

Article

Elder People and Personal Data: New Challenges in Health Platformization

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Abstract

In Uruguay, as in many countries around the world, healthcare providers are looking to digital technologies to enhance service provision. This includes introducing new data-intensive systems that facilitate connections between healthcare providers and patients and maintaining records of these interactions. This article considers the numeric ability of older citizens to critically assess the implications of platformization and datafication within the Uruguayan healthcare system with a view to identifying implications for digital literacy programs. The ability of older people to manage their personal data within healthcare systems shapes their ability to enact citizenship and human rights. This reality came into sharp relief during the recent Covid-19 pandemic, demonstrating the extent to which core social services have become datafied and digitally mediated, as well as their potential to deepen digital divides where senior citizens are concerned. Critical perspectives on technological change, well-being, and ageing offer useful perspectives on this challenge. Drawing inspiration from these perspectives, in this article, we explore the results of a digital literacy initiative that worked with 16 seniors to explore their experiences of personal data collection within Uruguay's new National Comprehensive Health System. Our approach simultaneously worked to build digital literacy while also revealing the complex relationships and disconnections between the ontological frameworks mapped onto healthcare by systems designers and the reality of older people. In the conclusions, we consider the implications of these observations for seniors' digital literacy interventions that foster seniors' critical understanding of their data subjectivity in the context of local healthcare systems.

Keywords

datafication; digital literacy; health care; platforms; seniors' digital literacy; senior citizens

Issue

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1. Introduction

Van Dijck et al. (2018) understand platforms as a kind of "programmable architecture" and argue that these systems should not be understood as mere intermediaries but as shapers of reality and ways of living. She argues that they are facilitated by new infrastructures for collecting data, and new ideologies about the power of data, which together have allowed for the introduction of new forms of "dataveillance" (Van Dijck, 2014). Further, data-veillance is institutionalised through the mechanisms of datafication (the collection and circulation of data),

commodification (its transformation into tradable entities), and algorithmically driven selection processes that curate interactions "through often black-boxed techno-commercial strategies" (Van Dijck et al., 2018, p. 41). The resulting platforms allow for continuous digitisation and monitoring of people's bodies and practices (Clarke & Greenleaf, 2018), and they also have ontological force (Helles & Flyverbom, 2019), which is to say that they have real implications for the constitution of discursive fields, institutional frameworks, and social experiences.

In these systems, rationally validated consent from data subjects proves to be an ongoing challenge. This is

partly because individuals do not fully understand the links between data transfer, processing, and monitoring (Méndez & Botti, 2021). However, it is also because they find themselves without alternatives to the platforms that increasingly condition access to essential social services. This creates the experience of “surveillance realism” (Dencik & Cable, 2017), in which people are aware of the normalisation of data gathering and their limited possibilities for agency within this new reality. This is often because systems themselves have been designed around modes of transacting that centre data collection and transaction management over situated identities and unique interactions. Furthermore, without effective spaces for complaint, platform users become complicit with the reproduction of platform logic to the detriment of people’s individual rights (Waisbord, 2013).

Gurumurthy et al. (2021) argue that, in stripping people of their identity data, platforms constitute new sites of exploitation in intelligence economies. Platform owners mobilise these data to produce instruments of economic and political control. People and communities lose decision-making autonomy as they become subordinated to the logics of “platformization,” built around the massive rollout of immediate gratification in exchange for personal data. In other words, the reductive logics built into platforms draw on and process data in ways that shape subjectivity and social experience and which overlook the complexity and plurality of human experiences, as in the case of people’s complex and varied experiences of ageing (Cozza et al., 2019; Powell, 2005).

Indeed, digital transformations in healthcare are creating new forms of technological mediation that older citizens have to navigate (Hintz et al., 2017). Past research has demonstrated that technological inequality has a significant and complex impact on older people (Casado-Muñoz et al., 2015; Hunsaker & Hargittai, 2018; Quan-Haase et al., 2018). This group was not only disproportionately affected by the recent Covid-19 pandemic due to the weaker immune systems that accompany age, but it also experienced digital inequality as the population group most excluded from access to information and communication technologies (ICTs), and the internet (Llorente-Barroso et al., 2021; Ramos-García et al., 2021). These conditions, of course, leave seniors at risk of being excluded from health care, but they also put them in the position of not being able to question how their personal data is taken up when they access services.

The importance of digital literacy as a condition for pursuing datafication in healthcare has been recognised for some time (Lun, 2018). But critical scholars have marked a distinction between the technical forms of literacy necessary to participate in digital transformation and the “personal data literacies” required for citizenship given the rise of platformized systems (Pangrazio & Selwyn, 2019). There appears to be a lack of awareness about the risks created by the uptake of personal data within health information systems, and a lack of capa-

city to analyse the costs and benefits of entering into these systems.

Research into seniors who lay on the other side of the “intergenerational digital divide” or “grey divide” has characterised older users as “upstarts,” “digital outcasts,” or “late adopters” (Peral-Peral et al., 2015). These characterisations present a homogenised view of the elderly population and lead to policies that fail to address the specific experiences and needs of diverse elderly populations. Recent studies have even found diverse technological uses among the various “technological generations” found within groups of older people (Loos & Ivan, 2022).

Research also confirms that ICT use significantly benefits older users’ quality of life, but these benefits are not automatic (Friemel, 2016; Sourbati, 2009). To the extent that elderly people use ICTs, they have more access to information, achieve greater autonomy of knowledge and psycho-emotional well-being and against cognitive decline, but the benefits of these flows depend on conscious, attentive, reflective, and moderated use of ICTs (Llorente et al., 2015; Shapira et al., 2007; Tatnall, 2014; Casamayou & Gonzalez, 2017; Li, et al., 2022).

However, the increased use of personal data for the delivery of essential services, combined with cultural assumptions about older people, can increase the exclusion experienced by this sector of the population (Sourbati & Loos, 2019). This demonstrates the need to support the development of digital capabilities among older people to enable their agency and recognise their societal contributions (Ramos-García et al., 2021; Urbina et al., 2022). The pandemic demonstrated that social services increasingly depend on digital capabilities—and that not having these put seniors’ access to services at risk, with negative implications for their rights (Llorente-Barroso et al., 2021, 2023).

Factors such as older people’s predisposition to use or understand technology, their desire to feel useful, or their need to remain integrated into society should be considered (Casado-Muñoz et al., 2015; Colombo et al., 2015). Several studies have criticised visions of technologically driven intervention that ignore the needs, perspectives, and beliefs of older people, or that take up paternalistic approaches (Greenhalgh & Stones, 2010; Joyce et al., 2015; Neven & Peine, 2017; Peine et al., 2014). Studies conducted in Uruguay (Escuder, 2015; Rivoir, Escuder, & Liesegang, 2020; Rivoir, et al., 2019; Rivoir, Morales, & Landinelli, 2020) reflect similar results regarding the motivations, uses, and perception of benefits by the elderly.

Recent studies extend these observations into the spaces of platformization and datafication in order to examine the implications of digitised models of service provision for older populations. These studies consider how procedures and categorisations embedded in information systems produce bias in knowledge about the elderly or how these systems “narrate” the elderly body. Dalmer et al. (2022) argue for abandoning stereotypes around age and socio-technical relations that often

inform the categories used in datafication and assert the need for a more diverse and participatory gerontological-technological culture. In their analysis of self-monitoring and surveillance through health technologies in the context of elder care, they demonstrate the socio-technical power of numbers over ageing bodies. Based on this, we should resist techno-optimism about the potential of these technologies to keep ageing populations healthy and autonomous. Rosales and Fernández-Ardévol (2020) meanwhile point out that platforms are often the product of discriminatory designs and algorithms. Addressing this problem requires that users be given greater control over the data provided to digital platforms and that algorithms be made more transparent.

These works express concern about how the new ontological forces and patterns of surveillance embedded in platformized services represent the needs, desires, or values of older people, and what they mean for policy, systems, and service offerings. More broadly, this literature considers the implications of datafied transactions within platformed systems for the expression of care, meaning and belonging. These considerations were magnified by the recent Covid-19 pandemic. It revealed the extent of the digital systems put in place to mediate everyday services and evidenced gaps in regulatory frameworks meant to uphold the digital rights of citizens (Lago & Rivoir, 2021; Nguyen et al., 2021), illustrating the potential for platformization and datafication to deepen digital inequalities.

2. Context

In 2007, Uruguay implemented results-oriented healthcare reforms to create standardised logics and improvements in service quality (Larrouqué, 2018). Users of the National Comprehensive Health System (SNIS) freely choose their private or public health provider and are entitled to universal and comprehensive health coverage. As of December 2019, 71.5% of the country's population was part of the system, with 23.5% being retirees. Among providers, 77% belong to the private sector, 20% to the public system, and 3% are private insurers (Junta Nacional de Salud Ministerio de Salud Pública, 2019).

In 2011, the SNIS created a national electronic health record (EHR; Agencia de Gobierno Electrónico y Sociedad de la Información y Conocimiento, n.d.) known as *Mi Historia Clínica Digital* or *My Digital Clinical History*. This system establishes a framework for data collection in which information collected by individual healthcare providers can be shared across instances of healthcare provision. Data collection and use is legislated by Law 18.331, which establishes that healthcare providers are responsible for implementing administrative procedures that guarantee the security and custody of EHRs. In addition, Uruguay has a personal data protection law that includes habeas data protections. These two data laws coincide in putting the responsibility for managing personal data on individual healthcare providers. Health providers must

guarantee informed consent, patient-doctor confidentiality, the security and confidentiality of EHRs, protection from tampering, and prevention of data leaks.

The experience of older groups in this system is of particular concern. Over the past two decades, Uruguay has seen strong diffusion of ICTs in the marketplace, accompanied by a dedicated national digital policy agenda to support technological uptake in social services, including healthcare. In 2015, given their experience of digital exclusion, the Uruguayan government created Plan Ibirapitá to provide senior citizens with devices, connectivity, and basic training. While the proportion of people over 65 accessing the internet rose from 12% to 49% between 2010 and 2019, uptake remains low, with only one in three using ICTs daily (Agencia de Gobierno Electrónico y Sociedad de la Información y Conocimiento, 2010, 2019).

While seniors are taking up ICTs in Uruguay, this group has uneven capacity and experience with digitised systems. Meanwhile, healthcare is taking up personal data and ICTs in new ways that have important implications for well-being. For programs such as these to be successful, they must be built on a situated understanding of how seniors experience the SNIS and EHR as well as how new forms of surveillance and new ontological forces map onto their lived reality.

3. Methodology

Given this backdrop, in the balance of this article, we share the results of an action-research intervention that used a set of data literacy interventions to explore seniors' perspectives on sharing personal data with healthcare providers (Reilly et al., 2020). This work was conducted from June to September 2021 in Uruguay, in Spanish, by researchers affiliated with the ICT Observatory (ObservaTIC) at the University of the Republic in Uruguay. It set out to identify older people's understanding of data, their perceptions about the use and value of that data, and their needs regarding the management of their personal data in platformed contexts. This work was carried out as part of a larger study of how people experience datafication in Latin America, funded by Canada's Social Sciences and Humanities Research Council (SSHRC). This work builds on a well-established relationship between ObservaTIC and the Centro Interdisciplinario de Envejecimiento (Interdisciplinary Center on Aging) in Uruguay focused on access to ICTs and digital literacy among older people in Uruguay.

This action-research intervention (Denzin & Lincoln, 2000) drew on "a praxis-oriented research tradition whose objects of concern are mediatization and informatization, and whose key demand is that our work responds to the world learners encounter" (Poyntz et al., 2020, p 8). Interventions were designed to evoke experiences and reflections with sharing of personal data as a starting point for dialogue and learning. This methodology facilitated an in-depth exploration of the

perceptions and visions of participants from their situated point of view (Arriazu, 2007). This action research intervention surfaced diverse experiences and ways of understanding and laid the groundwork for collective understanding and change (Sibilia, 2012). To this end, critical epistemological reflection was essential and aimed at addressing dogmatism around personal data (Vasilachis de Gialdino, 2009). A phenomenological engagement with the data is offered, centred on the perspectives shared by actors, with a view to developing a greater understanding of their experiences. This approach helps us understand participants' experiences and perspectives and is not meant to produce generalisations or representative results.

Initially, the project planned to carry out in-person workshops, but given the declaration of a national health emergency due to the Covid-19 pandemic and because the target population for this research is considered high-risk, community interventions were realised through synchronous Zoom meetings and asynchronous WhatsApp chats. Purposeful sampling was used to identify a small group of participants with diverse backgrounds. Open invitations were offered to people aged 65 and over (the retirement age in Uruguay), residing in any part of the national territory, and affiliated with a private health provider as established by Law 18.211, which regulates the National Integrated Healthcare System. These included providers affiliated with the Collective Medical Assistance Institution, the Private Medical Assistance Institution, or private insurance companies. Invitations were distributed via the National Network of Organizations for the Elderly, the National Organization of Associations of Retirees and Pensioners of Uruguay, and the Open University for Informal Ongoing Education of Older People. Based on the initial response, a heterogeneous sample was further developed by applying a snowball strategy (Goodman, 1961) which allowed us to amass a group of 16 participants.

The study was undertaken in two phases. Phase 1 included two synchronous Zoom meetings plus three weeks of asynchronous dialogues via WhatsApp, which were facilitated according to the techniques described above. The initial Zoom meeting served to outline the project, complete an informed consent process which followed Canadian Tri-Council standards for ethics as reviewed by the Office of Research Ethics at Simon Fraser University, introduce participants to each other, and explain how the dialogue would be managed over the coming weeks. These processes were animated by an activity in which participants thought about data concerning the many different names they carry as a person (nicknames, professional designations, etc.). Participants also discussed their access to and use of digital technologies and shared some initial thoughts about data.

In the first week via WhatsApp, the groups worked through a creative and participatory activity that allowed them to identify the types of data that they come into contact with in their daily lives and identify the mul-

tiiple meanings and valuations they attach to different forms of data. In the second week, the groups were asked to think critically and reflexively about the digital trails we leave in our daily lives. This established a foundation for discussing participants' perceptions of corporate data use and participants' material or symbolic valuations of data. Based on this, the groups were asked to contemplate their individual criteria for corporate use of personal data. Finally, the third week took up the themes of responsibility and security. Based on the view that people have practical knowledge that makes them experts in their own reality, participants were asked to identify potential ways to improve their daily experience where personal data is concerned.

The second phase was carried out via Zoom and constituted the closure of the process. Participants put the skills they had developed into practice by carrying out a "citizen data audit" of private healthcare providers, and they identified their needs and possible avenues for change. This work centred participants once again as experts in their own reality.

The synchronous meetings facilitated interactivity and dialogue between people in different geographical locations. They were complemented with asynchronous instances that allowed for more sustained and reflective exchanges. WhatsApp allowed participants to share and develop their perceptions with the group in a cumulative manner over a longer period. Participants were organised into three WhatsApp groups based on their frequency of WhatsApp use (every 1–4 hours, every 5–9 hours, more than 10 hours). Among the principal advantages of this research technique were reduced costs, better accessibility, lowered inhibitions among participants, easy transcription, and an alternative way of approaching communities to build local knowledge. The disadvantages included the potential for exclusion due to patterns of digital access or connectivity and barriers presented by digital competencies. The instruments used also prioritised digital communications mediated via text and audio, which removed other sources of information, such as non-verbal communication.

We analyse the experiences and reflections shared by participants, which have been organised into thematic dimensions. These are conceptualisations and perspectives on data, uses of data in healthcare service provision by participants, and the advantages and disadvantages of datafication in the healthcare service, given the needs of older groups. In what follows, we present aggregate results without distinguishing by gender, place of residence, or ICT use since we detected no substantial difference between segments.

4. Findings

4.1. Perspectives on Data

Given their phenomenological approach, workshops began by eliciting stories about participants' experiences

of data sharing in healthcare settings. These stories revealed participants' situated perceptions of what data is. We found that there was an important tension between how data (*el dato* in Spanish) is understood colloquially in Uruguay versus the way data has come to be mobilised in the context of healthcare platformization. Indeed, one participant offered that "the word data has different meanings depending on the context."

In Spanish *el dato* is understood colloquially to mean "the details" as in *dame el dato*, which could be translated as "give me the deets," as it might be said in English slang. Similarly, one participant shared:

Speaking of data, I think that the word is broader and can have other meanings. Who has not said or heard, "I'll pass on the data." This is referring to a situation in which it is assumed that the other person does not know, and that possibly few people know.

However, this understanding does not directly map onto how data is thought about in the Western scientific tradition that informs both healthcare and information systems management. Rosenberg's (2013) genealogical work shows that the word data entered English from Latin, meaning "to give." This usage emerged during Enlightenment debates about the nature of interpretation. Hence, as "dado" (from the Latin verb *dare* or Spanish verb *dar*—to give) passed into English as "data," it came to mean "what is taken as given" and became a basis for asserting reasoned processes of argumentation as distinct from hermeneutic forms of interpretation (see Rosenberg, 2013, p. 18).

This is a fascinating point to consider in a healthcare setting. Data can be understood as a starting point for reasoned assessments of health and wellbeing, but data is organised by culturally specific categories that are socially constituted as indicators of health. For example, weight is used as an indicator of health and well-being, but it has also been shown to produce weight stigma linked to negative health and well-being outcomes (Pearl et al., 2020). Meanwhile, our participants perceived data to be the information considered worth sharing in the context of social relations, which in this case would be shaped by cultural roles and power relations enacted between doctors and patients. Both the perception or experience of those relations and notions of what types of information are worth sharing will be specific to the cultural experience of elderly persons within the Uruguayan healthcare system.

With this in mind, it is interesting to note that participants recognised typical socially normalised determinants of personhood: name, height, identification number, nationality, date of birth, and sex. They shared that they frequently experienced healthcare as a transaction mediated by a narrow range of data categories and pointed out that refusing to share this data would exclude them from healthcare services: "It is really up to us whether we share [our data] or not. Because, of course,

we can refuse to share it. But that would imply being left out of the system."

This raises important questions about the nature of consent in healthcare for ageing subjects. Consenting to share one's data not only creates a basis for a medical diagnosis in the context of doctor–patient relations but also involves accepting a set of reductive categories that determine or "select" how ageing is viewed and how those categories mediate access to social services. Thus "what is taken as given" has become folded upon itself in the design of mediated healthcare systems as they come to establish the context for social relations. Or, returning to the concepts offered by Van Dijck et al. (2018), participants in healthcare systems become complicit in nurturing the "algorithms" that shape platform-driven selection processes, and thus also complicit in monitoring, and therefore ontologising, the elderly body in ways that removed autonomy over the definition of their own subjectivity.

Finally, we were struck by how participants introduced conceptions of data that flow from policy debates in the national public sphere. In a form reminiscent of Van Dijck's (2014) "dataism," terms like personal, private, or sensitive data were already present in our participants' narratives. Through our interventions, participants became aware that these terms are often reproduced in public discourse without careful consideration of their meaning. They revealed that while personal privacy has been heavily explored in public discourses about the digital economy, when it comes to datafication of health systems, the potential to enhance wellbeing, particularly given their advanced age, is as much or possibly more important to them than ensuring data security and privacy. This demonstrated a disconnect between the design solutions that convince users to take on new information systems (i.e., guaranteed data privacy), the cultural experience of data as something that mediates the experience of wellbeing, and the values or desires of elderly participants as simultaneously the subjects and the objects of health information systems.

4.2. Elderly People, Data, and Provision of Care

Our exploration of senior participants' experiences with data in the Uruguayan healthcare system also highlighted the extent to which individuals must navigate a complex information landscape marked by multiple actors, complex information flows, and competing interests, as well as the strategies used to manage this reality.

When healthcare providers are perceived as safe spaces, participants had few concerns with sharing health data. As one person put it, "When we are linked to a reliable provider, then perhaps we do not worry or question ourselves when sharing our data." In this context, data sharing is seen in positive terms:

We know that our data remains in the computer, and I am interested in keeping it there. Because in case of

an emergency, they already have our data, and they can help us. I think it's perfect that they are collecting it.

It is interesting to note the importance that participants placed on the reliability of the healthcare provider in the Uruguayan system, given that the system itself makes the provider the main point of care.

This same observation points to the potential for uneven use of data across the various instances that access the EHR system, which is made up of a variety of service providers, both public and private. As participants themselves noted, the exhaustive collection of data by the centralised EHR does not guarantee that information will be used productively during a medical consultation or that patients' needs or feelings will be taken into consideration. In a complex informational landscape, and given the competition between healthcare providers, this raises questions about the criteria older people might use to judge whether the EHR is being used appropriately to support their well-being.

Meanwhile, the system also creates a dependence on healthcare providers to access and make sense of health records. The SNIS has produced digital applications to facilitate self-management of healthcare, but as one participant shared: "I have an app from my provider that provides me with some things, but not access to all the data they have about me." Participants indicated little understanding of how their data "journeys" through the digital instances of the SNIS, to draw on the work of Bates et al. (2016), nor what implications the pathways traversed by healthcare data have for social and economic relations between patients, doctors, and third parties within the healthcare space.

Taking this into consideration, participants shared several concerns about the possible risks or disadvantages of sharing their data in Uruguay's healthcare landscape. Given the centralisation of health data, one person said, "If we look at things critically, we'll lose our minds because they have our lives in their hands." In this vein, participants shared their anxiety about the commodification of health data and its use for commercial or criminal purposes. As one person said, "I think certain people with bad intentions can employ data in an illicit way to offer services. They especially target older adults. We must be attentive."

As described in the context section above, the Uruguayan healthcare system includes a variety of controls to protect healthcare data. But our participants argued that information systems are only as good as those who use them. They saw human factors as the most likely cause of data breaches and argued that confidentiality clauses in regulations, national legislation, and control mechanisms are of little use if healthcare providers cannot be trusted.

These results suggest that for older adults in Uruguay, feelings of trust in relation to individual healthcare providers and demonstrated healthcare outcomes in terms

of wellbeing enhancements may outweigh datafication concerns or techno-optimist narratives when navigating healthcare options. Returning to larger considerations, when people feel they are being addressed with dignity as complete individuals and when their individual needs are being met, they may be less likely to express concern about the risks of digital surveillance. However, this set of observations raised an important tension between how individuals are treated and the nature of the overall system. When platformized surveillance and selective mechanisms lead to reductivism in healthcare practices, the potential for humanised care with dignity may be reduced.

4.3. Emerging Needs: Ethical Data Management and Responsible Citizenship

Lastly, we worked with participants to identify the criteria they might use to evaluate data uptake by medical service providers, and we used this activity to develop the critical data literacy of participants. By exploring criteria, we hoped to leave participants with tools that would help them better understand and navigate the datafied and platformed healthcare landscape and think through its implications for healthcare access as well as feelings of personal recognition, autonomy, and well-being.

One consideration that arose in this discussion was the issue of consent to share personal or health-related data. It emerged that confidentiality presents in unique ways for older adults. One participant expressed concern, for example, about how health data would move between different healthcare instances in the country, such as in-home healthcare providers, companion services, and medical doctors. This individual felt that "only the medical provider should hold [the data]." This example highlights the need for a culture of consent that puts the data subject at the centre of decision-making around who can access their data and for what purposes. This is a complex proposition given that older individuals may become increasingly reliant on family, the community, the state, or private health care services to provide for their well-being as they age.

The final workshop also helped participants explore criteria they might use to evaluate the use or uptake of health-related data. Responses here varied as participants tried to work through the complexities of how data gets taken up in the provision of care. One participant suggested that data must be handled according to "the parameters of ethics, medical ethics, administrative ethics." Others approached this question pragmatically, arguing, for example, that data shared with medical professionals should be used to improve health and well-being outcomes for all citizens. Still, other participants emphasised empathy and feelings as the main arbiters of data use, recalling contributions from data humanists such as D'Ignazio (2022), who writes about the need to sustain the humanity of numbers. In the

context of accelerated platformization and digitalisation, the participants demand humane and attentive health-care carried out with tact and dignity. They argue that this has been lost as “life” has been algorithmized and health and other social and community spaces have been platformed.

While there was no clear consensus around how data use should be evaluated within the healthcare system, it is interesting to note that participants were all drawn to considerations of care rather than, say, efficiency or business processes. It also shows that when given the chance, healthcare users are interested in and capable of evaluating platformized systems and asking questions about the black-boxed techno-commercial strategies (Van Dijck et al., 2018) that have so much force in shaping medical interactions and defining the elderly body.

The workshops concluded with discussions about how senior citizens can respond to the challenges of datafication. Given the complex information landscape described in the previous section, participants can be forgiven for being “a bit irresponsible or complacent. We do not make demands. We are very passive.” Another noted that “we do not exercise citizenship as much as we should.” Despite not expressing their citizenship around health data, participants certainly recognised the need for a critical position on their data subjectivity and its implications for health and wellbeing.

As an alternative and possible way forward, participants expressed the need for spaces where the elderly can share their experiences with the digitisation of healthcare and engage in peer-to-peer dialogue that would allow for empowerment and autonomy. As one person shared:

Now, to summarise a little: This group should continue because, for me, it has been a learning experience. Each time you talk, things come up that make us question more, make us question more whether we are sharing our data with care or not, whether we are doing things well or not for our benefit.

In the Uruguayan case, spaces such as these could be convened by groups such as the National Network of Organizations for the Elderly, the National Organization of Associations of Retirees and Pensioners of Uruguay, or the Open University for Informal Ongoing Education of Older People. But we feel it is also important to recognise such initiatives as an extension of digital literacy campaigns such as Plan Ibirapitá. That is to say, the focus should not only be on devices, connectivity, and training but should also extend into critical literacy skills that help people navigate the social impacts of the changing “programmable architecture” of the platform economy. Older people need spaces to discuss and figure out how to address the implications of platformization for changing standards of care and how this is shaping their subjective experience as senior citizens.

5. Discussion and Conclusions

In this article, the experiences and perspectives of elderly participants regarding platformization and datafication in the Uruguayan healthcare system were critically analysed to uncover implications for digital literacy programs. Drawing on a phenomenological approach, this work revealed complex relationships and disconnections between the ontological frameworks underpinning the platformization of health care and the reality and needs of older people, given their subjectivity.

This work confirmed the significance of context for the meaning of “data.” In particular, the polysemous perspectives on data revealed by this case account for the various aspects of digital subjectivity that emerged during the study. In the context of health care, data offer health and well-being indicators, which are taken up in the design of digital platforms. But participants also understand data as information worth sharing given the cultural context or specific social relations. In this context, participants often experience healthcare as a mere transaction of data flows, flows which appear to shape their identity as users and which come to narrate their ageing bodies.

This “data subjectivity” is shaped with or without patients’ consent, which means that they find themselves held hostage by the question of whether to share data. Refusal implies exclusion from health care services, but sharing makes them complicit in the reification of the categories they are subject to. This is how the categories that articulate local views on ageing, access to services, and, ultimately, citizenship are implicitly legitimised (Dalmer et al., 2022).

Participants indicated that while they value data privacy and security, they prioritise access to healthcare services since they are at a stage of life where this is important. As a result, concerns about the ontological power of dataveillance (Van Dijck, 2014) take second place after individuals’ immediate needs, values, and desires.

Beyond existing legislation or institutional mechanisms, participants focused on trust in their healthcare provider as the main guarantee of appropriate data use and management. This is because they attribute failures in data management and use to human factors. At the same time, it was evident that participants were unaware of Uruguay’s regulatory frameworks, which protect personal data, or specific regulatory provisions related to healthcare providers’ transfer, storage, and management of their data. Indeed, as individual subjects, they hold themselves responsible for not taking measures to protect their data or for not choosing to file complaints where they see failings in this system. In this sense, they take on individual responsibility for managing their own data (Sibilia, 2012). This, without a doubt, constitutes an obstacle to collective efforts to address shortcomings in information systems.

As our intervention unfolded, some participants came to demand ethical, responsible, and humane

mobilisation of their data. We attribute this to their growing literacy about data policy and uptake in Uruguay as the result of our interventions. This suggests that the criteria used by Uruguay's national agencies should be updated to recognise shifting experiences of data subjectivity over time. Beyond existing frameworks, including responsible and safe use, critical and reflective use, and creative and participatory use, it would be useful to recognise the situated nature of data and its complex relationship with changing subjectivities.

The spaces created for this study were effective spaces for the co-constitution of opinions about the management of data and allowed participants to reflect on and express opinions about the expression and transformation of their digital subjectivity. Spaces such as these would allow new subjectivities to emerge within the situated context of Uruguay's unique historical experience, culture, and health system. As other research has already pointed out (Dalmer et al., 2022; Rosales & Fernández-Ardévol, 2020), the involvement of older people in the evaluation of digital systems and their everyday manifestation, as in the case of healthcare settings, will ensure that their needs and values, and their vision of old age and ageing are reflected in policy frameworks for the digital economy—and from there the design standards applied to the development of digital technologies. In this sense, data literacy interventions can offer spaces for the development of older people's subjectivities in ways that reflect their unique and diverse experiences of datafication and help them articulate their unique needs and desires.

As Van Dijck et al. (2018) points out, platforms are not just intermediaries, but in this case and in the perception of older people, they truly structure the healthcare system, the type of care it offers, and the sense of well-being it makes possible. The work presented here detected the ontological weight of categories that risk reinforcing existing inequalities and exclusions of older people, as Rosales and Fernández-Ardévol (2020) have discovered. These elements are reminiscent of Dalmer et al.'s (2022) proposal to create a geronto-technological culture that is more diverse and participatory and leaves behind prejudices and stereotypical views of old age and ageing, given their consequences for health care. These factors have implications for digital literacy interventions for older people that require them to foster older people's critical understanding of digital subjectivity in managing their data in the context of contextualised health systems.

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Conflict of Interests

The author declares no conflict of interests.

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