

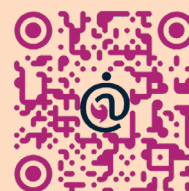


Focus Group Report

On human rights, digital rights,
and the welfare of older persons.

St@ndbyMe

PROJECT



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Imprint

Declaration: The organisations of all authors contributed to securing funding for this project. Georgios Pavlidis was responsible for the conception of the study, leading the project and the research, authored this report, conducted focus groups in Sweden, conducted the analysis for the Swedish data, and conducted the analysis of the reports from each country. The following individuals conducted focus groups in the respective countries, analysed their data, drafted reports, reviewed the manuscript, and contributed to the development of the questionnaires used in this research: Chelsea Anastasia Lazaridou, Alex Ågren, Peter Gehweiler, Steven McAvinue, Liliana Carrillo, Simona Matějková, and Jana Pšejová.

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Introduction

In the St@ndbyMe project we chose to conduct focus groups to capture how participants compare their experiences with each other, develop and generate ideas, as well as explore issues of shared importance about human rights, digital rights and older age. The focus groups were conducted in Sweden, Germany, Belgium, the Czech Republic, and Greece. All focus groups were conducted in the local or national language where the fieldwork took place.

For the focus groups with older persons, we aimed to recruit those older than 50 years old who use information and communication devices (ICTs), older persons that consider using ICT devices (for example smartphones, computers tablets, etc.) and currently lack the know-how (i.e., digitally illiterate), older persons that consciously avoid the use of ICTs, and older persons that have difficulties or are unwilling to use some devices selectively.

Besides the focus groups with older persons, we conducted focus groups with practitioners in care that provide their services to older persons, as well as with practitioners and volunteers who teach digital skills to older persons. We used a broad definition for caregivers, including healthcare personnel, nursing, and caring professionals, those who provide services directly to patients in hospitals, ambulatory care, or in patients' homes, as well as aides and assistants. Informal caregivers who provide care to older family member(s), or any other person in older age at their home, with or without any compensation foreseen for their caregiving services, were also included in the study.

For the focus groups with practitioners and volunteers that teach digital skills to older persons, we aimed to recruit practitioners in adult education who are, or were active, in teaching, training, or assisting older persons in the use of ICTs. This could include teachers or trainers, teaching assistants, instructors, volunteers, or professionals, working in formal and accredited institutions, or in non-formal educational settings (e.g., day-care centres), or within and through self-organized activities.

The inclusion criteria were that practitioners should be adults (i.e., 18 years or older) and thus able to provide consent for their participation in the study. Participants who could not communicate in the local or common language used in each focus group, as well as those unable to read the information sheet and sign the consent form of the study, were excluded from the focus groups. Older persons were to be excluded from the study if they could not provide consent for their participation due to known and diagnosed dementia, or due to any other known and diagnosed severe neuropsychological disorder (e.g., stroke, paranoid schizophrenia).

Methodology

Participants

To recruit participants, the St@ndbyMe project team placed an open call for participation through their communication channels (both personal and organizational), including social media, posters and flyers on the premises of their organisation, announcements in the local newspaper, and newsletters. In total, 34 older persons (six focus groups) participated in the respective focus group. Similarly, 22 practitioners in care (five focus groups) participated in the study, and 23 practitioners and volunteers teaching older persons digital skills (six focus groups) participated in the study. The demographic characteristics of the sample are presented below.

Table 1. Demographic characteristics of the focus groups participants

	Older	Care	Education
Age M (SD)	72.73 (9.63)	54.77 (8.36)	60.34 (14.23)
Gender N (male, female)	11, 23	1, 21	9, 14
Education (%)			
No degree	3	-	-
Primary education	3	9	8
Lower secondary	21	9	4
Upper secondary	6	13	9
Post-secondary	21	9	17
Tertiary higher	21	46	39
Master's degree	15	9	9
Doctoral	12	4	13
Country N			
Sweden	5	2	6
Greece	5	7	5
Germany	17	7	6
Czech Republic	3	3	3
Belgium	4	3	3
Frequent user of technology (%)	79	-	-
Digital skills ¹ M (SD)	3.79 (1.98)	-	
Years of experience	-	21.30 (9.39)	14.95 (12.10)
Setting (%)			
Formal	-	100 ²	26 ³
Non-formal	-	-	48
Informal	-	-	26

Footnotes:

This was measured with the question "Your skills in using tech devices (e.g., smartphones, computers tablets, etc.) or internet services (e.g., email, surfing, e-shopping, e-banking, etc.) are" in a 7-point Likert scale from 1 = Very poor to 7 = Very good

² All the participants in the care focus group provided care services in an accredited and formally acknowledged institutions, and their work is formally acknowledged and registered. The composition of their profession was 24% nurses, 15% personal assistants and trained caregivers, 28% social workers, 19% untrained caregivers, 10% doctors, 4% other.

³ 81% of the participants were a main educator or instructor teaching older persons digital skills, 39% declared other roles

Process

This was a semi-structured focus group design based on a guide drafted for this purpose beforehand (see Appendices A, B, C). The sessions were recorded and the focus group moderators kept notes during and after the end of the focus groups. The moderators listened to the recordings one more time and kept additional notes according to the instructions received for the analysis of the sessions.

Analysis

The analysis of the data followed principles of thematic analysis from Clark and Braun (2021)⁴. The steps of the thematic analysis were:

- Step 1: Become familiar with the data by listening to the recordings.
- Step 2: Generate themes. While listening to the recordings, the moderators took notes. The researchers then identified patterns or commonalities in their notes, which served as themes.
- Step 3: Search for themes. At this stage, the moderators examined the consistency of the patterns identified and assigned names to the resulting themes.
- Step 4: Review themes. The moderators went through their notes to see if all observations matched the matrix of themes. For each theme, they noted at least an excerpt that represented the theme.
- Step 5: Finalize themes. The moderators translated into English the themes and excerpts and drafted a report for each focus group. This is the material that they shared with the partners in dedicated workshops that were recorded, during which the moderator explored the themes and excerpts together.
- Step 6: Writing the findings and conclusions. The first author of this report (GP) took notes during the recorded workshop and summarised the findings of the research group. Then, GP read all focus group reports, from which common codes and themes were identified. Attention was placed to commonalities and differences in the findings of all partners. Then, the first author of the report (GP) listened to the recorded workshops again to verify that all themes match those discussed in the workshops.

Results

A summary of the themes that emerged from the analyses of the data are presented in Table 2. A common finding from this exercise was that all participants of the study had initially difficulties to relate the issues of digital rights to their personal life and practice. However, the relevance of human rights and digital rights to their personal life and practise was made clear to them during the focus groups (approximately one hour). Most themes did not uniformly emerge in all focus groups, something that can be explained by the different degrees of digital penetration in the various countries of the study, as well as by the different roles of the participants. In the table below, the horizontal alignment of the themes that emerged across the focus groups with older persons, care practitioners, and educators is depicted.

4 Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and psychotherapy research*, 21(1), 37-47.

Table 2. Themes that emerged from the thematic analyses of the focus group data with older persons, care practitioners, as well as practitioners and volunteers teaching digital skills to older persons.

Older persons	Care	Education
The initial difficulty of relating to human and digital rights	Human rights in care and the difficulty of linking them to digital rights	Awareness of human and digital rights
Generations and digital literacy as markers of personal competence	Older persons, care practitioners, and leadership falling behind ICT developments	Within a generational divide, older persons and educators do not keep up
Fear of digital environments	Concerns about digitalisation, dehumanisation, and the value of personal contact	Fear, shame, and other considerations in digital environments
The importance of accurate information and the perils of misinformation	Misinformation was discussed as part of the “Issues of digital exclusion and ambivalence about the benefits of ICTs” theme	The importance of accurate information and the perils of misinformation
The “digital obligation” and the issue of agency	The right not to use ICTs and the preference for “low” technology	The “digital obligation” and the right not to use ICTs
Issues of digital exclusion and ambivalence about the benefits of ICTs	Issues of digital exclusion and ambivalence about the benefits of ICTs	Issues of digital exclusion and ambivalence about the benefits of ICTs

Focus groups with older persons

Seven themes emerged from the focus groups with older persons. The themes, along with some excerpts as examples are presented below.

Theme 01: The initial difficulty of relating to human and digital rights

Most of the participants had no issues describing fundamental human rights and their function. Human rights were often interchangeably used with the notion of democracy. However, almost all the participants had initially difficulties connecting issues of digital exclusion, digital literacy, and digital access with human rights or digital rights. As a moderator observed in one of the focus groups in Greece with older persons:

“They had never heard or read about this topic, and it took some explaining for them to get into the subject and see how digital human rights are relevant to them.”

As a participant in the focus group in Sweden said:

“It’s just like a fog to me, I can say. It is nothing that I’ve... it is nothing that has come up in a way that I have had to take a stand on or think about at all. It just sort of like someone came and said, ‘Oh well, now you have to use this,’ and then... yeah, that’s how it is.”

Theme O2: Generations and digital literacy as markers of personal competence

The issue of generations as a marker of digital competence, with the older generation lagging in digital literacy, came out clearly in the focus groups. Generations were also used as an imaginary population divider, in which the younger generations are perceived as digitally literate and those who impose the pace and need to learn the use of ICTs on all age groups. This segregation was often combined with feelings of inferiority among older persons, who felt they belonged to a generation that cannot keep up with technological advancements on equal terms as younger generations. In the focus groups conducted in Sweden and Germany, participants discussed whether learning ICT skills should be considered a personal responsibility. In contrast, participants in the Czech Republic and Greece expressed strong views that the state should play a central role in providing ICT training for older adults and supporting those who are digitally excluded.

“Yes, but then that knowledge also has to exist. It is not just that you should be given a tablet; what we have been lacking at our age is the knowledge. We can afford to buy ourselves an iPad, we can afford to buy a smartphone. But our right—our human right—is that we must be able to use them.”

- Participant, Sweden.

“They told me at the bank to have my children do my e-banking, because I did not understand how to do something. I asked my son to show me. What are other people who do not have children supposed to do?”

- Participant, Greece

“They make us feel like idiots. How can we know all these things when nobody shows us?”

- Participant, Greece

“Young people grow up with these technologies, but for our generation it is much harder, and you often feel like you are falling behind.”

- Participant, Czech Republic

Theme O3: Fear of digital environments

Many participants expressed that they felt quite insecure and wondered how to remain safe when

they use ICTs. Their concerns about data security and data ownership were evident in all focus groups. Even for those with an adequate level of digital competence, the rapid pace of technological developments, the increasing complexity of digital environments, and the advanced ability of criminals to carry out digital fraud make the digital participation of older persons a challenging experience.

“Yes, it’s really tricky how... how close they have gotten now... how personal it all becomes. In the beginning you just laughed when you got an email written in bad Swedish. It was bad... no signatures and it was like... that is not how you send out a formal letter. But today they’re starting to learn, so now it’s starting to feel like I almost have to call and ask, is this real... it becomes more frightening.”

- Participant, Sweden

“I am mainly afraid of clicking something wrong and having my data misused, and then I no longer understand what is happening.”

- Participant, Czech Republic

Theme O4: The importance of accurate information and the perils of misinformation

Closely attached to the fear of using new technologies was a problematisation of how to secure access to reliable information. This concern related both to access to non-digital forms of information and less “hidden” information within complex digital structures for those who struggle to keep up with digital competence. The issues of spreading fake news and misinformation were also widely discussed.

“If you think about all this information from public authorities that suddenly is only available online. It should be a digital right to be able to access it; if they put it there, then they should make sure that everyone in Sweden can access the correct information.”

- Participant, Sweden

“It’s so widespread now that you can spread any kind of disinformation just to harm other people, it seems, or to gain power. Those seem to be the motives. Otherwise, what are they after? I do not know. That is how I feel about a lot of it. But maybe that is just being negative and feeling like a kind of...”

- Participant, Sweden

“Nowadays, you don’t really know what to trust – there is a lot of information, but it is getting harder and harder to tell which one is correct.”

- Participant, Czech Republic

Theme 05: The “digital obligation” and the issue of agency

The notion of digital obligation was negotiated in the focus groups, mainly when older persons attempted to discuss the meaning of digital rights. For instance, many participants across all countries did not like that they are obliged to be digital, especially when it comes to e-banking, e-gov, and e-health; they felt that they did not have a choice. But while there is no other option to retain analogue services and they are obliged to be digital, they do not have many opportunities to learn.

“ Digital rights? ... better say that we have digital obligations!”

- Participant, Sweden

“Well, no, I mean... you do not really have — how should I put it — the right to decide for yourself. It is someone else who has decided for me. It is Big Brother up there who has decided for me that now you must use this, otherwise you will not manage your life. That is how it is, that is how it feels.”

- Participant, Sweden

“They expect us to handle everything digitally, but no one asks whether we can actually do it or whether we even want to.”

- Participant, Czech Republic

Theme 06: Issues of digital exclusion and ambivalence about the benefits of ICTs

Many older persons are digitally excluded because digital transformations are evolving fast and not all can keep up with the developments. This was a common understanding that was not contested in all focus groups in all countries. Language also emerged as an issue. As many participants expressed it, a foreign (to them) language is used within and about digital environments. Whether digital transformations are a negative or positive development for society at large was a topic with evident ambivalence in the narratives of the participants, especially when it comes to Artificial Intelligence. As the moderators observed in the focus groups with older persons in Germany:

“Online shopping is perceived as socially disadvantageous because small businesses have to close down, leading to the increased power of large corporations. However, in rural areas, this option also brings advantages ...”

“The pros and cons of AI are discussed. Many are critical of the manipulation possibilities. AI is seen as advantageous in other applications, like medicine, smart homes, addressing labour shortages.”

- Moderator, Germany, notes about the focus group with older persons

Focus groups with care practitioners

Five themes emerged from the focus groups with practitioners in care. The themes, along with some excerpts as examples are presented below.

Theme C1: Human rights in care and the difficulty of linking them to digital rights

Care practitioners had no difficulty relating human rights to their work. They openly discussed issues such as human rights violations, ageism and neglect, financial abuse, and the rights to health, self-determination, and the right to choice. In their view, human rights are addressed in their workplace, but not through explicit “human-rights” language. Instead, topics that raise human-rights concerns are more often framed in terms of civil rights and democracy, professional codes of conduct, or legal obligations.

In contrast, the connection between digital rights and their practice became clear to them only during the focus groups. In this context, they spoke about the right to digital training, inequalities in older persons’ access to ICT, data sharing and digital inheritance, as well as other issues explored in the themes below.

“You have the right to decide for yourself about your own home and your own life. What kind of help do you want at home, for example, and that no one should make decisions over someone’s head. It is about creating participation and working with core values — a lot of focus on core values.”

- Care practitioner, Sweden, about human rights

“Also, they have noticed that older adults reject technology and social media because they are afraid to use it, it just seems too strange to them, and have no idea how to protect themselves if something goes wrong. Again, they do not see the connection (of digital rights) to their practices, although they feel that trainings would be very beneficiary to them and the older persons.”

- Moderator, Greece, notes about the focus group with social workers.

“We deal with human rights in our work all the time, even if we don’t call them that. It’s only now that I realise digital access and digital training are part of it as well.”

- Care practitioner, Czech Republic



Theme C2:

Older persons, practitioners, and leadership falling behind in ICT developments

Care practitioners reflected that some older persons have difficulties using the necessary health care or social welfare ICTs. In addition, many practitioners in care also have difficulties keeping up with technological developments implemented in their work, either because of a lack of motivation or because no adequate training was made available to them. They emphasised that teaching older persons digital skills is very important, but practitioners' workload does not allow them to assume the role of ICT instructor. Overall, they feel that the technological changes and their implementation in the care system are fast-paced, while the administration, leadership, and politicians are not often up-to-date in providing comprehensive and reliable guidelines.

“They used to trust us with everything, now they are afraid to sign any papers, they have become suspicious because they do not understand. Sometimes we do not even understand!”

- Care practitioner, Greece

“The digital development is outpacing us. Vast amounts of data are collected, transmitted to third parties, and analysed. Politics lag behind the development, while companies are much more adept.”

- Care practitioner, Germany

“The systems change very fast, but neither the clients nor we as staff really get proper training, and management often doesn't know how things should actually work.”

- Care practitioner, Czech Republic

Theme C3:

Concerns about digitalisation, dehumanisation, and the value of personal contact

The participants expressed concerns about several aspects of digitalisation in the care sector, including data security, privacy, and data ownership. The issue of data inheritance was raised in the focus groups of some countries, while the perception that digital transformations are progressing too rapidly in real life and in the care sectors, emerged as common points of discussion across all focus groups.

A broader concern was that digitalisation may risk dehumanising care, whereas and wherein personal contact and the presence of care personnel are considered irreplaceable. For this reason, digital solutions should be used thoughtfully — to support and enhance care practices and services, rather

than replace human interaction or human intervention.

“Technology can be helpful, but it must not replace personal contact — care without human presence simply doesn’t work.”

- Care practitioner, Czech Republic

“For some cases it is particularly important to have first a talk with the doctor instead of getting an email or SMS with medical results or medical appointments. People need explanations, information, from the doctors.”

- Care practitioners, Belgium

“It should help the staff, not take over from them. That is particularly important. We should not replace ourselves with robots — and you can see this happening everywhere now, in all sectors, no matter how you look at it.”

- Care practitioner, Sweden

Theme C4. Issues of digital exclusion and ambivalence about the benefits of ICTs

In all focus groups with care practitioners, the participants discussed in detail how a lack of digital skills can lead older persons toward digitally driven social exclusion. This concern, as well as those of data security, privacy, and data ownership, served as the starting point for their discussions, in which they weighed the advantages and disadvantages of digitalising the care sector and society more broadly.

This digitally driven exclusion from welfare was understood as violations of older persons’ human rights, and more specifically, their digital rights. Educating older persons in digital skills and providing reliable access to ICT devices and the internet were seen as key solutions.

However, participants also emphasized that these measures cannot be adequately implemented within healthcare settings, nor effectively carried out by healthcare practitioners.

“A major issue in this is barriers in terms of the ability to use public transport, where payment is now by cards, parking payment issues, and the use of technology for example, the placement of ATMs virtually prevents a person in a wheelchair from using them independently, either they can’t see the display or reach the keypad.”

- Social workers, the Czech Republic

“I do not know of anyone using such a thing (i.e., digitally mediated health); it sounds very expensive! Their pensions are barely enough for them to eat, this is a luxury.”

- Social worker, Greece

“If people don’t have digital skills or access, they are basically excluded from services, but this is not something healthcare staff can fix on their own.”

- Care practitioner, Czech Republic

Theme C5: The right not to use ICTs and the preference for “low” technology

In most focus groups, the practitioners in care discussed older persons’ right not to use ICTs, either because of choice or inability. On many occasions, “low” technology like SMS, phone calls, and the television was lifted as age-friendly and appropriate solutions for those having poorer digital skills than the average.

“It would be ideal to use television programs for (digital skills) education, as almost everyone (older persons) watches them.”

- Social workers, the Czech Republic

“It is also relevant to know that some people do not want or cannot be so digital due to a lack of digital skills. The hospital for example has chosen not to send emails to patients to remind them of appointments but has chosen to send SMSs from the digital agenda.”

- Care practitioners, Belgium

“Not everyone wants or is able to use digital technologies, and we should respect that — often a phone call or an SMS works much better.”

- Care practitioner, Czech Republic

Focus groups with adult educators

Six themes emerged from the focus groups with practitioners and volunteers teaching older persons digital skills. The themes, along with some excerpts as examples are presented below.

Theme E1: Awareness of human and digital rights

This group of participants was skilled in discussing issues related to human rights and digital rights. They reflected on the rights to education and self-determination, the need for age-friendly environments, and violations of older persons' human rights, such as ageism, abuse, neglect, and social exclusion. For most participants across the countries involved, the relevance of their work to digital rights appeared straightforward but somewhat abstract to discuss in simple terms. However, some variations in understanding and emphasis were observed, with the common observation that digital rights and human rights are a concern for all and in all age groups.

“If you don’t want to manage your property when you are 40, no one says anything and if you go bankrupt, they will say you made bad choices. At an older age, there is always the question “Is he capable of understanding what he is doing and the consequences of his decisions? Shouldn’t we do something to protect him?”

- Participant, Greece

“I have been interested in these kinds of things for a very long time, so I actually often lie to many of my course participants. Someone might ask, ‘Is this safe?’ and I say, ‘Yes, absolutely, that’s exactly how it works,’ even though of course it is much more complicated. We leave an enormous number of traces in everything we do digitally. If someone asks about that in an old-fashioned absolute way, the discussion becomes far too long. And the level of abstraction becomes too high if you start trying to reason through these questions without diving into philosophy.”

- Participants, Sweden

“Human rights are a natural part of our work, and digital rights are important as well, even though they are sometimes harder to explain in simple terms.”

- Participant, Czech Republic

Theme E2: Within a generational divide, older persons and educators do not keep up

Generations also surfaced as a topic of discussion among educators. Digital competence — often viewed as a natural attribute or “blueprint” for younger generations — was discussed as having

become the societal gold standard. As a result, older and less digitally proficient individuals are devalued, perceived as less skilled overall, and less productive. In addition, participants commonly concluded that digital transformation is progressing too quickly. This rapid pace leaves some people behind and creates challenges even for those teaching digital skills to older adults, who struggle to keep up with ongoing technological developments and related ethical issues.

“We talk about older adults, but compared to 20-year-olds, I realize how far behind I am, how much AI scares me, I don’t have time to understand the next step.”

- Participant, Greece

“Digital skills are treated as the standard today, so if you don’t have them, you are seen as less capable, even though the technology is changing faster than many of us can follow.”

- Participant, Czech Republic

Theme E3: Fear, shame, and other considerations in digital environments

Similarly to the other focus groups (i.e., with carers and older persons), the participants in the education focus groups raised concerns about data security, data ownership, the growing complexity of digital environments, and the risk of older persons becoming victims of digital threats. Within this context, participants observed that the beneficiaries of their courses (or of their support) often feel ashamed of their inability to keep up with the technological demands of contemporary society, also often linked to feelings of loneliness.

“Those who are excluded, those who need the most support, are ashamed or frightened to talk about their problems ... Shame of making mistakes when using new technologies (scanner cash register) ... requires the help of family, friends, or neighbours. However, it is not possible to make use of this help for every problem (loneliness, shame, not wanting to be a burden).”

- Moderators’ notes from the focus groups in Germany

“The way someone gets into the living room of your home through the tv or social media is unbelievable.”

- Participant, Greece

“A participant reported about a friend with a son with a disability who does not want to use the ePA (electronic health records). She does not want her son’s data to be stored; one never knows what might happen in the future, and German history (reference to the Third Reich) has shown what can happen (reference to eugenics where the government murdered persons with disabilities)”

– Moderator’s comment, Germany

“Many older learners are afraid of making mistakes online, and they often feel ashamed because they think everyone else can manage except them.”

“They even apologise for asking again, saying they feel embarrassed because they keep coming back to the same question.”

- Participants, Czech Republic

Theme E4: The importance of accurate information and the perils of misinformation

Similarly to the focus groups with older persons, the practitioners and volunteers who teach older person raised concerns of misinformation and the spread of fake news. They noted that older persons often do not know where to find necessary information or find it very difficult to access. Attention was placed on the ability to critically approach news and content in the social media.

“Those of us who work with this a bit, we become—in a way—almost brainwashed. We never accept anything as 100% true. We ask: is it fake or real? Could it really be like this? Where does it come from? But not everyone does that. Sometimes you hear people say, ‘Well, it was on Facebook,’ and then—‘Oh, then it must be true.’”

- Volunteer, Sweden

“Many people are unaware of existing assistance and support services and need to be made more aware. Billboards, radio, and newspapers should be used more for this purpose.”

- Volunteer, Germany

“A big challenge is that people often don’t know where to find reliable information, and social media makes it easier for misinformation to spread.”

- Participant, Czech Republic

Theme E5: The “digital obligation” and the right not to use ICTs

The notion of an existing digital obligation was discussed at length in the focus groups with practitioners and volunteers who teach digital skills to older persons. Whether framed as a basic human right or because of older persons’ inability, the non-use of ICTs to carry out essential transactions with public or private services, should be respected and addressed. The participants argued that analogue options should remain the primary mode of operation. Closely linked to this perspective was the idea that digital solutions should be supplementary to analogue alternatives, designed to support and facilitate the lives of both practitioners and citizens. Digital solutions should not repla-

ce analogue alternatives for essential goods and services (e.g., banking, transportation, shopping, paying). Participants expressed concerns that when digitalisation becomes the default, the social exclusion of older persons with limited digital competence is further deepened.

“The coronavirus pandemic has also increased the pressure on senior citizens to go digital.”

- Moderators comment, Germany

“We had seven people in the first group, and we had divided them into iPhone and Android users. And yes, they really have to learn this. It is very stressful for them — having to deal with BankID, having poor eyesight, and some having crooked fingers. It can be difficult to press the buttons on the phone. Things go wrong. These kinds of things are very stressful for the seniors.”

- Practitioner tutoring older persons the use of IT, Sweden

“People should not be forced to use digital services for basic things — there must always be an analogue option, and digital tools should support it, not replace it.”

- Participant, Czech Republic

Theme E6: Issues of digital exclusion and ambivalence about the benefits of ICTs

As with older persons and practitioners in care, the practitioners teaching older persons digital skills outlined that digital exclusion means social exclusion. The positives and negatives of digital transformations were negotiated with an evident ambivalence on whether older persons' welfare is sufficiently addressed, especially when it comes to Artificial Intelligence.

“But society works in such a way that we rely on it (technology) to a very high degree, and for that reason you have to be able to manage it. Otherwise, over time, you automatically become excluded.”

- Practitioner working in a library and supporting older persons with IT, Sweden

“The advantages and disadvantages of digitalization are addressed in the discussion (discovery of new opportunities, simplifications in everyday life). However, the participants view that it is not a matter of free choice to be online. “Rather, there is a compulsion towards digitalization, which affects human rights and their perception.”

- Moderators' comment on the focus group with volunteers, Germany

“When someone is digitally excluded, they are often socially excluded as well. Digital tools can help, but with things like AI we are not sure older people's needs are really being considered.”

Concluding remarks

Across all focus groups of the St@ndbyMe project with older persons, care practitioners, and digital skills educators, a consistent pattern emerges around six thematic areas (see Table 2). Despite strong awareness of fundamental human rights, most older persons initially struggled to see the relevance to their everyday life. This relevance was clearer to practitioners working with older persons, namely care practitioners and those teaching older persons digital skills.

Understanding digital rights, as well as establishing the link between human rights and digital rights, was a gradual process for older persons and care practitioners, but more straightforward for educators. Many felt that digitalisation had simply “arrived” without consultation, creating a sense of obligation rather than empowerment.

A central theme concerned generations and digital literacy. Older adults frequently compared themselves unfavourably to younger generations, describing feelings of inadequacy, shame, and dependence. While those in Sweden and Germany debated whether digital learning is a personal responsibility, participants in Greece and the Czech Republic emphasised a state duty to provide training and support. All groups agreed, however, on the notion that nowadays digital exclusion results de facto in social exclusion. Language barriers, disability-related accessibility issues, and poverty were highlighted as contributing factors. Therefore, purchasing ICT devices, access to the internet, and access to education in using ICTs should be central considerations of the welfare state in addressing the needs of disadvantaged groups of all ages.

Fear of digital environments was widespread. Participants across countries noticed how older persons experience anxiety about scams, data misuse, and the increasing sophistication of digital fraud. Even digitally competent older adults felt overwhelmed by rapid technological change and the increasing complexity of digital interfaces. This fed into concerns about misinformation, with many stressing that reliable information, both digital and non-digital, should be accessible as a matter of rights.

The notion of a “digital obligation” featured strongly. All participants described coercion into digital banking, e-healthcare, and e-government without adequate non-digital alternatives or support. This perceived loss of agency creates frustration and resistance both among older persons and among practitioners working with them. Educators and care practitioners argued that digital tools should support, and not replace, analogue options, especially for essential services.

Care practitioners and educators raised an additional concern: the risk of dehumanisation in care and dehumanisation in society at large. While digital tools can streamline work, they stressed that personal contact is irreplaceable. Care practitioners also described being undertrained for new systems, facing unclear guidelines, and lacking time to teach digital skills to older clients.

Digital-skills educators emphasized that shame, loneliness, and low confidence constitute major barriers to learning. They also noted that even educators struggle to keep up with rapid technological and ethical developments. Like other groups, they advocated for maintaining analogue alternatives and recognising the right not to use ICTs.

Many participants conveyed ambivalence about the societal benefits of digitalisation: while acknowledging advantages such as convenience, medical innovation, and solutions for rural areas, they feared its effects on small businesses, privacy, and manipulation through AI.

Overall, the findings show that digitalisation is not simply a technological shift but a human-rights issue, shaping agency, access, and social participation. Digital rights remain poorly understood yet deeply relevant, particularly as essential services move online. Irrespective of age, citizens desire not only access to technology but supportive and human-centred digital environments. Across all professional groups, the need for clearer policies, slower and more careful implementation of digital solutions, sustained training on human and digital rights, and preserved analogue options emerges as key messages. Digital transformation is an opportunity, but to be just, it must prioritise inclusion, autonomy, and choice over obligation.

Appendix A – Focus group Guide (Older persons)

Focus group with older adults

Date:

Interviewer:

Organization:

Location:

Participants' IDs:

Focus group ID: _____ (Organization/Day-Month-Year/Interviewer's initials (e.g., LiU/020323/GP)

Instructions

Make sure that the participants have read the Information Sheet, signed the Consent Form, and have completed the Demographics Questionnaire. Write immediately down the Focus Group ID and the Participants ID in the consent forms, and all the Participants' IDs in this guide.

Make sure that you inform the participants that there are no right or wrong answers. We want to ask about their experience (if any), understanding (if any), and problematization (if any) on these topics.

The interviewer poses the questions that are numbered below, one at the time. If any of these questions do not motivate a discussion, then the interviewer can use the prompts that are bullet-pointed under each numbered question. If the participants reply with a simple yes or no, you can always use the prompt "would you like to tell me a little more about that?"

This is a semi-structured focus group. That means that the discussion can evolve in a different order than the order of the questions posed in this guide. The focus group can end when you feel that all topics in the question items have been covered and the discussion does not provide any added information. The focus groups should be app. 60 minutes in duration.

Make sure that all participants in the focus group had their voice heard. It is expected that some participants will be more talkative, while others not so much. It is your role to encourage that all participants have had their opinion heard.

Make sure that the session is recorded by means that all voices from all participants can be heard clearly in the recorded file. To ensure that, run a test recording before you begin. Save the recorded file under the name of the Focus Group ID (Organization/Day-Month-Year/Interviewer's initials (e.g., LiU/020323/GP).

During the focus group, keep notes at the end of this document. During the focus group, your notes should be short allowing you to be attentive and within the flow of the discussion. You can take more detailed notes when you hear the recording again, long after the end of the focus group.

Right after the end of the focus group, write your reflections on what was said and what was your

overall feeling for the atmosphere and the group dynamics – or any other thing that may not be evident by listening the recordings, or/and not easily remembered long after the end of this focus group.

Now you are ready to go! Good luck!

Question items

1. What is your understanding of what human rights are?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?

2. How relevant do you think that human rights are to you?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

3. What is your understanding of what digital rights are?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?

4. How relevant do you think that digital rights and human rights are to your life, or in general to persons over the age of 65?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?

5. Our world becomes increasingly digitalized, meaning much in our daily lives and work is operated by and through digital means. Do you think that all persons from all generations manage to keep up with this digital transformation?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

6. (Follow-up questions to Q5). Do you think that there are human rights issues related to digital transformation and digital literacy in older age? Do you think that this is relevant to you?
7. For one reason or another, some do not use or prefer digital services over traditional exchanges. For example, some do not engage with e-banking and prefer exchanges in the bank counter for their transactions. Do you think that these and similar preferences are respected?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

8. (Follow-up questions to Q7). Do you think that there are human rights issues related to the non-use of digital services? Do you think that this is relevant to you?
9. Since the establishment and the dominant use of internet services from tech giants (e.g., Microsoft, Google), there has been an extensive discussion on data security, privacy, and data ownership. Do you think that all persons from all generations keep up with these developments?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

10. (Follow-up questions to Q9). Do you think that there are human rights issues related to data security, privacy, and data ownership? Do you think that this is relevant to you?
11. Since the establishment and the widespread use of social media (e.g., Facebook, Instagram, Twitter), there has been an extensive discussion on the spread of fake news, misinformation, and the right to freedom of expression. Do you think that all persons from all generations manage to keep up with these developments?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

12. (Follow-up questions to Q11). Do you think that there are human rights issues related to the spread of fake news, misinformation, and the right to freedom of expression? Do you think that this is relevant to you?
13. Now we have talked about several topics and issues that we address in the St@ndbyMe project from a human rights perspective. Have you ever addressed these issues when learning to use various technological devices, apps, etc. in the past?
14. It is the intention of our project team to develop an educational tool that addresses the needs of older persons to be informed on their digital rights from a human rights perspective. What are the thematic areas that you think should be covered in this training material? What form should this information material have?

Thank you for your participation!

Appendix B – Focus group Guide (Care)

Focus group with Practitioners in Care

Date:

Interviewer:

Organization:

Location:

Participants' IDs:

Focus group ID: _____ (Organization/Day-Month-Year/Interviewer's initials (e.g., LiU/020323/GP))

Instructions

Make sure that the participants have read the Information Sheet, signed the Consent Form, and have completed the Demographics Questionnaire. Write immediately down the Focus Group ID and the Participant ID in the consent forms, and all the Participants' IDs in this guide.

Make sure that you inform the participants that there are no right or wrong answers. They are merely asked about their experience (if any), understanding (if any), and problematization (if any) on the topics that the interview questions are introducing.

The interviewer poses the questions that are numbered, one at the time. If any of these questions do not motivate a discussion, then the interviewer can use the prompts that are bullet-pointed under each numbered question. If the participants reply with a simple yes or no, you can always use the prompt "would you like to tell me a little be more about that?"

The interviewer can use one of the expressions in italics (professional/voluntary/informal practise) depending on the professional/voluntary etc. profile of caregiving that the participants exercise.

This is a semi-structured focus group. That means that the discussion can evolve in a different order than the order of the questions posed in this guide. The focus group can end when you feel that all topics in the question items have been covered and the discussion does not provide any new information. The focus groups should be app. 60 minutes in duration.

Make sure that all participants in the focus group had their voice heard. It is expected that some participants will be more talkative, while others not so much. It is your role to encourage all participants to have had their opinion heard.

Make sure that the session is recorded by means that all voices from all participants can be heard clearly in the recorded file. To ensure that, run a test recording before you begin. Save the recorded file under the name of the Focus Group ID (Organization/Day-Month-Year/Interviewer's initials (e.g., LiU/020323/GP)).

During the focus group, keep notes at the end of this document. During the focus group, your notes should be short allowing you to be attentive and within the flow of the discussion. You can take

more detailed notes when you hear the recording again, long after the end of the focus group.

Right after the end of the focus group, write your reflections on what was said and what was your overall feeling for the atmosphere and the group dynamics – or any other thing that may not be evident by listening the recordings, or/and not easily remembered long after the end of this focus group.

Now you are ready to go! Good luck

Question items

1. What is your understanding of what human rights are?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?

2. How relevant do you think that human rights are to your professional/voluntary/informal practise with older persons?

Prompts:

- ☐ Was there any discussion in your workplace/setting of care provision about violations or the protection of the human rights of older persons?
- ☐ Were there any concerns in your workplace/setting of care provision that the human rights of older persons that you work with should be protected, or even might have been violated?

3. What is your understanding of what digital rights are?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?

4. How relevant do you think that digital rights are to your professional/voluntary/informal practise with older persons?

Prompts:

- ☐ Was there any discussion in your workplace/setting of care provision about the violation or the protection of the digital rights of older persons?

- ☐ Were there any concerns in your workplace/setting of care provision that the digital rights of older persons that you work with should be protected, or even might have been violated?

5. Our world becomes increasingly digitalized, meaning much in our daily lives and work is operated by and through digital means. Do you think that both practitioners and older persons in your professional/voluntary/informal practise manage to keep up with the digital transformation of health and care provision?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

6. (Follow-up questions to Q5). Do you think that there are human rights issues related to the digitally mediated provision of care? Do you think that these issues are relevant to your professional/voluntary/informal practise with older persons?

7. For one reason or another, some older persons do not use digital services in health or care settings. For example, some do not opt to have fall detection equipment installed in their houses while others have no access to such services in their residency areas. How are those issues addressed in your professional/voluntary/informal practise?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

8. (Follow-up questions to Q7). Do you think that there are human rights issues related to the non-provision or non-use of digitally mediated care? Do you think that this is relevant to your professional/voluntary/informal practise with older persons?

9. Since the establishment and the dominant use of application from tech giants (e.g., e-health apps and ecosystems), there has been an extensive discussion on data security, privacy, and data ownership. Do you think that both practitioners and older persons in your professional / voluntary / informal practise manage to keep up with these developments?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?

☐ Have you ever discussed this topic with others?

10. (Follow-up questions to Q9). Do you think that there are human rights issue related to data security, privacy, and data ownership in the provision of care? Do you think that this is relevant to your professional/voluntary/informal practise with older persons?

11. Since the establishment and the widespread use of social media (e.g., Facebook, Instagram, Twitter), there has been an extensive discussion on the spread of fake news, misinformation, and the right to freedom of expression. Do you think that both practitioners and older persons in your professional/voluntary/informal practise manage to keep up with these developments?

Prompts:

☐ Have you ever heard or read something about this topic?

☐ Have you witnessed something that brought you to these thoughts?

☐ Have you ever discussed this topic with others?

12. (Follow-up questions to Q11). Do you think that there are human rights issues related to the spread of fake news, misinformation, and to freedom of expression? Do you think that this is relevant to your professional/voluntary/informal practise with older persons?

13. Now we have talked about several topics and issues that we address in the St@ndbyMe project from a human rights perspective. Do you think that most professional or practitioners in care are ready to address these issues when working with older persons?

14. It is the intention of our project team to develop an educational tool that addresses the potential training needs of professionals and practitioners like you on the digital rights of older persons from a human rights perspective. What are the thematic areas that you think should be covered in this training material? What form should this training tool have?

Thank you for your participation!

Appendix C – Focus group Guide (Education)

Focus group with Practitioners in Adult Education

Date:

Interviewer:

Organization:

Location:

Participants' IDs:

Focus group ID: _____ (Organization/Day-Month-Year/Interviewer's initials (e.g., LiU/020323/GP)

Instructions

Make sure that the participants have read the Information Sheet, signed the Consent Form, and have completed the Demographics Questionnaire. Write immediately down the Focus Group ID and the Participants ID in the consent forms, and all the Participants' IDs in this guide.

Make sure that you inform the participants that there are no right or wrong answers. They are merely asked about their experience (if any), understanding (if any), and problematization (if any) on the topics that the interview questions are introducing.

The interviewer poses the questions that are numbered, one at the time. If any of these questions do not motivate a discussion, then the interviewer can use the prompts that are bullet-pointed under each numbered question. If the participants reply with a simple yes or no, you can always use the prompt "would you like to tell me a little be more about that?"

The interviewer can use one of the expressions in italics (*professional practise/or/the activities that you organize*) depending on the profile of the participants (e.g., professional or volunteers in adult education).

This is a semi-structured focus group. That means that the discussion can evolve in a different order than the order of the questions posed in this guide. The focus group can end when you feel that all topics in the question items have been covered and the discussion does not provide any new information. The focus groups should be app. 60 minutes in duration.

Make sure that all participants in the focus group had their voice heard. It is expected that some participants will be more talkative, while others not so much. It is your role to encourage that all participants have had their opinion heard.

Make sure that the session is recorded by means that all voices from all participants can be heard clearly in the recorded file. To ensure that, run a test recording before you begin. Save the recorded file under the name of the Focus Group ID (Organization/Day-Month-Year/Interviewer's initials (e.g., LiU/020323/GP).

During the focus group, keep notes at the end of this document. During the focus group, your notes

should be short allowing you to be attentive and within the flow of the discussion. You can take more detailed notes when you hear the recording again, long after the end of the focus group.

Right after the end of the focus group, write your reflections on what was said and what was your overall feeling for the atmosphere and the group dynamics – or any other thing that may not be evident by listening the recordings, or/and not easily remembered long after the end of this focus group.

Now you are ready to go! Good luck!

Question items

1. What is your understanding of what human rights are?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?

2. How relevant do you think that human rights are to your professional practise/or/the activities that you organize with older persons?

Prompts:

- ☐ Was there any discussion in your workplace/activity centre about the violation or the protection of the human rights of older persons?
- ☐ Were there any concerns in your workplace/activity centre that the human rights of older persons that you work with should be protected, or even might have been violated?

3. What is your understanding of what digital rights are?

Prompts:

- ☐ Have you ever heard about this topic?
- ☐ Have you ever read about this topic?
- ☐ Have you ever discussed this topic with others?
- ☐

4. How relevant do you think that the digital rights are to your professional practise/or/ the activities that you organize with older persons?

Prompts:

- ☐ Was there any discussion in your workplace/activity centre about the violation or the protection of the digital rights of older persons?

- ☐ Were there any concerns in your workplace/activity centre that the digital rights of older persons that you work with should be protected, or even might have been violated?

5. Our world becomes increasingly digitalized, meaning much in our daily lives and work is operated by and through digital means. Do you think that both older persons and practitioners in your field of practice manage to keep up with this digital transformation?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

6. (Follow-up questions to Q5). Do you think that there are human rights issues related to digital transformation and digital literacy? Do you think that this is relevant to your professional practise/or/the activities that you organize with older persons?

7. For one reason or another, some do not use or prefer digital services over traditional exchanges. For example, some do not engage with e-banking and prefer exchanges in the bank counter for their transactions. Do you think that these and similar preferences among older persons are respected and addressed properly?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

8. (Follow-up questions to Q7). Do you think that there are human rights issues related to the non-use of digital services? Do you think that this is relevant to your professional practise/or/the activities that you organize with older persons?

9. Since the establishment and the dominant use of internet services from tech giants (e.g., Microsoft, Google), there has been an extensive discussion on data security, privacy, and data ownership. Do you think that both practitioners and older persons in your field manage to keep up with these developments?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

10. (Follow-up questions to Q9). Do you think that there are human rights issues related to data security, privacy, and data ownership among users of internet services? Do you think that this is relevant to your professional practise/or/the activities that you organize with older persons?
11. Since the establishment and the widespread use of social media (e.g., Facebook, Instagram, Twitter), there has been an extensive discussion on the spread of fake news, misinformation, and the right to freedom of expression. Do you think that older persons in your professional practise/or/the activities that you organize manage to keep up with these developments?

Prompts:

- ☐ Have you ever heard or read something about this topic?
- ☐ Have you witnessed something that brought you to these thoughts?
- ☐ Have you ever discussed this topic with others?

12. (Follow-up questions to Q11). Do you think that there are human rights issues related to the spread of fake news, misinformation, and the right to freedom of expression? Do you think that this is relevant to your professional practise/or/the activities that you organize with older persons?
13. Now we have talked about several topics and issues that we address in the St@ndbyMe project from a human rights perspective. Do you think that most professional or practitioners in adult education activities are ready to address these issues when working with older persons?
14. It is the intention of our project team to develop an educational tool that addresses the potential training needs of professionals and practitioners like you on the digital rights of older persons from a human rights perspective. What are the thematic areas that you think should be covered in this training material? What form should this training tool have?

Thank you for your participation!