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Working Paper

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Suggested Citation: Ake-Kob, Alin et al. (2022) : Position paper on ethical, legal and social challenges linked to audio- and video-based AAL solutions, University of Alicante, Alicante, <https://zenodo.org/record/7326184>

This Version is available at:

<https://hdl.handle.net/10419/266350>

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Position paper on ethical, legal and social challenges linked to audio- and video-based AAL solutions

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This publication is based upon work from COST Action GoodBrother - Network on Privacy-Aware Audio- and Video-Based Applications for Active and Assisted Living, supported by COST (European Cooperation in Science and Technology).

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

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¹More information about the authors is available on the GoodBrother (COST Action 19121) website: <https://goodbrother.eu>.

Introduction

Active Assisted Living (AAL) technologies aim at improving the health, quality of life and well-being of older people and people living with frailty. AAL systems use various sensors to monitor an environment and its inhabitants and gather information to describe events, persons, objects, actions and interactions. Recent advances have given AAL devices the ability to 'see' and 'hear' through the use of cameras and microphones that are integrated into the devices'. However, their use can be seen as intrusive by some end-users, such as assisted persons and professional and informal caregivers.

In this position paper, we have used Alan Cooper's² persona technique to illustrate the utility of audio- and video-based AAL technologies. Therefore, two primary examples of potential audio- and video-based AAL users, Anna and Irakli, serve as reference points for describing salient ethical, legal and social challenges related to use of AAL.

These challenges are presented on three levels: **INDIVIDUAL**, **SOCIETAL**, and **REGULATORY**. For each challenge, a set of policy recommendations is suggested.



Anna
Older adult

- ▶ 77 years old, retired.
- ▶ Living alone (widow) in an urban area of Poland.
- ▶ Using an analogue mobile phone.
- ▶ Has a history of falls, which usually happen in the bathroom at night.

Her son, Piotr, who lives in a different part of the same city, has decided to provide her with a video monitoring technology that sends him and her healthcare provider an alarm signal with an image if a fall occurs. Anna is concerned about her privacy. She is afraid that the camera in the bathroom will allow someone to see her naked. Having a camera at home makes her uncomfortable, as she will feel like she is being watched all the time. Moreover, Anna frequently has her friends over to visit in her home and fears their reaction to being monitored. She fears that they will avoid her and that she will grow lonely.



Irakli
Care facility manager

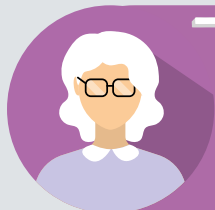
- ▶ 40 years old.
- ▶ Professional caregiver and manager of a care home for 50 people.
- ▶ He uses a smartphone, tablet, and laptop.

One of the main problems that Irakli faces in his facility is managing falls among residents. Irakli has been investigating possible solutions and has discovered video-based smart monitoring systems, which can help with fall prevention and fall detection. The solution also seems to be cheaper than other possible options. However, Irakli needs to consider issues arising from the installation of cameras from a legal and ethical perspective. He needs to understand the perspectives of residents, caregivers and family members regarding use of cameras. He must comply with the country's audio and visual information processing legislation.

²A. Cooper, About Face: The Essentials of User Interaction Design. Foster City, California: IDG Books, 1995.

INDIVIDUAL LEVEL

1. Autonomy and informed consent



Anna wants to preserve her autonomy and be able to live at home without support, with her informational privacy intact. To balance these two needs, she must be provided with clear information regarding the technology which can help her live at home but may impair her informational privacy to a certain degree. The trade-offs between the two values must be made clear to Anna in order for her to make an informed decision. Piotr wants to help Anna make the best possible decision based on her degree of autonomy. This decision should protect maximum beneficence and be based on clear information about the technology.



In addition to complying with legal requirements, Irakli should provide information to residents or their relatives if residents have lost autonomy, on how the technology has addressed ethical concerns related to data and privacy of older people living in the facility. The care workers should be included in this process.

Policy recommendations:

- 👍 Healthcare units overseeing management of ethical medical principles, such as autonomy, should produce means of communication (e.g., short videos or brochures) to reach relatives of older people like Anna, and managers of facilities, like Irakli. These means need to describe, in accessible terms, the importance of safeguarding the relevant principles when implementing and using audio- and video-based AAL systems. This can include showing how the technology works, how privacy-by-design approaches have been incorporated into the technology and how one can stop using the technology.
- 👍 Governments should provide financial and human resources to healthcare units in order to democratise information. Misuse of audio- and video-based AAL systems or their counterpart - unfounded scepticism - can be prevented by transparency and information.

2. Technology-driven isolation or solitude



Anna is afraid that installing the device will cause her friends and relatives to stop visiting her, either because they feel uncomfortable with it or because it will make it easier for them to monitor her from a distance. On the other hand, she finds the device useful because she feels reassured knowing someone can come and help her if she falls.



Irakli is afraid that installation of the device may lead to it replacing routines based on physical monitoring, which could be appropriate for some residents of the facility, but not for others.

Policy recommendations:

- 👍 Governments should map the strengths of older citizens to identify how they may wish to keep contributing to their local communities, to prevent them from being isolated.
- 👍 Governments should develop strategies to foster intergenerational solidarity by organising activities where citizens of different ages can interact, such as recreational activities or meetings where they can organise to help each other based on their respective strengths.
- 👍 Facilities need to be supported with free training and tools that help managers easily identify and decide what residents may be benefited from the use of AAL devices.

3. Privacy and consistent monitoring concerns with Active Assisted Living



- 👍 Help Anna overcome the feeling of surveillance and invasion of privacy.
- 👍 Assist Anna in dealing with potential changes to her daily routines (e.g., privacy-enhancing behaviours) and adaptations caused by monitoring.



- Irakli should protect the privacy of the care facility residents and employees, as much as possible.
- Irakli needs to alleviate surveillance concerns among the care facility residents, their family members and facility employees.

Policy recommendations:

- 👍 Ensure maximal involvement of facility residents, their family members and facility employees in the technology adoption process.
- 👍 Educate decision-makers on best practices in privacy protection and appointing a data controller.
- 👍 Integrate multi-stakeholder perspectives.

4. Digital literacy



- Ensure Anna understands how the technology works, the possible options regarding use of the technology - e.g., not having the camera on in the bathroom - and how the audio-visual data is stored.



- Ensure Irakli understands how the technology works and can explain it to the end-users.

Policy recommendations:

- 👍 Develop practical guidelines for the end-user and the carer, potentially aided by audio-visual material that is easy to understand (e.g., instructional videos).
- 👍 Provide both technical and pedagogical training to caregivers, so they can explain how to use the AAL technology to the end-users, simply and effectively.
- 👍 Raise awareness about online privacy implications and regulations.
- 👍 Implement long-term and regular digital education.

5. Universal design vs value sensitive design



- Anna needs a video-based monitoring system designed and adapted to her values.
- Anna would prefer the video-based monitoring system to be personalised, as opposed to having a universal design and features.



- Irakli would like to avoid implementing video-based monitoring systems without informing care home users.
- Irakli should not make a value trade-off between healthcare monitoring and surveillance in the implementation of video-based monitoring systems.

Policy recommendations:

- 👍 Technology developers need to involve users in the design and implementation of video-based smart monitoring systems.
- 👍 Public bodies and technology developers need to assess and review the user needs and values concerning design and implementation of video-based monitoring systems.
- 👍 Governments and policymakers should require the design and implementation of video-based smart monitoring systems to be adapted to individual needs.

SOCIETAL LEVEL

6. An organisational culture for ethical excellence



- Intermediary healthcare providers helping relatives use audio-video AAL devices need to ensure that their staff are trained regarding ethical use.
- Information and communications technology (ICT) companies and organisations lack tools that allow developers and researchers to acknowledge and understand Anna's concerns and to find ways to overcome her fears and challenges by working in multidisciplinary teams.



- Provide clear explanations to the healthcare workers in the facility on how each device's development has tackled ethical concerns related to data and privacy, and how the devices will be ethically integrated into healthcare routines to avoid clashes.
- Social care organisations need clear explanations that allow care providers and managers to understand and easily describe to users, workers and volunteers how each specific AAL product and service tackles ethical challenges.

Policy recommendations:

- Provide ICT companies and healthcare organisation managers with access to comprehensive guidelines and tools that allow them to implement ethical excellence processes and procedures adapted to their specific needs (e.g., CEN/TS17834:2022 European Professional Ethics Framework for the ICT Profession). Training should be complemented with communication materials written in accessible terms.
- Governments should consider providing financial support to ensure that additional training hours are compensated as working hours.
- Develop information and communication materials for older adults explaining the ethical challenges considered during development of digital tools and how they were overcome for adequate and compliant use, to promote trust and citizen empowerment.

7. Lack of access to equally distributed care



- Connectivity requirements for AAL are high but constant connectivity is not guaranteed. Constant system functionality is critical, and there cannot be any blackouts.
- Anna would find it difficult to get support for fixing the system if it malfunctioned.
- The system is expensive to install and maintain, placing strain on Anna's pension and savings.
- Increased digitisation of healthcare services leaves older and less tech-savvy citizens behind.



- The care home suffers staff shortages and the ICT technologies make it impossible for the system to be implemented in time.
- The responsibility for carrying out a thorough analysis of the system's capabilities, benefits and risks is given to an already strained and stressed workforce, so finding time to make sound decisions is a challenge.

Policy recommendations:

- Provide better digital infrastructure (e.g., high-speed broadband internet).
- Provide/offer subsidies to at-risk groups for installation of AAL systems.
- Ensure low-threshold support, e.g., an easily accessible 24/7 phone line.
- Keep non-digital alternatives in addition to digitised healthcare provision.
- Make it more attractive to become a caregiver: information and image campaigns in addition to greater job security and better pay.

REGULATORY LEVEL

8. Legal complexity



- Anna finds it difficult to understand her rights and navigate the complex legal framework.
- Anna is unsure of what obligations providers of AAL have and how she and others can ensure compliance with these obligations.



- Irakli uses AAL, but does not know what rights he and his patients have, nor is it clear to him what obligations arise for AAL providers and where to go in case of questions relating to the data processing, the security of the processing, technology malfunctions, liability issues relating to such malfunctions, etc.

Policy recommendations:

- Streamline legal compliance via practical guidelines that break down the rights and obligations of end-users. To this end, legal technologies that help guide a user through the complex legal framework can be implemented (e.g., simple decision trees that help determine the applicability of certain legislation and provide the user with recommendations).
- Reduce legal jargon and write legislation in clear, logical sentences. Follow and pursue guidelines that are pushing for more precise legislation, such as initiatives that look into making legislation 'digitally ready'.
- When communicating with the end-user, use visualisations or audio-visual tools to explain rights and obligations.
- Raise awareness about the consequences of non-compliance and pinpoint how compliance can be enforced and where to lodge formal complaints.
- Ensure that laws are written so they can be translated into a machine-readable format and can easily be embedded into system design at the start of development.

Table 1. An overview of the current legal framework related to Active Assisted Living technologies in the European Union

Privacy and data protection	The Charter of Fundamental Rights of the European Union, General Data Protection Regulation (GDPR), e-Privacy Directive, e-Privacy Regulation, Fair Information Principles
Cybersecurity	NIS Directive (and Digital Service Providers Regulation), Cybersecurity Act, NIS Directive II, Regulation on the security of Internet-connected devices, GDPR, Cyber Resilience Act
Product safety and liability	The Charter of Fundamental Rights of the European Union, Product Liability Directive, the Machinery Directive, the Radio Equipment Directive, the Toy Safety Directive, the General Product Safety Directive, Medical Device Regulation
Consumer protection	e-Commerce Directive, Digital Service Act, Digital Market Act, Platform to Business (P2B) Regulation, Directives on Consumer Protection
Intellectual property	The Charter of Fundamental Rights of the European Union, the Information Society Directive, the Directive on Copyright in the Digital Single Market, and the Software Directive
Anti-discrimination	The Charter of Fundamental Rights of the European Union, Employment Equality Directive, Racial Equality Directive, Gender Goods and Services Directive
Artificial intelligence	Artificial Intelligence Act, Initiative on civil liability and digital age
Data governance and information exchange	Data Governance Act, Data Act, Open Data Directive, Free Flow of Non-Personal Data Regulation, European Health Data Space, Single Digital Gateway, Whistleblowing Directive

Note: The legislation that is not yet in force is described in *italics*.
Source: own elaboration.

9. General Data Protection Regulation



- Anna is unaware of her rights under the GDPR and does not know how to take back certain control over data processing.
- Anna is not sure how to assess the trade-offs between highly personalised AAL technologies and more generic ones, in light of the processing of sensitive data.



- Irakli is unsure about his obligations under the GDPR and how to assess the sensitivity of the high-dimensional data he collects.
- Irakli finds compliance challenging since many requirements are vague and even conflicting.

Policy recommendations:

- 👍 Promote public awareness of the GDPR so that individuals understand and invoke their rights. Older and frailer individuals should be seen as an important target group here.
- 👍 Provide additional formal guidelines to make interpreting the law easier for developers of AAL technologies and promote compliance technologies that encode important aspects of the GDPR into products and services.
- 👍 Provide more research funding to support the development of innovative security and privacy by design solutions to complex legal issues.
- 👍 Provide clear guidance on distinguishing between the distinct categories of data – this can be a highly complex task and is currently the subject of significant legal uncertainty among developers of AAL technologies.
- 👍 Suggest methodological approaches that are acceptable to regulators so that controllers can understand how to quantify the risk of re-identification after they opt to anonymise or pseudonymise data.
- 👍 Increase awareness of the fact that pseudonymisation and anonymisation are not 'one-off exercises' and that appropriate security measures are required even when data are pseudonymised or anonymised.

10. Data handling, transparency, and consent



- Anna is in a vulnerable position in terms of consent. The information provided to her may be hard to understand, making consent difficult to get.
- Aside from being informed about what kind of information is being collected, Anna wants certainty about what information must be processed. Anna wants an answer on why the data are being collected and how and by whom they will be used.
- Anna is unsure about whether she needs to get the consent of her friends who come over to visit if she has AAL technologies installed in her room.
- Anna is unsure whether she will become a joint controller if she modifies the AAL product and adds privacy-preserving technology.




- Irakli is unsure how to prove that data subjects like Anna have given consent and also wonders how to structure transparency notices.
- Irakli is unsure how much information processing is needed for the functioning of the AAL technologies.

Policy recommendations:


- 👍 Promote awareness of the fact that the binary and one-off consent model is not suitable in the AAL context, and encourage the development of more flexible, customisable, gradual and progressive control systems (e.g., consider engaging with developers to establish (and validate) new consent tools, such as affirmations of consent through gestures).
- 👍 Promote the development of technical tools to obfuscate bystanders (e.g., computer vision techniques to obscure a bystander's identity when consent has not been provided).
- 👍 Promote the introduction of short, standardised, user-friendly forms for informational documents and consider engaging with developers to create icons that accurately and effectively present all the relevant features of products with respect to data processing.

- 👍 Ensure that the system enables customisations, i.e., different services. If Anna is comfortable sharing more accurate videos of herself, then the system can infer something about her anxiety and provide her with specific help. If she is not satisfied with a granular analysis of her image or video data, she can require the pictures to be blurred immediately. Such customised versioning would enable the system to comply better with the data minimisation principle.
- 👍 Issue-specific guidance, recommendations or codes of conduct on implementing data minimisation principle in assisted living contexts are needed, with a list of reasonable personal data categories to collect in such contexts.
- 👍 Make recommendations on reasonable data retention periods in assisted living contexts.

II. Privacy and security by design



- Anna wants to be empowered to exercise her right to self-determination.
- Anna wants the most privacy-preserving option to be used as the default and to potentially opt for more invasive data processing.
- A key concern for Anna is the security of her data, especially sensitive data collected during service provision.



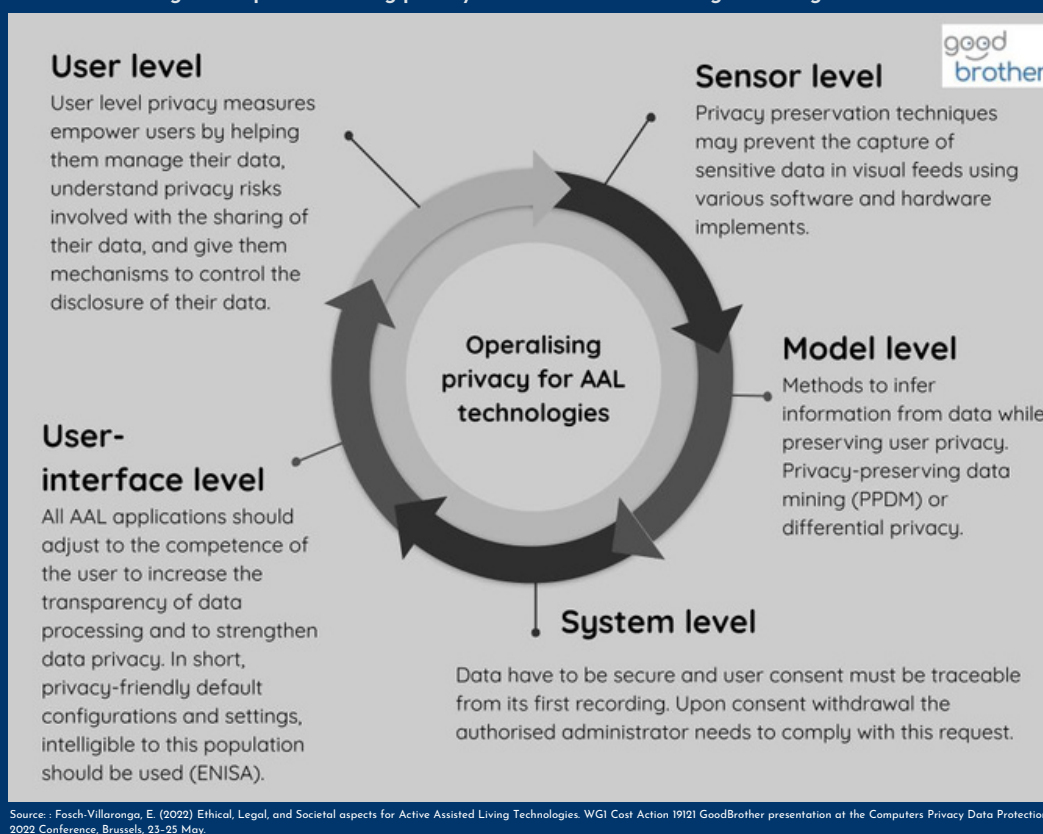
- Irakli is unsure about how to implement privacy-by-design into his practice.
- Irakli wants to know how to balance various needs (privacy protection vs. security) and how to conduct a Data Protection Impact Assessment (DPIA) to document the choices.
- Irakli has heard about cyberattacks against large databases and is afraid that patient data can be leaked.
- Irakli does not know how to safeguard all of the data under his control from the risks related to storage and transmission.

Policy recommendations:

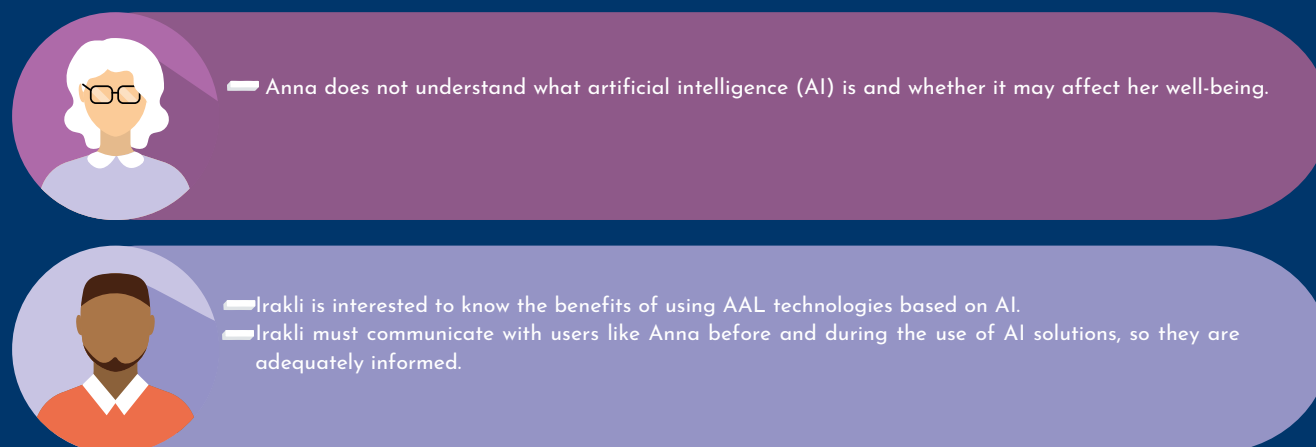
- 👍 Encourage developers and designers to divide each system into a meaningful set of design elements (e.g., user interface (UI) controls) for reviewing and managing users' personal data within and beyond the scope of the designed system and to use clear and accessible language for information dissemination, such as privacy nutrition labels³ to understand potential privacy risks and consequences.
- 👍 Make developers consider data protection by design and default techniques at different system levels to achieve data protection goals in a more concrete and methodologically sound way (see Figure 1).
- 👍 Encourage developers to introduce methods that remove personal or sensitive information (e.g., faces) at the user-interface level after an image has been captured, by employing visual obfuscation, data hiding, secure processing, blind vision and other intervention methods.
- 👍 Increase awareness about edge computing and local-only storing or processing as mechanisms to keep information processing as close to the source as possible in the context of AAL technologies.
- 👍 Provide guidance on the meaning of 'state-of-the-art' so that developers of AAL technologies understand which technical measures will satisfy regulators.
- 👍 Support the development of information management and security standards in the context of AAL technologies.
- 👍 Engage in cyber diplomacy to ensure that there is alignment concerning the international information security requirements for AAL technologies.

³P.G. Kelley, J. Bresee, L.F. Cranor, R.W. Reeder. A "nutrition label" for privacy. In Proceedings of the 5th Symposium on Usable Privacy and Security (SOUPS '09). Association for Computing Machinery, New York, New York, 2009, Article 4, 1-12.

Figure 1. Operationalising privacy for Active Assisted Living technologies



12. Artificial Intelligence Act



Policy recommendations:

- 👍 Provide basic education on AI so that all citizens can have an understanding of how it functions. Make sure this education is accessible to older and frailer individuals.
- 👍 Require rigorous data validation techniques.
- 👍 Require that AI systems are periodically verified to avoid the unintended introduction of biases.
- 👍 Require that sensor data are analysed for correctness, completeness and consistency before feeding them into higher-level algorithms for processing.
- 👍 Require relevant impact assessments of AI technologies, such as DPIAs, human rights impact assessments, ethical impact assessments and algorithmic impact assessments, to mitigate potential risks related to AI.
- 👍 Ensure that new rules regulating AI are fully aligned with existing legal frameworks to avoid inconsistency, fragmentation and duplication of requirements.

13. Medical Device Regulation



Anna is concerned about her physical well-being and the safety of the products used to protect her health.



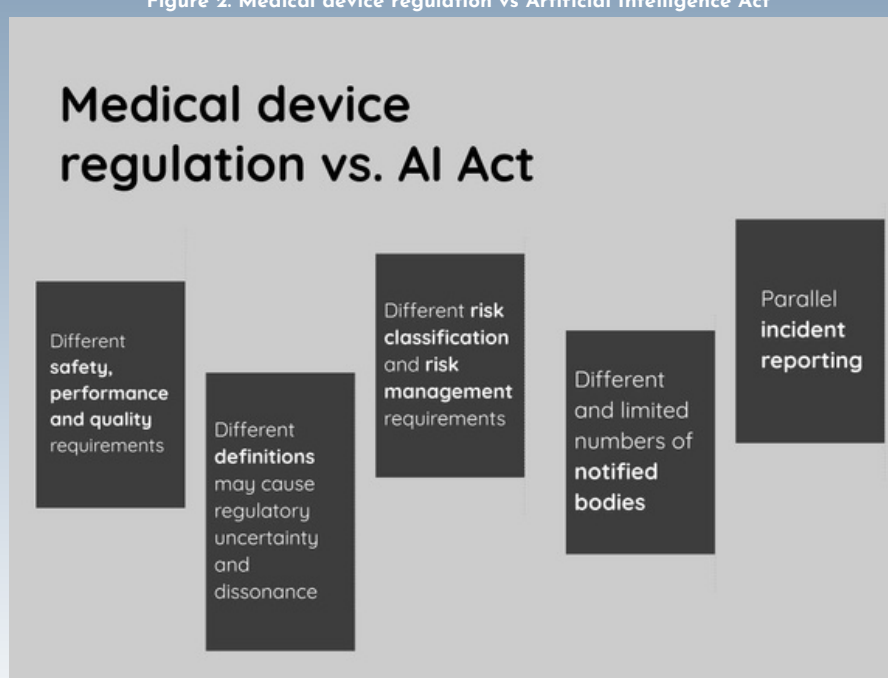
Irakli must be trained to fully understand both the Medical Device Regulation and the possible effects and risks that may arise from the use of medical devices and the data subject's (Anna) consent regarding use of her personal information.

Irakli should be capable of advising users professionally and objectively.

Policy recommendations:

- 👍 Promote awareness that health-monitoring tools used in assisted living contexts may be categorised as medical devices, depending on their intended use and specifications.
- 👍 Provide explicit guidance on distinguishing between health-monitoring tools and medical devices so that developers can better understand their compliance obligations. This distinction determines what rules apply.
- 👍 Ensure that there is alignment between the regulations on AI and the Medical Device Regulation.

Figure 2. Medical device regulation vs Artificial Intelligence Act



Source: Fosch-Villaronga, E. (2022) Ethical, Legal, and Societal aspects for Active Assisted Living Technologies. WGI Cost Action 19121 GoodBrother presentation at the Computers Privacy Data Protection 2022 Conference, Brussels, 23-25 May.

Conclusion

With the primary aim of raising awareness about the potential challenges in AAL design at the individual, societal and regulatory levels, we have provided a set of policy recommendations that can be used by AAL stakeholders and decision-makers. These recommendations align with the recognised approaches to technology design, such as value-sensitive design, ethics by design and privacy and security by design. The aforementioned ideas may steer the development, implementation, regulation and governance of AAL technologies towards more responsible and socially acceptable use. The challenges and recommendations in this position paper will be consistently updated, and we will soon – based on challenges identified herein and in a [white paper](#) – provide a set of guidelines for designers, developers and engineers on managing the ethical, legal and social aspects of AAL technologies.