Progressive Standards Around ICT for Active and Healthy Ageing

WP2 Ethical Framework

Deliverable 2.1
Ethical Framework for Standards
in the Context of ICT for AHA

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GA 727802

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Document Control

Deliverable	D2.1 Ethical Framework for Standards in the Context of ICT for AHA
WP	WP2 Ethical Framework
Delivery Date	31 May 2018
Dissemination Level	Internal (with proviso to continue to adapt the report in Year 2 of the project and produce a version that will be made publicly available, for the benefit of other projects and standardisation activities around ICT for AHA in general).
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Abstract	This report provides guidance on ethical tenets (principles) that should be observed and respected in standardisation work around ICT for AHA. It serves as a working paper for the material and guidelines that will be produced as part of the following PROGRESSIVE Work Packages and was the subject of wider consultation including older people: ● WP7: Use cases and interoperability in the context of different service models ● WP8: Development of age-friendly guidelines (including for procurement & coaching) ● WP9: Development of guidelines for the co-production of standards ● WP10: Development of 'first draft' guidelines for smart homes that are age-friendly

List of Abbreviations

AAL	active and assisted living (*formerly:* ambient assisted living)
AGE	AGE Platform Europe
AHA	active and healthy ageing
AI	artificial intelligence
BT	technical board (within CEN/CENELEC)
CEN	European Committee for Standardization
CENELEC	European Committee for Electrotechnical Standardization
CRPD	Convention on the Rights of Persons with Disabilities
D	deliverable
DMU	De Montfort University
EASTIN	European Assistive Technology Information Network
EHTEL	European Health Telematics Association
EIF	European Interoperability Framework
EN	European Norm / European Standard
ETSI	European Telecommunications Standards Institute
EU	European Union
GARI	Global Accessibility Reporting Initiative
GDPR	General Data Protection Regulation
GPII	Global Public Inclusive Infrastructure
IEC	International Electrotechnical Commission
ICT	information and communication technology
ISO	International Organization for Standardization
JWG	joint working group
M	mandate
NEN	The Netherlands Standardization Institute

ReEIF   Refined eHealth European Interoperability Framework

RFID   radio-frequency identification

RRI   responsible research and innovation

SAGA   Strategic Advisory Group on Accessibility

SSCC-CG   Smart and Sustainable Cities and Communities Coordination Group

SyC   systems committee (within IEC)

TC   technical committee (within CEN/CENELEC or ISO)

TQG   Telehealth Quality Group

UN   United Nations

W3C   World Wide Web Consortium

WAD   web accessibility directive

WCAG   web content accessibility guidelines

WG   working group

WHO   World Health Organization

WP   work package

Preamble

This document sets out the ethical framework that should support and underpin the 'change of mindsets' that is envisaged by PROGRESSIVE. It is meant to encourage anyone involved in standardisation processes to keep a clear eye and focus on the user (older person) perspective and to take the proposed ethical principles into consideration. The aim is to involve older people in standardisation processes and to develop standards that respond to or address the needs, wishes and challenges of older people.

The ethical framework is based on existing literature and policy documents (at European and international level), as well as experience and outcomes of other projects, feedback from the project's Advisory Board and, most importantly, the input and suggestions from older people and their representative organisations. PROGRESSIVE has indeed set up a User Task Force of Older Persons via AGE Platform Europe, i.e. the voice of older persons at EU level.

The User Task Force, together also with the PROGRESSIVE Advisory Board, have been actively involved in and consulted on the development and validation of this ethical framework.

PROGRESSIVE

Contents

1. Introduction

Today's population is ageing. Between 2015 and 2050, the proportion of the world's population aged over 60 years will nearly double from 12% to 22% and the pace of population ageing will be much faster than in the past.[1] In Europe, the number of people aged over 65 will double in the next 50 years, and the number of those aged over 80 will almost triple. Life expectancy will continue to increase yet unhealthy life years are reported as making up around 20% of a person's life.[2]

Even though we recognise that the vast majority of older persons are not frail or living with severe illnesses, ageing carries the greater possibility of people experiencing physical and cognitive challenges and impairments around mobility, gait, dexterity, vision, hearing, memory and chronic conditions.

It is recognised that information and communication technology (ICT) or ICT-based products and services can contribute to Active and Healthy Ageing (AHA). The many research initiatives as well as (commercial) product and service developments in Europe and worldwide around ICT to support active, assisted, healthy living and ageing, bear witness to this. AGE Platform Europe[3] states that ICT can indeed help older people to carry out daily activities, monitor their health, create social networks, increase participation in society and augment safety.[4]

Older people are sometimes seen as 'unable' or 'unwilling' to use ICT-based services and products, but a recent research report from The Age of No Retirement (UK), entitled "Age Does Not Define Us"[5], found that younger and older people have quite similar preferences and perspectives, and feel equally overwhelmed by the constant flow of new technologies. Yet both age groups also indicated a similar (high) level of dependency on the internet and, as an example, equally use online shopping. The report calls for a common approach to

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[1] World Health Organization, Ageing and health, http://www.who.int/mediacentre/factsheets/fs404/en

[2] European Innovation Partnership and Active and Healthy Ageing, https://ec.europa.eu/eip/ageing/about-the-partnership_en

[3] The European network of non-profit organisations of and for people aged 50+, which aims to voice and promote the interests of the 190 million citizens aged 50+ in the EU and to raise awareness on the issues that concern them most, http://www.age-platform.eu.

[4] Older people and Information and Communication Technologies – An Ethical Approach, AGE Platform Europe, http://www.age-platform.eu/images/stories/EN/pdf_AGE-ethic_A4-final.pdf

[5] Age Does Not Define Us - The Intergenerational Design Principles, A research report from The Age of No Retirement, http://www.ageofnoretirement.org/uploads/1c1588b37c4d55916468495ef1f648d3.pdf

product and service design and delivery across all ages and defines intergenerational design principles, which, as will be pointed out further in this document, also resonate with the PROGRESSIVE ethical framework.

"Active ageing" is about older people being and remaining actively involved in the workforce and labour market, in social and cultural life, in civic and political life, as employees or as entrepreneurs, consumers, active contributors, and volunteers, etc.

According to the WHO's Active Ageing Policy Framework:
"active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age. Active ageing applies to both individuals and population groups. It allows people to realize their potential for physical, social, and mental wellbeing throughout the life course and to participate in society according to their needs, desires and capacities, while providing them with adequate protection, security and care when they require assistance." [6]

Although an ageing population is often associated with the economic challenges around a society providing pensions, support and care, active and healthy older citizens are indeed net contributors to the economy as well, as noted above (as employees, entrepreneurs, carers, volunteers and consumers).[7,8]

More importantly, supporting an active and healthy life for older people is a moral imperative as it will increase the mental and physical wellbeing, satisfaction and happiness of older people and those who care for them and love them.

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[6] Active Ageing – A Policy Framework, A contribution of the World Health Organization to the Second United Nations World Assembly on Ageing, Madrid, Spain, April 2002, http://apps.who.int/iris/bitstream/10665/67215/1/WHO_NMH_NPH_02.8.pdf

[7] The benefits of an ageing population, The Australia Institute, http://www.tai.org.au/documents/dp_fulltext/DP63.pdf

[8] A Global Overview on Social Security in the Age of Longevity, Roland Sigg, International Security Association, http://www.un.org/esa/population/meetings/EGMPopAge/6_RSigg.pdf

2. The Contribution of Standards

Standards for ICT products, services and technologies that support active and healthy ageing can contribute to better usability, quality and safety of those products and services[9], as well as to their viability due to scaling effects and cost efficiencies. Usable and accessible products, services and environments are likely to be used by people of all ages, so - as a result - economies of scale can be attained.[10] Yet, it is important to realise that there is no such thing as "one-size-fits-all", so any standardisation work in ICT for AHA should still allow as much as possible for personalised or adaptable products and services that will best meet the need (especially care needs) and wishes of older persons. Focus should be placed on non-discriminatory approaches which can offer 'mainstream' accessibility of any and all products and services (this is the objective of the CEN Strategic Advisory Group for Accessibility[11]) instead of developing specific 'solutions' for what are perceived or actual problems or challenges faced by some older persons or people with disabilities. In this context such specific assistive devices should only be envisaged for persons with very particular needs that cannot be readily addressed through mainstream approaches.

It follows that a clear ethical balance needs to be upheld when it comes to developing standards that are relevant to ICT and AHA. Standards need to serve the users' best interests and wishes and not just satisfy purely technical, economic or commercial goals. This reflects the approach taken in the UN Convention for the Rights of Persons with Disabilities that affirmed the importance of ensuring that people are able to exercise their wishes.[12] In turn it can be seen that there can be a tension between the desire of policy and practice (often reflected in the contents of standards) to promote population health and wellbeing, perhaps according to organisational models, and the need to accommodate 'wishes' - the exercise of which may in themselves bring health and wellbeing benefits to individuals. Some reconciliation of the tension can, however, be made where mainstream

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[9] Standardisation as a powerful tool to address population ageing and support age-friendly environments in Europe, AGE Platform Europe, http://www.age-platform.eu/press-releases/standardisation-powerful-tool-address-population-ageing-and-support-age-friendly

[10] ISO/IEC Policy Statement, Addressing the needs of older persons and people with disabilities in standardization work, https://www.iso.org/files/live/sites/isoorg/files/archive/pdf/en/iso_iec_gen3_2000-en.pdf

[11] CEN/BT/WG 213 Strategic Advisory Group on Accessibility (SAGA), https://www.cencenelec.eu/standards/Sectors/Accessibility/Pages/default.aspx

[12] UN Convention on the Rights of Persons with Disabilities (CRPD), https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

products and services are configured in a more inclusive way that recognise the rights and accommodate such wishes.

This intermediate approach has repercussions for standardisation insofar as approaches that take a unilateral perspective that overlooks or discounts the wishes of individuals may fail to have properly taken into account the views and concerns of some stakeholders. One means of helping to overcome this is through introducing, where this is not already the case, an element of co-production (with those for whom the standards in question are intended to support).[13] A precondition for this is the adoption of mindsets which are open to more inclusive ways of thinking and are ready to dispense with traditional, and sometimes ageist, notions that regard older people as a collective group that is dependent and whose wishes may carry less value. This points to some key ethical considerations that relate to rights and the necessity of challenging what can be an ageist *status quo.* A further reference point to be considered is that relating to Responsible Research and Innovation (RRI) a multifaceted approach to ethics championed by the European Commission for adoption by research and industry. RRI, which emphasizes reflection and engagement, has substantial implications for the content (and approach) of standards and the process of standardisation (including the way in which citizens and users are engaged in it). All have ethical dimensions that demand attention around ICT for AHA. These are addressed below.

3. The Ethical Dimension

The position of older people in our societies has often been determined not just by age, health (or dependency) but by a raft of social norms that conspire to marginalise and segregate. These social norms have been anchored in negative language ('you can't teach an old dog new tricks', 'silver tsunami', the 'burden' of old age, etc.); in strategic policy approaches that separate out older people (using age thresholds for employment, retirement and welfare services); and in the way that products and services are structured and marketed (e.g. special housing or care 'schemes' for older people).

The notion of 'Active and Healthy Ageing' is, of course, designed to challenge such social norms or, perhaps, to introduce a new social norm that recognises older people in a new, and more accurate, way, which also adopts a life course approach. And even allowing for the

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[13] The issue of co-production and its benefits (for older people and a wider range of users / consumers) in the context of standardisation is being actively considered within the PROGRESSIVE project. A "Guide on User Co-production in Standardisation for Active and Healthy Ageing" has been developed. The guide provides guidance and practical tools on when and how to reach out to users and obtain their opinions on relevant questions. See https://www.nen.nl/Normontwikkeling/Progressive.htm.

fact that a minority of older people can be described as 'dependent' this does not detract from obligations (as indicated in the Convention for the Rights of Persons with Disabilities) to ensure that people's wishes are taken into account, regardless of age, disability, etc.

It follows that from the point of view of the PROGRESSIVE project the standardisation process is not just a matter for products and services around ICT for AHA to 'work' efficiently. It is also about their effectiveness and about the broader potential impact that might be made on the attitudes and approaches of a range of stakeholders. That broader potential impact reflects the shared concern of the project partners that standards (and the standardisation process) have often overlooked the needs of older people. This situation cannot be justified at a time when the demographic, social, political and (arguably) ethical dynamics that relate to the inclusion and empowerment of older people (as implicit in the AHA mantra) are gaining momentum.

The PROGRESSIVE approach to standards, therefore, is concerned not just with the development and promotion of standardised tools and approaches that are right in the context of ICT for AHA, but must also reflect the adoption of appropriate social norms. This, in turn, links to a call for a new ethical framework for standards and standardisation.

In the first instance it is necessary to note that taking an ethical approach to standards and standardisation around ICT for Active and Healthy Ageing, responds to fundamental rights that have generally been acknowledged in EU and global policy such as the Charter of Fundamental Rights of the European Union. In its article 25 (concerned with the rights of older people), the Charter *recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.*[14] The Political Declaration and Madrid International Plan of Action on Ageing set out at the Second World Assembly on Ageing in Madrid (2002), prioritised *"older persons and development; advancing health and wellbeing into old age; and ensuring enabling and supportive environments."*[15] Very relevant to this is the self-advocacy handbook developed by AGE, a PROGRESSIVE partner, which provides information about older people's rights and how to defend them.[16]

More specifically on the subject of standards, the European Parliament in its recent resolution of 4 July 2017 on standards for the 21st Century, stressed that: *"demographic ageing in Europe requires systematic incorporation of the needs of older persons and*

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[14] Charter of Fundamental Rights of the European Union, http://www.europarl.europa.eu/charter/pdf/text_en.pdf

[15] Political Declaration and Madrid International Plan of Action on Ageing, Second World Assembly on Ageing, Madrid, 2002, http://www.un.org/esa/socdev/documents/ageing/MIPAA/political-declaration-en.pdf

[16] Older Persons' Self-Advocacy Handbook on human rights, AGE Platform Europe, http://age-platform.eu/publications/older-persons-self-advocacy-handbook-human-rights

persons with disabilities, and other vulnerable members of society, in the development of standards, which are a suitable tool to help achieve an active and healthy society in Europe and to increase the accessibility of products and services for people." It also encourages a *"proper and early involvement of all relevant stakeholders."*[17]

It can be noted that the Rolling Plan for ICT Standardisation 2017 from the European Commission[18], which bridges EU policies and standardisation activities in the field of ICT, allows for increased convergence of the activities of standardisation makers towards European policy goals. It recognised active and healthy ageing as an important societal challenge, and calls for safety, security, affordability, accessibility, user involvement, autonomy, privacy protection and interoperability as key aspects of standardisation work.

The foregoing discussion has drawn from United Nations and European Commission sources, including that which relates to RRI. It enables, therefore, the drawing up of a list of ethical issues that have particular applicability in the world of ICT for AHA. It is suggested, however, that the provenance of many is such that they relate to an approach to products and services where the ethical imperative may be one associated with doing things for (or to) older people who are perceived as dependent. The ethical issue around empowering older people (whereby their 'wishes' are taken more fully into account) is often absent. For RRI, in fact, the ethical imperatives are around the actions and activities of the people within organisations, who, when innovating and conducting research need to remember who it is they are ultimately doing this work for. One of the key principles of RRI, 'engagement and involvement',[19] provide a starting point for those developing tools and services for older people, to understand the needs of those older people. Effective innovation, like effective standards are dependent on buy-in from those expected to use them. Engagement and undertaking co-creation activities with stakeholders therefore increases the likelihood of successful outcomes, either in business or in upholding standards. The European Commission philosophy and that of the PROGRESSIVE project are therefore closely aligned, with the understanding that 'RRI means that societal actors work together during the whole

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[17] European Parliament resolution of 4 July 2017 on European standards for the 21st century (2016/2274(INI)), http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2017-0278+0+DOC+XML+V0//EN

[18] Rolling Plan for ICT Standardisation 2017, European Commission, DG GROW, https://ec.europa.eu/docsroom/documents/24846/attachments/1/translations/en/renditions/native

[19] Wilford S, Fisk, M and Stahl, B (2016) 'Guidelines for Responsible Research and Innovation', Centre for Computing and Social Responsibility, De Montfort University, Leicester.

research and innovation process in order to better align both the process and its outcomes with the values, needs and expectations of European society'.[20]

This means that whilst a list is drawn up (below) of ethical issues, these have to be carefully considered and, in some cases, perspectives adjusted before they can be adopted as ethical tenets in relation to ICT for AHA.

Seventeen issues have been identified:
● Accessibility
● Affordability
● Autonomy
● Beneficence
● Care, Protection and Support
● Empowerment
● Equity/Equality
● Inclusion
● Interoperability
● Justice
● Non-discrimination
● Non-maleficence
● Privacy
● Safety
● Security
● Social Impact
● Usability

In discussions with the PROGRESSIVE User Task Force of Older Persons, 'dignity' and 'respect' were pointed out as overarching ethical principles that should be taken into account, but which are inherently covered by addressing the above list of issues. In their "Statement on Artificial Intelligence, Robotics and 'Autonomous' Systems"[21], the European Group on Ethics in Science and New Technologies (EGE) also mentions 'human dignity' as one of their ethical principles and democratic prerequisites.

The ETICA project[22], which investigated Ethical Issues of Emerging ICT Applications more generally, presented an even wider list of issues of ethical relevance and social impact. However, the above list covers the aspects that are considered most relevant within the

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[20] European Commission (2012) 'A Stronger European Industry for Growth and Economic Recovery' COM(2012) 582.

[21] Statement on Artificial Intelligence, Robotics and 'Autonomous' Systems, European Group on Ethics in Science and New Technologies, https://ec.europa.eu/research/ege/pdf/ege_ai_statement_2018.pdf

[22] Emerging Technologies Report, ETICA Project, http://www.etica-project.eu/deliverable-files/D.1.2%20Emerging%20technologies%20report%20final.pdf?attredirects=0&d=1

specific frame of ICT for AHA. The list could be refined in light of the ongoing work of the PROGRESSIVE project that will include further consultations with a range of older people. Each of the 17 is discussed below, although some aspects are combined as they are closely related.

4. Key Ethical Tenets

Seventeen ethical issues are brought together as nine tenets below. These are considered as potentially underpinning approaches to standards and standardisation in the world of ICT for AHA. As becomes apparent, the tenets can be (indeed, must be) seen from the perspectives of the providers and the users (consumers) of the products and services concerned. The tenets of inclusion, empowerment and justice can be potentially seen as relating to this and contributing to a 'balanced' approach.

4.1. Accessibility and Usability

Many (standard) ICT-based products and assistive technologies, as well as ICT-supported services and environments, are available or have been set up and designed to help people of all ages better interact with and carry out their daily activities within the increasingly digital world. Such products and services can range from magnifiers on computers to enable visually impaired people to access social media (which can in turn help to alleviate loneliness and isolation); to mobile phones with adapted (larger) physical or on-screen buttons; and to telecare and telehealth services (that can provide online support for people managing their health). Many carry particular applicability for older people. The Global Public Inclusive Infrastructure (www.gpii.net), EASTIN (www.eastin.eu) and GARI (www.gari.info) databases bear testimony to this.

Accessibility for those products and services relates both to physical accessibility (and usability for someone who may have e.g. mobility or dexterity problems) and also relates to availability and affordability (in the sense of 'economic or financial accessibility' – this is described below in 4.2.).

The importance of physical usability of such products or accessibility of services, environments, and buildings is quite evident. Indeed, if products/services cannot be properly used or accessed by older people, they may be substantially obsolete and fail in their intended purpose. Providers of such products or services will, at the same time, be restricting the size of their potential market and consumers might be less able to benefit from the cost reductions that can be realised within such markets. The European Commission places substantial emphasis on physical usability and accessibility through its promotion of 'design

for all' approaches. As noted by CEN-CENELEC the 'design for all' means 'design for human diversity, inclusion and equality. Its aim is to enable maximum use of products, goods and services'.[23]

The CEN and CENELEC endorsement, as two of the three main standards development bodies for the EU, of the concept of 'design for all' is very significant. It links with European Commission Mandates 473[24] and 420[25]. The CEN-CENELEC (2015) work programme, in fact, reflects the requirement of European Commission (2010) Mandate 473 that is '*committed to making sure that accessibility is integrated into European standards*'. The CEN Strategic Advisory Group on Accessibility (SAGA) is specifically in charge of monitoring the execution of Mandate 473 and includes representatives of National Standards Bodies, National Committees and ETSI, as well as organisations representing persons with disabilities and older people. There is, therefore, an element of their commitment that is concerned to ensure that the voice of older people is heard.

More specifically on web- and "e"-accessibility, the Web Accessibility Directive (WAD)[26] is already making 'accessibility' compulsory for public websites and apps, but the standard could easily apply to all kinds of (non-public) ICT products and services: websites, apps, hardware, non-web documents and more. And under Mandates 376[27] and 554,[28] the CEN-CENELEC-ETSI JWG on eAccessibility developed a European standard on "Accessibility requirements suitable for public procurement of ICT products and services in Europe" (EN

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[23] Design for All, CEN-CENELEC, https://www.cencenelec.eu/standards/Sectors/Accessibility/DesignForAll/Pages/default.aspx

[24] M/473, Standardisation mandate to CEN, CENELEC and ETSI to include "Design for All" in relevant standardisation initiatives, http://ec.europa.eu/growth/tools-databases/mandates/index.cfm?fuseaction=search.detail&id=461

[25] M/420, Standardisation mandate to CEN, CENELEC and ETSI in support of European accessibility requirements for public procurement in the built environment, http://ec.europa.eu/growth/tools-databases/mandates/index.cfm?fuseaction=search.detail&id=392

[26] EU Directive on the accessibility of the websites and mobile applications of public sector bodies, http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2016.327.01.0001.01.ENG&toc=OJ:L:2016:327:TOC

[27] M/376, Standardisation mandate to CEN, CENELEC and ETSI in support of European accessibility requirements for public procurement of products and services in the ICT domain http://ec.europa.eu/growth/tools-databases/mandates/index.cfm?fuseaction=search.detail&id=333

[28] M/577, Commission Implementing Decision on a standardisation request to the European standardisation organisations in support of Directive (EU) 2016/2102 of the European Parliament and of the Council on the accessibility of the websites and mobile applications of public sector bodies, http://ec.europa.eu/growth/tools-databases/mandates/index.cfm?fuseaction=search.detail&id=577

301 549),[29] fully compatible with the international Web Content Accessibility Guidelines (WCAG).[30]

There is also endorsement from The International Electrotechnical Commission's Systems Committee on Active Assisted Living (IEC SyC AAL), firmly recognising the importance of usability and accessibility for 'Active and Assisted Living (AAL)' products, services and systems as one of the most important factors to be considered for standards in this field.[31] And the Smart and Sustainable Cities and Communities Coordination Group (SSCC-CG) final report of 2015[32] puts accessibility at the heart of all aspects of cities (incl. smart homes and ICT) that are age-friendly.

The new ISO/TC 314 on Ageing Societies[33] has included accessibility and design for all as two of the nine main relevant areas for ageing and for older persons.

The aforementioned 'Age Does Not Define Us' report calls for 'clear and intuitive' solutions in the sense of being easy to understand and easy to work out how to use (i.e. usability), as well as accessible in the sense of being easy to find, reach or use either online or off. This last point about being available or accessible 'offline' is quite important. In fact, the PROGRESSIVE User Task Force insists that 'non-digital options' should still be made available for services that are increasingly being offered via online platforms, at the risk excluding those (older) users who do not have access to, or who do not use, the internet or mobile technologies. In Sweden for instance, the National Pensioners' Organisation raised the issue of an increasing focus on cashless payments and the fact that certain population groups, in particular older people, may face problems because they are not able to use these systems.[34] In this respect, programmes to promote and support the digital skills or eSkills of older people are important to secure and increase their access and use of new technologies (this is further explored in paragraph 4.7. around 'inclusion').

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[29] EN 301 549, Accessibility requirements suitable for public procurement of ICT products and services in Europe, http://www.etsi.org/deliver/etsi_en/301500_301599/301549/01.00.02_30/en_301549v010002v.pdf

[30] Web Content Accessibility Guidelines, World Wide Web Consortium (W3C), https://www.w3.org/TR/WCAG20 and https://www.w3.org/TR/WCAG21

[31] Revised Draft Strategic Business Plan, IEC SyC AAL, http://www.iec.ch/public/miscfiles/sbp/SYCAAL.pdf

[32] SSCC-CG Final Report, ftp://ftp.cencenelec.eu/EN/EuropeanStandardization/Fields/SmartLiving/City/SSCC-CG_Final_Report-recommendations_Jan_2015.pdf

[33] ISO/TC 314, the International Organization for Standardization Technical Committee on Ageing Societies, https://www.iso.org/committee/6810883.html

[34] Swift transition to cashless payment raises concerns in Sweden, http://platform.progressivestandards.org/swift-transition-to-cashless-payment-raises-concerns-in-sweden

On a very practical level, a recent report[35] from the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA) Action Group C2 on interoperable independent living solutions presents recommendations on personal user experience (PUX) for active and healthy ageing (AHA) solutions. These recommendations provide specific suggestions to make AHA products and systems more 'usable' and how standards can contribute to this (see below in 'The Implications for Standards' section).

To maximise the inclusion and help empower older people (seen as further ethical tenets below), it is necessary that information about (how to use) specific products and services is also accessible. Much of the information and advice is online - though this is less accessible to those (older) people who do not have the required computer skills or resources, i.e. who lack digital skills. And even when such information is accessible, it may be difficult to ascertain the quality of that information. Standards may help with this.

The Implications for Standards:

With regard to 'Accessibility and Usability' there is already much attention in the world of standards. Their pursuit represents an ethical imperative that reflects a need for recognition of the rights of older people to have access to and be able to use ICT-based solutions for AHA and, crucially, for the issue to be addressed within standards for *all* products and services.

The PUX recommendations for AHA solutions (see above) do provide practical guidelines for increased usability and accessibility, and suggest that the application of standards in the development of those solutions, will indeed help to address the ethical goal of making solutions (products, systems, services) more usable and accessible.

4.2. Affordability

Affordability, in its sense of economic or financial accessibility, is another ethical issue, as it can help ensure greater equality of opportunity for all (older) people in accessing products or services that relate to their wishes and needs - regardless of whether they relate to some of the challenges that may arise in older age relating to exclusion, marginalisation, physical or cognitive decline. For technologies (including ICT) AGE has affirmed that these can only be

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[35] EIPonAHA Action Group C2 (2018). Personal User Experience (PUX) Recommendations and Lessons Learned. Guidelines for manufacturers and developers of Active and Healthy Ageing solutions aiming for a Personal User Experience. Feb. 2018. http://gpii.eu/pux/guidelines

fully inclusive and benefit everyone if they are not only physically accessible, but more importantly, economically accessible.[36]

The principle of design for all is again important in this respect. Special, niche products or services that are designed only to support very specific challenges, risk being quite expensive because of high development costs and can relate to relatively small numbers of potential users. Of course, that is not to say that products or services for such people (of any age) shouldn't be pursued. But there is an accompanying imperative that calls for 'design for all' approaches to ensure that products and services, as well as having 'default' settings, have built in flexibilities or configurabilities (able to be changed or adjusted by users) that can, wherever reasonable, enable small numbers with exceptional needs to be accommodated - with (it follows) some economies of scale being attained.[37] As a consequence products and services can become more affordable (larger demand, lower price).

Standards, it can be noted, can be seen as a driver for such scalability and sustainability with this possibly contributing to the increased affordability.[38] A proviso, however, applies in that overly stringent standards can raise the cost of products and services – these then potentially becoming less affordable for those in the greatest need.

The Implications for Standards:

With regard to 'Affordability' there appears to be little attention in the world of standards. This, instead, is left to 'the market'. However, whilst this may represent a logical perspective given the link between standards and market development, there is at least an ethical imperative that requires attention to our changing demography and *ipso facto* the number and range of older people to be found within the markets with which product and service providers are concerned. Insofar as some older people can be disproportionately disadvantaged in such contexts, the imperative becomes stronger.

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[36] Older people and Information and Communication Technologies – An Ethical Approach, AGE Platform Europe, http://www.age-platform.eu/images/stories/EN/pdf_AGE-ethic_A4-final.pdf

[37] ISO/IEC Policy Statement, Addressing the needs of older persons and people with disabilities in standardization work, https://www.iso.org/files/live/sites/isoorg/files/archive/pdf/en/iso_iec_gen3_2000-en.pdf

[38] Workshop on "An alternative for the future: Silver Economy for cities and regions", organized by the SEED Coordination and Support Action, Brussels, 10 October 2017, http://silvereconomyawards.eu/news/accelerating-silver-economy-european-regions-and-cities

4.3. Autonomy and Empowerment

Autonomy is one of the four ethical principles that were defined by Beauchamp and Childress[39] in their framework for (bio)medical ethics issues. Whilst conceived from the point of view of clinicians there is no doubt that the call to recognise the 'autonomy' of the patient was important in starting to redress what may, in earlier decades, be regarded as rather an authoritarian (and disempowering) approach to aspects of medical care. While questions remain about the degree of autonomy that should be afforded to patients, the principle has been widely accepted within the clinical field. In any case it accords with the perspective taken in the PROGRESSIVE project that people, as responsible citizens, should be empowered to make decisions about their lives even when they are the recipients of medical care. It is, therefore, a laudable ethical tenet. The three other (ethical) principles put forward by Beauchamp and Childress are beneficence, non-maleficence and justice (see below).

The issue of autonomy is, of course, also relevant outside of the field of medical care. After all, many older people experience a lack of autonomy or the capacity for self-determination in a variety of contexts, often impacted by inappropriate social norms (noted earlier) that are reflected in a number of societal barriers (e.g. in relation to services or products offered that have not taken account of their needs); discriminatory approaches to product or service provision (e.g. of separate accommodation); ageism (e.g. reflected in approaches that result in older people being less favoured in the workplace); structural design or features (rendering buildings, transport and the wider environment less accessible); and sensory or cognitive impairment (meaning that a significant proportion of older people even with support, including technologies, can be disadvantaged). Some such barriers are, of course, particularly evident in hospitals and other institutional care settings – with new technologies often introduced with 'management' in mind rather than people's empowerment and autonomy.

Outside institutional settings similar shortcomings in the approach to products and services can be apparent. Assistive technologies can be 'presented' in a 'take it or leave it' kind of way without adequate consideration of the older person's needs and choices. The process of (informed) consent is clearly compromised in such situations. And it must be noted that new dangers are arising from such inadequate approaches because of the (cyber-) threats to older people when linked within e.g. telecare and telehealth services that carry substantial quantities of personal information.[40] Yet further challenges arise with the advent of Artificial Intelligence (AI) where devices are operating in accordance with complex algorithms that can

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[39] Beauchamp T.L. and Childress J.F., (2001) Principles of Biomedical Ethics, 5th edition, New York: Oxford University Press

[40] It is difficult to overstate the importance of this issue in view of the quantity of 'legacy' equipment that may leave users (and service providers) particularly exposed and the especial vulnerability of some older people who have entrusted much personal data to such services.

evolve, for instance, in response to user behaviour or lifestyles. The EGE ethical principles (for AI, robotics and autonomous systems) which were referenced before, suggest *"human responsibility and thus control over and knowledge about 'autonomous' systems as they must not impair freedom of human beings to set their own standards and norms and be able to live according to them. All 'autonomous' technologies must, hence, honour the human ability to choose whether, when and how to delegate decisions and actions to them."*

In its 'Urgent Upgrade' report on ethical and societal issues raised by digitisation, the Rathenau Instituut[41] claims that the issue of autonomy is playing a more significant role as technology filters, fill in, or take over more decisions for people. This development is clearly manifest in all sorts of domains: online platforms that filter information, smart environments that anticipate behaviour, persuasive technology that can exercise influence consciously and at a deliberately low level, and robotics that take over tasks partially or entirely. The issue of autonomy whereby people still have the space and the freedom to choose is therefore becoming an increasingly important matter.

The position is increasingly complex but does not detract from the importance of autonomy and empowerment as ethical tenets. The fact that the extent of autonomy that might be desirable can be difficult to attain presents certain challenges and, arguably, points to the increasing importance of an ethical perspective being adopted by product and service providers - not just to configure these more appropriately but also to lay strong foundations that will engender the trust of users / consumers (of any age). Empowerment, it follows, is normally possible at least to some extent - a useful starting point for which is engagement. There is, however, a related danger that any engagement process can lose value if undertaken as a tick box exercise or for its own sake but does not actually empower those involved.

The notions of *self-determination* and *freedom of choice* are closely related to autonomy and are equally important. In a report[42] released in July 2017, the UN Independent Expert on the enjoyment of all human rights by older persons warns that the use of assistive technologies (incl. robots) inevitably touches on the enjoyment by older persons of their human rights, including their dignity and autonomy, informational self-determination and non-discrimination and equality. The report does insist on the need for assistive technologies to foster autonomy and independence but without increasing social exclusion (also discussed as a separate

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[41] Urgent Upgrade: protect public values in our digitized society, Rathenau Instituut, https://www.rathenau.nl/en/publication/urgent-upgrade-protect-public-values-our-digitized-society

[42] Report of the Independent Expert on the enjoyment of all human rights by older persons, UN Human Rights Council, https://www.age-platform.eu/sites/default/files/Report%20of%20the%20UN%20Independent%20Expert%20on%20digitalisation%20and%20use%20of%20robots_2017.pdf

ethical tenet in this paper). Just as important is to give older persons the choice to accept or refuse the technological support proposed to them.

Finally, note must be made of the position regarding autonomy and empowerment in relation to (mainly older) people with dementia (and or other cognitive impairment). This, of course, presents additional challenges and may, for some, mean that reference points for engagement and consent must include carers or other authorised persons. There is, however, clear evidence that adequate levels of communication are possible for many people at least in the less advanced stages of dementia. It follows that for many products and services that the ethical imperative around autonomy and empowerment is undiminished for people with dementia - albeit that special consideration will need to be in place and the extent to which objectives relating to the same are achieved will, in some cases, be compromised. Issues relating to the legal the legal capacity of persons with intellectual disabilities and/or mental health problems have been addressed by the European Union Agency for Fundamental Rights.[43]

The Implications for Standards:

With regard to 'Autonomy and Empowerment' there appears to be growing attention in the world of standards. This reflects the emerging rights agenda that can be linked with notions of consumer choice. The important thing is that the position of users / consumers stands to be enhanced in the minds of providers of products and services. Linked with this is, arguably, some indication of 'changing mindsets' that will both help the framing of standards in new ways and ensure that there is greater receptiveness among product and service providers to the approaches set out therein.

4.4. Beneficence and Non-maleficence

Beneficence and non-maleficence, respectively doing good and not doing harm to the individual, are important considerations and cornerstones of any ethical framework. This may be argued as especially the case for the providers of some products and services for older people in view of the minority who may be especially vulnerable and less able to exercise choices. Beneficence and non-maleficence provide a backdrop to this consideration of ethics in the context of ICT and AHA. They touch upon issues of quality and risk avoidance, but also safety, security and privacy.

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[43] Legal capacity of persons with intellectual disabilities and persons with mental health problems, European Union Agency for Fundamental Rights, http://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems

Looking at applied ethics in eHealth, Whitehouse and Duquenoy[44] considered non-maleficence as relating to increasing the quality of healthcare and reducing its risk (hence quality and safety). They looked at beneficence as a proactive approach that promotes wellbeing, increases the level of safety (rather than just reducing risk) and protects people.

Within the frame of the implementation and use of 'person-centred technology' for persons with disabilities, the ImPaCT in Europe project[45] defined beneficence as working for the benefit of the individual. Translated into working with people it is about doing our best for those whom we support. This will normally involve ascertaining the expressed needs of the users of products and services, a matter that can be pursued through co-productive approaches. It may also mean doing exploratory research for the benefit of potential users, looking for solutions to problems that they may encounter, continuously assessing the usefulness of the products developed or services provided. Beneficence is also about balancing benefits of treatment against risks and costs. For the healthcare professionals this means acting in a way that benefits the patient. With regard to non-maleficence, the ImPaCT in Europe saw this as focused on safeguarding and the safety of devices preserving privacy (noted below as an ethical tenet) as well as preventing the exploitation of the user.

Interestingly, in analogy to the Hippocratic Oath taken by medical doctors vowing to uphold specific ethical standards, a Technologist's Hippocratic Oath[46] was suggested recently as an optional oath for building ethically considered experiences, in which technologists specifically vow to apply their abilities for the *benefit* and value of the end user.

The Implications for Standards:

With regard to 'Beneficence and Non-maleficence' ICT for AHA represents an area that has arguably been underexplored. Key aspects of both are of particular importance in the context of standards where the attempt is made to balance risk against autonomy. Achieving that balance may be easy in the context of e.g. product safety; but may be less easily pursued where the primacy normally given to the wishes and choices of service users may be in tension with e.g. the statutory responsibilities of care organisations that are concerned with risk and protection.

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[44] Whitehouse D. and Duquenoy P., (2009) 'Applied ethics and eHealth: principles, identity, and RFID' in Matya V., Cvrcek D., Fischer-Huebner S., (eds) *The Future of Identity in the Information Society – Challenges for Privacy and Security*, FIDIS/IFIP Internet Security & Privacy Summer School 2008, Boston: Springer, pp. 44-57

[45] Ethical Framework for the Implementation and Use of Person Centred Technology for Persons with Disabilities, ImPaCT in Europe, http://www.easpd.eu/sites/default/files/sites/default/files/impact_ethical_framework_final_1.pdf

[46] 'Technologist's Hippocratic Oath – An optional oath for building ethically considered experiences', Built to Adapt, https://builttoadapt.io/technologists-hippocratic-oath-94b88d3fe480

4.5. Care, Protection and Support

As noted in the introduction to this report, only a minority of older people are frail and dependent. And even that frailty and dependency does not detract from the ability of most to express wishes and exercise choices, nor does it impact on their right to do so. It follows that the PROGRESSIVE project endeavours to retain a positive, but realistic, perspective on AHA, recognising that some older people have significant health or support needs (arising e.g. out of mobility and dexterity, sensory or cognitive impairments) that may be assisted through products and services whether developed using 'design for all' principles or with specific needs in mind.

Where problems can arise, however, is in relation to the tension (as indicated for 'non-maleficence', above) between the aspirations of older people and the normative frameworks (around e.g. safety and protection) that underpin some service provision. It is recognised, in this context, that many statutory services (whether or not provided by public, private or third sector bodies) have an honourable history that is rooted in charity and welfarism. What is good within such services must be highly valued and care, protection and support must, therefore, have its place as an ethical touchstone. This touchstone is not, however, one without the necessary provisos that relate to the absolute need for personalised approaches to care which both allow for and respond to the wishes, choices and aspirations of service users.

Tronto[47] points to an 'ethics of care' concerned with the attentiveness, responsibility, competence and responsiveness of staff. The PROGRESSIVE project sees relevance in this insofar as ICTs, as well as providing people with access to the wider world (and, therefore, helping with empowerment and autonomy) can help staff to 'see' or to 'notice' when care or support is needed. Special considerations apply for (older) people with cognitive impairments. And though some researchers such as Sorrell[48] argue that full autonomy may be unrealisable for people with such impairments this does not detract from the right of such service users for their wishes and choices to be respected. The need for a 'balance', as noted for 'beneficence and non-maleficence', applies. More than this, the exercise that weighs up the benefits of different approaches must take new account of the potential usefulness of ICTs in this context (as tools that help with support and care but which also can open up new means and methods of communication outside of the world of care and care services).

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[47] Ash A., (2014) 'Safeguarding Older People from Abuse'. The Policy Press, Bristol.

[48] Sorell T., (2011) 'The Limits of Principlism and Recourse to Theory: The Example of Telecare', Ethical Theory and Moral Practice, 14, pp369-382.

The Implications for Standards:

With regard to 'Care, Protection and support' it is clear that standards can play an important part in ensuring that quality benchmarks are achieved. There is often, however, a tendency, with management considerations in mind, for some services to be 'delivered' (a term that tends to imply a one-way process) according to standards that are based narrowly on routine practices. These can, as a consequence, offer barriers to more personalised approaches (in a context where the giving (not 'delivery') of care is an intensely personal matter. There is an imperative, therefore, for standards to build in the flexibility to respond to personal needs as well as, where appropriate, seeking to ensure that management (and associated risk issues) are addressed.

4.6. Equality, Equity, Justice

Justice, i.e. making fair decision regarding competing needs or claims, is the fourth dimension of the above referenced Beauchamp and Childress[49] ethical framework (next to autonomy, beneficence and non-maleficence). It is very much an access-related principle in the sense of providing equal (same) or equitable (fair) availability of, or opportunity to access, products and services. Hence we have put the concepts of equality, equity and justice together. Justice also links with certain aspects of affordability (availability and access may depend on cost), inclusion, (non-)discrimination, but also privacy. Such matters have greater salience for older people where health and income inequalities are both substantial and may be particularly extreme for women.

With regard to services, a danger arises in our increasingly digital world insofar as the planning of provision to individuals can be assisted through the collection and analysis of personal data. Many ICT products (incorporating different sensors) are now able to monitor activity in a way that can help with, for instance, the identification of a fall or a deterioration in health. But at the same time such products and related services may be monitoring behaviour - in either case raising concerns about invasions of privacy and impacting (as noted earlier) on the way that consent is obtained.

Decisions that may be based on personal data raise concerns. The Rathenau Instituut[50] points out that digitisation means that people and their behaviour can be analysed in all sorts of ways. This, they argue, could result in discrimination, unequal treatment and wrongful

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[49] Beauchamp T.L. and Childress J.F., (2001) Principles of Biomedical Ethics, 5th edition, New York: Oxford University Press

[50] Urgent Upgrade: protect public values in our digitized society, Rathenau Instituut, https://www.rathenau.nl/en/publication/urgent-upgrade-protect-public-values-our-digitized-society

exclusion of people. Based on their profile, people could e.g. be denied access to an insurance plan or have to pay a higher price for the same product. The EGE statement on artificial intelligence[51] claims that the technologies should contribute to global justice and equal access to the benefits and advantages that they can bring. Like the Rathenau Instituut, EGE warns of the downside arising from the accumulation of detailed and massive data on individuals and that will put pressure on the idea of solidarity through e.g. systems of mutual assistance such as in social insurance and healthcare.

The Implications for Standards:

With regard to 'Equality, Equity and Justice' the world of ICT provides opportunities to engage and involve (older) people in new ways. This is subject to issues around 'accessibility' (one of our ethical tenets) and is, perhaps especially, an area where for older people issues of equality, equity and justice must be brought into focus. Standards, therefore, in seeking to reflect changing social norms, must also consider any predisposition to inequality or injustice. Greater engagement with and the inclusion of older people can help guard against this.

4.7. Inclusion, Non-Discrimination, Social Impact

Many older people face significant challenges as they age. Many of these are less to do with the natural process of ageing, rather it is the impact of a rapidly changing and technologically focused world. Partly as a consequence of this, older people may be relatively isolated (this bringing many health and wellbeing challenges), not only from society and their local community, but also from the advantages that an ICT-enabled world can bring.

The rate of technological change has been rapid and all-pervasive. The lack of understanding and awareness among a part of the older population (in large part due to many types of ICT having been largely absent from their homes or places of work) has meant that they lack the skills and resources to engage in opportunities that ICT can bring. Exercising those 'digital skills' (or eSkills), as noted earlier in this report, could help alleviate isolation; give access to information, education, training and work opportunities; and open up the means of engaging socially with others in new ways.

Next to this skills related barrier, there can also be motivational barriers: there is often a lack of perceived benefits of ICT solutions among older persons, which makes them less motivated to learn or less motivated to use them.

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[51] Statement on Artificial Intelligence, Robotics and 'Autonomous' Systems, European Group on Ethics in Science and New Technologies, https://ec.europa.eu/research/ege/pdf/ege_ai_statement_2018.pdf

Paradoxically for older people, however, it appears that the widening of ICT opportunities may increase the extent of isolation for a shrinking minority who lack the necessary skills. There can be consequences for personal wellbeing and health reflected in higher levels of loneliness, low morale, the taking of less exercise and poorer nutrition. This is not just a matter for social policy. It is a matter that must directly concern manufacturers, designers, procurers and suppliers of products and services.

The Intergenerational Design Principles from the Age of No Retirement[52] talk about 'human connection' (helping people to feel connected to other people) and 'sustainability' in terms of social unity and inclusivity.

Inclusion also means involving the user/consumer (older person) in the development and design of products and services, and indeed in the development of standards on which they are based. This process of co-creation or co-production is fully embraced within PROGRESSIVE (cf. Guide for User Co-production) and by its User Task Force. The Technologist's Hippocratic Oath[53] concurs by saying that technologists should strive to directly connect with the audience of the solutions they create.

The Implications for Standards:

With regard to 'Inclusion, Non-Discrimination and Social Impact' standards appear to be largely absent. They are issues relating to our wider society that are relevant, however, to a wide range of areas for which standards are developed. It is essential, therefore, that those engaged in standards development are consistently aware of the 'bigger picture' that relates to our societal cohesiveness (involving both inclusivity and non-discrimination). Appropriate design of products and services, as supported by standards, can help with this.

4.8. Interoperability

In the specific area of ICT for AHA, the 'Action Aimed at Promoting Standards and Interoperability in the Field of Active and Assisted Living' of the AAL Association,[54] just like

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[52] Age Does Not Define Us - The Intergenerational Design Principles, A research report from The Age of No Retirement, http://www.ageofnoretirement.org/uploads/1c1588b37c4d55916468495ef1f648d3.pdf

[53] 'Technologist's Hippocratic Oath – An optional oath for building ethically considered experiences', Built to Adapt, https://builttoadapt.io/technologists-hippocratic-oath-94b88d3fe480

[54] Action Aimed at Promoting Standards and Interoperability in the Field of AAL, Deliverable D5: Final Report, Ambient Assisted Living Association, 2016, http://www.aal-europe.eu/wp-content/uploads/2016/11/AAL_JP_Interop_D5_Final_Report_2016.pdf

the IEC SyC AAL,[55] calls for standardised interfaces between systems, system components and services, i.e. (technical) interoperability: the ability of components to work together in a seamless manner. The report argues that interoperability is a key requirement for the success (at least in commercial terms) of AAL related products and services. The PROGRESSIVE project recognises, furthermore, that a related 'success' applies where interoperability brings greater choice (and, therefore, offers greater accessibility) to users.

The attention now being given to 'smart homes' within the PROGRESSIVE project provides a particular area within which the merits of interoperability can be seen. It begins to justify the selection of 'interoperability' as an ethical tenet. The project sees such smart homes as fitting within (smart and) age-friendly communities. Much of the advantage to be gained from ICT in such contexts is around energy efficiency, transport and navigation systems, municipal services and (importantly) health and support services. All are of relevance to older people - and it can be noted that 'smart homes' and 'age-friendly communities' are in focus within the ongoing work of the PROGRESSIVE project.

In the area of health and healthcare a particular aspect of interoperability is in evidence but has been generally confined to institutional settings. The importance of such interoperability, not just in technical, but also in semantic terms ('meanings' that can relate to e.g. medical conditions, treatments, drugs), is obvious and can of course be very relevant to older people who have particular conditions and are self-managing or accessing health related services. There remains however much complexity. Picture a patient in a hospital bed surrounded by monitors, an infusion pump, a ventilator and a pulse oximeter. This equipment is typically purchased from different manufacturers and each may come with its own proprietary interface technology. This means hospitals have to spend scarce time and money setting up each technology in a different way instead of the devices being equipped with a consistent means for connectivity. This adds to the costs of care.[56] The potential for 'decentralisation' of much healthcare to the home is compromised in this context.

Technical interoperability, i.e. the ability of different IT systems or software to communicate, exchange and make use of information is, therefore, an ethical issue. 'Plug-and-play' technology, where the user does not need to worry about the correct functioning of, and interaction between, different devices or software when used together, can be important for safety and also care, protection and support (an ethical tenet noted above). Interoperability is, furthermore, about user-friendliness (usability), choice and affordability (yet a further

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[55] Revised Draft Strategic Business Plan, IEC SyC AAL, http://www.iec.ch/public/miscfiles/sbp/SYCAAL.pdf

[56] Opinion: Interoperability is an ethical issue, Becker's Health IT & CIO Review, 2015, https://www.beckershospitalreview.com/healthcare-information-technology/opinion-interoperability-is-an-ethical-issue.html

ethical tenet noted above). It may, furthermore, guard against manufacturer or supplier 'lock-in'. This makes interoperability an ethical imperative.

Semantic interoperability of ICT systems (noted above in relation to healthcare), is equally important as technical interoperability. It has applicability for a wide range of goods and services. So, just like technical interoperability, semantic interoperability has to be taken into account when setting standards for ICT products and services.

As noted in the European Interoperability Framework (EIF),[57] legal and organisational interoperability are two additional levels of interoperability that need to be considered (next to technical and semantic interoperability). Legal interoperability points to compatible legislation and regulatory guidelines that define the boundaries for interoperability across borders, but also within a country or region. It can also point to laws and policies pertaining to access and reuse of data. Organisational interoperability covers the interoperability of (public) services based on a better integration of business processes and exchange of information between (public) administrations. In this context, organisational interoperability means integrating or aligning cross-organisational business processes and formalising relationships between service providers and consumers.

Commitment to interoperability is very high at EU level. In the Tallinn eGovernment Declaration (2017),[58] the principle of 'interoperability by default' was agreed to in order to facilitate the digital transformation of public administration and services.

Interoperability is further explored in its own right within WP7 of the PROGRESSIVE project (including consideration of the ReEIF, the Refined eHealth European Interoperability Framework,[59] that offers an framework for managing interoperability and standardisation challenges in the eHealth domain).

The Implications for Standards:

'Interoperability' as an ethical tenet represents a difficult area for standards insofar as many stakeholders would argue for 'free' operation of the market. However, there is increasing recognition of the potential benefits of interoperability (most apparent in the semantic sense, but also evident for technical interoperability) and of the growing importance of the issue as greater emphasis is given to the wishes and choices of users of products and services. This,

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[57] The New European Interoperability Framework (EIF), https://ec.europa.eu/isa2/eif

[58] Tallinn Declaration on eGovernment, https://ec.europa.eu/digital-single-market/en/news/ministerial-declaration-egovernment-tallinn-declaration

[59] Refined eHealth European Interoperability Framework (ReEIF), eHealth Network, https://ec.europa.eu/health//sites/health/files/ehealth/docs/ev_20151123_co03_en.pdf

together with the other ethical tenets will be the focus of attention of the new ISO/TC 214 on Ageing Societies.

4.9. Privacy, Safety, Security

Products and services need to be safe and secure to use or access, not causing physical or other harm to the user. (Older) people will use ICTs if there is trust in respect of reliability and the way in which, for some devices and related services, their personal data is held and used. There is, however, a tension between accessibility and the security of ICT that needs careful consideration. Particular note must be taken of those ICTs that help to increase the safety of the user. These are characteristically found within telecare (and telehealth) services and are increasingly championed in the developing field of 'smart homes'.

Digitisation provides opportunities to set up more secure systems. Yet at the same time, digitisation is also introducing new vulnerabilities. Cybersecurity now has much greater importance because of the increasing number of devices and services being connected to the Internet. The impact of cyber-breaches surpasses the level of data leaks and misuse of data, and is shifting to a new level of e.g. hacked cars that can be steered remotely and pacemakers that can be set to deliver fatal shocks. For our security, it is therefore increasingly important that the operation of digital systems has built in safeguards[60]. There is a link here with interoperability, with this potentially coming at price if it is accompanied by diminished security (in relation e.g. to personal data). The vulnerability of systems may be particularly high where legacy equipment is retained within systems and services in the world of ICT for AHA.

It follows that, in the digital world, where everything is (online) 'data', privacy has become a major concern. Indeed, there is an absolute imperative that ICT systems (and the personal data they gather, store or transfer) must be protected from unlawful access or misuse.

Privacy also relates to the use of ICT in observation systems through the use of e.g. cameras and sensors, which can help formal and informal carers to monitor an older person's status or which can send an automatic alert when a fall has been detected. But such systems obviously also mean a potential intrusion into the personal space of the older person.

Many of the developments in assistive technologies require the collection of personal data. Personal health monitoring devices for example, are likely to gather and send health information directly to a doctor remotely. The security issues such as the dangers of hacking will need to be resolved at the design stage. However, the data itself is protected by data

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[60] Urgent Upgrade: protect public values in our digitized society, Rathenau Instituut, https://www.rathenau.nl/en/publication/urgent-upgrade-protect-public-values-our-digitized-society

protection regulation within the EU, which is now significantly strengthened by the General Data Protection Regulation (GDPR) which is newly in force.[61]

The new regulation builds upon the old, and gives far more emphasis on protection of individual rights to control their data. The rights include subject access, greater rights to have inaccuracies corrected or erased, measures to limit direct marketing, measures to prevent automated decision-making and profiling, and rights to data portability and strengthened rules on consent which requires unambiguous informed consent that is checked and verified.

Possibly one of the greatest changes that will occur that is particularly of importance to the provision of ICTs for AHA is the requirement to be able to show compliance with the GDPR by the strict maintenance of records regarding the way that data is collected, stored, processed and shared. With the greatly strengthened requirements alongside penalties of 4% of annual turnover or 20m Euros for non-compliance, many organisations will need to urgently revisit their policies on data protection.

The Implications for Standards:

There is much 'hype' around the potential of ICT (e.g. relating to robotics, smart homes, wearable and implantable devices) to transform our lives - bringing commercial benefit to (European) companies and 'revolutionise' the way that care and support services can be accessed and used. The latter are, of course, of particular importance in view of the potential needs of a minority of older people. With regard to standards around 'Privacy, Safety and Security', the voice of such older people must be heard in this context - with consideration given to this ethical tenet as standards are developed. Linked with this is the right of (older) people to withdraw from ICT based services or to access services in other ways. The GDPR is a key reference point for this incorporating some rights such as those relating to consent and to be forgotten (and personal records deleted). It may be that standards around ICT for AHA, particularly older ones that have been in force for several years, will need to be revised in light of the new GDPR regulations.

5. Validation of the Ethical Tenets

The above ethical tenets or principles are often closely linked. All are relevant within the frame of ICT for AHA and are important in order to assess key aspects of the 'fitness for purpose' of standards and the standardisation process. Sometimes, taking into account one

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[61] GDPR Key Changes, An overview of the main changes under GPDR and how they differ from the previous directive, EU GDPR Portal, https://www.eugdpr.org/the-regulation.html

ethical principle, will nearly automatically also imply that one or more of the others are being met. In other cases there may be tensions.

As part of a consultation carried out in PROGRESSIVE, a validation took place in summer 2017 of the core ethical tenets to consider their implications when it comes to standards around ICT for AHA. The consultation[62] included a questionnaire on the "Ethical Tenets of ICT Standards for Active and Healthy Ageing" (see ANNEX 1). Three questions were posed. Six of the nine concepts described above were included as suggested key ethical principles (Q1):

- empowerment
- inclusion and non-discrimination
- accessibility and usability
- care, protection and support
- affordability
- interoperability

In addition, RRI was added to the list as an ethical concept.

"Beneficence and non-maleficence," "equality, equity and justice" and "privacy, security and safety" were left out of the list in the questionnaire. The first two were left out on account of them being considered part of all basic ethical frameworks. The third tenet of "privacy, security and safety" was added as a test to incentivise open feedback from respondents on other applicable and important ethical tenets.

A second question (Q2) in the consultation asked for *"what other key ethical tenets should drive the ICT standardisation process for active and healthy ageing,"* and therefore also allowed for "free-form" answers.

Finally, the questionnaire asked about *"how respondents would assess compliance with above tenets"* (Q3).

The responses to Q1 are summarised in figure 1. The majority of respondents found the first six ethical tenets in the list to be very important ethical aspects for standards and standardisation around ICT for AHA, with "accessibility and usability" selected by *all* respondents (100%) as a key ethical tenet.

"Responsible research and innovation" (RRI) was seen as important by only half of the respondents. In the free-form answers (to Q2) and in personal discussions during events where the ethical framework was presented, it was argued by several respondents that RRI

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[62] The consultation (part of PROGRESSIVE WP4) was e-mailed to stakeholders on July 21, 2017 and again on September 13, 2017. Seventeen responses were received to the online consultation. Furthermore, the AAL Forum (Coimbra, Portugal, 2-4 October 2017) was also used to obtain feedback on the topics of this consultation. Responses confirmed the results of the online consultation and agreed with the proposed ethical tenets.

is 'hard to define as an ethical tenet'. It is indeed true that RRI is more of a framework itself, to support an *"approach that anticipates and assesses potential implications and societal expectations with regard to research and innovation, with the aim to foster the design of inclusive and sustainable research and innovation[63]."* Hence, RRI should arguably not be considered as an ethical tenet on its own, but should be located at the basis of any and all research and innovation projects and activities, including the development of new standards for ICT products and solutions for AHA.
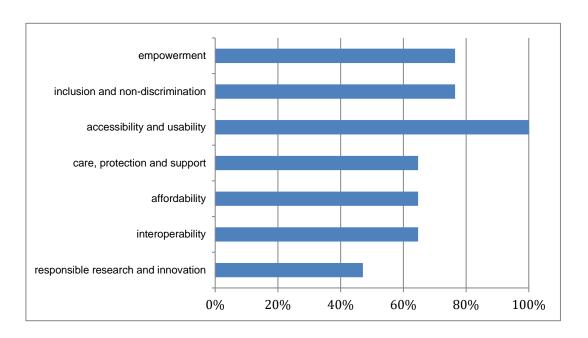

Figure 1 – Percentage of respondents agreeing with the proposed ethical tenets

Thirty percent of the respondents also made a specific remark (in their answers to Q2) that data protection, privacy, and (cyber)security should definitely be included as ethical imperatives in the framework.

Overall, the consultation confirmed to a large degree the importance of the proposed ethical tenets, providing support for an overall ethical framework for standards in the context of ICT for AHA based on these principles.

Furthermore, collaboration and discussion with the PROGRESSIVE User Task Force of Older Persons and with the PROGRESSIVE Advisory Board has provided equal validation of this ethical framework.

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[63] European Commission, Horizon 2020, Responsible research and innovation:
https://ec.europa.eu/programmes/horizon2020/en/h2020-section/responsible-research-innovation

In terms of the assessment of compliance to standards, the main proposals made by questionnaire respondents and Task Force members were to:

- work with user panels (when developing or assessing the appropriateness of specific standards);
- set up a "checklist" that could be used by standards developers in order to guide them - and other parties involved.

Involving and working with user panels or asking for user input or feedback is in itself already an act of "inclusion" and "empowerment", and so it immediately responds to an ethically underpinned approach to standardisation. This provides important backing of the work that is done within the PROGRESSIVE project around co-production, where a 'guide on user co-production in standardisation for Active and Healthy Ageing',[64] has been developed which provides various methodologies that can be used to 'co-produce' standards with users/older persons.

A factsheet on this 'Ethical Framework' will be produced and will allow standards developers (and other stakeholders) to check or even 'rate' their work to see if the standards that are being developed take into account the various ethical tenets.

6. Looking to the Future

The fact that older people are not a homogenous group must never be overlooked. There are differences in the *healthy* life years expectancy between countries, gender and socioeconomic groups. The range of ages considered by policy makers and others tends to be from 50 onwards. But it is important to note that the 'oldest old' are often disregarded in policy making because there are no separate statistics about them (traditional cohorts are from 50 or 55 to 64 and 65+, which basically results in an invisibility of the specific needs and habits of the older old).

The 50+ age group represents a large and increasing proportion of the population, and definitely also includes those with still many years of employment and active, healthy life to come. Current economic and social factors mean that more people in the European Union who are currently in their 40s, 50s and 60s will need to stay in paid employment longer than might have been previously expected. Adapted or assistive technologies and services at home and in the workplace, therefore will become even more important to enable people to support themselves and continue to work later in life. This is explored in more detail within

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[64] Guide on User Co-production in Standardisation for Active and Healthy Ageing, NEN, https://www.nen.nl/Normontwikkeling/Progressive.htm

the PROGRESSIVE project through the development of guidelines and roadmap for standards around ICT for AHA for smart homes and communities that are age-friendly.

In addition, as technologically skilled people age, this cohort brings new challenges and opportunities for ICT for AHA. Such people are likely to already be engaged in the use of ICT at work and socially, and so the adoption of different technologies that may relate to their independence, care and support becomes easier.

It is acknowledged, however, that people 'remain' with the technologies that they use either in their youth or in the prime of their lives. Hence, it is not necessarily evident that today's 40-60 year olds will favour the latest/emerging technologies once they get older, meaning there will always be that need for adapted technologies that take into account the specific needs and wishes of older people. And those who are very old, often frail and who are nearing the end of their lives may need different, and/or higher, levels of what is often personal support that may supplement of support the use of ICT.

Overall, it can be foreseen that some ethical concerns will grow. The new ethical concerns range from the risk of loss of human contact through ICT and remote monitoring to concerns about privacy. Ethical standards, based on the tenets pointed to in this preliminary report, would be a step towards inclusive and effective ICT for AHA.

7. ANNEX 1 – Consultation (questionnaire) on the Ethical Tenets of ICT Standards for Active and Healthy Ageing

Ethical Tenets of ICT Standards for Active and Healthy Ageing

We - as PROGRESSIVE project partners - believe key ethical tenets need to apply to assess key aspects of 'fitness for purpose' of standards and the standardisation process. This questionnaire aims to validate with you the core ethical tenets to consider when it comes to ICT standards for active and healthy ageing.

Question 1: Please select from the list below the ethical tenets that ICT standards for active and healthy ageing should follow:

- ☐ empowerment
- ☐ inclusion and non-discrimination
- ☐ accessibility and usability
- ☐ care, protection and support
- ☐ affordability
- ☐ interoperability
- ☐ responsible research and innovation

Question 2: What other key ethical tenets should drive the ICT standardisation process for active and healthy ageing?

Question 3: How would you assess the compliance with the tenets above? *(Please provide us with references if you know any methodology to assess some of the principles above.)*