

D1.6 Policy recommendations



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Personalised coaching for well-being and care of people as they age

Approvals

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Short Abstract

Based on the results from the pilots, the interaction with the Forum of Advisory Stakeholders and the overall project findings, this document provides a set of recommendations that can be taken up by policy makers at European level. The recommendations address healthy ageing and wellbeing from a preventative approach and touch upon data protection, digital technologies for healthy ageing, and market dynamics in the silver economy.

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Policy Recommendations, Policy Making, Ageing, Wellbeing, Education, Digital Divide, Social Determinants of Health, Health Inequalities, Ethics, Co-Design, Pseudonanonymisation, Automated-Decision Making, Data Management, Human Rights, Interoperability, Scientific Validation, Exploitation

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Introduction

Marston et al. (2020)¹ in their paper "COVID-19 and the secret virtual assistants: the social weapons for a state of emergency" affirm: "The COVID-19 pandemic brings two key issues into focus when considering technology. Firstly, the integral nature of technology to modern society and in national emergency situations. The second issue underscores the need for affordable and accessible technology. During the current social restrictions, many citizens, if not all, face economic uncertainty and many are at the risk of poverty. There is little merit in positing technology as a critical tool, if it is unaffordable and inaccessible, especially at this time."

Further they provide a rational for Virtual Assistants (VAs) as tools meeting the two challenges mentioned earlier: "VAs are unique in so much as they offer connections to digital services using voice alone, removing the need to acquire digital skills that many other technology types require. (...) VAs can assist the user to develop new routines, whilst also learning current routines, followed by supporting users to maintain a sense of familiarity during what are unprecedented and strange times."

Marston et al. are well aware of the issues linked to the use of virtual assistants: VAs require a stable internet connection; VAs can make mistakes; people living with speech impairments might struggle to interact thus increasing the risk for the system to make errors and undermining the person's self-esteem; VA-collected data might be stored on a cloud outside the jurisdiction of the VA provider or user thus threatening users' privacy...

Since the beginning of the NESTORE journey, exchanges with third parties have allowed project partners to debate the pros and cons of using VAs for health prevention and promotion at length. NESTORE engaged with older adults and potential users of the NESTORE system via its co-design and piloting activities – respectively the Experts by Experience (EbE) and the pilot participants. Advisors representatives of key stakeholders (older persons, informal carers, general practitioners, public health authorities, etc.) have been consulted all along the project lifetime through the regular meetings of the Forum of Advisory Stakeholders (FAS). Finally, representatives of various universities, research groups, civil society organisations, policy makers, and industrial stakeholders have been met on the occasion of bilateral meetings or public events.

Those exchanges have contributed to refine and inform NESTORE's ambition to use the great potential of VAs to adopt a comprehensive preventive approach to health – in particular healthy ageing.

Some of the lessons learnt along the NESTORE project could actually inform the practice of third parties or benefit future policies and funding programmes from the European Commission in fields covered by the project – namely: Automated Decision Making, AI-enabled Technologies, Prevention, and Healthy Ageing. Hence these policy recommendations (deliverable 1.6), addressing the key issues that we noted European policy makers could consider as to improve the quality of ageing in our digital societies.

The recommendations are grounded on the main focus of the NESTORE project, i.e. prevention and well-being, suggesting a path to change both our policies and practices in the European Union.

¹ Sheerman L, Marston HR, Musselwhite C and Morgan D. COVID-19 and the secret virtual assistants: the social weapons for a state of emergency [version 1; peer review: 1 not approved]. *Emerald Open Res* 2020, **2**:19 (https://doi.org/10.35241/emeraldopenres.13571.1)





Methodology

These policy recommendations are the results of several consultation processes within the consortium and with third parties. Among the internal consultations organised by the project, we count:

- Conversations with NESTORE partners in relation to their field of expertise, in particular: the
 University Politecnico di Milano (POLIMI) as coordinator, lead partner on market exploitation of the
 NESTORE results as well as Data Protection Officer (DPO), the University of Barcelona as lead partner
 on ethical issues, AGE Platform Europe as the advocacy organisation representative of older persons,
 and ROPARDO as lead partner on technological integration;
- Feedback by the Sheffield Hallam University in charge of the NESTORE group of Experts by Experience mobilised for the co-design methodology;
- Regular and ad hoc exchanges with the Forum of Advisory Stakeholders (FAS)², via e-mail exchanges and face-to-face meetings³.
- Regular and ad hoc exchanges with AGE Platform Europe's policy officers, in particular to liaise with the Green Paper on Ageing and the European Council Conclusions on Human Rights, Participation and Well-Being of Older Persons in the Era of Digitalisation.

Among the conversations held with third parties, the NESTORE project organised several events to seek the views of experts and field organisations on the areas of interest for these recommendations:

- On 4 September 2019, Lab4Living from the Sheffield Hallam University ran a workshop with the support of AGE Platform Europe at the Open Living Lab Days 2019 about NESTORE Co-design methods for ageing well presenting the 'Exhibition-In-A-Box' toolkit⁴;
- On 16 September 2019, the Fondazione POLIMI opened the doors of the University Politecnico di Milano to 10 older persons invited by the FAS member, Gray Panthers, for a first focus groups of the project and debate on the role of digital devices for healthy ageing and primary prevention⁵;
- On 3 October 2019, a public event in Rotterdam, Netherlands gathered a multidisciplinary panel to present local initiatives, discuss the added value of public and private data for health prevention and promotion, and return on investment when digitalising public health policies⁶;
- On 4 December 2019, the symposium of EHTEL the European Health Telematics Association invited our partner Dr. Itziar De Lecuona of the Bioethics & Law Observatory in Barcelona to present NESTORE as a case study in a panel on "Sharing in an AI-Friendly Environment: Data Donation and more"?

⁷ See report: https://www.ehtel.eu/images/EHTEL_Symposium_Report.pdf (NESTORE's mentioned on page 17)





² See a presentation of the FAS: https://nestore-coach.eu/advisory-board

³ See for instance: https://nestore-coach.eu/-/advisory-board-confirms-several-key-principles

⁴ See report: https://nestore-coach.eu/-/report-nestore-co-design-methods-for-ageing-well

⁵ See report: https://nestore-coach.eu/-/-it-is-very-important-that-systems-are-integrated-otherwise-we-are-bombared-with-information-potential-nestore-user-says

⁶ See report: https://nestore-coach.eu/-/digital-ecosystems-for-healthy-ageing-a-partnership-for-ageing-well-

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• On 18 February 2020, NESTORE along with two other Horizon 2020 projects in virtual coaching organised a webinar on how to handle data sharing in compliance with the latest European regulations and ethics in research projects on healthy ageing⁸;

- On 29 October 2020, in a workshop organised for the International Multi-modal Coaching Interaction ICMI2020⁹ by the PM-15 consortia¹⁰, NESTORE brought forward its lessons learnt through multi-modal coaching.
- On 28 January 2021, the Hub Talk "Integration of mHealth into health systems" provided NESTORE with insights from other experts on reimbursement model on digital health applications and a comparative view on the health app reimbursement frameworks.
- On 29 January 2021, the European Commission's e-Health Stakeholder Group organised a webinar entitled "Unlocking the potential of mHealth". NESTORE representatives from Politecnico, HES-SO and AGE attended and exchanged on the quality and reliability of health and well-ness apps.
- On 8 February 2021, the ITU, AARP and UNDESA organised a webinar entitled "Digital Technologies and Older Persons: A smart mix" in the occasion of the 14th Annual AARP UN Series during the 59th session of the Commission for Social Development.
- On February 9 2021, the IN4AHA project organised a short public event in the occasion of its Kick-off meeting, "How to deliver the promise of digital innovation in active and healthy ageing? The kick-off meeting of the project IN-4-AHA".
- On 25 February 2021, the NESTORE final event offered an additional platform to exchange on
 prevention and well-being through digital solutions, calling on board also representatives from the
 European Commission (DG CONNET and DG SANTE), representatives from the PM-15 group and
 external stakeholders.
- The authors of this report also ran bilateral conversations with experts from the European Commission Directorate General for Communications Networks, Content and Technology (DG CNECT), the European Commission Directorate General for Health and Food Safety (DG SANTE) and AGE Platform Europe's Policy Coordinators in charge of the technological and human rights dossiers.

¹¹https://mhealth-hub.org/





⁸ See report: https://nestore-coach.eu/-/webinar-on-data-sharing-in-digital-healthy-ageing-projects

⁹ See presentations: https://nestore-coach.eu/-/multimodal-ecoaches-the-presentations

¹⁰ The various Horizon2020 projects funded by the SC-PM-15 call on Personalised coaching for well-being and care of people as they age.

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Recommendations

The following list summarizes the recommendations included in this report per thematic chapter.

These recommendations are intended to foster policy support to **mainstream digital solutions.** It is key to listen to what users and consumers say, to ground research in co-creation, to avoid fragmentation in technological development and users' experiences, while sustaining social impact and user- friendly communication (cf. Chapter 3). And by following the specific recommendations below, resulting from the project's experience.

Address ageism, during and post-pandemics

- The EU should take a leading role in implementing the United Nations' Decade of Healthy Ageing (2020-2030), especially with regard to the implementation of its pillar mainstreaming ageing in all areas;
- Develop exchanges of knowledge and good practices towards age-inclusive digital goods and services for active and healthy ageing;
- Fund future research about ageing and digital technologies encompassing sound trials to fill the gaps of lacking evidence regarding the benefits of such technologies for healthy ageing;
- Support trainings to tackle stereotypes and to promote positive exposure, intergenerational relations and experiences;
- Support local and regional authorities to strengthen and sustain their social care systems, services, social and physical environments, so as to enhance health, equity and well-being and allow users the option between digital and non-digital services;
- Support assessing how technologies can interfere with people's rights both in the development and use of artificial intelligence.

Tackle the root causes of health inequality across the lifecourse

- Tackle the root causes of bad health in later life and age-related disability by addressing socio-economic inequalities across the life course;
- Promote healthy lifestyles and address inequalities over the life course, as well as detecting and modifying early and mid-life risk factors of impaired function and chronic diseases;
- Promote policies and funds to cope with the digital and health divide through the life course and across literacy level and incomes;
- Support local and regional authorities to strengthen and sustain their social care systems, services, social and physical environments, so as to enhance health, equity and well-being through age-friendly communities and allow users the option between digital and non-digital services;
- Further develop, where appropriate, mechanisms for the participation of civil society in decision-making in relation to older persons in the digital world;
- Sustain a strong European public health programme and the budgetary prioritisation of health promotion, disease prevention, pandemic management and reduction of health inequalities across the European research programmes.





Ensure accessibility and affordability of digital technologies for ageing well and equitably

- Guarantee that pilot activities are performed in the optimal conditions regarding the safety, accessibility and reliability of the system to be tested;
- Collect reliable, disaggregated and GDPRcompliant data regarding the digital divide for people aged 75 and over;
- Ensure funds for a wide broadband Internet coverage including in rural areas where the availability of healthcare services might make digital interaction all the more critical:
- Partnerships with the profit and non-profit private sector are crucial not only to strive innovation, but also to ensure that disadvantaged groups can have equal access to phone, internet and other media.

Co-Design and co-create

- Provide guidance to EU-funded research projects in the field of active and healthy ageing to address ageism, be it in their methodology or their communication;
- Incentivise and support EU-funded research projects in providing clear, simplified consent-forms by cognitively adapting language and using corrective feedback;
- Support EU-funded research projects in increasing the accessibility of co-design methods during the project proposal evaluation and in granted project;
- Encourage research projects to include a diversity of older people in their co-design activities;





Secure data for all

- Empower and train citizens and users and provide them with mechanisms to control the use of their data and exercise their rights.
- Ensure that every project aiming to conduct pilot activities includes a data sharing agreement during the preparation of the consortium agreement under the leadership of the coordinating partner;
- Coordinate trainings and a resource repository to guide the adequate implementation of pseudonymisation in research projects where personalisation is needed;

Regulate Automated-Decision Making

- Sustain the adoption of binding regulations to help close the protection gaps currently existing with regard to combating discrimination on all grounds outside the labour market;
- Adopt a comprehensive strategy to safeguard against the use of personal data and data systems in ways that perpetuate discrimination and exclusion:
- Support Member States in their efforts to increase the digital literacy of citizens and consumers regarding automated-decision making systems to increase the understanding of the possibilities, limitations and potential risks of such systems.





1. Wellbeing and prevention: success factors to ageing well

Among the projects funded by the so-call PM-15 call for proposal, NESTORE is the only virtual coach intended to support healthy ageing in a preventive approach. Although NESTORE is mainly intended to healthy individuals willing to sustain their good health, the very fact that potential users are healthy might be the reason why they don't find it necessary to adopt a virtual coach for ageing well. This approach triggered interesting discussions with the Forum of Advisory Stakeholders (FAS) on several occasions. The FAS highlighted that if the objective of NESTORE is to prevent frailty and counteract the effects of biological ageing, the main challenge will be to stimulate behavioural change for healthy people either willing to sustain their good health or to further improve their condition.

The various discussions, in particular with the Forum of Advisory stakeholders¹², emphasized the importance to consider the stigmatisation of older people and the diversity of older age (section 3.1), the socio-economic inequalities in terms of access to resources and outcomes, and ensure that NESTORE will not reinforce those inequalities (section 3.2), as well as the accessibility and affordability of digital technologies such as NESTORE and the skills required to attain tangible results through their deployment (section 3.3).

1.1. Address ageism in the field of technologies for active and health ageing

Various research works have shown that ageism has detrimental effects on the health and well-being of older persons: the World Health Organisation reminds that people who think positively about ageing have on average 7.5 years more in life expectancy¹³. Recent systematic review by Chang et al. (2020) showed that ageism led to significantly worse health outcomes in 95.5% of the studies¹⁴. Their analysis confirms that the detrimental impact of ageism on older persons' health has been occurring simultaneously at both structural and individual level in five continents. Similarly, a publication by Officer et al. (2020) showed that the "likelihood of an individual or a country being ageist was significantly reduced by increases in healthy life expectancy and the proportion of older people within a country".

But generalised ageist stigmas – be they internalised by older people or diffused to them by third parties – also carry the risk of a reduced confidence and interest in engaging with technology by older people. A distorted view of old age may result in low expectations regarding the capacity of older persons to adopt mainstream technologies which are considered as more intuitive to young people (to the difference of assistive devices 'designed for them')¹⁶.

In addition to ageism, it should be noted that older women are at particular risk of exclusion from digital technologies due to the combined effect of ageism with sexism. Such risk of exclusion was for example demonstrated in instances where artificial intelligence uses discriminatory models within its systems¹⁷. The overall intersection of ageism and other grounds of dissemination should be carefully considered.

¹⁷ See: https://www.wired.com/story/what-does-a-fair-algorithm-look-like/





¹² Ref. D8.3.2. Final report on the FAS activities

¹³ See: https://www.who.int/ageing/ageism/en/

¹⁴ Chang E-S, Kannoth S, Levy S, Wang S-Y, Lee JE, Levy BR (2020) *Global reach of ageism on older persons' health: A systematic review.* PLoS ONE 15(1): e0220857. https://doi.org/10.1371/journal.pone.0220857

¹⁵ Officer A, Thiyagarajan JA, Schneiders ML, Nash P, de la Fuente-Núñez V. Ageism, Healthy Life Expectancy and Population Ageing: How Are They Related?. *Int J Environ Res Public Health*. 2020;17(9):3159. Published 2020 May 1. doi:10.3390/ijerph17093159

¹⁶ For further developments: https://euroageism.eu/projects/living-lab-ecosystems-for-co-design-with-older-people/ and https://euroageism.eu/policy https://euroageism.eu/policy <a href="projects/internet-connectedness-of-older-adults-in-the-time-of-connectedness-of-older-adults-in-the-time-of-connectedness-of-older-adults-in-the-time-of-connectedness-of-older-adults-in-the-time-of-connectedness-of-older-adults-in-the-time-of-connectedness-of-older-adults-in-the-time-of-connectedness-of-older-adults-in-the-time-older-adults-in-the-ti

Similarly, a multi-cultural approach when designing digital technologies is becoming inevitable as the older population is becoming more and more diverse with migrant workers ageing in the host country, especially in big cities¹⁸. Aware of such trends, the 2017 report¹⁹ of the UN Independent Expert on the rights of older people had called for an equal access to assistive technologies and robots to all older people regardless of their level of income, ethnic or cultural origin, religion, physical or mental ability, gender, or place of residence.

NESTORE intended to challenge ageism in design by adopting a co-design approach²⁰. Policies can further support this: to ensure technologies intended to support active and healthy ageing effectively serve this purpose for all older people, it is critical that ageism in the technological and digital fields is addressed.

This document therefore recommends the European Commission to:

- Take a leading role in implementing the United Nations' Decade of Healthy Ageing (2020-2030)²¹, especially with regard to the implementation of its pillar mainstreaming ageing in all areas;
- Develop exchanges of knowledge and good practices towards age-inclusive digital goods and services for active and healthy ageing;
- Fund future research²² about ageing and digital technologies encompassing sound trials to fill the gaps of lacking evidence regarding the benefits of such technologies for healthy ageing ²³;
- Support trainings to tackle stereotypes and to promote positive exposure, intergenerational relations and experiences²⁴;
- Support local and regional authorities to strengthen and sustain their social care systems, services, social
 and physical environments, so as to enhance health, equity and well-being and allow users the option
 between digital and non-digital services;
- Support assessing "how technologies can interfere with people's rights both in the development and use of artificial intelligence".²⁵.

1.2. Tackle socio-economic determinants of health inequality across the life course

People's diversity grows with age; there is no more heterogeneity in one age cohort than in the oldest one as older people accumulate life experiences that will shape their socio-economic condition and health status. Old age – per the definition of the ATHLOS researchers²⁶ – reflects accumulated disadvantage such as geographic location, gender, ageist attitudes and practices.

²⁶ See: https://www.age-platform.eu/special-briefing/we-are-not-all-old-same-age-life-expectancy-policy-matter





¹⁸ See: https://nestore-coach.eu/-/advisory-board-confirms-several-key-principles

¹⁹ See: https://age-platform.eu/special-briefing/assistive-technologies-and-robots-age-welcomes-new-un-independent-expert%E2%80%99s-report

²⁰ https://nestore-coach.eu/es/-/-exhibition-in-a-box-nestore-s-road-to-co-creation

²¹ See: https://www.who.int/ageing/decade-of-healthy-ageing

²² The EU H2020 MSCA-ITN EuroAgeism project is, in that sense, a very good practice. See for instance the work of Ittay Mannheim on the role of ageism as a possible barrier to adoption and use of digital technologies. See: https://euroageism.eu/staff/mannheim-ittay/

²³ See: https://nestore-coach.eu/-/health-prevention-and-promotion-policy-recommendations-under-preparation-by-nestore

²⁴ See: https://data.consilium.europa.eu/doc/document/ST-11717-2020-INIT/en/pdf

²⁵ See: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-artificial-intelligence_en.pdf

Paradoxically, people in most need of support are not the ones with the skills to make most of these new digital technologies. Thus, the challenge of a preventive device such as the NESTORE coach to target individuals with both unhealthy behaviours to change and a minimum level of digital literacy and income to be able to access and interact with the device.

Patch-up solutions like the NESTORE coach might work well for older adults going through a transitory period and willing to receive a short-term support to adapt to a new life environment: after moving to a new place, after retiring from formal employment, after a good friend or the spouse passed away, etc. Alternatively, NESTORE might be the adequate support tool to accompany new healthy habits in parallel of medical monitoring and advice by general practitioners²⁷.

NESTORE worked on key dimensions of human well-being (physical, cognitive, social and nutritional aspects). Ensuring people age in good health, however, depends from a wider policy effort to decrease health inequality early in the ageing process. The approach needs to be comprehensive (takes account of all areas of life) and preventive (addressing the conditions shaping one's health rather than curing the consequences of those conditions). Although prevention in old age is key, it would be important to consider prevention from a life-course perspective for better results.

Therefore the authors of the present deliverable recommend that the European Commission contributes to:

- Tackle the root cause of bad health in later life and age-related disability by addressing socio-economic
 inequalities across the life course, through dedicated policies and funds, as recommended by the
 ATHLOS project²⁸;
- Promote policy frameworks healthy lifestyles over the life course, as well as detecting and modifying early and mid-life risk factors of impaired function and chronic diseases as recommended by the SAPEA report²⁹;
- Promote policies and funds to cope with digital divide that will prevent Europeans with the lowest levels of (digital) literacy and lowest incomes to access digital opportunities to improve their health³⁰;
- Support local and regional authorities to strengthen and sustain their social care systems, services, social and physical environments, so as to enhance health, equity and well-being through age-friendly communities³¹ and allow users the option between digital and non-digital services;
- Further develop, where appropriate, mechanisms for the participation of civil society and older persons themselves in decision-making in relation to older persons in the digital world³²; digitalisation must be shaped involving older persons and according to their diverse needs and abilities³³;

³³ See: https://www.age-platform.eu/sites/default/files/AGE-BAGSO Joint statement on EU Council conclusions-Sept20.pdf





²⁷ See: https://nestore-coach.eu/-/advisory-board-confirms-several-key-principles

²⁸²⁸ See: http://athlosproject.eu/measuring-inequalities-of-development-at-the-sub-national-level/

²⁹ See: https://www.sapea.info/topics/ageing/

³⁰ See also from the Erasmus+ DIGITOL project: https://www.age-platform.eu/policy-work/news/digital-literacy-older-people-overview and from AGE Platform Europe: https://www.age-platform.eu/policy-work/news/age-responds-eu-consultation-digital-education-it-more-urgent-ever-reach-out-older

³¹ Also see the joint statement of the Action Group D4 of the European Innovation Partnership for Active and Healthy Ageing, May 2019

³² See: https://data.consilium.europa.eu/doc/document/ST-11717-2020-INIT/en/pdf

• Sustain a strong public health programme and the budgetary prioritisation of health promotion, disease prevention and reduction of health inequalities in the EU's post-2020 research programme³⁴.

1.3. Ensure accessibility and affordability of technologies for wellbeing

The COVID-19 pandemic, and the measures of physical distancing that came along, showed once again the importance of digital technologies to access services³⁵. Whilst digital means have being widely used to communicate and to access services during the various national lockdowns, an important number of persons could not access online shopping, banking, video call platforms, e-learning and other opportunities to meet their basic needs and remain socially engaged³⁶.

The hurdles experienced during the COVID-19 pandemic confirms the importance of several issues discussed within the NESTORE project, e.g. with regard to the affordability. Discussions with the Forum of Advisory Stakeholders led to the adoption of an exploitation scenario where public authorities would include NESTORE as part of a package of services for active and healthy ageing, and thus provided for free to its citizens.

NESTORE was centred on prevention and motivation boost to sustain healthy behaviours. Because of the importance of prevention for living and ageing well and of the need to avoid further inequalities as those described in section 3.2, equal access to assistive technologies must be ensured to all older people regardless of their level of income, ethnic or cultural origin, religion, physical or mental ability, gender, or place of residence. The UN Independent Expert on the on the enjoyment of all human rights by older persons stresses that age limits constitute a form of discrimination as they impede older people from accessing the support they might need³⁷.

Therefore, this deliverable recommend that the European Commission contributes to:

- Guarantee that pilot activities are performed in the optimal conditions regarding the safety, accessibility
 and reliability of the system to be tested, by allowing projects the flexibility to accommodate changes
 along the journey;
- Collect reliable, disaggregated, and GDPR-compliant data regarding the digital divide for people aged 75 and over;
- Ensure funds for wide broadband Internet coverage including in rural areas where the availability of healthcare services might make digital interaction all the more critical;
- Partnerships with the profit and non-profit private sector are crucial not only to strive innovation, but
 also to ensure that disadvantaged groups can have equal access to phone, internet and other media, e.g.
 by retailing to community centers, residential and day-care settings, public institutions, and by ensuring
 the affordability and inclusiveness of the private sector's digital offers (both devices and Internet
 subscriptions).

³⁷ See: https://age-platform.eu/special-briefing/assistive-technologies-and-robots-age-welcomes-new-un-independent-expert%E2%80%99s-report





³⁴ European Committee of the Regions, 136th Plenary Sessions, 7-9 October 2019, Opinion "Active and Healthy Ageing", NAT/VI-037.

³⁵ See: https://euroageism.eu/policy_projects/internet-connectedness-of-older-adults-in-the-time-of-covid-19/

³⁶ See: https://www.age-platform.eu/sites/default/files/Human rights concerns on implications of COVID-19 to older persons updated 18May2020.pdf

2. Ethics: achieve trust in digital technologies

Technologies can help realise older people's rights to health, autonomy, independence and to ensure their full participation in society. But digitalisation also carries along key challenges, in terms of safety, autonomy, privacy and equal treatment... among others. Although this generation of research and innovation projects are the first ones to experience the General Data Protection Regulation (GDPR) since its application on 25 May 2018, the current human rights frameworks and binding legislations do not sufficiently address issues arising from technological innovation.

NESTORE is one of those examples of European research project about ageing and wellbeing where the convergence of technologies poses ethical, legal and societal aspects. These recommendations aim to support the progressive adaptation of our legal and policy frameworks in order to ensure that technologies respect older people's preferences and lifestyles (section 4.1), adapt to each user without profiling (section 4.2), comply with latest legislation regarding data management (section 4.3).

2.1. Co-create technologies to ensure they 'fit users' life'

Negative stereotypes of older adults as being incompetent may lead to different forms of exclusion including in research, clinical research and randomized controlled trials. Mannheim et al. (2019) discusses the need to include older people in the design of digital technology to achieve the objective of wellbeing that such technologies carry. The paper demonstrates the dilemmas researchers face when considering the participation of older adults to their research (regarding the capability of older people to participate, provide valuable information, and to knowingly consent) as well as the ingrained stereotypes that might hinder the genuine inclusion of older adults in the design process of technologies for ageing well³⁸.

In NESTORE, the co-design methodology³⁹ refined by researchers in Lab4Living (Sheffield, UK) has helped colleagues on the project in Italy, Spain and the Netherlands⁴⁰ to facilitate a number of workshops to elicit participant experiences and to scaffold conversation around what technology meant to them. Participants shared their views on a prototype of tangible coach. In Italy, they also tested the wearables while Dutch and Spanish users tested the app, the chatbot and discussed the prioritization of the coaching activities.

Following this series of workshop, an expert group (of experts by experience $-\operatorname{EbE}^{41}$) was established in the UK and participated in a few extra sessions to define caracteristics that would define the main requirements of the NESTORE system. It came out that workshop participants had stressed the importance to reflect on the cost of the coach and how data privacy and security will be assured. The coach should also provide levels of options as user's choices are critical to empower individuals. These requirements were clustered by the researchers into three major headings: Trust $-\operatorname{Cost} - \operatorname{Fits}$ my life⁴². In a later stage, the group tested ideas with concrete tangible objects and prototypes to reflect on how the system should look like.

⁴² All findings from the co-design methodology used in NESTORE are available in D7.1: Report on Needs, Values and Suggestions to Co-Design: https://nestore-coach.eu/documents/20182/71466/NESTORE_D7.1.pdf/bb442d8a-02f2-436f-857f-957b7f13468e





³⁸ Mannheim, I., Schwartz, E., Xi, W., Buttigieg, S. C., McDonnell-Naughton, M., Wouters, E. J., & Van Zaalen, Y. (2019). Inclusion of older adults in the research and design of digital technology. *International Journal of Environmental Research and Public Health*, *16*(19), 3718.

³⁹ See: <u>https://nestore-coach.eu/use-cases</u>

⁴⁰ See: https://nestore-coach.eu/news1/-/asset_publisher/QwZ34QfCXHdj/content/a-flourishing-of-co-design-across-europe

⁴¹ See: <u>https://nestore-coach.eu/-/nestore-expert-by-experience-group-</u>

The participation of older adults to the design of digital technologies for ageing well is necessary at several level, say Mannheim et al. First, their participation is critical to explore the new business opportunities to age groups that were, until now, uncovered by the sector of digital technologies. Second, their insights would contribute to a better understanding of factors that influence the acceptance of these technologies: older people are an heterogeneous group whose part of it might be "reluctants" to technological innovation, while some other might be "saavy-users", per the categories of Quan-Haase et al. (2018)⁴³. As a response to this call for older people's involvement in research, Mannheim et al. provide suggestions of how to include older adults in the research and design of digital technologies.

NESTORE's co-design approach and its results, alongside with the experiences gathered via other co-design and co-creation activities in Horizon2020 projects, proves that the methodological framework can be solid and viable, but policies should be sustained to encourage those efforts to release even more promising results.

Therefore, this deliverable encourages the European Commission to:

- Provide guidance to EU-funded research projects in the field of active and healthy ageing to address ageism, be it in their methodology or their communication;
- Incentivise and support EU-funded research projects in providing clear, simplified consent-forms by cognitively adapting language and using corrective feedback;
- Support EU-funded research projects in increasing the accessibility of co-design methods during the project proposal evaluation and granted project reporting periods;
- Encourage EU-funded research projects to include a diversity of older people⁴⁴ in their co-design
 activities, applying gender mainstreaming to their research practice as well as making an effort to reach
 out to older people that are less well-off, older people living with a disability, older people of colour or
 from an ethnic minority, etc.

NESTORE's partners will moreover follow the World Health Organisation (WHO) work during the Decade of Healthy Ageing and in particular the WHO's role of guidance on how to run research works that 'do-no-harm'; the guidance is not out yet, but it will be important for partners to align to what the Decade will deliver on that front.

2.2. Secure data for all

Health monitoring devices carry the potential of seeing a health insurance company implement a no-claims bonus system where individuals adopting healthy lifestyles would be rewarded with a return on their premium subscriptions while individuals who would not meet the objectives set for this refund would pay a higher price. The insurance would only be able to distribute refunds or penalties in case the results of the health monitoring systems (their clients' data) are shared with the company.

Such models are problematic on different fronts: first because it makes individuals carry the full responsibility for their health status without considering the structural factors that might influence their health and yet remain

⁴⁴ See in the report of the UN Independent Expert of July 2017 aforementionned, the following recommendation: 'Participation begins with the direct involvement of older persons in the design and development of assistive products and extends to the planning, delivery and evaluation of services. (…) Specific efforts must be made to include marginalized groups and those not adequately covered in representative organizations of older persons, such as indigenous people, migrants and refugees, ethnic, cultural or linguistic minorities, and those with complex support needs.'





⁴³ Quan-Haase, A.; Williams, C.; Kicevski, M.; Elueze, I.; Wellman, B. (2019). Dividing the grey divide: Deconstructing myths about older adults' online activities, skills, and attitudes. Am. Behav. Sci., 62, 1207–1228.

out of their control (see section 3.2); second because it carries the risk for the company to use these data for profiling and discriminate its clients according to their health status, for instance.

In a world where users demand sound data protection and transparent use of data, and the digital innovation is grounded on extensive and growing data use, NESTORE decided to adopt an ethical approach based on principles such as legitimate purpose, proportionality and data minimisation. Eventually, NESTORE produced a data protection impact assessment (DPIA) and a map of risk, with related risks' mitigation and action plan, aimed at protecting its final beneficiaries. The data protection impact assessment is a living document including a data management plan adapted to the pilot research, whose content is checked by the Principal Investigator's Data Protection Officer (DPO).

The approached used by NESTORE to ensure personalisation without profiling was pseudonymization: depending on the consent given by the study participants, project partners are allowed (or not) to retrieve the name of the participant to inform him/her about a health risk. For example, should an arrythmia be detected, NESTORE is entitled (or not) to inform the study participants.

In light of both the diversity of needs and health status in later life as well as the risks of malicious use of older people's data in case their personal data was shared with unintended third party, the protection of people's privacy and anonymity cannot be underestimated.

To support an informed debate and practice on the use of health data, this deliverable invites the European Commission to:

- Empower citizens and users and provide them with mechanisms to control the use of their data and exercise their rights⁴⁵.
- Ensure that every project aiming to conduct pilot activities includes a data sharing agreement during the preparation of the consortium agreement under the leadership of the coordinating partner;
- Coordinate trainings⁴⁶ and a resource repository to guide the adequate implementation of
 pseudonymisation in EU-funded research projects where personalisation is needed (e.g. could be
 referred the CNIL Privacy Impact Assessment (PIA), a much recommended set of documents
 including PIA methodology, knowledge base, glossary, and case studies).

2.3. Regulate Automated-Decision Making

While data are generating new business models, Àngels Barbarà - Director of the Catalan Data Protection Authority - considers that data protection rights should be the new mechanism to guarantee the rights of consumers⁴⁷. While Barbarà stressed the importance for users and consumers to provide their informed consent, and to exercise their rights by filing complain when they feel that their rights have been violated, such procedures might appear tedious or inaccessible to some users and consumers. Among the reasons preventing

⁴⁷ See: <a href="https://apdcat.gencat.cat/en/actualitat/noticies/noticia/Barbara-La-proteccio-de-dades-es-linstrument-que-permet-garantir-els-drets-dels-consumidors-en-un-entorn-on-les-dades-son-la-base-del-negoci





⁴⁵ This reccommendation is also shared with the Horizon2020 DigitalHealthEurope project, namely through its consultation on data sharing governance: https://digitalhealtheurope.eu/wp-content/uploads/2020/11/Consultation-Paper-Citizen-controlled-health-data-sharing-governance.pdf

⁴⁶ NESTORE's webinar on data sharing in digital health projects gathered more than 70 participants thus testifying of the great interest of the community for further information and guidance on the topic. A summary and recording of the webinar can be found here: https://nestore-coach.eu/-/recording-webinar-on-data-sharing-in-digital-healthy-ageing-projects

users to exercise their rights is the fact that Automatised-Decision Making systems are complex, some users might feel incompetent, or might struggle to demonstrate the discrimination they are the victim of.

The risk of discrimination is yet real. In its February 2019 response⁴⁸ to the European Commission's consultation on the White Paper on Artificial Intelligence - A European Approach, AGE Platform Europe stressed the importance to pay attention to proxies when considering the risk of discriminatory outcomes. This is particularly true for automated decision-making where the criteria in use will be neutral and respect the regulation, but proxies could generate discrimination, e.g. by using someone's place of residence, health status, or salary level as proxies to race, age, gender given the existing socio-economic inequalities and geographical segregation that still exist in our modern societies.

NESTORE practically worked on those dimensions first when describing the personas to be used by the project and then during exchanges with other PM-15 projects, and in particular during the webinar in November 2019.

In echo to several Manifestos published in the recent years, such as the Data for Humanity Initiative⁴⁹, the analysis of Andreou et al.⁵⁰ or the joint Manifesto⁵¹ by the Open Society European Policy Institute (OSEPI) and the European Consumer Organization (BEUC), the authors thus invite the European Commission to consider:

- Sustaining the adoption of binding regulations to close the protection gaps currently existing with regard to combating discrimination on all grounds outside the labour market e.g. intensifying efforst to adopt the draft directive Equal Treatment Directive COM(2008)0426 currently standing by in the Council of the European Union;
- The adoption of a comprehensive strategy to safeguard against the unethical use of personal health data
 and data systems in ways that perpetuate discrimination and exclusion and/or deal with senstive data
 such as in the health/medical field, particularly when they affect vulnerable groups who already face
 high levels of inequality;
- To support Member States in their efforts to increase the digital literacy of citizens and consumers regarding automated-decision making systems to increase the understanding of the possibilities, limitations and potential risks of such systems.

3. Mainstreaming solutions: listen to the final beneficiaries

"Increasing digitalisation comes with tremendous opportunities and challenges for living in old age⁵⁰". In order for all ages to reap the benefits of digital solutions, digitalisation must be tailored to the final users and accommodate their diverse needs and abilities. Older persons must get access to digital infrastructure and devices that allow them to receive relevant information and reach social networks, independent of their financial resources or living places. Adequate digital, health and media literacy programmes must be developed it is

⁵¹ Open Society European Policy Institute (OSEPI) and The European Consumer Organization (BEUC), *A Human-Centric Digital Manifesto for Europe: How the Digital Transformation Can Serve the Public Interest*, Open Society Foundation, September 2019: https://www.opensocietyfoundations.org/publications/a-human-centric-digital-manifesto-for-europe





⁴⁸ See: https://age-platform.eu/policy-work/news/artificial-intelligence-%E2%80%93-age-replies-consultation-ethical-guidelines

⁴⁹ See: http://www.bigdata.uni-frankfurt.de/dataforhumanity/

⁵⁰ A. Andreou, S. Laulhe-Shaelou, D. Schroeder. *Current Human Rights Frameworks*. Deliverable 1.5 of the SHERPA project (Horizon 2020 project funded by the European Commission under Grant Agreement no. 786641). April 2019

moreover important that "analogue participation in society is guaranteed even in times of increasing digitalisation", avoiding leaving behind who experiences the highest vulnerabilities.

While the advantages of digitalisation are widely recognised⁵⁰, it remains a priority to call for sound legal protection against the risk of intrusion and fraud, and of age discrimination especially where automated decision making is used.

The pandemic further incentivised many older people to go online, but digital means will never fulfil the basic need for human contacts. This has been repeteadly stressed by various Steering Board meetings in NESTORE and it is confirmed by the preliminary results of the pilots' implementation⁵²-⁵³. Solutions cannot be mainstreamed if they are not conceived with their final users.

The recently published Green Paper on Ageing⁵⁴ moreover stresses the key aspect of **innovating throught the life-course**. It is important for the European Commission to be consistent between the various approach it takes in sustaining innovation and assistive technologies, considering the overall life-span of European citizens. A life-course approach should be integral part of the research solutions in Horizon Europe and the other European programmes for research.

Such approach emerged also during the pilot preparation and the policy event in Rotterdam, when the project discussed with policy makers about the integration of ages working together digitally on goals. That would create new opportunities, both on social well being as by nudging healthy lifestyles. NESTORE focused on seniors, but how could integration with youngsters help to improve social networks (may be with gamification)? At one of the co-desing worksops we saw that seniors enjoyed the game Pokemon go, because of the contacts with their grandchildren.

Among the pleas users convey to the digital stakeholders and public authorities, the authors of this report selected four important issues, which strongly emerged during the NESTORE project and the exchanges with the PM-15 group, i.e.:

- Avoid (technological) fragmentation
- Adress market concentration
- Lead innovation hand in hand with social protection
- Sustain a plain and user-friendly communication

NESTORE will be pleased to follow, via its partner AGE Platform Europe, the policy work sustained by the current Trio Presidency of the European Union⁵⁵: the three countries holding the successive Presidency of the EU – Germany, Portugal and Slovenia - promote people's autonomy and participation in later life. The 'Trio Declaration on Active Ageing' calls for a joint approach in EU ageing policies that should be rights-based; integrate a life-course perspective; be cross-sectorial and value older people's contribution.

 $[\]frac{ageing}{^{55}} \underline{\text{https://www.age-platform.eu/policy-work/news/eu-trio-presidency-commits-joint-ageing-approach}}$





⁵² This point was moreover particularly stressed during the final event of NESTORE, on February 25 2021: https://nestore-coach.eu/-/the-end-of-the-road-not-the-end-of-the-journey-

⁵³ Joint statement by AGE Platform Europe and BAGSO on the Council conclusions about "Human rights, participation and well-being of older persons in the era of digitalisation", 29 September 2020, https://www.age-platform.eu/sites/default/files/AGE-BAGSO Joint statement on EU Council conclusions-Sept20.pdf

⁵⁴ See: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12722-Demographic-change-in-Europe-green-paper-on-ageing

3.1. Avoid (technological) fragmentation

The above lessons learnt and derived recommendations are especially issued by the interactions from designers, developers and researchers with users, being potential users and interested stakeholders (such as the FAS members and civil society organisations), the pilot users in NESTORE and user surveys (cf. Exploitation report).

Without duplicating the details of the technical deliverables, it is however relevant to share a specific recommendation issued by the project: "it is very important that these integrated systems are developed because at the present time we are bombarded with information and technology that they possess, not always providing us with good service⁵⁶."

Taking stock of this, NESTORE worked with a comprehensive architecture that integrates three interconnected and complementary components essential for the e-Coaching activity: the Monitoring System, the Decision support system (DSS) and the Virtual Coach . These components integrate each other and allow also other applications to be easily added. It results in a unique system the users can rely on, avoid fragmentation, which is also well perceived by the user, interacting with one system rather than different aggregate pieces.

NESTORE is a comprehensive system in this perspective where the decision support system integrates and evaluates all the different sources (data coming from the sensing layer, user profile and preference, lifestyles etc...). And it is an interoperable system, able to include parts/piece of technology already on the market and integrate it.

3.2. Address market concentration

In the joint Manifesto⁵⁷ by the Open Society European Policy Institute (OSEPI) and the European Consumer Organization (BEUC) to which AGE Platform Europe contributed, a series of recommendations is dedicated to competition policy. The authors call the European Commission to "work with the European Data Protection Board (EDPB), the European Data Protection Supervisor, DG Competition and national authorities responsible for competition, data protection and consumer protection to investigate and address those business models in the digital economy that have the potential to affect consumers' human and economic rights".

In NESTORE, the analysis of axisting virtual coaching competitors⁵⁸ has permitted to classify them in a two-level matrix according to two characteristics: Target users (i.e. group of consumers in the predetermined target market; healthy citizens and chronic patients) and Dimensions (i.e. dimensions addressed in relation to the five NESTORE dimensions or type of chronic disease addressed; mono and multi).

Beyond the importance to take account of fundamental rights in the assessment of consumer welfare in digital markets, the monitoring of competitors and regulations for fair competition are all the more important, considering the sizes of dominant players – such as Amazon Alexa and Google Home, in the field of Virtual Assistants .

⁵⁸ See: https://nestore-coach.eu/-/a-preliminary-market-analysis-identifying-the-context-in-which-nestore-is-evolving





⁵⁶ https://nestore-coach.eu/-/-it-is-very-important-that-systems-are-integrated-otherwise-we-are-bombared-with-information-potential-nestore-user-says

⁵⁷ OSEPI and BEUC, op. cit.

In order to allow European innovators to be competitive on the European market, and in echo to the work of OSEPI and BEUC, the authors invite the European Commission to use all competition law and consumer protection mechanisms possible to ensure markets remain open to new entries, e.g. by targeting the behaviours of dominant players that have the effect of raising barriers to access and/or locking in consumers; and to prioritize measures to tackle mergers that lead to excessive market concentration.

3.3. Build a European investment market for innovations with social impact

Innovations for prevention and healthy ageing are typically solutions that can be resource depending for the development of a solution, but carry benefits on the long-run. NESTORE having adopted a preventive approach, it is not surprising that debates hold within the frame of the project identified the issue of return on investments⁵⁹. Although the preventive approach promises consistent savings on health-care costs in the future, public and private investors agree that funds must intervene nowadays to develop preventive solutions that will only provide return on investment in many years from now.

Challenges related to the financing of preventive solutions and policies very much reflect the analysis⁶⁰ by Maduro et al. (2018) regarding the need to build a European social impact investment market. This is all the more applicable in case of preventive solutions that aim to address the socio-economic inequalities at the root of many unhealthy later lives. Besides the technological innovation of NESTORE, affordability is then an essential success factor of such solutions.

The systematic literature review on Social Return on Investment (SROI) and the cost-benefit analysis has shown that quantified metrics to depict the social return of investment are still missing. More action is needed on this field.

Similar to the call of the Maduro et al. for stronger synergies between the European Structural and Investments Funds (ESIF) and European Fund for Strategic Investment (EFSI)⁶¹, the authors recommend that the future Horizon Europe programme should attract private investors for successful Horizon Europe research projects that contain a dimension of social innovation and deliver impact on clearly identified political priorities of the European Union. Moreover, the European Commission, with the support of the European Investment Bank, should develop the financial instruments necessary to correct the mismatch between the mainstream financial products currently being offered by finance institutions and the specific needs of the innovations that meet a social need and require to remain affordable to achieve its objectives of accessibility by low-income groups in most need (e.g. in terms of maturity, risk, interest rates, etc.).

⁶¹ Op. cit. page 88: "This European financial instrument would then work jointly with national financial instruments in selecting national investment funds or specific projects (depending on the wholesale or retail nature) to be jointly financed. The advantage of this model would be to have a European wide approach to the attraction of private investment for social impact investment in different Member States. The involvement of the EIB expertise would also raise trust in private investors at that level of the market. Finally, the creation of such financial instrument (that could be called the European Fund for Social Innovation and Impact Investment) would also provide a much needed visibility at the European level to the social innovation and social impact investment agenda."





⁵⁹ See: https://nestore-coach.eu/-/health-prevention-and-promotion-policy-recommendations-under-preparation-by-nestore

⁶⁰ Maduro, M., Pasi, G., Misuraca, G., Social impact investment in the EU. Financing strategies and outcome oriented approaches for social policy innovation: narratives, experiences, and recommendations, EUR 29190 EN, Publications Office of the European Union, Luxembourg, 2018, ISBN 978-92-79-81783-0, doi:10.2760/159402, JRC111373

3.4. Focus on clear and friendly communication

"It becomes more and more difficult to get and remain updated, and it is often so complex that we give up. At the same time, should I be to choose about an health application or to adopt NESTORE for my daily living, I would feel confused". ⁶² Users and potential users refer very often about their challenges in getting to know a system and navigate it (let alone how to deal with technical issues, bugs et similia). When solutions are not co-created with the final beneficiaries, the risk of neglecting their expectations is very high.

Besides, the market currently offers millions of digital solutions for well-being, and chosing one own's path can become complicated. The worked carried out by Politecnico di Milano within the project's exploitation strategy clearly showed how little informed people are about smart applications for health and well-being, and how scarse the opportunities for getting clear and friendly communication are. No surprise the users feel like their are in a dangerous jungle, where finding the right help is or seems complicated, and where they feel their privacy and health data are at stake.

A final note therefore addresses itself to the service providers, both virtual and real one. From insurers, to companies, from gym halls to medical doctors, it is important to keep communication clear and effective towards the users. Here the role to be played by the Institutional actors, European and national ones, is pivotal.

Additional remarks for future projects

NESTORE got the chance of living the first COVID-19 pandemic. It has been an unexpected challenge, which brought various issues to light. However, it also represented the opportunity to suggest alternative ways of being connected. As the project partner Preventie Collectief highlighted "many social support initiatives have emerged, also in Schiedam, but people who are not connected to social networks turned out to be difficult to reach. A second important lesson is that it is of preventive importance to have sufficient digital skills as to possess digital resources. Both to access resources and to maintain a healthy lifestyle".

The reflection developed by Preventie Collectief offers also additional insights: "we have increasingly come to think in terms of "social and digital ecosystems for prevention and health" and a "social health infrastructure also supported through digital technology". Just like waterways, cycle paths, walking routes, bridges, etc., a society needs a social infrastructure. This social infrastructure is important for people to also be able to organize personal health environments, supported by digital tools. Creating culture, social embedding and stimulating contexts are important for health and nudging healthy behavior. People can be understood mainly because of the networks in which they participate. These networks in particular are important for prevention. The focus should be on the development of those supportive networks. Social factors are also of the utmost importance for people who do have digital skills and access to technology".

NESTORE focused on healthy people aged 65 plus. However, in this way, the project could not explore how technology can contribute to healthy behavior in people in very disadvantaged situations. "In that case, technology alone will not help, but all relevant aspects that can contribute to healthy behavior must be looked at integrally. How do you reach these groups? How do they overcome the digital divide? What social and psychological potential do people have to work on healthy behavior? Which context factors can contribute to stress reduction?", states Preventie Collectief and AGE Platform Europe.

⁶² Translation from Italian quote, Grey Panther (FAS member): https://www.grey-panthers.it/speciale/speciali/ricordate-n-e-s-t-o-r-e-il-progetto-per-migliorare-la-vita-dei-senior-arriva-al-traguardo/primo-focus-group-con-gli-amici-grey-panthers-per-il-progetto-nestore/">https://www.grey-panthers.it/speciale/speciali/ricordate-n-e-s-t-o-r-e-il-progetto-per-migliorare-la-vita-dei-senior-arriva-al-traguardo/primo-focus-group-con-gli-amici-grey-panthers-per-il-progetto-nestore/">https://www.grey-panthers.it/speciale/speciali/ricordate-n-e-s-t-o-r-e-il-progetto-per-migliorare-la-vita-dei-senior-arriva-al-traguardo/primo-focus-group-con-gli-amici-grey-panthers-per-il-progetto-nestore/">https://www.grey-panthers.it/speciale/speciali/ricordate-n-e-s-t-o-r-e-il-progetto-per-migliorare-la-vita-dei-senior-arriva-al-traguardo/primo-focus-group-con-gli-amici-grey-panthers-per-il-progetto-nestore/





Last but not least, projects like NESTORE should never underestimate the willingness from participants to remain involved in the research projects they contributed to. Such work generates new networks and ties, thus intervenining in the social dynamics of the local context in which it developped. AGE and Preventie Collectief ask themselves "how can participants continue to participate in the networks that have been built? How can their efforts also be of significance to other people in their social circle?". It should be moreover reminded that every pilot project enters in people's home, works with their routines, explores their life. It should not be neglected that every intervention brings some disruption, positive and/or negative, in the life of participants. Exploring what people behave after NESTORE is equally important.





Infographics: NESTORE policy recommandations (short)







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