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DIGITAL SOVEREIGNTY OF OLDER CITIZENS FOR A SELF-DETERMINED USE OF PERSONAL HEALTH RECORDS: E-LEARNING DESIGN AND STUDY RESULTS FROM THE EPA-COACH PROJECT.

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Abstract

Promoting digital literacy and digital sovereignty has become one of the key policies in Europe. Digital sovereignty has been defined as the ability to act and exercise freedom of choice in the digital world. While digital services and applications offer great opportunities for the older generations to live independently and communicate with family and friends, the digital sovereignty of citizens including older adults has become a concern of policy-makers. Hence fostering digital sovereignty has been seen as an important objective for a self-determined use of digital media including control over own data. This paper presents an approach to designing an e-learning application for senior learners, which is aimed at fostering the digital sovereignty of older citizens in using Personal Health Records (PHR) in Germany. This e-learning application, called ePA-Coach, is designed in a research project funded by the Federal German Ministry of Education and Research to offer an opportunity for citizens 65+ to acquire digital skills needed for the self-determined use of PHR. The paper presents the digital literacy framework for exercising digital sovereignty related to PHR, which was developed in the ePA-Coach project based on the European Digital Competence Framework. We describe how this framework was applied in the design of micro-learning units and combined with gamification techniques from the Octalysis framework. Finally, we outline results from two exploratory studies with older citizens which revealed strong preferences for design elements related to digital sovereignty such as choice and control of the learning progress.

Keywords:

Digital sovereignty, digital literacy, digital citizenship, personal health records (PHR), electronic health records (EHR), Digital Competence Framework (DigComp), micro-learning, senior learners, older citizens.

Introduction

Digital citizenship has been traditionally defined in relation to the opportunities and abilities for the use of technology with the aim of participation in society (Mossberger et al. 2007). While citizenship has focused on the relationship between citizens and the national state (Bennett, 2007), digital citizenship has emphasised individual choices and rights to participate in society, addressing the question of "how the digital facilitates new forms of participation" (Pangrazio & Sefton-Green, 2021, p. 18). From the perspective of the omnipresent "datafication" in the sense of "taking all aspects of life and turning them into data" (Cukier & Mayer-Schönberger, 2013), digital citizenship has been linked to digital literacy and its specific elements, such as (personal) data literacy, as a response to these socio-technological challenges (Pangrazio & Sefton-Green, 2021). Traditionally, data literacy emphasised normative descriptions of performance, evidence, skills, knowledge, attitudes, and behaviours, following influences from workforce demands (Pangrazio & Sefton-Green, 2021; Örtegren, 2022). Similarly in education, normative approaches to digital literacy have been common or even over-represented (Örtegren, 2022). In Europe, the "DigComp" framework (Digital Competence Framework) developed by the Joint Research Centre of the European Commission, has highlighted the use of digital technologies not only for work and learning but also for inclusion and participation in an increasingly digitalised society (Ferrari 2013; Redecker 2017). The "DigComp" framework defines "engaging in online citizenship" as one of the core dimensions of digital competence. Online citizenship means "to participate in society through online engagement, to seek opportunities for self-development and empowerment in using technologies and digital environments, to be aware of the potential of technologies for citizen participation" (Ferrari 2013, p. 5). In this sense, the "DigComp"

framework has recognised that digital citizenship and participation in society have become a matter of competence.

It seems that in the face of the advances of digitalisation and datafication, the focus of digital literacy has shifted from mastery to sovereignty. The notion of "digital sovereignty" has been used in reference to the state, economic and individual levels (Pohle, 2020). Individual digital sovereignty has emerged as a response to concerns about citizens' control over their own data and has focused on empowering citizens to make use of digital technologies in a responsible and self-determined way (Pohle, 2020). Digital sovereignty goes beyond knowing how to download an app or use an online service and includes "the ability to assess the consequences of one's own online actions" (Stubbe, Schaat & Ehrenberg-Silies, 2019). Therefore, "the development of digital literacy in all stages of life has been seen as the basis for sovereign action in the digital world" (Pohle, 2020, p. 17).

While digital services and applications offer great opportunities for the older generations to live independently and communicate with family and friends, older adults also need to know how to use digital media in a self-determined way and understanding what happens with their data (Stubbe, Schaat & Ehrenberg-Silies, 2019). Promoting digital literacy and digital sovereignty of older citizens has entered policy-agendas in Europe. In 2022 the Council of Europe published "The Digital Era? Also my Era!", in which it calls for promoting digital literacy among senior citizens, to ensure equal access to digital services, provide training to navigate digital environments, and a range of measures for digital inclusion of older citizens (Hermans, 2022). While many spheres of life of older citizens have been impacted by digital technologies, information and services related to health (eHealth, mHealth) often play a central role. Numerous digital technologies and services have been developed to support healthcare-related activities such as diagnosis, consultation, treatment, documentation and communication with senior patients. The use of such digital health services is closely linked to digital literacy. Fostering digital literacy of older citizens, who may be less digitally experienced and competent, has become an important equity issue (Millard A, et al, 2018).

The introduction of Electronic Health Records (EHR) and Personal Health Records (PHR) has aimed to enhance digital health services. While the EHR has been used to increase the quality of healthcare and serve as digital repository with patients' information controlled by health organisations (e.g. hospitals, laboratories, clinics), the PHR has been used to enable citizens to store and manage their own health-related data and serve as health records controlled by the patient (Roehrs, 2017). EU member states have applied different legal approaches to the implementation and regulation of EHR/PHR. For example, in Germany, the Appointment Service and Supply Act (TSVG), requires health insurance funds to provide policy-holders with PHR (called elektronische Patientenakte, ePA) from 2021 onwards. In Germany, health insurance funds offer different PHR systems to their policy-holders and allow patients to electronically collect, manage and share health-related data, such as medical history, medication, treatment reports, and vaccinations[1]. PHR enables patients to choose whether to share or not to share their health data with healthcare stakeholders (Roehrs, 2017). By allowing patients to make decisions about their digital health records, PHR follows a patient-centric approach (Buchem et al., 2023). Key challenges in PHR adoption include concerns about privacy, security, insufficient measures for impaired people, usability issues, and unclear benefits (Segall et al, 2011; Taha et al., 2014; Roehrs, 2017; Poss-Doering et al., 2018).

Previous studies have shown that the use of the PHR requires a set of competencies ranging from the general capability to use digital technologies to the specific skills in the management of digital medical records according to regulations within a given national healthcare system (Day et al., 2012). For older citizens, who typically have less experience using digital technologies, using PHR may be a barrier to equal participation in the healthcare system (Gellner et al. 2021). The study by Taha et al. (2013) showed that both middle-aged adults (40-59 years) and older adults (60-85 years) experience difficulties in using PHR, such as managing common health tasks, reviewing and interpreting lab results, which is especially challenging for older adults with lower numeracy skills and less technology experience (Taha et al., 2013). Further studies pointed out that the needs of specific populations, including older adults, have to be taken into consideration when designing and deploying PHR. The study by Day et al. (2012) showed that computer and health literacy is one of the three key factors influencing how effectively patients are able to use PHR, the other two factors being an individual perception of convenience

[1] https://www.gesundheitsindustrie-bw.de/en/article/news/ehr-and-phr-digital-records-in-the-german-healthcare-system

and perceived transparency. Additionally, age-related changes in cognitive abilities, e.g. working memory, processing speed, and reasoning, may affect the ability of older adults to perform more complex PHR tasks (Taha et al., 2013). Since older generations usually have less experience in using digital technologies, the introduction of the EHR/PHR has called for measures aimed at fostering digital literacy and the digital sovereignty of older adults. Ensuring that older adults are given an opportunity to acquire the competencies necessary for a self-determined use of PHR is important from a societal perspective (Gellner, Kaiser & Buchem, 2021; Buchem, Kauth, Kirschen & Katzer, 2023). The UN Sustainable Development Goals, especially Goal 3.8 "Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all"[2] are relevant for digital sovereignty in using PHR by older citizens.

The ePA Coach e-learning application presented in this paper aims to offer an opportunity for citizens 65+ to acquire digital skills needed for the use of PHR in Germany. The application was developed in the ePA-Coach project, a three-year R&D project funded by the German Federal Ministry of Research and Education. The ePA-Coach project aims to foster the digital sovereignty of older citizens in the context of PHR and to deliver an interactive learning application that allows senior learners to acquire digital competencies relevant to digital sovereignty in using PHR. Further sections present the competence framework developed in the ePA-Coach project with the aim of fostering the digital sovereignty of older citizens in using PHR, the design of the ePA-Coach application based on this competence framework, and the results from two exploratory studies with older citizens aimed at understanding which e-learning design elements are valued by senior learners and how these are related to digital sovereignty. The paper ends with conclusions and recommendations for further research.

Competence Framework for Digital Sovereignty

The digital competence framework developed in the ePA-Coach project is based on the European Digital Competence Framework, the "DigComp" framework (Vuorikari et al, 2022). The DigComp framework provides a frame of reference that can be adapted to the needs of different populations. The key five areas of competence are (1) Information and data literacy (the ability to search, evaluate, and manage digital information and data); (2) Communication & collaboration (the ability to communicate and collaborate effectively using digital technologies); (3) Digital content creation (the ability to create and edit digital content such as text, images, and video); (4) Safety (the ability to use digital technologies safely and protect personal data and privacy); (5) Problem-solving (the ability to use digital technologies to solve problems and make informed decisions). Each competence area includes several competencies subdivided into four levels: (1) Foundation; (2) Intermediate; (3) Advanced; (4) Highly Specialised. The digital competence framework in the ePA-Coach project adapted by the DigComp structure and defined five key competence areas in relation to the use of PHR by older citizens: (1) Basics & access (basic knowledge about PHR, registration, authorisation); (2) Handling of information & data (managing data, searching, filtering, deleting); (3) Communication & collaboration (exchanging health data with healthcare stakeholders, allowing and revoking access, authorising a representative); (4) Digital content creation (adding data and information to PHR); and (5) Safety (understanding PHR terms of use, declaration of consent, termination, revoking termination). The "problem-solving" competence area was addressed in the ePA-Coach framework by adding practical tasks across all five dimensions. Compared to the DigiComp framework, the number of levels was reduced to three (Beginner, Advanced, Expert) with the aim of reducing the complexity and enhancing understanding among senior learners. The three levels have been differentiated into complexity, autonomy, and cognitive levels (Figure 1). A detailed overview of the ePA-Coach competence framework was described by Gellner, Kaiser & Buchem (2021).

[2] https://www.un.org/sustainabledevelopment/health/

	Level 1 Beginner	Level 2 Advanced	Level 3 Expert
Complexity Level	low, basic and easy tasks	higher, clearly defined tasks	highest, best practices for given tasks
Autonomy Level	independant, with guidance if needed	independant, with minimum guidance	guiding others, adapting to others' needs
Cognitive Level	remember	understand and apply	apply

Figure 1. The structure of the ePA-Coach digital competence framework in the context of the PHR use.

The competence framework was then used to allocate and develop e-learning units at all three levels. There is a progression in the design, with the beginner units offering more theoretical information and tasks in the form of single/multiple choice, true/false, fill the blanks to sort the paragraphs questions, and the advanced units offering more complex and application-oriented exercises, for example in the form of embedded click dummies, which are used to practice real-life challenges related to the use of PHR. Similarly, the support in the units is scaffolded as the learner becomes increasingly confident in using the application. At the highest level (advanced), there is no help beyond the description of the scenario and it is possible for the learner to take the wrong path.

The design of learning activities at each level is informed by the Octalysis framework(Chou, 2019). The Octalysis framework defines eight core drives as fundamental types of motivations in both gamified and non-gamified contexts. The Octalysis framework suggests that these core drives motivate and engage individuals in various activities, including learning, and that designers and developers can use these core drives to create engaging and motivating learning experiences. Based on this approach and starting from an extensive literature review, followed by interviews with experts from the project team and the evaluation of preferences of senior learners, a senior-friendly gamification approach was developed to enhance motivation to learn and to use the ePA-Coach application. Figure 2 shows the final version of the Octalysis framework adjusted to the preferences of senior learners using values from the two exploratory studies described below.

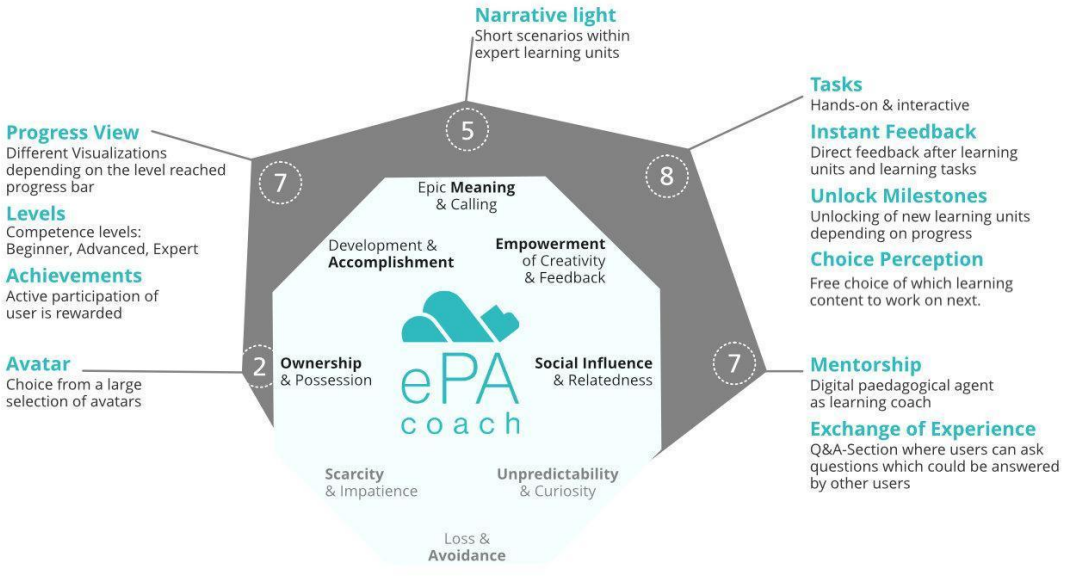

Figure 2. The Octalysis framework in the ePA-Coach project.

Overall, the ePA-Coach application was designed with a senior-friendly UX in mind by making the GUI very clear and senior-friendly, e.g. the interface has high contrasts, a larger, customisable font, and a clear typeface.

Design

The competence areas which are relevant to the ePA-Coach application were elaborated and prioritised with the help of the DigComp reference framework and the formulations were adapted to the context of ePA-Coach. Within the five competence areas, e-learning units were designed for the three levels, i.e. beginner, advanced, and expert. The entire program consists of 28 learning units, i.e. 12 beginner units, 11 advanced units, and 5 expert units. All units are designed as micro-learning units with micro-contents (Buchem & Hamelmann, 2010). Learners can freely choose what they want to learn next. The choice is only limited in that, within a competence area, all learning units of a competence level must first be completed in order to unlock the next level. Unlocking a level corresponds to the gamification techniques *Unlock Milestones* and *Levels* from the Octalysis framework. There are two ways to display competence areas in the ePA-Coach application – as clickable tiles with a progress bar (gamification technique *Progress View*) for the representation of the personal learning progress, or as a fictitious map (gamification technique *Narrative*) with marked locations for a competence area (Figure 3).

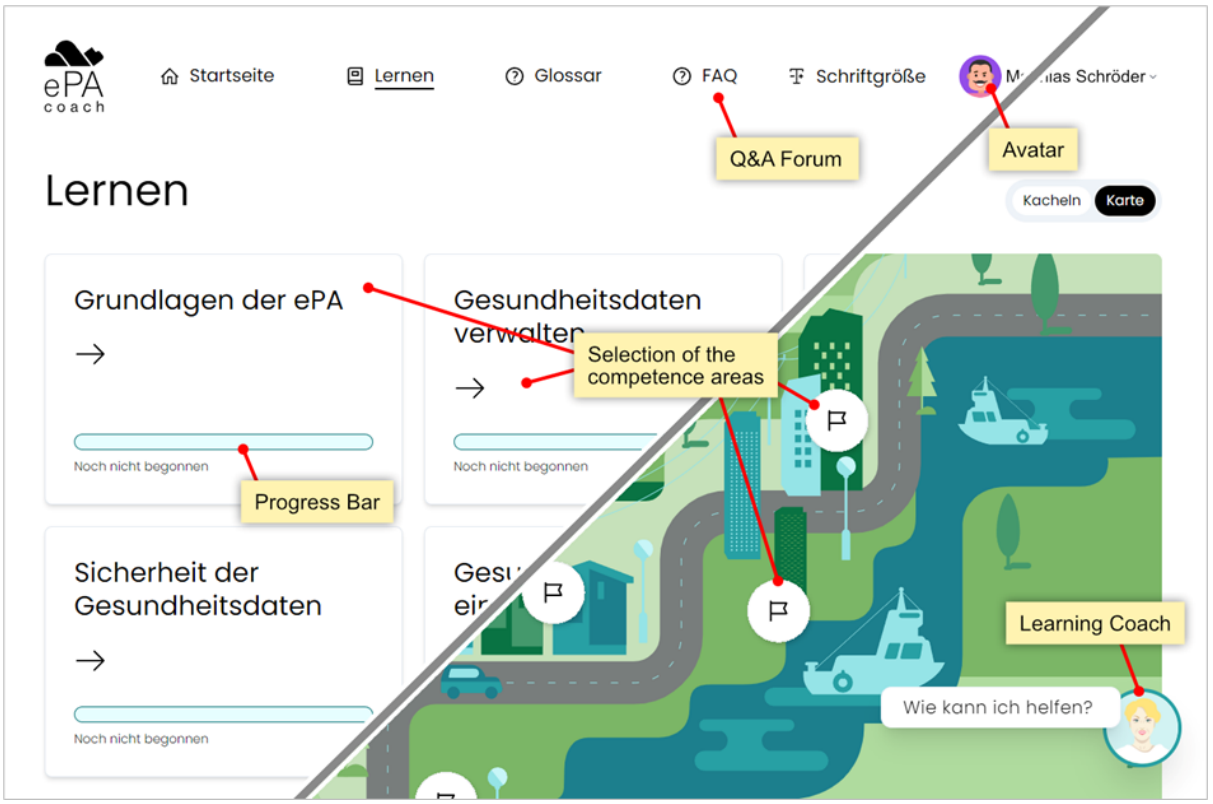

Figure 3. The ePA-Coach application, the learning area overview

As visualised in Figure 3 the basic design (left section) is oriented to the needs of senior learners, e.g. calm design, discreet use of colours, high contrasts, and a large and adjustable typeface. The element “avatar” can be selected by learners and used for interaction in the Q&A section. The AI-based “learning coach” (right, bottom section) is available to learners at all times and offers context-dependent assistance, and refers to appropriate resources, e.g. glossary.

The 28 learning units vary in complexity and are structured from general to specific, following the 3-level structure. Units at different levels were designed according to different instructional design models. *Beginner units* are based on the instructional design of *Nine Events of Instruction* by Gagné et al. (1992). Learning content is acquired independently by learners and consolidated with interactive exercises, such as single and multiple-choice, gap-filling texts, sorting tasks, and a final task. *Advanced* units are structured according to the *4C/ID* model by Kirschner et al. (2013). Here, practical learning tasks (gamification technique *Tasks)*, must be completed via simulations, which are implemented as click dummies with sub-tasks related to specific challenges. The support decreases with the growing complexity of the tasks (scaffolding). First learning tasks contain direct click instructions. Further tasks include only indirect instructions. The last tasks are completed with

little support, in the form of hints. *Expert units* synthesise information from previous units and acquired knowledge is applied. This is done by first describing a scenario (gamification technique *Narrative)* and learners are challenged to apply previously acquired knowledge to solve more complex tasks in this scenario. In all learning units, knowledge and skills can be assessed and consolidated through learning tasks. These do not have any influence on the completion of a unit. Some tasks in the form of learning checks must be completed correctly in order to complete a unit and to increase progress in the competence areas. The gamification technique of *direct feedback* is applied to inform learners about their learning progress and possible difficulties. Learners can use a Q&A forum to share experiences with other learners (gamification technique *Exchange of Experience*). Active participation in the Q&A is rewarded (gamification technique *Achievements)* by ratings of answers by other learners.

Results

Based on the findings from two exploratory studies, the final e-learning concept and design were developed in several iterations. The recruitment of participants was primarily undertaken by the project partner Charité – Berlin University of Medicine, using an internal subject database, and with the help of stakeholders such as Berlin Senior Citizens' University and LMU Munich. The first study helped to gain insights into the assessment of the core drives proposed by Chou (2019). The results are based on the responses of a total of 41 senior learners aged 66 to 93 years old (average 74.7 years). The first study was conducted in May 2021. The second study provided insights into the perception of the ePA-Coach application, which was developed based on the iterated concept and taking into account results from the first evaluation. The evaluation began in June 2022 and ended in October 2022, resulting in 46 participants aged 65 to 88 years (average 73 years). Results from both studies were described in detail by Gellner and Buchem (2022) and Buchem et al. (2023). Here we outline results relevant to the discussion about digital sovereignty.

The results of the first study showed that the 41 senior participants perceived the following core drives as particularly motivating: *Development & Accomplishment* and *Empowerment of Creativity & Feedback.* These core drives are closely linked to digital sovereignty, such as development and empowerment. Core drives *Epic Meaning & Calling* and *Loss & Avoidance* was perceived as rather demotivating. Another aspect that emerged from the first study was related to how different gamification elements were perceived by older adults in the context of PHR. The results showed that *Instant Feedback* and *Practical Tasks* were perceived as most motivating, followed by *Unlock Milestones*, *Progress View*, *Levels*, and learning with a *Narrative*. Some of these elements are again closely related to digital sovereignty, especially in relation to controlling and monitoring own progress. The fourth main aspect examined in the first study was player types, which were derived from the *Gamification User Types Hexad Scale* by Marczewski (2015), which is a framework for understanding user motivations and it is based on six key motivational styles or player types. The study revealed that senior participants considered themselves to belong to *Free Spirit* and other intrinsic player types such as *Socialiser* and *Philanthropist*. These again closely correspond to the concept of digital sovereignty.

The results from the second study related to the design of the ePA-Coach application showed that the inclusion of *Instant Feedback* was valued highly by all 46 senior participants. The strong preference for this design feature was followed by the visualisation of the individual progress using the *Progress View* and the division of learning components into levels using *Steps & Levels*. The two latter gamification elements are connected to the core drive *Development & Accomplishment,* which was rated as the most motivating element, the same as in the first study. The second study revealed that the implementation of the core drive *Empowerment of Creativity & Feedback* received higher ratings than elements belonging to the core drive *Development & Accomplishment*. *Empowerment* included elements of *Instant Feedback, Unlocking Milestones*, *Practical Tasks,* and *Choice Perception*. Compared to these results, the core drive *Social Influence & Relatedness* was not perceived as valuable. This core drive included four elements: *Mentor* for learning support, *Experience Sharing* with other users, *Friendship* for adding acquaintances from real life as digital friends and seeing *Online Status*. All of these elements received neutral to negative ratings. Gamification elements belonging to the core drive *Ownership & Possession*, i.e. having your own *User Avatar* and *Action Reward* through unlocking more user avatars, also received low ratings. These results indicate that senior learners tend to value elements that enhance their individual digital sovereignty related to making choices, controlling and monitoring progress, and receiving instant feedback as opposed to social aspects related to friends, status, sharing or even mentoring.

Conclusions

This paper presented an e-learning design for enhancing the digital sovereignty of older citizens. This ePA-Coach e-learning application was designed to create an opportunity for citizens 65+ to acquire digital skills needed for the self-determined use of Personal Health Records (PHR) in the context of healthcare in Germany. The digital literacy framework for exercising digital sovereignty related to PHR was developed based on the European Digital Competence Framework and applied to design micro-learning units with micro-content using gamification techniques inspired by the Octalysis framework. The results from two exploratory studies with older citizens revealed strong preferences for design elements related to digital sovereignty. Senior learners perceived *intrinsic* core drives *Development & Accomplishment* and *Empowerment of Creativity & Feedback* with their different elements, such as free choice, hands-on tasks, instant feedback, unlocking milestones, progress view, levels, and achievements for active participation, to be particularly motivating. These results indicate that e-learning designs for senior learners, especially those aiming at enhancing digital sovereignty, should focus on creating possibilities of free choice, monitoring their own learning, hands-on practice, instant feedback, and meaningful achievements for active participation. In contrast, senior participants did not perceive *extrinsic* core drives related to the status, unpredictable tasks, and social influence as valuable. Our results also showed that support by a digital *Mentor* or coach received neutral ratings, indicating that senior participants felt somewhat ambivalent about this kind of support, again indicating a strong need for self-determined use. An interesting result is also the self-assessment of being an intrinsic player type (Free Spirit, Socialiser, Philanthropist) as opposed to extrinsic player types. Most participants perceived themselves to be *Free Spirits* who are characterised by the need for autonomy and freedom of choice, both in movement and in expression, which closely corresponds to the concept of digital sovereignty. Hence it can be concluded that senior learners tend to have a strong preference for different aspects related to digital sovereignty in relation to the design of e-learning. However, it must be emphasised that the results from both exploratory studies must not be generalised. Both studies have obvious limitations related to small sample sizes and the choice of participants from one country only. Future research with larger and international samples could explore in more detail, whether the need for digital sovereignty in e-learning applies to other populations of senior learners, and how this need can be achieved through the design of e-learning applications in eHealth/mHealth.

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