

Aging in Data:

Public Participatory Workshop Barcelona 2024

Friday 31 May 2024
Summary Report

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Acknowledgement of Country

In the spirit of reconciliation we acknowledge the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

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INTRODUCTION

In May 2024, we held a creative participatory workshop in collaboration with colleagues from the *Aging in Data* research network (*AiD*), the Open University of Catalonia (UOC) and RMIT Europe. This workshop was part of three days of collaboration and critical discussion around ageing and data with researchers from across the world. This group of international experts was brought together through the *AiD* network—an initiative “that explores how an era of unprecedented digital data-gathering impacts and governs how we grow old in our communities” (Aging in Data, 2024). *AiD* is funded by the Canadian Social Sciences and Humanities Research Council (SSHRC), housed at the ACT Lab at Concordia University and led by Kim Sawchuk and Constance Lafontaine.

Our aim in the workshop was to engage the international expertise of researchers working on ageing and data alongside the invaluable lived experience of older adults and policymakers in Catalonia to think creatively about how data and ageing might be entangled to create equitable ageing futures. The workshop was conducted at UOC and delivered by Larissa Hjorth and Caitlin McGrane from RMIT University, Australia.

We conducted three creative exercises using two methods drawing from design scholarship—cultural probes, and speculative future and design playing cards. Cultural probes are objects that invite participants to reflect on their everyday behaviours in unusual ways with a view to designing future innovations (Gaver, Dunne & Pacenti, 1999; Boehner, Gaver & Boucher, 2012). We deployed postcards as cultural probes in two of the exercises—the short, text-based prompts invited participants to explore what they were expecting to get from the workshop, and what they learned at the end of the workshop.

The third exercise consisted of a modified version of the speculative futures and design game *The Thing From the Future* (TTFTF) (Candy & Watson, 2015). TTFTF was originally designed as a method for prompting players to generate entertaining or thought-provoking hypothetical objects in the near, short and distant future. We modified the game to make it simpler for novices to play, especially those who had never engaged with speculative design before.

Through these exercises, participants generated a range of ideas for how data could be used in more egalitarian, creative and critical ways to create better futures in which to age. We invited participants to reflect on what we need to get right as we continue to age in an increasingly datafied world—raising important questions around how we protect communities’ privacy, rights, dignity and wellbeing in the creation of these ageing futures.

*“How an era of
unprecedented digital
data-gathering
impacts and governs
how we grow old in
our communities”*

Aging in Data, 2024

MOTIVATIONS: COLLABORATION AND DIFFERENCE

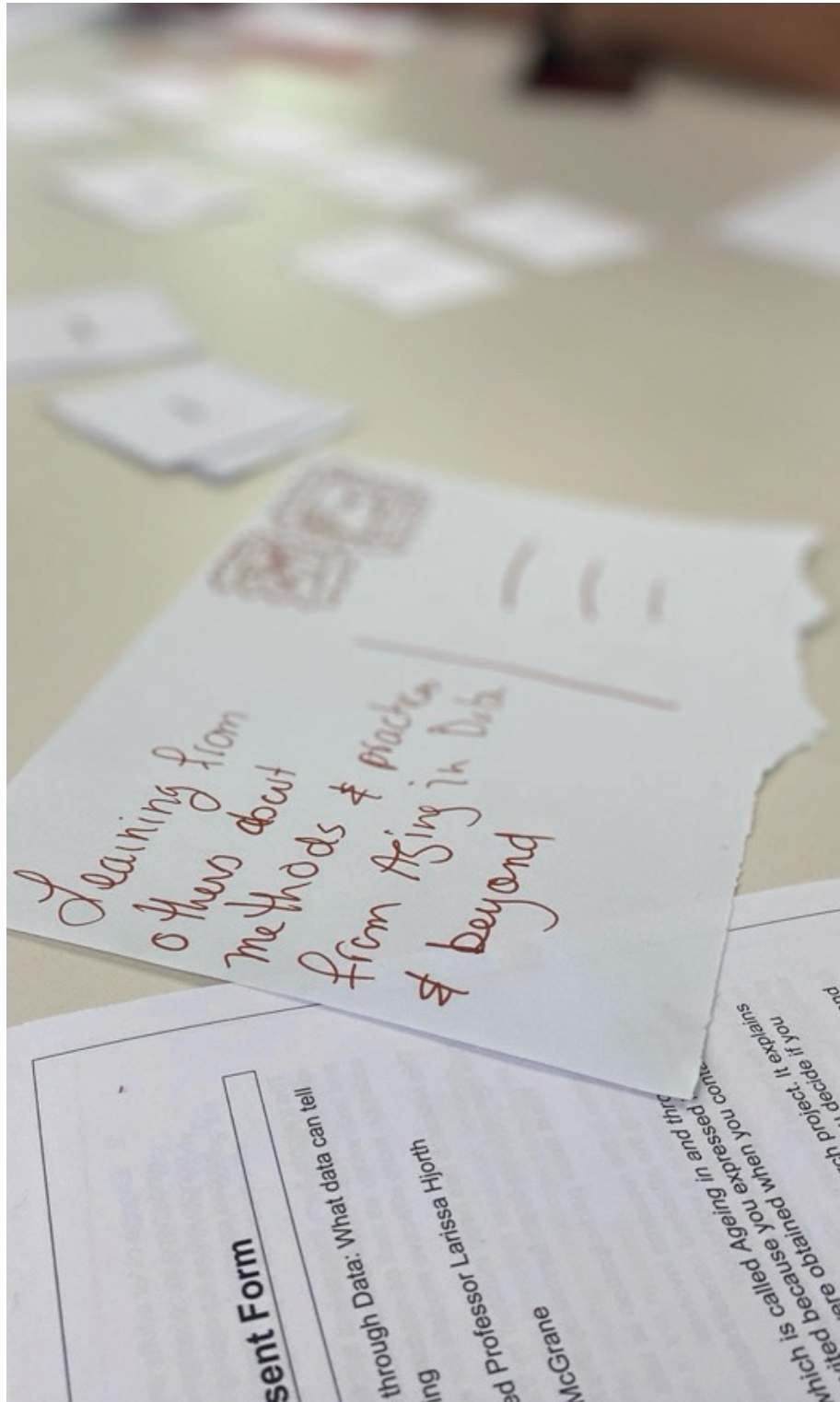
The first exercise we asked participants to complete when they arrived and sat down at tables was a postcard about what motivated them to come to the workshop. Our aim with using this postcard prompt was to understand how participants were feeling about the workshop when they entered, which would tell us how they were anticipating contributing and what they might learn. The responses to the motivations prompt are summarised in a word cloud in Figure 1:



Many participants emphasised the importance of hearing perspectives, experiences and differences from both the researchers and participants. Participants were motivated to attend to hear ideas, learn new methods, creatively collaborate, meet new colleagues and deepen their understanding of the “intersections between ageing and data” as one participant put it on their postcard.

Figure 1: Motivations postcard word cloud

The diversity of experiences in the room also meant that some participants who typically work on ageing policy in Catalonia or using non-creative methods were motivated to see how their expertise could be enhanced through the workshop. An emphasis on knowledge-sharing and collaboration demonstrated how participants were motivated to work together on complex challenges around ageing and data.



*“Learning from
others about methods
& practices from
Aging in Data &
beyond.”*

**Workshop Participant,
2024**

Figure 2: Postcard prompts
for workshop motivations

THINGS FROM AN EQUITABLE AGEING FUTURE

We invited participants to collaborate with each other in small groups through an amended version of *The Thing From the Future* (TTFTF) (Candy & Watson, 2015) that we call *Things From an Equitable Ageing Future*. The original TTFTF game, developed by Stuart Candy and Jeff Watson at Situation Lab, asks participants to use card-based prompts to describe a ‘future thing’ based on the parameters set out in the cards. The original version of TTFTF contains 108 cards organised into four areas, Arc, Terrain, Object, Mood, that offer a vast array of possible permutations. Taking inspiration from these areas, we created four vectors: Theme, Question, Artefact/Outcome and Timeline. We also limited the number of options in each category so as not to overwhelm participants and to simplify translations between Catalan and English when required.

The aim was for each group of participants (approximately 4-5 in each group) to develop an artefact or outcome in relation to ageing and data that would help us imagine or create equitable ageing futures. The theme and question were linked and were intended to guide participants to help them formulate a response. Groups could choose artefact/outcome(s) and timeline cards depending on their discussion and design choices. The card options are summarised in the table below.

At least one group touched on each theme, however given that most participants were familiar with *AiD*, groups tended to coalesce around the theme of data justice and harm. Groups experimented and played with the cards—amending the questions and combining artefacts/outcomes to draw out the intricacies of the themes. As Group 5 put it, “only one artefact/outcome cannot solve the issue alone, they are all complementary.” Recognising the intersections, overlaps, interdependences of the themes is a significant challenge in the game but one that allows participants to focus deeply and design collaboratively towards a shared goal.

“The aim was... to develop an artefact or outcome in relation to ageing and data that would help us imagine or create equitable ageing futures”

Workshop Participant, 2024

Theme	Data harm & justice	Care	Health			
Question	What data harms and justice concerns do older people have? How can these concerns be mitigated?	How will care practices and policies need to adapt to the increasingly datafied world in which we age?	How will health practices and policies need to adapt to the increasingly datafied world in which we age?			
Artefact/ Outcome	Game	Media resource	Policy	Practice guide	Service	Event
Timeline	1 year	3 years	5 years	10 years	20 years	

Table 1: *Things From an Equitable Ageing Future* cards

Group 1, 'The Roses': Care, Policies/Services/Practice Guides and 20-25 Years.

The first group, who named themselves the Roses developed a concept of a wheel of care or a 'lasso' of care that would deliver policies, services and practice guides. These interconnected outcomes would create futuristic (20 years in the future) "Data Wranglers" that lived alongside people to help them navigate complex data decisions. The Roses wanted to trouble models of care that are "paternalistic", emphasise reciprocity and "find ways to think of care to enhance the agency of older persons in particular and places their needs, always at the centre."

Group 1 also challenged the framing of the question around care and instead wanted to ask how "the datafied world... should adapt to our care needs and to the practices identified by those who are going to be implicated." In Group 1's vision, control over one's data was central to the design and delivery of their outcomes. As they put it, "it should be controlled by us as we continue not only to age but to live." Group 1 were attuned to the interconnectedness and mutual dependency of many approaches to data and ageing. Instead of seeing the idea of an outcome as one thing, they instead framed the delivery of multiple outcomes around mutuality, respect and reciprocity.

"Find ways to think of care to enhance the agency of older persons in particular and places their needs always at the centre"

Group 1, The Roses, 2024

Group 2: Data harms & justice, Game and 5 Years.

The second group's aim was to raise awareness and knowledge about how older people's mobile practices are ambivalently monitored and used. Group 2 suggested one way to do this would be through a game where players embody "an urban planner who has to use mobile data to decide changes to a city environment... allowing people to see how when these changes are made by data they lead to unexpected results. And to open a conversation around the kinds of data we need to consider when we're making changes to societies, communities, cities and streets so people can be informed about the holes in the data."

Playing the game and seeing how widely available mobile tracking data is would hopefully raise questions for players around possible privacy issues with data tracking as well as illuminate the unforeseen or unconsidered consequences of data-based decision making without community consultation. Group 2 were also mindful that they wanted their game to consider how people who don't use a smartphone might be excluded from the development of urban planning policy and practice. Group 2 considered the wide-ranging implications of data including how its uses might be simultaneously useful, exclusionary and potentially harmful. Larissa added that this idea might be adapted into an observatory to bring communities into dialogue with policymakers for transparency around data collection, use and decision-making.

Group 3, 'Openrithms': Data harms & justice, Game and 20 Years.

Group 3, who called themselves Openrithms—a portmanteau of 'open data' and 'algorithms'—wanted to challenge the dominance and influence of algorithms by breaking open these hidden mechanisms that control so many aspects of our everyday lives. Their goal was to give back power to “the common people” and leverage trust and mutuality between people and machines. Their vision was futuristic, expecting this gamified intervention to be available in 20 years' time when (ideally) large tech corporations will have less power. Openrithms understood that algorithms remain closed for two reasons—“a human reason that people don't want to share them, and the technical reason that they have become so sophisticated that we don't really know what they are doing.” Their challenge to themselves was to build a grassroots game that would enable players to “discover the laws of the algorithmic world” through collaboration with machines. Openrithms wanted to explore the parallels between the natural world and algorithms by not attempting to fight the algorithms and instead working alongside them and cooperating to eventually create transparent algorithmic policy.



Figure 3: Participants in Group 4 arrange their *Things From an Equitable Ageing Future* cards

Group 4: Data harms & justice and Event/Game

Group 4 combined data justice and harms with health data concerns and ethics. They had two aims. The first was to “inform and raise awareness about people’s data footprints” (i.e. what public and private health data is being captured about them). The second was to inspire “policymakers and the general public to generate ideas about how people want their health data to be managed” (i.e. the ethics of health data management). The group wanted their outcomes to visualise the entanglement between careful data practices and policies and the datafied world of health policy. To achieve their aims, the group proposed a public event that would be gamified in some way and would bring together four intersecting and overlapping groups: government, academia, citizens (of all ages) and industry.

Group 4 wanted to “tell the real story” about data and health ethics by emphasising that “care [is not practiced] through algorithms” because these automated decision making systems are biased and could lead to unfavourable outcomes, particularly for older people. The group wanted to use data visualisation tools to show how data intersects with ageing across the life course, deploying some “scary examples” that would challenge the increasing reliance on data and datafication practices.

Group 5, ‘Data Civic Centre’: Health, Community Resources and 10 Years.

Group 5 were the only group to exclusively focus on the theme of health and envisioned the creation of a data-based civic centre. This Civic Centre would combine health and personal data to create chat bots that would help citizens understand the intricacies of their data. Through the civic centre, citizens would be empowered with knowledge about where and how their data was gathered, stored and used, and given personalised suggestions for how they could alter their “capacity to act” with and through their data. Through these personalised mapping tools, policymakers would be able “to identify easily who participates in data sharing and who is not participating, and why”.

Another participant asked, “on the topic of justice, can we ethically capture data about who is not coming [to the Data Civic Centre]? Everything we do is always focused on who is willing to volunteer and then others are excluded, so this is a really good idea, but from a data ethics point of view, are we allowed to go and capture these people?” Questions around missing data are related to digital exclusion. While older people are more likely to experience digital exclusion, we also recognise the importance of principles such as ‘The Right to be Forgotten’ and digital privacy as a human right. The possibility of a data civic centre could address these concerns by empowering citizens to have agency and autonomy over their data and withdrawing their data if they would prefer to be excluded.

“Everything we do is always focused on who is willing to volunteer and then others are excluded”

Group 5, Data Civic Centre 2024

Group 6, 'La Colla Cuidadora': Care, Event/Media Resource -> Service/ Practice Guide and 1-3 Years.

La Colla Cuidadora (LCC) is an existing group of people in Barcelona who support each other in their common responsibility of informal caring, often for older family members. Their name can be translated in English to 'a group of friends', demonstrating the strong bonds of mutual and reciprocal care that exist between the members. Two members of La Colla Cuidadora joined the workshop to bring their lived experience to Group 6. Group 6 chose the shortest timeframe, 1-3 years, because through lived experience they know what needs to be done to support existing social groups for those providing care.

The group chose to focus on those needs in designing the outcome—an event and media resource that would eventually lead to services and practice guides for more experienced members of the group to share their knowledge with informal carers who are just beginning. For Group 6, the focus for the services and practice guides needed to be hyperlocal at a neighbourhood or even street level because this was a need identified by existing members of La Colla Cuidadora. The initial outcome of an event and media resource would raise awareness of the needs of the carers—at present all their care work is volunteer, meaning they sorely need government funding to ensure future carers get the help and support they need.

As one La Colla Cuidadora explained, “looking after people is heavy” for those doing the caring. The group wanted to mobilise local media “to reach more people so that they know more about the issues faced by the care-giving reality” and put pressure on politicians to guarantee the much-needed support. Group 5 suggested La Colla Cuidadora could “create more community life... that surpasses the most caring act and reaches other activities (e.g. community lunches, farm markets in the neighbourhood, group trips to nearby places)”. The vision shared by La Colla Cuidadora demonstrated the importance of incorporating lived experience when designing future-focused outcomes for communities.

“Create more community life... that surpasses the most caring act and reaches other activities”

Group 6, La Colla Cuidadora, 2024



Figure 4: La Colla Cuidadora members explain how the groups work and what supports they need.

REFLECTIONS: SURPRISES AND DISCOVERIES

The final activity in the workshop was another postcard where participants were invited to share what was the most surprising thing they had learned or discovered in the workshop. The aim with this concluding postcard prompt was to understand what knowledge or perspectives the participants had taken from their participation in the workshop. We wanted to finish on a positive note because discussions around data ethics and datafication can be overwhelmed by the challenges of these concepts. In their responses to the postcards, many participants described being surprised and intrigued by the methodological usefulness of speculative design-based games such as TTFTE. These responses align well with the prompts at the beginning of the workshop where participants were interested to hear new perspectives and work collaboratively. Responses to the reflection postcard prompt are summarised in a word cloud in Figure 5:

Participants were surprised and, in some cases, amazed by the



imaginative approaches to data and datafication discussed in the workshop. Many participants were surprised by how useful a speculative design approach could be to think about and design in the present, suggesting we had met some of their motivations for attending the workshop. One participant was surprised by the optimism towards technology in the room, which indicates that although data and its intersections with ageing can be complex and present difficulties in discussion, taking a creative approach can generate innovative, thoughtful, ethical and just approaches.

Figure 5: Reflections postcard word cloud

CONCLUSION

We are grateful to the participant group for their time and input into this workshop. Although time was limited, participants thoughtfully and proactively moved into a design space around ageing and data. The concepts generated during the *Things From an Equitable Ageing Future* exercise demonstrated the importance of bringing diverse groups together, especially engaging people with lived experience and policymakers together with academics. The complexities of living in an increasingly datafied world cannot be addressed in isolation and require deep collaboration between stakeholders to create meaningfully equitable futures. We recognise the constraints of deploying technologies and data and welcomed the ways groups problematised tech-driven mechanisms as total “solutions” to complex social, economic and political problems. At the same time, groups also meaningfully engaged with these complexities in ways that aimed to address constraints and exclusions embedded technologies and data.

Future research deploying our methods might, as suggested by a participant from La Colla Cuidadora, ask participants to engage with one theme at a time across a workshop or a series of workshops. We would also like to engage more informal carers and those who receive this care in our research to better incorporate diverse lived experience. Finally, we invite other researchers, care practitioners, policymakers and older adults to experiment with these methods in their own contexts to contribute towards *AiD*’s community of practice in this space.

“The complexities of living in an increasingly datafied world cannot be addressed in isolation and require deep collaboration”

McGrane and Hjorth, 2024

