Standards, Older People’s Needs and the Standardisation Process: Challenges and Dilemmas for the PROGRESSIVE Project

Medetel 2017
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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
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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: Concerns about Standards

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

- Failure to adequately consider needs of older people?
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Age Friendly Communities

A1: Standards for Generic ‘Design for All’ Approaches in Homes, in Communities and on Transport
B1: Standards for Accessible Transport and Navigation
B2: Standards for Retirement Villages
B3: Standards for Community Safety and Security
B4: Standards for Smart Buildings and Workplaces
B5: Standards for Community Development / Cohesion

Reformed and Empowering Services

C1: Standards for Housing including Care Homes and Smart Homes
C2: Standards for Home Safety and Utility Services
D1: Standards for Privacy and Confidentiality including Personal Data
D2: Standards for Social Alarms, Telecare and Activity Monitoring

Accessible, Affordable and Supportive Homes

E1: Standards for Health, Social Care and Housing Services
E2: Standards for Services for Education, Learning, and Literacy
E3: Standards for Medicines, Therapies, Nutrition, etc.
E4: Standards for Preventative Health, and Self-Management
E5: Standards for Leisure
E6: Standards for End of Life (Palliative) Care

Active, Healthy and Empowered Older People

F1: Standards for Home Support Services and Tasks with Devices including Robots / Robotics, Lifts, Hoists and other relevant Assistive Technologies (for user/carer)
F2: Standards for Personal Care Services and Tasks (with Devices including relevant Assistive Technologies (for user/carer)

Domains and Fields for AHA

A2: Standards for Political and Social Engagement and Support for Citizenship
A3: Standards for Shopping, Banking, Pharmacy Use and ‘High Street’ Activity
A4: Standards for Telehealth and Telemedicine (incl. mHealth, Smart TV, etc.)
A5: Standards for eHealth

B3: Standards for Community Safety and Security
B4: Standards for Smart Buildings and Workplaces
B5: Standards for Community Development / Cohesion

C2: Standards for Home Safety and Utility Services
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PROGRESSIVE: Concerns

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- Failures in addressing consumer perspective?
- When (and how) should standards consider older people?
- What are the *ethical* issues?
- 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)
PROGRESSIVE: Concerns

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Are Standards Failing Consumers?

• Probably not ... but contested views
  • certain benefits e.g. governance, quality controls, occupational health, safety, environmental protection, etc.

• Increasing role for services as well as products
  • interoperability

• Facilitation of international trade

• Fostering or restricting innovation?

• Reducing costs?

• Problem of ‘prescription’ versus ‘flexibility’
What are the PROGRESSIVE Concerns?

• Failure to adequately consider needs of older people?
  • Too directed at commercial objectives?
  • Failures in addressing consumer perspective?
  • When (and how) should standards consider older people?
• What are the ethical issues?
• Are all of ‘fields’ of AHA covered (do they need to be)?
• How (and when) should **older people** be **involved** in the **standardisation process**?
Older People in Standardisation Process?

• Are older people present already?
  o increasingly yes, it appears ... but still trapped in old ways of thinking?

• Are co-production a luxury or necessity?
  o could they overcome some shortcomings of standards (at least for AHA)?

• How would such approaches work?
  o can’t we do it on-line?
  o are they affordable?
    o how inclusive?

• Do we need them at all?
  o or should we simply focus on raising awareness and changing social norms?
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:
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
<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>
</tr>
</thead>
<tbody>
<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>
</tr>
<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
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