sector bodies; Professional and Trade bodies; Third (Voluntary) Sector bodies</td>
</tr>
<tr>
<td><strong>Abstract</strong></td>
<td>Standard establishes ‘minimum requirements that should be met by any teleassistance service’. Such services are seen as operating 24 hours a day and providing an ‘immediate response to various contingencies’. This includes their role in tracking the geographical position of users. It is focused on service provision rather than on the technologies.</td>
</tr>
<tr>
<td><strong>Relevance to Active and Healthy Ageing</strong></td>
<td>Standard relates to an important range of services that are proven to support independent living. By far the majority of users of such services are older people. Their role often complements that of formal and informal carers.</td>
</tr>
<tr>
<td><strong>Usage</strong></td>
<td>Not known.</td>
</tr>
<tr>
<td><strong>Comment</strong></td>
<td>Standard offers useful operational framework with a limited range of linked performance indicators. These include those that relate to mobile responses (where the latter are included). Particular attention is given to the * protocols for working with and providing information to and obtaining consent (*‘acceptance of service’) from service users; * knowledge, expertise and training of service staff; and * accessibility and operation of devices in the homes of users.</td>
</tr>
</tbody>
</table>
PROGRESSIVE Response: Consultations / Fora via www.progressivestandards.org

Project Standardisation Forum in Brussels

... report and consult on ‘direction of travel’ of project

- involving range of stakeholders
- referencing domains and fields
- working on framework for co-production

Launch event in Brussels

... guidelines

... new ‘Forum for European AHA Standards’ established
PROGRESSIVE Response: Key Outputs and Activities (Guidelines)

Guidelines with ICT and AHA in mind … for standards around

• Age-friendly environments
• Smart homes
• Interoperability

… and for the standardisation process around

• Co-production
PROGRESSIVE Response: Consultations / Fora via www.progressivestandards.org

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... plus

‘Forum for European AHA Standards’ established
PROGRESSIVE: Concerns about Standards

• Voluntary (or not)?
• Failure to adequately consider needs of older people?
  • Too directed at commercial objectives?
    • What are the ethical issues? ...
• Failure to adequately address consumer perspective?
• When (and how) should they consider older people?
• Are all of ‘fields’ of AHA covered (do they need to be)?
• How (and when) should older people be involved in the standardisation process?
What are the Ethical Issues?

- The right, status, equality of (all) older people
  - ethical imperative: inclusion, non-discrimination
  - ethical imperative: empowerment

- The needs of (some) older people arising from physical and sensory challenges
  - ethical imperative: accessibility and usability
  - ethical imperative: care, protection and support

- The special position of older people as consumers
  - ethical imperative: cost (affordability); interoperability of goods and services
  - ethical imperative for commercial organisations: RRI (Responsible Research and Innovation) ... responsibility
Delivering on the Ethical Imperatives:
(1) Key Terms and Phrases (2) Interoperability and Standards

- The language we use
- The way we think
- We should be
  - jettisoning inappropriate social norms
  - challenging and changing the practices that follow from them
    - adopting a new language
    - adopting new thinking about what is ‘good practice’
- PROGRESSIVE as an exemplary approach?
Delivering on the Ethical Imperatives:

(1) Key Terms and Phrases

(2) Interoperability and Standards

• More than a ‘Glossary’
  - relating to the ethical imperatives
  - rejecting top-down ‘we know what’s good for the old-folk’ approaches
  - demanding new age-positive language

• Active and Healthy Ageing
  - much more than riding bicycles and perfect teeth
Delivering on the Ethical Imperatives:

(1) **Key Terms and Phrases**

(2) **Interoperability and Standards**

- **Active and Healthy Ageing**
  - much more than riding bicycles and perfect teeth
Delivering on the Ethical Imperatives:

(1) **Key Terms and Phrases**

Some less favoured terms and phrases

- the elderly
- tsunami
- burden
- suffer
- delivery
- dependency ratio

And for good measure

- best practice
- retirement
- needs, dependencies

Plus concerns re. jargon

- co-production

(2) **Interoperability and Standards**

Some alternatives (more favoured)

- older people
- increase in (growing) number
- challenge
- with
- provide (and access)
- age ratio

And for good measure

- good practice
- ?
- capabilities, assets

Plus concerns re. jargon

- collaborative working (etc.)
Delivering on the Ethical Imperatives:

(1) Key Terms and Phrases (2) Interoperability and Standards

- Types of interoperability
  - technical (think - data, signalling protocols, ‘plug and play’, etc.)
  - semantic (think - meanings ... a particular challenge for the EU28)
  - organisational (think - governance, funding frameworks, jobs, etc.)

- Erroneous (?) tendency to think of interoperability only for health
  - EHRs, etc. ... important - but this is narrow thinking!
  - need initial broadening to take account of well-being, self-management, etc.
  - needs addressing better in the telehealth and telecare context

- Other contexts
  - use of shopping, banking, leisure services, etc.
  - community security (CCTV systems, pedestrian safety, etc.)
  - smart homes and connected (IoT) devices from lighting to stairlifts
  - assistive robots and robotics

... but beware cyber-threats!
Delivering on the Ethical Imperatives:

(1) Key Terms and Phrases (2) Interoperability and Standards

- Adopting the new language / way of thinking
- Having response to ethical imperatives
  - accessibility (and usability), affordability
  - inclusion, non-discrimination
  - empowerment
  - care, protection and support
  - interoperability, responsibility
- Enshrining ethical perspectives in standards
- Answering some key questions around
  i) What makes an area (issue) specifically relevant to older people ... a lot of what we do should (must?) be generic
  ii) What areas around AHA are ripe for standards development?

... consider PRO EIPAHA work
Delivering on the Ethical Imperatives:
(1) Key Terms and Phrases (2) Interoperability and Standards

• PRO EIPAHA: Roadmap for Standardisation on AHA
  o standards perspective looked forward to 2020
• Very high priorities
  o eHealth (semantic interoperability) ...
    e.g. for EHRs, frailty and dependency scales, data protection / security
  o social care record
  o falls prevention devices
  o cognitive accessibility of ICT products
• High priorities
  o falls risk use cases; falls risk assessments
  o technical interoperability for the IoT
  o quality criteria for health & wellness apps
  o structures for non-institutional care; care interventions
  o health profession qualifications
Round Up

- Standards have a role to play but crucial to these are
  - the way we think and the language we use
  - the extent to which they can respond to a range of ethical imperatives
- PROGRESSIVE project is taking a lead for AHA ...
  - following on from PRO EIPAHRA
    - new understandings
    - new approaches
    - repository of standards
Thank You
Diolch yn Fawr

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www.progressivestandards.org